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The Indigenous Determinants of Health as Predictors for Diabetes and Unmet Health Needs Among Urban Indigenous People: A Respondent-Driven Sampling Study in Toronto, Ontario

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Abstract

National statistics commonly present Indigenous peoples as a falsely homogenous group of people experiencing disproportionate ill health when compared to non-Indigenous peoples. There are significant gaps in statistical information regarding the health services access barriers experienced by Indigenous people that disrupts the quality of care they receive or prevents them from accessing care altogether. Our Health Counts Toronto is a community-based study that employed respondent-driven sampling (RDS) methodologies to sample 917 urban Indigenous adults. Prevalence estimates and prevalence ratios were calculated using RDS-II weights and adjusting for clustering by shared recruiter in SAS 9.4 and SAS-callable SUDAAN 11.0 software. This study estimated that 14.85% (95% CI: 9.56, 20.14) of the study population had a self-reported diabetes diagnosis and 27.68% (95% CI: 20.56, 34.81) reported an unmet health need. Regional-level health assessment data is essential to tackle the health inequities endured by Indigenous peoples in Canada and system-level changes are necessary to decrease barriers to health care for Indigenous people.

Keywords

Our Health Counts, urban Indigenous, Indigenous health, unmet health needs, diabetes, determinants of health, Toronto

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List of Abbreviations

Abbreviation	Term
AHT	Anishnawbe Health Toronto
APS	Aboriginal Peoples Survey
CCHS	Canadian Community Health Survey
CCDSS	Canadian Chronic Disease Surveillance System
GSS	General Social Survey
NHS	National Household Survey
NIHB	Non-Insured Health Benefits
OCAP®	Ownership Control Access Possession
OHC	Our Health Counts
RDS	Respondent Driven Sampling
RHS	Regional Health Survey
SES	Socioeconomic Status
SGMT	Seventh Generation Midwives Toronto
TCPS	Tri-Council Policy Statement
TRC	Truth and Reconciliation Commission
UAHC	Urban Aboriginal Health Centre
WLH	Well Living House

Chapter 1

1. Introduction

Indigenous people have suffered a wide range of consequences as a result of European contact, including environmental dispossession, drastic social and cultural changes, traditional food and medicine suppression, and a disproportional rate of disease and chronic illnesses. Unfortunately, these negative consequences have continued on to the present day (Polonco & Arbour, 2015; Richmond & Ross, 2009). Indigenous people experience increased rates of adverse health conditions when compared to the rest of the Canadian population, with higher rates of infectious diseases, suicide, substance abuse and addictions, as well as obesity and diabetes (Mikkonen & Raphael, 2010).

In 2016, it was reported that 7.0% of people living in Canada have diabetes, which has remained relatively stable over the past couple of years (Statistics Canada, 2017a). However, there are a number of conflicting statistics that report different prevalence estimates of diabetes among the Indigenous population in Canada. For example, when using data from the Canadian Chronic Disease Surveillance System (CCDSS), in 2008, the prevalence of diabetes among First Nations was 17.2% of First Nations living on-reserve and 10.3% of First Nations living off-reserve. The prevalence among Inuit and Métis peoples was approximately 6.8% and 7.3%, respectively (Pelletier, Dai, Roberts, & Bienek, 2012). In 2011-2014, the Canadian Community Health Survey (CCHS) estimated the prevalence of diabetes among First Nations, Inuit and Métis peoples was 8.2%, 6.4%, and 2.6%, respectively (Statistics Canada, 2016a). In 2012, the Regional Health Survey (RHS) identified 16.2% of First Nations living on-reserve in Canada have diabetes (First Nations Information Governance Centre [FNIGC], 2012). The data sources may differ based on the different methods used to collect diabetes information from participants and the different time points the data was collected; however, all of these national statistics paint the picture that Indigenous peoples have a significantly higher rate of diabetes when compared to the non-Indigenous population in Canada (Pelletier et al., 2012). However, these studies only capture self-reported diabetes, therefore individuals with pre-diabetes or those that have undiagnosed diabetes will not be captured in these prevalence estimates. It is suspected that these

statistics offer an under-representation of the actual prevalence of diabetes among the entire Indigenous population in Canada due to limitations in diabetes surveillance within this population (Public Health Agency Canada, 2011).

Although generally considered as under-representative of the Indigenous population, national statistics still identify health inequalities among Indigenous peoples when compared to non-Indigenous peoples in Canada, thereby suggesting that larger gaps may exist than what is seen in these statistics. Despite the frequency of health inequalities, Indigenous people are not provided with adequate health care and may avoid accessing conventional medical services because of common experiences with discrimination, racism and delivery of low quality health care (Adelson, 2005; Allan & Smylie, 2015; National Aboriginal Health Organization [NAHO], 2003). It would be easy to assume that people facing such adverse health issues would be making regular visits to health care facilities, but that is not the case when it comes to the Indigenous population. A poll from the National Aboriginal Health Organization (NAHO) in 2003 reported Indigenous people received less of the necessary health care services than the rest of the Canadian population, and when they did receive health care it was perceived as lower quality. Specifically, those that accessed services reported events in which they received unfair or inappropriate treatment (NAHO, 2003).

Today, more than half of Indigenous people reside in urban settings and this urbanization is expected to increase (Snyder & Wilson, 2012). Many of the aforementioned challenges are experienced by the urban Indigenous population (Norris, Clatworthy, & Peters, 2013); there have been a number of access to health care barriers for Indigenous people living in urban settings including financial challenges, transportation barriers, and housing. There have also been reports of health care delivery barriers such as racism, and cultural barriers experienced by urban Indigenous people when accessing health care (Place, 2012; Waldram & Layman, 1989). This becomes extremely problematic because one of the main reasons that Indigenous people relocate to urban settings is to get better access to health care services (Newhouse & Peters, 2003); however, research has concluded that urban Indigenous people may face additional barriers (Senese & Wilson, 2013), especially those who move or relocate more frequently than others (Snyder & Wilson, 2012).

Another common barrier urban Indigenous people face is challenges regarding financial coverage for health care services, which often disrupts access to health care services (Belanger, 2010). There are ongoing governmental debates over who has financial responsibility over Indigenous peoples' health, because policy states that health is a provincial responsibility, however the federal government is also mandated to support First Nations health under their jurisdiction (Belanger, 2010; Peters, 2006; Reading & Halseth, 2013). Federal support has been restricted to only status First Nations living on-reserve and Inuit living on their traditional territories (Peters, 2006; Reading & Halseth, 2013); therefore, there have been a number of complications for those who do not hold status, for those who hold status and live off-reserve, and for Métis individuals (Browne et al., 2009), because such individuals do not qualify for Non-Insured Health Benefits (NIHB). NIHB is medical coverage for status First Nations and Inuit in Canada that includes coverage for prescription drugs, medical supplies and equipment, mental health counselling, dental and vision care, and medical transportation. NIHB is funded through Health Canada (Government of Canada, 2017). Those that are exempt from NIHB do not have access to the same services and benefits as those who qualify (Reading & Halseth, 2013) such as exemption from taxes, housing support, and health services (Senese & Wilson, 2013). Due to jurisdictional barriers and the consequences of the ongoing disputes between governments in Canada, Indigenous health is compromised (Belanger, 2010).

Those who live off-reserve do not have the same access to community- or band-run health care services. Services that are controlled by community or band-run organizations are more likely to have culturally aware and safe services and practices (e.g. traditional healers and medicines), therefore those that have to seek care off-reserve will likely not have access to the same types of culturally relevant services (Waldram, 1990). In a study conducted by Laura Senese and Kathi Wilson (2013), urban Indigenous people living in Toronto expressed the negative health impacts they have experienced as a result of discrimination and disrespect for Indigenous cultures and identities in urban health services. Furthermore, they expressed their frustration with the inability to access health care services and benefits that they are entitled to as a result of living off-reserve (Senese & Wilson, 2013).

Reversely, those who live on-reserve do not have the same access to hospital or at-home care due to allocation of funds. Specifically, federal health care funds are being allocated to the reserve and cover a narrower range of health services, while provincial health care services are delivered off-reserve. Complications arise when status First Nations people move between these systems to access their health care needs, as uncertainty over funding obligations leads to contesting jurisdictional mandates. A prominent example that demonstrates these jurisdictional challenges is the case of Jordan River Anderson, a young boy who died in hospital after waiting two years for the federal and provincial governments to agree on payment for the child's home care. Jordan's case influenced the development of Jordan's Principle, which is meant to resolve jurisdictional issues surrounding care for First Nations children that states "the government should immediately adopt a child-first principle, based on Jordan's principle, to resolve jurisdictional disputes involving the care of First Nations children" (Blackstock, 2012, p. 368). These jurisdictional disputes are common regarding non-status First Nations, Métis and Inuit peoples. It wasn't until recently that non-status 'Indians' and Métis peoples were included as the federal government's responsibility in the constitution as a result of the case Daniels v. Canada (Smith, 2016), however this new recognition does not include extending access to federal programs and services available to status Indians, such as NIHB or tax exemptions (Madden, Frame, Davis, & Strachan, 2016).

In response to the health inequities endured by Indigenous peoples in Canada, the Truth and Reconciliation Commission (TRC) (2015) has made a number of calls to action for the governments to acknowledge the wrongdoings in Canadian history and the negative effects of colonialism on Indigenous peoples. Of the 94 calls to action, 7 (#18-24) of them aim to respond to Indigenous peoples' health and wellbeing. The specific calls to action are:

1. "#18: We call upon the federal, provincial, territorial and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties;
2. #19: We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between

- Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services;
3. #20: In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of Métis, Inuit, and off-reserve Aboriginal peoples;
 4. #21: We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority;
 5. #22: We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients;
 6. #23: We call upon all levels of government to:
 - a. increase the number of Aboriginal professionals working in the health-care field,
 - b. ensure the retention of Aboriginal health-care providers in Aboriginal communities,
 - c. provide cultural competency training for all health-care professionals;
 7. #24: We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism (Truth and Reconciliation Commission [TRC], 2015, pp. 322-323).”

Public institutions and all levels of governments (i.e. federal, provincial, and municipal) in Canada have a history of marginalizing, oppressing and try to force assimilation upon Indigenous peoples. It is now their duty to reconcile with Indigenous peoples by first acknowledging the damages they have caused through a history of colonialism. In addition to governmental support to work towards reconciliation, it is important to acknowledge and consider these calls to action when doing research focused on Indigenous people's health. Since the overall focus of this thesis is Indigenous health, only the health-related calls to action have been presented. For this research, these calls to action were used as a guiding basis that were strongly considered and reflected upon in the goals and objectives of this thesis. The recommendations in this thesis were also strongly influenced by these calls to action. If these calls are ever going to be put into action, Indigenous research needs to continue to focus on and relate to these changes that are proposed by the TRC (2015).

This chapter will outline the current issues with national statistics on Indigenous peoples, with a specific emphasis on health-related data and its under-representation of Indigenous people. This review will highlight some of the key challenges raised by other researchers in the Indigenous health field and provide the rationale for improving epidemiological studies involving Indigenous people and their data. Afterwards, the *Our Health Counts (OHC)* project will be briefly introduced, and how the research for this thesis is situated within the larger *OHC* project will be presented. This is followed by some basic statistics about Toronto, Ontario to set the context of the study. Lastly, an overview of the thesis goal and main objectives will be provided.

1.1 Current National Data on Indigenous Peoples in Canada

There are two main Indigenous health status data sources in Canada, the National Census and the Aboriginal Peoples Survey (APS), that allow respondents to self-identify as First Nations, Inuit, and/or Métis (Smylie & Anderson, 2006). Additionally, there are a range of other statistical data sources that have some information available on Indigenous people. The Canadian Census, with a response rate of approximately 98% (Statistics Canada, 2016a), is a national survey administered to all Canadians every five years (Statistics Canada, 2016b). This survey collects basic statistical data for most of the population, as well as a more detailed long-form survey that captures more information on socioeconomic status, health status, education, family and marital

status, and housing (Statistics Canada, 2017b). Due to a political decision made by the Prime Minister in 2011, the long-form census was replaced by the National Household Survey (NHS). However, due to the low response rate, lack of quality of data (Sheikh, 2013) and change in political leadership, the long-form census was brought back in 2016. Therefore, data representative of the general population is fairly comprehensive in Canada.

The APS is a Canada-wide questionnaire administered by Statistics Canada in 1991, 2001, 2006, and 2012 that collected data on education, employment, health, language, income, and housing and mobility among Indigenous people (Statistics Canada, 2012). Another data source that differentiates between First Nations, Métis, and Inuit individuals is the General Social Survey (GSS), which is also administered by Statistics Canada. This survey uses random-digit dialing to get a sampling frame of approximately 25,000 Canadians and interviews individuals based on different yearly themes including caregiving and care receiving, family, victimization, and health (Statistics Canada, 2013a).

The CCHS is another data source that captures the health status of Indigenous peoples, however it does not differentiate between First Nations, Inuit and Métis identities. Instead, they are all classified as “Aboriginal of North America” (Browne, McDonald, & Elliot, 2009). The CCHS captures cross-sectional data on health status, lifestyle and social conditions, and the use of health care services (Statistics Canada, 2013b). Unfortunately, these surveys have not included individuals living on reserve and therefore, these data sources are under-representative and only approximately 66% of the Indigenous population living in Canada is captured in these data (Smylie & Anderson, 2006).

There is one other data source that captures national statistics regarding health status of Indigenous peoples: The First Nations RHS. The RHS targets First Nations people living on-reserve and in northern communities in Canada (Browne et al., 2009) and is a cross-sectional dataset that focuses on traditional Indigenous and Western beliefs and worldviews of health and wellbeing (FNIGC, 2017). The RHS employs a key feature that the previous surveys lack, which is Indigenous leadership and governance over the research and health information. This is considered a more ideal approach to Indigenous health research (Smylie & Firestone, 2015),

however, this survey targets only First Nations on reserve and does not capture Inuit and Métis populaces, or Indigenous peoples living in urban settings.

Janet Smylie and Michelle Firestone (2015) identify two key challenges to current national data sources: the lack of Indigenous identity indicators and the lack of Indigenous leadership and governance over Indigenous-specific data. Out of the five data sources previously identified, all of them face at least one of these challenges. While the Census, the APS, the CCHS and GSS are not led or governed by Indigenous peoples, communities or organizations, the CCHS and RHS do not have Indigenous identifiers further than “Aboriginal of North America” or “First Nations”, respectively. In addition to these challenges, most Indigenous health research has focused on quantifying ill health among the Indigenous population (Richmond & Ross, 2009). Despite their limitations, the numerous national databases that have health assessment data on Indigenous peoples, provide evidence that there is indeed a health equality gap between the Indigenous and non-Indigenous population in Canada.

These national data are under-representative of the Indigenous population (Smylie & Anderson, 2006; Smylie & Firestone, 2015), yet conclusions are being made based on these statistics (Chandler & Dunlop, 2015; O’Neil, Reading, & Leader, 1998). Most data on ill health among Indigenous peoples in Canada are presented as high-level aggregate statistics, and not disaggregated by community or population sub-groups (Chandler & Dunlop, 2015; Walter & Andersen, 2013). This is problematic in that it suggests that all Indigenous people have a similar risk of these adverse outcomes and paints the picture that all Indigenous peoples are ill (Chandler & Dunlop, 2015) which is in fact not true. For example, the national rate of suicide among Indigenous peoples in Canada is often viewed as much higher than their non-Indigenous counterparts; in reality there are some communities that do suffer from high rates of suicide and then there are communities that have never experienced a single suicide (Chandler & Dunlop, 2015). These national data therefore suggest that being Indigenous is a risk factor for suicide, as well as many other diseases, where we see prevalence among Indigenous people above the national average. These generalizations also lead to a disregard for community-specific Indigenous identity, because these national statistics do not differentiate between the many different and unique nations across Canada, but instead group all Indigenous peoples as the same

(Kukutai, 2011; Walter & Andersen, 2013). Maggie Walter and Chris Andersen (2013) further explain that,

statistics are used to describe our population profiles and geographical distribution, and, almost universally across the colonized first world, our lagging levels of educational achievement, labor market participation, health, and economic status. They are nation-states' chief tool for ascertaining and presenting the official 'who', 'what', 'where', and 'how' of Indigenous life. Often positioned as a subset of overall national social trends, these data are accepted as a straightforward, objective snapshot of an underlying reality. As such, they have also become the backbone for the creation and implementation of social policy for Indigenous peoples (Walter & Andersen, 2013, p. 8).

Canada is renowned for using census data and other national data sources to determine funding levels for social and health programs for Indigenous peoples across the nation (Walter & Andersen, 2013), which again is problematic because these national surveys only capture a small proportion of Canada's Indigenous population (Smylie & Anderson, 2006; Smylie & Firestone, 2015).

For Indigenous health research, it is imperative that research moves away from aggregating all Indigenous people as one collective group because there are many different distinct nations and cultures within the Indigenous population in Canada. In addition, there are unique challenges for Indigenous peoples that are living away from their traditional territories in Canada's urban centres. There is a need for community-level data so that instead of creating health programs based on these national statistics, researchers and public health professionals can collaborate with communities to understand their specific needs and develop plans that respond to specific local concerns and patterns. Seeking to understand the community and their needs is essential in Indigenous health research, especially to initiate change (Richmond & Ross, 2009).

1.2 The *Our Health Counts (OHC)* Project

In response to the recent urbanization, lack of quality health assessment data, and lack of regional-level data on urban Indigenous peoples in Canada, Dr. Janet Smylie along with the Ontario Federation of Indian Friendship Centres (OFIFC), the Métis Nation of Ontario (MNO), the Ontario Native Women's Association (ONWA), and the Tungasuvvingat Inuit (TI) developed a project to provide a population-based sample of urban Indigenous people in Hamilton and Ottawa, originally. The main goal of *Our Health Counts (OHC)* is to create an Indigenous-led and governed urban Indigenous database, that captures health information data on urban Indigenous people that is missing in some of the previous data sources identified. The *OHC* project extended onto Toronto and London in later years. The project used participant's personal networks to sample the urban Indigenous population within the given city. Each project aims to create partnerships with local Indigenous organizations to develop research priorities, objectives and specific methodologies. Thus far, the project has been completed in four Ontario cities. It has been completed in Hamilton targeting First Nations and twice in Ottawa targeting Inuit and Métis, separately (Smylie, Firestone, Cochran, Prince, Maracle, Morley, Mayo, Spiller, & McPherson, 2011). *Our Health Counts (OHC): Developing a Population Based Urban Aboriginal Cohort to Assess and Enhance Individual, Family, and Community Health and Wellbeing* is in its' final stages in Toronto and London, however, the uniqueness of these later studies is that they include First Nations, Inuit and Métis populaces.

All data for this study was collected from the *OHC Toronto* urban Indigenous peoples' health in partnership with the Well Living House (WLH) and community partners, Seventh Generation Midwives Toronto (SGMT). A community-driven approach was used throughout the entire process of this project where reciprocal research goals and objectives were established and will be presented shortly.

1.3 Toronto, Ontario

Toronto is the largest metropolitan area in Canada and has been continuously growing over the past decade. A metropolitan area is defined as having at least 100,000 people residing within a given urban area where there is a large amount of social and economic opportunities (Statistics Canada, 2017c). In 2015, it was reported that the total population of Toronto was approximately

6,129,900 (Statistics Canada, 2016c). In 2006, the Census estimated that there were approximately 26,575 Indigenous people living in Toronto (Statistics Canada, 2010). According to the 2011 NHS, there were approximately 19,265 Indigenous people living in Toronto (Statistics Canada, 2011), and according to the 2016 Census, there were approximately 23,065 Indigenous people living in Toronto (Statistics Canada, 2017e). These national-level studies provide widely differing estimates of the Indigenous population living in Toronto. When reviewing these estimates side-by-side and seeing such varying estimates across the different years presented, the reliability of the sources is questionable, and these numbers become misleading, thus leaving the floor open to the question, how many Indigenous people *actually* live in Toronto, Ontario?

Janet Smylie (2016) argues that these estimates provide a false representation of the actual Indigenous population living in Toronto. Based on findings from the *OHC Toronto* study, the Indigenous population living in Toronto is conservatively estimated to lie between 45,000 to 73,000 individuals because a number of participants identified that they did not complete the 2011 Canadian Census and/or the 2011 NHS. Therefore, Statistics Canada actually has an underestimate of the Indigenous population living in Toronto by at least half (Rotondi, O'Campo, O'Brien, Firestone, Wolfe, Bourgeois, & Smylie, 2017).

These findings reinforce the importance of regional-level data when using statistics to define and describe Indigenous populations in Canada and shows how essential projects like *OHC* are for understanding (accurate) current trends among Indigenous populations in a given (regional-level) location. Given the Indigenous control of the *OHC* project and use of personal networks for sampling purposes, there is a more reliable process for capturing people that are oftentimes excluded or left out of national data sources. It is evident that the findings from the secondary data analysis portion of this thesis will be an accurate and valuable representation of the urban Indigenous population living in Toronto because of the Indigenous methodologies and expertise used to guide the *OHC Toronto* project, as well as the large sample size of urban Indigenous participants who participated in *OHC Toronto*. There was also a low count of missing data across the sample, thereby suggesting a high level of trust among participants in answering survey questions and reducing biases associated with lack of truthfulness among participants.

