

Access to the Aboriginal Diabetes Initiative in Three First Nations Communities in Yukon Territory, Canada

by
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A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
In partial fulfillment of the requirements of the degree of

Master of Arts

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Winnipeg

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Abstract

Type 2 Diabetes (T2D) has been described as both an epidemic and endemic in First Nation (FN) populations in Canada. Federally, culturally appropriate prevention and management programs funded through the Aboriginal Diabetes Initiative (ADI) can support those living with T2D within FN communities. Health Directors and administration staff working and participating in health services (n=6) were interviewed in order to describe the nature and variation of T2D supportive care services available within communities, and the extent to which ADI programs have been funded. Results indicated that participants perceived that capacities and barriers exist when accessing and implementing ADI funding and associated T2D services. These barriers derived from the policy structure of the ADI and varying degrees of community capacity in FNs. Findings from this study were used to develop recommendations for both the Federal and Territorial Government to improve equity in ADI funding and T2D supports for Yukon FN residents.

Acknowledgements

“The University of Manitoba campuses are located on original lands of Anishinaabeg, Cree, Oji-Cree, Dakota, and Dene peoples, and on the homeland of the Métis Nation.

We respect the Treaties that were made on these territories, we acknowledge the harms and mistakes of the past, and we dedicate ourselves to move forward in partnership with Indigenous communities in a spirit of reconciliation and collaboration” (University of Manitoba, 2015, p. 9)

As I reach the end of this thesis, I owe deep gratitude to many supporters who helped me along the way.

First and foremost I would like to thank my mentor and academic advisor, Dr. Tracey Galloway, for the constant support and guidance she gave me throughout this research. Thank you for the timely responses on reviews and other requirements, as well as your encouragement in my other academic endeavours. It was a privilege to work with you. Your commitment to your work is truly remarkable. Thank you for letting me be a part of your larger study and I hope that my thesis supports the research you started.

I would like to also thank my extremely dedicated examining committee Dr. Josée Lavoie and Dr. Linda Larcombe. I cannot thank you enough for sharing your time and taking an interest in the study topic. I would like to thank Dr. Judith Bartlett who guided me in the early stages of this research through the discussion of contemporary issues in Indigenous health, decolonizing research frameworks, and the process of locating myself within my research. Also at the University of Manitoba I would like to thank all of the supports that encourage graduate students to succeed: the Department of Anthropology, the University of Manitoba Anthropology Students’ Association, and the Faculty of Graduate Studies.

I would also like to extend my gratitude to all the participants and members of the communities who were involved in this study. This study could not have been completed without your generosity, stories, and support. Additionally, I would like to thank the Council of Yukon First Nations for being a collaborator and partner in this research and sharing your supports. This study would also not have been possible without funding from the Canadian Institutes of Health Research (Funding Reference No. 134071) and the J.G. Fletcher Award from the University of Manitoba.

Lastly, I owe the deepest and most sincere gratitude to my family and friends for their moral support and unconditional love. Your support helped me to see the bigger picture of this thesis.

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List of Acronyms

AANDC – Aboriginal Affairs and Northern Development Canada

ADI – Aboriginal Diabetes Initiative

AHS – Aboriginal Head Start

BMI – Body Mass Index

CBRTs – Community-based Reporting Templates

CCHS – Canadian Community Health Survey

CDS – Canadian Diabetes Strategy

CIHR – Canadian Institutes of Health Research

CYFN – Council of Yukon First Nations

FN(s) – First Nation(s)

FNIHB – First Nations and Inuit Health Branch

FPG – Fasting Plasma Glucose

FSGAs – Final and Self-Government Agreements

FTA – Financial Transfer Agreement

HBA1C – Glycated Hemoglobin Test

INAC – Indigenous and Northern Affairs Canada

NHS – National Household Survey

NIDDM – Non-Insulin Dependent Diabetes Mellitus

NIHB – Non-Insured Health Benefits

NPHS – National Population Health Survey

NT – Northwest Territories

OCAP – Ownership, Control, Access, Possession

OGTT – Oral Glucose Tolerance Test

PCBs – Polychlorinated Biphenyls

PHAC – Public Health Agency of Canada

POPs – Persistent Organic Pollutants

RHS – Regional Health Survey

SPSS – Statistical Package for the Social Sciences

T2D – Type 2 Diabetes

TRC – Truth and Reconciliation Commission of Canada

A Note on Terminology

As per the request of the Canadian Institutes of Health Research (CIHR), under which this study is funded, this Master of Arts thesis uses terminology preferred by FNs, Inuit, and Métis peoples in Canada (CIHR, 2013). When discussing FNs, Inuit, and Métis peoples collectively the term Indigenous is used instead of Aboriginal. This is because the term Aboriginal is a construct of the Canadian Constitution of 1982, where the term was not chosen by the people that it represents (CIHR, 2013). The use of Aboriginal “glosses over” unique cultural, historical, and independent complexities that should be recognized (National Collaborating Centre for Aboriginal Health, 2011a, p. 14). The term Aboriginal should be replaced with Indigenous, because “the use of the term “Aboriginal” is inherently tied to colonialism and is another example of colonial imposition on Indigenous identities, rendering their perception of its use as negative and diminishing” (CIHR, 2013, p. 1). The term Indigenous does not have the same negative connotations and “denotes a collective history among Indigenous Peoples of the world regardless of borders, and [is] broader than the Constitutional and legal definitions” (p. 1). Further, use of the term Indigenous can relate to both humans and plants and is a tribute to the relationships that Indigenous peoples have with traditional territories (CIHR, 2013). As there are various ways to define Indigeneity, with respect to policy and traditional cultural attributes, the most defining characteristic is self-determination by Indigenous peoples themselves (see also Indian and Northern Affairs Canada, 2002 & Stephens, Nettleton, Porter, Willis, & Clark, 2005).

As nation-wide terminology may be considered a further colonizing practice by sheltering the full expression of individual cultural affiliations, it is imperative to acknowledge and represent cultural differences within the Indigenous populations of Canada. Therefore, to

coincide with guidance from CIHR, this Master of Arts thesis uses the term Indigenous when referring to FN, Inuit, and Métis peoples of Canada collectively, and refers directly to Yukon FNs when appropriate. In addition, the term FNs is also an umbrella term that encompasses the many different cultural groups in Canada (Cree, Dene, Dakota, Anishinaabe, Blackfoot, etc.). This research collaborates with three of the 14 FNs in Yukon, each with particular histories and territorial affiliations that are recognized. At the request of the partners in this research, the Council of Yukon First Nations (CYFN), the names of the communities, as well as the participants do not appear in this thesis, or any publication or presentation resulting from this thesis.

Lastly, many institutes and agencies still use the term Aboriginal when discussing Indigenous peoples in Canada. Such examples include Health Canada, the ADI, and the Statistics Canada surveys of the National Population Health Survey (NPHS), the Canadian Community Health Survey (CCHS), and the National Household Survey (NHS). When information is obtained from these sources, the term Aboriginal is not changed, but in all other instances what is used is the preferred term; Indigenous.

Chapter One: Introduction and Research Objectives

Canada is a country with universal health care, yet health disparities among its residents remain a public health concern (Frohlich, Ross, & Richmond, 2006). Reasons for health disparities arise from a complex combination of social, economic, cultural, and political inequalities (Adelson, 2005; Frohlich et al., 2006; Horton, 2006; Iwasaki, Bartlett, & O'Neil, 2005; Loppie-Reading & Wien, 2009; Stephens et al., 2005; Tjepkema, 2002). While health and living conditions have improved over the past century among all Canadians, Indigenous populations (FNs, Inuit, and Métis) have higher rates of health concerns (Adelson, 2005; Jacklin & Warry, 2011; Tjepkema, 2002). Critics of the health care system blame these inequalities on inadequate funding of Indigenous health care programs, Indigenous peoples' avoidance of Western medical systems, or remoteness of communities in relation to health care facilities (Newbold, 1998). In addition, these complex inequalities for Indigenous populations result from historical and systematic oppression over many generations since the time of European colonization (Newbold, 1998; Stephens, Porter, Nettleton, & Willis, 2006; TRC, 2015). Acts of marginalization and colonization include racism, assimilation to European values, residential school systems, as well as cultural, social, and physical isolation (Bodirsky & Johnson, 2008; Gone, 2008; Howard, 2014). These acts create health disparities which include higher burdens of disease (Adelson, 2005; Frohlich et al., 2006; Garro, 1995; Horton, 2006; Kaler et al., 2006; Newbold, 1998; TRC, 2015).

Among the most common health concerns for Indigenous populations are rising rates of obesity, cardiovascular disease, and T2D, not only in adults, but increasingly in children and youth as well (Ball & McCarger, 2003; Lobstein, Baur, & Uauy, 2004). T2D, formerly known as non-insulin dependent diabetes mellitus (NIDDM), is chronic, debilitating, costly, and a leading

cause of premature morbidity and mortality (Benyshek, Martin & Johnson, 2001; Daniel et al., 1999). Indigenous Canadians have a greater prevalence of T2D than the rest of the Canadian population, and the disease has thus been referred to as both an endemic and epidemic (Harris et al., 1997; Iwasaki, Bartlett, & O'Neil, 2004; Oster et al., 2011; Young, Reading, Elias & O'Neil, 2000). Diabetic complications include atherosclerotic cardiovascular disease, heart attack or stroke, blindness, renal failure, hypertension, neuropathy which can lead to non-traumatic limb amputation, and depression (ADI, 2000; Benyshek et al., 2001; Bruce & Young, 2008; Canadian Diabetes Association, 2004, 2011; Fonseca, 2003; King, Sanguins, McGregor, & LeBlanc, 2007; Martens, Martin, O'Neil & MacKinnon, 2007; PHAC, 2005). These complications can be detrimental, as in general, morbidity and mortality are elevated among individuals who have one or multiple diabetes-related complications (ADI, 2000). These complications can result in five to ten years lower life expectancy (Canadian Diabetes Association, 2011). High prevalence rates of T2D and associated complications can be damaging to overall health and well-being of Indigenous populations.

In response to higher prevalence of T2D in Indigenous populations, diverse diabetes services and programs are available, largely with family-oriented or community-based approaches (e.g. Alberta Center for Active Living, 2012; Armour, Norris, Jack, Zhang, & Fisher, 2005; Daniel et al., 1995; Hanley et al., 2005; Ho, Gittelsohn, Harris, & Ford, 2006; Oster et al., 2011; Oster, Shade, Strong, & Toth, 2010). To provide health supports to Indigenous Canadians, the Federal Government funds on-reserve¹ FN populations, and the Provincial and Territorial Governments deliver health services off-reserve. FN communities may have some kind of on-site

¹ A reserve is Crown land that is set aside for the exclusive use of those registered under the Indian Act of 1876 (Adelson 2005).

health facility, such as a health center or nursing station², but it may only provide limited services and care for chronic diseases such as T2D. The preventative and supportive program for people living with T2D that is examined and evaluated in this study is the ADI, operated by Health Canada's First Nations and Inuit Health Branch (FNIHB), under the jurisdiction of the Federal Government. The ADI is examined by analyzing interview-based participant perceptions surrounding the access and implementation of the ADI in three of the 14 FNs in Yukon, Canada.

As one of Canada's three territories, Yukon lies in the northwest corner of Canada, with the Arctic Circle crossing through. The name "Yukon" derives from the Locheux word "Yuk-un-ah", meaning "Great River", referring to the Yukon River (Travel Yukon, 2015). Yukon occupies a surface area of roughly 483,000 square kilometers and approximately 36,000 residents, the majority of which live in the capital city of Whitehorse (Travel Yukon, 2015). In national survey data, it is estimated that approximately 23% of the population in Yukon identify as Aboriginal, the majority of which self-recognize as FN (Horne, 2010; Statistics Canada, 2006, 2013a). There are 14 FN groups, but a long history of residence in the area has created historical and continuing relations between many of these Nations (Government of Yukon, 2008; Horne, 2010; Nadasdy, 2012).

The premise of this study is that the ADI's current funding structure, alongside a gradient of capacity and infrastructure³, results in unequal distribution of ADI resources in the 14 FNs in Yukon. The purpose of this study is not to disregard the ADI as an important source of support for communities; rather, it is meant to identify limitations and barriers in the federal health

² The designation of health center or nursing station is often determined based on community size, as well as remoteness from major highways and large urban centers. Nursing stations are located in communities that have a lower population and are located in remote areas. Health centers are often located in communities that have access to major highways, and have larger population sizes. Nursing stations often have at least one part to full-time nurse and is visited periodically by doctors, dentists, and other health care specialists.

³ Infrastructure in this thesis refers to community-based physical and organizational structures that are utilized to implement health related services.

structure that are perceived by participants in Yukon FN communities, those both with and without Final and Self-Government Agreements (FSGAs). A critical evaluation of current federal health programs is essential to improve the policies and practices that can aid in resolving health inequities between FN and non-FN populations in Canada (Brooks, Darroch, & Giles, 2013). This study recognizes that there are community-based capacities, as well as observable barriers, when staff are accessing, creating, and implementing sustainable ADI funding and diabetes prevention and management services.

Barriers exist in the socio-political environment in which health-based programs are funded. These barriers can include, but are not limited to: the political environment (federal, provincial/territorial, regional, municipal, and Indigenous); the socio-political history; the location of communities; the availability of qualified healthcare personnel; and other determinants of health (housing, water, infrastructure, access to nutritious foods) (Canadian Diabetes Association, 2011). These barriers can make it challenging to implement lifestyle recommendations that prevent the onset of T2D and diabetes-related complications. As such, the purpose of this study is to identify barriers that communities experience when accessing and implementing ADI funding. This is done using a capacity-based approach by reflecting on community-based abilities and adapting recommendations at both the community level and the level of the Federal Government to improve the access and implementation of ADI funding and resources (Israel, Schultz, Parker, & Becker, 1998). The three objectives of this study are to understand community-level access to health services, and the ADI through a historical and critical lens by:

- 1.) Identifying the need for T2D services and programs funded through the ADI in three Yukon FNs, based on participant perspectives;

- 2.) Identifying both capacities and barriers that exist when accessing and implementing ADI funding, either internal to communities, or external with respect to the Federal Government and;
- 3.) If there is a need for T2D services, develop recommendations that Yukon FNs and the Federal Government can take to increase the number, quality, and efficacy of ADI programs and related T2D services in communities today, and in the future.

This study is part of a territory-wide participatory research investigation of federal health funding policy and health program efficacy in the 14 Yukon FNs (*The Impact of Proposed Change in Federal Health Funding Policy on Health Programs Operating in Yukon First Nations Communities*, Dr. Tracey Galloway, Principal Investigator, CIHR Funding Reference No. IPH 134071). Within this territory-wide research, programs administered through Health Canada's FNIHB, the Public Health Agency of Canada (PHAC), and Indigenous and Northern Affairs Canada (INAC)⁴ are analyzed. The purpose of this study, within the context of the larger territory-wide research, is to produce a qualitative analysis and develop recommendations for federal policy makers and administration staff in FNs regarding the access and implementation of ADI, based on interview data analyzed from three of the 14 FNs.

⁴ INAC was formerly known as the Aboriginal Affairs and Northern Development Canada (AANDC) and was changed in 2015 when Prime Minister Trudeau announced the new cabinet (Office of the Prime Minister, 2015b). All references prior to 2015 will use AANDC in citations.

Chapter Two: Literature Review

2.1 Introduction

As the purpose of this study is to identify current availability of T2D services and the access and implementation of ADI funding in three Yukon FNs, this chapter provides a review of available literature that explores issues related to this research. This review examines the current demographic profile of Indigenous populations in Yukon and Canada. A discussion of T2D prevalence within Indigenous populations emphasizes: diabetes-specific economic costs in Canada; and diabetes screening. A discussion of Indigenous determinants of health and well-being examines: Indigenous epistemology and worldview; how health and well-being are portrayed in national surveys, and how T2D is conceptualized in Indigenous populations; personal and population level effects of marginalization and colonization; traditional and non-traditional food use in Yukon; as well as cultural relevance in health care. Whenever possible, the discussion surrounding social determinants of health focuses on Yukon FNs. Next, a brief exploration of FN history and governance in Yukon is provided. Lastly, this chapter discusses the ADI in regards to: the history of FN health services in Canada; how the ADI is positioned within the federal health sector; the two distinct divisions, the *First Nations On-reserve and Inuit in Inuit Communities Program*, and the *Métis, Off-reserve Aboriginal and Urban Inuit Promotion and Prevention Program*; and ADI's funding history since the time of its commencement. The chapter concludes by discussing the relevance of these topics to the purpose and objectives of the study.

2.2 Demographic Profile of Indigenous Peoples in Canada

In 1982, the Canadian Constitution Act recognized three groups of Aboriginal peoples in Canada: FNs, Métis, and Inuit (King, Smith, & Gracey, 2009). Each of these groups has distinct histories, languages, cultural attributes, and geographical territories (King et al., 2009). Over 600 FN/Indian bands have been recognized in Canada (Indigenous and Northern Affairs Canada, 2014; Jacklin & Warry, 2011; King et al., 2009; Statistics Canada, 2013a). These numbers illustrate a rich history and diversity of FN peoples across the country. Indigenous peoples are distributed over much of Canada, with the northern territories having higher proportions of Indigenous populations, followed by the prairie provinces and Ontario (Jacklin & Warry, 2011). In 2006 it was estimated that there were over 1.1 million people in Canada who reported Aboriginal identity⁵ (Statistics Canada, 2006). Of this total, FNs comprised the largest group, at over 698,000 persons, followed by Métis, at over 389,000 persons, and Inuit, at over 50,000 persons. Between 1996 and 2006⁶, there has been a 29% population increase in FNs and a 45% increase in total individuals reporting an Aboriginal identity (Statistics Canada, 2006).

More recently⁷, according to the 2011 NHS⁸, it was estimated that more than 1.4 million⁹ people in Canada self-identify as Aboriginal, of which 0.6% live in Yukon (around 7,705

⁵ Refers to those persons who reported identifying with at least one Aboriginal group, that is, North American Indian, Métis or Inuit, and/or those who reported being a Treaty Indian or a Registered Indian, as defined by the *Indian Act* of Canada, and/or those who reported they were members of an Indian band or First Nation (Statistics Canada, 2006).

⁶ Only the Indian reserves and settlements that participated in both censuses are included when comparing data between 1996 and 2006 (Statistics Canada, 2006).

⁷ Several factors need be taken into account when comparing data on Aboriginal peoples between the 2006 Census and the 2011 NHS as there are: differences in the wording and in the format of Aboriginal questions; differences in methodology; legislative changes, for example Bill C-31 in 1985 and Bill C-3 in 2011, which affect concepts such as Aboriginal identity and registered Indian status; changes made to the definition of reserves; differences in the list of incompletely enumerated reserves; a higher non-response error in 2011 compared to 2006; and some people report their Aboriginal identity and/or ancestry differently from one data collection period to another (Statistics Canada, 2013a).

⁸ The NHS is a voluntary, self-administered survey that was introduced in 2011 to replace Census Form 2B (Statistics Canada, 2013a).

⁹ Estimates are affected by the incomplete enumeration of 36 Indian reserves and Indian settlements in the NHS. For these reserves or settlements, NHS enumeration was either not permitted or was interrupted before it could be completed, or was not possible because of natural events (specifically forest fires in Northern Ontario) (Statistics Canada, 2013a, b).

persons) (Statistics Canada, 2013a, b). In comparison to non-Aboriginal Canadians, those with Aboriginal ancestry accounted for about 4.0% of the total 2011 Canadian population, 3.8% of the population in 2006, 3.3% in 2001, and 2.8% in 1996 (King et al., 2009; Statistics Canada, 2013a). While higher prevalence may be indicative of changes in Indigenous self-identification in surveys, from this time comparison, it was evident that the recognized Indigenous populations of Canada is growing.

This growth may have been due in part to Indigenous populations having greater numbers of young individuals. From the 2006 Canadian Census, it was estimated that the median¹⁰ age of the total Aboriginal population was 27 years, 25 for FNs, and 40 for the non-Aboriginal population (Statistics Canada, 2006). Similar results were obtained from the 2011 NHS, in which the median age of the total Aboriginal population was 28 years, 27 for FNs, and 41 for non-Aboriginal population (Statistics Canada, 2013a). The greater prevalence of young individuals may have been from both high birth rates and lower overall life expectancy (Adelson, 2005; Jacklin & Warry, 2011; Statistics Canada, 2013a).

While life expectancy has risen in Indigenous populations, it still fell below the average for non-Indigenous Canadians (Adelson, 2005; First Nations Information Governance Centre, 2012). It was estimated that both total Aboriginal identity, and FNs populations are expected to continue to rise, and have a greater proportion of young individuals, compared to non-Aboriginal Canadians (Statistics Canada, 2006). The average annual growth rate of the Aboriginal population was expected to range between 1.1% and 2.2% until 2031, while in comparison, the annual growth rate of the non-Aboriginal population was expected to average 1.0% annually (Statistics Canada, 2006). Lemchuk-Faval & Jock (2004) suggested that the increased birth rate

¹⁰ The median age refers to the exact age where half of the specified population is younger, and the other half is older (Statistics Canada, 2006). This can be used as a measure of the prevalence of young versus older individuals.

and life expectancy will have greater impact on contemporary and future health care systems in Canada.

2.3 Type 2 Diabetes

Diabetes mellitus encompasses a group of health disorders that can be further divided into the clinical categories of Type 1 Diabetes, T2D, gestational diabetes, as well as an early on-set period called pre-diabetes (American Diabetes Association, 2014; Canadian Diabetes Association, 2008; Diabetes Policy Review Expert Panel, 2009; PHAC, 2005). This review focuses primarily on T2D and prevention during pre-diabetic stages. T2D is formerly known as adult on-set diabetes and NIDDM, where diagnosis usually occurs after the age of 40 (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). There is increasing evidence that this disease is now becoming more prevalent in youth, with an earlier average age of on-set than previously (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Ball & McCarger, 2003; Campbell, 2002; Dean, 2002; Dean, Young, Flett, & Wood-Steiman, 1998; Kaler et al., 2006; Young, Dean, Flett & Wood-Steiman, 2000).

The prevalence of T2D in the 2010 Canadian population was estimated to be 7.6%, with a projected prevalence of 10.8% by 2020 (Canadian Diabetes Association, 2011). It has been estimated that T2D is directly responsible for approximately 5,500 deaths annually in Canada, with an increasing rate of 60,000 cases annually (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). The Canadian Diabetes Association (2011) estimated that one in four Canadians currently live with T2D, undiagnosed diabetes, or pre-diabetes, and this is expected to rise to one in three by 2020, if current trends continue.

These trends in the rising prevalence of T2D are profound when considering the biological effects that T2D has on the body. T2D is a metabolic disorder in which body cells fail to respond to normal actions of the hormone insulin (First Nations Information Governance Centre, 2012). This condition is known as insulin resistance, where “normal levels of insulin are insufficient to produce a normal insulin response” (p. 123). T2D develops after the inability to break down glucose leads to a threshold increase in the production of insulin to overcome insulin resistance. This phenomenon is commonly referred to as ‘glucose intolerance’ where the “capability to normally metabolize glucose is diminished” (First Nations Information Governance Centre, 2012, p. 124). Together with insulin resistance, the inability to metabolise glucose leads to health complications such as obesity and hypertension, and together are viewed as a cluster of disorder that may share a common pathogenesis collectively termed ‘metabolic syndrome’ (Basciano, Frederico, & Adeli, 2005; Benyshek et al., 2001; First Nations Information Governance Centre, 2012; Kaler et al., 2006).

As insulin resistance can take years to develop, and may be separate from the onset of T2D, the period before diagnosis is known as pre-diabetes (Canadian Diabetes Association, 2008). Pre-diabetes can last several years for young adults and is a critical phase where people can reduce their chances of becoming diagnosed in part by lowering abnormally high blood glucose levels, which are not yet at the threshold for diagnosis (Diabetes Policy Review Expert Panel, 2009). Young and Mustard (2001) report that undiagnosed cases of T2D represent an “unseen but clinically important burden” of T2D (p. 24). Both undiagnosed T2D and pre-diabetes can cause significant metabolic derangements and impact long-term health. If left unrecognized and untreated, more than half of the population who currently have pre-diabetes are expected to reach the threshold of diagnosis within eight to ten years (Diabetes Policy Review Expert Panel, 2009).

Pre-diabetes and diagnosed T2D both constitute major public health concerns in Canada as these rates are related to wider diabetic complications and cardiovascular disease, and are expected to continue to increase, due to both the growing and aging population and the rise in clinical obesity¹¹ (Diabetes Policy Review Expert Panel, 2009).

Obesity is recognized as a major public health concern in North America and is implicated as a risk factor for developing T2D (Bryan & Walsh, 2004; Drewnowski & Specter, 2004; Masi, 2008). It is commonly suggested that physical activity and changes in diet and consumption patterns through individual or community-based initiatives are major modifiable risk factors for both obesity and T2D (Bryan & Walsh, 2004; Canadian Diabetes Association, 2010; Drewnowski & Specter, 2004; Haman et al., 2010; Health Canada, 2011a; King, Gill, Allender, & Swinburn, 2011; Strong, Mathers, Epping-Jordan, & Beaglehole, 2006). Although the prevalence of obesity can vary widely between communities and geographic locations, for all Canadians, obesity prevalence increases with advancing age, and is highest among women of low income and education levels, and more common in Indigenous women than in men (Bryan & Walsh, 2004).

2.3.1 Type 2 Diabetes in Indigenous Populations in Canada

T2D disproportionately affects more Indigenous than non-Indigenous peoples in Canada (Bodirsky & Johnson, 2008; MacMillan, MacMillan, Offord, & Dingle, 1996; PHAC, 2005; Young, Reading, Elias, & O'Neil, 2000). In the past fifty years, T2D has gone from being virtually unknown in FN populations, to a health concern of epidemic proportions (Garro, 1995; Young et al., 2000). Although national FN population prevalence rates of T2D rely on many

¹¹The most common determinant of clinical obesity is the Body Mass Index (BMI) which is calculated by the person's weight (in kg), divided by height (in m²) (Diabetes Policy Review Expert Panel, 2009).

levels of government and administration surveys, continuous surveys show a steady and rapid increase in prevalence of this disease (Young et al., 2000). Prevalence rates can range from two to five times higher in FN than non-FN populations (ADI, 2000; Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Dyck, Osgood, Lin, Gao, & Stang, 2010; Health Canada, 2011b; Oster et al., 2011; Waldram, Herring, & Young, 2006). Occurring in children as young as 5 years of age, T2D accounts for almost all cases of diabetes in Indigenous populations (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative 2002).

Sparks & Duke (2009) presented a comparative epidemiological assessment from the PHAC in Yukon from 1999-2006 that showed women were more likely to live with diabetes than men. The reverse was true when comparing diabetes rates in the southern and eastern provinces in Canada (Sparks & Duke, 2009). While differences in prevalence were not statistically significant, recognition of how men and women perceive T2D differently, make lifestyle choices, and the additional biological and social implications of gestational diabetes among women and their children continues to be important (Canadian Diabetes Association, 2011; Egeland, Skjaerven, & Irgens, 2000; Iwasaki et al., 2004; Young, Dean, Flett, & Wood-Steiman, 2000). Further, gender analysis is important when understanding effects of stress from living with T2D, where women can be in a “triple jeopardy” if they are the sole providers of families, influenced by racism, sexism, and ethnicity (Iwasaki et al., 2005, p. 979). As such, there are differences in male and female perspectives of living with and managing T2D (Iwasaki et al., 2004). It is imperative that research addresses the ways that gender shapes the construction of health and well-being for Indigenous men and women living with T2D (Anderson et al., 2003; Wilson, 2003).

2.3.1.1 Health Data

The time comparison of diabetes prevalence rates in Yukon and Canada presented is used to contextualize participant perceptions of T2D in *Chapter Five: Discussion*. While local clinical data and electronic medical records exist, and would be more reliable, they were not accessible for this research. Instead of local clinical data, national survey estimates of T2D prevalence was available and is presented in this section. Researchers need to use caution when comparing health data from the NPHS and CCHS as they have different surveying methods and reporting procedures. In particular, comparisons across surveys may not be consistent as the wording of questions, selection of participants, information recorded, and collection of self-reported data are different (First Nations Information Governance Center, 2012). The NPHS conducted longitudinal and cross-sectional health surveys in the provinces and territories from 1994-1999¹² (Brisebois, Mathieu, & Bédard, 2003). The NPHS included subjects such as: disability; diseases and health conditions; health care services; lifestyle and social conditions; mental health and well-being; as well as prevention and detection of diseases (Statistics Canada, 2012).

Following a similar purpose of continual health data collection and surveying, the CCHS began in 2000 by collecting health status, health care utilization, and health determinants in Canadian populations (Statistics Canada, 2015a). It conducted surveys of 110 health regions¹³ through a cross-sectional design (Béland, Bailie, Catlin, & Singh, 2000; Statistics Canada, 2015a). Starting in 2007, the CCHS collected data annually instead of every two years, and reduced the sample size to 65,000 respondents from 130,000 respondents during each reference period from 2001-2005 (Statistics Canada, 2015a). While the main purpose of CCHS data was to

¹² Longitudinal NPHS studies conducted in Canadian provinces continued after the biennial cross-sectional data collection in Canadian territories ended in 1999 (Brisebois et al., 2003).

¹³ Health regions are administrative areas defined by provincial ministries of health according to provincial legislation. For complete Canadian coverage, each northern territory represents a health region (Statistics Canada, 2015b).

inform health surveying and population-based health research, this study utilized CCHS data to understand temporal changes in diabetes rates at the levels of Yukon and Canada (Statistics Canada, 2015a). Due to the population sizes of Yukon FNs compared to the larger-urban centers, estimates of individual FNs are not consistent with territorial estimates. As diabetes prevalence is estimated at the territorial level, estimates within Yukon contain “use with caution” indicators. This data will generally be an underestimate of actual diabetes rates within FN communities.

While estimates within Yukon contain data quality flags known as “use with caution” indicators, a comparison of diabetes rates in Yukon and Canada from 1994-1996 is presented in Table 2.1. From the period of 1994-1996, it is estimated that Yukon had a lower diabetes prevalence than Canada as a whole.

Table 2.1 Diabetes Prevalence in Yukon and Canada from the NPHS

Year	Diabetes Prevalence ¹ (%)	
	Yukon	Canada
1994	2.4 ^E	3.0
1996	2.5 ^E	3.2
1998	2.0 ^E	3.5

¹ Reported for both sexes, population aged 12 and over who reported that they had been diagnosed by a health professional as having diabetes (Statistics Canada, 2001, 2005).

^E designates a “use with caution” indicator, meaning that the data have a coefficient of variation from 16.6% to 33.3%, representing that caution should be taken when interpreting the value (Statistics Canada, 2001, 2005).

Diabetes rates in Yukon and Canada from the CCHS in Table 2.2 can be compared to age-standardized¹⁴ rates of the same survey (Table 2.3). While “use with caution” indicators are present for Tables 2.2 and 2.3, most estimates fall within a 4-7% range. From all tables, data shows that the general trend since 1994 has been an increase in prevalence of diabetes for both Yukon and Canada. Increasing the amount of screening and continuous surveying for T2D and related health conditions, lifestyles, and complications in Yukon are important steps in

¹⁴ Age-Standardization is a statistical adjustment that allows for a more accurate comparison between two populations when they have very different age structures (Statistics Canada, 2016).

understanding health disparities that exist between FN and non-Indigenous populations in Canada.

Table 2.2 Diabetes Prevalence in Yukon and Canada from the CCHS

Year	Diabetes Prevalence ¹ (%)	
	Yukon	Canada
2003	3.7	4.6
2005	4.3 ^E	4.9
2007	4.6 ^E	5.8
2008	2.7 ^E	5.9
2009	4.2 ^E	6.0
2010	5.5 ^E	6.4
2011	4.5 ^E	6.1
2012	8.6 ^E	6.5
2013	5.0 ^E	6.6
2014	7.8	6.7

¹ Since 2007, data for the CCHS are calculated yearly instead of every two years. Weighting controls on the proportion of Aboriginal and non-Aboriginal as well as capital and non-capital residents have been put in place for Yukon. Population aged 12 and over who reported that they have been diagnosed by a health professional as having Type 1 or 2 diabetes. Diabetes includes females 15 and over who reported that they have been diagnosed with gestational diabetes (Statistics Canada, 2015c).

^E designates a “use with caution” indicator, meaning that the data have a coefficient of variation from 16.6% to 33.3%, representing that caution should be taken when interpreting the value (Statistics Canada, 2015c).

Table 2.3 Age-Standardized¹ Diabetes Rate in Yukon and Canada from the CCHS

Year	Age-Standardized Diabetes Rate ²	
	Yukon	Canada
2003	5.2 ^E	4.2
2005	4.9 ^E	4.3
2007	5.3	5.1
2008	2.3 ^E	5.0
2009	4.2 ^E	5.1
2010	5.4 ^E	5.4
2011	4.2 ^E	5.1
2012	6.9 ^E	5.2
2013	4.7 ^E	5.3
2014	7.3	5.2

¹ Age-Standardized is per 100,000 persons (Statistics Canada, 2016).