1.4 Thesis Goals and Objectives

Through dialogue with the *OHC* team, and specifically the SGMT, this project identified an independent line of inquiry utilizing the *OHC* data from Toronto. The primary goal of this thesis is *to determine whether the distal, intermediate, and proximal determinants of health are predictors for unmet health needs and diabetes diagnosis among urban Indigenous people living in Toronto, Ontario*. The main aims of the research project are:

- 1) to provide prevalence estimates for the demographics of Indigenous people living in Toronto;
- 2) to provide an estimate of the prevalence of diabetes among Indigenous people living in Toronto, Ontario;
- 3) to provide an estimate of frequency and range of unmet health needs experienced by Indigenous people in Toronto;
- 4) to determine what types of Indigenous determinants of health predict whether an individual is more at risk of a diabetes diagnosis
- 5) to determine what types of Indigenous determinants of health predict whether an individual may experience an unmet health need;
- 6) to analyze the relationship between diabetes-positive individuals and use of traditional medicine, conventional medicine or a combination of both; and
- 7) to inform the development of effective diabetes programming that addresses access barriers prevalent among Indigenous people living in Toronto, Ontario.

This thesis will begin with a review of the current literature on the provided topic, an outline of the methodologies and statistical analysis plan will be provided, and then the findings will be presented and discussed. Lastly, conclusions will be drawn, and recommendations will be presented based on the findings and my expertise as an Indigenous researcher.

Chapter 2

2. Literature Review

This chapter defines the Indigenous peoples of Canada and provides a brief overview of the colonial history of Canada and its impact on Indigenous health and wellbeing. This chapter will discuss and compare diabetes prevalence estimates among Indigenous peoples and non-Indigenous peoples in Canada. The main focus of this chapter is to discuss the proximal, intermediate, and distal determinants of Indigenous peoples' health and wellbeing, as well as the health services access barriers endured by Indigenous people. Biomedical and traditional Indigenous approaches to health and wellbeing will be discussed and compared. Lastly, concrete examples of Indigenous people's experiences using mainstream health services in urban centres will be explored.

2.1 Defining Indigenous Peoples of Canada

Indigenous peoples in Canada constitute approximately 4.9% of Canada's population (Statistics Canada, 2017d). The World Health Organization (2012) defines Indigenous peoples in Canada as First Nations, Inuit and Métis individuals who identify themselves as being a part of a distinct cultural group, who are descendants from the original inhabitants of such territories, such as North America, before modern states and boundaries were created (World Health Organization [WHO], 2012). The term 'First Nations' is a more appropriate terminology that replaces the word 'Indian' that represents both status and non-status First Nations peoples. Status First Nations are registered under the *Indian Act of 1876*, whereas non-status First Nations are not (Indigenous and Northern Affairs Canada [INAC], 2012). The term 'Inuit' refers to an Indigenous group that lives in Northern Canada, throughout Nunavut, Northwest Territories, Northern Quebec and Northern Labrador (INAC, 2012). The term 'Métis' describes peoples with a distinct culture of mixed ancestry, typically of First Nations and European descent, who identify as such (INAC, 2012). Although these groups identify separately, each group suffers from increased rates of adverse health conditions and pressing health issues, when compared to the rest of the Canadian population (National Collaborating Centre for Aboriginal Health [NCCAHA], 2013). In this thesis, the terms Indigenous and Aboriginal will be used

interchangeably to refer to the diverse groups of status and non-status First Nations, Inuit, and Métis peoples in Canada.

There has been a recent and significant increase in the urbanization of Indigenous people in Canada, where more than half of Indigenous people are now residing in urban settings (Norris et al., 2013). Specifically, 54% of Indigenous people live in urban areas (Statistics Canada, 2008). An urban area is considered an area with a “population of at least 1,000 and no fewer than 400 persons per square kilometer” (Statistics Canada, 2002). One of the main reasons Indigenous people move to urban settings is to get better access to health care services (Newhouse & Peters, 2003). However, better health care is not always the case. There have been a number of issues reported surrounding primary health care for Indigenous people living in urban settings including financial challenges, transportation barriers, housing, and cultural barriers (Place, 2012; Wylie & McConkey, forthcoming).

As aforementioned, this thesis will discuss all Indigenous peoples of Canada. However, the main focus of this thesis is to understand the impacts and implications of diabetes and unmet health needs on Indigenous people living in urban settings due to the goals and objectives of *OHC Toronto*. This is not to be exclusive of other Indigenous populations, however there are notable gaps in the research and urban Indigenous people experience unique challenges, therefore there is a need for more attention to be paid to this unique population.

2.2 Overview of Indigenous History in Canada and Its Impact on Health and Wellbeing

Since first contact, there have been a number of historical events that have taken place in Canada that have contributed to the present health equality gap that exists between the Indigenous and non-Indigenous population. Colonial practices that restricted Indigenous peoples’ access to land, food and water have dramatically contributed to the ill health of Indigenous peoples in Canada (Reading, 2015). Prior to contact, Indigenous peoples and communities (of Canada) lived independently on the territory that is now called “North America.” Communities established their own political, economic and social processes, that were disrupted by European settlers upon contact (Belanger, 2010).

As a means of controlling the influx of European settlers into Indigenous lands, colonizers developed laws that would “protect” Indigenous lands. The *Indian Act of 1876* was a form of government regulation used to define First Nations identity and assimilate First Nation peoples. Although Métis and Inuit peoples were excluded from the legal definition of an Indian during these times, they still have similar experiences of ill health (Reading, 2015). Charlotte Reading (2015) defines the *Indian Act of 1876* and explains “the health-related, systems-level determinants resulting from this policy document are far-reaching and influence almost every aspect of First Nation peoples’ lives” (Reading, 2015, p. 9). Forms of cultural disenfranchisement and encroachment took place by forcing Indigenous people to reside on reserved lands, as well as criminalizing Indigenous cultural practices, traditions, and languages (Belanger, 2010; Reading, 2015; Robbins & Dewar, 2011). Indigenous people were removed from their traditional territories and forced to move onto reserved lands, which were considered to be “insufficient to sustain food production through either agriculture or ranching” (Reading, 2015, p. 6). In addition, these reserved lands had reduced access to animals for hunting and poor water quality as a result of colonial development and advancement on nearby lands (Reading, 2015).

Disruption of traditional social systems including sanitation systems as well as food acquisition and distribution left Indigenous communities vulnerable to European disease, to which they had limited previous exposure. Smallpox, measles, tuberculosis, and many more became epidemics, and wiping out entire communities and significantly reducing the overall population of Indigenous peoples in Canada (Belanger, 2010; Reading, 2015). Indigenous people then had to rely on Western medicine (Reading, 2015) because the *Indian Act of 1876* banned traditional medicine and healing practices; such practices were deemed as witchcraft by Christians, and Indigenous people were imprisoned if caught practicing these traditions (Belanger, 2010).

Residential schools were another mechanism of assimilation through forcing Indigenous peoples to conform to Christian beliefs and ways of living. Indigenous children were removed from their homes and taken to residential schools for months and/or years at a time, where they were punished for speaking their language or practicing their traditions. There were also many reports

of physical, mental, and sexual abuse from the Indigenous individuals who had attended these institutions (Allan & Smylie, 2015; Belanger, 2010; Reading, 2015; Robbins & Dewar, 2011), in which a number of Indigenous children did not survive (Allan & Smylie, 2015) and many Indigenous men and women still suffer from the impacts of trauma endured at these institutions (Reading, 2015).

These colonial acts have contributed to the loss of many Indigenous languages and traditions including medicinal knowledge and healing practices (Robbins & Dewar, 2011). When these government regulations were enforced, Indigenous health began to deteriorate because people were removed from their culture, their language, and their land, which is considered a fundamental component of health and wellbeing among Indigenous peoples (Allan & Smylie, 2015; Richmond & Ross, 2009). Colonization is a key determinant of health for Indigenous peoples in Canada and their health continues to suffer from this legacy (Belanger, 2010; Robbins & Dewar, 2011; Allan & Smylie, 2015). Colonization will be explored as a key determinant of health throughout this thesis and will hold the position as a hypothesized predictor for two health outcomes.

In order to move forward and heal from these gruesome historical events, Robbins & Dewar (2011) state that, “for optimum health outcomes, use of traditional Indigenous health perspectives (Indigenous Knowledge) is paramount to the planning and development of contemporary healing for Indigenous communities” (Robbins & Dewar, 2011, p. 5). This statement suggests that as a form of reconciliation, Indigenous peoples need to have culturally appropriate healing resources and health care services that include traditional Indigenous medicines, healing practices, and ways of living. To take this into consideration, uses of conventional and traditional Indigenous approaches to health will be explored and compared in this thesis.

2.3 Diabetes

Diabetes was identified as a research priority by community partners and in collaboration with SGMT and WLH, diabetes became a focal point of this thesis as a means of responding to the needs identified by the community. Self-reported diabetes diagnosis holds a number of positions

in this thesis. First, it is used as a descriptive variable to understand the prevalence of diabetes among Indigenous adults in Toronto. Second, it is used as an outcome for the logistic regression model where the *Indigenous* determinants of health are framed as the explanatory variables. Lastly, it is used as a descriptive variable and has been cross-tabulated to understand use of traditional Indigenous approaches and conventional approaches to medicine among urban Indigenous adults with and without a self-reported diabetes diagnosis.

Diabetes is a chronic disease that has two forms. Type 2 diabetes is the most common form of diabetes and is characterized by insulin resistance in the body and/or a decrease in insulin secretion. This causes the body to be unable to adequately break down glucose, which leads to excess glucose in the bloodstream (Fagot-Campagna, Pettitt, Engelgau, Burrows, Geiss, Valdez, Beckles, Saaddine, Gregg, Williamson, & Narayan, 2000; Polonco & Arbour, 2015). Type 2 diabetes has become an epidemic in Canada; however, this disease disproportionately affects the Indigenous population as a whole and has also been rapidly increasing among Indigenous children and youth (Polonco & Arbour, 2015). Type 1 diabetes accounts for only 5-10% of diabetes cases and is characterized by insulin deficiency that typically onsets on individuals under 20 years of age (Daneman, 2006). *OHC Toronto* survey does not differentiate between the two types of diabetes and therefore will not be identified in the analysis.

Diabetes is a public health concern in Canada and increasingly for the Indigenous population of Canada. In the past couple of decades, there has been a rise in the prevalence of diabetes among Canadians (Young, Reading, Elias, & O'Neil, 2000). Using data from the Canadian Chronic Disease Surveillance System (CCDSS), in 2008, 6.8% of Canadians (2.4 million people) held a diabetes diagnosis, which represents a 70% increase since 1998/1999. The prevalence of diabetes among First Nations living on-reserve was 17.3% and 10.3% among First Nations living off-reserve. The prevalence among Inuit and Métis peoples was 6.8% and 7.3%, respectively. Therefore, when compared to the general Canadian population, Indigenous peoples have an approximately 4-5 times higher prevalence of diabetes. Furthermore, there is a greater prevalence of childhood diabetes and a higher incidence of diabetes-associated complications among the Indigenous population when compared to the general Canadian population (Pelletier et al., 2012). Additionally, First Nations individuals who have diabetes have a higher rate of other co-

morbidities (FNIGC, 2012) and complications, such as blindness, limb amputation, and organ failure (Bobet, 1998). This high rate of co-morbidities becomes extremely problematic, resulting in a 5 times higher risk of death from diabetes for Indigenous women when compared to non-Indigenous women (Young et al., 2000). While estimates of diabetes prevalence among Indigenous peoples is available through a number of national sources, First Nations living in urban centres, as well as Métis and Inuit peoples are often not adequately accounted for. This makes it difficult to understand the impact of diabetes on urban Indigenous peoples (Lavallée & Howard, 2011). Self-reported diabetes among the Indigenous population in Canada has been estimated using the APS, CCHS, and RHS, however these surveys only estimate the national prevalence of diabetes among this population. These national statistics can falsely represent the Indigenous population in Canada, as the prevalence of diabetes varies based on nation, culture, and geographic location (Young et al., 2000).

Thus far, the majority of Indigenous health research on diabetes in Indigenous peoples has focused on genetic susceptibility; however, type 2 diabetes in the Indigenous population is too complex to be examined only through genetic factors. Understanding the determinants that influence the development of diabetes is essential in addressing this illness that disproportionately affects Indigenous people (Polonco & Arbour, 2015; Reading, 2015).

Charlotte Reading (2015) quotes David Butler-Jones (2008) and suggests:

if we limit our analysis to its proximal determinants, as is often the case, we will continue to focus our attention on obesity, poor diet, and sedentary lifestyle. If however, we explore further, we will likely encounter additional determinants such as economic (remote locations with expensive shipping costs) barriers to accessing health market or country foods, as well as physical environments that do not always support health-promoting exercise (crowded housing, lack of sidewalks or walking trails, cold weather, lack of accessible recreational infrastructure or programs (Butler-Jones, 2008). If we search deeper still for the determinants responsible for shaping these conditions, we discover the root of the problem – a colonial structure – fashioned from the centralization of Aboriginal peoples into remote communities and reserves, the oppressive nature of the Indian

Act, the damaging legacy of residential schools, racial discrimination in social environments and the labour market (Reading, 2015, p. 11).

Diabetes research need to focus less on genetic susceptibility and lifestyle choices, and more on other determinants that influence the development of diabetes (Polonco & Arbour, 2015; Reading, 2015).

The impacts of colonization have an overall negative effect on health and wellbeing of Indigenous peoples and contributes to the higher rates of diabetes seen across Indigenous populations (Oster, Grier, Lightning, Mayan, & Toth, 2014). Research has shown diabetes to be related to loss of participation in activities related to cultural continuity (Lavallée & Howard, 2011; Oster et al., 2014), such as eating traditional Indigenous foods (Richmond & Ross, 2009). Individuals with lower SES are more susceptible to chronic diseases because they are more likely to engage in risk factors such as unhealthy diet, sedentary lifestyle, and smoking (Gracey & King, 2009). Such environmental and social factors play a large role in the development of diabetes as well as morbidity and mortality related to diabetes. Research needs to focus on a balance between all of those factors to determine why there is such a high prevalence of diabetes among Indigenous peoples (Polonco & Arbour, 2015). In addition to more research needed on the determinants of Indigenous peoples' health as predictors for diabetes, more research needs to target urban Indigenous peoples in order to understand the extent of the problem and impact of diabetes on this specific population.

2.4 Unmet Health Needs

Unmet health needs will be a complex variable in this thesis because it will hold two positions. First, unmet health needs are considered an intermediate determinant of health, and secondly as an outcome for the logistic regression model where the Indigenous determinants of health are framed as the explanatory variables. Research has shown that marginalized groups such as people with mental illnesses, people with addictions, and Indigenous people are less likely to seek or access needed health care when compared to their non-Indigenous counterparts (Browne, Smye, Rodney, Tang, Mussell, & O'Neil, 2010). The distal, intermediate and proximal determinants of health will be explored as explanatory variables for health care access in this section.

Colonialism is the number one social determinant of Indigenous peoples' health and wellbeing. Colonialism has had some effect on all Indigenous peoples in Canada and is still evident today. For example, systemic racism and discrimination are still alive today within mainstream health care systems (Allan & Smylie, 2015; Wylie & McConkey, forthcoming) and research has concluded that Indigenous individuals who experience racism and/or discrimination within the health care system are less likely to access health care services (Allan & Smylie, 2015; NAHO, 2003). In addition to the negative effects of colonialism and its influence on health care access, there are a number of other social and cultural determinants of health that influence whether an Indigenous person will access health care services (Browne et al., 2010).

Cultural continuity and social support networks are protective factors against ill health for Indigenous people. Speaking Indigenous languages and consuming traditional Indigenous foods are activities related to cultural continuity (Reading & Wien, 2009; Rotenberg, 2016), and are explored in this research. Social support networks, defined by individuals having family or friends to rely on during a time of need (i.e. ill health) (Rotenberg, 2016), are also examined. Use of traditional healers or traditional Indigenous medicines and practices is also another form of cultural continuity. Past research has shown that urban Indigenous people with lower income and education attainment were less likely to use traditional healers as a form of medicine when they sought health care (Snyder & Wilson, 2012).

There are a number of proximal determinants of health that can contribute to this trend of unmet health needs, such as higher rates of poverty and unemployment and lower educational attainment levels and as previously stated, Indigenous people in Canada experience higher rates of all of these unfortunate qualities (Reading & Halseth, 2013). Research has shown that urban Indigenous individuals who have a lower household income and have lower education attainment are less likely to access health care services. There were mixed results regarding employment status, in which some employed individuals sought health care more than unemployed individuals and vice versa (Snyder & Wilson, 2012). An explanation for unemployed individuals seeking health care could be attributed to having more excess time available to seek care

compared to those who are employed, whereas an explanation for employed individuals seeking health care could be having better access to transportation.

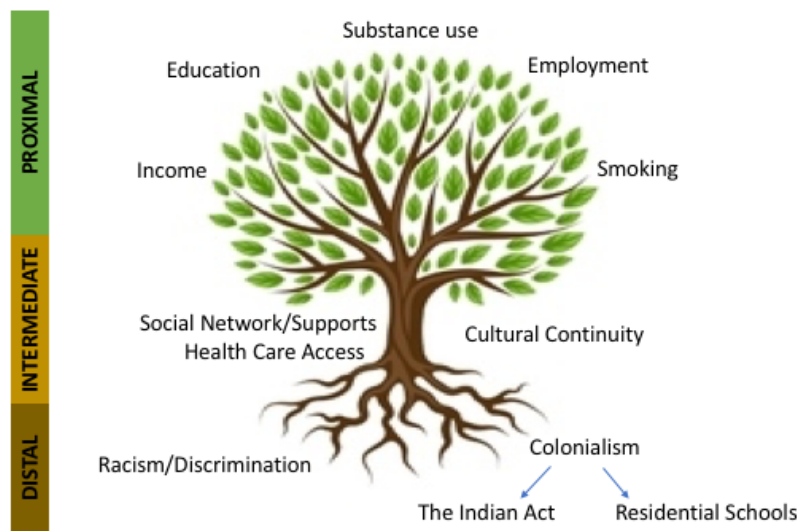
2.5 Determinants of Indigenous Peoples' Health

The World Health Organization (2005-2008) defines social determinants of health as “the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness”, and are strongly influenced by economic, social and political factors (WHO, 2005-2008). In the last decade, there has been more focus on social circumstances and less on individualistic biological approaches to explaining and understanding the health and wellbeing of individuals and communities. The social determinants of health have been identified as key factors in explaining the health inequalities that exist between Indigenous and non-Indigenous peoples in Canada (de Leeuw et al., 2015). While risky behaviours such as smoking, poor diet, and substance use play an important role in the health of an individual, these factors actually only explain a fraction of poor health outcomes (Reading & Halseth, 2013). Evidence shows that social factors such as income disparities, early childhood development, social inclusion and exclusion, employment and working conditions, and education play a vital role in the health and wellbeing of individuals and communities (de Leeuw et al., 2015). Furthermore, it has been stated that social determinants, as a whole, are considered to be the primary determinants of health (Raphael, 2009). These social determinants will affect an individual's health and wellbeing throughout their entire life. Evidence suggests that those that are at the lower end of the social gradient suffer from poorer health outcomes when compared to those who are at the higher end of the social gradient (Wilkinson & Marmot, 2003).

Charlotte Reading (2015) depicts the determinants of Indigenous peoples' health with the use of a tree which represents both social and structural determinants of health. Structural determinants of health extend beyond the social determinants of health and includes structures and systems that have contributed to the health equality gap between Indigenous people and non-Indigenous people. Structural determinants that historically and contemporarily affect Indigenous peoples' health include: The *Indian Act of 1876*, Indian hospitals, residential schools, systemic discrimination, and other colonial policies in Canada (de Leeuw, Lindsay, & Greenwood, 2015). Using Reading's (2015) framework, there are three categories of determinants of Indigenous

peoples' health that are represented by the tree: 1) the distal determinants of health as the roots; 2) the intermediate determinants of health as the trunk, and 3) the proximal determinants of health as the crown. The distal determinants of health are those that are deeply embedded in society and include historical, political and economic systems. The distal determinants of health are the roots that sustain and nourish individuals; Indigenous people have been strongly influenced by the legacy of colonization that have stunted their growth as independent and healthy people. The intermediate determinants of health are those that connect the proximal and distal determinants such as governmental influences, health care and health promotion, social supports, and educational and institutions and the justice system. The proximal determinants of health include behavioural and environmental factors such as, early child development, income, education, employment and working conditions, culture, and social support networks. Since distal, intermediate, and proximal determinants are all interconnected, it is obvious that distal determinants or *roots* have a strong influence on the evolution of each individual's *tree* (Reading, 2015; Reading & Wien, 2009). Please refer to Figure 1 for a depiction of the distal, intermediate, and proximal determinants of health in the form of a tree. Not all distal, intermediate, and proximal determinants of health are identified in this figure. Only the distal, intermediate, and proximal determinants of health that were further explored in this thesis are identified in this image.

Figure 1: A tree depicting the distal, intermediate, and proximal determinants of Indigenous peoples' health using Reading's (2015) Indigenous framework.



Everyone experiences variations of the above mentioned determinants of health. Oftentimes, Indigenous people have a more negative experience with these determinants of health when compared to non-Indigenous populations that strongly influences the health disparities experienced by Indigenous people (Reading, 2015). Charlotte Reading's (2015) categorization of distal, intermediate, and proximal determinants of health and wellbeing will be the basis for evaluating the determinants of Indigenous peoples' health in this thesis. Specifically, this study will examine how these determinants of health have an influence on urban Indigenous people's self-reported diabetes diagnosis and experiences of unmet health needs. Below will be discussed the most prominent determinants of Indigenous peoples' health and wellbeing using this Indigenous ideation.

2.5.1 Distal Determinants of Indigenous Peoples' Health

Since European contact, Indigenous peoples have suffered the negative consequences of colonialism. Through policies that promoted assimilation to dominant societal ways and beliefs, environmental dispossession and cultural disenfranchisement, the health of Indigenous peoples began to deteriorate (Polonco & Arbour, 2015; Richmond & Ross, 2009). Distal determinants of health are difficult to measure, as colonialism is the most prominent distal determinant of Indigenous peoples' health. Given that there are no existing measurements for colonialism within the *OHC Toronto* data set, two proxy measures have been selected to measure experiences of colonialism. Attendance at residential schools and experiences of discrimination within the health care system represent the outcome of colonial policies and legacies and have been selected as proxy measures; therefore, their relationship to health will be further explored.

Residential Schools

Residential schools were the most horrific and widespread act of colonization against Indigenous peoples in Canada. In 1842, Canadian officials took responsibility for educating First Nations people with the goal of assimilation, ostensibly to ease their transition into mainstream society. In actuality, residential schools were a form of cultural genocide, where Indigenous children were forced to adopt Christian ways and beliefs. In 1874, formal institutions were developed far away from Indigenous communities. At residential schools, children were away from home from

8 months to many years at a time, were forced to cut their hair and change their clothing, were disciplined for speaking their Native languages and forced to do manual labour (Belanger, 2010). Over 150,000 children were forced to attend these institutions and it wasn't until 1996 that the last Canadian residential school closed (Belanger, 2010; Robbins & Dewar, 2011; Allan & Smylie, 2015).

Oftentimes, children that attended these schools were malnourished, physically and sexually abused, experimented on and/or infected (often deliberately) with tuberculosis from the overcrowding of these institutions (Belanger 2010; Reading, 2015). There was a low survival rate from residential schools and approximately only 50% of children that attended these institutions returned home (Reading, 2015) due to high rates of death and displacement from their communities and families. Unsurprisingly, residential school survivors reported that their experience negatively impacted their health and wellbeing, as well as their parenting skills, thus reinforcing intergenerational trauma (Reading & Wien, 2009).

Racism and Discrimination

Racism and discrimination have a direct negative impact on health and wellbeing (Larson, Gillies, Howard, & Coffin, 2007; Priest, Paradies, Stewart, & Luke, 2011; Williams & Mohammed, 2009; Wells, Gonzalez, Gladney, & Onello, 2014). Almost all Indigenous peoples in Canada have faced some form of discrimination or racism in their lifetime. Negative stereotypes of Indigenous peoples in the media have reinforced widespread views of Indigenous peoples, that in turn shape discriminatory attitudes and practices. Research has shown that racial minorities with perceived discrimination experience higher rates of health conditions such as diabetes, hypertension, and cardiovascular diseases (Wells et al., 2014). Many times, unfortunately, this discrimination and racism is experienced in the mainstream health care system (Allan & Smylie, 2015; McConkey, 2017; Wylie & McConkey, forthcoming) and has influenced whether an Indigenous person will or will not access health care services in Canada (Adelson, 2005; Allan & Smylie, 2015; NAHO, 2003). Research has shown that some Indigenous people refuse to access health care services due to discriminatory practices and policies at the systemic level (Adelson, 2005).

2.5.2 Intermediate Determinants of Indigenous Peoples' Health

Intermediate determinants of health that will be taken into consideration throughout this thesis include health care access, cultural continuity and social support systems because these factors are thought to connect and influence both the distal and proximal determinants of health. The *OHC Toronto* survey asked respondents whether they had unmet health needs, their participation in a number of cultural continuity activities, and the size of their personal support system. The relation of each of these determinants to Indigenous peoples' health will be explained further.

Health Care Access

While universal access to health care services is promised to all “Canadians”, not all people living in Canada have equal access to services (Reading & Halseth, 2013). Indigenous people experience a number of barriers to accessing basic health care services including systemic barriers, cultural barriers, geographical challenges, and economic barriers. Systemic barriers that have been reported include: long waiting lists, lack of coverage by NIHB, and transportation challenges (Browne et al., 2009; Place, 2012; Reading & Wien, 2009). These barriers are amplified for Indigenous people living in rural and remote areas due to the geographical location and distance from health care services (Reading & Halseth, 2013). However, there have been some significantly disturbing events that have taken place in urban centres as well. A particularly extreme scenario is the case of Brian Sinclair, a double-amputee Indigenous man of Winnipeg, who was referred to the hospital for a bladder infection. Due to Brian's disability and appearance, health care workers had assumed Brian was just seeking a place to sleep and “sober up.” Despite coming in with a doctor's referral, Mr. Sinclair was ignored by dozens of health care workers as he waited in the emergency department to be triaged into the system; he ended up dying after waiting over 30 hours (Dehaas, 2014). This is a prominent example of an act of systemic discrimination against Indigenous peoples that exemplifies significant barriers to accessing needed health care for Indigenous peoples living in large urban centres.

Cultural barriers that have been experienced include: inadequate care received, culturally inappropriate services, difficulty getting traditional care, and preference to not seek western care. Many health care workers are unaware of Indigenous approaches to health and wellbeing that are not valued in the conventional medical system (McConkey, 2017), which is where cultural

barriers stem from. Geographical challenges include: doctors not available in area, services not available, and lack of a health care facility in the area. The economic barriers that were reported are: transportation costs, cost of care, and finances related to child care (Reading & Wien, 2009). There have also been reported challenges surrounding health care coverage (Place, 2012; Senese & Wilson, 2013) and discrimination in the system (McConkey, 2017; Place, 2012; Senese & Wilson, 2013; Wylie & McConkey, forthcoming), which often influences whether an individual will seek health care (Allan & Smylie, 2015).

Jurisdictional funding barriers have become a large issue, as federal, provincial and territorial governments debate over who has financial responsibility for Indigenous peoples (Belanger, 2010; Peters, 2006). Federal governments are supposed to have fiduciary responsibility for status and non-status First Nations and Métis peoples (Smith, 2016), however, there have been complications and ongoing disputes between governments regarding funding health services for Indigenous people (Browne et al., 2009).

Cultural Continuity

Cultural continuity is considered an essential component of Indigenous peoples' health and wellbeing and is an umbrella term that explains the extent to which an individual or community is connected to their sense of self and community as Indigenous peoples in a social and cultural context (Reading & Wein, 2009). Some of the activities that are considered as forms of cultural continuity include: speaking Indigenous language(s), engaging in hunting, fishing, trapping and/or gathering traditional Indigenous foods (Reading & Wien, 2009; Rotenberg, 2016). Research shows that individuals who engage in different forms of cultural continuity and are connected to their traditional roots are often protected against poor health outcomes, most specifically mental health disorders (Chandler, 2000; Chandler & Lalonde, 2008; Reading & Halseth, 2013).

Social Supports

Research has concluded that having a strong social and emotional support system or network is considered as a protective factor for health and wellbeing (Ozbay et al., 2007; Reading & Halseth, 2013; Wilkinson & Marmot, 2003). Social support and emotional support systems can

range from one to countless members of an individual's family or friends (i.e. non-relatives) and the level of support received can vary among individuals and communities. Level of support is influenced by an individual's socioeconomic status (SES) due to the higher social cohesion in areas of higher status (Reading & Halseth, 2013), in which social cohesion is defined as "the quality of social relationships and the existence of trust, mutual obligations and respect in communities or in the wider society, which helps to protect people and their health" (Wilkinson & Marmot, 2003, p. 22). Christine Rotenberg (2016) conducted a quantitative analysis on the social determinants of Indigenous peoples' health and health outcomes using the 2012 APS data. In regard to urban Indigenous people, those who reported having strong social or cultural support on the 2012 APS were more likely to have better health outcomes (Rotenberg, 2016).

2.5.3 Proximal Determinants of Indigenous Peoples' Health

Proximal determinants of health are health factors that have a direct impact on an individual's health and wellbeing (Reading & Wien, 2009; Reading, 2015), and are thought to be the most obvious, like the leaves on a tree. Health behaviours and the physical environment influence the health and wellbeing of an individual; however, due to the interconnectedness of the distal, intermediate and proximal determinants of health (Reading & Wien, 2009; Reading, 2015), it would be inaccurate to conclude that these determinants are strictly shaped by an individual's lifestyle choices or health behaviours, as systemic factors have a significant influence on behaviour.

Proximal determinants of health that will be taken into consideration throughout this thesis include household income, employment status, education level, smoking status and alcohol use. The relation of each of these determinants to Indigenous peoples' health will be explained further.

Income Inequalities

Income or SES is considered to be the most important determinant of health and wellbeing. Low SES creates a number of challenges for an individual including: poor living conditions, food insecurity, and access to adequate education, which may lead to negative physical, psychological and emotional health outcomes. Low SES and/or poverty are higher among the Indigenous

population when compared to the general Canadian population. This inequity largely influences the health and wellbeing of Indigenous peoples, where it has a negative impact on life-expectancy (Reading & Halseth, 2013). Life expectancy among First Nations peoples still remains lower than the non-Indigenous population in Canada (Health Canada, 2011).

Unemployment and Working Conditions

Alongside SES, unemployment and working conditions play a vital role in the health and wellbeing of an individual. Evidence suggests that people who face unemployment and/or job insecurity have a higher risk of health complications including mental health issues, self-reported ill health, and heart disease (Wilkinson & Marmot, 2003). Poor working conditions can also lead to individuals engaging in unhealthy behaviours such as smoking, alcohol and drug abuse, poor nutrition and being physically sedentary (Dooley, Fielding, & Levi, 1996). Unemployment rates are higher among Indigenous people when compared to the non-Indigenous people in Australia, New Zealand, and Canada (Reading & Halseth, 2013). Using the APS in 2011, 15.3% of Indigenous adults living off-reserve were unemployed, whereas 7.8% of non-Indigenous adults were unemployed in Canada. It is also noteworthy to mention that the unemployment rates decreased with higher educational attainment (Rotenberg, 2016).

Education

Education levels influence the health and wellbeing of an individual. Research has shown that the lower the level of educational attainment the poorer the health and wellbeing of an individual (Rotenberg, 2016; Wilkinson & Marmot, 2003). In 2006, 34% of Indigenous adults acquired less than a high school diploma compared to 15% of non-Indigenous adults in Canada. Evidence also suggests that Indigenous people are underrepresented at the post-secondary level, as fewer Indigenous people hold a university degree when compared to their non-Indigenous counterparts (Reading & Halseth, 2013).

Smoking

Smoking is associated with an increased risk of chronic health conditions and mortality (US Department of Health and Human Services, 2004). When compared to non-Indigenous peoples, Indigenous people living off-reserve reported a higher proportion of daily smoking habits by

approximately two-fold in 2012. Individuals who smoke are more likely to have negative health outcomes such as cancer or cardiovascular disease (Rotenberg, 2016).

Substance Use – Alcohol

Substance use has a negative impact on health and wellbeing and increases an individual's risk of engaging in risky behaviours (Baskin-Sommers & Sommers, 2006). Alcohol was first introduced to Indigenous peoples during the fur trade in the 1600s (McCormick, 2000), and still has a prominent impact on Indigenous peoples today. Throughout history, Indigenous peoples were removed from their own culture and lifestyles and forced to practice European culture and reside on reserve lands. The inadequate social conditions that Indigenous peoples lived in as a result of these colonial practices created an increased susceptibility to alcohol and other substances (Khan, 2008; Reading & Halseth, 2013). This has resulted in a higher prevalence of substance use and abuse among the Indigenous population when compared to the non-Indigenous population in Canada (McCormick, 2000; Rotenberg, 2016). Contrarily, according to the RHS (2002/2003), First Nations living on reserve have lower rates of alcohol use when compared to the general population; however, First Nations who do use alcohol tend to be heavier drinkers and are more often hospitalized as a result of substance use (FNIGC, 2003; Public Health Agency of Canada, 2006). Furthermore, there has been a high proportion of alcohol-related deaths among the Indigenous population (York, 1990).

2.6 Biomedical vs. Indigenous Perspectives of Health and Wellbeing

Biomedical and traditional Indigenous perspectives and practices are two very distinct approaches to health and wellbeing (Wilson & Richmond, 2009) and will be further explored in this section. First, it is important to have an understanding of these two systems, and how combining the two is beneficial to maximally support the health and wellbeing of the Indigenous population in Canada. Canadian health care approaches are based on the assumption that the body and mind are separate, and this concept has evolved into a system where the definition of a disease or illness is a dysfunction or mechanical breakdown of the body or mind that requires treatment, most commonly through the use of prescription medications, radiation, and/or surgery (National Cancer Institute, n.d.; Wilson & Richmond, 2009). While biomedicine seeks to treat

disease and illness in isolation, Indigenous health practices incorporate methods that focus on treating an individual as a whole (Wilson & Richmond, 2009).

Prior to and since first contact, Indigenous people held their own perceptions of health and wellbeing. While all nations and cultures have unique teachings and understandings of health and wellbeing, most have common principles within these different ideologies. A common representation of an Indigenous health model encompasses a more holistic approach, which focuses on the intimate connection between a *being* and the larger system that that *being* lives within, including balance and interconnectedness among individuals, community, and the environment (Robbins & Dewar, 2011). For example, a depiction of health among the Anishnaabe is the medicine wheel; this concept consists of four sections (i.e. physical, mental, emotional, and spiritual), which represents the four essential elements of health and wellbeing. This worldview holds the ideology that in order to be at optimal health, it is critical to maintain harmony and balance in all four quadrants because that is the ultimate determinant of health for Indigenous peoples. It is believed that healing is required when there is an imbalance (Tagalik, 2015).

Traditional healing is another important aspect of health and wellbeing that has been formally defined by the Royal Commission of Aboriginal Peoples (RCAP) (1996) as “practices designed to promote mental, physical and spiritual well-being that are based on beliefs, which go back to the time before the spread of western scientific bio-medicine” (RCAP, 1996). Rituals, ceremonies, herbal remedies, and natural healing practices are forms of traditional healing and were commonly performed by traditional healers and midwives who used natural medicines provided by animals or the land (Postl, Cook, & Moffatt, 2010; RCAP, 1996). Medicines and healing practices are used by traditional Indigenous healers to keep away illness and/or to restore balance among the four elements of health and wellbeing. As a means of keeping the culture and traditions alive for future generations, it is imperative to ensure this knowledge and practice is maintained and is not lost (Robbins & Dewar, 2011).

Understanding the Indigenous worldview of health in addition to using conventional health practices is essential in combatting the health equality gap (Marshall, Marshall, & Bartlett,

2015). This is the idea of *Two-Eyed Seeing*, which refers to the idea that one eye is used to understand traditional Indigenous Knowledge, while the other eye is used to understand Western or conventional knowledge. The most important part of this idea is using both eyes together at the same time to ensure harmonization of these two worlds. Marshall and colleagues (2015) state that, “*Two-Eyed Seeing* is needed to help understand how traditional knowledge from an ancient culture can work for a better and healthier world” (Marshall et al., 2015, p. 22). This is especially important when discussing the Canadian health care system. This idea can be used as a metaphor for the combination of traditional Indigenous concepts of health and conventional medical practices because this concept encourages physicians and medical students to draw upon new technologies as well as traditional Indigenous ways of living. This can be applied to promote better health outcomes for not just the Indigenous population, but for everyone living in Canada (Marshall et al., 2015).

2.6 Indigenous Experiences with Mainstream Health Care Services in Canada

Conventional health services are the primary source of health care for Indigenous peoples in Canada (Waldram, 2013), however, a poll from the National Aboriginal Health Organization (NAHO) in 2003 reported that Indigenous people received less needed health care than the rest of the Canadian population, and when they did receive health care it was perceived as lower quality. The survey also revealed that Indigenous people preferred to use traditional medicines and healing services, but commonly refrained from using these services because it was not covered by health insurance plans (NAHO, 2003). Indigenous people are not provided with adequate health care and may avoid accessing conventional medical services because of common experiences of discrimination, racism, and delivery of poor quality health care (Adelson, 2005; Allan & Smylie, 2015; NAHO, 2003). For example, Indigenous women seeking medical care in the conventional health care system often experience poor quality of services, discrimination, and negative judgments about their health status or lifestyle choices (Lallo, 2014).

Sherri Lallo (2014) explains the experience of an Indigenous woman who received culturally insensitive care by a physician when she went into the labour. A cultural belief is to not buy any clothes or supplies for a baby until they are born, and the physician criticized the woman for not being prepared for her hospital visit. Another Indigenous woman, who was pregnant and an was

struggling with addictions, had a negative experience when seeking help for her unborn baby from a medical professional. Instead of helping this woman, the physician showed disgusted facial expressions and angrily yelled at her. This woman recalls feelings of shame and helplessness and refused to continue prenatal care due to these negative experiences (Lallo, 2014). There have been multiple reports of Indigenous women experiencing similar encounters with physicians which have left many women unwilling to seek prenatal care in a conventional health care setting due to fear of child apprehension and lack of quality and culturally relevant care (Lallo, 2014).

In a similar research project, Annette Browne & Jo-Anne Fiske (2001) conducted a qualitative study focusing on Indigenous women's experiences using the mainstream health care system. There were common experiences of racism and discrimination among these women, as well as, feeling like intruders into an unwelcoming system where they were further marginalized (Browne & Fiske, 2001). An Indigenous woman shared her experience in the health care system:

so it's us and them. And we feel like we're using, we're intruders on their system. A lot of time, I feel that way. And probably a lot of Native people would feel the same, I think, that we're intruding, it's their service (Browne, & Fiske, 2001, p. 137).

When women feel like intruders within their own country when seeking something that is a human right (i.e. health care), it is evident that there is an issue within the system, not the individual.

It is through an accumulation of negative experiences that Indigenous people have faced when using the conventional health care system that continue to marginalize and disadvantage Indigenous people and their health and wellbeing (Browne & Fiske, 2001). Another factor that may contribute to the negative experiences that Indigenous people have experienced when accessing conventional health services can be explained by James Waldram (2013) who suggests that, "less deliberate influences on Aboriginal healing are also evident in contemporary approaches, and elements of Christianity, 'New Age' alternative and complementary therapies, and popular culture are evident" (Waldram, 2013, p. 197). This suggests that there is lack of access and/or willingness to provide traditional Indigenous medicine and healing practices within

the conventional medical system because alternative approaches are considered as inferior to western approaches to medicine (McConkey, 2017; Walker & Behn-Smith, 2015).

These identified experiences suggest that past generations of Indigenous people have had a myriad of challenges in health and social systems that have had a negative impact on their health. The health of future generations is going to continue to be negatively influenced by the ongoing assimilative, marginalizing, and oppressive practices that ignore the Indigenous determinants of health and continue to blame individuals for their own health status. This needs to be understood and addressed by everybody working within the Canadian health care system in order to move forward and heal from these colonial legacies, as well as to provide Indigenous patients with optimal services to support their health and wellbeing.

In response to the racist and negative health care experiences endured by many Indigenous people, there have been some attempts to increase access to quality and culturally safe health care in Canada. Some of these strategies include health services directed by Indigenous personnel such as: communities managing their own health services on reserve, the establishment of the First Nations Health Authority in British Columbia, the Aboriginal Health Access Centres in Ontario, and Urban Aboriginal Health Centres (UAHCs) (Allan & Smylie, 2015). In the last decade there has been an emergence of UAHCs across Canada, which has been an efficient way of providing quality and culturally competent health care to Indigenous people in urban centres. Through the combination of traditional Indigenous medicines and conventional health services, these centres are dedicated to providing quality health care and are mandated to culturally fulfill the health needs of Indigenous people in urban centres (Benoit, Carroll, & Chaudhry, 2003). Anishnawbe Health Toronto (AHT) is an UAHC with two locations located in Toronto, Ontario and staffs a multidisciplinary team of physicians, nurses, counselors and Elders, including a number of Indigenous staff. Indigenous professionals are in control of the administration of services and are dedicated to using traditional Indigenous approaches and combine care as a form of healing, regaining balance and growing their Indigenous patients (Anishnawbe Health Toronto, 2011; Benoit et al., 2003). These services have also been deemed successful and essential for the health and wellbeing of Indigenous people in urban centres (Allan & Smylie,

2015; Benoit et al., 2003), and can provide examples for a comprehensive response to improving health care for urban Indigenous people.

2.7 Conclusion

National statistics suggest that there is a health equality gap between the Indigenous population and non-Indigenous population in Canada. Unfortunately, national statistics on Indigenous peoples in Canada are under-representative of the population (Smylie & Firestone, 2015) and therefore, we are unsure just how large of a health inequality gap truly exists. Furthermore, national data paints the picture that all Indigenous peoples are the same and not distinctive by nation, community, culture, or geographic location. There are a number of conflicting national data sources that provide different diabetes prevalence estimates among the Indigenous population in Canada, however all data suggest that Indigenous peoples have a much higher rate of diabetes when compared to the non-Indigenous population. Raising awareness about the existing health equality gap between Indigenous and non-Indigenous peoples in Canada is important; however, understanding why these patterns exist is imperative (Richmond & Ross, 2009). Regional-level health assessment data for Indigenous peoples, combined with opportunities for Indigenous people to share their experiences with health care, are essential in understanding trends of diseases among a specific community, nation, or urban centre, which is what the *OHC* project aims to provide.