² Since 2007, data for the CCHS are calculated yearly instead of every two years. Weighting controls on the proportion of Aboriginal and non-Aboriginal as well as capital and non-capital residents have been put in place for Yukon. Population aged 12 and over who reported that they have been diagnosed by a health professional as having Type 1 or 2 diabetes. Diabetes includes females 15 and over who reported that they have been diagnosed with gestational diabetes (Statistics Canada, 2015d).

^E designates a “use with caution” indicator, meaning that the data have a coefficient of variation from 16.6% to 33.3%, representing that caution should be taken when interpreting the value (Statistics Canada, 2015d).

Further, it was important to understand how diabetes rates differ between FN and non-Aboriginal populations in Yukon¹⁵. Diabetes prevalence was compared between FNs and the non-Aboriginal population for the interval 2007-2010 (Table 2.4). Table 2.4 indicates that diabetes rates were considerably higher in FN populations than in the non-Aboriginal population.

Table 2.4 Diabetes Prevalence in FNs Populations in Yukon and Canada

Year	Aboriginal Identity Population	Diabetes Prevalence ¹ (%)	
		Yukon	Canada
2007-2010	FN (living off-reserve)	4.9 ^E	8.4
	Non-Aboriginal	4.2	6.0

¹ Weighting controls on the proportion of Aboriginal and non-Aboriginal as well as capital and non-capital residents have been put in place for Yukon. The term “FN” refers to the FNs populations living off-reserve. Population aged 12 and over who reported that they have been diagnosed by a health professional as having Type 1 or 2 diabetes. Diabetes includes females 15 and over who reported that they have been diagnosed with gestational diabetes (Statistics Canada, 2015e).

^E designates a “use with caution” indicator, meaning that the data have a coefficient of variation from 16.6% to 33.3%, representing that caution should be taken when interpreting the value (Statistics Canada, 2015e).

In addition to the NPHS and CCHS, the data from the First Nations Regional Health Survey (RHS) can be included. The RHS was the first Canadian survey under complete FNs control, following the purpose of producing both culturally and scientifically valid survey data regarding the contemporary health of FN peoples living in Canada. As Statistics Canada surveyed FN peoples living off-reserve, the inclusion of results from the RHS, which included FN peoples living on-reserve and above the 60th parallel, considerably increased the estimated prevalence of those currently living with diabetes (First Nations Information Governance Center, 2012). With a sample size of over 21,000 participants, from 216 FN communities, the RHS of 2008/10 estimated that the age-standardized prevalence of diabetes for FN adults age 25 years or older was 20.7% (First Nations Information Governance Center, 2012). It was clear from both surveys that diabetes in both the Canadian and FN populations is increasingly becoming more prevalent.

¹⁵ In Yukon, all FN persons live in Indian Settlements or within Traditional Territories set forth by FSGAs. A settlement is considered a census division and is “usually located on Crown lands under federal or provincial/territorial jurisdiction. Indian settlements have no official limits and have not been set apart for the use and benefit of an Indian band as in the case with Indian reserves” (Statistics Canada, 2015b).

2.3.1.2 Thrifty Genotype Hypothesis

The theory of a ‘thrifty genotype’ was proposed to explain the prevalence variance of T2D, and other conditions under the umbrella of the ‘metabolic syndrome’, across different populations, including Indigenous groups in North America (Neel, 1962). While this hypothesis has been contested and controversial, it is still discussed within academic literature as a founding assumption about T2D prevalence and Indigenous populations (e.g. Fee, 2003; Gluckman, Hanson, & Pinal, 2005; McDermott, 1998; Speakman, 2008; Young, Reading, Elias, & O’Neil, 2000). The hypothesis suggested that there was an increase in the frequency of T2D as more people came to enjoy the “blessings of civilization” (Neel, 1962, p. 357). Focusing on bodily responses to changes in subsistence practices, Neel (1962, 1999) hypothesized that populations more adapted to hunting and gathering practices have less incidence of T2D, due to both subsistence practices and regular high endurance physical activity. New types of stressors associated with changes in subsistence, physical activity, colonization, and sedentism also produced higher risk factors for developing T2D (Neel 1962, 1999).

The hypothesis suggested that for human ancestors, the diabetic genotype was “thrifty” in the sense that it was utilized for survival (Neel, 1962). The example commonly provided is that hunter-gatherer and pre-industrial societies with this genotype would have a survival advantage in times of food shortage (Cordain et al., 2005; Neel, 1962). Neel (1962, 1999) suggested that adipose reserves during famine allowed people to not die of starvation, thus preserving their genetic composition for possible future reproduction. In response to this theory, Speakman (2008) proposed that during famine, the majority of individuals do not die of starvation, but die of diseases such as cholera and typhoid, and disorders like diarrhoea (Speakman, 2008). Throughout human history, famines with significant mortality to shape genetic inheritance of

surviving individuals were rare (Speakman, 2008). Similarly, Neel (1969, 1999) relied on the notion that these genes would expect obese people to sustain fecundity longer due to famine. Speakman (2008) contends that the reduced fecundity argument is flawed because “famines are almost universally followed by periods of enhanced fecundity, which offsets the decline observed during the famine itself” (p. 1611). Instead of adaptive selection for the thrifty genes, Speakman (2008) argues that it may be genetic drift throughout human migration which resulted in what he terms the “drifty gene” hypothesis (p. 1611).

To further understand the thrifty genotype hypothesis and its relevance to contemporary Indigenous populations and T2D prevalence, it is important to note that rapid industrialization expanded the use of high-carbohydrate foods to replace subsistence living off of low-carbohydrate and high protein diets (Cordain et al., 2005). Additionally, as the quantity of food became more static, the proposed genotype relying on these food shortages was no longer a survival advantage, but a disadvantage as it predisposed individuals to development of both obesity and T2D (Neel, 1962). The thrifty genotype model is suggested to reflect the changes that Indigenous populations in Canada endured in the eighteenth and nineteenth centuries during European colonization.

The thrifty genotype hypothesis has been controversial because of its neglect of Indigenous social and political determinants of health that have profound impacts on health status, as well as an inaccurate reliance on biological standpoint theory (McDermott, 1998; Speakman, 2008). As Fee (2003) explained, researchers may use the thrifty genotype hypothesis as a “crude proxy for the presumed genetic differences” between populations (p. 2988). As screening for diseases can be expensive, researchers recognized a need to know who is at risk for particular diseases, to limit the amount of screening and testing that takes place. Many people outside of the presumed

‘risk races’ have gotten the disease, and many people within them have not (Fee, 2003). Further, this thrifty genotype model has been criticized as it could not explain particular patterns of T2D in all populations (Gluckman et al., 2005).

Higher than average prevalence of T2D in Indigenous populations may not be from a genetic pre-disposition, but “represents an extreme example a physiological effect arising from past and continuing malnutrition (including adult obesity and lack of micronutrients), poverty and social marginalization” (McDermott, 1998, p. 1192). Further, this “social marginalization” may encompass “measurable effects of social class, education, income, poverty, and racism” (McDermott, 1998, p. 1192). This study does not seek to support or disprove the thrifty genotype hypothesis, but it acknowledges the importance of understanding this complex health phenomena using social, political, historic, and contemporary factors that influence population level prevalence trends.

2.3.1.3 Socio-Economic Determinants

While biological risk factors such as genetic inheritance, obesity, weight gain, and hypertension may all contribute to higher prevalence of T2D, researchers have an obligation to also examine structural and social inequalities that create societal risk factors (Hoy, 2009; Neel, 1962, 1999; Young, 2003). Social concerns include not only health and well-being related issues such as physical, financial, and psychological stress of diabetes management and caring for family members with the disease, but also marginal economic conditions such as poverty, unemployment, trauma, violence, and cultural oppression (Iwasaki et al., 2004; Sherifali, Shea, & Brooks, 2012). Biological factors are confounded by the living standards, political, economic, and social subjugation that Indigenous populations endure (Daniel et al., 1999; Gone, 2008). Societal inequalities and disparities may also include changing family social structure, changing

diets, food insecurity, limited employment options, overcrowding or poor living conditions, available infrastructure, access to safe and reliable water resources, societal stressors, as well as cultural variations (Adelson, 2005; Bombay, Matheson, & Anisman, 2009; Canadian Diabetes Association, 2011; Daniel et al., 1999; Sherifali et al., 2012).

Prevalence of T2D is also closely associated with income level. The risk of developing T2D is higher among Canadians with a lower socio-economic status, compared to those with a higher socio-economic status (Diabetes Policy Review Expert Panel, 2009). The level of income in Indigenous families affects all aspects of social and economic life, and can directly relate to T2D prevalence by the quality and quantity of food that families can afford. To understand T2D prevalence in Indigenous populations, analysis of dietary changes from traditional to market foods is important because of an increased production of insulin in response to a diet rich in carbohydrates (Cordain et al., 2005). As discussed in an impending section, low-carbohydrate diets may be suitable for the prevention of obesity and T2D in Indigenous populations during pre-diabetes stages, as well as for treating complications after diagnosis.

Biological and societal factors are not mutually exclusive, but intertwined to create deeply embedded inequalities and disparities. Benyshek et al. (2001) propose an etiology for T2D as a “political disease” that relates to the collective histories of colonization and assimilation of Indigenous peoples in Canada (p. 41). These structural factors need to be examined not only in relation to T2D, but in conjunction with other consequences of involuntary acculturation (Berry, 1990). These consequences can be biological, such as chronic diseases and nutrition, or political, economic, and cultural-social and psychological changes such as values, motives, attitudes, suicide, conflict and aggression, and substance abuse (Adelson, 2005; Berry,

1990; Chandler & Lalonde, 1998, 2008; Dapice, 2006; Frohlich et al., 2006; MacMillan et al., 1996).

2.3.2 Economic Costs of Type 2 Diabetes in Canada

According to the Canadian Diabetes Association (2011), T2D management costs the Canadian healthcare system and economy \$11.7 billion annually, and is expected to rise to \$16 billion by 2020. In Yukon, the estimated direct costs of treating diabetes will double from \$3 million to \$6 million from 2000 to 2016 (Ohinmaa et al., 2004; Sparks & Duke, 2009). Financial costs for people living with diabetes include medications, devices, and supplies, which can vary in price depending on community location and the public programs and services available (Canadian Diabetes Association, 2011). Direct costs from medication and supplies can range from \$1,000 to \$15,000 annually, with an average of \$5,000 (Diabetes Policy Review Expert Panel, 2009; PHAC, 2005). Increasing costs of equipment used for diabetes management continues to burden individuals, families, and communities across Canada (Jacobs, Blanchard, James & Depew, 2000; Ohinmaa, Jacobs, Simpson & Johnson, 2004). The expected costs of T2D management are expected to increase because the prevalence of diagnosed T2D is rising (Barton, Anderson, & Thommasen, 2005; Canadian Diabetes Association, 2010; Ohinmaa et al., 2004).

To assist with some of the costs associated with T2D, there are different federal and provincial/territorial health plans that Indigenous peoples can receive. Registered FN peoples may receive coverage through the Non-Insured Health Benefits Plan (NIHB), for supplies that are not covered under provincial or territorial health care plans. Non-status Canadians may receive coverage from private health insurance plans or income assistance programs, or pay for these services out of pocket (Health Canada & Assembly of First Nations, 2011). NIHB may

provide coverage for medical transportation, eye care, dental care and medication, but does not cover all medications, equipment, services, or travel costs, where the additional costs of maintaining diabetes-specific medications and supplies can be a financial hardship for FN peoples living with T2D (Health Canada & Assembly of First Nations, 2011).

2.3.3 Screening for Undiagnosed Type 2 Diabetes

National administrative health surveys may underestimate diabetes prevalence among Indigenous populations in Canada, even when on-reserve communities are included (Oster et al., 2011). It is estimated that the prevalence of T2D in Indigenous populations is two to three times higher than reported due to the number of undiagnosed cases (Diabetes Policy Review Expert Panel, 2009). This is because T2D is frequently diagnosed in older populations but also occurs in younger generations (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Ball & McCarger, 2003; Lobstein, et al., 2004). Lack of diagnosis may derive from an absence of physicians in remote communities and/or an inability to access Western medical environments (King et al., 2009; Oster et al., 2011). Screening procedures and education about risk factors associated with T2D are not always readily available within communities (Oster et al., 2011).

More resources directed at increasing the frequency of screening programs in FN communities are needed, where improvements would increase recognition of undiagnosed T2D and cases of pre-diabetes (Backholder, Chen, & Shaw, 2012; Dean et al., 1998; First Nations Information Governance Centre, 2012). Additionally, if screening procedures were readily accessible in communities, more Indigenous peoples may get tested (Barton et al., 2005). This is largely a response to inadequate, dismissive, or unresponsive care that Indigenous peoples have recognized within the Western medical system (Barton et al., 2005). Oster et al. (2011) suggests

that accurate and regular T2D surveying is essential to “plan health care delivery and translate knowledge into policy and funding decisions” (p. E803). Early diagnosis and treatment of chronic diseases can reduce complications and can delay premature morbidity (Backholder et al., 2012; Hoy, 2009). It is imperative that the health care delivery system addresses geographical, economic, political, cultural, and socio-historical barriers to increase prevention and management strategies for FN populations living with T2D (Toth, Cardinal, Moyah, & Ralph-Campbell, 2005).

2.4 Indigenous Determinants of Health and Well-Being

Determinants of health can be defined as “the circumstances in which people are born, grow up, live, work, and age, and the systems put in place to deal with illness” (Chokshi, 2010, p. 182). The social gradient in health in Canada is related to the unequal distribution of power, income, goods, and services (Marmot, Friel, Bell, Houweling, & Taylor, 2008). This unequal distribution determines access to health care, education, employment, housing, and communities, and chances of leading an overall “flourishing life” (Marmot et al., 2008, p. 1661). Unequal distribution of resources is a global phenomenon, but in Canada, unequal access to socio-economic and political resources for Indigenous peoples has resulted from a history of colonization and unfair economic and political arrangements (Lee, 1992; Marmot et al., 2008). In essence, who receives health resources is socially determined, and Indigenous peoples in Canada are at the lower receiving end (Marmot, 2005).

While determinants of health can be discussed in relation to all peoples of the world, Indigenous Canadians have had unique cultural and historical experiences that create Indigenous-specific determinants of health. These determinants include, but are not limited to, relations of holism, community, land, territory, sovereignty, culture, health, well-being, and self-

determination (Loppie-Reading & Wien, 2009). In anthropology, nursing, and the health care system more broadly, investigating determinants of health and health disparities for Indigenous populations and other minority groups in Canada and around the world are not new (e.g. Chokshi, 2010; Derose, Gresenz, & Ringel, 2011; Hebert, Sisk, & Howell, 2008; Isaacs & Schroeder, 2004; Johnson, 2013; Loppie-Reading & Wien, 2009; Marmot, 2005; Reading & Nowgesic, 2002; Satcher, 1999; Solar & Irwin 2010; World Health Organization, 2012), and this review discusses how social and environmental factors may influence the health of Indigenous peoples in Canada, with reference to Yukon FNs. In addition to this review, the conceptual framework discussed in *Chapter Three: Conceptual and Methodological Frameworks* explains how this study was understood and conceptualized in-part using an Indigenous determinants of health framework.

2.4.1 Indigenous Epistemology and Worldview

Indigenous determinants of health and well-being derive from an epistemology about how the world is constructed. In comparison to Western epistemology, Indigenous world view is characterized by structures that include: a belief in unseen powers in the ecosystem; knowledge that all things in the ecosystem are dependent on each other; knowledge that reality is structured according to linguistic concepts; and a belief that personal relationships reinforce the bond between persons, communities, and ecosystems (Battiste & Henderson, 2000). Similar to these structures, Indigenous epistemology is fluid and non-linear, where knowledge is transmitted through experiences, stories, and oral narratives, which are fundamental bases of collective histories (Cruikshank, 1994; Bodirsky & Johnson, 2008; Hutchinson et al., 2014; Kovach, 2005; Lavallée, 2007; Thomas, 2005). Collective histories, told over many generations, continue to

promote spirituality, social and mental or emotional health, healing, and well-being (Cruikshank, 1994).

Indigenous construction of health and well-being is holistic, whereas biomedical or Western perspectives have been described as constructing health as the absence of illness and disease (Iwasaki et al., 2005; King et al., 2009; Stephens et al., 2006). From an Indigenous perspective, well-being refers to collective spirituality, tradition, knowledge, histories, experiences, health, stress, and culture always in connection to a sense of family, belonging, and community (Adelson, 2000, 2005; Bartlett, 2003, 2005; Browne & Fiske, 2001; Iwasaki & Bartlett, 2006a, 2006b, Iwasaki et al., 2004, 2005; King et al., 2009; Kovach, 2005; Richmond, Ross, & Egeland, 2007; Stephens et al., 2005). The incorporation of multiple aspects of life is illustrated among some FN groups using the Medicine Wheel¹⁶, where health is achieved through a harmony of mental, emotional, physical, and spiritual well-being, in association with the surrounding environment and landscape (Bartlett, 1995, 1998; Dapice, 2006; First Nations Centre, 2007b; King et al., 2009; Lavallée, 2007; Lemchuk-Faval & Jock, 2004; Loppie-Reading & Wien, 2009; McIvor, Napoleon, & Dickie 2009; Wilson, 2003).

There is a fundamental cultural and traditional relationship that Indigenous peoples have with the land, where one can obtain natural medicines and sacred plants such as tobacco, cedar, sage, and sweet grass (Hill, 2003; Lavallée, 2007; McIvor et al., 2009; Wilson, 2003). As a determinant of health, ‘therapeutic landscapes’, or a strengthening of the relationship between Indigenous communities and the land, can provide another avenue for achieving overall health and well-being (Gesler, 1991; Wilson, 2003). This is because land is an integral part of

¹⁶ The Medicine Wheel is identified differently by FN peoples across Canada. Not all FN peoples associate with the Medicine Wheel. Among FN populations the four directions of the wheel often come to represent different things such as the four directions: north, east, south, and west; health and well-being aspects such as spiritual, mental, emotional, and physical; colours such as white, yellow, red and black; animals such as white buffalo, eagle, red tail hawk, and bear; and medicine such as sweetgrass, tobacco, cedar and sage (Dapice, 2006).

Indigenous identity (Wilson, 2003). Relationships to the land do not exist solely on the ground, but are also in the minds of individuals and communities (Wilson, 2003). Unfortunately, Indigenous epistemology and fundamental relationships to the land are not well represented in health surveys, a fact which widens the gap between Indigenous and Western understandings of health and well-being.

2.4.2 Representation of Health and Well-Being in Surveys

For many health survey instruments, such as the CCHS, the meaning of health and well-being for Indigenous populations may not be adequately portrayed (Adelson, 2005; Richmond et al., 2007). What is commonly lacking is the interpersonal representation of health and spirituality in connection to a sense of culture, community, and the ecosystem (Adelson, 2005; Wilson, 2003). In addition to surveys, Western-style interviews and research methods tend to focus on the individual, beginning from preliminary stages such as defining participant questions all the way to finalizing and publishing reports (Kovach, 2005). From an Indigenous perspective, compromised health may arise from a multitude of perspectives such as natural causes, imbalances in gender obligations and responsibilities, difficult life events, from spirits, as a penalty, or from being cursed (Dailey, 1958; Gone, 2008).

The multitude of pressures and causes of stress that can compromise health may not be fully recognized by a Western medical professional. As an example, Western medicine understands T2D as localized within individual bodies and caused by poor diet and little exercise (Bruyere & Garro, 2000; Sunday & Eyles, 2001). In contrast, Indigenous epistemology may recognize T2D as: imbalances in life; the effects of inter-generational stress from colonization and residential schooling; and living a non-traditional life (Bodirsky & Johnson, 2008; Bruyere & Garro, 2000; Garro, 1995; Howard, 2014). Another common belief is that the dietary

transition from living off the land to urbanized subsistence living is a major cause of recent increased prevalence of T2D (Garro, 1995; Gracey, 2002). Some Anishinaabe refer to T2D as a “sugar sickness”, relating to the increased consumption of carbohydrate-rich foods that are unfamiliar to traditional life (Garro, 1995, p. 40). It is important to use Indigenous epistemology because it creates a space where Indigenous peoples can express themselves without the imposition of Western related terms or ideas, which can lead to further colonization (Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Stephens et al., 2005).

2.4.3 Effects of Marginalization and Colonization

Despite unique cultural affiliations and histories, all Indigenous populations in Canada share experiences of marginalization, colonization, racism, assimilation, and oppression. These events adversely create prolonged stress and affect physical, social, emotional, and mental health and well-being in Indigenous societies (Bodirsky & Johnson, 2008; Gone, 2008; Gracey & King, 2009; Lavallée, 2007; Lee, 1992). These events are known to have “deleterious effects on a number of biological systems” which can in turn give rise to a greater susceptibility to illness (Evans, Barer, & Marmor, 1994, p. 13). These events may dispose individuals to further stressors, and increase vulnerability to the transmission and expression of various diseases, including a higher prevalence of T2D (Bodirsky & Johnson, 2008; Bombay et al., 2009; Howard, 2014). These processes are understood as being tightly embedded within the context of ill health, poverty, and disempowerment (Bodirsky & Johnson, 2008; Green, Hoppa, Young, & Blanchard, 2003; Howard, 2014; Iwasaki & Bartlett, 2006b).

One of the most prevalent factors in compromised health and well-being for Indigenous peoples is intergenerational stress due to a loss of traditional lifestyles (Iwasaki & Bartlett, 2006b; Lee, 1992; Martens et al., 2007). In Canada, the residential school system is considered a

deliberate attempt to assimilate Indigenous peoples into the dominant European culture (Bodirsky & Johnson, 2008; Dapice, 2006; Howard, 2014; Jacklin & Warry, 2011; Lee, 1992; Newbold, 1998; TRC, 2015). For Indigenous people, assimilation results in: the loss of cultural identity; reduction in the use of oral narratives in traditional language; reduction in traditional subsistence practices; separation of families; physical and psychological abuse; numerous trans-generational health consequences; and forced dispossession of land and continued social exclusion (Bodirsky & Johnson, 2008; Cruikshank, 1994; Dapice, 2006; Gracey & King, 2009; Howard, 2014; Indigenous Physicians Association of Canada – Association of Faculties of Medicine of Canada (IPAC-AFMC) Aboriginal Health Curriculum Subcommittee, 2008; King et al., 2009; Kuhnlein & Recevuer, 1996; Kuhnlein, Recevuer, Souedia, & Egeland, 2004; Lee, 1992; Loppie-Reading & Wien, 2009; Martens et al., 2007; Newbold, 1998; TRC, 2015).

More recently, throughout Canada, there are various types of reconciliation and healing initiatives aimed at restoring Indigenous culture and identity (Bodirsky & Johnson, 2008; Castellano, Archibald, & DeGagné, 2008; Howard, 2014; Jacklin & Warry, 2011; McIvor et al., 2009; Stewart, 2011; TRC, 2015). Revitalization of traditional language, culture, and medicine has both a fundamental and sacred role for FNs in Canada (Hill, 2003; Lee, 1992; McIvor et al., 2009). Many communities will assert that their language, culture, and heritage is “at the heart of what makes them unique and what has kept them alive in the face of more than 150 years of colonial rule” (McIvor et al., 2009, p.6). In summary, through Indigenous discourse, understanding the stress that derives from colonial events is imperative to understand Indigenous determinants of health not only at a national level, but in a sub-cultural context. The focus on cultural and historical contexts is also important when understanding traditional lifestyle

practices, where their association with T2D risk factors within Yukon FNs can be examined further.

2.4.4 Traditional and Market Foods in Yukon

It has been hypothesized that the decline of traditional subsistence practices, such as hunting, fishing, and trapping, corresponds with higher obesity and T2D prevalence in Indigenous populations (Benyshek et al., 2001; Bodirsky & Johnson, 2008; Haman et al., 2010; Ho et al., 2006; Kuhnlein & Receveur, 1996; Kuhnlein et al., 2004; Nakano, Kediuk, Kassi, & Kuhnlein, 2005). The decline in traditional subsistence practices in Yukon has been continuously documented (e.g. Wein, 1995; Kuhnlein et al., 2004; and Nakano et al., 2005). Nakano et al. (2005) found that among Dene and Métis children in Yukon, the majority of dietary consumption was of market foods, with land animals and plants contributing only an average of 4.3%-4.7%. Further, Kuhnlein et al. (2004) found that traditional foods were more commonly consumed by older individuals than by the younger generations.

This is important because market foods contain fewer essential nutrients and more carbohydrates than traditional foods which have more protein, iron, zinc, copper magnesium, phosphorus, potassium, riboflavin, vitamin E, and vitamin B6 than market-based foods (Nakano et al., 2005; Willows, 2005). These essential nutrients are important, especially in younger generations during years of intense growth. Market-based carbohydrate-rich foods are a primary source for glucose consumption, and thus implicated in the etiology of early-onset T2D (First Nations Information Governance Centre, 2012; Willows, 2005).

The transition to a reliance on market-based foods is relatively recent in Indigenous history, where traditional diets of FN peoples were low in carbohydrates until permanent settlements through European colonization occurred (Bodirsky & Johnson, 2008; First Nations

Information Governance Centre, 2011; Haman et al., 2010; Willows, 2005). This idea is further supported because most Indigenous languages do not have words to describe T2D or traditional healing related to the disease (Garro, 1995). Further, it is likely that this rapid dietary transition over a couple generations has created complex social, environmental, and economic conditions that lead to risk factors relating to increases in obesity and T2D (Sharp, 2009). Although Nakano et al. (2005) recommend that traditional foods should be consumed more often and replace market foods, Sharp (2009) suggests that there may be environmental toxins within plants and animals that can also cause a higher prevalence of T2D in populations who consume them.

Sharp (2009) describes that water sources and wild game, waterfowl, fish, and various plant species may have toxins that have bio-accumulated¹⁷ and bio-magnified¹⁸ through different trophic levels. This can be detrimental for populations who consume species that have an increased toxicity. The toxins that commonly undergo these processes, and that may have a direct relationship to T2D, include methylmercury, polychlorinated biphenyls (PCBs), and persistent organic pollutants (POPs) (MacMillan et al., 1996; Sharp, 2009). The lipophilic nature and chemical stability of POPs causes them to coalesce in adipose tissue (Haman et al., 2010). This accumulation can contribute to the “production and release of inflammation-related adipose tissue proteins”, which are intricately involved in chronic metabolic disorders such as T2D (Haman et al., 2010, p. S29).

Areas in Northern Canada, such as Yukon and Northwest Territories (NT), which have a history of mining may also experience higher levels of arsenic in the surrounding environment (Bodirsky & Johnson, 2008; Coates, 1991; Koch, Wang, Reimer, & Cullen, 2000; Sharp, 2009).

¹⁷ Bio-accumulation occurs when an organism absorbs a toxic substance at a rate greater than which the substance is lost (Sharp, 2009).

¹⁸ Bio-magnification refers to substances, other toxins, increasing in concentration and they move up a trophic level (Sharp, 2009).

For example, arsenic is absorbed by lichens which is a primary food source for species of caribou (*Rangifer tarandus*), an animal that is commonly harvested by Indigenous peoples in northern Canada (Koch et al., 2000; Sharp, 2009). In Yukon, some caribou and moose may also have higher than average mercury, cadmium, lead, and zinc concentrations in muscle, kidney, and liver meat which are continually being investigated as risk factors for developing T2D (Gamberg, 2006; Schuster, Gamberg, Dickson, & Chan, 2011; Sharp, 2009). Although these chemicals may have low toxicity levels when taken separately, people should be cautious of the combined effects which can be additive or synergistic and can cause greater risk for developing obesity and T2D (Sharp, 2009). Schuster et al. (2011) describe that the daily risk posed by mercury exposure is low when evaluated on a g/person/day consumption basis. While overall consumption of caribou contributes essential nutrients, those that have high levels of mercury are usually detectable and their herds can be avoided by policy and risk-management assessments if available (Schuster et al., 2011).

While both market and traditional foods have potential risk factors associated with developing T2D, it is imperative that as social, environmental, and economic pressures continue to challenge traditional food security¹⁹, communities are aware of the transition and risk factors associated with T2D, obesity, and cardiovascular disease (Garro, 1995; King et al., 2009; Schuster et al., 2011). It is also important that “lived histories of food” such as collective acknowledgement of historical realities surrounding changing eating habits are recognized (Ferzacca, 2004, p. 43). Actions and lifestyles surrounding food preparation, such as hunting, fishing, trapping, and horticultural activities have cultural and social benefits for Indigenous people, whether traditional foods are consumed or not (Agriculture and Agri-Food Canada, 1998;

¹⁹ “Food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life” (Food and Agriculture Organization of the United Nations, 1996).

Bodirsky & Johnson, 2008; Bruyere & Garro 2000; Iwasaki & Bartlett, 2006b; Haman et al., 2010; King et al., 2009; Willows, 2005; Wilson, 2003). Wilson (2003) reports that hunting, fishing, trapping, and horticultural activities are important because they allow individuals to pursue both physical and spiritual connections to the land that are important for physical, emotional, spiritual, and mental health.

To support traditional lifestyles, the ADI can contribute funding to build community-based food security strategies such as: communal kitchens and gardens; healthy food programs; store-based education; skill development activities; as well as food harvesting, preparation, and preservation (Health Canada, 2011a). Although there are potential risk factors for developing T2D from Indigenous subsistence practices in northern Canada, the disease is a multifactorial health condition, and there are other possible risk factors not yet fully explored in scientific and cultural research that can contribute to the observed high prevalence rates (Sharp, 2009). To lower prevalence rates and understand potential risk factors holistically, health care for Indigenous populations needs to be culturally meaningful.

2.4.5 The Importance of Cultural Relevance in Indigenous Health Care

Due to the historic and continuing acts of assimilation and marginalization experienced by Indigenous peoples in Canada, it is imperative to produce a preventative and supportive infrastructure for health care for Indigenous groups that is culturally meaningful and acknowledges collective histories. Browne & Fiske (2001) identify that FN women's experiences with health care are shaped by racism, discrimination, and structural inequalities. FN on-reserve communities may receive federal health services, but they have been founded on a colonial ideology that emphasizes paternalism, dependency on government, victim blaming, and medicalization of health issues (Browne & Fiske, 2001; Elias, O'Neil, & Sanderson, 2006;

Iwasaki & Bartlett 2006a; Waldram et al., 2006; Young, 1984). What is needed is to provide positive and holistically grounded health care to Indigenous communities throughout Canada.

The adoption of culturally appropriate health services provides many positive outcomes as it questions colonial assumptions about Indigenous peoples and their health (American Association of Diabetes Educators, 2007; Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003). The TRC (2015) Calls to Action numbers 22 and 23 address the need for cultural competency when delivering health services to Indigenous communities. Baba (2013) describes cultural competence as a set of behaviours, attitudes, and policies that come together to enable effective work in cross-cultural situations. Competency domains may include, but are not limited to: primary and emergency care; prevention, promotion and protection; communication; ethics, leadership and teamwork; empowerment; community relations; and administration (Baba, 2013). A recent issue in cultural competence is the idea that “cultural communities exist as isolated societies with shared, homogeneous cultural meanings” (IPAC-AFMC Aboriginal Health Curriculum Subcommittee, 2008, p. 10). Power relationships, gender, sexuality, spiritual beliefs, and socio-economic status may remain “invisible” to care providers, thus creating culturally unsafe practices (IPAC-AFMC Aboriginal Health Curriculum Subcommittee, 2008, p. 11). The implication of culturally safe health services is a dominant discourse due to the multicultural nature of Canada. This is the recognition of respect for cultural identity of others and takes into consideration the history out of which people understand their health and well-being (Anderson et al., 2003; Jacklin & Warry, 2011; Kreuter et al., 2003; TRC, 2015). A central tenant of cultural safety is that it is the patient who defines what “safe service” means to them (IPAC-AFMC Aboriginal Health Curriculum Subcommittee, 2008, p. 11).

Cultural relevance provides the ability to locate health and well-being concerns within a historical and social context. This includes the ability to connect the dynamics that both individuals and communities encounter to broader socio-economic and political issues and institutions. It is therefore important for health educators and physicians to demonstrate an understanding of cultural backgrounds and lived histories of Indigenous populations (American Association of Diabetes Educators, 2007; Elias et al., 2006). For FN peoples, this requires that health care providers understand the importance of traditional and holistic medicines (Hill, 2003). This is also true when implementing disease-specific interventions, such as T2D prevention and support (Barton et al., 2005). In a study identifying methods to cope with stress among Indigenous men and women with living with diabetes in Manitoba, Canada, Iwasaki et al. (2005) suggest that people should use collective cultural strengths to facilitate healing or coping with experiences of stress.