In regard to the determinants of Indigenous peoples' health, it has been concluded that as the number of social predictors for ill health experienced by an individual increase, the more likely they are to report poor health outcomes; therefore, the determinants of health are considered to have a "compounding effect" (Rotenberg, 2016). Distal, intermediate, and proximal social determinants that may predict a diabetes diagnosis and unmet health needs experienced by Indigenous people will be the focal point of this thesis. Using the tree metaphor to understand the determinants of health of Indigenous peoples' health, the experiences of colonialism are deeply embedded in an individual, as are the roots of a tree. These roots will strongly guide and impact an individual's life. Colonial practices like the *Indian Act of 1876* and residential schools were major forms of environmental dispossession, cultural genocide and disenfranchisement, which forced Indigenous people to reside in inadequate social conditions. These distal determinants

influence the intermediate determinants of health and challenge an Indigenous person's ability to engage in cultural continuity practices and to have a social support system. Research has concluded that individuals who participate in cultural continuity practices and activities are more likely to live a healthier life and lead a healthier lifestyle. Forms of cultural continuity protect Indigenous people from mental health and addictions illnesses (Chandler, 2000; Chandler & Lalonde, 2008), which could influence an individual's choice to engage in risky behaviours such as smoking and substance use. The social conditions that Indigenous people were forced to live in influence the proximal determinants of health such as education, employment, and SES. Like the crown of the tree, these proximal factors strongly influence what an individual grows into. At the same time, the choices and behaviours at the proximal level are strongly influenced by the roots and trunk, for example, the corresponding social factors that shape what options and choices people have in life. Through this depiction, it is easier to understand how all of the distal, intermediate, and proximal determinants of health are interconnected and influence one another, therefore revealing the misconceptions of putting the blame and responsibility of Indigenous peoples' health on the individual. Instead of focusing only on the proximal determinants of health, it is essential to include an exploration of the distal and intermediate determinants of health when conducting research or making inferences about Indigenous peoples' health and wellbeing. We need to move past blaming individuals for their health status and acknowledge the social determinants that play a role in an individual's health and wellbeing, especially as a key mechanism of moving forward from the colonial legacies and ongoing practices that still affects many Indigenous people today.

The literature suggests there are a number of health service access barriers that Indigenous people experience which may influence whether they pursue health services or programs. Among those who did access mainstream services, there were a number of unmet needs identified and negative experiences endured by Indigenous patients. It has been concluded that special attention should be paid to Indigenous people when they access health care services, as they have a very different concept of health and wellbeing compared to mainstream Canadian society. Research has shown that Indigenous people prefer to use traditional Indigenous medicine and healing practices during their patient journeys, however these services are commonly not offered as part of their care plan. UAHCs and other services that incorporate

traditional Indigenous approaches into their care plans have been deemed successful by Indigenous patients in meeting their complex health and wellness needs. Therefore, expanding these Indigenous run and guided health services, or the adoption of these types of holistic services into the conventional health care system would be a valuable contribution to addressing the gaps in Indigenous health status through improving access to appropriate and quality health care.

Regarding this thesis, *OHC Toronto* data is used to understand the demographics, self-reported diabetes diagnosis, self-reported use of traditional Indigenous approaches and conventional approaches to medicine, and unmet health needs of Indigenous adults in Toronto. Using Charlotte Reading's (2015) Indigenous determinants of health framework (i.e. the tree), this survey data will also be used to understand the Indigenous determinants of health as predictors of unmet health needs and self-reported diabetes diagnosis to identify the linkages across the distal, intermediate, and proximal determinants of health and their influences on health outcomes. Due to the exploratory nature of this research, there is much that can be gained from this work. While not all aspects of the literature review had urban-specific context, the outcome of this work is to hopefully add to that growing area of research and find solutions specific to urban Indigenous people in Canada. This thesis will provide a base for understanding the different distal, intermediate, and proximal determinants of health that predict unmet health needs and/or diabetes diagnosis among urban Indigenous people. This information will be useful for developing policies, recommendations, strategies and even future research that focuses on improving the social conditions of urban Indigenous peoples as a means of mitigating health inequities among this population in Canada.

Chapter 3

3. Methodology and Design

This chapter will provide a brief overview of Indigenous research methodologies and will present a detailed explanation of respondent-driven sampling. Additionally, this chapter will provide a list of the descriptive and health-related measures used in the quantitative analysis and will describe the processes of the statistical analysis.

3.1 Research Ethics

Research ethics approval has been granted by St. Michael's Hospital Research Ethics Board (REB) and permissions to conduct a quantitative analysis of the *OHC Toronto* data set has been granted by Western University's REB and by the owners of the data, Seventh Generation Midwives Toronto (SGMT).

3.2 Indigenous Research Methodologies

As a result of traditional western research practices, Indigenous peoples and communities have endured an overwhelming amount of negative experiences (Castleden, Sylvestre, Martin & McNally, 2015; Cochran, Marshall, Garcia-Downing, Kendall, Cook, McDubbin, Gover, 2008; Smith, 2013). Linda Smith (2012) says “the word itself, ‘research’ is probably one of the dirtiest words in the Indigenous world’s vocabulary” (Smith, 2013, p. 1) due to the history of western research practices on Indigenous communities. Western research is an act of imperialism and is closely tied to colonization, as the colonizers (i.e. those with more power and privilege) objectified and studied Indigenous societies and cultures from their own point of view, completely disregarding Indigenous ways of knowing and actually claiming Indigenous knowledge as their own (Smith, 2013). Indigenous peoples were viewed as “a ‘race’ of people who were physically and intellectually inferior to other humans and were headed for extinction” (Laycock, 2011, p. 6).

Westerners collected data on Indigenous people and their communities, interpreted the research findings and then brought these interpretations back to the community (Smith, 2013), for the sole purpose of benefitting and further advancing their own career or research (Castleden et al., 2015). Oftentimes, research findings perpetuate that Indigenous peoples and communities are ill (Cochran et al., 2008; Chandler & Dunlop, 2015). This is especially true when national statistics are used for purposes of assessing the health status of Indigenous people. Most national statistics present Indigenous peoples in Canada as one group instead of disaggregating by community, culture and/or nation (Chandler & Dunlop, 2015), thereby, ignoring heterogeneity in health between different communities, cultures and nations. Aggregate health assessment data that presents Indigenous people as ill comes with its own stigmatization (Cochran et al., 2008). As Cochran and colleagues (2008) state, “no community wants to have the reputation of having the most alcoholics or the most people with mental disorders” (Cochran et al., 2008, p. 23). Such statistics create a misguided representation that Indigenous peoples have a problem that needs to be fixed (Cochran et al., 2008). Instead of developing strategies to address the existing health disparities (Adelson, 2005; Castleden et al., 2015) researchers would come into the community, conduct research and then leave, with little to no benefit for the community’s health and wellbeing (Castleden et al., 2015; Cochran et al., 2008).

It was not until quite recently that these approaches were deemed inappropriate and Indigenous health research frameworks and methodologies were developed that differed from western approaches to ensure research practices were culturally safe (Walter & Anderson, 2013; Smith, 2013). Indigenous methodologies focus on reframing research to include an Indigenous paradigm, as defined as a belief system that guides action (Wilson, 2001), that includes Indigenous worldviews, knowledge, context, relationship and ways of knowing (Walter & Anderson, 2013; Wilson, 2001). Indigenous people are considered as more than just the subjects of research; they are the knowledge holders that should contribute to all aspects of the research (Walter & Anderson, 2013).

Western research’s main focus is gaining knowledge - the process of finding knowledge and owning it (as the researcher). Using an Indigenous paradigm, knowledge is relational and shared and cannot be owned by an individual. Shawn Wilson (2001) explains that relationships are

essential to executing Indigenous methodologies; specifically, he suggests, “for research, it is important to think about our relationship with the ideas and concepts that we are explaining. Because this relationship is shared and mutual, ideas or knowledge cannot be owned or discovered” (Wilson, 2001, p. 177). These relationships refer to an individual’s relationship with all of creation, therefore it is essential to understand the accountabilities and obligations to the relationships and knowledge guiding the research with Indigenous peoples (Wilson, 2001). More formally, the Tri-Council Policy Statement (TCPS) has been reformed to include more culturally appropriate research methodologies and practices when conducting research with or on Indigenous people in Canada. TCPS now has a chapter dedicated to research involving the First Nations, Inuit and Métis peoples of Canada and was designed as a framework for researchers (Government of Canada, 2015).

The TCPS has provided Indigenous health researchers with a framework and a list of recommendations that should guide the developmental processes of their research in order to obtain ethical approval (Ermine, Sinclair & Jeffery, 2004). These recommendations were originated by Ermine and colleagues (2004) and the list of recommendations and how they will be applied to this thesis project are:

- 1) Indigenous peoples’ jurisdiction
- 2) Advancing the ethical space
- 3) Research agreements
- 4) Empowerment and benefits
- 5) Protection of intellectual and property rights
- 6) Ownership, Control, Access, and Possession (OCAP®)
- 7) Education
- 8) Dissemination of guideline principles
- 9) Consent and timeline conflicts

Indigenous peoples’ jurisdiction is in place because each community partner holds ownership over the data; for example, *OHC Toronto*’s community partners are SGMT, who own, control, have access and decides who else may access, and possess the data. Regarding ethical space, The *OHC* project is a community-based longitudinal study that targeted Indigenous people living in a

number of urban cities. Careful consideration has been taken upon developing the project to ensure that proper and culturally relevant research methodologies were enforced throughout every aspect of the project. Additionally, the Principal Investigator of the project is Dr. Janet Smylie, a well-known Métis physician and Indigenous health researcher in Canada. Furthermore, community partners are involved in every stage of the research project to ensure proper Indigenous health methodologies are being respected.

Data partnerships and data sharing agreements with urban Indigenous communities were a key element of this research for Indigenous governance and management of their own health assessment data (Smylie & Firestone, 2015). Research and data-sharing agreements are also developed with other organizations, students, and workers who will come in contact with the data, in which research project goals and objectives are subject to change in order to align with the community's research goals and priorities. Indigenous empowerment and benefits are considered because the community partners govern and manage the data. This is very empowering for the community because they will have control over their own health assessment data and will be involved in determining the risks and benefits of future research involving the data. Means of intellectual and property rights protection will be enforced through the research agreement and data sharing agreements as a means of protecting Indigenous Knowledge.

OCAP® are a registered trademark of the First Nations Information Governance Centre (FNIGC) and these principles are a guiding mechanism for the research project because all data analyzed is in complete ownership, control, access and possession of the community partners. OCAP® principles are often used to guide Indigenous health research to ensure adequate governance and management of health data. *Ownership* refers to the Indigenous organization and/or community being the primary data holders of Indigenous Knowledge that is encapsulated within the information. *Control* reflects the promise that the Indigenous organization and/or community will have complete control over resources and will be the primary decision-makers in every aspect of the research cycle, from formation of the research question to dissemination of findings. *Access* refers to data-sharing agreements, in which, the organization and/or community will have direct control over who can access data. Finally, *possession* is the idea that the data will be properly stored and protected, and Indigenous organizations and/or communities will

remain in control of data information (FNIGC, 2014). Regarding this thesis, OCAP® principles will be the guiding factors for dissemination and knowledge translation. There will be a final report drafted and major findings fact sheets created for community partners. The community will be the decision-makers of whether further dissemination and knowledge translation of the findings will occur. The opportunity of applying for publications in academic Indigenous health journals and presenting findings at Indigenous health conferences will be available for those involved in the research project.

Education will be ongoing throughout the whole project. The *OHC* research team comes from a number of academic backgrounds, in which everyone can learn from each other to ensure the integrity of the overall project. To build on this knowledge, guiding principles will be available for dissemination because every step of the research will be documented throughout the duration of the project. This will aid in recognizing the strengths and challenges of Indigenous research methodologies and has the potential to add to the current literature on Indigenous research methodologies in practice.

Regarding consent and timeline conflicts, participant consent was originally collected by researchers involved in the *OHC Toronto* study. For purposes of this thesis, participant informed consent was not needed because this thesis focuses on secondary data analysis and there was no direct contact with participants. In regard to timeline conflicts, the most important part of this research project was creating a reciprocal, trusting, relationship with SGMT. It is essential to build a foundation of trust upon which respectful research can take place, despite the fact it may be time-consuming.

The above are frameworks for Indigenous methodologies in general, but now the focus will be narrowed in on Indigenous *health* methodologies. Alison Laycock (2011) suggests that Indigenous health research methodologies should take a participatory approach and should include: a focus on research that can be transferred into practices to make a difference to health status of Indigenous people; have Indigenous control of the research agenda; have Indigenous control of the research process; improve processes for quality control; and improve processes for consultation and negotiation of research (Laycock, 2011, p. 17). In order for this process to

occur, it is necessary to employ more than just a western approach to research. Instead, building reciprocal and trusting relationships needs to occur between the researcher and Indigenous community where community-specific guidelines and principles need to be acknowledged, determined, and followed.

In regard to my involvement with the *OHC* project, my journey began in March of 2016 where I informally met with Janet Smylie at a community event hosted by my thesis supervisor at Western University. We discussed my research interests and I shared my concerns about being an Indigenous person in the field of Epidemiology and Biostatistics and the limitations to traditional data sets that undermined my interests in pursuing an Indigenous methodological approach. Janet introduced the *OHC* project to me and together we decided that I should consider nesting my thesis in the *OHC Toronto* project, pending approval by the community. After following-up with the research team regarding my interest in the *OHC Toronto* study, I was invited to attend the WLH and SGMT research team meeting in Toronto on August 16, 2016. At this roundtable meeting, we opened with a prayer and a smudge, we were updated on the progress of the study (data collection was complete and data cleaning was in progress), and I was able to introduce myself and express my interest in the *OHC Toronto* study. SGMT and WLH asked me what my research interests were and then they told me what their research priorities were. Through this discussion, we developed a research question for my thesis that focused on research priorities that needed to be addressed for the community and my research interests that would also meet the requirements for my thesis.

On January 11, 2017, I submitted a project request form that outlined the research question, objectives, benefit to Indigenous communities, and data analysis plan. In early March of 2017, I was approved by SGMT and WLH and was able to nest my thesis in the *OHC Toronto* project. I was then added to their ethics agreement and in late March of 2017, I was granted access to *OHC Toronto* data for adults. Throughout, I kept in close touch with WLH and SGMT. In December of 2017, I proposed to revamp my original objectives to include a new objective and to manipulate the data to be more inclusive of some qualitative themes that were identified among one of the key questions used in my data analysis. I proposed these changes to WLH and SGMT and was approved to conduct these additional analyses in late December of 2017.

The reason I wanted to share my journey is because I am in a quantitative discipline that does not always put forth the effort to respect, understand and/or incorporate Indigenous methodologies when conducting quantitative analyses on Indigenous peoples (Allan & Smylie, 2015). There has been a history of inappropriate research in Indigenous communities. Methodologies that are community-based, focus on relationship-building, and incorporate Indigenous Knowledge can ensure Indigenous health research supports the goal of closing the health disparity gap and improve access to health services for this population (Cochran et al., 2008; Wallerstein & Duran, 2006). Indigenous people are more than just numbers or statistics, we are people that are alive and fighting for our health and wellbeing. I wanted to share the importance of respecting the community or people that may be subjects of any given study. While data on Indigenous people is important, it is more important to understand community needs before just producing numbers that the researcher may believe are relevant. It is essential to work with Indigenous peoples and communities in understanding priority research goals and objectives, and to not just explore the depth of health inequities that exist but reasons behind why they exist. These were many of the unwritten goals of my thesis as an Indigenous researcher and I wanted to stress the importance of such methodologies to future researchers, because it has been identified that the process of research and the methodologies employed can be more important than the outcome of the research for Indigenous communities (Smith, 2013).

3.3 Data Sampling: Respondent-Driven Sampling

Approximately 4.9% of Canada's population are Indigenous people (Statistics Canada, 2017d). Given the small proportion of Indigenous people in comparison to non-Indigenous people, Indigenous people can be difficult to sample and can be considered a "hidden population" in Canada due to the unknown sample size of the population in a given city and because identifying within the population can be stigmatizing (Heckathorn, 1997). Respondent-driven sampling (RDS) is a relatively new probability sampling method that was developed to sample the hidden population of people who inject drugs (Heckathorn, 1997), which that was used extensively to sample HIV-positive men (Magnani et al., 2005; Ramirez-Valles et al., 2005). RDS is a modified form of snowball sampling. Similar to snowball sampling, RDS targets hidden populations, where "hidden" refers to having no existing sampling frame (Heckathorn, 1997; Ramirez-Valles

et al., 2005). However, other sampling methods such as simple random sampling and snowball sampling are inadequate for capturing a large sample of a hidden population (Heckathorn, 1997; Magnani, Sabin, Sidel, & Heckathorn, 2005); therefore, RDS is a great approach to overcoming some of the limitations and bias associated with other sampling methods (Magnani et al., 2005). Indigenous people are relational and are community- and family-oriented beings (Castellano, 2015; Walker & Behn-Smith, 2015), therefore it can be assumed that Indigenous people are networked with one another and using personal networks to recruit Indigenous people in an urban context is a useful sampling methodology.

RDS uses a dual-incentive chain-referral system with a selected number of participants that are responsible for recruiting more subjects from the study's target population. Incentives are provided for individuals who participate and for each additional participant they recruit (Heckathorn, 1997). Participation is voluntary because the participant must appear at the study site in order to participate and receive their incentive (Magnani et al., 2005). Researchers are responsible for selecting the initial participants, also known as "seeds". Seeds are normally selected based on diverse characteristics in order to get a heterogeneous sample of the target population and are responsible for recruiting a previously determined number of subjects from their personal network (Heckathorn, 1997; Ramirez-Valles et al., 2005). Those recruited continue to recruit from their personal network and follows a Markov chain processes. A Markov chain is a sequence where the previous state predicts what will happen next (Karlin, 2014). Relating this model to RDS, a selected participant will predict the next set of participants in the study due to their personal networks and relationships between recruiter and recruit(s). This same selected participant will not predict future participants. This cycle continues until the target sample size or "equilibrium" is reached (Ramirez-Valles et al., 2005).

When the final sample becomes independent of seeds, the sample composition is considered to be stable and at equilibrium (Heckathorn, 2002; Ramirez-Valles et al., 2005). Equilibrium means that sample composition is stable and does not change with successive waves of recruitment. Equilibrium is obtained by having enough cycles of recruitment, also known as "waves" and is easier to reach if the original seeds that were selected hold diverse characteristics of study interest. This also ensures greater heterogeneity across the sample (Ramirez-Valles et al., 2005).

Generally, equilibrium is reached within 4 or 5 waves, however this differs across variables. When there is higher homophily between participants, it takes longer to reach equilibrium and when there is higher heterogeneity between participants it takes fewer waves to reach equilibrium. Therefore, bias related to the selection of original seeds is reduced as the recruitment chains increase in length (Ramirez-Valles et al., 2005).

As a means of controlling the sample size and reducing biases, there is a quota on the number of subjects each participant can recruit from their personal network (Heckathorn, 1997), recruiter-recruit relationships are recorded, and each participant's personal network size is documented (Magnani et al., 2005; Ramirez-Valles et al., 2005). Having a recruitment quota allows for the development of longer recruitment chains and reduces the likelihood of having a homogenous sample (Magnani et al., 2005; Ramirez-Valles et al., 2005). This approach, therefore, reduces the biases associated with participants recruiting individuals with similar qualities as their own (Ramirez-Valles et al., 2005) and individuals with larger personal networks to recruiting more participants than individuals with smaller personal networks (Heckathorn, 1997).

In order to account for non-random sampling biases that are associated with this type of sampling, RDS-II methods were employed, and the sample was weighted using network size. The probability of recruitment differs between those who have larger network sizes than others, therefore more weight is given to those who have smaller network sizes because they are representing a greater number of individuals who did not get sampled as a result of the study design (Heckathorn, 1997; Magnani et al., 2005).

RDS was used to access the Indigenous population for multiple *OHC* studies that took place in different Ontario cities, including Hamilton, Ottawa, London and Toronto. The Hamilton and Ottawa studies targeted First Nations, Métis and Inuit individuals separately, therefore targeting an even smaller proportion of Indigenous people per study. Using RDS methods, these studies were deemed extremely successful (Smylie et al., 2011) due to the ability to get significant coverage of the target population using these methods (Ramirez-Valles, Heckathorn, Vazquez, Diaz & Campbell, 2005). Specifically, *OHC Hamilton* met their target sample size of 750 First

Nations adults and children within four and a half months using RDS methods (Smylie et al., 2011).

For RDS to work properly, there are four essential elements that must be incorporated into the study's methodology. These include: 1) recruit patterns must be documented; 2) there should be a maximum number of recruits allowed per participant; 3) information on each participant's network size must be collected; and 4) a pre-existing relationship must exist between the recruiters and recruits (Magnani et al., 2005). The *OHC Toronto* project ensured all four of these key elements were included in the study. First of all, recruits were linked to their recruiter using unique coupon codes that were entered into a database upon the participant's arrival to the study site. Second, participants were given a maximum of 3 to 5 coupons to disperse to their personal network. Lastly, data on participant's personal network size and relationship to their recruiter was collected when they voluntarily participated in the study.

3.4 Sample Size and Data Collection

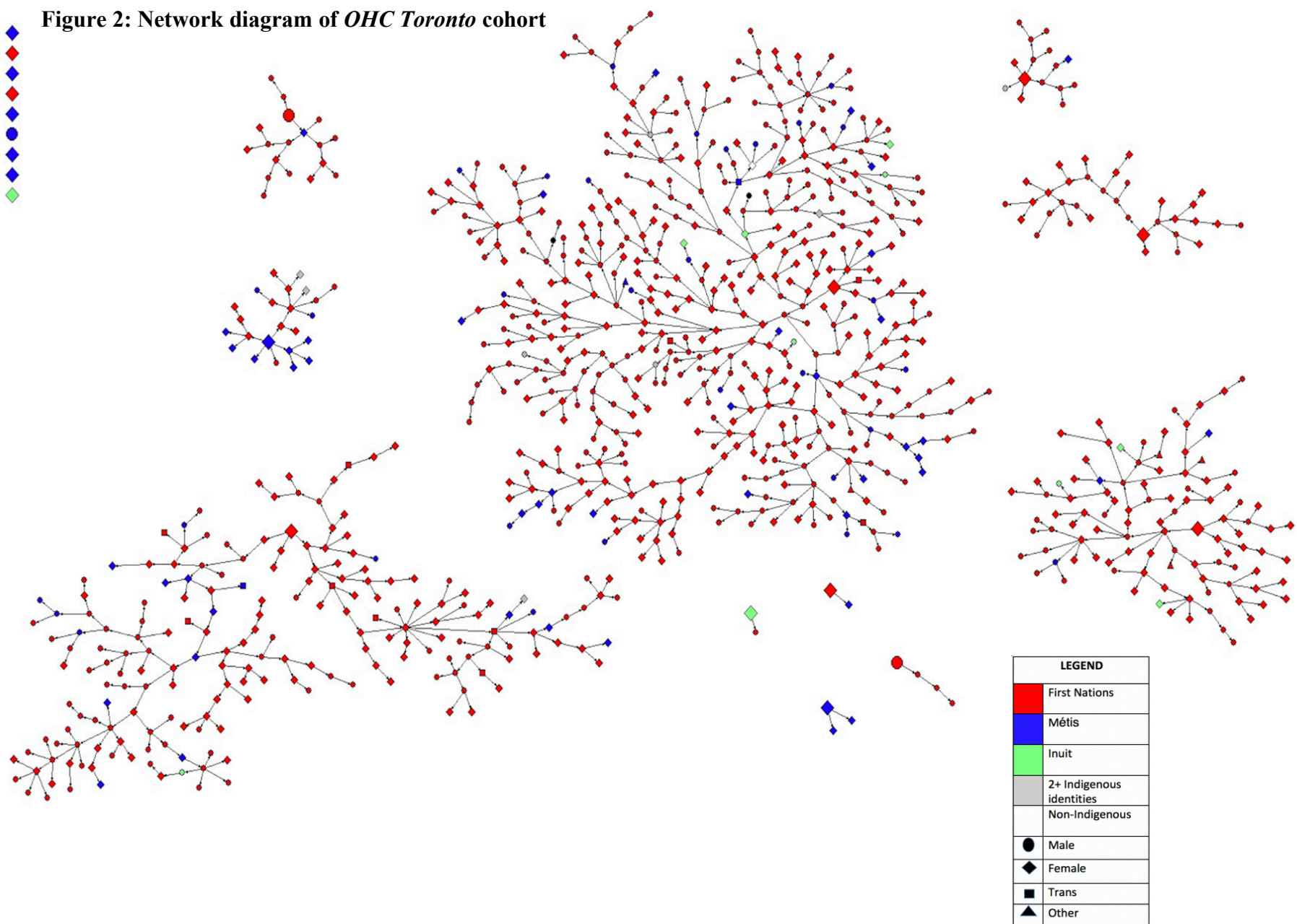
The *OHC Toronto* project used a RDS framework to recruit 918 adult participants, in which 917 individuals were Indigenous and 1 individual was non-Indigenous with an Indigenous child. Adult participants were classified as 15 years of age or older. Adults that self-identified as being Indigenous (i.e. First Nations, Inuit or Métis) or have a child that self-identifies as being Indigenous, and currently reside, work or access services in Toronto were included in the *OHC Toronto* study.

There were 20 original seeds who were selected by community partners and the *OHC Toronto* research team prior to commencement of the project. Seeds were recruited based on specific demographic and social factors including Indigenous status, gender, educational attainment, marital status, parental status, age, sexual orientation, social network size and personality. Each seed was provided with a maximum of 3 coupons that they were to give to 3 different individuals from their personal networks. For the first 8 months of the study, each recruit was provided with 3 coupons to recruit with, however the number of coupons provided to recruits was increased to 5 for the 3 remaining months in order to reach the desired target sample size. Therefore, from this point on each recruit was provided with 5 coupons to recruit a maximum of 5 individuals

from their personal networks, and the cycle continued creating long chains of recruiters and recruits. *OHC Toronto* used a dual-incentive system, in which, each participant received a \$20 CAD honorarium upon completion of the survey, an additional \$10 CAD honorarium for acting as a proxy respondent for the child survey (not used in this thesis) and an additional \$10 CAD for each of their recruits that completed the survey. Each coupon had a unique code on it that allowed researchers to link each recruiter to their recruit. Participants were required to share their personal network size and their personal relationship to their recruiter.

OHC Toronto used RDS methodologies to recruit 918 participants spread over 19 waves of recruitment. Given that equilibrium is reached within 3 to 4 waves of recruitment (Ramirez-Valles et al., 2005), it can be assumed that equilibrium was reached in the OHC sample, as the two longest waves in the sample were 16 and 19 waves in length and the majority (88%) of participants were recruited from 3 of the original seeds. The network diagram, also known as recruitment tree, in Figure 2 displays how sampling occurred by ethnicity and gender. Seeds are represented by the larger shapes, and this figure shows that only 11 out of the 20 seeds initiated a recruitment chain. The 9 single isolates in the top left corner are seeds that did not recruit any other participants.

Figure 2: Network diagram of *OHC Toronto* cohort



Indigenous students and allies were hired and trained to administer surveys to participants. Surveys were completed between the timeframe of April 2015 to March 2016. Each participant completed a 60- to 90-minute adult survey and was given the opportunity to complete an additional 10- to 15-minute child survey, if they had a child and desired to do so. Interviewers administered the surveys verbally and manually entered respondents' answers to survey questions with an Ipad. Participants had the option of choosing between 3 different sites in Toronto to attend for the survey interview, or those who were less mobile were able to select a home visit to participate in the study. The sites in Toronto included Queen West Central Toronto Community Health Centre, Seventh Generation Midwives Toronto's birth centre, and the Native Canadian Centre of Toronto.

The focus of this thesis is on Indigenous adults; therefore the 1 non-Indigenous participant was removed and data on children will not be included in the analysis.

3.5 Measures

A number of demographic and health-related variables were selected for comparison based on relevance, availability of information in the *OHC Toronto* dataset, and community needs and research priorities. First the outcome variables used in the logistic regression models are presented. Afterwards, the explanatory variables used in the logistic regression models are presented. The explanatory variables are the determinants of Indigenous peoples' health, expressed using an Indigenous framework. The determinants of health are broken down into distal, intermediate, and proximal determinants of health.

All variables used in the logistic regression model were collapsed to binary variables. This allowed each explanatory variable to serve as either a risk or protective factor for experiencing an unmet health need. The reference category for each explanatory variable was the more negative of the two categories (i.e. below LICO) as a means of building on strengths of the community. The reason for this binary categorization was because that majority of the explanatory variables were binary in the survey tool. Education status and employment status were collapsed to be binary variables because due to the numerous categorizations presented, these variables were more informative in the logistic regression analysis when collapsed into

binary variables. Social network was collapsed because Indigenous people are family- and community-oriented peoples, and the difference in network size was not as relevant as differentiating between participants who have a social network and those who do not have a social network (i.e. being connected or not being connected to family or community).

3.5.1 Demographic Measures

Below is a list of the demographic factors that were considered in the analysis phase of this thesis. The following demographic factors were analyzed for purposes of describing and understanding the population sample.

Self [Aboriginal] identity

A categorical question was used to determine how the participant self-identified as being Indigenous. The survey respondents were asked “how do you self-identify” with possible answers as being “First Nations”, “Métis”, and/or “Inuit”. Respondents were asked to check all answers that may apply to their self-identification. Those that selected more than one Indigenous identities were recoded to “multiple Indigenous identities”.

Age

An open-ended question was used to determine the age of the participant. Survey respondents were asked “what is your date of birth” and were expected to express their birth using exact day, month and year. Age was recoded to categorize individuals into the following age ranges: “15-24”, “25-34”, “35-44”, “45-54”, “55-64”, and “65 or older”.

Gender

A categorical question was used to determine the gender of the participant. Survey respondents were asked “what is your gender” with possible answers being “female”, “male”, “trans”, or “other”. Respondents who selected “other” had the opportunity to specify their answer.

Income

An open-ended question was used to determine household income. Survey respondents were asked “what is your best estimate of the total income, before taxes and deductions, of all

household members from all sources in the past 12 months” with respondents expected to provide an exact dollar figure. If respondents were unsure or uncomfortable answering that question, they were asked the follow-up question, “can you estimate in which of the following groups your household income falls? Was the total household income from all sources...” with possible answers being “less than \$20,000”, “20,000 to less than \$30,000”, “30,000 to less than \$40,000”, “40,000 to less than \$50,000”, “50,000 to less than \$60,000”, “60,000 to less than \$70,000”, “70,000 to less than \$80,000”, “80,000 to less than \$90,000”, “90,000 to less than \$100,000”, or “more than \$100,000”. Income was recoded to categorize individuals into the following household income ranges: “less than \$20,000”, “\$20,000 – \$39,999”, “40,000 – \$59,999”, “60,000 – \$79,999”, “80,000 – \$99,999”, and “more than \$100,000”.

Education Status

A categorical question was used to determine the level of education completed by the participant. Survey respondents were asked “what is the highest level of schooling you have ever completed” with possible answers being “less than grade 9”, “some high school”, “completed high school”, “some college or specialized training”, “completed college or specialized training”, “some university”, “some post-secondary education”, and “completed post-graduate education”. Education was recoded to the following four categories: “some high school or less”, “completed high school”, “some or completed college”, “some or completed university”.

Employment Status

A categorical question was used to determine the employment status of the participant. Survey respondents were asked “which of the following best describes your current employment status” with possible answers being “part-time”, “full-time”, “seasonal”, “self-employed”, “homemaker”, “any other informal paid work such as babysitting, housekeeping”, “student”, “retired”, “unemployed”, or “other”. Respondents who selected “other” had the opportunity to specify their answer.

Since multiple options were similar to one another and 34 respondents selected “other” and were able to provide qualitative explanations, similar responses were re-coded into the following 5 categories: “full-time/self-employed”, “part-time/seasonal/informal work”, “retired”, “student”,

and “unemployed.” Two additional categories were created to acknowledge themes that emerged from qualitative responses. These include “unable to work due to medical reasons (ODSP)”, and “volunteer”.

Lived Prior to Toronto

A categorical question was used to determine where the participant lived prior to living in Toronto. Survey respondents were asked “where did you live before you moved to Toronto?” with possible answers being “I have lived in Toronto all my life”, “First Nation reserve in Canada”, “Métis settlement in Canada”, “Inuit land claim territory in Canada”, “small town or rural area in Canada”, “Canadian city”, “US”, or “international”.

3.5.2 Health Outcome Measures

Below are the two outcome measures that were used for logistic regression models in the analysis phase of this thesis.

Diabetes

A binary question was asked to determine if participants had diabetes. Survey respondents were asked “do you have diabetes as diagnosed by a health care provider” with possible answers being “yes” or “no”. Self-reported diabetes diagnosis was used as an outcome in one of the logistic regression models.

Unmet Health Need

The binary question, “in the past 12 months, was there a time where you felt you needed health care services but did not receive them” with possible answers being “yes” or “no”. Unmet health need was used as an outcome measure for one of the logistic regression models. In the other logistic regression model, where self-reported diabetes diagnosis is the outcome, unmet health need was used as an explanatory variable in the model.

To describe the types of unmet health needs experienced by participants, individuals who responded “yes” to “in the past 12 months, was there a time where you felt you needed health care services but did not receive them” were asked the following categorical follow-up question

“why was this need unmet” with respondents asked to check all of the following answers that apply. Possible answers ranging from “doctor not available”, “not covered by non-insured health benefits”, “service not available in my area”, or “other”. Respondents who selected “other” had the opportunity to specify their answer. A full list of possible answers for this survey question can be found in Appendix A.

3.5.3 Measures of the Distal Determinants of Health

Below is a list of the distal determinants of health that were considered in the analysis phase of this thesis. As previously mentioned, generational and intergenerational residential school attendance and experiences of racism/discrimination by a health care professional were used as proxy measures for colonialism because they both represent the outcome of colonial policies and legacies and due to the availability of information in the *OHC Toronto* dataset.

Residential School Attendance

A binary question was asked to determine if the participant had attended residential schools. Survey respondents were asked “were you ever a student at a federal residential school, or federal industrial school” with possible responses being “yes” or “no”.

A categorical question was asked to determine if the participant had any relatives that attended residential schools. Survey respondents were asked “were any of the following members of your family ever a student at a federal residential school or a federal industrial school” with respondents asked to check all of the following answers that apply. Possible answers were “your great-grandmother(s), “your great-grandfather(s)”, “your grandmother(s)”, “your grandfather(s)”, “your mother”, “your father”, “your current spouse or partner”, “your brothers or sisters”, your great auntie(s) or uncle(s)”, “your aunts or uncles”, “your cousins”, “other relatives”, or “no”.

Racism/Discrimination

A binary question was asked to determine if participants have ever experienced racism and/or discrimination by a health care professional. Survey respondents were asked “have you ever been treated unfairly (e.g. treated differently, kept waiting) by a health professional (e.g. doctor, nurse, etc.) because you are Aboriginal” with possible answers being “yes” or “no”.

3.6.4 Measures of the Intermediate Determinants of Health

Below is a list of the intermediate determinants of health that will be considered in the analysis phase of this thesis.

Unmet Health Need

Unmet health need was previously presented as a health outcome for one of the logistic regression models. Here it is framed as an explanatory variable for the logistic regression model where self-reported diabetes diagnosis was the outcome. A binary question was asked to determine if participants experienced unmet health needs in the last year. Survey respondents were asked “in the past 12 months, was there a time where you felt you needed health care services but did not receive them” with possible responses being “yes” or “no”.

Cultural Continuity

Four proxy measures for cultural continuity were analyzed separately in the logistic regression analysis to understand the individual effect of each cultural continuity practice on experiences of unmet health needs and self-reported diabetes. The proxy measures for cultural continuity include: participation in ceremony, use of traditional medicines, speaking Indigenous language(s), and eating traditional Indigenous foods.

A binary question was asked to determine if participants actively participate in traditional Indigenous ceremony. Survey respondents were asked “do you participate in traditional Indigenous ceremony” with possible answers being “yes” or “no”.

A binary question was asked to determine if respondents used traditional Indigenous medicines or practices. Survey respondents were asked “do you use traditional Indigenous medicines or practices to maintain your health and wellbeing” with possible answers being “yes” or “no”.

A binary question was asked to determine if participants speak Indigenous language(s). Survey respondents were asked “do you speak an Aboriginal language or languages” with possible answers being “yes” or “no”.

A categorical question was asked to determine if participants have routinely eaten traditional Indigenous foods in the last year. Survey respondents were asked “in the past 12 months, how often have you eaten traditionally hunted/gathered/grown and/or country foods” with possible responses being “often”, “a few times”, or “not at all”. Consumption of traditional food was recoded to have a binary classification. Respondents that selected “often”, or “a few times” were recoded to “yes” and those that selected “not at all” were recoded to “no” to distinguish those that did and did not consume traditional Indigenous foods.

Social Support Network

A categorical question was used to determine the extent of social support for each participant. Survey respondents were asked “about how many close friends and close relatives do you have, that is people you feel at ease with and can talk to about what is on your mind” with possible answers being “0”, “1-2”, “3-5”, “6-10”, or “more than 10”. Social support network was recoded to have a binary classification. Respondents that selected “1-2”, “3-5”, “6-10” or “more than 10” were recoded to “yes” and those that selected “0” were recoded to “no” to distinguish between participants that did have and participants that did not have a social support network. For purposes of this study, this variable was collapsed into a binary variable because it was not relevant to compare the difference in size of personal networks. It is more informative to understand the difference between Indigenous people who have or do not have a personal network (i.e. not isolated vs. isolated) rather than Indigenous people who have larger networks than others.

3.5.5 Measures of the Proximal Determinants of Health

Below is a list of the proximal determinants of health that will be considered in the analysis phase of this thesis.

Income – low income cut-off

Household income was recoded to determine whether participants were above or below Statistics Canada’s before-tax low-income cut-off (LICO) point for Toronto (using population size for large metropolitan area). LICO uses the assumption that an average family spends approximately 43% of their after-tax income on food, shelter, and clothing. The calculated threshold is based on

the higher percentage of income a family needs to dedicate towards food, shelter and clothing (Statistics Canada, 2015).

For purposes of the *OHC Toronto* study, LICO was calculated using reported household income, reported number of people living off of the household income and the population size of Toronto. Participants were recoded to “above LICO” or “below LICO” based on whether they were categorized above or below the calculated threshold.

Employment

Employment status was recoded again to have a binary classification of participants.

Respondents that selected “full-time/self-employed” or “part-time/seasonal/informal work” were recoded to “paid employment” and respondents that selected “retired”, “student”, “unemployed”, “unable to work due to medical reasons (ODSP)”, or “volunteer” were recoded to “no paid employment”.

Education

Education was recoded again to have a binary classification of participants. Respondents that selected “some high school or less” or “completed high school” were recoded to “high school or less” and respondents that selected “some or completed college” or “some or completed university” were recoded to “post-secondary”.

Smoking

A binary question was asked to determine whether participants currently smoke. Survey respondents were asked “at the present time, do you smoke cigarettes” with possible answers being “yes” or “no”.

Substance Use – Alcohol

A binary question was asked to determine whether participants use alcohol. Survey respondents were asked “during the past 30 days, have you had a drink of beer, wine, liquor or any other alcoholic beverage” with possible answers being “yes” or “no”.

3.6.6 Measures of use of conventional medicine and a combination of traditional Indigenous approaches and conventional approaches to medicine

Below is a list of the measures regarding combined use of medicine that were used in the analysis phase of this thesis.

Use of conventional medical services

A categorical question was asked to determine the last time participants sought care from a provider. Participants were asked “when did you last see a doctor or nurse practitioner” with possible answers ranging from “less than 1 year ago”, “5 years or more ago” to “never”. A complete list of possible answers for this survey question can be found in Appendix B.

For purposes of this study, only those that responded to “less than 1 year ago” were used for comparison against use of traditional medicine to align with the assumption that those who use traditional Indigenous medicines to maintain their health and wellbeing have used them in the past year.

Combination of services

Use of conventional medical services and use of traditional Indigenous medicines were combined and recoded to the following four categories to determine use of services: “conventional use only”, “traditional use only”, “combination of services”, and “no use of services”.

This measure was also used to determine and compare the use of services among participants that identified as having a self-reported diabetes diagnosis against participants that identified as not having a diabetes diagnosis.

3.6 Statistical Analysis

An RDS data frame was created using R 3.3.3 software (R Core Team, 2013) and all statistical data analysis was completed using SAS 9.4 software (SAS Institute Inc., Cary, NC, USA) and SAS-callable SUDAAN 11.0 (RTI Institute, 2013). The PROC SURVEYFREQ function was

used to compute population-based prevalence estimates throughout analysis and PROC RLOGIST function was used to produce logistic regression models, including prevalence ratios from average marginal risks.

3.6.1 RDS data frame

An RDS data frame was created using R 3.3.3 software. Three new variables were created that allowed RDS weights to be calculated and clustering to be taken into consideration throughout analysis. First, the variable “recruiter id” was created to distinguish each participant’s recruiter identification. This information is provided through the code on each coupon and allows us to identify the different chains by shared recruiter. Second, the variable “seed” was created to “calculate the identification for each seed at each node of the recruitment tree” (p.17). Lastly, the variable “wave” was created to “calculate the length of the recruitment tree at each node” (p.18) (Handcock, Gile, Fellows, & Neely, 2017).

3.6.2 RDS-II Weights and Clustering

RDS-II weights were calculated in SAS 9.4 software (SAS Institute Inc., Cary, NC, USA) to produce weighted frequencies and their associated 95% confidence intervals. RDS-II weighting takes the probability of recruitment among participants into consideration and adjusts for the unequal probability of being recruited based on participants varying network sizes (Salganik & Heckathorn, 2004; Volz & Heckathorn, 2008). RDS-II weights were calculated using the inverse of a participant’s network size, specifically using the following formula:

$$\text{RDS-II weights} = 1/\text{degree}$$

where degree refers to personal network size (Salganik & Heckathorn, 2004). These weights were calculated prior to data analysis and were included beside the WEIGHTS statement to account for sampling bias that arises when there is overrepresentation or underrepresentation of participants with larger or smaller network sizes, respectively. For example, those less likely to be recruited (based on their smaller self-reported network size) will be given more weight than those who are more likely to be recruited (Johnston & Sabin, 2010; Salganik & Heckathorn, 2004; Volz & Heckathorn, 2008).

Since recruiters tend to recruit individuals with similar characteristics and behaviours as their own (Ramirez-Valles et al., 2005), having a limit on the number of coupons each participant receives reduces over-recruitment bias and allows for the growth of larger chains and more waves of recruitment (Magnani et al., 2005). Therefore, the characteristics and behaviours of the final sample composition will not be able to be traced back to the initial seeds, thereby making the recruitment chains independent after equilibrium is reached (Ramirez-Valles et al., 2005). Adjusting for clustering by shared recruiter will account for non-independence within recruitment chains (Bauer, Scheim, Pyne, Travers, & Hammond, 2015; Scheim, Bauer, & Shokoohi, 2016). Clustering arises when multiple recruits have a shared recruiter which artificially decreases the variance of the estimates. To take clustering into account, recruiter ID was included beside the CLUSTER statement throughout analysis as a means of adjusting for clustering by shared recruiter. Many times, seeds are disregarded in RDS data and not accounted for in clustering. To avoid this, each seed was given their own unique recruiter ID. Therefore, each seed was adjusted for (as their own cluster) throughout analysis.

RDS-II weights and adjustment for clustering by shared recruiter were completed throughout analysis to reduce bias associated with RDS methods and to produce estimates that can be generalizable to Toronto's networked Indigenous adult population.