Diabetes management needs to be accomplished holistically by maintaining balance and harmony between the mind, body, and spirit (Iwasaki & Bartlett, 2006a, 2006b; Iwasaki et al., 2005). Whenever possible, it is also beneficial to have Indigenous health care workers, who can provide culturally relevant care, as well as empower communities (Lemchuk-Favel & Jock, 2004). Overall, culturally appropriate prevention and management resources will aid in contributing to an improvement of health and well-being for Indigenous populations across Canada (American Association of Diabetes Educators, 2007; Browne & Fiske, 2001; IPAC-AFMC Aboriginal Health Curriculum Subcommittee, 2008; Krueter et al., 2003; Stephens et al., 2006). Gone (2008) discusses the importance of cultural relativism in the idea that, for many Indigenous communities, local cultural interventions are legitimate clinical prescriptions for the promotion of health and well-being by acknowledging “our culture is our treatment” (p. 314).

Like managing T2D, King et al. (2007) argue that ethno-cultural affiliation and gender both influence the process of making lifestyle changes related to cardiovascular disease risk. For some FN peoples, management is influenced by intrapersonal, interpersonal, and extrapersonal factors. Management can include elements such as: beliefs about the origins and causes of illness; the role of family and communities; challenges in accessing culturally appropriate information; as well as access to financial resources. Therefore, it is important to not only address prevention of T2D, but management as well (King et al., 2007). Similarly, a study in British Columbia reveals that participants desire the incorporation of traditional ceremonies in their T2D education and management (Barton et al., 2005).

In summary, cultural relevance in Indigenous health care is important because it takes conventional clinical approaches and amalgamates traditional Indigenous values that coincide with realities of historical and contemporary colonial practices, settlement, and urban life (Adelson, 2005). Increasing cultural competency is a key resource for increasing health equity for all Canadians (Teal & Street, 2009). Cultural relevance leads a path for Indigenous self-determination of health issues using both Western and Traditional knowledge. For Yukon FNs, self-governance is a key mechanism that begins a process of implementing cultural relevance in health care (Horne, 2010).

2.5 Yukon First Nations' History

Yukon counts seven different Athapaskan languages that traditionally have been spoken by FN peoples: Northern Tutchone; Southern Tutchone; Gwich'in; Hän; Upper Tanana; Kaska; and Tagish (Cruikshank, 1981; Yukon Native Language Centre, 2015). The other language traditionally spoken is distantly related to the Athapaskan family and known as Tlingit. Tlingit speaking peoples are originally from the southwest Alaskan coast, parts of British Columbia, and

southern Yukon. As there are traditionally no strict borders between neighbouring FNs, there are fluid boundaries between the languages spoken as well (Yukon Native Language Centre, 2015). While colonization over the past half-century has resulted in the variety and usage of Indigenous languages to decline, many FN peoples in Yukon still recognize their heritage as one or more of the seven Athapaskan language groups (Ferguson, 2010).

Within Yukon, there is much overlap in where these language groups are located. Northern Tutchone peoples live in central Yukon, and Southern Tutchone peoples live throughout south-western Yukon, eastern Alaska, and north-western British Columbia (Ferguson, 2010; Yukon Native Language Center, 2015). Gwich'in and Hän peoples live in central and northern Yukon, as well as the northwest corner of NT and northeast Alaska (Yukon Native Language Center, 2015). Upper Tanana peoples occupy western Yukon along the Yukon-Alaska border and Kaska peoples live in the southeast area of Yukon. Further, Tagish peoples are located in southern Yukon, near Whitehorse and surrounding areas (Yukon Native Language Center, 2015).

FN peoples in Yukon seasonally travelled and traditionally hunted, fished, and trapped for fur as the main sources of subsistence and economy (Coates, 1991; Cruikshank, 1981; Ferguson, 2010; Nadasdy, 2012; Yukon Native Language Centre, 2015). This included the use of terrestrial species of caribou, moose, sheep, mountain goat, gophers, rabbit, squirrel, and other small mammals, as well as aquatic species of salmon, trout, sockeye, coho, and chinook (Cruikshank, 1981). During times of abundance, food was dried and stored in caches for winter (Cruikshank, 1981). Animal skins were tanned for clothing, tents, blankets, and boats. Elaborate feasts known as potlatches were held to commemorate special occasions, such as marriages, naming ceremonies, good hunting, and memorials. Terrestrial flora species were also used for

subsistence and medicine for healing (Cruikshank, 1981; Yukon Native Language Centre, 2015). Traditionally, most FN social relations in central and southern Yukon were structured according to matrilineal kinship structures with exogamous marriages and alliance between kin groups (Cruikshank, 1981). Long before trading posts were established, the FN peoples travelled and traded with their neighbours to the south, the Tlingit people, and with the Copper River people to the north (Cruikshank, 1981; Vanstone, 1982). Later, FN peoples traded with European settlers for goods.

2.6 Contemporary Governance in Yukon First Nations

FN peoples had traditional forms of governance before colonial and patriarchal imposition of the *Indian Act* of 1876 (Coates, 1991; Horne, 2010; Jacklin & Warry, 2011; Loppie-Reading & Wien, 2009). The *Indian Act* and its colonial process diminishes self-determination and creates a lack of influence of FN peoples in politics (Horne, 2010; Loppie-Reading & Wien, 2009). This is beginning to change as efforts to improve Yukon FN's' autonomy in the domain of health are already underway as communities implement Final and Self-Government²⁰ Agreements (Christensen, 2008; Council of Yukon First Nations 2016a, b; Horne, 2010; Indian and Northern Affairs Canada, 2008; Nadasdy, 2012). Discussions and settlement claims began in 1973 when Elijah Smith presented the Government of Canada with a document entitled *Together Today for Our Children Tomorrow* (Nadasdy, 2012; Yukon Indian People, 1973). This document is the first comprehensive land claim formally accepted by the Government of Canada, and is an important step for continual discussions of land claims and self-governance in Yukon (Nadasdy, 2012).

²⁰ Self-Government Agreements emerge from Chapter 24 of the Umbrella Final Agreement and are completed alongside Final Agreements. (Council of Yukon First Nations, 2016a, b; Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990).

Following *Together Today for our Children Tomorrow*, in 1990 the Umbrella Final Agreement between the Government of Canada, the Council for Yukon Indians²¹ and the Government of Yukon was finalized (Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990). The Umbrella Final Agreement was not a legal document, but represented a political agreement between the Government of Canada, Government of Yukon, and the CYFN (Council of Yukon First Nations, 2016b; Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990; Indian and Northern Affairs Canada, 2008). The Umbrella Final Agreement guided Yukon land claim discussions between individual FNs, and the Yukon and Federal Government, and was a foundation for FSGAs (Council of Yukon First Nations, 2016b; Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990; Nadasdy, 2012). 11 FNs have signed FSGAs, guided by the Umbrella Final Agreement (Table 2.5) (Christensen, 2008; Council of Yukon First Nations, 2016a, b; First Nations Information Governance Center, 2012; Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990; Government of Yukon, 2008; Horne, 2010; Indian and Northern Affairs Canada, 2008).

²¹ The Council for Yukon Indians changed its name to the Council of Yukon First Nations in 1995.

Table 2.5 Yukon FNs and Associated Communities

Yukon FN¹	Communities
Champagne and Aishihik FNs (1995)	Haines Junction
Caracross/Tagish FN (2006)	Carcross
FN of Nacho Nyak Dun (1995)	Mayo
Kluane FN (2004)	Burwash Landing
Kwanlin Dun FN (2004)	Whitehorse
Liard FN and Kaska Tribal Council*	Watson Lake
Little Salmon Carmacks FN (1997)	Carmacks
Ross River Dena Council*	Ross River
Selkirk FN (1997)	Pelly Crossing
Ta'an Kwäch'än Council (2002)	Whitehorse
Teslin Tlingit Council (1995)	Teslin
Tr'ondëk Kwëch'in (1998)	Dawson
Vuntut Gwitchin FN (1995)	Old Crow
White River FN*	Beaver Creek

¹ In parenthesis is the year when FSGAs came into effect for that FN. FNs that have not settled land claims and remain Indian Bands under the Federal Indian Act are marked with an asterisk (Christensen, 2008; Council of Yukon First Nations, 2016a; First Nations Information Governance Center, 2012; Government of Yukon, 2008; Horne, 2010; Indian and Northern Affairs Canada, 2008).

Under direction of the Umbrella Final Agreement, individual FN Final Agreements provide guaranteed access to terrestrial and aquatic resources, and establish the FN as a co-manager of all natural and cultural resources in its traditional territory (Christensen, 2008; Council of Yukon First Nations, 2016b; Government of Canada, Council for Yukon Indians, & Government of Yukon, 1990; Horne, 2010; Indian and Northern Affairs Canada, 2008; Nadasdy, 2012). In addition to land claims discussed under Final Agreements, Self-Government Agreements allow FNs to enact independent laws affecting the rights of their citizens. While these Agreements create opportunities for independent jurisdiction in the areas of taxation, land management, development assessment, etc., the Yukon and Federal Government have shared authority in many areas. Final Agreements are legally binding documents, and constitutionally protected to form part of the highest law in Canada. FSGAs enable FNs to gain power over decision-making for their region, in particular, they establish future security for their land and right to self-govern (Christensen, 2008; Council of Yukon First Nations, 2016a; Government of

Canada, Council for Yukon Indians, & Government of Yukon, 1990; Horne, 2010; Indian and Northern Affairs Canada, 2008; Nadasdy, 2012).

Self-governance can be considered one of the most important determinants of health in FNs, in which political decision-making to control their lands, economies, education systems, and social and health services are determined collaboratively (Horne, 2010; Indian and Northern Affairs Canada, 2008; Jacklin & Warry, 2011; Loppie-Reading & Wien, 2009; National Collaborating Centre for Aboriginal Health, 2011a). The historical, socio-economic, and political influence of a community has a major effect on the way in which health care policy is attributed and implemented (Atkinson, Medeiros, Henrique, Oliveira, & de Almeida 2002). These influence FN autonomy, space for local voice in decision-making, and health care implementation (Atkinson et al., 2000). The political structure of the FN, either with FSGAs or without, has an effect on the implementation of ADI funding and resources.

2.7 The Aboriginal Diabetes Initiative

As the program under study is the ADI, this section provides contextual background on: the ADI's history; the two divisions of *First Nations On-reserve and Inuit in Inuit Communities Program* and *the Métis*, and *Off-reserve Aboriginal and Urban Inuit Promotion and Prevention Program*; ADI' purpose; and mandate. The first section discusses the history of health services in Canada, acknowledging influential developments in the evolution of health care policy for Indigenous populations in Canada. Next, a discussion is provided of the ADI's divisions in terms of how funding is allocated for on-reserve and off-reserve FN populations. The ADI's funding history since its creation in 1999 is then examined, with a focus on the ADI's mandate for effectively promoting the prevention and management of T2D.

2.7.1 History of Health Services in Canada

To understand the current organization and financial management of health services for Indigenous populations in Canada, it was imperative to explore the historical context and major developments of health care in Canada. When the first European settlers came to Canada, and FN and Inuit communities were decimated by communicable diseases, there was little effort to control disease outbreaks and few means to do so (Campbell, 2002). Health Canada (2007) describes that it was not until 1904 that the Department of Indian Affairs created a position to develop medical programs and facilities for Indigenous Canadians. In 1945, the Department of National Health and Welfare was created, and by 1962 the Medical Services Branch was formed. The *Policy of the Federal Government concerning Indian Health Services* of 1974 reiterated that the Federal Government had no obligation to provide health services to Indigenous Canadians. Following this, a new *Indian Health Policy* of 1979 recognized the need for community development and partnerships between Indigenous populations and Canadian health care systems. It recognized the circumstances under which many Indigenous communities existed, such as how Indigenous peoples were at a disadvantage compared to most other Canadians in terms of health services (Health Canada, 2007). Created in 1999, the ADI was a key component of the Canadian Diabetes Strategy (CDS) which sought to reduce the incidence of T2D in Indigenous populations through health promotion and awareness (Health Canada, 2011a). In 2000, the Medical Services Branch was renamed the FNIHB, which administers the ADI and other health and social programs designed to address the gap in health outcomes between Indigenous and non-Indigenous Canadians (Health Canada, 2007, see also MacMillan et al., 1996, Table 1).

2.7.2 Aboriginal Diabetes Initiative Divisions

The ADI includes two major divisions administered regionally through Health Canada's FNIHB: 1. *First Nations On-reserve and Inuit in Inuit Communities Program* and 2. *Métis, Off-reserve Aboriginal and Urban Inuit Promotion and Prevention Program* (Health Canada, 2013). The *On-reserve Communities Program* makes up 75% of the program and is not competitive, whereas the *Off-reserve Prevention Program* funding is competitive, and delivered through a proposal request, requiring peer review for approval (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Health Canada, 2013). Both divisions allocate funds based on a funding formula, following program guidelines (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). For the *On-reserve Communities Program*, funding is provided for three major categories: care and treatment; prevention and promotion; and lifestyle support; while for the *Off-reserve Prevention Program*, only prevention and promotion is funded (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002).

Health services for FN and Inuit peoples living outside of their traditional communities, such as urban areas or cities, and Métis are typically delivered by the provincial or territorial governments in which they reside (Health Canada, 2011a; National Collaborating Centre for Aboriginal Health, 2011b). Federal health departments and agencies play a limited role, typically providing time-limited support for culturally meaningful programs such as the ADI (Health Canada, 2011a). It is evident that differences in how funding is allocated affect the ability of FN peoples to access health services and resources, depending on where they reside (National Collaborating Centre for Aboriginal Health, 2011b).

2.7.3 Aboriginal Diabetes Initiative Funding History

In 1999, the CDS was allocated \$115 million for five years, and the ADI was portioned with \$58 million of those funds (Health Canada, 2011a, PHAC, 2013b). To ensure a collaborative process of decision-making, “a National ADI Steering Committee was formed to guide the implementation and delivery of the ADI, and includes representatives from the major Aboriginal representative organizations, Health Canada, and the National Aboriginal Diabetes Association” (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002, p. 11). Through continual collaboration from 1999-2000, the Steering Committee identified the program’s mandate, needs, and priorities (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). During this initial Phase 1, the purpose of the ADI was to facilitate comprehensive, collaborative, and integrated approaches to diagnosing and managing T2D within Indigenous populations and communities for five consecutive years (1999-2004) (Health Canada, 2011a; Toth et al., 2005). The purpose of this initial phase was to build a “foundation of awareness” for future ADI programming (Health Canada, 2011a, p. 4).

As Phase 1 of the ADI was a pilot project, its efficacy in implementing diabetes programming needed to be evaluated to ensure further funding from Health Canada. The Accountability and Evaluation Working Group of the ADI was created and included members of the FNIHB, representatives from the Congress of Aboriginal Peoples, Inuit Tapiriiksat Kanatami, the Assembly of First Nations, the First Nations of Québec and Labrador Health and Social Services Commission, and Battleford Tribal Council (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). In 2002 the Accountability and Evaluation Working Group produced an Evaluation Framework which proposed an evaluation strategy to be

used during each five-year Phase of the ADI. Evaluations for each five-year Phase of the ADI were assessed on two levels. Level 1 focused on “ongoing performance measurement” (p.12). This level included “monitoring, gap analysis and project evaluation for projects conducted in years three through five” (p.12). Subsequent analysis was conducted at Level 2 which was “a final summative evaluation focusing on final program outcomes and impacts and the effectiveness of the ADI in reaching program goals and objectives” (p.12). Further, this report discussed evaluation outcomes, expectations, challenges, tiers, questions, and component-level indicators to assess ADI efficacy. As discussed in *Chapter Three: Conceptual and Methodological Frameworks*, this study used similar interview questions as those produced by this report (Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002). In addition to program evaluations, the ADI was also required to submit a performance report every three years to the FNIHB (ADI, 2006). This performance report provided a source of baseline data for ongoing evaluations and an update for various stakeholders on the progress of each Phase of the ADI (ADI, 2006).

Health Canada (2011a, 2013) described that after Phase 1 (1999-2004), the ADI was further funded by the Government of Canada with \$190 million for Phase 2 which took place over the next five years (2005-2010). Phase 2 was based on four key components: primary prevention and health promotion; screening and treatment; capacity building and training; and research, surveillance, evaluation, and monitoring. The first component, primary prevention and health promotion, focused on community-led and culturally-significant activities that promote diabetes awareness, healthy eating, and physical activity. The second component, screening and treatment, focused on increasing regular screening for the early diagnosis and complications caused by diabetes. This second component also focused on providing education and support for

people living with diabetes, to create better self-management and coordination of services. The third component, capacity building and training, focused on training community diabetes prevention workers and educating health professionals working with communities in areas such as diabetes education, health promotion, and cultural competency. The final component, research, surveillance, evaluation, and monitoring, focused on establishing partnerships with appropriate research agencies and organizations to jointly fund diabetes research (Health Canada, 2011a, 2013). Although the main objective of the ADI was to support the *On-reserve Communities Program*, Phase 2 provided limited support for the *Off-reserve Prevention Program*. Phase 2 funded over 60 projects in Canada involving over 55,000 participants (Health Canada, 2011a, 2013). Further reflection during Phase 2 emphasized the need for evaluation to include: partnerships with FNs, Inuit, and Métis; less administrative burden on communities; the use of culturally appropriate methods; and lastly, to use previous evaluations to improve the ADI in future and subsequent Phases (ADI, 2006).

Phase 3 (2010-2015) of the ADI committed \$275 million to build on progress made in communities over Phase 1 and 2, as well as to seek new communities to implement ADI programs. Phase 3 continued to emphasize the four key components of Phase 2, as well as contribute four new areas of improved focus: initiatives for children, youth, parents and families; diabetes in pre-pregnancy and pregnancy; community-led food security planning to improve access to healthy foods, including traditional and market foods; and enhanced training for health professionals on clinical practice guidelines and chronic disease management strategies (Health Canada, 2011a, 2013). ADI funded activities may vary from one community to another, but could include cultural and traditional activities such as traditional food harvesting and

preparation, canoeing, drumming, dancing, and games (ADI, 2000; Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Health Canada, 2011b).

In 2015, then Federal Health Minister Rona Ambrose announced that the Government of Canada committed “\$120.5 million per year for seven health programs that help reduce the health gap” between Indigenous and non-Indigenous Canadians, of which \$46.8 million will be given annually to ADI to start Phase 4 (Health Canada, 2015a). While the ADI has been continuously funded since 1999, it has undergone periodic revision in which it has the potential to be denied. As *Chapter Five: Discussion* examines further, this instability can be problematic for FNs when trying to plan and implement long-term stability for T2D programming within their communities.

2.8 Summary and Relevance to Study

This review has discussed the distribution of FN and Indigenous populations in Yukon and Canada, emphasizing a growing proportion of Canadian populations in which T2D related health services may be utilized. The implications of Indigenous determinants of health were important for understanding not only the history of health services, but the reasons why health services are shaped the way that they are today. This review discussed the prevalence of detrimental effects of T2D, and how Indigenous peoples perceive determinants of health. From this discussion, it was important to understand how T2D-specific, and holistic health services more broadly, are accessed and implemented.

Although several studies have investigated Indigenous determinants of health, none have discussed these determinants in comparison to the ADI in Yukon. In part, due to the remoteness of some Yukon FNs, minimal studies have been conducted on the access to health services. Through the discussion of Indigenous determinants of health and the history of the ADI, this

review has implied that there needs to be an evaluation at the community level to assess how services are provided in Yukon FNs. As the objectives of this study were to assess the need for T2D supports and the ADI, identify both capacities and barriers in the funding and operating of ADI programs, and to develop recommendations that Yukon FNs and the Federal Government can take to increase access to quality ADI programs and T2D supports locally available, it is important to understand colonial processes and their effect on the current health funding structure. As such, an important question explored in this study was how the implementation and utilization of the ADI in Yukon FNs compares to Health Canada's mandate. The next chapter discusses how the study concerning these limitations in current knowledge of FNs T2D related health services and ADI in Yukon was completed.

Chapter Three: Conceptual and Methodological Frameworks

3.1 Introduction & Design Overview

This chapter discusses the conceptual and methodological framework utilized in this study. The chapter begins by providing the methods related to community-based participatory research, through an exploration of: ethical considerations and research consent; participant recruitment; participant consent; and the process of data collection. Next, a discussion of the conceptual framework utilized in this study is presented. Within this framework two models (i.e. Kilbourne, Switzer, Hyman, & Crowley-Matoka, 2006 and Loppie-Reading & Wien, 2009) are detailed for their impact on both recognizing and increasing health equalities between Indigenous and non-Indigenous populations in Canada. Next, this chapter discusses how the study is situated within a broader process of decolonizing Indigenous health and the paradigms of biocultural and critical medical anthropology. This chapter then provides the methods used during content analysis of the participant interview data, and concludes by discussing how the results of the study were validated to ensure complete and accurate coverage of the participant's ideas.

As a brief study design overview, the method for this study was a process of participant ethnography by interviewing and contextually analyzing responses from Health Directors and administration staff in three Yukon FNs. The purpose was to understand community-based capacities and barriers in accessing and implementing T2D related health programs and ADI funding. Communities vary in their current capacity to access and implement ADI funding. A major strength of this analysis was the engagement of Health Directors and administration staff who pursued solutions to the health disparities that exist for FN residents in their communities. Responses from interviews were used to inform recommendations for policy and procedural

change at both the levels of the Federal Government and the FNs themselves, to improve equity when accessing T2D services and implementing ADI funding.

3.2 Participatory Research Process

The participatory research process began when Dr. Galloway partnered with the CYFN to explore the efficacy of four federal health programs in all 14 Yukon FNs. This study is part of this larger research, focussing on one health program, the ADI, and three of the 14 Yukon FNs. Before data collection and CIHR funding (No. IPH 134071) commenced, Dr. Galloway signed a Research Partnership Agreement (Appendix A) and a Research Protocol agreement (Appendix B) with the CYFN Health and Social Department. Additionally, to perform research in Yukon, a Yukon – Canada Scientists and Explorers Act Licence (Appendix C) was obtained through the Heritage Branch of the Territorial Government’s Department of Tourism and Culture.

The Research Partnership Agreement and Research Protocol guided the study to ensure that ethical guidelines for Yukon FNs’ communities, as well as Ownership, Control, Access, and Possession (OCAP^{TM22}) principles, were followed (First Nations Centre, 2007a; Schnarch, 2004). As stipulated in the Research Protocol,

In recognition that the First Nations collectively own data relevant to their communities, if at any stage of the research an individual FN wishes to access the data, the researcher (Dr. Galloway) will provide them with a de-identified set of the data collected to date from their community. (p. 5)

Subsequently, a copy of each de-identified interview transcript has been provided to all FNs that participated, to hold as records of the study. As a mechanism of control, the Yukon Health and Social Development Commission and the CYFN guided the research design and will approve all final reports of the study before dissemination. The FN communities in which interviews were

²² OCAP is a registered trademark of the First Nations Information Governance Centre.

conducted have ownership and control to use and disseminate all de-identified data relevant to those FNs.

3.2.1 Ethical Considerations and Research Consent

Dr. Galloway's CIHR funded research, including research conducted through this study, received ethical approval from the University of Manitoba Joint-Faculty Research Ethics Board (J2014:087) (Appendix D). In addition to adhering to the study's overarching Research Partnership Agreement and Research Protocols with CYFN, and the principles of OCAP™, this research was funded through the CIHR which has its own mandate for participatory research with Indigenous peoples in Canada. To comply with the CIHR mandate, all aspects of research adhered to the 2014 *Tri-Council Policy Statement (TCPS-2) on Ethical Conduct for Research Involving Humans*, specifically *Chapter 9, Research Involving the First Nations, Inuit, and Métis Peoples in Canada*, throughout the entire study. This included recognizing that research involving Indigenous peoples has been carried out primarily by non-Indigenous researchers and have not reflected Indigenous worldviews. This research emphasized a community-based participatory approach in which the CYFN and participants were included in research purpose and design. Prior to research commencing, I completed the TCPS 2: Course on Research Ethics (CORE) (Appendix E) and the University of Manitoba Research Integrity Online Course: Arts and Humanities (Appendix F). In addition, before participatory research began I signed a Confidentiality Oath to ensure protection of data derived from this study (Appendix G).

At the request of the Research Partnership Agreement and Research Protocols with the CYFN, and to ensure confidentiality and autonomy for the participants in this study, data were de-identified. This meant that names of communities and participants did not appear in the transcribed interview data, this thesis, or any publications and presentations resulting from this

thesis. This was extremely important as there were 14 communities that participated in the overall research, three of which were included in this study. De-identification was also important as participants could be easily identified based on their employment position (i.e. their position as Health Director of a FN). During the transcription process data were de-identified, whereby each participant was assigned an informant letter/name by myself, the transcriber, to protect their identity. In all forms of data dissemination, including this thesis, participants are designated codes using letters A through F. Both the electronic copies of the de-identified transcribed interview data and the paper-based interview data were stored in a secure location at the University of Manitoba before returning data back to the FNs. The electronic interview data were secured using password-protected technology. All data forms were only accessible to myself and Dr. Galloway, and to the CYFN at their request. Following the OCAP™ principle of Possession, copies of the de-identified transcribed interview data were provided to Health Directors of Yukon FNs.

3.2.2 Participant Recruitment

Interviews were conducted with staff of the FN that had knowledge of the process of obtaining federal health funding, a direct role in accessing or implementing ADI funds, or a role in creating health promotion, prevention, and/or supportive programs within their communities. Health Directors and administration staff were chosen as they were the primary people who could share this information. Persons in these positions had knowledge about current community organization and infrastructure, and could relay concerns or needs from other community members. As a member of the community, they could provide experiences about accessing health care as a resident of the FN. A limitation was that these informants may have perceived conditions differently than other community residents as their work interacted with federal health

funding allocation. Proper randomization was not achieved because the purpose of the study and questions asked required participants with selective knowledge within the FN. The CYFN provided Dr. Galloway with a contact list of Health Directors and support staff for all Yukon FNs. Dr. Galloway contacted potential interviewees by phone and email to determine if they would participate in the study (Appendix H). Six interviews were conducted with individuals from three Yukon FNs.

3.2.3 Participant Consent and Data Collection

Participants were asked to choose a place and time of their convenience for their interview, and all chose to be interviewed in their workplaces. Dr. Galloway administered an informed consent session to each participant prior to the initiation of data collection (Appendix I). Included in the consent process for each participant was a discussion of the purpose of the study, the potential risks and benefits of participating, how long the interview would take, and how their confidentiality would be protected. These explanations were conducted in a way that ensured participants could understand their role in the study. Participants were asked if they had any questions or concerns about the consent process, the consent form, or the interview process prior to consent being signed. It was made clear that at any time, the participants could withdraw from the study by means of phone call or email, or by simply stopping the conversation, and their responses would not be included in analysis and translation of knowledge. For each participant in the study, extra care was taken to conduct the interview in an environment that respected, acknowledged, and supported cultural differences (Browne, 1995). Ethical dilemmas associated with selective and small sample sizes, such as participant rights to autonomy, were recognized (Ford & Reutter, 1990).

All interviews were conducted in July 2015, in English, and each interview lasted approximately 30 minutes to one hour. Interviews were not digitally-recorded as the methodology of this study was developed during workshops with the Yukon Health and Social Development Commission at the CYFN. Members of the Commission requested that interviews not be digitally recorded. For the communities included in this study, two researchers, Dr. Galloway, and I were present taking notes, each as a back-up for the other. It was agreed that this method, combined with the preliminary presentation of results with discussion at a meeting of the Yukon Health and Social Development Commission would be sufficient to assess the validity and accuracy of findings. During each interview, notes were made by hand, relaying information about the discussion.

Open-ended, semi-structured interviews were conducted in order to understand from participant perspectives, the current processes and social realities of ADI health program implementation and efficacy. The open-ended nature of the interview questions allowed the conversation to be shaped by what each participant brought up. This meant that the conversation could adapt with minor changes to allow for further discovery and insight into the complexity of capacities and barriers in accessing and implementing T2D supports and ADI funding recognized by the communities. These interviews focused on natural, local, and real-life situations that currently affected communities.

The questions asked (Appendix J) approximate questions asked during program-level evaluation of the ADI (see Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002 pg. 22-25). Shared questions asked in both ADI program-level evaluations and this study included: *“To what extent has ADI been implemented within the community?”* and *“Have ADI funds built or contributed to infrastructure relating to diabetes*

prevention?” The semi-structured approach to data collection provided the potential to discuss many contemporary domains surrounding health policy and implementation, and informants were keen to explore the linkages between diabetes programming and many health and social circumstances experienced by FN citizens. Because of this, Dr. Galloway and I acknowledged appropriate limits and restricted our intrusiveness to the focus of the study (Fort & Reutter, 1990).

3.3 Conceptual Framework

This study utilized a conceptual framework for the purpose of clarifying concepts and proposing relationships among elements in the study. The analysis of elements that derived from interview-style data collection provided a context for interpreting study findings, and to explain observations within the interviews themselves. Conceptual and theoretical models and frameworks were reviewed to understand two separate but interrelated components: health disparities; and program efficacy present in Indigenous communities in Canada. While there were many valuable models that were specific to areas of Indigenous health and well-being (e.g. First Nations Centre, 2007b; Health Canada & Assembly of First Nations 2015; Jeffery et al., 2006; Mignone & O’Neil, 2005; National Aboriginal Health Organization, 2006; National Collaborating Centre for Aboriginal Health, 2010), they were not specific to program and policy efficacy.

Additionally, many models examined health disparities or public health and intervention models (e.g. Anderson et al., 2003; Atun, de Jongh, Secci, Ohiri, & Adeyi, 2010; Carlisle, 2000; Coveney, 2010; Derose et al., 2011; World Health Organization, 2012) but included aspects such as genetic testing and/or the use of biological samples, gender analysis, patient interviews, top-down or government-to-community approaches, qualitative research designs, or other factors that

were beyond the scope of this study. The conceptual framework utilized in the study was based on two influential models for examining health disparities present in Indigenous communities in Canada: Kilbourne et al. (2006) and Loppie-Reading & Wien (2009). These two models were combined to create a three step process (Figure 3.1), whereby Kilbourne et al. (2006) provided Step 1, Step 2a, and Step 3, while Loppie-Reading & Wien (2009) provided Step 2b.

Figure 3.1: Conceptual Framework for Decolonizing Indigenous Health: An Amalgamation of Kilbourne et al. (2006) and Loppie-Reading & Wien (2009).

Step 1

Detecting health disparities

- Defining health disparities
- Defining target populations
- Measuring disparities
- Considering selection and confounding factors



Step 2a

Understanding health disparities at the level of the

- Patient/Individual
- Provider
- Clinical encounter
- Health care system



Step 2b

Understanding Determinants of Health

Proximal

- Health behaviours of individuals
- Physical environments
- Social environments, employment, income and education
- Food Insecurity

Intermediate

- Community infrastructure, resources, and capacities
- Health Care Systems
- Education Systems
- Environmental Stewardship
- Cultural Continuity

Distal

- Historic, political, social, and economic contexts
- Colonization, racism, and social exclusion
- Self-determination



Step 3

Increasing health equity

- Intervene
- Evaluate
- Translate/disseminate
- Change policy

These two models were then integrated with an underlying approach to health equity by understanding how these inequities form from power differentials in an attempt to decolonizing Indigenous, and FN-specific health (Bartlett et al., 2007; Jacklin & Warry, 2011). This approach

recognized the implication of continuing colonial processes and policies, and had a goal to create a process in which governing policies could be reconstructed through a process of Indigenous self-determination and self-governance (Jacklin & Warry, 2011). The focus on decolonizing Indigenous health was supported by the conceptual framework because decolonizing health required an Indigenous determinants of health model to understand policy and practice at the federal, provincial/territorial, and community level (Jacklin & Warry, 2011). As Martens et al. (2007) argued, conceptual “models that include the social determinants of health remind us of the importance of underlying social conditions and their effects on health outcomes” (p. 230). As the ultimate purpose of this study was to increase health equity between Indigenous and non-Indigenous populations in Canada, situating this study within a framework of decolonization was appropriate.

The conceptual framework was designed to fit within a Yukon FN's context by including not only an underlying approach to decolonizing Indigenous health, but proposing continually flexible relationships between Indigenous determinants of health. While Kilbourne et al. (2006) could have explored many different social and health disparities with populations around the globe (e.g. Johnson, 2013), Loppie-Reading & Wien's (2009) focused on interactive layers of influence on determinants of health created specifically for Indigenous populations in Canada. This emphasis on Indigenous epistemology was important to holistically identify health inequities that existed in Yukon FN's. While health may have been considered a biological phenomenon, this conceptual framework also considered an anthropological understanding of health disparities by consulting with biocultural and critical medical disciplines within anthropology.

3.3.1 Detecting, Understanding, and Reducing Health Disparities Framework

The first of two models used to create the conceptual framework for this study was produced for use in epidemiology by Kilbourne et al. (2006), and emphasized three phases: detecting; understanding; and reducing health disparities that arise from the distribution and access to resources in a health care system. This framework was unique from others in that it forced a precise definition of health disparities and target populations, and it provided a process for moving forward in reducing health disparities between different populations (Kilbourne et al., 2006).