3.6.3 Analysis of Demographic Measures (Objective 1)

The PROC SURVEYFREQ procedure produces population estimates and frequencies from survey data (SAS Institute Inc., 2010). The PROC SURVEYFREQ function was used to compute contingency table frequencies with 95% confidence intervals of the demographics of networked Indigenous people living in Toronto. Demographic factors in the descriptive analysis include: Aboriginal status, age, gender, household income, education, employment status, and location lived prior to Toronto.

3.6.4 Prevalence of Diabetes (Objective 2)

The PROC SURVEYFREQ function was used to compute a simple 2-by-2 table to estimate the frequency and 95% confidence intervals of the prevalence of diabetes. This frequency was cross-

tabulated to determine the prevalence of self-reported diabetes diagnosis among First Nations, Métis and Inuit participant sub-groups.

3.6.5 Frequencies of Experienced Unmet Health Needs (Objective 3)

Similarly, the PROC SURVEYFREQ function was used to compute contingency table frequencies with 95% confidence intervals to provide a proportion of unmet health needs experienced by Indigenous people in Toronto. Unmet health needs include: health care provider not available, lack of trust, waiting list, transportation barriers, cultural barriers, coverage, could not afford direct care, inadequate care, missed appointment/did not seek care, service was not available in area, could not get time off work, childcare, was excluded because I was under the influence of alcohol or other substances, experiences with racism and/or discrimination, issues with identification/health card, and paperwork/lack of information.

3.6.6 Sociodemographic Predictors for Unmet Health Needs and Diabetes Diagnosis (Objective 4 and 5)

The PROC RLOGIST function in SAS-callable SUDAAN (RTI Institute, 2013) statistical software is used to perform logistic regression on survey data. Logistic regression uses odds ratios to describe the relationship between outcomes and explanatory variables. The sample design is incorporated into analysis and maximum likelihood methods are used to fit linear logistic regression models. There has been a recent shift away from relying on odds ratios to understand associations between an outcome variable and binary explanatory variables in public health. More recently, risk ratios and risk differences have been used instead of odds ratios to estimate these relationships in population-based studies. While both odds ratios and risk ratios measure the association between a binary outcome and an explanatory variable, risk ratios are more intuitive and easier to interpret for population-based studies (Beiler, Brown, Williams, & Brogan, 2009), such as *OHC Toronto*. Odds ratios are commonly misinterpreted; therefore, risk ratios were calculated instead of odds ratios in the logistic regression models because they were more relevant for the outcomes of interest. Misinterpretation of results can become dangerous for Indigenous health research because Indigenous peoples have already experienced a history of mistrust with researchers (Castleden et al., 2015; Cochran et al, 2008; Smith, 2013).

To present the associations between the determinants of health and unmet needs and the determinants of health and diabetes diagnosis, risk (prevalence) ratios were calculated using average marginal risks in SAS-callable SUDAAN software. PROC RLOGIST, the survey logistic regression function in SAS-callable SUDAAN, in addition to ADJRR functions were used to produce model-adjusted risks (RTI Institute, 2013) among each variable included in the logistic regression and risk ratios between the outcome and binary explanatory variables of choice. Average marginal predictions are used to calculate these estimates and compare the predicted risk of the outcome between two explanatory variable subgroups (for example, those who speak an Indigenous language and those who do not speak an Indigenous language), while controlling for other factors (Beiler et al., 2009).

Model-adjusted risks were calculated using the following equation:

$$M_r = \frac{\sum_{i=1}^n w \{\exp(\alpha_r + \beta x_i) / [1 + \exp(\alpha_r + \beta x_i)]\}}{\sum_{i=1}^n w}$$

where M_r is the average marginal prediction for the probability that the outcome is occurring (outcome=1; for example, for outcome unmet health need, outcome=1 refers to experiencing an unmet health need). The α coefficient and the β coefficient are the products of the weighted maximum likelihood estimates of the logistic regression analysis using reference categories. Weighted average of complex survey design is accounted for to calculate marginal risks and is denoted by w and x_i , representing the value of the variable under investigation, while controlling for other covariates (Beiler et al., 2009).

Model-adjusted risk ratios are derived from the model-adjusted risks and were calculated using the following equation:

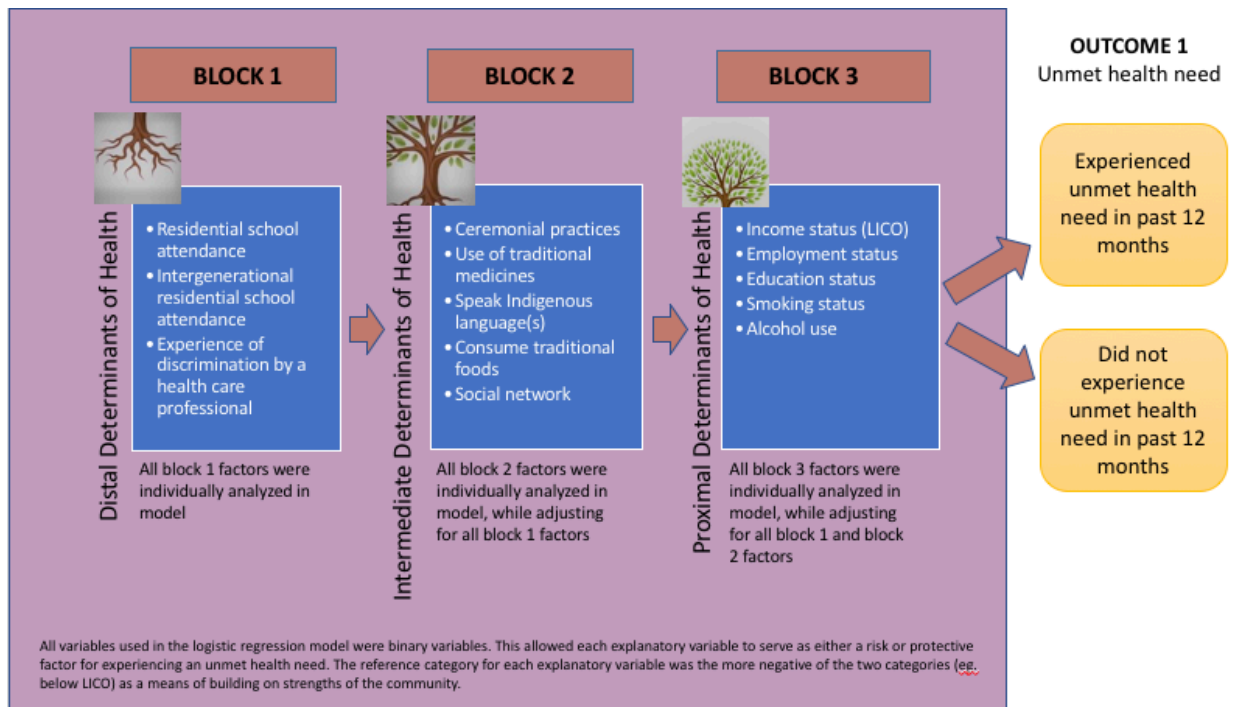
$$RR_{s/t} = \frac{M_s}{M_t}$$

where s and t refer to the 2 possible events of the binary explanatory variables (Beiler et al., 2009).

Two separate analyses were conducted with the two different outcome variables. For both analyses, the distal determinants of health, intermediate determinants of health, and proximal determinants of health were treated as the explanatory variables and analyzed individually. Explanatory variables were blocked together throughout analysis based on whether the explanatory variable of interest was in the distal, intermediate, or proximal category as a means of controlling for confounding variables. Specifically, the distal determinants of health were analyzed individually, without controlling for any other determinants of health. The intermediate determinants of health were also analyzed individually, while controlling for all (3) of the distal determinants of health. The proximal determinants of health were also analyzed individually, while controlling for all of the distal determinants of health and the intermediate determinants of health. For the outcome unmet health needs, there were 8 intermediate determinants of health, whereas for outcome self-reported diabetes diagnosis, there were 9 intermediate determinants of health that were controlled for. The difference is because unmet health need was treated as an outcome and an intermediate determinant of health in this study. Therefore, it would be redundant to control for unmet health need as an intermediate determinant of health when the outcome is the same variable.

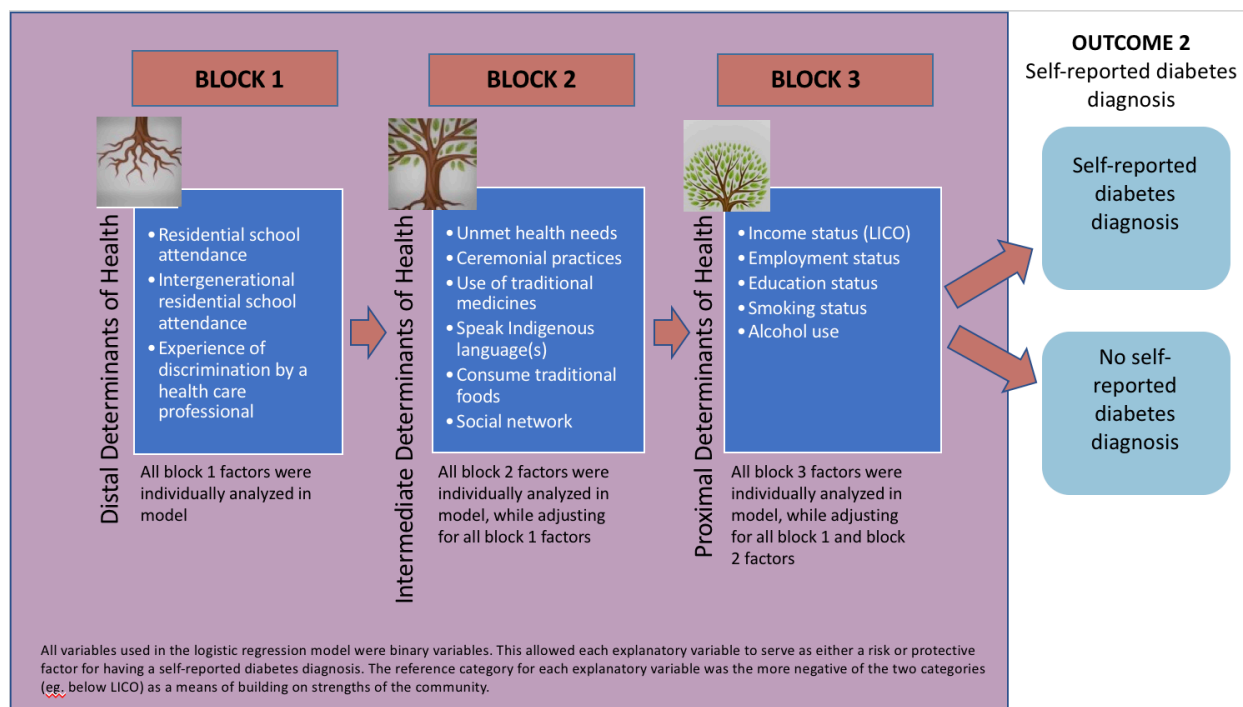
For the first analysis, the outcome was experiencing an unmet health need in the past 12 months. Refer to the conceptual model of the distal, intermediate, and proximal determinants of health predictors for unmet health needs among Indigenous adults in Toronto in Figure 3.

Figure 3: Conceptual model of the distal, intermediate, and proximal determinants of health predictors for unmet health needs among Indigenous adults in Toronto



For the second analysis, the outcome was having a self-reported diabetes diagnosis. Refer to the conceptual model of the distal, intermediate, and proximal determinants of health predictors for self-reported diabetes diagnosis among Indigenous adults in Toronto in Figure 4.

Figure 4: Conceptual model of the distal, intermediate, and proximal determinants of health predictors for self-reported diabetes diagnosis among Indigenous adults in Toronto



3.6.7 Diabetes and Combined use of traditional Indigenous and Conventional Approaches to Medicine (Objective 6)

The PROC SURVEYFREQ function in SAS statistical software was used to compute contingency table frequencies with 95% confidence intervals to provide an estimate of the proportion of participants that used conventional medicine only, traditional medicine only, combined services, or neither services. This frequency was cross-tabulated to determine the use of conventional medicine only, traditional medicine only, and a combination of services among diabetes-positive and diabetes-negative individuals.

In conclusion, Indigenous methodologies and OCAP® principles have guided this thesis project throughout the entire duration of this academic journey. RDS methods were employed to sample 918 adult participants in Toronto, Ontario using 20 initial seeds. Using Charlotte Reading's (2015) Indigenous determinants of health framework, a statistical analysis plan was formulated and presented using two conceptual models. Biases associated with RDS methodologies were adjusted for throughout the statistical analysis and the following chapter will present the results of the findings from the statistical analysis.

Chapter 4

4. Results

A total of 918 people completed the adult *OHC Toronto* survey. One person was removed from the data analysis because they did not identify as Indigenous. Therefore, results will only reflect the 917 Indigenous participants.

This chapter will explore the demographic statistics, self-reported prevalence of diabetes, and proportions of the types of unmet health needs experienced among urban Indigenous adults in the *OHC Toronto* study. Afterwards, proportions of the determinants of Indigenous peoples' health will be presented and the relationship between the determinants of health and self-reported diabetes and the determinants of health and experiences of unmet health needs will be presented. Lastly, the relationship between diabetes-positive individuals and use of conventional medicine, traditional medicine, and combined use of services are explored.

4.1 Demographic Statistics

Demographic factors and corresponding proportional statistics are explained below and presented in Table 1. These include: Aboriginal status, age, gender, household income, education, employment status, and where participants lived prior to Toronto.

First Nations represented 85.91% of the participants. Métis and Inuit individuals represented 13.68% and 0.37%, respectively. Few respondents reported multiple Indigenous identities and account for approximately 0.45% of participants. Age of participants varied between 15 years and older than 65 years, in which, 24.16% were between ages 45-54 and 21.23% were between ages 15-24. There was almost equal participation between males and females, each representing 49.95% and 48.59% of the population, respectively. Household income ranged between less than \$20,000 to more than \$100,000, in which, 67.33% of participants' income was less than \$20,000 and 22.09% of participants' income ranged between \$20,000 to \$39,999. Education status ranged between some high school or less to some or completed university, in which, 49.67% of participants had some high school education or less and 24.68% of participants had some or completed college education. The majority of participants self-reported as being unemployed.

Specifically, 61.52% of participants identified as being unemployed, whereas, 9.38% of participants held full-time positions or were self-employed and 9.34% of participants held part-time positions or had seasonal/informal work. Prior to living in Toronto, 41.62%, of participants lived in another Canadian city, while 22.14% of participants lived on a First Nations reserve in Canada.

Table 1: Weighted demographics of Indigenous adults in *OHC Toronto* study

Indigenous Adults		n	%	95% C.I.
Aboriginal Status	First Nations	805	85.91	80.30, 91.53
	Métis	89	13.46	7.87, 19.06
	Inuit	11	0.37	0.11, 0.64
	Multiple Indigenous identities	8	0.45	0.00, 0.96
Age	15-24	106	21.23	13.34, 29.11
	25-34	204	19.48	14.42, 24.54
	35-44	186	21.43	14.51, 28.34
	45-54	235	24.16	15.82, 32.49
	55-64	139	10.39	6.92, 13.85
	65+	47	3.32	1.75, 4.89
Gender	Male	423	49.95	41.21, 58.70
	Female	477	48.59	39.91, 57.28
	Other	5	0.47	0.00, 1.06
	Trans	12	0.98	0.04, 1.93
Household Income	Less than \$20,000	569	67.33	59.41, 75.26
	\$20,000 – \$39,999	190	22.09	14.34, 29.84
	\$40,000 – \$59,000	65	4.56	2.43, 6.69
	\$60,000 – \$79,999	22	1.14	0.44, 1.85
	\$80,000 – \$99,000	15	0.99	0.20, 1.77
	More than \$100,000	42	3.88	1.96, 5.80
Education	Some high school or less	392	49.67	42.34, 56.99
	Completed high school	171	17.85	11.94, 23.76
	Some or completed college	226	24.68	18.16, 31.21
	Some or completed university	126	7.80	5.21, 10.39

Employment Status	Full-time/Self-Employed	171	9.38	6.51, 12.25
	Part-time/Seasonal/Informal Work	112	9.34	6.34, 12.33
	Retired	53	3.22	1.73, 4.70
	Student	83	15.06	8.21, 21.90
	Unable to work due to medical reasons (ODSP)	17	1.25	0.00, 2.83
	Unemployed	477	61.52	53.72, 69.32
	Volunteer	4	0.24	0.00, 0.53
Lived Prior to Toronto	Canadian city	342	41.62	34.25, 49.00
	First Nations reserve in Canada	176	22.14	15.46, 28.81
	Toronto	202	18.23	13.19, 23.27
	International	4	0.52	0.00, 1.17
	Inuit land claim territory	3	0.09	0.00, 0.21
	Small town or rural area	152	16.23	10.30, 22.16
	US	22	1.17	0.22, 2.12

4.2 Prevalence of Diabetes

The prevalence of self-reported diabetes among all participants was 14.85%. This was further broken down to identify prevalence among First Nations, Métis and Inuit participants; the prevalence of self-reported diabetes among these subgroups is 12.42%, 2.43%, and 0.01%, respectively. Corresponding estimates and confidence intervals are presented in Table 2.

Table 2: Weighted prevalence of self-reported diabetes among First Nations, Métis and Inuit adults in *OHC Toronto* study

Prevalence of Diabetes		Number with diabetes n	Prevalence of Self-reported Diabetes %	95% C.I.
Aboriginal Status	First Nations	148	12.42	7.76, 17.07
	Métis	8	2.43	0.00, 5.02
	Inuit	1	0.01	0.00, 0.02

Total			14.85	9.56, 20.14
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4.3 Unmet Health Needs

Among participants, 72.32% reported that they did not have an unmet health need in the past 12 months, whereas 27.68% reported having unmet needs. Those who reported having an unmet need were given the opportunity to select all of the unmet needs they experienced from a list of 23 options. Therefore, there were a total of 468 observed unmet needs identified among the 224 participants who identified as having any unmet health need.

Among those with unmet health needs, 23.50% of respondents reported that a doctor was not available, 16.81% reported they had a lack of trust in the health care provider, 15.48% identified that they felt the health care they were provided was inadequate, and 14.22% reported that they could not afford transportation. Additionally, 43.14% of participants selected the option ‘other’ unmet need. Table 3 presents a comprehensive list of all 23 options for unmet health needs and their corresponding frequency estimates and confidence intervals.

Participants who selected the option ‘other’ were given the opportunity to verbally express the unmet need they experienced. Participants expressed a variety of unmet needs. Some examples of these qualitative responses include: not enough family physicians, waiting lists, communication barriers, family responsibilities, not having identification or valid health card, information and health literacy barriers, and experiences of attitudinal and systemic discrimination.

Table 3: Weighted frequency estimates of unmet health needs among Indigenous adults in OHC Toronto study

Unmet Health Needs (n=224)	n	%	95% C.I.
Doctor not available	43	23.50	8.07, 38.93
Nurse not available	4	0.50	0.00, 1.34
Lack of trust in health care provider	42	16.81	1.99, 31.63
Waiting list too long	37	13.91	5.14, 21.48

Unable to arrange transport	22	12.73	0.00, 27.69
Could not afford transport	34	14.22	0.00, 29.09
Difficulty accessing traditional healer and/or medicines	8	2.25	0.12, 4.37
Do not have health benefits from my work	8	4.32	0.00, 9.98
Do not have NIHB	11	9.90	0.00, 24.92
Not covered by NIHB	11	2.46	0.22, 4.69
Prior approval for services under NIHB was denied	5	0.13	0.00, 0.28
Could not afford direct cost of service/care	17	3.49	0.72, 6.26
Felt health care provided was inadequate	41	15.48	5.53, 25.42
Felt service was not culturally appropriate	15	10.22	0.00, 25.21
Chose not to see health professional	21	12.67	0.00, 27.58
Service was not available in my area	11	2.85	0.19, 5.52
Could not get time off work	8	1.45	0.00, 3.19
Did not have safe or reliable childcare option	3	0.23	0.00, 0.58
Could not afford childcare	3	0.23	0.00, 0.58
Was referred to a specialist but had	11	1.02	0.14, 1.90

difficulty getting an appointment			
Was referred to a specialist and got an appointment but missed it	10	1.80	0.33, 3.26
Was excluded because I was under the influence of alcohol or other substances	8	1.95	0.11, 3.79
Other	95	43.14	26.18, 60.11

4.4 Weighted frequency estimates of sociodemographic predictors

The distal determinants of health that will be examined are residential school survivor experience, intergenerational residential school survivor, and experiences of discrimination by a health care professional. The majority, 89.22%, of participants did not attend residential schools. However, intergenerational residential school survivors accounted for 68.16% of participants. Among participants, 72.10% have never experienced racism and/or discrimination by a health care professional. A breakdown of the variables representing the distal determinants of health and their corresponding estimates and confidence intervals can be found in Table 4, along with the estimates of the intermediate and proximal determinants of health.

The intermediate determinants of health that will be examined are unmet health needs, engaging in ceremonial practices, use of traditional Indigenous medicines, speaking Indigenous languages, consumption of traditional Indigenous foods, and social network. The majority of respondents, 72.32%, did not have an unmet health care need in the past 12 months. In regard to cultural continuity, 65.22% of participants did engage in ceremonial practices; 49.37% of participants used traditional Indigenous medicines; 41.53% of participants can speak an Indigenous language; and 50.20% of participants eat traditional Indigenous foods. The majority, 90.85%, of participants had a social network.