The following two sub-sections discuss how the first two phases of Kilbourne et al.'s (2006) framework (i.e. detecting and understanding health disparities) were applied to this study and a Yukon FNs contexts. This third phase, here referred to as *Increasing Health Equity (Step 3)* is discussed after a description of Loppie-Reading & Wien's (2009) framework, *Indigenous Proximal, Intermediate, and Distal Determinants of Health (Step 2b)*.

3.3.1.1 Detecting Health Disparities (Step 1)

The first phase of this study's conceptual model attempted to understand health disparities between different populations by defining and detecting disparities, target populations, measuring disparities, and by considering selection and confounding factors (Kilbourne et al., 2006). Kilbourne et al. (2006) defined health disparities as "observed clinically and statistically significant differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations that are not explained by the effects of selection bias" (p. 2114). For this study, health disparities meant that there were observable differences in the prevalence of diabetes for residents of Yukon and Canada, and differences in prevalence between FN and non-Indigenous populations in Canada. Additionally, this meant that

there were observable differences in the ability of Yukon FNs to access and implement ADI funding and resources, community health data, health care programs, and/or education to support persons preventing or living with T2D.

In Kilbourne et al.'s (2006) framework they defined the target population as “vulnerable” (p. 2113). The change in terminology for usage in this study’s conceptual framework stemmed from the idea that the term ‘vulnerability’ is often associated with a reductionist research approach, and this study did not consider vulnerability as a dominant aspect in understanding health disparities. This research was not structured in a discourse of victimization because despite continuing acts of colonization, marginalization, and racism that FNs have undergone, people have been resilient. The purpose of this step in Kilbourne et al.’s (2006) model was really to define the *target population* in which health disparities are more likely to arise, to further understand and reduce disparities within that population. As researchers and the general public have understood Indigenous populations to be at greater risk for developing obesity and T2D (Canadian Diabetes Association, 2011; Neel, 1962, 1999; Young, Reading, Elias, & O’Neil, 2000), the first phase (Figure 3.1), included defining the target population, which referred to the entire Yukon FN population.

Kilbourne et al. (2006) emphasized having a statistically significant quantitative basis for arguing that health disparities exist, and how inequalities may have changed over time. Having a quantitative basis supported the validation of methods for intervening, evaluating, disseminating knowledge, as well as implementing policy changes. While participants were asked what access to health data and diabetes prevalence rates for their FN they had, this study utilized a mixed methods approach (Johnson & Onwuegbuzie, 2004) by also consulting with national survey rates of diabetes between Yukon and Canada and between FN and non-Indigenous populations

presented in *Chapter Two: Literature Review* and then contextualizing it in *Chapter Five: Discussion*.

Lastly, Kilbourne et al. (2006) emphasized considering selection and confounding factors that may impact the research. For this study, health disparities could only be considered in the communities that participated in interviews. While this study could not make generalized observations for all Yukon FNs, comparisons of the differences in access and implementation of ADI funding and T2D related health programs between Yukon FNs with and without FSGAs was acknowledged. If disparities existed, what could be done to increase health equity and access to resources? Additionally, participants were chosen for this study based on their prior knowledge about their FN and its history of access to the ADI and supports for T2D. It was important to consider the effect that non-representative data could have on the analysis of the whole FN.

3.3.1.2 Understanding Health Disparities (Step 2a)

The second phase of Kilbourne et al.'s (2006) model attempted to understand health disparities at the level of the patient/individual, the provider, the clinical encounter, and the health care system. Kilbourne et al. (2006) emphasized that it was fundamental to understand how health disparities are perceived at various levels because there were alternative views of why disparities may arise or currently exist. A limitation of this study was that only one of these levels, or type of personnel, were interviewed, and the other levels within this model could not be fully explored.

As the primary goal of the study was to understand community access and implementation of the ADI, this study did not interview individual patients and residents within communities, or primary health care providers. Contemporary understandings of the status of

health care relating to T2D and access and implementation of ADI funding came from the community Health Directors and administration staff who participated in the interviews. Participants in this study had either first-hand experience as a patient themselves, or could relay stories and recollections from other individuals within the community through their history in their position. Interview discussions included community functions, requests and needs, the patient-provider relationships, personal experience, discussions with community residents, or when they provided such services themselves.

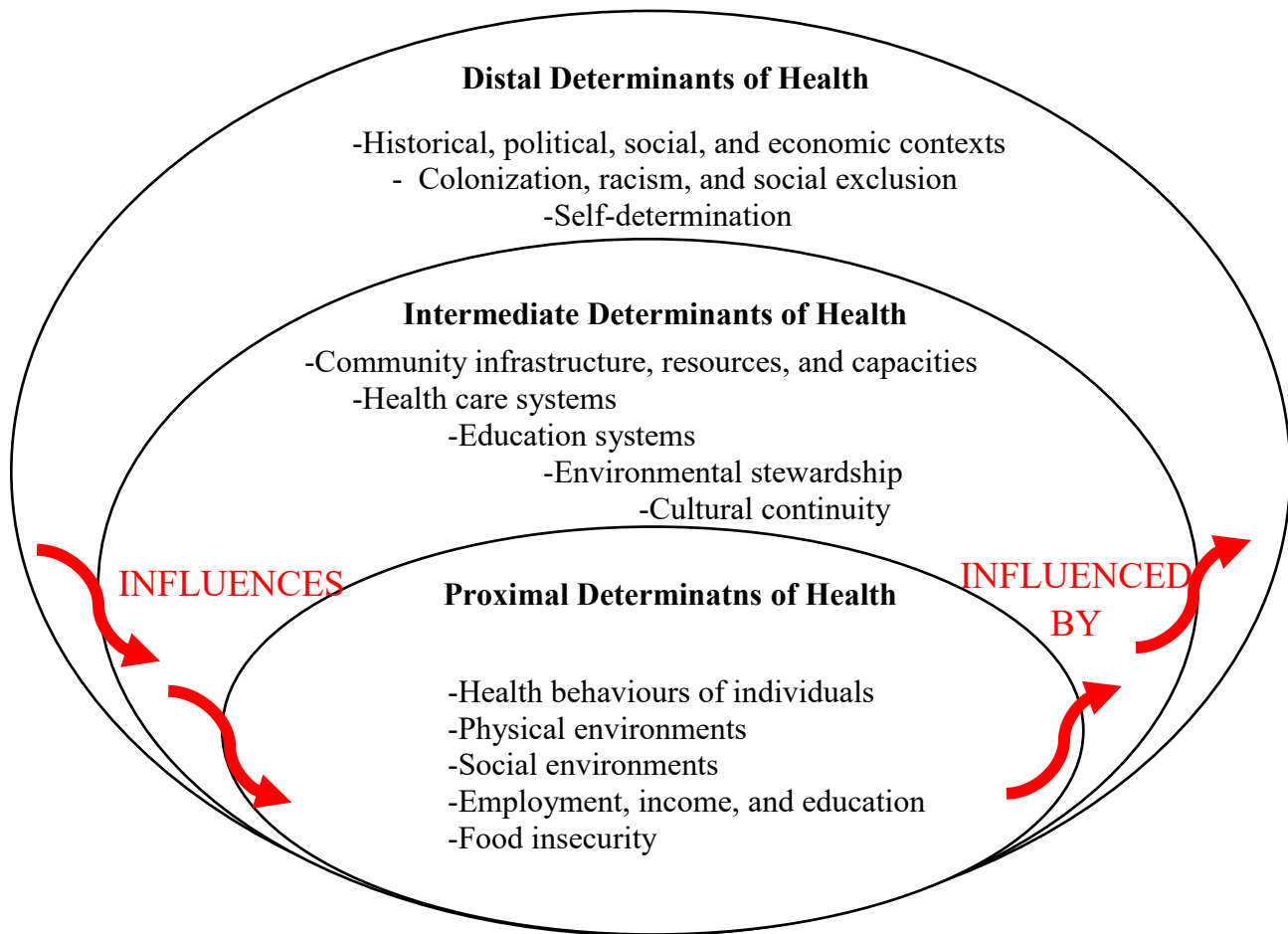
At the level of the health care system more broadly, organizational factors are increasingly being recognized as important determinants of health disparities, and is “being held accountable for improving quality of care” (Kilbourne et al., 2006, p. 2117). It is nearly impossible for health care organizations to improve quality of care if there are differences in the understanding about what the health needs of the community are, and why health disparities exist. For this study, the process through which Health Directors within FNs access, receive, and implement ADI funds is explored. To further understand what is meant by health disparities at the level of the health care system, ADI’s mandate is examined in *Chapter Five: Discussion* (Health Canada, 2011a, 2013), and how the ADI funds are meant to increase access to health care supports. This is then compared with the interview derived data, to determine if there are similarities in what ADI funds are used for, the needs of the communities, and why health disparities exist. To explore why and how health disparities may be perceived differently, and to better understand health disparities at these various levels, the second step in Figure 3.1, *Understanding Health Disparities*, is further divided by adding the second model by Loppie-Reading & Wien (2009). Differences in understanding can be conceptualized by analyzing

Indigenous determinants of health at three interrelated spheres: proximal; intermediate; and distal (Loppie-Reading & Wien, 2009).

3.3.2 Indigenous Proximal, Intermediate and Distal Determinants of Health (Step 2b)

While Kilbourne et al. (2006) emphasized understanding health disparities from various levels of health care, this was taken a step further to encompass Indigenous determinants of health through a non-hierarchical model produced by Loppie-Reading & Wien (2009). As determinants were known to influence a diverse array of health capacities and behaviours, it was important to understand Indigenous-specific determinants of health at three interrelated spheres: proximal; intermediate; and distal (Figure 3.2). The overlapping layers accounted for the “pathways through which determinants express influence” (Loppie-Reading & Wien, 2006, p. 25). On the right side, proximal determinants were influenced by intermediate determinants, which were further influenced by distal determinants. Likewise, on the left side, distal determinants influenced intermediate determinants, and further influenced proximal determinants. It was acknowledged that while models such as this could add “additional layers of abstraction” to current Indigenous health models, it also reflected “the reality of ... a complex and dynamic interplay of social, political, historical, cultural, environmental, and economic” forces (Loppie-Reading & Wien, 2009, p. 26).

Figure 3.2. Representation of the relationship between Indigenous determinants of health. Adapted from Loppie-Reading & Wien (2009).



While these three spheres appeared as hierarchal levels, elements were actually very flexible in their ability to move and impact health in various spheres. For example, while colonization, racism, and social exclusion were placed as a distal determinant of health and had influence over both intermediate and proximal health, it could have also acted as a proximal determinant. As a distal determinant of health, colonization has shaped federal and provincial/territorial governments, including contemporary access to health care, but racism and social exclusion can also occur as a proximal determinant by individual acts towards Indigenous peoples today. While situated in this three-sphere relationship, the functionality of each element

discussed was non-hierarchical and interrelated to create a holistic cycle of influence, in not only sectors of health and well-being, but socio-economic opportunities as well. While elements could have been placed in different spheres, all elements interacted together to determine social access and opportunities that shape health and well-being.

While the relationships proposed by Loppie-Reading & Wien (2009) in Figure 3.2 could have been expressed through flow charts or boxes, the represented relationship was provided in a circle. A circle was chosen as it has sacred meaning to FN peoples such as a dominant symbol of nature, and represented wholeness, health and well-being, the Medicine Wheel, and lifecycles (First Nations Centre, 2007b; Lavallée, 2007). In part, understanding influences of Indigenous determinants of health in this representation related to sharing and healing circles, which are concerned with gaining knowledge and healing through open and respectful discussion (Lavallée, 2007). To provide a more detailed description of the correlating, connecting, and influential relationship of these three spheres, the following three sub-sections discuss how Loppie-Reading & Wien's (2006) three spheres of Indigenous determinants of health model can be applied to conditions that exist for Yukon FNs.

3.3.2.1 Proximal Determinants of Health

According to Loppie-Reading & Wien (2009), proximal determinants have a direct impact on Indigenous people's physical, emotional, mental, and spiritual health. Proximal determinants can be understood to include: living environments, such as overcrowding and family violence; health behaviours of individuals; physical environments; and social environments such as employment and income, education, and food insecurity. For this study, some of these aspects are considered. Physical environments can be understood as infrastructure, housing, and settlement structure, in both historical and contemporary conditions (Loppie-Reading & Wien, 2009). To understand

how the physical environment impacts health, I consider how the location of the community influences health behaviours, choices, and the ability to access health care and food. Social environments such as employment, income, and education, are considered because of the consequences that systematic and continual “colonization, colonialism, systemic racism and marginalization”, here classified as distal determinants, have had on Indigenous peoples being “denied access to resources and conditions necessary” to maximize socio-economic status (Loppie-Reading & Wien, 2009, p. 9). For this study, social environments are understood as supportive infrastructure available at the community level. The question asked here is, what social supports for living with T2D do individuals have access to? What sort of barriers exist in the access or availability of these supports?

For this study, food insecurity was considered a determinant of health, especially in remote Indigenous communities in Canada. Access to nutritious and affordable food depended on not only location, but historical and contemporary socio-political contexts. For this research, open-ended interview discussions on T2D provided the ability to examine access to fresh foods within the community, ability to hunt or have access to greenhouses, costs of foods located near the community, and access to education about healthy versus unhealthy foods. In conclusion, proximal determinants of health focused on elements that affected daily life and decision-making, but Loppie-Reading & Wien (2009) acknowledged that the mechanisms through which proximal determinants influence health are not well articulated in the literature. To further understand why proximal determinants of health arise, it was important to consider influential processes from intermediate determinants of health.

3.3.2.2 Intermediate Determinants of Health

Intermediate determinants were conceptualized as the origin of influence for proximal determinants where “poverty and deleterious physical environments are rooted in a lack of community infrastructure, resources and capacities, as well as restricted environmental stewardship” (Loppie-Reading & Wien, 2009, p. 15). Intermediate determinants included: interaction with health care systems; education systems; community infrastructure; resources and capacity; environmental stewardship; and cultural continuity. Infrastructure at the community level that was considered in this study included administration buildings, schools, daycare, health centers, grocery stores, and cultural community centers, which could all directly influence health behaviours, access to health care, and food insecurity. All aspects within a community influenced the health of individuals and families. Also influential were “inadequate social resources”, such as qualified individuals who could develop and implement programs, which, if absent, could further restrict access to funding (Loppie-Reading & Wien, 2009, p. 17). For this study, aspects of community infrastructure emphasized health services currently available versus services needed. The question asked here was what are the implications if services are not available within the community? How did staff communicate with each other and/or their service providers? What types of resources existed for staff who seek assistance with questions regarding the application or implementation process for federal funding?

3.3.2.3 Distal Determinants of Health

Lastly, Loppie-Reading & Wien (2009) identified distal determinants of health as having the “most profound influence on the health of populations because they represent political, economic, and social contexts that construct both intermediate and proximal determinants” (p. 20). Distal determinants recognized effects of historical, political, social, and economic

consequences such as colonization, racism, social exclusion, and self-determination (Loppie-Reading & Wien, 2009). These factors could influence all aspects of community health and well-being, for past, contemporary, as well as future generations.

A major self-determination factor in this study was the form of governance that the FN has. This study engaged with FNs with and without FSGAs. The question asked here was, how do FSGAs create differences in the access and implementation of ADI funding, T2D supports, and subsequent health disparities that arise from these differences? In conclusion, once health disparities were understood from multiple contexts and spheres of influence, something needed to be done to actually increase health equity. This was done by following Kilbourne et al.'s (2006) third step of reducing health disparities, here referred to as increasing health equity.

3.3.3 Increasing Health Equity (Step 3)

While Kilbourne et al. (2006) discuss reducing health disparities, this thesis refers to this step as increasing health equity between Indigenous and non-Indigenous Canadians, particularly in terms of the quality of access to ADI funding and T2D related health programs and supports for Yukon FNs. The reason for this change in terminology stems from the study's holistic and capacity-based approach (Israel et al., 1998), instead of a reductionist framework. As this study emphasizes an Indigenous knowledge creation approach, it is preferred to discuss this step in a positivist perspective. To accomplish change, Kilbourne et al. (2006) propose intervening, evaluating, translating or disseminating knowledge, and changing policy.

Intervention was understood as providing programs and supports that could directly lead to a reduction in the prevalence of a disparity (Kilbourne et al., 2006). One way to accomplish this was to tailor health services to meet the needs of the target community, or provide intervention programs based on specific health disparities. For this study, the ADI focussed on

reducing prevalence of T2D within Indigenous communities in Canada by acknowledging that funding could be tailored to meet community-specific needs and incorporate Indigenous cultural preferences, lifestyles, and traditions (ADI, 2000; Accountability and Evaluation Working Group of the Aboriginal Diabetes Initiative, 2002; Health Canada, 2011b). Evaluating current health systems were important for making changes at the policy level by identifying potential barriers to effective implementation (Kilbourne et al., 2006). For this research, the component evaluated was the funding methods of the ADI, and its effectiveness at reducing measured disparities in Yukon FNs.

Translating or disseminating knowledge referred to providing education and access to information about health and well-being to a larger audience. The purpose of knowledge translation in this study was that Yukon FNs benefited by having a study published that supports their perceptions of contemporary access to federal health funding in regards to the ADI and T2D. With the support and permission of the Yukon Health and Social Development Commission and the CYFN, this research will be disseminated to the wider academic audience by means of academic articles, presentations at various conferences, and promotion of the study through interviews and networking. Lastly, Kilbourne et al. (2006) acknowledged changing policy as a method of increasing health equity. To make an impact on policy change, this thesis created recommendations of changes to be made at the level of Yukon FN communities, the Federal Government, as well as for the connection and relationship between the community and the Federal Government.

In conclusion, Kilbourne et al. (2006) provided an influential model because health researchers, practitioners, and policy makers have the greatest opportunities to reduce or eliminate differences in the quality, quantity, and access to health care services that communities

receive. However, addressing health disparities, especially in terms of access to supportive infrastructure from ADI funding, was a complex, and multidimensional phenomenon. To better understand such a phenomenon, the model of distal, intermediate, and proximal determinants of Indigenous health produced by Loppie-Reading & Wien (2009), was added to Kilbourne et al.'s (2006) model to create a more holistic and Indigenous-specific conceptual framework. As with Indigenous epistemology and perspectives of health, wellbeing, and T2D, this combination of two interrelated conceptual models was multifaceted with factors that operate at stratified levels and spheres that continually interact with one another. The combination of these two models provided strengths in terms of the other's limitations. Where Loppie-Reading & Wien (2009) provided a context for understanding health disparities more holistically, Kilbourne et al. (2006) provided a strategy for increasing health equity through knowledge translation and policy change.

3.3.4 Decolonizing Indigenous Health: An Underlying Approach to Health Equity

The combined conceptual framework was situated within the broader implications of decolonizing Indigenous health to recognize fundamental differences between health care systems for FN, Métis, and Inuit groups in Canada. Jacklin & Warry (2011) suggested that FN health status, services, and policy, “have evolved from, and are part of, colonial systems... [and] that the decolonization of First Nations health care is a necessary step toward the equity of health care” (p. 373). To understand health disparities using a decolonization framework, it was necessary to establish that the historical and contemporary relationship that exists between the Federal Government and FNs is the root cause of current health status, inequalities, and solutions (Howard, 2014; Jacklin & Warry, 2011).

Colonialism in Canada, combined with federal and provincial/territorial government imposition on FNs' development and governance should be considered as an, if not the, underlying cause of determinants of health (Howard, 2014; Jacklin, 2009). As an act of coming to know the past, a discourse of decolonization does not mean that FN people's health is understood as a collective phenomenon, ignoring cultural diversity and recognizing communities as having been "passive to colonialism", but that the underlying structure characterizing federal health systems is based on a colonial legacy, affecting all FN peoples (Jacklin & Warry, 2011, p. 376). This means that previous governing acts in Canada have "undermined culturally based conceptions of disease, illness, and treatment rooted in Indigenous knowledge" (Jacklin & Warry, 2011, p. 377).

Decolonizing Indigenous health means recognizing that the solution to complex health issues in FN communities "lies outside what is arbitrarily labelled the health sector", and instead, lies within foundational public policies governing the health sector (Jacklin & Warry, 2011, p. 385). To create space in which change can occur, it is necessary to acknowledge the historical basis that founded governing policies. Authority over community life needs to be placed back into the hands of the FN itself, instead of previously held colonial government authority (Jacklin, 2009; Jacklin & Warry, 2011). Through the processes of taking back agency and reclaiming self-identity, FNs can begin to gain greater control over health implementation in their communities. At the individual and community level, decolonizing Indigenous health could mean reclaiming traditional Indigenous subsistence practices, thus revitalizing food knowledge, cultural integrity, and community cohesiveness, which are all "inextricably linked to health" (Bodirsky & Johnson, 2008, p. 1).

Further, decolonizing Indigenous health can include producing Indigenous-guided decolonizing research methods, such as Bartlett et al.'s (2007) six-step process of: rationalizing; enabling; facilitating; experiencing; accepting; and enacting decolonizing research using Indigenous knowledge, reciprocal building, and respectful relationships. In conclusion, a decolonizing Indigenous health framework recognizes that steps need to be taken within research and policy to include FN peoples in the decision-making process as well as the delivery of health systems. Ultimately, increased control over health care systems leads to improved health within FNs (Jacklin, 2009; Jacklin & Warry, 2011).

3.3.5 Anthropological Connection: Biocultural and Critical Medical Anthropology

The conceptual framework produced for this study aligns itself within an anthropological framework of biocultural anthropology, whereby people are viewed as both biological and social/cultural beings, in constant relationship with their surrounding physical, social, and political environment (Dufour, 2006; Goodman & Leatherman, 1998; Khongsdier, 2007; McElroy, 1990). This means that health can be viewed more holistically, as both a physical and social phenomenon, with biological responses and social characteristics influencing one another. This approach can bridge the gap between physical and social characteristics of health, while rethinking basic assumptions about health (Khongsdier, 2007; McElroy, 1990). This can be done by asking new questions, and seeing new relationships between determinants of health for different populations (Khongsdier, 2007; McElroy, 1990). For this study, the emphasis is to understand ADI funding access and implementation in response to social and historical factors that create unique living conditions in Yukon FNs. In addition, it is commonly understood that T2D arises from a lack of physical exercise and poor diet, but this study asks new questions as to

why living conditions permitting these phenomena exist, in a format of rethinking the basic assumptions made about health of FN communities.

Further, biocultural anthropology can take a critical medical approach, in which ethnographic approaches to biocultural studies considers the political economy of health (Baer, Singer & Johnsen, 1986; Singer, 1989; Witeska-Mlynarczyk, 2015). Grounded in Foucauldian theories of biopower, discipline, and politics, critical medical anthropology proposes that health disparities are determined by socio-economic structures that perpetuate poverty and disadvantages (Carroll, 2013, 2014; Witeska-Mlynarczyk, 2015). For example, differential political and economic power is an avenue through which Indigenous groups in Canada have been systematically disadvantaged. During research, individual perceptions and experiences are introduced, but the “macrosocial process” of political and economic forces is not forgotten (Witeska-Mlynarczyk, 2015, p. 387). Anthropologists can ask questions such as “Who has power over the agencies of biomedicine? How and in what form is this power delegated?” (Baer et al., 1986, p. 96). By critically reflecting on how contemporary Western health care practices are constructed, and their delegation of the decision-making process, anthropologists can better understand how health disparities are influenced by socio-economic structures (Witeska-Mlynarczyk, 2015). Further, this approach can analyze the lasting effects of social inequity on health outcomes for politically disadvantaged populations (Baer et al., 1986). Understanding health within political systems shows how power differences shape social processes (Erasmus & Gilson, 2008).

While a biocultural approach was used to understand perceptions of T2D in FN communities, a critical medical anthropological approach was used to identify who is ultimately in control of ADI funding decisions, and the subsequent implications of such control (Baer et al.,

1986; Witeska-Mlynarczyk, 2015). This study identified how the use of ADI funding varied between Yukon FNs with and without FSGAs. As control was important in identifying health inequalities, understanding the history of both the ADI and FN communities was important. This study also emphasized the effects of various levels of determinants of health, through the promotion of health equity (Baer et al., 1986; Witeska-Mlynarczyk, 2015). Individual FNs have a gradient of access to resources, in part, due to their historical legacy with federal and provincial/territorial governments. Constructed thought its history, Indigenous epistemology was an important factor in understanding social and cultural determinants of health and well-being for contemporary populations impacted by T2D.

3.4 Content Analysis Procedure

Founded in Grounded Theory research, this study utilized a qualitative and inductive content analysis procedure to understand participant perceptions during interviews (Corbin & Strauss, 1990, 2008; Glaser & Strauss, 1967; Green, 2014; Imenda, 2014; Sandelowski, 2000). This method consisted of identifying themes and categories that emerged from interview data. The analysis was inductive in that it attempted to make broader generalizations from interview-driven observations. In this process, observations during interviews were made, a pattern of elements was discerned, generalizations of the elements were made, and these patterns and elements were used to infer an explanation of the phenomena observed. The explanation of phenomena was understood both within the interviews themselves and more largely within the community in terms of the questions set forth in the study objectives.

A benefit of the content analysis procedure was that it allowed the researcher to stay close to the original data and yet allowed for categories to be generated and conclusions to be drawn (Burnard, 1991). It was possible to “distil words into fewer content related categories”,

while still producing a “systematic and objective means of describing and quantifying phenomena” (Elo & Kyngäs, 2008, p. 107). Content analysis has been widely used in qualitative research to explore a diversity of social science and humanities disciplines and health related topics such as: health care practices in nursing (Elo & Kyngäs, 2008; Juvani, Isola & Kyngäs, 2005); effects of social media on the delivery of health promotion (Ramanadhan, Mendez, Rao & Viswanath, 2013); HIV/AIDS (Jesus, 2007; Mo & Coulson, 2009); gender studies (Neuendorf, 2011); usage of internet during prostate cancer (Broom, 2005); and heart failure (Europe & Tyni-Lenné 2004).

The aim of the content analysis procedure was to produce a “detailed and systematic recording of the themes and issues addressed in the interviews and to link the themes and interviews together under a reasonably exhaustive category system” (Burnard, 1991, p. 462). To accomplish this aim, the content analysis procedure undertaken in this study was adapted by methods discussed by Burnard (1991) for use in analyzing qualitative interview transcripts based on Grounded Theory. The first step taken, after all interviews were conducted, was transcribing notes that were made during interviews. These transcribed notes were electronically compiled into password-protected files. All participants and their communities were de-identified during this process.

The second step, following coding procedures for qualitative analysis developed by Burnard (1991), was to break down each interview into single-line sentences where coding could then take place. Beside each line of the transcribed interview, words, thoughts, and phrases that captured what was being expressed was written down (Elo & Kyngäs, 2008). This stage was done first by hand, where emerging elements were coded based on words, phrases, or ideas expressed by the participants. This stage was done multiple times to ensure that an exhaustive list

of elements could be obtained from the transcribed interviews. Further, the aim of this stage was to “become immersed in the data” (Burnard, 1991, p. 462). From this step, an exhaustive list of elements that arose during coding was compiled that could then be further categorised. Having done this initial coding first by hand, it allowed for some sense of categories that could be made and how certain elements could be group together.

The third step was to import the original single-line sentence transcribed interviews into the qualitative research software NVivo 10 created by QSR International Pty Ltd. A software license was purchased for full access to NVivo 10 during the study. A combined method of both manual and software assisted methods of content analysis was used to achieve the best results (Leech & Onwuegbuzie, 2011; Walsh, 2003; Welsh, 2002). Because pre-coding was already done, NVivo 10 was mainly used as an organizing tool. Each of the interviews were imported individually, so that characteristics from each interview could be analyzed separately. The unit of analysis was the transcribed interview data because the software allowed for a visual representation of categorizing similar elements into categories and themes. NVivo 10 allowed for the creation of various levels at which the elements could be organized. The information collected during the interviews led to the theme development, with the support and background knowledge from the review of literature to provide supporting points. This process was inductive in that there were no pre-existing categories to place elements derived from interviews. Data analysis and the grouping of elements consisted of organizing and re-organizing elements into categories and themes multiple times, to ensure a best fit, and to highlight ideas that participants brought up during the interviews.

NVivo 10 referred to categories created as Nodes, where Parent Nodes were considered higher order categories, and Child Nodes referred to lower order categories that contain multiple

elements, phrases, and ideas derived directly from the interviews (Walsh, 2003). Each Parent Node may have had more than one Child and Sub-Child Node. The next step taken was to begin to categorize the list of elements identified in coding by different Nodes so that similar elements could be grouped together (Burnard, 1991). The purpose of collapsing elements under higher order headings was to collapse similar or dissimilar elements into broader categories (Burnard, 1991; Elo & Kyngäs, 2008). The purpose of creating broader categories was to provide a means of describing the phenomena and relating it to a broader conceptual framework (Burnard 1991; Elo & Kyngäs, 2008).

The nature of this research, which emphasized understanding health disparities, FN people's health, T2D, and access to ADI funding needed to be understood holistically. Much like how Loppie-Reading & Wien (2009) explained that proximal determinants were influenced by intermediate determinants, which further were influenced by distal determinants, there were various spheres of interaction when understanding health disparities in Yukon. For this study, this meant that some participant's ideas contained more than one element, and in this case the element could be sectioned under more than one Node. For example, the use of visual aids as a method of communication fell under the Child-Node *First Nation Culture* as well as *Education*. The final step, after elements derived from interviews were finalized into Nodes, was to determine how these categories related to one another, and how elements may influence each other. This step determined how categories from elements related to both the interviews, as well as to the conceptual framework for understanding health disparities and increasing health equity.

3.5 Validity

This study stressed the importance of doing research *with*, rather than *on* communities, which "affirms the value of communities' experiential knowledge and stresses a collaborative

process” (Leung, Yen, & Minkler, 2004, p. 500). The emphasis here was that researchers and communities “co-create knowledge” during the research process (Leung et al., 2004, p. 500). To co-create knowledge, and to guard against researcher bias, the study was validated by utilizing a respondent validation process, in which the results of the research were discussed with the participants of the study (Leung et al., 2004; Mays & Pope, 2000). The participants’ reactions to the results were also incorporated into the final documentation of results and recommendations of the study (Mays & Pope, 2000).

This validation was done by presenting the findings to the Yukon Health and Social Development Commission on March 3, 2016 in Whitehorse. In this presentation, I discussed the results of my research and the implications of my results in regards to the research questions and goals of the study. To promote collaboration there was a discussion of how well I represented general impressions of ADI access and implementation, if there were any errors in my interpretation, and what aspects may be missing or still need to be added to my analysis and discussion. This presentation and feedback process was invaluable to explaining the results within the larger academic literature. For those who were not present at the Yukon Health and Social Development Commission Meeting in March 2016, a teleconference was set up with participants, myself and Dr. Tracey Galloway during May, 2016.

3.6 Summary

This chapter presented the conceptual and methodological frameworks utilized in this study. This chapter began by presenting the steps taken during participatory research, including: how ethical considerations and research consent was obtained for this study; how participants were selected and recruited to take part in this study; how participant consent was provided; and how participant data was collected and kept confidential. This chapter also presented the

conceptual framework in which detecting, understanding, and reducing health disparities was understood through Kilbourne et al. (2006), and understanding Indigenous proximal, intermediate, and distance determinants of health was understood through Loppie-Reading & Wien (2009). This combined framework was situated on an underlying approach to decolonize Indigenous health, as well as a biocultural and critical medical anthropological approach to understand Indigenous health in a holistic and critical manner. Next, this chapter outlined the content analysis procedure taken to understand participant perceptions. Content analysis was done using a qualitative inductive approach, founded in Grounded Theory. Lastly, this chapter outlined the process through which the study results were validated, by presenting them to participants of the study and the Yukon Health and Social Development Commission.

Chapter Four: Results

4.1 Introduction and Overview

This chapter presents the results of the study's first objective, which is to understand participant perceptions of T2D prevalence. This chapter also presents the results of the study's second objective, which is to identify how participants perceive capacities and barriers when accessing and implementing ADI funding. Analysis of interview data reveals the significance of community strengths, cultural values, traditions, and historical conditions in terms of the access and implementation limitations of the ADI within three Yukon FNs. The study findings are characterized by a capacity-based approach, which recognizes community resources that can be utilized to gain better access to ADI funding and resources. Participants recognize capacities at the community level, as well as perceived barriers to accessing and implementing T2D education, awareness, prevention, and management programs from two distinct but interrelated levels: within FN communities, and at the level of the Federal Government. To understand the relationship between these two levels, it is important to recognize the step between them, here referred to as *Between the Community and the Federal Government*. All participants view this three-point relationship in similar ways, identifying present-day barriers to ADI implementation and T2D programs as a local versus 'out there' perspective. The study's third objective, to produce recommendations for accessing and implementing ADI funding at both the local and the federal level, is discussed in *Chapter Five: Discussion*.

I locate most elements discussed during interviews within the local or community level. This is important because it illustrates how participants, both at the levels of Health Director and administration, as well as local community residents, understand the world of health services.

What I primarily observed through the interview process is how everyday decision-making, lived experiences of health, and service delivery transpires for Yukon FN residents. Participants explain that program delivery at the community level is influenced by the relationship that the FN itself has with the Federal Government through land claim discussions and the signing of FSGAs. All participants discuss the distance that exists between the Federal Government and the community in which they work. This distance is further explored through community perspectives of the Federal Government. These are contextualized in *Chapter Five: Discussion* within perspectives from Health Canada's FNIHB which administers the ADI.

4.2 Community-Based Sample

Results of this study included the findings from six interviews with participants who held Health Director or administrative positions within three Yukon FNs. All participants had varying degrees of connection to the community in which they worked, and had knowledge of diabetes prevalence, access to services and programs, community capacity, and ADI funding procedures. With limited resources and time to conduct more interviews, these participants were targeted because they possessed specialized knowledge related to the objectives of the study. When possible, data analysis incorporated participant quotations in order to support and recognize the views of participants. To maintain confidentiality for the participants in the study, the results used non-identifiable aliases. While the sample in this study were non-random and may not be representative of all FN residents in Yukon, participants' particular expertise contributed to building a sense of understanding access to ADI funding.

4.3 Terminology

The presentation of results uses specific terminology within the context of this study. The term *resident* refers to an individual living in a FN that may or may not self-identify as FN. *Citizen* refers to a FN resident who self-identifies as having Indigenous heritage, and is recognized by the FN as Indigenous. The term *service* refers to a system providing a public need such as grocery stores, health education, and individualized consultation whereas the term *program* refers to specific events administered by a service. For example, a program may be food subsidy in the form of purchase vouchers, in part associated with a grocery store service. Another example of a program would be foot care, in part associated with the larger service of personalized T2D health care. As communities are not homogenous, both FN and non-FN residents of a community may access services and programs. Both services and programs within a community may be both formal and informal, as well as funded through a variety of sources, such as the communities themselves, and/or departments at the territorial or federal level.

4.4 Node Organization Overview

During the exploration and coding of interview transcripts, several capacities of the communities, as well as perceived barriers to implementing ADI funding were recognized. All participants identified capacities in terms of achieving overall health and well-being and that could contribute to T2D awareness and prevention. These included: dedicated community-based staff; FN cultural attributes such as traditional food harvesting; strong sense of community, and in some cases a strong sense of leadership; and community resilience. Participants identified barriers when accessing T2D programming. These included: inadequate facilities; high turn-over or lack of staff in administrative or health care positions; lack of specific programs, resources, and supports needed in the community; difficulties in the ability to effectively use and implement

health data of the community; variable connection and integration with other communities for support; varying availability of educational resources; limited access to nutritious and affordable food; variable perceptions of the current needs and issues within communities; travel to obtain health services and food; the impact of continuing colonial ideas that affect the implementation of services available; the location of the community; lack of both internal and external health funding; and limitations in the territorial and federal health program application process.

It was fundamental to understand at what level these barriers exist. The results indicated that barriers do not originate from one source only, but are part of a larger phenomenon of health disparities and unequal access to health resources for Indigenous communities. This was also supported by the conceptual framework in which proximal, intermediate, and distal indicators of health all contributed to present-day conditions (Loppie-Reading & Wien, 2009). Participants' perceived that both capacities and barriers exist when accessing and implementing ADI funding. Using NVivo 10, participants' ideas were organized in a hierarchal fashion showing subsequent relationships and stratification (Figure 4.1). Most topics contained both capacities and barriers perceived by the participants. As this study emphasized a holistic understanding of how access to health programs related to T2D, many elements could be placed within multiple topics. In recognition of the complex and real-life situations that occur, this analysis did not consider ideas or concepts to be mutually exclusive. As such, Table 4.1 included an '*Examined in Other Nodes*' section, in which ideas were influential to the topic presented, but were more predominant in other topics.

Figure 4.1 Topic Organization Overview

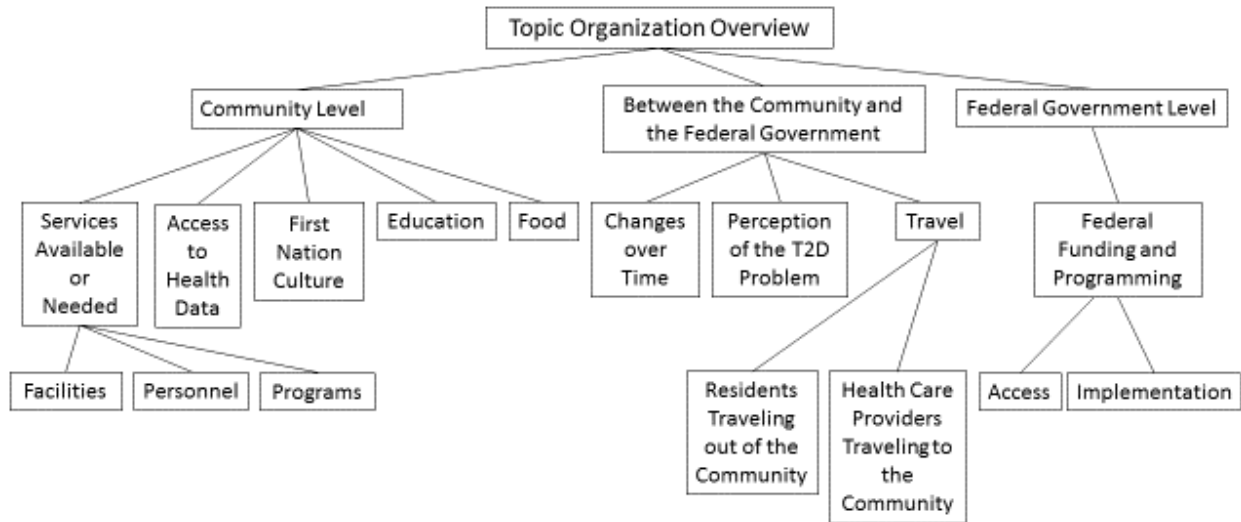


Table 4.1 Summary Chart for the Organization of Interview Discussions

Parent Node	Child Node	Sub-Child Node (if applicable)	Elements Derived from Interviews
At the Community Level	Services Available or Needed	Facilities	<ul style="list-style-type: none"> -infrastructure -health centers, nursing stations -grocery and convenience stores -police and fire -daycare and schools -Yukon College Annex -Administration facility <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -Elders' facility -greenhouses and gardens
		Personnel (Health and Administration)	<ul style="list-style-type: none"> -resident nurses, doctors, community health representatives, health care workers, home support workers -dietitians, dentists -trained daycare, teachers, and support staff -family social support worker -activity and youth coordinators -counsellors -health care workers and support staff who are both territorially and federally funded as well as FN funded -combined abilities to provide services and resources -transport residents to facilities -high turnover positions -limited staff -education, experiences and qualifications of

			<p>staff</p> <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -travelling services and staff who may have continuing colonial ideas/impressions about the community
		Programs	<ul style="list-style-type: none"> -holistic health programs -nutrition services -foot care -daycare -cooking programs -delivering medications -counselling and Alcoholics Anonymous, smoking and substance abuse programs -screening and diabetes testing -individualized consultation -education and awareness through visual aids <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -residential school healing -food subsidy and/or food delivery and preparation
	Access to Community Health Data	N/A	<ul style="list-style-type: none"> -RHS data -health data not available in accessible formats -varying ability to use health data effectively -understanding risk through CANRISK study results
	First Nation Culture	N/A	<ul style="list-style-type: none"> -history, land claims, languages -political environment and self-governance -sense of leadership, creating plans for the future -connection with other communities -hunting and fishing -greenhouses and gardens -connection to the land -holistic health and well-being promotion -sense of community/communities coming together -Elders' facility -residential school healing <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -education and awareness through visual aids -family health promotion and involvement -need for new programs that get away from colonial legacies and meets the needs of communities
	Education	N/A	<ul style="list-style-type: none"> -nutrition services and education about healthy eating -more education about T2D is directed at

			<p>adults than at youth</p> <ul style="list-style-type: none"> -need more education on prevention directed at teenagers -understanding false advertising -there is an importance on getting the messages right <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -daycare and schools -Yukon College Annex -individualized consultation -education and awareness through visual aids -understanding risk through CANRISK study results -knowledge and expectations surrounding T2D has changed
	Food	N/A	<ul style="list-style-type: none"> -food subsidy and/or food delivery and preparation -cookbooks -need more food options for diabetics <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -hunting and fishing -greenhouses and gardens -nutrition services and education on healthy eating -food purchasing may be done external to the community
Between the Community and the Federal Government	Changes over Time	N/A	<ul style="list-style-type: none"> -knowledge and expectations surrounding T2D has changed -more awareness and education is available now then every before -loss of previously held services (cooking programs, T2D programs, youth center, daycare) -constantly adjusting to the current needs of the communities -need for new programs that get away from colonial legacies and meets the needs of communities -taking charge of changes within FN communities <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -residential school healing -variability in how problematic T2D is within FN communities
	Perception of the T2D Problem	N/A	<ul style="list-style-type: none"> -variability in how problematic T2D is within FN communities -T2D rates are growing in the adults, not just the teenagers

			<ul style="list-style-type: none"> -people generally want to know if they have T2D or not -residents are spread out over different locations, so is T2D <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -counselling and Alcoholics Anonymous -understanding false advertising -travelling services and staff who may have continuing colonial ideas/impressions about the community
	Travel	Residents Travelling out of the Community	<ul style="list-style-type: none"> -travel to the closest mid-to-large sized community to obtain health services -referral process for services that are unavailable within the FN -food purchasing may be done external to the community -due to the community location it can be hard to get fresh fruits and vegetables -people want services available within the community so they do not have to travel
		Health Care Providers Travelling to the Community	<ul style="list-style-type: none"> -dentists, doctors, nurses may come at irregular or infrequent visits -presentations on health concerns -no continuity for the patients in terms of relationship building, and records -may have continuing colonial ideas about the community
At the Level of the Federal Government	Federal Funding and Programming	Access	<ul style="list-style-type: none"> -ADI funding is combined in a Financial Transfer Agreement (FTA) from the Federal Government for FNs with FSGAs -need to apply for more funding -difficulties exist in application processes -there is a need for supportive resources for funding applications -creating plans for the future is important in the implementation of programs and funding -barriers exist in the NIHB program compensation process <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -high turnover positions -varying ability to use health data effectively
		Implementation	<ul style="list-style-type: none"> -family health promotion and involvement -there may be no T2D-specific programs -differences in reporting procedures for FNs with and without FSGAs <p><i>Examined in Other Nodes:</i></p> <ul style="list-style-type: none"> -food subsidy and/or food delivery and

			preparation
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4.5 At the Community Level

The first category in the three-point relationship surrounded daily activities at the community level. As all participants were either citizens of the FN, or worked within the FN, it was evident that this analysis would encompass participant’s perceptions at the community level. As participants used their different experiences to discuss contemporary access to health services and programs, their ideas may differ from those of other community residents. Participant’s experiences were rooted in their community’s history and the capacities apparent in the community itself. These experiences were further discussed through the services available or needed, access to health data, culture, education, and food available within communities.

4.5.1 Services Available or Needed

At the center of the discussion on community-based capacities and barriers was the conversation about what health programs were currently available or needed within communities. Participants identified essential components that were needed. These have been separated into *Facilities*, *Personnel (Health and Administration)*, and *Programs*.

4.5.1.1 Facilities

Participants discussed varying degrees of space and facilities available for use, but many lacked infrastructure or had inadequate funding for necessary improvements and upgrades. Two FNs had access to community health centers. Of these two FNs, one had a health center directly within the community, and the other FN was able to access services from a health center in a

neighbouring community. The other FN that participated in this study had a nursing station, all with resident nurses. While the discussion centered on facilities designed for T2D care such as health centers and nursing stations, the conversation also included police stations and fire halls, local grocery and convenience stores, and daycare and schools. For two FNs, the distance to convenience stores was minimal as there were stores located within the communities, but participants recognized that the majority of shopping was conducted in larger urban areas such as Whitehorse. For the other FN, no grocery and convenience stores were locally available. While the relative distance to grocery and convenience stores was perceived as a barrier for some communities, the ability to partake in traditional practices was identified as a community-based capacity and highly desired practice for all FN people. The availability of a youth daycare and school with FNs-specific cultural practices was also recognized as important. Participants identified that these facilities could further influence family dynamics, decision-making, and education surrounding contemporary health issues such as T2D.

All participants acknowledged that residents could take adult education courses online through Yukon College. Residents used telephones, computers, and the internet to access course content and converse with instructors. Two FNs did not have a Yukon College Annex and the other had some space available within an administration building for residents to use their computers. All participants recognized the need for more infrastructure such as computers and study space to increase residents' access to education. Participant F identified that while their administration building offered a public space for residents to use their computers for videoconferences, there was a lack of education on how to operate computer software, and technology did not work or was outdated. The participant identified that better education surrounding technology used for online courses was needed. This included native language

classes through Yukon College that could contribute to improving the holistic health and well-being residents and their families.

Similarly, participants identified the need for a more adequate administration building as the current facility did not have enough space for staff to work. If no space was available for administration staff to work within the community, then positions may not stay filled, or travel would have to be considered. Participants explained that a renovated or extended administration building with more office space could improve staff recruitment and retention. Further, more storage space, conference style venues, and meeting spaces would enhance the quality of the work environment.

4.5.1.2 Personnel (Health and Administration)

Participants identified that program access and success relied on having trained and knowledgeable personnel available which included: resident nurses; doctors; community health representatives; health care and home support workers; dietitians; dentists; trained daycare staff/teachers; family social support workers; youth and activity coordinators; and counsellors. While variability existed in what personnel were available and what they were able to achieve, all participants discussed, or provided examples of, staff dedication. This dedication was understood as a strength of the FN in which people were resilient to the barriers that they faced when accessing health services. Participants described that personnel were provided by territorial, federal, or FN funding streams.

Participant A noted that their FN had a half-time health care worker that was Yukon Government funded and had an important responsibility to administer medications and provide foot care. The FN also had two home support workers that were FN funded that could provide

transport of residents to facilities, but could not administer medications. This FN had a Yukon Government provided dietician that was regularly available within the community. The participant described that having a health care worker and dietician funded by the Yukon Government took pressure off the FN to provide that position themselves. The participant also discussed the availability of a family social support liaison and a case manager which had the responsibilities of advising families in need and aiding in the process of filling out forms. The presence of a youth activity coordinator was also discussed but it was acknowledged that more could be done that is culturally-relevant and diabetes-specific. The FN also had a daycare with trained child education staff, but lacked funding for an Aboriginal Head Start (AHS) program.

Participants B and C discussed that although personnel were not locally available, as no health center, school, or police station existed within the community, these were accessible at the next neighbouring community. At the neighbouring health center, there was a doctor available roughly every two weeks for a few days a week. It was encouraged that appointments with the doctor were arranged ahead of time. All specialized care and emergency services were conducted several hours' distant in Whitehorse. The FN had a large community center and daycare facility with staff and Elders available, but also lacked funding for an AHS program. This was seen as a barrier because the participants recognized that AHS was highly desired within the community. While daycare was inexpensive for families, it was a considerable financial commitment for the FN.

Participants D and E identified that their local staff provided overlapping roles for residents. For example, participant D discussed the changing nature of their role due to the current needs of the community. This included implementing youth and Elder activities, as well as administrative and financial duties. While a resident nurse was available within the

community, participants explained that more frequent doctor, dentist, and dietician services were needed. Participant D also identified that more cultural camps children and youth, hosted by Elders, would be beneficial for both parties. During these types of activities, Elders shared traditional knowledge that provided a benefit for holistic health and well-being. Participant E explained that this is important because traditional knowledge and oral storytelling may lead to a reduction in T2D as youth learn about the current status and history of FN people. Additionally, participants identified a need for more youth and adult counsellors for suicide prevention and alcohol awareness such as in the form of Alcoholics Anonymous. While counselling was available in all FNs, participants described that more resources for these programs would be beneficial to reach more people, and provide more support for those who currently use the programs.

Participants described that the lack of staff available, as well as the observance of high turnover in administrative positions was a major issue in recruiting and retaining qualified personnel. As an issue of location, participants explained that communities were viewed as a more desirable place to work if they were in close proximity to required amenities (i.e. grocery and convenience stores, schools, daycares), employment for spouses, parks and celebrated traditional territories, as well as to major urban centers such as Whitehorse. Communities which satisfy a greater number of these requirements often had steadier employment rates and were able to recruit more employees. Participants also discussed this as an issue when qualified candidates for various health and administration positions may become approached by other FNs and offered employment in their community. Participants identified many factors that created turnover, but more supports and incentives for people to stay local could help reduce its prevalence. As participant D noted, having to train new staff is like “*re-inventing the wheel*” all

over again. In summary, the combined education, experience, and qualifications of staff at various levels of administration influenced the implementation of T2D services. As these limitations or barriers constantly occurred, it produced inconsistent conditions, creating inabilities to build and expand infrastructure at the community level.

4.5.1.3 Programs

Participants discussed a diverse array of programs that could contribute to the prevention and management of T2D. These included: holistic health programs; health and wellness activities; nutrition services; foot care services; daycare; cooking programs; food subsidy and/or delivery/preparation services; delivering medications; psychological counselling, Alcoholics Anonymous, and smoking/substance abuse; as well as screening programs and T2D testing. When participants discussed service availability, it was noted that many community residents wanted to keep the services local. Ultimately this could “*keep the community viable*” as participant C explained.

Depending on the facilities and personnel available, some FNs were able to provide individualized consultation and counselling services in their communities. Community health representatives, counsellors, and/or health program administrators met with individuals or small families to discuss various health concerns. Participants identified that individualized consultation was conducted during diagnosis of T2D, and by providing guidance with everyday tasks such as shopping to read and understand food labels, pregnancy, and family health promotion. Individualized consultation was considered an important service as it supported FN cultural strengths by having traditionally-oriented programs. For services performed within the community, participants discussed the importance for people to have personalized services, relay their concerns, and ask questions in a culturally safe and respectful environment. As participant F

clarified, explaining T2D and other health related concerns with the use of visual aids was important in terms of effectively describing what is biologically occurring.

Participant A described that a major limitation of individualized consultation was its time consuming process. This became important when there were limited health staff available, where time spent providing individual consultation limited the ability to prepare and deliver other forms of health care. Also relevant was the notion that for some consultation and counselling, people had to be located near the community to access them. If it was not feasible for the resident to travel to attend individual consultation (i.e. inability to take time away from work or other responsibilities, no daycare for kids, no vehicle or ride available) then the service provider would travel to the resident. The participant described that a large part of the FNs' health budget was utilized to deliver individualized services to residents who were unable to travel. While travel was considered a financial burden for FNs, it was also considered manageable, as due to the size of the community and frequency of requests, most needs were able to be fulfilled.

4.5.2 Access to Health Data of the Community

An imperative factor in both applying for, and sustaining, health programs related to T2D was that Health Directors and administrative staff needed to be able to access relevant, reliable, and recent community-specific health data. This included factors such as the demographic profile, smoking rates, and how many people were diagnosed with T2D or had pre-diabetes. To understand this aspect, participants were asked what kind of access to health data they had for their community. The main form of health data identified was information generated for each community from the 2008/10 RHS (Phase 2). Participants reported either having no access to RHS data, or having some access.

When digital records were available, some participants discussed that they were in a format that was not accessible by administration staff. In accordance with the RHS mandate to support OCAP™ principles, community-specific data was provided to communities in the form of Statistical Package for the Social Sciences®²³ (SPSS) spreadsheets. When delivered, FNs received training in the operation of the SPSS® application by CYFN staff. High turn-over in administration positions made it impossible for some communities to retain trained personnel, a fact which produced wide discrepancies in the FN communities' abilities to use the RHS data effectively. There was a gradient of responses in terms of what Health Directors were able to access, and how they utilized health data. For the majority of participants, if data were available, it was kept as a record and rarely utilized. Participant C reported that data were available but they were “*only as good as you can do something with it*”, highlighting the need to have more education about how to effectively implement and use health data. While the CYFN provided some capacity for FNs such as how to store and utilize health data, not all FNs in Yukon are a part of the CYFN. Participants described that improving data usage could be important for FN staff to support requests for funding by providing community-specific prevalence rates.

Participants D and E described how the 2014 Yukon CANRISK Diabetes Screening Project²⁴ came to test adults for T2D in their community at the local nursing station. Participant F described that the CANRISK team came and the community was given access to that data. As the objectives of CANRISK were to identify risk in Indigenous youth and assess the pre-diabetic

²³ SPSS is a registered trademark of the company International Business Machines Corporation (IBM).

²⁴ To further understand the prevalence of undiagnosed T2D and pre-diabetes in Yukon FNs, the PHAC, Yukon Government, the Office of the Chief Medical Officer of Health, the CYFN, and FN Councils set up the Yukon CANRISK Diabetes Screening Project in 2014 (Hanley, Jiang, & Peekeekoot, 2015). This project recruited Yukon adults aged 20-39 to take the CANRISK Canadian Diabetes Risk Questionnaire (PHAC, 2013a) with additional samples taken for Fasting Plasma Glucose (FPG), Oral Glucose Tolerance Test (OGTT), and Glycated Hemoglobin Test (HbA1C). Participants were given the results of their tests, and told whether they had undiagnosed diabetes or pre-diabetes (Hanley et al., 2015). From the results of the Yukon study, screening processes and regular T2D testing were needed as regularly delivered services (Hanley et al., 2015). CANRISK was an important assessment as it has been proven to be a statistically valid tool to assess T2D risk in multi-ethnic populations (Robinson, Agarwal, & Nerenberg, 2011).

population, many older adults and Elders wanted to get tested and were not able to, as they fell outside of the age range for the study (20-39 years). The participant described that the older adults and Elders felt an urgent need to be screened, as T2D was recognized as a contemporary health issue, residents were familiar with health consequences of T2D, and the service was locally provided for residents who could not travel to access screening services. This discussion suggests perceptions of inadequate access to screening services readily available within FNs.

4.5.3 First Nation Culture

All participants emphasized the importance of FN cultural attributes as a strength in the viability and sustainability of services and programs to improve local community health. Interview discussions involved history, land claims, self-governance, language, education, culturally relevant health services, and traditional cultural and historically significant facilities. Cultural continuity and sense of leadership were important in the health and well-being of FN residents. One of the key barriers in managing T2D related to the political environment of the FN which was determined by the control granted through FSGAs. It was understood that FNs with FSGAs had a higher level of perceived control over the implementation of services and programs available, as well as a sense of direction for the future. FSGAs structure in part determined facilities, personnel, and programs available, but did not change the services that were wanted.

This discussion of governance was further explored as participants emphasized having connections and integration with other FNs, such as being part of the CYFN and attending regularly held meetings of the Yukon Health and Social Development Commission. Participants discussed that while not all Health Directors may be able to attend all meetings regularly, having supportive connections and partnerships that were exterior to the FN were considered both culturally and logistically important. For many participants, this sense of external

communication could be discussed, but not all participants viewed their connection with other FNs in Yukon as strongly. Some FNs, may lack both FSGAs and membership to CYFN.

Participants understood that the degree to which a FN lacks these increased its isolation.

Participant E reported that traditional cultural aspects and values such as hunting and fishing were still very important within the community, and helped to promote holistic health and well-being. In particular, the participant noted that people have “*pretty strong connections*” to traditional practices such as hunting and fishing for white fish, grouse, and rabbit. Participant D noted that it would be beneficial to have culturally-based activities such as a community hunt or butchering lessons that could interact with local culture, tradition, history, education, language, and health. In association with a connection to the land, participants noted that there was a desire to have a greenhouse and community garden available, so that people could grow fresh food locally. For one FN, a gardener was available in the year previous, but the community was unable to continue funding the position. While community residents had access to the greenhouse, it was hard to maintain without continuous attention. Being outdoors and contributing to the growth and well-being of the community were seen as desirable outcomes for improving overall health.

In addition to a physical sense of community, participant A noted that people were coming together, there was less blaming and people were “*seeking to help and consult rather than shame*”. The feeling of having a strong sense of community was discussed as a fundamental aspect of growth and healing. Participant E noted there also needed to be an Elders’ facility “*to keep our Elders with us*”. In accordance with supporting Elders, participant E emphasized that it was important to have more residential school healing for both first and second generations

affected, where “*without residential school healing it really is continuing on to the next generation*”. Here the participant was referring to the colonial legacy.

The colonial legacy was important as it created a cascade of events that changed both biological and cultural aspects at the individual and community level. Participant E noted that they did not want to send people away from their community to large urban centers such as Whitehorse for services and treatments. This idea was also reflective of the legacy of residential schools, in which youth were forcefully relocated outside of their home community. Participants D and E discussed that the FN had applied for funding for residential school healing but they did not get approved. In conclusion, FN cultural attributes and representations were identified by all participants as aspects in not only infrastructure and services, but in achieving overall health and well-being at the individual, family, and community levels.

4.5.4 Education

Participants discussed the availability of T2D education and health choices in the context of access to all types of education, which could subsequently impact decision-making. Choices and decision-making, based on prior knowledge or education, were considered important for preventing and managing T2D. Participant F highlighted the importance of being able to explain the risks of T2D and outcomes for overall health and well-being. Participant A noted that education and awareness of T2D and healthy life choices currently existed, in the form of health care providers travelling to the community to deliver services, but that people would like to see more local options implemented and regularly available. Educational requests were preferentially and usually provided through individualized consultation.

Participant A noted that most education about T2D was directed at adults, and the need for more education to be directed at children and youth. It was suggested that an effective way to

target youth and adults for T2D awareness and prevention was to hold more holistic and family-based health programs. Participant F noted that, in terms of education, there needed to be better translation and spread of awareness about the effects of alcohol and smoking on T2D and pregnancy. The participant explained that this could help in both the prevention and management of T2D through decision-making and choice evaluation.

Additionally, decision-making was important when people were faced with false advertising. Participant F provided an example relating directly to T2D by describing that if a food product reported to contain no sugar, it still may have carbohydrates which turn into sugar. In this case, people needed to not only be able to read the label effectively, but needed to understand additional layers of information that are presented through false advertising. Another example of advertising related to terminology such as “organic”, and what food means to be “organic”. The participant explained that food fresh from the land may be more nutritious than the food labeled organic in stores. These examples were characterized by the participant in which *“there is an importance on getting the messages right”*.

4.5.5 Food

Participants acknowledged that decisions surrounding food choices were influenced by a variety of factors that were external to the families themselves. These factors included the distance of the community to Whitehorse and the local availability of nutritious foods. The two important aspects that all participants noted as desirable or available was food subsidy in the form of food purchase vouchers, and/or food delivery and preparation services in the form of Meals-on-Wheels and community luncheons. Purchase vouchers were usually provided to expecting or new parents, and could range from \$100-\$200 monthly. Counselling on purchasing and preparing healthy foods was provided. Participants explained that this helped to ensure that

families were receiving adequate guidance during food purchasing, and that funding was being utilized to the extent of its purpose.

Participant A stated that in their FN, they have been able to offer a mixture of Meals-on-Wheels, school lunches, and meals for Elders. While not all FNs were able to offer Meals-on-Wheels, as there was limited funding to pay for staff, food, a vehicle, and gas in some communities, some variation of a community luncheon was available in all FNs. Participants B and C described that their FN was able to hold weekly community luncheons at their community center. Meals-on-Wheels was informally available; after their luncheon, people were able to take additional food home, and/or deliver it locally to those who were unable to attend. Other participants D and E explained that in their FN, while they had never had Meals-on-Wheels, they were able to utilize funds from the FN's budget to hold luncheons for Elders three times a week. For these luncheons, a cook was hired to prepare traditional foods. Participant A noted that a problem with community luncheons was that there could sometimes be discrepancies between what youth and Elders preferred to eat. For example, Elders often wanted traditional foods such as hunted or trapped meats, and youth preferred market foods such as pizza.

Participant F discussed community-specific cookbooks available for families who would like more education about healthy eating. While cookbooks were available, they were also high in demand and there might not be enough for everyone who would like one, as they were costly to produce. Cookbooks emphasized recipes that supported diabetic lifestyles and food choices. This helped families to understand how to prepare nutritious meals within their homes. Another feature of cookbooks included traditional food promotion, where families could use country and store-bought food together. This provided both a spiritual and cultural connection as families had

support in preparing meals using traditional subsistence strategies learned from community Elders.

The discussion of food included the current options for people who were diabetic or trying to prevent T2D when they were not at home. Participant F stated that when adults and youth go to places such as a movie theater, and there were minimal nutritious options for snacks and beverages. The participant made the analogy of “*having to choose the lesser of two evils*”. The participant explained that, if people wanted to be healthy, then they needed to have healthy options available to make an informed decision. In this way, the participant was advocating for more options for people living with T2D.

4.6 Between the Community and the Federal Government

The second category in the three-point relationship was the connection that exists between the FN and the Federal Government. It was discussed by all participants that they felt as though the FN and the presence of the Federal Government was separated. This space was explored through changes that have occurred within the FN, perceptions of T2D prevalence and management, as well as travel to obtain health services.

4.6.1 Changes over Time

Participants described that T2D programs were not static. Each participant discussed significant changes over time in both governance of their FN, as well as program availability, community demographics, and perceptions surrounding T2D. It was noted by participant A that the knowledge and expectations surrounding T2D have changed. The participant described that there was more awareness and education about T2D and healthy living available now than ever before, with a comparison to around thirty years ago. While services were available that addressed awareness and education, all three FNs had lost services and programs that were

previously available. For example, participants A, B, C, and F described the loss of T2D-specific educational programs. Participant A explained that T2D programming depended on external funding. While the FN had received a one-time instalment of funding for T2D from the PHAC in the past, the funds were quickly utilized to service people within the community. The PHAC funding allowed for the creation of individualized health seminars/counselling, workshops for home care workers, and the creation of cookbooks.

Participants B and C discussed that as their FN had FSGAs, they were able to utilize the limited funding they had for addressing the current needs of the community. This meant that diabetes-specific programming was not continuously provided, and instead, counselling was targeted as a higher priority. While the participants recognized the need to prioritize, they also acknowledged the need for both services in their community. Participants felt an injustice in having to choose which programs would be provided, as both T2D and counselling were needed.

Participants D and E explained that their FN experienced both the reduction in T2D-specific programming and the closure of a youth center and daycare. Due to the small size of the community, there was not enough population growth to sustain a youth center and daycare. Participant D discussed a need for these amenities now as there were more youth present within the community and the demand for youth programming and services was high. This was considered important as people within the community struggled with substance abuse and culturally-based activities for youth could help to reduce substance abuse in younger generations. For T2D-specific programming, the participant recognized that there have been services and programs for people in the past, such as community awareness workshops, but the current priority was counselling for substance abuse and suicide. While T2D-specific programming, a youth center, and daycare were previously available, the participant identified it was a struggle to

incorporate these services again as staff have left the community and funding was not available for large-scale construction of amenities.

As participants B and C from a smaller FN with FSGAs explained, the flexibility of their funding arrangements meant that they were able to constantly adjust to the changing needs of the community. The size of the FN, in comparison to the staff and resources available, made the adjustment to individualized services easier. By being flexible, the participants discussed the ability to create and hold services and programs for T2D awareness at an on-demand basis. This was seen as important when the participants expressed the idea that coming up with new locally-developed programs was an improvement over colonial-style programming that was imposed from the Federal Government. The idea of creating their own programs was an important factor when implementing services for FN residents as it reduced colonial impressions of paternalism and hierarchy.

This was further expressed in the idea that as a FN with FSGAs, “*we are not waiting anymore*”, where participants B and C discussed taking charge of what was going on and making things happen for themselves. As participant C clarified, “*we are trying to do things with or without funding*”. This passion and dedication within the community highlighted strengths that FSGAs could bring, and the need for the ability to implement positive social changes over time. This was understood in contrast to FNs without FSGAs in which participants expressed frustration at having to rely on decision-making at the level of the Federal Government. The need to utilize funding in accordance with the ADI mandate was seen as a struggle as participants felt there were misperceptions of the current needs and capacities of communities.

4.6.2 Perception of the Type 2 Diabetes Problem

Variability existed in what participants described as the current rates of T2D within their community. Participant E commented that T2D was an important issue within their community, where the “*half [the population] that are not diabetic are pre-diabetic*”. While people were aware of T2D and knew and understood effects of the disease, people might not be able to afford, or have preferences other than, the recommended foods. For participants D and E there was a recognized need for T2D programming because “*rates are quite high*”. Participant F reported that “*there are many people with diabetes*” and that rates were growing in the adult population, but not as much in the youth. Further, participant F reported that people generally wanted to know if they had T2D or not. This, to participant F, showed that people were interested and involved in current health issues.

On the other hand, participants B and C recognized that T2D was prevalent, but not as prevalent as other conditions within their community. One example of this was the perception that counselling and Alcoholics Anonymous were needed more than T2D-specific services. The participants felt that there was limited access to unhealthy food in the community and that high rates of traditional subsistence practices helped to reduce T2D prevalence among residents. While the participants had varying perceptions of T2D prevalence, participant F noted that residents may be spread out and as such, a large part of the FNs’ health budget may be used for travel expenses incurred to provide services and programs.