The proximal determinants of health that were examined are household income and whether participants were above or below the low-income cut-off point in Toronto, employment status, education, smoking, and alcohol use. Among participants, 13.04% were above the low-income

cut-off; 18.72% had some form of paid employment; and 32.48% of participants had some post-secondary education. Among participants, 37.10% identified as not being current smokers and 32.49% reported not using alcohol in the past 30 days.

Table 4: Weighted distal, intermediate, and proximal determinants of health among Indigenous adults in *OHC Toronto* study

Distal Determinants of Health	n	%	95% C.I.
Residential School Survivor	908		
Yes	77	10.78	4.88, 16.67
No	831	89.22	83.33, 95.12
Intergenerational Residential School Survivor	822		
Yes	598	68.16	59.86, 76.46
No	224	31.84	23.54, 40.14
Experiences of Racism/ Discrimination by a Health Care Worker	899		
Yes	278	27.90	20.84, 34.97
No	621	72.10	65.03, 79.16
Intermediate Determinants of Health			
Health Care Access – unmet needs	915		
Yes	224	27.68	20.56, 34.81
No	691	72.32	65.19, 79.44
Cultural Continuity – Ceremonial Practices	914		
Yes	695	65.22	57.15, 73.28
No	219	34.78	26.72, 42.85
Cultural Continuity – use of traditional medicines	913		
Yes	566	49.37	42.02, 56.72
No	347	50.63	43.28, 57.98
Cultural Continuity – speak Indigenous language(s)	917		
Yes	440	41.53	32.75, 50.31
No	477	58.47	49.69, 67.25
Cultural continuity – eat traditional foods	913		
Yes	537	50.20	42.83, 57.58

No	376	49.80	42.42, 57.17
Social Network	915		
Yes	823	90.65	87.45, 93.85
No	92	9.35	6.15, 12.55
Proximal Determinants of Health			
Income Status	903		
Below Low-Income Cut-off	715	86.96	83.41, 90.50
Above Low-Income Cut-off	188	13.04	9.50, 16.59
Employment Status	917		
No paid employment	634	81.28	76.94, 85.62
Paid employment	283	18.72	14.38, 23.06
Education Status	915		
High school or less	563	67.52	60.86, 74.17
Post-secondary	352	32.48	25.83, 39.14
Smoking Status	911		
Yes	617	62.90	55.61, 70.18
No	294	37.10	29.82, 44.39
Alcohol Use	912		
Yes	608	67.51	60.60, 74.42
No	304	32.49	25.58, 39.40

4.4.1 Determinants of Indigenous peoples' health as predictors for diabetes diagnosis

Without controlling for any covariates, networked Indigenous adults in Toronto who did not attend residential schools were 74% less likely to hold a self-reported diabetes diagnosis (RR=0.26, 95% CI: 0.11, 0.61). No other variables were associated with diabetes. A complete breakdown of weighted model-adjusted risks, model-adjusted risk ratios and corresponding 95% confidence intervals can be found in Table 6.

Table 5: Weighted model-adjusted risk for the distal, intermediate, and proximal determinants of health on self-reported diabetes diagnosis among Indigenous adults in OHC Toronto study

Distal Determinants of Health	n	AMR	RR	95% C.I.
Residential School Survivor	905			
Yes		0.44	1.00	
No		0.11	0.26	0.11, 0.61*

Intergenerational Residential School Survivor	820			
Yes		0.18	1.00	
No		0.13	0.75	0.34, 1.64
Experiences of Racism/ Discrimination by a Health Care Worker	896			
Yes		0.18	1.00	
No		0.14	0.77	0.29, 2.03
Intermediate Determinants of Health				
Health Care Access – unmet needs	807			
Yes		0.20	1.00	
No		0.15	0.77	0.35, 1.66
Cultural Continuity – Ceremonial Practices	806			
Yes		0.13	0.60	0.35, 1.03
No		0.22	1.00	
Cultural Continuity – use of traditional medicines	806			
Yes		0.13	0.68	0.33, 1.39
No		0.19	1.00	
Cultural Continuity – speak Indigenous language(s)	807			
Yes		0.17	1.09	0.63, 1.89
No		0.16	1.00	
Cultural continuity – eat traditional foods	805			
Yes		0.17	1.17	0.63, 2.20
No		0.15	1.00	
Social Network	807			
Yes		0.16	0.97	0.41, 2.31
No		0.17	1.00	
Proximal Determinants of Health				
Income Status	797			
Below Low Income Cut-off		0.17	1.00	
Above Low Income Cut-off		0.12	0.73	0.32, 1.65
Employment Status	804			
No paid employment		0.17	1.00	
Paid employment		0.09	0.53	0.27, 1.03
Education Status	803			
High school or less		0.17	1.00	

Post-secondary		0.13	0.76	0.41, 1.39
Smoking Status	801			
Yes		0.17	1.00	
No		0.15	0.91	0.46, 1.82
Alcohol Use	802			
Yes		0.12	1.00	
No		0.24	2.07	0.89, 4.85

Analysis conducted on each of the distal determinants of health did not adjust for other co-variates. Analysis conducted on each of the intermediate determinants of health adjusted for residential school attendance, intergenerational residential school attendance, and experience of discrimination by a health care provider. Analysis conducted on each of the proximal determinant of health adjusted for residential school attendance, intergenerational residential school attendance, experience of discrimination by a health care provider, unmet health need, cultural continuity, and social network.

4.4.2 Determinants of Indigenous peoples' health as predictors for unmet health needs

Using risk ratios, statistical non-significance is shown when the confidence interval includes the value of 1, because a risk ratio that equals 1 shows no effect; therefore, risk ratios that did not include 1 are considered statistically significant ($p < 0.05$) and are marked with an asterisk (*).

Without controlling for any covariates, networked Indigenous adults in Toronto who did not experience racism by a health care professional were 54% less likely to experience an unmet health need (RR=0.46, 95% CI: 0.27, 0.79). When controlling for residential school attendance, intergenerational residential school attendance, and experiences of discrimination by a health care professional, networked Indigenous adults in Toronto who did use traditional Indigenous medicines were 53% less likely to experience an unmet health need (RR= 0.47, 95% CI: 0.28, 0.80). However, when controlling for the same covariates, networked Indigenous adults in Toronto who did eat traditional Indigenous foods were 127% more likely to experience an unmet health need (RR=2.27, 95% CI: 1.34, 3.83). When controlling for residential school attendance, intergenerational residential school attendance, experiences of discrimination by a health care professional, all aspects of cultural continuity, and social network, networked Indigenous adults in Toronto who held post-secondary education or higher were 26% more likely to experience an unmet health need (RR=1.26, 95% CI: 1.26, 3.06). A complete breakdown of weighted model-adjusted risks, model-adjusted risk ratios and corresponding 95% confidence intervals can be found in Table 5.

Table 6: Weighted model-adjusted risk for the distal, intermediate, and proximal determinants of health on experiences of unmet health needs among Indigenous adults in OHC Toronto study

Distal Determinants of Health	n	Predicted Marginal Risk	RR	95% C.I.
Residential School Survivor	908			
Yes		0.33	1.00	
No		0.27	0.81	0.28, 2.32
Intergenerational Residential School Survivor	822			
Yes		0.30	1.00	
No		0.19	0.63	0.27, 1.47
Experiences of Racism/ Discrimination by a Health Care Worker	899			
Yes		0.21	1.00	
No		0.45	0.46	0.27, 0.79 *
Intermediate Determinants of Health				
Cultural Continuity – Ceremonial Practices	808			
Yes		0.25	0.84	0.48, 1.48
No		0.30	1.00	
Cultural Continuity – use of traditional medicines	808			
Yes		0.18	0.47	0.28, 0.80*
No		0.37	1.00	
Cultural Continuity – speak Indigenous language(s)	809			
Yes		0.29	1.25	0.72, 2.15
No		0.24	1.00	
Cultural continuity – eat traditional foods	807			
Yes		0.35	2.27	1.34, 3.83*
No		0.15	1.00	
Social Network	809			
Yes		0.27	1.29	0.70, 2.38
No		0.27	1.00	
Proximal Determinants of Health				
Income Status	799			

Below Low Income Cut-off		0.28	1.00	
Above Low Income Cut-off		0.19	0.70	0.40, 1.23
Employment Status	806			
No paid employment		0.27	1.00	
Paid employment		0.24	0.88	0.55, 1.41
Education Status	805			
High school or less		0.20	1.00	
Post-secondary		0.40	1.26	1.26, 3.06*
Smoking Status	803			
Yes		0.27	1.00	
No		0.25	0.92	0.58, 1.46
Alcohol Use	804			
Yes		0.28	1.00	
No		0.22	0.79	0.47, 1.32

Analysis conducted on each of the distal determinants of health did not adjust for other co-variates. Analysis conducted on each of the intermediate determinants of health adjusted for residential school attendance, intergenerational residential school attendance, and experience of discrimination by a health care provider. Analysis conducted on each of the proximal determinant of health adjusted for residential school attendance, intergenerational residential school attendance, experience of discrimination by a health care provider, cultural continuity, and social network.

4.5 Diabetes and Combined use of traditional Indigenous and Conventional Approaches to Medicine

The largest group, 41.62%, of participants reported using a combination of conventional services and traditional Indigenous medicines, while, 39.07% of participants reported using only conventional services, 11.56% of participants reported using neither conventional services or traditional Indigenous medicines, and 7.75% reported using only traditional Indigenous medicines. See Table 5 for corresponding estimates and confidence intervals.

Table 7: Self-reported use of conventional medicine, traditional medicine, and a combination of services in *OHC Toronto* study

	Number reporting use (n=913)	Prevalence of use %	95% C.I.
Conventional Use Only	283	39.07	31.73, 46.38
Traditional Use Only	69	7.75	4.21, 11.28
Combination of Services	497	41.62	34.50, 48.74

No Use of Services	64	11.56	5.13, 17.98
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Use of conventional medicine, traditional medicine, and a combination of services was further broken down among individuals with and without a self-reported diabetes diagnosis. Among participants with a diabetes diagnosis, 56.08% reported using conventional medicines only and 40.10% reported using a combination of conventional services and traditional Indigenous medicines.

Among participants without a diabetes diagnosis, 43.04% reported using a combination of conventional services and traditional Indigenous medicines and 34.45% reported using conventional medicines only. A breakdown of services used and corresponding estimates and confidence intervals among participants with and without a self-reported diabetes diagnosis can be found in Table 8.

Table 8: Relationship between diabetes-positive individuals and use of conventional medicine, traditional medicine, and a combination of services in *OHC Toronto* study

	Diabetes-positive			Diabetes-negative		
	n (n=156)	%	95% C.I.	n (n=754)	%	95% C.I.
Conventional	44	56.08	36.13, 76.02	237	34.45	26.77, 42.14
Traditional	2	0.48	0.00, 1.21	67	9.22	5.05, 13.38
Combination	105	40.10	21.27, 58.93	391	43.04	34.66, 51.42
No Services	5	3.34	0.00, 8.04	59	13.29	5.82, 20.78

In conclusion, the statistics presented in this chapter identify high rates of disadvantage across the sample across the Indigenous determinants of health and examined health outcomes. The implications of these findings will be discussed in the following chapter, with a specific focus on exploring the urban Indigenous experience identified in *OHC Toronto*.

Chapter 5

5. Discussion

This chapter will discuss the implications of the findings of the statistical data analysis. First, the demographics and diabetes prevalence will be discussed and comparative national health assessment data on Indigenous peoples will be challenged. Second, diabetes, unmet health needs, and corresponding distal, intermediate, and proximal determinants of health will be examined. Lastly, the use of conventional and traditional Indigenous medicines among Indigenous people with a diabetes diagnosis will be considered and recommendations for effective urban Indigenous diabetes programming will be shared.

5.1 Demographics of Indigenous adults in Toronto, Ontario

The findings from this study showed high rates of disadvantage across the *OHC Toronto* sample. Among the urban Indigenous population in Toronto, there were many reports of low household income, in which the majority were below the LICO. There were also high reports of low educational attainment and unemployment. These findings are similar to the results of the 2006 Census and 2011 NHS. As national statistics suggest, Indigenous people living in Toronto are more disadvantaged than their non-Indigenous counterparts. Reports suggest that urban Indigenous people have lower household incomes and are often more likely to be below the LICO. In addition, urban Indigenous people are less likely to complete post-secondary education and have higher rates of unemployment than non-Indigenous people in Toronto (Statistics Canada, 2010).

Statistics Canada suggests that there were approximately 23,065 Indigenous people living in Toronto (Statistics Canada, 2017e) in 2016, approximately 19,265 Indigenous people living in Toronto (Statistics Canada, 2011) in 2011, and approximately 26,575 Indigenous people living in Toronto in 2006 (Statistics Canada, 2010), however *OHC Toronto* estimated that there may be 2 to 4 times more Indigenous people actually living in Toronto. This estimate was generated by the high reports of Indigenous participants who reported not completing the 2011 Census in the *OHC Toronto* study (Rotondi et al., 2017). Given the inaccurate estimate of the Indigenous population in Toronto using national statistics and the corresponding demographic report on

Indigenous people in Toronto, there is really no true understanding of what the *actual* demographics of urban Indigenous adults in Toronto were prior to the *OHC Toronto* study. However, there were many similarities between national reports and the *OHC Toronto* study findings. As suggested above, both data sources show disadvantage in urban Indigenous populations; however, the depth of inequities may be masked in national data sources.

National statistics, such as the Census and the NHS, present social inequities between Indigenous and non-Indigenous peoples in Canada, however these national statistics are under-representative of the true Indigenous population (O'Neil et al., 1998; Smylie & Anderson, 2006). At a national-level, these estimates are under-representative of the Indigenous population because they do not sample on-reserve Indigenous populations and only sample those that have stable housing. At a regional-level and in addition to the aforementioned issues with the Census, such national data sources may hold urban Indigenous sampling bias. It is hypothesized that urban Indigenous people who have higher household income, are more stably housed, and have higher education are more likely to participate in the Census. Thereby, the Census would have a higher sample of wealthier, housed, and educated Indigenous people, therefore masking the depth of social inequities that exist between the urban Indigenous and non-Indigenous population in Canada.

Census data and other national statistics do prove that Indigenous people experience greater inequities when compared to non-Indigenous people; however, these statistics fail to capture the depth of inequities endured. This has led some to believe that urban Indigenous people tend to have improved social and health status in comparison to Indigenous peoples living in rural or remote settings. Given the high rates of disadvantage discovered across the urban Indigenous adult sample in *OHC Toronto*, it can be concluded that this is a myth, because the findings suggest that urban Indigenous peoples are indeed disadvantaged. While there is no direct comparison of accurate data that truly represents the social and health status of on- and off-reserve Indigenous peoples, it can be concluded that both on- and off-reserve Indigenous populations experience health inequities and social disadvantage when compared to the non-Indigenous population in Canada.

Since the Canadian government relies on Census data to fund social and health programs across the nation (Walter & Andersen, 2013) and these national statistics are under-representative of the *actual* Indigenous population (Chandler & Dunlop, 2015; Rotondi et al., 2017), it is assumed that social and health programs for Indigenous people may be underfunded. Given that Census data does not assess health or social wellbeing of Indigenous peoples living on-reserve and offers a significant under-representation of urban Indigenous peoples, the Canadian government needs to consider data sources that are Indigenous-led and governed because the current funding system for Indigenous health is faulty. When available, the Canadian government and provincial governments should refer to regional-level data when funding Indigenous-specific services to ensure that adequate resources are being allocated to meet the needs of urban Indigenous peoples because they are commonly left out of the funding equation at different governing levels. For example, in Ontario, Chiefs of Ontario (COO) are the regional representatives for First Nations. COO advocates for Provincial Territorial Organizations (PTOs), who are also mandated to work with First Nations communities (i.e. mostly on-reserve). A funding model that is more inclusive of First Nations, Inuit, and Métis at all governing levels is needed to ensure the health and wellbeing of urban First Nations, Inuit, and Métis are a priority as well. This proposed model is not to counter the existing funding model for health services on-reserve; rather, it is an addition to be more inclusive of Indigenous populations residing in urban settings. It is imperative to ensure both urban and on-reserve Indigenous communities have access to the necessary health and social services because many Indigenous people have strong connections to both reserve and urban settings. Therefore, this new model should increase to be inclusive of the needed Indigenous health services in urban settings; however, should be in coordination with the highly needed improved health services on-reserve. Additionally, this funding model should reflect the principles of self-determination, where urban Indigenous communities or organizations would have governance over the funds and urban Indigenous health services. This same principle should also apply for funds on-reserve.

The TRC (2015) recommends that the federal government funds more Indigenous health research with the goal of closing the existing health equity gap between Indigenous and non-Indigenous peoples in Canada. To accomplish this, having accurate and meaningful data on Indigenous health in Canada is essential. Furthermore, this information needs to be disaggregated

by community, nation, culture, and geographic location to fully understand the needs of the many different Indigenous peoples in Canada. This information should further be divided to understand the specific needs of Indigenous peoples living in both urban and on-reserve settings. Given the high proportion of Indigenous people that now reside in urban settings, it is particularly important to understand their specific needs and the gaps in care experienced by urban Indigenous peoples living in different urban centres.

In order to get meaningful and accurate health assessment data on urban Indigenous people, more studies like *OHC* need to take place. The only study that samples the entire population in Canada is the Census, however, there are many shortcomings in relation to health estimates regarding urban Indigenous people in the Census. The *OHC Toronto* study shows that the Census significantly undercounts urban Indigenous people in their estimates, as many Indigenous peoples reported not participating in the national Census (Rotondi et al., 2017). Due to the history of mistrust in Indigenous communities with western research methodologies (Castleden et al., 2015; Cochran et al., 2008; Smith, 2013), Indigenous people may be more trusting and willing to participate in Indigenous-led and governed studies, such as *OHC*. The low rate of missing data in *OHC Toronto* is evidence that there was high trust across the participating sample. While *OHC* does not sample all Indigenous people in a given city, it does offer a more representative indication of health status than national surveys because of the RDS techniques used and the large sample size captured in the study, thereby providing accurate health estimates among urban Indigenous peoples in Toronto. Furthermore, *OHC* takes place in different urban centres and provides respondents with the opportunity to share their specific nation(s) and/or band affiliation; therefore, estimates among different nations can be produced and generalized to the networked Indigenous population in specific geographic locations (i.e. urban centres). Results may only be generalized to the networked Indigenous adult population in the urban centre under study, however, since data is able to be disaggregated by nation and/or community the data is more useful in understanding trends among these subgroups in urban centres.

5.2 Diabetes

National statistics suggest that Indigenous peoples have a higher prevalence of diabetes when compared to non-Indigenous peoples in Canada. Specifically, it has been reported that

Indigenous peoples have an approximately 4-5 times higher prevalence of diabetes (Pelletier et al., 2012). Most estimates on the prevalence of diabetes among Indigenous peoples are only high-level aggregate statistics and are not disaggregated by city, nation or community. Since prevalence of diabetes varies based on nation, culture and geographic location (Young, Szathmary, Evers, Wheatley, 1990; Young et al., 2000) and such distinctions are not captured in national surveys, these estimates can offer a false representation of the true prevalence of diabetes among Indigenous peoples in Canada. In a study that looked at the different patterns across the different provinces and territories in Canada, Ontario had the second highest rates of diabetes among Indigenous peoples. Diabetes diagnosis were also higher in Southern and Eastern regions when compared to Northern regions and with rates particularly higher among urban Indigenous peoples. It is hypothesized that these distributions in diabetes prevalence are higher among those that experience long-term lifetime changes, such as disruptions in hunting, fishing, and gathering traditional foods (Young, et al., 1990).

OHC Toronto estimated that approximately 15% of Indigenous adults in Toronto hold a diabetes diagnosis. High rates of diabetes among Indigenous peoples has been linked to Indigenous people relying on a more westernized diet that has increased their consumption of processed foods, carbohydrates and refined sugars (Richmond & Ross, 2009; Young et al., 2000), which is commonly the case among Indigenous peoples living in the city. Lack of ability to eat traditional Indigenous foods or hunt, fish, and gather traditional Indigenous foods in the city can contribute to this high rate of diabetes in urban Indigenous populations, as it has been hypothesized that a diabetes diagnosis is linked to the lack of access and consumption of traditional Indigenous foods (Richmond & Ross, 2009). In addition to accessing traditional foods, *OHC Toronto* showed that there was a high proportion of Indigenous people living below the LICO, thereby forcing them to rely on processed foods, because those living in poverty are unable to afford healthy and nutritious foods for themselves and their families. Research has shown that Indigenous peoples are less likely to get needed health care when compared to non-Indigenous peoples (Browne et al., 2010); therefore, there is likely a high rate of Indigenous people that go without screening, have pre-diabetes, or have undiagnosed diabetes because of their reluctance to access health care. This sample would also not capture non-networked Indigenous people who have diabetes, as RDS methodologies only sample people who are networked.

As aforementioned, *OHC Toronto* has the ability to disaggregate by nation and culture of participants. This information could be used to understand trends among the different cultures and nations. Future diabetes research should focus on conducting a qualitative needs assessment among the different nations and cultures that have a diabetes diagnosis in Toronto to get a better understanding of the specific needs within these subgroups. This information could help guide the development of strategic plans in combatting this epidemic that disproportionately affects urban Indigenous peoples. This would also be beneficial in the development of diabetes programs and services that are specific to urban Indigenous peoples. Such services can be funded and planned accordingly to better meet the needs of the many different Indigenous people that reside in urban settings. In addition, *OHC Toronto* has estimated that approximately 15% of Indigenous people living in Toronto hold a diabetes diagnosis, therefore diabetes resources, programs, and services specific to Indigenous people in Toronto should be funded based on these numbers, instead of using aggregated data (i.e. Census data) to fund social and health programs for Indigenous peoples.