4.6.3 Travel

Due to the large geographic distances between Yukon towns, the location of the FN was an important barrier to accessing adequate health services and food. A major discussion in terms of location surrounded the relative distance between the community and available services,

larger urban centers, as well as major roadways. Some FNs situated along or near a major roadway may have more tourists visiting the community, and thus the capacity to acquire more revenue. In particular, location influenced the time needed for travel between communities and to get to available services. FNs in Yukon were located between one and a half to nine hours away from Whitehorse by car. Of this range, on average, FNs were located five hours away. While the discussion focussed on T2D-related services such as foot care and education, it also included all health services such as check-ups, dentist, eye care, etc. A distinction was made between travelling out of the community for services, and health care providers travelling to the community to deliver services.

4.6.3.1 Residents Travelling out of the Community

All participants discussed the idea that if someone needed a service and it was not available within their community, residents were required to travel to the next mid-to-large sized community (e.g. Whitehorse) that offered that service. Depending on the purpose of the trip and nature of the services needed, the resident seeking treatment would often be driven by another person. Participants described that residents may need to be driven to appointments because the person did not have a license, was too ill, or did not own a vehicle. This was discussed as a barrier because treatments and service appointments were scheduled during the day, in which one, or both persons travelling would have to take time off of work, childcare, or other responsibilities. Due to location, travel was considered costly in terms of both money spent travelling (e.g. gas, food), as well as time taken away from other duties (e.g. work, need for daycare). For some residents, long travel distances necessitated meals and overnight stays at their destination which imposed additional burdens of time and money. As participant F acknowledged, many citizens did not have regular doctors, so to get tested for T2D, or for other

consultations, they would have had to go the emergency and wait. This added an additional time commitment. When people needed services that were not available within the community they could get a referral from a community health representative or health care provider at a local health center or nursing station and then make an additional appointment in another community that had the service available.

In addition to health services, travel was also a barrier to accessing nutritious foods. As participants D and E noted, most, if not all, food purchasing was done at the nearest mid-to-large sized community. Due to location, it was costly and difficult to obtain fresh fruits and vegetables, and families relied on foods that were cheaper, and less nutritious, such as shelf-stable processed and packaged foods. These decisions were identified to be a consequence of the costs needed to travel to shop for food, the distance and infrequency of trips to obtain food, and the need to have food last between available trips. From this discussion there was also a general consensus that there was a desire to have services and food available locally so people could be able to both live and thrive within their community.

4.6.3.2 Health Care Providers Travelling to the Community

In addition to residents travelling out of their community to obtain services, there were some health services that were brought into the community. Mobile services that were delivered in communities included territorially and federally funded dentists, doctors, and nurses. Also available were presentations on various health matters such as T2D, counselling, or parenthood by specialists external to the community. As participant D explained, these visits occurred at irregular or infrequent intervals. Participant A discussed that travelling services meant that there was no continuity for the patients in terms of relationship building or health records. Additionally, some of the service providers that came had continuing colonial ideas or

impressions about FN people. Participant A provided the example in which service providers external to the community may expect peoples' health to be poor and expect a high frequency of substance abuse.

4.7 At the Level of the Federal Government

4.7.1 Federal Funding and Programming

The third and final category in the three-point relationship was the level of the Federal Government. This discussion reflected Health Director and administration staff perceptions of the Federal Government with regards to accessing and implementing ADI funding. This discussion did not include perceptions of communities from the Federal Government.

4.7.1.1 Access

Fundamental to understanding current ADI availability and efficacy in Yukon was the discussion of how ADI funding was currently accessed by Health Directors. Participants were asked how ADI was funded and delivered to the FN. Participant A reported on how funding was received for a FN that have FSGAs. The participant described that that funds were combined as a payment from their FTA or "*draw down money*" from the Federal Government. The FN administration determined how it would best be used, depending on the local and current needs of its residents. If the amount of ADI funding from the FTA was not enough to implement a service or program, then FNs' Health Directors would apply for various other forms of funding through both the Yukon Government and the Government of Canada.

Participants identified that current ADI funding is not sufficient, and communities actively seek other funding opportunities and financial supports on top of their ADI funding from the FTAs. Participants B, C and D noted that difficulties exist in the application process for external funding. For example, participant B described that it would be more manageable for

their staff if there was a simpler application form to fill out, such as one form that serves for a variety of programs or funding sources. Further, participant B suggested that having more detailed descriptions of the application process, as well as feedback on submitted and rejected applications, would benefit administrators by learning more about the process. Participants described that it would be beneficial if the application process was more flexible with an identifiable funding range known ahead of time to help with the budgeting process. Participants also recognized that being able to understand, implement, and utilize health data effectively was imperative to creating a strong funding application.

Participants B, C and D noted that there was a need for supportive resources for creating applications and funding proposals. It was suggested that this could be achieved through more communication or connection to the CYFN, the Yukon Health and Social Development Commission, or support staff to assist with the application process. Participants explained that would be beneficial for staff to share both their successful and rejected applications to learn the process of applying for funding together. Additionally, the design of funding applications had a time delay, in which applications were due long before funding could be granted and implemented. This meant that staff applying for funding had to create long-term plans for the sustainability of programs, which was difficult when there was high turn-over in administrative positions.

Lastly, participants discussed that difficulties exist when applying for compensation for health care costs from the NIHB program such as managing the reporting process and providing all required documentation for submission. An additional constraint was the denial of coverage when emergencies or other duties prevented patients from receiving care. Further discussion and recommendations relating to the NIHB program is presented in *Chapter Five: Discussion*.

4.7.1.2 Implementation

As all communities and participants had experiences with federal funding procedures, and had received some kind of funding previously, this study was interested in how funding was utilized. All participants explained that ADI funding was usually used in conjunction with other funding sources to provide personnel, services, and programs for residents. For a FN with FSGAs, it was reported that ADI funding was used to support family health promotion, such as reading labels and education and decision-making during shopping. In this case, the service that operated may not be thought of as ‘specific to diabetes’, but related to overall health and well-being, which could help in managing prevention and living with T2D.

Participants explained that for Yukon FNs with FSGAs, there no longer exists a reporting procedure on how FTA funds are used. For FNs without FSGAs, the FN must deliver budgets and produce reports on how the funds are used by the community. Participants describe that flexibility in reporting allows a FN with FSGAs to use funds for current needs within the community. The discussion of access and implementation of ADI funding is further discussed in *Chapter Five: Discussion* by further recognizing differences produced by funding models and governance structures on the delivery of deferral health services and programs.

4.8 Results Summary

This chapter began by presenting results for the first objective of the study which was to present participant perceptions of T2D prevalence. Participants explained that T2D was an important health issue within communities, but may not be as prevalent as other health conditions, such as the need for psychological counselling. This chapter also presented the structured results of six interviews from three Yukon FNs that describe how participants understand the world of health services. The study was informed by a capacity-based approach,

in which community resources were identified. This analysis found capacities at the community level, as well as perceived barriers. The combined results indicated a three-point relationship of understanding access and barriers to program funding from the level of the community, between the community and the Federal Government, and at the level of the Federal Government. Most reflections and discussions surrounded the community level. Results from this study are discussed in the next chapter by contextualizing participant perceptions within relevant academic literature and further develop meanings and relationships related to the research questions and conceptual framework of this study.

Chapter Five: Discussion

5.1 Introduction

This chapter presents the study results which are understood through an exploration of how public health policies shape current health disparities between FN and non-Indigenous populations in Canada. This chapter situates the study's results within Kilbourne et al.'s (2006) framework of understanding health disparities, Loppie-Reading & Wien's (2009) analysis of proximal, intermediate, and distal determinants of health, and through a decolonizing Indigenous health perspective (Bartlett et al., 2007; Jacklin & Warry, 2009). Next, this chapter defines community capacity, with regards to the effective implementation of ADI funding. This is integral to understand the variability that exists between Yukon FNs with regard to the delivery of diabetes-related programming. This chapter then discusses the study's three objectives, emphasizing the two forms of governance in Yukon FNs, those with and without FSGAs, as they create foundational differences in how ADI funding is accessed and implemented. Further, a comparison of the ADI's mandate to current diabetes programs in three Yukon FNs is included. The study is then contextualized within the discipline of anthropology, specifically a biocultural understanding of health, and a critical medical approach to understanding health services. Lastly, this chapter summarizes the limitations of this study.

5.2 Relation to Conceptual Framework

The conceptual framework of this study examines health disparities and determinants of health for FN peoples by combining models created by Kilbourne et al. (2006) and Loppie-Reading & Wien (2009). This study explores how health disparities arise from various spheres as determinants of health (i.e. proximal, intermediate, and distal) by Loppie-Reading & Wien (2009) and through a recognition that various levels of health care exist by Kilbourne et al.

(2006). Through this exploration, I am able to understand capacities that FNs have, and barriers that exist when accessing services and programs funded by the ADI. These capacities and barriers are used to create feasible recommendations in support of Kilbourne et al.'s (2006) step of increasing health equity by evaluating, translating, disseminating knowledge, and changing policy. Kilbourne et al. (2006) encourage creating recommendations that can enable a change in policy, and the recommendations set forth in this chapter are meant to support FNs in their initiatives to increase health equity, and to inform the Federal Government of policy and procedural changes that are needed to ensure equity in access and implementation of ADI funding, and more holistically, a more equitable T2D and chronic disease management system for FN populations.

As previously discusses, the conceptual framework is situated within the broader implications of decolonizing Indigenous health (Bartlett et al., 2007; Jacklin & Warry, 2011). As an overarching theme to this research, this study contributes to decolonizing Indigenous health by assessing: health disparities that exist; the reasons for, and implications of, health disparities in Yukon FNs; capacities that FNs have; barriers that exist when implementing T2D services and programs and funding through the ADI; and feasible recommendations to increase equity in access to health care related to T2D. Through a discourse of decolonization, this study recognizes that the unique history that FNs have with federal and provincial/territorial governments is the key to holistically addressing complex relationships that have created inequities.

5.3 Defining Community Capacity

The capacity of Yukon FNs to create and support services and programs funded through the ADI is important. Canadian organizations and program officers define capacity in part by the

infrastructure that communities have, and the ability for communities to use infrastructure to implement programs (Health Canada, 2015b; Health Canada & Public Health Agency of Canada, 2015). For example, a performance indicator of “the capacity of First Nations and Inuit communities to deliver community-based health promotion and disease prevention programs and services”, is the “[number] of workers who completed training for healthy living programs (specifically – Aboriginal Diabetes Initiatives – Community Diabetes Prevention Workers)” (Health Canada, 2015b). In addition to infrastructure, the abilities of trained personnel to implement long-term planning of services are also used as indicators of relative capacity between communities (Health Canada & Public Health Agency of Canada, 2015). This definition of capacity is often understood as an asset-based approach, in which communities either have, or do not have, a number of characteristics.

While the inclusion of these variables can be considered an indicator of capacity between communities, it is not a holistic definition of capacity. Definitions of capacity in Indigenous communities can be much broader and inclusive of local social networks, sense of community, community cohesion, Elders, history, power, values, culture, territory, language, identity, and sovereignty (Chino & DeBruyn, 2006; Christensen, 2008; Goodman et al., 1998). This study does not utilize an asset-based approach based on inclusion or exclusion criteria. Instead, it focuses on capacities that assist communities to access health care services. Capacity in this study refers to the ability to utilize community-based abilities to implement effective T2D services through both the ADI and alternative funding sources. A major source of capacity for Yukon FNs is a holistic approach to health care for residents, which encompasses the flexibility to address health issues as they arise. While this study is not able to address all issues surrounding capacity of the selected communities, through interview discussions, I am able to

evaluate to some extent the relative capacity between FNs. Capacity building is an integral step to increasing health equity (Chino & DeBruyn, 2006; Christensen, 2008). As capacity may increase when health care decisions and funding are transferred to FNs, Yukon FNs without FSGAs may not be able to develop or harness their capacities to a similar extent.

5.4 Research Objectives

The purpose of this study is to identify health inequalities that exist between Yukon FN and non-Indigenous populations in Canada. Further, the purpose is to identify issues of access and implementation of the ADI in three Yukon FNs through a historical and critical lens. From a systematic process of participatory research, data collection, and analysis, the three objectives of this study have been successfully completed. While this study is able to identify health inequalities that exist, future knowledge translation with communities, and government departments is an on-going process. Addressing these inequalities will be continued through publications, conference presentations, and communication of research findings to the Government of Canada.

5.4.1 Research Objective #1

The first objective of this study is to identify the need for T2D services and programs funded through the ADI in the three Yukon FNs that participated in the study. This was done by contextualizing participant perspectives of diabetes to health data presented in *Chapter 2: Literature Review*. By identifying the changing trends in diabetes rates, there is a recognition *why, how, and how much* of a health issue diabetes is within Yukon FNs. The purpose of comparing participant perceptions to national T2D estimates is to understand if community perceptions match available data on T2D in Yukon FNs. This understanding is the basis for the second and third research objectives, which are to identify capacities and barriers that exist when

accessing and implementing ADI funding, and to create recommendations at the local and federal level to create more equitable access to T2D services and ADI funding for all residents of Yukon FNs.

Participants understand T2D as an important health issue within communities. While community-specific prevalence rates are not available for this study, all participants recognize that residents of their community have been affected by T2D. Participants state that, the “*half [the population] that are not diabetic are pre-diabetic*”, “*rates are quite high*”, and that “*there are many people with diabetes*”. While participants have various characterizations of estimated T2D rates, all recognize T2D as an important chronic disease that affects holistic health and well-being. This demonstrates that T2D is perceived an important health issue. There is a significant need for services and programs funded by the ADI. A reason for the variation between participants’ understanding of T2D rates is that, for some, other conditions within communities take precedence. For example, two participants explain how T2D is a health concern, but not as much of an issue as the need for psychological counselling.

Participant perceptions of T2D rates can be further contextualized with population-level T2D prevalence data from the NPHS and CCHS for the period 1994-2014 (Table 2.1, 2.2, and 2.3). These data illustrate an increase in the rate of T2D in both Yukon and Canada. As rates are increasing, there is a need for the ADI to be implemented to its fullest extent in Yukon FNs. A limitation of the analysis is that the majority of data for Yukon contain “use with caution” indicators, which means these data may not accurately represent T2D rates within the region. These estimates therefore produce an unreliable basis for determining health disparities between regions of Canada. Further, T2D data from the CCHS during the period of 2007-2010 (Table 2.4) illustrates a higher prevalence in Yukon FNs populations than the non-Aboriginal population.

Taken together, participant perceptions and the national data indicates that T2D rates are increasing, making diabetes management a prominent issue for Yukon FN residents and there is a real need for ADI funding and T2D services. The quality of diabetes data depends on a number of factors: the purpose and extent of survey collection; self-reported versus measured collection; and coverage within health regions. One of the challenges with Yukon's relatively small population is that data cannot always be disaggregated into smaller segments without compromising the reliability of data, or potentially revealing the identity of participants. While efforts have recently been made to increase data coverage such as the RHS (First Nations Information Governance Center, 2012), and the restoration of the long-form census (Government of Canada, 2015a), the results of this research indicate that the issue needs to be continually addressed, with recommendations for policy change presented in subsequent sections of this chapter. In addition to containing "use with caution" indicators, the prevalence data does not explain the distribution of T2D in Yukon and FN populations. There is a myriad of economic, social, and environmental factors that contribute to these rates. In summary, T2D is understood as a contemporary health issue in Yukon FNs, and an area of health inequity compared with non-Indigenous populations in Canada, even if there is insufficient support from national and regional health data.

5.4.2 Research Objective #2

The second objective of this study is to identify what capacities and barriers exist when staff are accessing and implementing ADI services and programs, either internal to communities or external with respect to the Federal Government. Community-based capacities are considered resources that FNs could use to gain more equitable access to health care services related to T2D (Christensen, 2008). This objective also explores how governance, specifically FSGAs,

contributes to community-based capacities and barriers to successfully accessing and implementing ADI funding.

Each of the three FNs have varying capacities in accessing and implementing ADI funding and T2D supports, and data presented are a compilation of perceptions from only the three FNs that participated in this study. Due to this small sample size, I am able to produce results with limited generalizability for all Yukon FNs. Through discussions with the Yukon Health and Social Development Commission, I learned that there are FNs in which travel is not considered a significant barrier, while for others it is. There are also FNs in which there are many active services, programs, and research for T2D currently being implemented, while in others there are not. An additional barrier is the relatively small size of FN communities. Those FNs with relatively low numbers of citizens face a situation in which current funding formula may not recognize the substantial needs of communities (Lavoie et al., 2005). The purpose of discussing perceived capacities and barriers is to support FNs that do not have equal access and capacity for implementation, and bring attention to this issue in order to increase equity for all FN persons in Yukon.

In Yukon, while no formal diabetes strategy has been adopted by the Territorial Government, there are various responses to diabetes such as the Yukon Diabetes Reference Group, Chronic Disease Management Program, Diabetes Education Centre, Telehealth, Healthy Living Project, Yukon Health Care & Chronic Disease Program, as well as various diabetes resources such as the Yukon Diabetes website²⁵ which has a Do-It-Yourself Manual and a Diabetes Resource Guide (Sparks & Duke, 2009). The ADI is different than these responses in that it is a national strategy. The ADI is funded via FTAs in each FN with FSGAs, and it is

²⁵ www.yukondiabetes.ca

competitively applied for by FNs without FSGAs. Lavoie et al. (2005) suggest that, while transfer agreements facilitate an improved community response to local priorities, they also assume that communities have relatively high capacity to implement services and programs. Participants perceive that expectations of community capacity may be challenged by an inability to create community infrastructure and maintain personnel. Table 5.1 summarizes participants' perceptions of capacities and barriers that exist when accessing ADI funding for health services.

Table 5.1 Perceived Capacities and Barriers when Implementing Health Services

Capacities	Barriers
-varying facilities are available, but community facilities/services may serve multiple functions	-inadequate funding and resources to improve current facilities or build new facilities to hold services and programs
-ability to access food through traditional subsistence practices (i.e. greenhouses, hunting, fishing, trapping, berry picking)	-travel is needed to get to grocery and convenience stores that sell nutritious food at affordable prices -limited resources to implement sustainable greenhouses, gardens, and community hunts
-ability to use services to promote holistic health and well-being	-specific services for chronic diseases are not adequately available (i.e. T2D, foot care)
-ability to take courses online through Yukon College	-supports needed for online education such as computers, technical expertise, study space, and educational resources not adequately available
-local health and administration personnel are dedicated and have a combined ability to provided limited services	-health-care specific personnel (i.e. doctor, nurse, health care aid, dietician, counsellors) are not adequately available locally -high turnover in health and administration positions -while travel can be used to serve multiple purposes (e.g. visiting, shopping, etc.), overall travel for health care services and appointments can be both a financial and time burden
-emphasis on individualized consultation for personalized services in a culturally safe environment	-depending on current demand, there may be limited resources (i.e. funding, staff, time)
-varying access to recent community health data (i.e. demographics, disease distribution)	-data provided in an unusable format (i.e. computer software, knowledge of application) -limited resources on how to effectively use health data
-FN cultural attributes (i.e. history, culture, self-governance, language, strength, sense of community and leadership)	-limited supports for residential school healing
-connections and integration with other FNs (i.e. CYFN, Yukon Health and Social Development	-not all Yukon FNs are a part of the CYFN -Processes of land claim settlements that created

Commission)	tension between FNs due to the need to identify and split traditional territory is still felt
-FSGAs allows communities to have greater autonomy over health services, and flexibility in their implementation	-not all Yukon FNs have FSGAs -gained autonomy and power without supports, resources, and continuing education can create burdensome amount of work for local staff
-food subsidy (i.e. food purchase vouchers) and/or delivery and preparation services (i.e. Meals on Wheels and community luncheons)	-there may be discrepancies in food preferences between Elders, adults, and youth
-some services are able to be held within communities from travelling health care staff (i.e. dieticians, doctors, dentists, nurses)	-limited continuity for patients in terms of relationship building or health records -travelling services may have continuing colonial ideas about Indigenous peoples and their health
-funding is regularly provided through FTAs for FNs with FSGAs	-funding may not be adequate to improve health care access
-FNs have the ability to apply for various other forms of Government funding (such as the ADI in FNs without FSGAs)	-complexity of the application process creates barriers when submitting a successful application. -limited supportive resources for creating applications and proposals for funding.

Barriers that participants perceive when accessing health services are similar to those reported in the Yukon 2008/10 RHS (First Nations Information Governance Center, 2012; Health Intelligence Inc., 2014). The RHS reports that barriers include²⁶: doctor/nurse or service was not available in their area; health facility (nursing station or hospital) not available; waiting list too long; unable to arrange transportation; difficulty getting traditional care; not covered by NIHB; prior approval for services under NIHB was denied; could not afford direct costs of care, transportation costs, or childcare costs; felt care was inadequate or not culturally appropriate; chose not to see health professional (First Nations Information Governance Center, 2012; Health Intelligence Inc., 2014). The RHS illustrates that from 2008 to 2013 there was a general increase in the amount of travel for medical purposes reported by Yukon FNs, with the majority destination being Whitehorse (Health Intelligence Inc., 2014). As evident from participant

²⁶ Percentages reported in Health Intelligence Inc. (2014)

perceptions in this study and the 2008/10 RHS, travel is one of the most significant barriers people face when accessing daily health care.

5.4.2.1 Governance as a Determinant of ADI Access and Implementation

A major determining factor of participant's perceived ability to access and implement ADI funding is the FN governance structure. There are observed differences in the abilities of communities to access and sustain continuous ADI funding. Some Yukon FNs, particularly FNs without FSGAs, may lack the capacity to secure ADI funding, meet objectives of the ADI mandate, and complete required reporting procedures. Additionally, smaller, mid-sized, and more remote communities, with comparatively less capacity than larger FNs, may not be able to implement all objectives of the ADI or support as many initiatives within the community as are needed due to a lack of capacity or infrastructure. Larger-sized Yukon FNs with greater capacity are generally able to support more T2D programs, services, training, and research that relate to the ADI mandate.

Table 5.2 summarizes community-based implementation of diabetes programming by three of the 14 Yukon FNs and compares them to the full extent of programming covered under the ADI mandate. The purpose of this discussion is not to present the limitations of each FN, but rather, to illustrate that differences exist in the extent of diabetes programming provided by communities. This is done by acknowledging the processes of acquiring and implementing ADI funding for each type of governance, and identifying areas of policy that could be changed to create more equitable conditions for all FNs, particularly between those with and without FSGAs.

Table 5.2 ADI’s Mandate Compared to Community-Based Implementation

ADI Mandate¹		Community-Based Implementation²	
Developed in ADI Phase 1 (1999-2004)	-increasing awareness of T2D -reducing incidence of diabetes-related complications	Current use of ADI funding through FTAs or approved applications	-family health promotion by providing services at an on-demand basis (i.e. aid in reading food labels, individual consultation about questions regarding diabetes prevention and management) -food subsidy (i.e. food purchase vouchers) and/or delivery and preparation services (i.e. Meals on Wheels and community luncheons) -ADI funding is used in conjunction with other funding sources to support current and local needs in FNs with FSGAs.
Developed in ADI Phase 2 (2005-2010) in addition to Phase 1 components	-primary prevention and health promotion from community-led activities such as: walking clubs; weight-loss groups and fitness classes; community kitchens and gardens; activities for children in school; healthy eating policies in schools; and culturally-oriented traditional food harvesting, berry picking, picnics, canoeing, drumming, dancing, and games. -screening and treatment of diabetes and related complications -capacity building and training for community diabetes workers -research, surveillance, evaluation, and monitoring of health programs		
Developed in ADI Phase 3 (2010-2015) in addition to Phase 2 components	-initiatives for children, youth, parents, and families -diabetes in pregnancy (gestational diabetes) -community-led food security planning to improve access to nutritious foods -enhanced training for health professionals on clinical practice guidelines and chronic disease management strategies		

¹ (Health Canada 2011a, 2013)

² Community-based implementation was combined from participant responses from 2015 interviews. Implementation is not-representative of all programs and services currently taking place within all Yukon FNs.

While there is no regulatory requirement for Yukon FNs with FSGAs that receive ADI funding through FTAs to adhere strictly to the ADI mandate, the mandate can be used as a guideline for programing. In particular, the mandate emphasizes programs, services, and

initiatives that can increase knowledge about T2D and provide more awareness for unhealthy conditions relating to higher T2D prevalence (Health Canada, 2011a, 2013). The mandate also recognizes the need for continual capacity improvement and training for health care professionals working with Indigenous communities (Health Canada, 2011a, 2013).

With greater autonomy over how ADI funding can be used, Yukon FNs with FSGAs can utilize funds to meet current and changing needs of their communities. Participants describe how ADI funding is utilized for family health promotion, food subsidy and/or delivery and preparation services, and funding sources are used jointly to implement supports for local needs. This is not to say that mandated ADI programs such as education and awareness surrounding gestational diabetes, and training for health professionals are not seen as important by community members. Rather, many FNs are limited in terms of available funding and local capacity to implement supportive services and programs. ADI funding is used in conjunction with other funding sources delivered through FTAs for Yukon FNs with FSGAs, and with other funding sources obtained for by FNs without FSGAs.

FNs with FSGAs are allocated funding amounts based on the number of registered citizens living within the FN. For example, services and programs related to health, education, social services, and culture and language are funded for the benefit of citizens, as defined by each individual FN²⁷. The Yukon First Nations Self-Government Act (1994) acknowledges that a person's citizenship status is determined "in accordance with the constitution" of the FN (p. 2). This means each FN may determine eligibility for citizenship differently from other FNs. In addition, FNs may define citizenship differently than federal health departments. When

²⁷ Information obtained from an undisclosed Yukon FN FTA.

discrepancies exist between the FN and the Federal Government definitions of citizen and eligibility of health services, it can create disparities in health funding allocation.

Yukon FNs without FSGAs remain as recognized Bands under the Indian Act, and do not receive ADI funding annually through a FTA. For these FNs, ADI funding is competitive and if funds are received, services must adhere to the ADI mandate (Table 5.2). In regards to the implementation of ADI programs, Health Canada (2011a) describes that for Yukon FNs without FSGAs applying for ADI funding:

Communities and organizations are encouraged to address their specific needs, build on strengths, and draw on traditions to help community members lead healthy lives, prevent or delay diabetes where possible and offer support to manage the condition effectively if it occurs. They are also encouraged to be innovative in their approaches to tackling diabetes, form strong partnerships where needed, employ local knowledge, and work together to reduce the burden of diabetes. (p. 18)

Yukon FNs without FSGAs seeking to carry out ADI-funded activities need to submit a funding plan to their regional ADI office in Ottawa, ON. Varying community capacity creates a situation whereby the abilities of individual FNs to successfully submit funding applications is highly variable. Further, when applying for funding, communities are encouraged to consider: ADI objectives; main and extended components of Phase 2 and 3; guiding principles; the needs of the population; how community members will be engaged in the design, development, planning and implementation of the project; how data will be collected; and evaluation measures. Contribution agreements between community members, organizations, and regional/national offices are amended by the FNIHB prior to funding being released for program implementation (Health Canada, 2011a). This funding structure also requires a rigorous reporting process, in which communities are assessed in their ability to adhere to the mandate.

For Yukon FNs without FSGAs, program expenditures from ADI funding are reported using Community-based Reporting Templates (CBRTs) (Health Canada, 2011c). All health-

related expenditures are reported on the same CBRT form. This 51 page template covers programs related to the ADI, but also other Health Canada programs such as AHS, Children's Oral Health Initiative, National Aboriginal Youth Suicide Prevention Strategy, National Native Alcohol and Drug Abuse Program, as well as healthy living and communicable disease control and management programs (Health Canada, 2011c). Participants explain that this detailed reporting process is laborious. Participants explained that this reporting process is also problematic for FNs when high turn-over of administrative staff continues.

According to Health Canada (2011b), "ADI reaches more than 600 Aboriginal communities across Canada" (p. 2). Most ADI funding is allocated for Canadian provinces since that is where the majority of FNs are located (Indigenous and Northern Affairs Canada, 2014). While both Yukon and NT recognize the ADI as an important program for managing T2D, limited capacity within communities is recognized as a constraint upon program implementation (Government of Northwest Territories, 2015). Similar to participant perspectives in this study, FNs in NT report that community wellness programs, such as the ADI, are seen as "prescriptive" and "[do] not always align with the community needs or priorities" (Government of Northwest Territories, 2015, p. VI). Difficulties in accessing and implementing ADI funding are not only localized within Yukon.

In summary, it is evident that barriers exist when accessing and implementing ADI funding both within, and external to, communities (i.e. the Federal Government), and depend on whether or not a FN has signed FSGAs. FSGAs have an impact on community capacity to implement ADI resources while federal policy procedures maintain inequalities in access to services needed in Yukon FNs. For Yukon FNs without FSGAs, the complex application process and competitive funding model maintains the colonial legacy in communities. Application and

reporting procedures can be demanding for Yukon FNs without FSGAs, and specifically for communities that have limited capacity and resources to develop successful applications. Changes need to be made in policy structure to take pressure off of FNs' administrative staff.

While the ADI is administered through the FNIHB, the AANDC (2011) recognizes “reducing the administrative and reporting burden” as an aspect of improving funding arrangements (p. 6). For accessing resources, supports, and programs related to the ADI and T2D, participants suggest ways that these processes could be improved. The purpose of identifying these barriers is to make recommendations regarding the creation of more equitable policy and funding models. These recommendations include not only additional funding, but an increase in sustainable community-based capacity. The next section provides recommendations that can create more equitable conditions for FNs, both with and without FSGAs, applying for, and implementing federally sanctioned funding.

5.4.3 Research Objective #3

The third objective of this study is to develop recommendations that enable Yukon FNs to increase the number, quality, and efficacy of ADI programs and T2D services. Participants describe barriers that exist at two separate, but interrelated categories: at the level of the community, and at the level of the Federal Government. These two categories are intimately connected through a process of interaction. This connection is explored in another category, here referred to as “*Between the Community and the Federal Government*”. In the following subsections, each of these three categories are discussed separately and a summary of feasible recommendations that can increase the number, quality, and efficacy of ADI implementation and T2D services and programs is presented for each category.

5.4.3.1 At the Community Level

While these recommendations are intended to build program capacity within communities, they are not the sole responsibility of FNs. Yukon and Federal Government departments have a responsibility to the TRC (2015) Calls to Action for decolonizing Indigenous health. The purpose of these recommendations is not to put more accountability on FNs, but to address root causes of persistent barriers that exist when accessing and implementing ADI funding and T2D services.

The first recommendation at the community level is to strengthen community capacity, such as knowledge, skills, training, resources, and supports for administrative and health care staff, individuals, and families. Some measures that could be taken to increase community capacity include the development of a Yukon-based trained position that serves as a reservoir of knowledge about federal health funding, specifically how the ADI is funded in FNs both with and without FSGAs. A person in this position could aid FNs with FSGAs by co-developing T2D programming that meets the needs of communities. This person could also aid FNs without FSGAs during the application and reporting processes required by the ADI. With knowledge and resources about how to both effectively apply for and utilize ADI funding, stronger T2D-based programming could become available to FN residents.

It is understood that the people most affected at the community level have the best idea of the systems that need to be addressed to create positive social change. Participants perceive that the diversity of needs at a local level are unlikely to be managed by national strategies. Community-based capacity is defined differently by health-based agents of the ADI and the Federal Government than FNs themselves. As an example, a participant in this study describes the need for residential school healing within the community, for both first- and second- generations

affected. This is an important step in building community capacity because colonization, racism, marginalization, and disparities in health and living conditions for Indigenous communities needed to be acknowledged, prior to moving forward. The participant describes that an application for residential school healing was recently rejected, and funding could not be gained to have more supports for residents. This could be improved by health agencies allocating more resources and funding for residential school healing, having a local reconciliation center in each community, and more outreach from agencies developing reconciliation initiatives. In accordance with the TRC (2015) report, all FNs need equal opportunity to participate in reconciliation, which is one aspect that can empower individuals to make positive social changes within their communities.

The second recommendation is to promote growth in capacity and education through local empowerment. By building community capacity, people can become empowered to achieve the greatest possible autonomy over their health and well-being by providing supports for decision-making. As the concept of empowerment can take different meanings under different cultural contexts (Solar & Irwin, 2010), it is important that Yukon FNs define what empowerment means to their residents. Participants describe that a major source of empowerment is the ability of a FN to maintain and support qualified staff. Further, participants explain that FNs are commonly understaffed, putting additional responsibilities on remaining employees. These stressful conditions could be improved if support from the Federal Government, the Yukon Government, and FNs could better support current employees. There could be a concerted effort to improve staff workplaces. While better infrastructure, such as additional office, meeting, and break spaces are needed in some communities, staff counselling and support, outreach supports from health-

based funding agencies, and workplace support groups could all empower staff to remain in their positions.

The third recommendation is to continue to increase initiatives that provide local access to nutritious and affordable food, and opportunities for physical activity. Participants emphasize the value that FNs place on healthy lifestyles. Local production is considered an aspect of improved food security and encourages participation in FN cultural activities which are beneficial for a number of biological and psychological aspects of health. Using local greenhouses and hunting as sustainable resources is a desirable and cost-effective way to reduce lifestyles associated with T2D. While individual families may have gardens and participate in hunts, community-wide activities could improve community cohesion. Two participants discuss that a local community greenhouse was constructed, but that there are an insufficient number of paid positions to maintain the daily tasks of its management. If desired, a recommendation is to incorporate greenhouse maintenance into volunteer or school-based activities.

The fourth recommendation is to continue to address T2D holistically using Indigenous culture and capacities of the FN rather than simply attempting to fix deficits (Bartlett et al., 2007; Iwasaki & Bartlett, 2006b; Iwasaki et al., 2005). For ADI programs, there is an emphasis on holistic methods that recognize community capacities, but communities are often unable to address all issues relating to the ADI mandate. While Yukon FNs with FSGAs do not have to adhere to the ADI's mandate, there are constraints on the number and quality of services communities are able to provide. By emphasizing holistic health and well-being, communities are able to address lifestyles associated with chronic diseases, but also other current health issues within communities.

Addressing T2D as a holistic health issue can be accomplished as Health Directors, community health workers, and FN residents continue to understand T2D as a disease that can be influenced by many aspects of daily life. As dietary choices and physical health are commonly associated with T2D management, services and programs that emphasize these aspects, which may or may not focus specifically on T2D, can influence T2D prevalence. If T2D support are needed for community residents, and funding is not sufficiently available to deliver T2D-specific services, staff can translate messages about the influence of dietary choices and physical health through other programs.

For example, while some participants in a FN with FSGAs utilize ADI funding for community luncheons, these luncheons provide residents with an opportunity to discuss food decisions. In addition, communities speak of the need for psychological counselling for their residents. In some communities, this is seen as more of a priority than T2D services. Improving access to counselling can shape the overall health of individuals and their families, and in turn, can aid in preventing and managing T2D. A Health Director explained that some residents use food as a coping mechanism, and by encouraging counselling, the person may change their food choices.

In summary, the recommendations within this section relate to activities at the community level. These recommendations are not the sole responsibility of FNs, but can be achieved through partnerships, communication, and collaboration with the federal and/or territorial governments, as well as various health organizations. A final summary of recommendations at the community level to increase the quantity and quality of T2D supports through ADI funding includes:

- ❖ Continuing to **build local capacity** such as knowledge, skills, training, resources, and supports within the community such as administration and health care staff, individuals, and families.
- ❖ Continuing to **empower** people to achieve the greatest possible autonomy over their health and well-being by providing all available supports for decision-making.
- ❖ Continuing and increasing initiatives that **provide local access** to nutritious and affordable food and opportunities for physical activity such as local greenhouses and community hunts.
- ❖ Continuing to address T2D as a disease that affects **holistic health and well-being**.

5.4.3.2 Between the Community and the Federal Government

It is important to recognize that more than just geographical distance exists between Yukon FNs and the administration of the ADI within the Federal Government. There is also a cultural and political distance that exists. This space is filled with a history of colonial processes that shape current health practices, where individual FNs are many steps removed from the decision-making processes of the ADI. This section discusses recommendations that can be taken to decolonize the way Yukon FNs receive health care funding, as well as to strengthen collaboration between FNs and Federal Government departments. The recommendations are the responsibility of local communities, the Yukon Government, the Government of Canada, and any organizations that form a partnership with Yukon FNs. Similar to the recommendations made at the community level, these are not meant to put additional accountability on FNs, instead they are meant to strengthen capacities that are already present within communities. The recommendations are also meant to address gaps in social and political collaboration between FNs and various health and government departments.

The first recommendation in this section is the continuation of coordination, communication, and collaboration through partnerships between Yukon FNs, the CYFN, the Yukon Health and Social Development Commission, the Yukon Government, the Government of Canada, and various organizations working with FNs. Participants identify the need for coordination and communication between not only residents of the same community, but of different FNs as well. This coordination is most evidently seen through the CYFN in which eleven of the 14 FNs in Yukon have joined (Horne, 2010). The CYFN provides supports for both administration staff and residents to access health care. Additionally, the Yukon Health and Social Development Commission is open to all FNs in Yukon, whether a part of the CYFN or not. This social connectedness has many benefits that participants recognize such as meetings with staff from all FNs, communication with Yukon Government health agents, support of a data analyst and a full-time NIHB navigator. Continual collaboration can help to ensure a comprehensive response to rising T2D prevalence in Yukon FN populations.

The second recommendation is to continually improve and expand outreach programs to reduce the burden of travel for FN residents. Outreach in this study refers to health care services, programs and screening, healthy living, as well as diabetes-specific education that can be delivered to FNs. The need for outreach derives from the time-constraint that participants perceive as a barrier when travelling for health services. While at this time it is not economically feasible that all communities have local access to all services, by increasing the amount of outreach programs that are delivered regularly to Yukon FNs and expanding resources and funding for outreach programs currently ongoing, there will be more equitable dissemination of health services and education related to T2D within the Territory. This can be beneficial for both citizen and non-citizens living in remote FNs.

One outreach program that all participants describe as needed within communities is foot care services. Currently, “foot care for Yukon people living with diabetes does not meet the standard of care outlined in the Clinical Practice Guidelines²⁸” (Sparks & Duke, 2009, p. 12). Further, Sparks & Duke (2009) argue that access to foot care services is not accessible to the majority of FN residents. As a major barrier in accessing regular foot care is travel, educating and training more people to deliver foot care services within their communities, families, and households is important. This training could be providing by the Yukon Government through Yukon College, and would provide employment for local citizens.

The last recommendation at this level relates to barriers apparent in the process through which FN citizens access compensation through the NIHB program. Yukon FN citizens perceive the NIHB program as a major barrier to accessing health care due to inconsistent application of its current requirements and regulations. The NIHB program does not cover all medications or travel costs for accessing health services, and coverage may be denied on the basis of incomplete applications and failure to adequately produce paperwork to confirm health appointments. The use of health services is shaped by people’s ability to access NIHB compensation. At the March 2016 Yukon Health and Social Development Commission meeting, there was a general consensus that a recommendation of this study should be to continually improve resources for FN citizens when accessing and receiving compensation through the NIHB program. While the CYFN has one NIHB staff member to help residents navigate the process of NIHB funding, more supports for this position, and/or the inclusion of another position could improve how citizens access NIHB. Another recommendation is that the Federal Government needs to review the current NIHB mandate and policies to understand the implications of the current program structure for FN citizens.

²⁸ Please see Canadian Diabetes Association (2008) for Clinical Practice Guidelines

In summary, the recommendations made at this level relate to relationship building between FN communities, the Yukon Government, the Government of Canada, as well as various health organizations. As there is a recognized distance, geographically, culturally, and politically, that exists between individual FNs and the Federal Government, these recommendations can aid in closing the current space that exists. A final summary of recommendations at the level between the community and the Federal Government includes:

- ❖ Continuation of **coordination, communication, and collaboration** between Yukon FNs, the CYFN, the Yukon Health and Social Development Commission, the Yukon Government, the Government of Canada, and various organizations.
- ❖ Continually **improving and expanding outreach programs** that reduce the burden of travel for FN residents.
- ❖ Continually **improving resources** for FN citizens to access and receive compensation **through the NIHB program** and a **review of current NIHB mandates and policies**.

5.4.3.3 At the level of the Federal Government

The last set of recommendations are for policy change and intervention at the level of the Federal Government. As most aspects surrounding policy and access to ADI funding are controlled by the Federal Government, recommendations are put forth to support participant perceptions of barriers that exist with current ADI funding arrangements. Recommendations in this section also lie outside policy change surrounding the ADI, and refer to limitations in assessing reliable community-based health data in Yukon and within FN communities.

The following recommendations are directed at the Federal Government because, as a national response to rising T2D rates in Canada, the Government of Canada's CDS recognizes the need for adequate supports for Indigenous persons living with T2D (PHAC, 2013b). While

the primary responsibility of protecting health equity for Canadians rests within all sectors of government (Solar & Irwin, 2010), nationally mandated programs can only change through policy modification in the level that they are administered. There is a need for major shifts in public policy to create an environment in which decolonization of Indigenous health care systems can succeed (Zimmet, Alberti, & Shaw, 2001). Zimmet (2000) suggests that traditional approaches to health care will not reduce the T2D epidemic, and instead, decolonizing the changes to policy are needed for socio-economic conditions that exist for Indigenous communities. Green et al. (2003) support this theory by adding that “population-based prevention programs which focus only on lifestyle modification would likely not be successful” in reducing the T2D epidemic (p. 558). Green et al. (2003) suggest that significant changes “require comprehensive policy interventions above and beyond lifestyle modification” (p. 558). In summary, these underlying suggestions on policy change and socio-economic and political structures are incorporated into the following recommendations in a discourse of decolonizing health care systems for Yukon FNs.

The first recommendation at the level of the Federal Government is the need for a commitment of consistent and adequate funding for the ADI and Health Canada’s CDS. Consistent funding is essential to continue to support FN peoples living with T2D in Yukon. As evident from this study, there is a dependency on federal funding policies for accessing resources to managing T2D. Participants describe that current ADI funding formula does not adequately encompass all T2D supports needed within FNs. Funding formulas need to consider the obligation that FNs have to provide supports to non-citizens residing in a FN. Funding formulas should be altered to allow for coverage of all residents of a FN, whether or not all have

citizenship status in that FN. The commitment to consistent funding from the ADI will also aid staff to financially plan future services and programs within their communities.

The second recommendation relates to changes that are needed in federal funding application procedures. Participants acknowledge that several barriers exist when both completing successful applications, and if required, completing fiscal reporting on that funding. Participants describe the need for more transparent application guidelines particularly for clearer requirements, the need for personnel to aid in the grant writing processes, and feedback on applications that were not successful. Participants also state that miscommunication exists between the applicant and the health agency that is reviewing and administering the funding. Participants describe their own personal experiences in which they have been unsure of what the application requires and had limited support to reduce this barrier. For example, some applications do not describe in clear or sufficient detail how funding decisions are made or how much funding may be awarded. Without knowing how much funding could be awarded, participants describe that applicants either budgeted too much or too little for services, which may cause the application to be rejected. It would be beneficial for applicants to have a contracted federal health policy staff position that could provide more guidance on applications.

While these supports may exist, some FNs may be unaware of this information and unsure how to locate these resources. If health agencies acknowledge the variable capacities that exist between FNs, changing funding procedures that reflect those inequities would create greater opportunities for staff to gain funding for FN communities. More outreach from funding agencies could also aid staff to create successful applications, by having more knowledge about agency-specific processes of administering funding. Participants recommend that applications be

re-designed in a way that allows staff with a variety of grant-writing abilities to submit successful applications.

While Yukon FNs without FSGAs send ADI applications to the regional office in Ottawa before submission to the national office, not all health-based applications are peer-reviewed before submission. While participants identify the design of funding applications to be a barrier and suggest changes from funding administration, this recommendation also includes the need for more supports for applicants during the grant writing process. A Yukon-based position serving all 14 FNs to provide guidance on grant writing could be beneficial for all applicants. Having this position could create more equity between FNs in Yukon.

Another barrier that participants describe during the application of health funding is the need for feedback on rejected applications. If an application is not successful, it would be beneficial for the applicant(s) to have a clear understanding of the decision, and if possible, comments on areas that the application could be improved. This communication could aid staff in creating more successful applications in the future. Communication of these successes and challenges between applicants and FNs would also be beneficial for staff. This could be accomplished through an annual meeting of FNs staff, and could be included in pre-existing meetings such as the Yukon Health and Social Development Commission.

In addition to barriers that exist in the application process, for Yukon FNs without FSGAs, the reporting process for funding received from the ADI is also identified as a barrier. Participants perceive that barriers exist as reporting procedures are time-consuming and unclear guidelines on how best to represent and report funding allocations further complicate the process. As the Honourable Carolyn Bennett, Minister of Indigenous and Northern Affairs comments regarding ceasing of discretionary compliance measures related to the Financial Transparency

Act²⁹, “these initial steps will enable us to engage in discussions on transparency and accountability that are based on recognition of rights, respect, co-operation, and partnership and that build towards a renewed, nation-to-nation relationship with Indigenous Peoples” (Government of Canada, 2015b). The Federal Government needs to address how policies regarding reporting processes for ADI funding can be changed to support FNs without FSGAs.

Reporting guidelines could become more transparent for FN staff by containing clearer guidelines on how best to report the use of funding. Participants suggest a less rigid and formal reporting procedure, and instead, one that allows flexibility and individualization by the FN. Reporting procedures need to acknowledge that staff have varying capacity. While I suggest that a Yukon-based position is created to guide all applicants from the 14 FNs during grant writing processes, this position, or a separate position, could aid FNs in the reporting process. A person in this position could have knowledge of ADI-specific reporting processes, aid in the completion and peer-revision of the report before submission.

The third recommendation is the need to expand access to supportive resources for FNs from various departments and organizations (e.g. Telehealth, FNIHB, ADI, NIHB, and the Canadian Diabetes Association). Supportive resources may include, but are not limited to: resource and information sharing, professional development, answering questions regarding application processes and paperwork, question and answer sessions, and educational workshops. While these are needed at the community level, policy changes in these areas are more likely to be implemented by levels of government and health departments administered by the Government of Canada. These supportive resources could be available by phone, email, or in-person and

²⁹ The First Nations Financial Transparency Act (Bill C-27) was initiated in 2013 which made it mandatory of Bands across Canada to release financial expenditure or have government funding withheld (Government of Canada, 2015b).

could be funded by the Yukon Government, the Federal Government such as from Health Canada, as well as from the CYFN.

The fourth recommendation is a commitment to ensure the collection of reliable and consistent health data (e.g. diabetes, chronic diseases, obesity, BMI). Consistent data are needed to better understand and justify dissemination of resources for T2D within Yukon. If provided in usable formats, these data could also support staff during their application of health care funding. As T2D prevalence has been increasing, can more specific and comprehensive data be produced at the community level? How have trends in diabetes, chronic diseases, obesity, BMI, and other factors included under the Metabolic Syndrome changed over time? While individual, patient-level changes may be documented during patient-physician consultation, these data are not collated and publically available.

While population-level changes are needed to justify considerable policy changes at the level of Federal Government, these changes are also under the jurisdiction of the national government. Community-level data collection is needed for FNs to assess current health issues within their community. Both Yukon and Federal Governments have the capacity to increase the coverage of collecting community-specific data. The TRC (2015) support this recommendation in that they assert in call number 19, “we call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gap in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends” (p. 2-3). While this recommendation addresses the collection of health data, further changes can be made within national surveys to address inadequate sample sizes and population coverage.

The last recommendation at the level of the Federal Government is the need for changes to be made within national surveys, in which sample sizes are not large enough to generate reliable data on Yukon FN people. As the result of small sample sizes over a larger geographical territory, data cannot be reliably aggregated to reveal disparities between the populations in Yukon. Statistics Canada could increase the sampling frame in the territories. This recommendation is largely a response to the analysis of national health survey data in this study. “Use with caution” indicators are prevalent for most estimations of T2D prevalence within FNs and Yukon. These errors do not produce reliable estimations for FNs’ staff trying to implement services and programs related to diabetes. Continual improvements in survey methodology and design are needed to minimize the effects of these errors (Lyberg, 2012).

As T2D is known to be an epidemic and endemic health disparity for Indigenous populations (Harris et al., 1997; Iwasaki et al., 2004; Oster, 2011; Young, Reading, Elias, & O’Neil, 2000), more precise and consistent health surveying of geographical or health regions that are usually excluded from national surveys is needed. As supported by Hanley et al. (2015), there is a need for continuous screening and regular T2D testing for Yukon residents. Expanding survey borders and increasing the total population reached is necessary. While data regarding health-based disparities is not the sole responsibility of the Federal Government, fixing this gap needs investment from the Government of Canada.

In summary, the recommendations made within this section relate to activities at the level of the Federal Government. These changes may mean not only improving current funding systems, but changing the system in a discourse of decolonization. It is hoped that these recommendations inform a review of the ADI funding structure. Without listening to the voices of the FN participants in the study and their experiences in accessing federal health funding relating to

T2D, decolonizing Indigenous health cannot happen. Fixing these gaps needs investment, in not only funding, but time, capacity, and resources. A final summary of recommendations at the level of the Federal Government includes:

- ❖ A **commitment of consistent and sufficient funding** for the ADI and Health Canada's CDS.
- ❖ **Changes in funding application procedures** for health-related infrastructure, services, and programs funded by federal and/or territorial governments and health organizations.
- ❖ **Expansion of access to supportive resources** (e.g. Telehealth, FNIHB, NIHB, Canadian Diabetes Association) to provide education and programming for those who require supports for decision-making, paperwork, etc.
- ❖ Commitment to ensure the **collection of reliable and consistent** health data (such as diabetes, chronic diseases, obesity, BMI).
- ❖ **Changes to national surveys** in which sample sizes are not large enough to generate reliable data.

5.5 Biocultural and Critical Medical Considerations

This study is an anthropological inquiry in that it addresses participants' perceptions of capacities and barriers that exist when accessing and implementing ADI funding and T2D services by recognizing that contemporary funding protocols shape experiences of health for Yukon FN residents. Varying capacities within FNs creates an unequal distribution of T2D services throughout the territory. Barriers that participants perceive do not only surround access and coverage of funding sources, but relate to larger issues of injustice, colonialism, identity, and health and well-being. Colonial processes in Canada shape Indigenous peoples' health in detrimental ways. It is important to support research through a discourse of decolonization,

incorporating methods that recognized complex biological and social aspects of health, as well as the political environment in which health care is accessed and delivered.

By incorporating a biocultural understanding of health (e.g. Dufour, 2006; Goodman & Leatherman, 1998; Khongsdier, 2007; McElroy, 1990), individuals are not understood solely as biological bodies that do or do not contain the chronic disease of T2D. Instead, people are understood as both biological and cultural/social individuals, and their access to health care is shaped by social and political processes. By further situating the study within a conceptual framework that emphasizes various determinants of health (Loppie-Reading & Wien, 2009), this study is able to better understand how T2D care is lived for Yukon FN residents. In summary, this approach bridges the gap between the physical and social aspects of health (Khongsdier, 2007; McElroy, 1990), while also critically analyzing current systems in place to manage health care.

Critical medical anthropology is utilized to understand the political economy of health and how it shapes current access to health care in Yukon. As Baer et al. (1986) asks, “who has power over the agencies of biomedicine? How and in what forms is this power delegated?” (p. 96), this research critically assesses the ADI. While Yukon FNs with FSGAs have great autonomy over how ADI funding is utilized, it is out of their control how much funding is granted, and how the process of funding allocations are distributed. For FNs without FSGAs, the Federal Government has power over decision-making for allocations made from competitive applications. By understanding power in decision-making, and like a biocultural perspective of health, by further situating the study within a conceptual framework that emphasizes understanding health disparities and areas of policy change needed (i.e. Kilbourne et al., 2006), this study is able to create recommendations to increase equity of T2D resource allocations.

While recommendations are made at community level and the level of the Federal Government, policy change is essential in increasing health equity.

5.6 Limitations

Limitations of this study shaped the recommendations produced, as well as the depth to which knowledge was co-created. The study was limited by small sample size: I interviewed six participants from three of the 14 Yukon FNs. While FNs both with and without FSGAs were included in this study, perceptions of access to health care and ADI funding from these three may be different than the other 11 that were not included in this study. The consistency with which participants expressed their experiences accessing health care and with ADI funding suggests similar barriers exist across Yukon.

The participants for this study were chosen based on their knowledge of the process of obtaining federal health funding, and/or they had a direct role in accessing and implementing ADI funding. A limitation of this selection-bias was that these participants may perceive conditions differently than community residents who did not have a role in accessing federal health funding. Further, the study was limited by only interviewing one type of personnel, either Health Directors or administrative staff. If other types of personnel within the community were interviewed (i.e. nurses, community health representatives, residents seeking health care), a more holistic representation of the capacities and barriers that exist when accessing T2D supports could be achieved.

5.7 Summary

This chapter provided a rationale for how capacities, barriers, and recommendations were understood with insights from the conceptual framework, and through a discourse of decolonizing Indigenous health. Next, this chapter provided a discussion of this study's results

by contextualizing participants' responses with academic literature, exploring further the major themes presented during analysis, as well as how the results were used to answer the research questions of this study. For the first research question, participants understood T2D as a prevalent issue in Yukon FNs. This was supported with reference to national health data from the NPHS, CCHS, and RHS which indicated a rising prevalence of T2D since 1994. The second research question emphasized understanding how participants perceived capacities and barriers when accessing and implementing ADI funding and T2D services. There was a general consensus that available funding for health programs does not match current needs. This discussion was used to create recommendations at the level of FN communities and the Federal Government. To represent the complex relationship that exists between Yukon FNs and the Federal Government, this study also included recommendations to improve collaboration between these two levels. Lastly, this chapter situated the study's results within the discipline of anthropology, focussing specifically on a biocultural understanding of health, and a critical approach to understanding health services.

Chapter Six: Summary and Conclusion

6.1 Findings: Meaning and Importance of Increasing Health Equalities

This study has found that because of high prevalence of T2D in FN's populations, including that of Yukon FN communities, there is a need for FN's to gain support and strengthen partnerships with federal administrations. It is necessary for both FN's and federal and territorial governments to implement policy and create sustainable infrastructure to hold culturally sensitive health services. There is a major concern at the territorial level of Yukon that the operation of ADI as a federally funded health program is constrained by factors both within the Yukon FN's communities as well as factors inherent to the program itself. As the results and discussion of this study has expressed, strengthening the capacity for communities to deal with determinants of health requires engagement of multiple levels of agencies and government (World Health Organization, 2012).

This study created recommendations for policy change at the level of the Federal Government, and at the community level. This process has contributed to the conversation about increasing the health and sustainability of health programs in Yukon FN's communities. Similar to other research (e.g. Frohlich et al., 2006; Newbold, 1998), this study has found that improvements in health status will not come from improved access to health care services alone, but through increasing capacity and control over Indigenous determinants of health and well-being. While more funding is often considered a solution, it will not cover what is needed to ensure more people have sustainable access to funding sources. What is needed is better guidance through funding processes, changing policies, providing education and training so that

people can create positive social change within their communities, and more infrastructure to hold programs in the communities.

6.2 Study Recommendations and Federal Government Commitment

This study comes at an important time with the recent 2015 change in Federal Government. Regarding the health of all Canadians, Prime Minister Justin Trudeau wrote in the Ministerial Mandate Letter addressed to the Minister of Health, “the federal government must be an essential partner in improving outcomes and quality of care for Canadians” (Office of the Prime Minister, 2015a). As described in the Minister of Health Mandate Letter, a top priority is to “engage provinces and territories in the development of a new multi-year Health Accord” (Office of the Prime Minister, 2015a). If this multi-year Health Accord (Office of the Prime Minister, 2015a) includes Yukon FNs with and without FSGA, it can be utilized to support recommendations made.

Further, as Prime Minister Trudeau wrote in Minister of Indigenous and Northern Affairs’ Mandate Letter, “It is time for a renewed, nation-to-nation relationship with Indigenous Peoples, based on recognition of rights, respect, co-operation, and partnership” (Office of the Prime Minister, 2015b). The strengthening of this nation-to-nation relationship has been addressed in this thesis in which Yukon FNs and the Government of Canada are disconnected geographically, culturally, and politically. As discussed in the Minister of Indigenous and Northern Affairs Mandate Letter, a top priority for the new government is to “work with the Minister of Finance to establish a new fiscal relationship that lifts the 2% cap on annual funding increases and moves towards sufficient, predictable and sustained funding for First Nations communities” (Office of the Prime Minister, 2015b). Prime Minister Trudeau also wrote, “We committed to a responsible, transparent fiscal plan for challenging economic times... We have also committed to set a higher

bar for openness and transparency in government.” (Office of the Prime Minister, 2015b). As policies surrounding Indigenous health care are top priorities for the Federal Government mandate, it is hoped that policy changes are made in light of the recommendations set forth by this thesis.

6.3 Suggestions for Further Research

While this research focused on T2D and the ADI in selected Yukon FNs, research of this nature is needed in other communities and with other funding supports. Decolonizing Indigenous health is an important step to creating more equitable access to health care in Canada. It would be interesting to focus future research on not only Health Directors who understand ADI, but to include focus groups of community members who live and experience health inequalities in a range of different sectors. The impact that travelling for food and health services can have on an individual, family, and community can significantly contribute to health status and well-being, and deserves further focus. While this study in part focused on a longitudinal analysis of changes that have occurred in Yukon since ADI’s establishment in 1999, a more in-depth focus on consequential community-based capacity changes since the time of colonization is important to fully explore decolonizing Indigenous health.

While health care and community-based organization may be provided differently across the territories and provinces in Canada, and interesting study would be to compare these Yukon results to similar studies in the NT, Nunavut, or the provinces. If results were obtained that show similar community-based assets and barriers in implicating federal funding, could policy changes be made that benefit all Indigenous communities?

6.4 Conclusion

Despite the fact that the study was carried out in three of the 14 Yukon FNs, the results are reflective of similar situations in other communities in Yukon, not in the sense of statistical representation, but in the sense of transferability of knowledge about the results and recommendations of this study. Despite having only six participants, this study selected highly knowledgeable informants, and the sample size reflects the reality of the population. However, the consistency within the six responses suggests that these understandings of T2D and the ADI are common within Yukon FNs. While each person had unique past experiences that shaped their current reflections of the relationship between their community and the Federal Government, all responses were shaped by colonial processes that impact all Indigenous peoples in Canada.

In summary, more funding for ADI services and programs, more infrastructure to hold programs in the communities, and more capacity building and knowledge about how to apply for more funding for T2D programs is needed. It is hoped that this research will benefit the ongoing efforts of Indigenous groups in addressing health and well-being, and informing the Federal Government about policy research. Overall, access to basic health care services and diabetes management in particular brings us back to the importance of an accessible health care system as being the basic determinant of health outcomes, even in a supposedly industrialized nation with universal access to healthcare (Martens et al., 2007).

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Appendix A – Research Partnership Agreement between the CYFN Health and Social Department as guided by the Yukon FN Health and Social Development Commission and Dr. Tracey Galloway, University of Manitoba, 10 September 2014. (4 pages)

The impact of Federal health programs on health inequalities in Yukon First Nations communities

The researcher Dr. Tracey Galloway, Assistant Professor at the University of Manitoba, and the Health and Social Department of the Council of Yukon First Nations as guided by the Yukon Health and Social Development Commission agree to conduct the above-named research project with the following understanding:

1. The purpose of this research project, as discussed with and understood by all parties:

Following the First Nations principles of ownership, control, access, and possession (OCAP), to conduct a community-centered evaluation of the capacity of Yukon First Nations to access and implement federal health programs, with the goal of developing capacity and identifying barriers to program access and implementation, and thereby improving health outcomes for Yukon residents.

2. The scope of this research project (that is, what issues, events, or activities are to be involved, and the degree of participation by community residents), as discussed with and understood by all parties, is:

The project will trace the history of program funding, identify which programs are operating in which communities, evaluate the effectiveness of existing programs, identify barriers to program access in communities, and examine the impact of these programs on health inequalities in Yukon.

3. Methods to be used, as agreed by the researchers and the community, are:

by Oct 2014	• map program mandate and goals
Oct 2014 - Dec 2015	• map program delivery in 14 communities
Oct 2014 - Dec 2015	• evaluate program delivery in 14 communities through observation, depth interviews and community meetings • interim and regular reports with Health and Social Development Commission and Council of Yukon First Nations
Dec 2015	• analysis and preparation of initial comprehensive report by the researcher
Jan 2016	• researcher and co-investigators meet with Health and Social Development Commission to present initial comprehensive findings; opportunity for analysis, feedback and refinement of findings
Feb 2016	• preparation of final comprehensive report by researcher
Feb-Mar 2016	• seek approval of final report and final agreement on its dissemination from the Health and Social

	Development Commission (prior to dissemination)
by Aug 2016	• presentation of final comprehensive report <i>in person</i> by researcher at community meetings in 14 communities
by Oct 2016	• presentation of final comprehensive (electronic and hard copy) report to stakeholders: communities, CYFN, YAWC, Yukon Health and Social Services, AANDC, Health Canada, PHAC and others
beginning Oct 2016 and ongoing	• dissemination of findings in scholarly publications and conferences

4. Community training and participation, as agreed, is to include:

We will employ a Research Coordinator at the CYFN offices in Whitehorse YU to coordinate communication and logistics between FN communities, CYFN, YG and the university. Duties will include communication with communities, identification of key stakeholders, subject recruitment, assisting the researcher with obtaining informed consent from participants, collecting data, coordinating communication, planning and chairing meetings.

5. Information collected is to be shared, disseminated, and owned/stored in these agreed ways:

a. This Research Partnership Agreement represents a legally binding agreement that governs the collection, use and disclosure of the data generated by this research. Arrangements for stewardship of the data collected in this research are intended to respect OCAP principles of data ownership by First Nations and to prevent applications for access to the data through the federal Access to Information Act or any similar provincial or territorial law that fails to recognize First Nations as government or protect First Nations collective information.

b. For the duration of the research, the researcher and research coordinator will jointly maintain a record of research activities including digital and print copies of interview transcripts.

c. After the end of the research, these data will be de-identified to remove all personal identifiers such as names and addresses. The collective dataset will become the shared property of both CYFN and Dr. Tracey Galloway and will be used solely for the purpose of dissemination through conferences and scholarly publication, in all cases with the approval of the Health and Social Development Commission.

d. The individual community datasets will be transferred to the respective First Nation and become the sole property of the relevant First Nation. Its use

determined by the scope of the participants' consent and by regulations determined by that First Nation.

e. If opportunities for Knowledge Translation arise after the cessation of the research period, such as the opportunity to inform Auditor's Reports or Parliamentary Committee hearings, the researcher may make written application to the Health and Social Development Commission to provide the results of the collective research project in that context. The decision whether to permit the use of the results of the study will be at the sole discretion of the Health and Social Development Commission, after consultation with the relevant First Nations.

6. Informed consent of individual participants is to be obtained in the following ways:

The written informed consent of participants will be obtained prior to the collection of all data, such as interviews and focus groups. Where necessary, translation services will be provided to ensure knowledge of English is not a barrier to participation. All study participants will be adults (18 years or older).

7. The names of participants and the community are to be protected in these agreed ways:

Data will be de-identified to remove all personal identifiers such as names and addresses. In addition, the researcher will in all cases seek the guidance of the Health and Social Development Commission on the necessity of removing community identifiers to mitigate the possibility of stigma arising from historical processes.

8. Project progress will be communicated to the community in these agreed ways:

- In-depth interviews and community meetings (Sept 2014 - Dec 2015)**
- Presentation of initial comprehensive findings to Health and Social Development Commission with opportunity for feedback and refinement of findings (Fall 2015)**
- Seek approval of final report and final agreement on its dissemination from the Health and Social Development Commission (Feb-Mar 2016)**
- Presentation of final comprehensive report in person by researcher at community meetings in 14 communities (by Aug 2016)**
- Presentation of final comprehensive report (paper) to stakeholders: communities, CYFN, YAWC, Yukon Health and Social Services, AANDC, Health Canada, PHAC and others (by Oct 2016)**

Research Partnership Agreement Between the CYFN Health and Social Department as guided by the Yukon First Nation Health and Social Development Commission and Dr. Tracey Galloway, University of Manitoba, 10 Sept 2014

9. Communication with the media and other parties, (including funding agencies) outside the named researchers and the community, will be addressed in these agreed ways:

In all cases, the researcher will consult with the Health and Social Development Commission regarding the release of project results to the media or other parties.

10. Funding - The Primary Investigator has acquired funding and other forms of support for this research project from:

The Institute for Aboriginal People's Health at the Canadian Institute for Health Research \$100,000, Funding Reference No. 134071

Signatures

Name (please print): Ruth Massie, Grand Chief
Organization: Council of Yukon First Nations
Date: Sept. 15/14
Signature: _____

Name (please print): Michelle Kolla, Executive Director
Organization: Council of Yukon First Nations
Date: _____
Signature: Sept 8/14

Name (please print): Lori Duncan (Project Lead)
Organization: Council of Yukon First Nations
Date: Sept 8/2014
Signature: _____

Name (please print): Tracey Galloway (Researcher)
Organization: University of Manitoba
Date: Sept 6, 2014
Signature: _____

Appendix B – Research Protocol: Supplementary Document to the Partnership Agreement between the CYFN Health and Social Department as guided by the Yukon FN Health and Social Development Commission and Dr. Tracey Galloway, University of Manitoba, 10 September 2014. (12 pages)

Yukon First Nations' Research Protocol

Project Information Sheet and Checklist

This checklist is intended to be used to ensure that OCAPTM (Ownership, Control, Access, and Possession) principles and other ethical guidelines are followed when research is conducted in Yukon First Nations' communities.

The researcher team members would normally complete this form and then review it with a community representative. Changes would then be made by the researchers as required in keeping with the community's wishes.

This document outlines a number of practical considerations such as the duration of the research project and names and affiliations of the research team members. In addition, it provides a means to review OCAPTM principles with the research team to ensure that these principles will be followed during the data collection phase of a planned research project and after the data is collected.

This document can be used as the main research agreement or as a supplementary document to another research agreement. Researchers affiliated with academic institutions will typically need to complete an ethical review form. Such ethical review forms should also be reviewed when this checklist is completed.

Today's Date: **10 Sept 2014**

Title of research project and a brief description of the project:

Title: The impact of Federal health programs on health inequalities in Yukon First Nations communities

The purpose of this study is to conduct a community-centered evaluation of the capacity of Yukon First Nations to access and implement federal health programs, with the goal of developing capacity and identifying barriers to program access and implementation, and thereby improving health outcomes for Yukon residents. The project will trace the history of program funding, identify which programs are operating in which communities, evaluate the effectiveness of existing programs, identify barriers to program access in communities, and examine the impact of these programs on health inequalities in Yukon.

Expected duration of research project:

Sept 2014 – Aug 2016

Location of research project:

Research Protocol: Supplementary Document to the Partnership Agreement Between the CYFN Health and Social Department as guided by the Yukon First Nation Health and Social Development Commission and Dr. Tracey Galloway, University of Manitoba, 10 Sept 2014

Yukon First Nation	Communities
Vuntut Gwichin First Nation	Old Crow
Tr'ondëk Hwëch'in	Dawson
First Nation of Nacho Nyak Dun	Mayo
Selkirk First Nation	Pelly Crossing
White River First Nation	Beaver Creek
Kluane First Nation	Burwash Landing
Champagne and Aishihik First Nations	Haines Junction
Little Salmon Carmacks First Nation	Carmacks
Ross River Dena Council	Ross River
Kwanlin Dun First Nation	Whitehorse
Ta'an Kwäch'än Council	Whitehorse
Caracross Tagish First Nation	Carcross
Teslin Tlingit Council	Teslin
Liard First Nation	Watson Lake
Kaska Tribal Council	Watson Lake

Names of researchers, titles, roles in the research:

- **Dr. Tracey Galloway, Assistant Professor, Department of Anthropology, University of Manitoba (Principal Investigator and the primary researcher responsible for data collection and analysis)**
- **Lori Duncan, Health and Social Director, Council of Yukon First Nations (Project Lead, Knowledge User and the primary contact for Council of Yukon First Nations and the Yukon Health and Social Development Commission)**
- **Dr. Brendan Hanley, Medical Officer of Health, Department of Health Services, Yukon Government (Knowledge User)**
- **Dr. Sharon Bruce, Professor, Community Health Sciences, Faculty of Medicine (Co-investigator)**
- **Dr. Josée Lavoie, Director of Manitoba FN Centre for Aboriginal Health Research and Associate Professor, Faculty of Medicine, University of Manitoba (Co-investigator)**
- **Dr. Noreen Willows, Associate Professor of Community Nutrition, Faculty of Agricultural, Life and Environmental Sciences, University of Alberta (Co-investigator)**

Name of organization/ agency or university/college and address:

Principal contact:

Dr. Tracey Galloway
Department of Anthropology
435 Fletcher Argue Building
University of Manitoba
Winnipeg MB R3T 2N2

Time Commitments, Consent, Possible Risks and Benefits to Participants

Please record the number and type of research activities. Record the amount of time required to complete these activities eg. Interviews, group activities, focus groups:

- **Individual interviews – 30-90 minutes each, 5-10 per community, depending on availability of participants**
- **Focus groups – 30-90 minutes each, 2-5 per community, depending on availability of participants**
- **Community meetings – 60-120 minutes each, depending on availability of participants**

How will the First Nation benefit from participation?

The products of the research (a report) will be delivered to communities and stakeholders at CYFN, YAWC, Yukon Health and Social Services, AANDC, Health Canada, PHAC and used to guide program development, funding models, capacity building in communities, and to lobby the federal government for reform of the competitive program funding models currently in place.

The results of the research will be returned in person at community meetings in each community by the researcher (Galloway). Participants who attend will be informed not only of the specific results pertaining to their community and the Yukon-wide analysis, but will also be informed of the ways in which results are being translated at the territorial and federal level to inform policy, improve health services in Yukon First Nation communities, and reduce the health inequities experienced by indigenous people living in Yukon.

How is the research relevant to the research participants and the local community?

Currently few federal health programs designed for First Nations communities are actually reaching First Nations residents of Yukon communities. The programs that do operate, such as Aboriginal Headstart and the Canadian Perinatal Nutrition Program, are unequally distributed among Yukon First Nation communities. This is due to a combination of factors

including competitive program funding, federal budget allocation processes, and limited capacity in many communities to negotiate the complex and competitive system required to access and operate federal health programs. This project aims to map federal program and budget allocations and describe the barriers to equitable program funding and operation in all of Yukon's 14 First Nation communities.

What are the possible risks associated with participation?

There are no major identifiable risks associated with participation. However it may be distressing for some community residents, Elders or program staff to discuss the health and social conditions and barriers to improvement that are experienced at times in some communities. It is possible that interviews and focus groups may elicit feelings of frustration or sadness that will be distressing for some participants. The researcher and research coordinator at CYFN will ensure local health service providers are made aware that the research is occurring so that such supportive services that exist in communities are available to residents.

Will monies or gifts be provided to research participants? If so, please specify.

Honoraria will not be provided.

How will the culture and values of the First Nation community be respected?

Guided by the research coordinator at CYFN, we will contact communities through their Health Directors and identify local individuals who can be identify key informants for interviews and focus groups. In all communities, Elders will be consulted to provide knowledge about the local community and insight into how federal programs have or have not influenced the community over the years. We will at all times respect the traditions of sharing and hospitality in communities. To make the experience of participation comfortable, we will purchase beverages and food items (tea, coffee, bannock, fruit/berries) from local stores and caterers to share at community meetings. If interviews take place in people's homes, a suitable gift (fruit tray, flowers) will be provided.

How will informed consent be obtained?

Written, informed consent (signature or personal mark) will be obtained from all participants of interviews and focus groups. Translation services will be provided where needed to ensure Elders and other residents are fully aware of the protocols and potential outcomes of their participation in the research.

How will confidentiality be ensured?

Participants in interviews and focus groups will be asked in private whether they assent to the collection of their data in the presence of the researcher, research coordinator and family members or in the case of focus groups, other members of the group. Their wishes in this regard will be respected.

How will anonymity be ensured?

For the duration of the research, the researcher and research coordinator will jointly maintain a record of research activities including digital and print copies of interview transcripts. After the end of the research, these data will be de-identified to remove all personal identifiers such as names and addresses. Identified versions of the data will be destroyed.

Application of OCAP™ Principles

How will the following principles be applied?

Ownership

Within OCAP™ guidelines, each First Nation community owns the data collected in their respective communities rather than the researcher(s). The data is collectively owned by the First Nation rather than one individual or a group.

Briefly describe how the research team will ensure that the First Nation has ownership of data (raw and other data) and any reports generated from the research. Also see the questions on page five as several questions pertain to ownership issues.

a. The Research Partnership Agreement of which this document is a supplementary document represents a legally binding agreement that governs the collection, use and disclosure of the data generated by this research. Arrangements for stewardship of the data collected in this research are intended to respect OCAP principles of data ownership by First Nations and to prevent applications for access to the data through the federal Access to Information Act or any similar provincial or territorial law that fails to recognize First Nations as government or protect First Nations collective information.

b. For the duration of the research, the researcher and research coordinator will jointly maintain a record of research activities including digital and print copies of interview transcripts. However in recognition that the First Nations collectively own data relevant to their communities, if at any stage of the research an individual First Nation wishes to access the data, the researcher (Galloway) will provide them with a de-identified set of the data collected to date from their community. The request may be made in writing by any member

of the First Nation's governing council or their delegate. The researcher will comply with the request within a period no longer than 7 days from receipt of the request.

c. After the end of the data research, all data will be de-identified to remove all personal identifiers such as names and addresses. The collective dataset will become the shared property of both CYFN and Dr. Tracey Galloway and will be used solely for the purpose of dissemination through conferences and scholarly publication, in all cases with the approval of the Health and Social Development Commission.

d. The individual community datasets will be transferred to the respective First Nation and become the sole property of the relevant First Nation. Its use determined by the scope of the participants' consent and by regulations determined by that First Nation.

e. If opportunities for Knowledge Translation arise after the cessation of the research period, such as the opportunity to inform Auditor's Reports or Parliamentary Committee hearings, the researcher may make written application to the Health and Social Development Commission to provide the results of the collective research project in that context. The decision whether to permit the use of the results of the study will be at the sole discretion of the Health and Social Development Commission, after consultation with the relevant First Nations.

Control

The First Nation or representatives of the First Nation, have the right to control all steps of the research process.

How and when will community members or a representative of the community be consulted and involved before, during and after the research process?

As member of the Health and Social Development Commission, the Health Directors of First Nations communities have been involved in ongoing discussions and workshops regarding the development of this research since November 2012. Lori Duncan of the Health and Social Department of the Council of Yukon First Nations will continue to serve as Project Lead for the project and will supervise the Research Coordinator based in the CYFN offices in Whitehorse. Opportunities for future guidance by the Health and Social Development Commission include:

- researcher and co-investigators will meet with Health and Social Development Commission to present initial comprehensive findings; opportunity for analysis, feedback and refinement of findings (Jan 2016)**

- **researcher will meet to seek approval of final report and final agreement on its dissemination from the Health and Social Development Commission (prior to dissemination, Feb-Mar 2016)**
- **presentation of final comprehensive (electronic and hard copy) report to stakeholders including the Health and Social Development Commission**

How and when will draft reports produced by the researcher(s) (with the collected data) be reviewed by the First Nation or representatives of the First Nation? How will it be shown on the reports that this material has been reviewed *and approved*?

The researcher will meet to seek approval of final report and final agreement on its dissemination from the Health and Social Development Commission (prior to dissemination, Feb-Mar 2016). If approved by consensus, the final report will contain the statement: “This research has been reviewed and approved by the Health and Social Development Commission, Council of Yukon First Nations, [date]”.

How will the First Nation or its representative be involved in the distribution of any reports produced with the data? How will the researcher (s) inform the First Nation community, or its representative, about the distribution of any reports or other materials produced with the data?

The presentation of findings to communities (by Aug 2016) pre-dates presentation of the final hard-copy report to Yukon Health and Social Services, AANDC, Health Canada, PHAC (by Oct 2016). If funds permit, presentation of the final report to these agencies may occur in person, for example to Yukon Government staff. Should members of the Health and Social Development Commission and individual First Nations wish to participate in these Knowledge Translation activities, and should funds permit, the researcher welcomes such participation.

If opportunities for Knowledge Translation arise after the end of the research period, such as the opportunity to inform Auditor’s Reports or Parliamentary Committee hearings, the researcher may make written application to the Health and Social Development Commission to provide the results of the collective research project in that context. The decision whether to permit the use of the results of the study will be at the sole discretion of the Health and Social Development Commission, after consultation with the relevant First Nations. It is hoped that members of the governing council of the First Nations, or their delegates, may wish to participate in these Knowledge Translation activities, such as appearances at Parliamentary Committee hearings. The researcher welcomes such collaborations and will work closely with First Nations and CYFN to ensure the results of the research reach a wide audience and promote health system improvement.

Funding

Who is the primary funder for this research project?

**The Institute for Aboriginal People's Health at the Canadian Institute for Health Research
\$100,000, Funding Reference No. 134071**

Are the researcher(s) required to report to this funder? If yes, please specify what this reporting will entail.

The researcher is required to submit Annual Reports that stipulate research activities and budgetary accounting. The researcher will provide copies of these reports to the Council of Yukon First Nations annually and to individual First Nations upon written request.

Access and Possession

First Nations have the right to access and possess any research that is being done with them and about them. This protocol ensures that First Nations have full access and possession of all research related documents and other materials.

How will access and possession of all data (raw data and other data) be ensured? Will copies of any community specific data be sent to the First Nation? When? To whom? How will security be ensured?

- a. For the duration of the research, the researcher and research coordinator will jointly maintain a record of research activities including digital and print copies of interview transcripts. However in recognition that the First Nations collectively own data relevant to their communities, if at any stage of the research an individual First Nation wishes to access the data, the researcher (Galloway) will provide them with a de-identified set of the data collected to date from their community. The request may be made in writing by any member of the First Nation's governing council or their delegate. The researcher will comply with the request within a period no longer than 7 days from receipt of the request.**
- b. After the end of the data research, all data will be de-identified to remove all personal identifiers such as names and addresses. The collective dataset will become the shared property of both CYFN and Dr. Tracey Galloway and will be used solely for the purpose of dissemination through conferences and scholarly publication, in all cases with the approval of the Health and Social Development Commission.**

c. The individual community datasets will be transferred to the respective First Nation and become the sole property of the relevant First Nation. Its use determined by the scope of the participants' consent and by regulations determined by that First Nation.

Will copies of the community specific data (raw and other data) also be kept by the researcher(s) during the duration of the research project?

For the duration of the research, the researcher and research coordinator will jointly maintain a record of research activities including digital and print copies of interview transcripts.

How long after the completion of the research project will the researchers keep the data?
Where will the data be kept?

The researcher will maintain a record of the de-identified data for the purposes of Knowledge Translation activities relevant to the project. The data will be housed in a password-protected spreadsheet and word files on the researcher's password-protected computer.

If opportunities for Knowledge Translation arise after the cessation of the research period, such as the opportunity to inform Auditor's Reports or Parliamentary Committee hearings, the researcher may make written application to the Health and Social Development Commission to provide the results of the collective research project in that context. The decision whether to permit the use of the results of the study will be at the sole discretion of the Health and Social Development Commission, after consultation with the relevant First Nations.

Please specify if anyone, other than the researcher(s), will have access to this data (raw and other data), and for what purpose, until it is destroyed.

After the end of the research period, no other person shall have access to the data without the written permission of the Health and Social Development Commission, after consultation with the relevant First Nations.

Other considerations – Data Storage, Outputs and Distribution

Data Storage

All data are expected to be kept in a secure manner by all parties. For example, data is expected to be stored in a locked filing cabinet. Electronic versions of documents are to be stored on a password protected computer or laptop.

During the research, the data will be housed in a password-protected spreadsheet and word files on both the researcher's and the research coordinator's password-protected computers. Use of the data by graduate students will occur on password protected computers under the supervision of the researcher (Galloway). All copies of the data in students possession will be destroyed at the completion of their duties, the destruction supervised by the researcher (Galloway).

After the end of the research period, the data will be housed in a password-protected spreadsheet and word files on the researcher's and CYFN's password-protected computers. Paper files relevant to the research will be kept in locked filing cabinets to which only the researcher/CYFN has the key.

Copies of the data for individual First Nations will take the form of password-protected spreadsheet and word files on memory keys.

Outputs, Authorship and Distribution

No ISBN number, copyright or trademark will be permitted unless permitted by the First Nation.

What types of reports or other materials will be produced with the data (raw data and other data)? How many reports or other materials will be distributed? To which groups?

In addition to presentations of research results in communities, the main research output is a Final Comprehensive Report (electronic and hard copy). The Health Director of each First Nation will have a chance to review and approve the report at a meeting of the Health and Social Development Commission in Whitehorse (January 2016) and again by email (Feb-Mar 2016) prior to the dissemination of results to communities and the dissemination of the Final Report.

Secondary research outputs will take the form of publications in peer-reviewed scholarly journals and conference presentations by the researcher (Galloway), her graduate students and the Project Lead (Lori Duncan).

Will any of the information collected be posted on a website, blog or any other widely available public domain?

The report will be available on the CYFN website.

How will the research participants be acknowledged in any report or any other material including internet based material?

Research Protocol: Supplementary Document to the Partnership Agreement Between the CYFN Health and Social Department as guided by the Yukon First Nation Health and Social Development Commission and Dr. Tracey Galloway, University of Manitoba, 10 Sept 2014

Research participants will be acknowledged in the final report (electronic and hard copies) in the Acknowledgements section in a statement approved by the Health and Social Development Commission during their review of the final report draft.

Will the media be informed of this project or any of the results from this project?

The decision whether to permit the dissemination of the results of the study through media will be at the sole discretion of the Health and Social Development Commission, after consultation with the relevant First Nations. *In all cases, the researcher will consult with the Health and Social Development Commission regarding the release of project results to the media or other parties.*

Will this research be published? Who will be the author of this publication? How will the research participants be acknowledged?

Results of the research will be published in peer-reviewed scholarly journals and at conference presentations by the researcher (Galloway), her graduate students and the Project Lead (Lori Duncan). The participation of First Nations contributors will be acknowledged in each and every publication.

Other Considerations

Are there any other items that should be reviewed and taken into consideration before launching this research project?

No

Follow-up

In order to ensure that these guidelines are being followed throughout the duration of the research project, all parties agree to review this document on the following date (s):

15 January 2015

15 January 2016

Agreement

I agree that the proceeding guidelines are acceptable. I agree to follow these guidelines. If circumstances change, I agree to meet in order to make mutually agreed upon changes to this document.

Researcher(s)

Tracey Galloway

20 Sept 2014
Date

This document was produced by the Council of Yukon First Nations (CYFN) Health and Social Department in 2012. This document can be modified as necessary by persons working for Yukon First Nations' Governments and CYFN employees. Other persons wishing to modify this document or use this document are asked to contact the CYFN Health and Social Department.

Reference

First Nations Information Governance Centre. (2010) The First Nations Principles of OCAP™. *First Nations Information Governance Centre*. Retrieved April 10, 2012, from <http://rhes-ers.ca/search/node/ocap>.

Appendix C – Yukon Canada Scientist and Explorers Act Licence. (2 pages)



Tourism and Culture

Box 2703, Whitehorse, Yukon Y1A 2C6

**CULTURAL SERVICES BRANCH
HERITAGE RESOURCES UNIT**

File No.: 6800-20-1007

May 14, 2015

TO: Dr. Tracey Galloway (University of Manitoba)
Environment, Habitat Management (V-5R)
Lands Use Section, Lands Branch (K-320)
ASTIS, Arctic Institute of North America
Regional Land Use Planning (K-32)
Health & Social Services (H-1)
All Yukon First Nations

RE: Dr. Tracey Galloway (University of Manitoba)

Please be advised that the attached License has been issued under the Yukon Scientists and Explorers Act (1958).

Sincerely,

✓ Jeff Hunston, Manager
Heritage Resources Unit

Enclosure

**YUKON - CANADA
SCIENTISTS AND EXPLORERS ACT
LICENSE**

PURSUANT to the provisions of the Scientists and Explorers Act (1958) of the Yukon, permission is hereby granted to:

Dr. Tracey Galloway (University of Manitoba)

to enter the Yukon Territory to conduct scientific research with respect to:

The Impact of Federal Health Programs on Health Inequalities in Yukon First Nations Communities.

GENERAL CONDITIONS

1. A complete, final report of the research conducted under this license shall be submitted, in duplicate, within one year of completion or termination of the project.
 - a) A field or progress report, including descriptions or catalogues of collections made (where applicable) shall be submitted in duplicate on, or before, the expiry date written below.
 - b) The Licensee shall provide a copy of any report or article published on the research conducted under this license to Heritage Resources Unit.
2. All camps shall be established according to the provisions of the Territorial Land Use Regulations.
3. All steps shall be taken to avoid unnecessary disturbance of wildlife.
 - a) No camp site shall be established within 2 km of an active raptor nest.
 - b) When using aircraft, maintain a minimum of 1,000 feet over wildlife such as sheep, raptor nests and migrating caribou.
 - c) Pay particular attention to bear habitat, and take all steps necessary to avoid contact with bears such as use of bear fence, bear-proof containers and maintain a clean camp.
 - d) All camps should be temporary/non-permanent with no structures, and entirely removed at the conclusion of the field work.
4. The Licensee shall meet with, inform and receive permission from First Nation(s) of the field activities conducted under this license on their settlement land(s), and shall not proceed if permission is not gained from the First Nation(s). The Licensee shall provide a copy of any report or article published on the research conducted under this license to the First Nation(s).
5. The Licensee shall strictly observe all applicable Territorial and Federal legislation and regulations.

OTHER CONDITIONS:

NIL

THIS License is valid for the period **May 1st** to **September 30th**, 2015.

DATED at the City of Whitehorse, in the Yukon Territory, this **14th** day of **May**, A.D., 2015.

Appendix D - University of Manitoba Joint-Faculty Research Ethics Approval Certificate. (1 page)



UNIVERSITY
OF MANITOBA

Research Ethics and Compliance

Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

March 30, 2015

CIHR
42389

TO: Tracey Galloway
Principal Investigator

FROM: Susan Frohlick, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2014:087
"Federal Health Funding Policy and Yukon First Nations"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.


The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix E– Certificate of Completion of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE), September 14, 2014. (1 page)

**PANEL ON
RESEARCH ETHICS**
Navigating the ethics of human research

TCPS 2: CORE



Certificate of Completion

This document certifies that

Kirsten Bruce

*has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)*

Date of Issue: 14 September, 2014

Appendix F – Certificate of Completion of the University of Manitoba Research Integrity Online Course: Art and Humanities, September 22, 2014. (1 page)



UNIVERSITY
OF MANITOBA

The University Of Manitoba

Certifies that

Kirsten Bruce

Completed the

Research Integrity Online Course: Art and
Humanities

September 22, 2014

Gary Glavin
Associate Vice-President (Research)

Appendix G – Signed Confidentiality Oath for Translators, Research Coordinators, and Research Assistants. (1 page)

Federal health funding policy and Yukon health programs
Application to University of Manitoba Fort Garry Campus Research Ethics Board

Dr. Tracey Galloway, Principal Investigator
CIHR Fund No. 1PH 134071

Appendix: Confidentiality Oath for Translators, Research Coordinators, and Research Assistants

Translators, Research Coordinators, and Research Assistant Oath of Confidentiality

I Kirsten Bruce (Print name)

understand that all of the information I have access to related to the study entitled: “Federal Health Programs in Yukon First Nation Communities” must be kept confidential. In order to ensure participant privacy and confidentiality of information I agree that I will not disclose or discuss any information disclosed by study participants. My signature below indicates my pledge to maintain the confidentiality of all information revealed to me through the interviews and/or transcription/translation and analysis of participant interviews.

(Signature)

July 27, 2015
(Date)

Appendix H – Recruitment Script (2 pages)

Appendix: Recruitment Script - XXXXXXXX First Nation

Good morning,

My name is Tracey Galloway from University of Manitoba and this is Lori Duncan from Council of Yukon First Nations...Nice to meet you. We will be visiting visiting XXXXXX in two weeks as part of a study of how federal health programs operate in Yukon First Nations communities.

The purpose of the study is to improve access to federal health programs for Yukon First Nations communities. Although programs such as Aboriginal Head Start and the Aboriginal Diabetes Initiative are designed by the federal government to serve First Nations communities, not all communities have access to these programs. For example, XXXXXXXX has no XXXXXXXX program here.

We are looking to speak to people who can tell us about the history of federal health programs in this community. We will ask you questions about how programs have operated in the past and what makes it difficult to access these programs. Our goal is to see if we can identify exactly what XXXXXXXX needs to be able to access and implement these programs.

The Health Director, XXXX XXXXXXXX, is a partner in the research and knows we are here contacting health services staff and community members. However that does not mean you are required to participate. Participation in the study is entirely voluntary. There will be no consequences to you if you decide that you would prefer not to participate. There are many reasons people decide not to participate in research. You will not be required to give your reasons. No one will know whether you participated or not in the study. Your privacy will be respected.

If you agree to take part in this study, you will be asked to give your consent for participation. Your consent is entirely voluntary and can be withdrawn at any time during the study period between now and March 31, 2016 by simply speaking to us - "I don't want to participate any more" - or by telephoning us. There is no penalty for withdrawing your participation - your name and responses are simply removed from the data and any research records pertaining to you are destroyed.

If you do decide to take part in the study, we will ask you to participate in either an interview, a focus group, or a larger community meeting.

The information you share in the research will be kept confidential and will in no way affect your job status or your involvement with federal health programs, either as an employee or a community member. The information from individual communities will be kept confidential, so the Health Director here in XXXXXX and program administrators in Whitehorse and Ottawa will not be able to identify individual participants or communities.

Do you want some time to consider whether you would like to participate? Would you like me to contact you again in a few days to see if you have decided? If you like, I can give/send you the Information and Consent form and you can read it over. If you have any questions, please phone me anytime.

Federal health funding policy and Yukon health programs
Application to University of Manitoba Fort Garry Campus Research Ethics Board

Dr. Tracey Galloway, Principal Investigator
CIHR Fund No. IPH 134071

Whether you participate in the study or not, it's been very nice meeting you. Thank-you for your time.

Appendix I – Research Participant Information and Consent Form. (6 pages)

**RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
XXXXXXXX First Nation**

Title of Study: “Federal Health Programs in Yukon First Nation Communities”

Principal Investigator: Dr. Tracey Galloway
425 Fletcher Argue Building
University of Manitoba
Winnipeg MB R3T 2N2

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or Elders before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand. If you require a translator to help understand the consent process, one will be provided for you.

Purpose of Study:

The purpose of this research is to determine what supports are needed to improve access to federal health programs for Yukon First Nations communities. Although programs such as Aboriginal Head Start and the Aboriginal Diabetes Initiative are intended to serve First Nations communities, currently not all communities have access to these programs. This study will trace the history of how these programs are funded in each community, identify which programs are operating in communities, identify barriers to program access, and examine the impact of these programs on people’s overall health. The goal is to make programs more widely accessible to people living in Yukon communities and therefore improve health outcomes for First Nations people. An estimated 150 people will take part in this study.

Research Partners and Funding:

The Council of Yukon First Nations (CYFN) is a partner in the study and has signed a Research Partnership Agreement with the Researcher. It was CYFN’s recommendation that the research take place in all 14 First Nations communities in Yukon. The researcher will visit each community to collect the data and, later, to return the results. The study employs a Research Coordinator at the CYFN offices in Whitehorse.

The study is funded by the Canadian Institutes of Health Research.

Study procedures:

The Data Collection for the study will take place between April and October 2015. The Researcher, Dr. Tracey Galloway, will visit your community along with a Research Assistant or Research Coordinator.

If you take part in this study, you will be asked to participate in one or more of the following procedures:

- an **Interview**: 30-90 minutes long, in your home, workplace or a Community or Elders centre
- a **Focus Group Meeting** together with 3-4 other participants: 30-90 minutes long, in a Community or Elders centre
- a **Community Meeting** with many other participants: 1-1.5 hours long, in a Community or Elders Centre

During the Interview, Focus Group or Community Meeting, you can stop participating at any time. There are no consequences for withdrawing your participation from the study.

The results of the study will be returned to each community in the form of a Community Presentation by the researcher. These Community Presentations will take place between April and October 2016. A written Report of the study findings will be provided to the Council of Yukon First Nations and to each First Nations Community.

Risks and Discomforts:

There are no major identifiable risks associated with participation. You and your family will experience no change in access to health programs as a result of your participation in the study.

However it may be distressing for some people to discuss their personal health concerns or the health and social conditions and barriers to improvement that are experienced at times in some communities. It is possible that interviews and focus groups may elicit feelings of frustration or sadness that will be distressing for some participants. Although we require focus group participants to respect the confidentiality of information shared in group meetings, there is a small chance others may not do this and your opinions may be made known in the community. The Researcher and Research Coordinator at CYFN will ensure local health service providers are made aware that the research is occurring so that support workers in

communities and at mental health units in Whitehorse are available to residents who need support.

Benefits:

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will help improve access to federal health programs such as Aboriginal Head Start and the Aboriginal Diabetes Initiative in your community.

Costs:

There is no financial cost to you of participating in the study.

Payment:

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality:

Information that you share during Interviews, Focus Groups and Community Meetings will be treated as confidential. All personal identifiers such as your name and address will be removed from the records by the Researcher.

We ask you to treat as confidential all opinions and feelings shared by others in focus groups and community meetings. We ask you to respect the privacy of other participants by keeping their names and statements confidential.

For the duration of the research, the Researcher and Research Coordinator will keep a record of research activities including digital and print copies of interview transcripts. Digital records will be kept in password-protected files. Paper copies will be kept in a locked secure area. Only the Researcher and Research Coordinator will have access to these records.

After the end of the research, all data will be de-identified to remove all personal identification such as names and addresses. The dataset will become the shared property of both CYFN and Dr. Tracey Galloway and will be used solely for the purpose of through conferences and scholarly publication, in all cases with the approval of the Health and Social Development Commission.

Electronic copies of the individual community datasets will be transferred to the respective First Nation and become the sole property of the relevant First Nation. Their use will be determined by the scope of the participants' consent and by regulations determined by that First Nation.

Information gathered in this research may eventually be published or presented in public forums such as scholarly journals and academic conferences, however your name and other identifying information will not be used or revealed.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

Voluntary Participation/Withdrawal from the Study:

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not in any way affect your employment status or the ability of you or your family members to participate in federal health programs.

To withdraw your participation at any time between now and the end of the study period (March 31, 2016), you may simply speak to the Researcher in person OR contact the Researcher or Research Coordinator at the telephone numbers listed below.

Ethical Approval:

The study protocol has been reviewed and approved by the Council of Yukon First Nations and the Joint-Faculty Research Ethics Board at the University of Manitoba.

Supportive Care for Distress Related to the Study:

If you experience discomfort or anxiety resulting from this study, there are services available to assist you. These include:

- An Indian Residential Schools Resolution Health Support Worker, Jackie, is available at this toll-free 24-hour Survivor Support Line for communities 1-866-533-3030
- Staff at the XXXXXXXXX First Nation Health Centre are also available to support you: 867-XXX-XXXX
- Many Rivers Counselling and Support Services provides counselling services in your community 1-867-667-2970 (Collect calls accepted)
- The Government of Yukon provides mental health assessments, treatment, referrals, supportive counselling, and individual and group therapy. These services can be arranged by calling 1-800-661-0408 Extension 8346

These service providers will be made aware that the study is taking place in your community prior to the research activities. Please feel free to contact them at any time.

Legal Rights:

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator from her legal and professional responsibilities.

Questions:

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study contact the study staff:

Dr. Tracey Galloway, Researcher 1-800-432-1960 Toll-free
1-204-480-1025 Office
tracey.galloway@umanitoba.ca
tracey.galloway@utoronto.ca

Lori Duncan, Research Coordinator, CYFN 1-867-393-9200
lori.duncan@cyfn.net

For questions about your rights as a research participant, you may contact The University of Manitoba, Research Ethics Board Office:

Maggie Bowman, Human Ethics Coordinator 1-800-432-1960 Toll-free
1-204-474-7122 Office
margaret.bowman@umanitoba.ca

Study results and published findings:

The results of the study will be returned to each community in the form of reports and community presentations. If you wish to obtain a copy of the report or any publications related to the study, contact the Researcher or Research Coordinator at:

Dr. Tracey Galloway, Researcher 1-800-432-1960 Toll-free
1-204-480-1025 Office
tracey.galloway@umanitoba.ca

Lori Duncan, Research Coordinator, CYFN 1-867-393-9200
lori.duncan@cyfn.net

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent:

I have read this consent form. I have had the opportunity to discuss this research study with Dr. Tracey Galloway_and/or her study staff. I have had my questions answered in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study: Yes ____ No ____

Participant signature_____Date _____
(day/month/year)

Participant printed name: _____

Appendix J – Semi-Structured Interview and Focus Group Guide. (1 page)

Semi-structured Interview and Focus Group Guide

This project examines the history of federal health programs in Yukon First Nations communities. It is specifically concerned with the following programs, designed or modified for use in Canada's Indigenous population:

- Aboriginal Diabetes Initiative (ADI)
- Aboriginal Head Start (AHS)
- Children's Oral Health Initiative (COHI)
- Perinatal Child Nutrition Program (PCNP)

For each of the programs:

1. To your knowledge, has this program ever operated in this community (describe history and current program)?
2. How is the program funded?
3. How is the program delivered?
4. How many community members are served by this program? Obtain details on frequency, volume and quality of service.
5. Who manages/administers the program in this community? What portion of this person's duties is dedicated to administering this program?
6. In your opinion, does adequate capacity to administer the program exist in this community? What additional capacities are needed?
7. How many program staff are in this community? What portion of their duties are dedicated to operating this program?
8. In your opinion, does adequate capacity to staff the program exist in this community? What additional capacities are needed?
9. Who manages federal reporting for this program? What portion of their duties are dedicated to reporting for this program?
10. In your opinion, does adequate capacity for program reporting exist in this community? What additional capacities are needed?
11. In what community facility does this program operate? In your opinion, is this facility an appropriate and adequate space for the program? What additional facilities are needed?
12. What assistance does the community receive from the federal agency responsible for this program? Describe the quality and quantity of this assistance.
13. In your opinion, is there adequate federal support and assistance for this program? What additional supports and assistance are needed?
14. What barriers exist in accessing funding or resources for this program? To your knowledge, have these barriers changed over time?
15. In your opinion, how effective is this program in this community?