5.2.1 Indigenous determinants as predictors for self-reported diabetes diagnosis

Research needs to focus more on the determinants of Indigenous peoples' health as explanations for disease susceptibilities opposed to solely focusing on genetic factors (Polonco & Arbour, 2015; Reading, 2015). While there is lack of research that looks explicitly at the different determinants of health experienced by Indigenous people with a diabetes diagnosis, understanding disease trends and connecting them to the determinants of health experienced by Indigenous people could facilitate understanding in why Indigenous people are more prone to chronic diseases like diabetes. Instead of blaming individuals for their health, there would be a wider understanding that Indigenous people experience a number of distal, intermediate, and proximal determinants of health that strongly influence their health and wellbeing. Such explanations could change the way that disease prevention specific to Indigenous peoples is handled. To take this one step further, research should focus on understanding the needs of urban Indigenous peoples in this context to develop programs and services that are culturally appropriate and relevant for this unique population.

While there is no way to change the colonial legacy of residential schools, it is evident from this study that attendance of residential schools negatively impacted health and wellbeing, as not attending residential schools acted as a protective factor for diabetes. From being forced to eating unhealthy processed foods and/or being malnourished, being physically and sexually assaulted and being disciplined for practicing their own culture (Belanger, 2010), it is to no surprise that those who attended residential school have compromised health and wellbeing. Through residential schools, culture has been lost (Belanger, 2010; Reading, 2015) and those that participate in cultural continuity activities have better health outcomes (Chandler, 2000; Chandler & Lalonde, 2008; Reading & Halseth, 2013). As a means of diabetes prevention and promoting health and wellbeing among Indigenous peoples, cultural revitalization and programs that aid in regaining cultural identity need to be funded and established because unfortunately the Canadian governments cannot go back in time and reverse what happened to the children that attended residential schools. However, following up on the apologies made by both Prime Minister Harper (2010) and Prime Minister Trudeau (2016) regarding residential schools, more funding from the federal government should be allocated to resources that work towards culture revitalization for Indigenous peoples. This support should increase and extend to include urban Indigenous people, who are oftentimes away from their traditional territories and the cultural activities in their home communities while residing in an urban centre.

Chronic diseases (like diabetes) are more common among individuals with lower SES, in which, unhealthy diet, sedentary lifestyles, and smoking are more prevalent among these individuals and are all risk factors for chronic disease (Gracey & King, 2009). As we have learned from research and the *OHC Toronto* study in particular, urban Indigenous peoples experience disadvantage in relation to the proximal determinants of health, in which, the majority of participants are below the LICO, do not have paid employment, and have low educational attainment. Consistent with previous research regarding high rates of cigarette and alcohol use among Indigenous peoples, the majority of participants identified as current smokers and drinking alcohol in the past 30 days. Given the high rates of disadvantage across the urban Indigenous population in Toronto, diabetes programs and services should consider these specific determinants of Indigenous peoples' health for purposes of a chronic disease prevention strategy. As research has reinforced,

those that have better social and economic situations are more likely to have better health outcomes, therefore we cannot ignore the determinants that influence ill health.

This is exploratory research, as there has not been a study that framed the determinants of Indigenous peoples' health as predictors for a diabetes diagnosis in a quantitative analysis. This work should be used as a model for future quantitative research to further understand the associations between the determinants of Indigenous peoples' health and diabetes and/or other chronic diseases in both urban and on-reserve Indigenous populations. This could also be done qualitatively; qualitative research should focus more on understanding why and how the determinants of health are affecting urban Indigenous peoples in ways that are different than their non-Indigenous counterparts, as well as their Indigenous counterparts living on-reserve. Future research in this context would create a baseline of understanding how the determinants of Indigenous peoples' health may predict different chronic diseases, which is essential for developing strategies to mitigate the risks associated with different chronic diseases that disproportionately affect urban Indigenous peoples in Canada.

5.3 Unmet Health Needs

The results of this study align with the current literature and research on health services access barriers among urban Indigenous peoples in Canada. Indigenous people in Canada have experienced and commonly face a number of barriers to accessing basic health care services (Browne et al., 2009; Place, 2012; Reading & Wien, 2009). Results from the *OHC Toronto* study show that approximately 27.68% of Indigenous adults have an unmet health need. When compared to the 10.00% of non-Indigenous adults that have an unmet health need in Ontario, urban Indigenous people have almost 3 times higher rates of unmet needs.

Looking deeper into the types of unmet health needs experienced, a high proportion of Indigenous people in Toronto acknowledged that a doctor or nurse was not available when they last sought health care. Research has shown that Indigenous people may have difficulties accessing a family physician due to common beliefs that Indigenous people may be more difficult to care for (McConkey, 2017) because they are viewed as an ill population (Chandler & Dunlop, 2015). While some participants had difficulties accessing a physician, many have had

negative experiences when accessing health services that have left them believing physicians are untrustworthy. Indigenous patients commonly experience racism and discrimination in the health care setting (Allan & Smylie, 2015; McConkey, 2017) and this can influence whether they will seek health care or not (Adelson, 2005; Allan & Smylie, 2015; NAHO, 2003). Research has also shown that some individuals develop a strategy for dealing with racism prior to accessing some health care services (Allan & Smylie, 2015). A number of participants reported their experience with discrimination by a health care provider and identified that they preferred not to seek health care. Participants acknowledged the long wait times they have experienced when accessing health services. Research has shown that this is a common barrier among Indigenous patients in Canada when accessing emergency care (Brown et al., 2009; Place, 2012; Reading & Wien, 2009). Due to the long wait times in an urban emergency room combined with attitudinal discrimination of the health care workers in the emergency room, an innocent Indigenous man's life was claimed in Winnipeg (Dehaas, 2014). The numerous findings in *OHC Toronto* and other research has demonstrated that Indigenous people are still experiencing racism and discrimination in the health care system, hindering their ability to access a physician or preventing them from seeking care altogether. It is evident that there is a problem within the health care system itself, which creates and perpetuates access barriers for Indigenous people, even though they are recognized as populations in high need of health services.

Jurisdictional barriers have influenced whether Indigenous people can receive or access specific health care services (Belanger, 2010). Due to ongoing disputes between the federal and provincial governments, there have been instances where Indigenous people, including children, had to go without services that were needed to save their life (Blackstock, 2012). There are also a number of issues surrounding eligibility for health care benefits covered by NIHB. Although the federal government has fiduciary responsibility for all Indigenous peoples, only status First Nations and Inuit peoples have access to NIHB. Since non-status First Nations and Métis individuals do not qualify for NIHB, this could contribute to the proportion of respondents who identified as having barriers to NIHB. Additionally, NIHB does not provide Indigenous peoples access to all eligible health services and benefits based on residency status. Those that live off-reserve do not have the same access to services as those that live on-reserve (Reading & Halseth, 2013; Senese & Wilson, 2013) and those that live off-reserve may have less support navigating NIHB access due to lack of training of staff working with Indigenous people in urban centres.

Therefore, since *OHC Toronto* targeted urban Indigenous people, there could be a higher representation of individuals that had barriers surrounding NIHB, therefore increasing the number of respondents that reported experiencing barriers related to NIHB.

The federal government has fiduciary responsibility for status and non-status First Nations and Métis peoples (Smith, 2016), however urban Indigenous peoples do not have access to the same types of services that Indigenous peoples living on on-reserve have. In addition to a lack of access to the services themselves, urban Indigenous peoples commonly have challenges regarding health care benefits (Senese & Wilson, 2013). This is related to federal funds being allocated to reserves (Blackstock, 2012), despite the fact that the majority of Indigenous peoples now reside in urban centres (Synder & Wilson, 2012). Just recently, the health care of non-status First Nations and Métis individuals were included under the federal government's responsibility (Smith, 2016). However, this does not ensure access to federal programs and services that are available to status First Nations or First Nations living on-reserve. Given this new recognition, federal funding structures related to Indigenous health and wellbeing need to be revamped to be inclusive of all status and non-status First Nations living on- and/or off-reserve, as well as Métis and Inuit populations. A new funding structure that collaborates with provincial health care funding structures with the goal of improving health and social conditions for all Indigenous populations and extends to include all Indigenous peoples in Canada is a necessary step to mitigating jurisdictional barriers experienced. With the majority of Indigenous peoples now residing in urban centres (Synder & Wilson, 2012) and the underestimation of urban Indigenous people residing in urban cities, there needs to be a significant increase in funding allocated to supporting social and health programs and services for urban Indigenous peoples.

Research has shown that Indigenous people experience a number of cultural barriers when accessing health services (Reading & Wien, 2009). Some respondents identified the difficulties in accessing a traditional healer. Other respondents believed that the services they received were culturally inappropriate or care received was inadequate. Research has shown that health care workers in a large Ontario city were unaware of traditional Indigenous approaches to health and wellbeing and despite this ignorance, many health care workers do not give the same value to Indigenous approaches as they do to conventional medicine (McConkey, 2017). These attitudes

among health care workers can influence whether a patient has a positive or negative experience and how they are treated could prevent them from continuing to access services in the future.

Economic barriers experienced by Indigenous patients can hinder access to health services (Reading & Wien, 2009). Given the majority of the sample population was below the LICO, it is no surprise that there was a high number of economic barriers identified by participants. Many participants identified they had a transportation barrier and the inability to pay for health care or child care, a direct result of the low SES of the population (Reading & Wien, 2009). Barriers related to geographical location and availability of services have also been identified by Indigenous people in Canada and considered a serious concern among Indigenous people living in rural or remote locations (Reading & Wien, 2009). However, it is evident that Indigenous people living in large urban centres still experience barriers related to location and availability of services. Given that Toronto is the largest metropolitan area in Canada (Statistics Canada, 2017c) and the large sample size of the *OHC Toronto* study, participants are likely to reside in varying locations all over Toronto. Those that live more centrally may have better access to services than those that live in other areas due to the locations of service. Given that the more affordable housing tends to be far away from downtown Toronto, it becomes even more difficult to access Indigenous-specific and/or hospital-based services that are located downtown for those that cannot afford to live in Toronto's downtown core. Geographical location of services has a direct impact on the ability to arrange or afford transportation, which again, is strongly influenced by the low SES of the population (Reading & Wien, 2009).

Urban Indigenous people experience a range of unmet health needs, as demonstrated by current research and is evident in the findings from *OHC Toronto*. This explication and validation of the range of barriers experienced by Indigenous people trying to access the health care they need, even within Canada's largest urban centre, confirms the inadequacy of existing services. This research confirms that additional resources and supports are needed to facilitate access to health services for Indigenous people living in urban centres. A number of systemic, cultural, geographic, economic, and access barriers have been identified in current research on Indigenous people living on-reserve; this research reveals that the same barriers are experienced by Indigenous people living in urban centres as well. In addition to the TRC (2015)

recommendation for the federal government to take responsibility for all Indigenous peoples' health needs, system-level strategies need to be put in place to facilitate inclusion of the Indigenous populations and to ensure they are receiving equitable and culturally appropriate care in Canadian health care settings.

The gaps in health care providers' knowledge about Indigenous peoples' history, health beliefs and determinants of health create an imperative need for cultural safety training. Training should facilitate a comprehensive understanding of Indigenous specific determinants of health, including an overview of the history of Indigenous peoples in Canada, the health inequities endured by Indigenous peoples, the many different nations and cultures, and shares teaches health care workers about the Canadian health funding model for Indigenous peoples. Increasing awareness about the history of Indigenous peoples and how it has detrimentally affected their health and wellbeing could alter perspectives of health care workers and potentially reduce attitudinal discrimination against Indigenous patients. Understanding culture could help to ensure that Indigenous peoples' values and perspectives of health and wellbeing are included in care plans. Teaching health care workers about the funding model for Indigenous peoples in Canada would allow for better continuity of care because workers would be aware of the types of services and medicines that are covered by the different health coverages for First Nations, Inuit and Métis. Changing attitudes of health care workers through cultural safety training is a long process; however, such training does have the potential to change attitudes and reduce disparities among minority groups in health services (Majumdar, Browne, Roberts & Carpio, 2004). Mandating all health care workers to engage in cultural safety training specific to Indigenous peoples in Canada would be a good place to start, as recommended by the TRC (2015). This training should begin in medical school and be ongoing throughout an individual's medical career as a means of creating additional opportunities for learning and building skills in relation to cultural safety that is specific to Indigenous peoples and other minority populations. This type of training model would support the goal of ensuring that Indigenous people are currently and will continue to receive adequate and culturally safe health care.

5.3.1 Indigenous determinants of health as predictors for experiences of unmet health needs

As previously discussed, a number of unmet health needs were experienced by Indigenous adults in Toronto. Unsurprisingly, those who did not experience discrimination by a health care professional were less likely to experience an unmet health need. While discrimination was not included as a choice in the list of 23 unmet health need options, discrimination was a common theme expressed through qualitative responses to the “other” category. While research shows that Indigenous people often experience racism and discrimination in health care settings (Allan & Smylie, 2015; McConkey, 2017), and has impacted whether patients will seek care in the future (Adelson, 2005; Allan & Smylie, 2015; NAHO, 2003), the estimated risk is probably under-representative of the actual risk because respondents were only expected to report unmet health needs in the past 12 months. Those who may have experienced racism or discrimination in the past may not have even accessed health services in that timeframe as a result. As aforementioned, cultural safety training needs to be mandated among all health care workers in Canada and more Indigenous people need to be hired in health services in urban settings as a means of minimizing discriminatory experiences that are often endured by Indigenous people in health care settings. Minimizing experiences of discrimination would also positively influence the health and wellbeing among this population.

OHC Toronto showed that use of traditional medicine was associated with a decreased likelihood of experiencing an unmet health need among participants. As this study has shown, approximately 7% of participants reported using traditional medicines only, therefore these participants would not be relying on western medicine and accessing health services in the past 12 months. In addition, those who participate in cultural continuity activities have more positive health outcomes and those who use traditional medicines are those who would be more connected to their Indigenous roots (Chandler, 2000; Chandler & Lalonde, 2008; Reading & Halseth, 2013), thereby needing to rely less on health services. Oppositely, the findings from *OHC Toronto* suggest that eating traditional foods is associated with an increased likelihood of participants experiencing an unmet health need. There has been a shift in what is considered as traditional Indigenous foods. Certain foods that were not traditionally considered Indigenous foods are being considered traditional Indigenous foods in more modern days, such as foods that

are high in fat and carbohydrates (i.e. Indian Tacos and Bannock). In the *OHC Toronto* survey tool, information on the types of traditional Indigenous foods participants were consuming was not collected. Participants who included more modern and unhealthy traditional Indigenous foods as traditional Indigenous foods in their response may account for the high rate of participants who experience unmet health needs. Individuals who regularly eat the modern traditional Indigenous foods may be more prone to health challenges related to an unhealthy diet (e.g. diabetes). It could be assumed that individuals with health challenges related to diet are more regularly seeking health care and thereby experiencing unmet health needs.

The *OHC Toronto* study also found that those who had post-secondary education or higher were more likely to experience an unmet health need. It is assumed that those who have higher education are more likely to seek or access health care when needed and thereby may be regularly accessing health care and may be more likely to report an unmet health need. Research shows that Indigenous people expect to be treated poorly when they seek health care and oftentimes they prepare for this mistreatment before accessing services or do not seek care at all (Allan & Smylie, 2015). Those who are more educated may not accept this mistreatment as a norm and report unmet health needs.

While much research focuses on barriers to health services among Indigenous people in Canada, more research needs to focus on understanding the determinants of Indigenous peoples' health and how they are associated with experiencing unmet health needs. In addition to conducting similar quantitative research, qualitative studies such as a needs assessment of the Indigenous population of Toronto would build a more detailed understanding of the actual needs of urban Indigenous people in relation to health services. Most research focuses on actual experiences of health services access barriers and does not focus on reasons why Indigenous people are continuing to experience these barriers or building solutions to overcome these barriers. Incorporating the distal, intermediate, and proximal determinants of health as explanations for unmet health needs should be explored both quantitatively and qualitatively in future Indigenous health research.

5.4 Use of traditional Indigenous and conventional approaches to medicine

Research has demonstrated that Indigenous people have negative experiences with mainstream health services in Canada (Eby, 2007; Reading & Wein, 2009; Richmond & Ross, 2009). In addition to the unmet health needs that were examined, Indigenous perspectives and practices surrounding health and wellbeing are not valued or fully understood by health care workers and there is a lack of willingness to provide such services in the conventional medical system (Lallo, 2014; Waldram, 2013). While many Indigenous people have expressed their preference for using traditional Indigenous approaches to health and wellbeing, many have also identified that they have to refrain from such approaches because they do not have access to such services or services are not covered by their health insurance (e.g. work benefits and/or NIHB) (NAHO, 2003).

While the *OHC Toronto* study does not examine an explicit combination of services (i.e. centres offering both traditional Indigenous and conventional approaches), it does measure use of conventional medicine (i.e. care from a doctor or nurse) in the past 12 months and ongoing use of traditional Indigenous medicines. Using these measures, approximately half of participants reported using traditional Indigenous medicines for their health and wellbeing. Of those who used traditional Indigenous approaches, the majority were also using conventional medical services simultaneously. While traditional Indigenous medicines come in many different forms and differ across nations and culture, there was no way of understanding the specifics of the traditional Indigenous medicines that participants used or where these medicines were accessed or used. However, there has been an emergence of UAHCs across Canada and there is one located in Toronto. Since UAHC's are dedicated to improving the health and wellbeing of urban Indigenous people through offering a combination of traditional Indigenous and conventional approaches to health care that is culturally relevant and appropriate in urban centres, they have been embraced by Indigenous people (Benoit et al., 2003). AHT (a UAHC in Toronto) likely contributes to the high proportion of participants who reported using conventional and traditional Indigenous approaches to health and wellbeing in Toronto. While UAHCs are still emerging, there are limited locations across Canada, especially in the northern communities. Since these centres have demonstrated success in providing culturally appropriate care to Indigenous people living in urban centres (Benoit et al., 2003), there is a need for more UAHCs in Canada to meet

the specific health services needs of urban Indigenous people. This would partially address the TRC (2015) suggestions that more funding should be allocated to developing new healing centres specific to Indigenous peoples. Given that the majority of Indigenous people live in urban centres (Snyder & Wilson, 2012), establishing more UAHCs across Canadian cities would be an efficient way of facilitating access to culturally appropriate services for Indigenous peoples in Canada.

In recent years, there have been more discussions regarding *Two-Eyed Seeing* in Indigenous health research. This ideology allows Indigenous peoples to be able to walk in two worlds – both the western and Indigenous, through integrating the knowledge within each system (Marshall et al., 2015). As the TRC's (2015) calls to action recommend the Canadian health care system to recognize the value of Indigenous approaches and perspectives to health and wellbeing, applying this ideology to health services in Canada would promote better health outcomes for Indigenous peoples through understanding the benefits of both western and Indigenous approaches to health and wellbeing. Incorporating *Two-Eyed Seeing* to conventional or Indigenous-specific health services could help to change the common perception that Indigenous approaches to health and wellbeing are less valuable than evidence-based western approaches to medicine. This ideology would ensure that western or Indigenous practices are not to be viewed as holding greater or lesser value than the other. Such approaches would create a more welcoming environment in the health care setting and could create better health care journeys and experiences among Indigenous people who use health care services. Additionally, this could potentially influence more Indigenous people to seek health care when needed instead of avoiding health services.

5.4.1 Diabetes and use of traditional Indigenous and conventional approaches to medicine

Among individuals without diabetes, the largest group used a combination of services. Due to the high proportion of individuals without diabetes who also used conventional medicine only, these proportions suggest that individuals who regularly seek conventional medical services are less likely to hold a diabetes diagnosis. Conventional medical services offer disease prevention and screening, in which, it could be assumed that individuals who regularly seek conventional services engage in screening and are monitored for diseases like diabetes. This suggestion could also be applied to the combination of services, where we see individuals who seek conventional

medical services in addition to traditional Indigenous medicines are even less likely to hold a diabetes diagnosis. Some of the reasons behind this relationship are those who use traditional Indigenous medicines may be more connected to their traditional roots, such as eating traditional foods, speaking Indigenous languages, and participating in cultural activities. Research demonstrates that Indigenous people who engage in activities related to cultural have more positive health outcomes (Reading & Wien, 2009; Rotenberg, 2016) and again those who seek conventional medical services on a regular basis are more likely to undergo regular screening and monitoring for diseases such as diabetes.

5.5 Recommendations for Effective Diabetes Programming

First and foremost, there is a need for accurate regional-level health assessment data on Indigenous peoples across Canada that is governed and led by Indigenous communities, as modeled by *OHC Toronto*, in order to understand current health trends and priorities within communities and urban centres. Most national statistics group all Indigenous peoples as the same and do not differentiate between communities, nations or cultures (Kukutai, 2011; Walter & Anderson, 2013), and therefore do not provide locally relevant, community-specific data. Regional-level data that is governed and led by Indigenous communities could influence the federal government to develop a better health funding structure for all Indigenous peoples in Canada that allocates resources to ensure appropriate services are available to meet the current health needs and priorities identified in a given area. Indigenous communities could ensure that policy recommendations and impacts reflect the health needs and priorities of the communities themselves. This could also ensure that different nations and cultures would get the necessary resources for services needed or preferred regarding diabetes treatment, as diabetes trends vary based on nations, cultures and geographical location (Pelletier et al., 2015). Additionally, perspectives and approaches to health and wellbeing differ across the many different Indigenous nations and cultures in Canada and it is important to ensure all cultural values are respected in health care settings.

Due to the disproportionately high rates of diabetes affecting Indigenous peoples in Canada (FNIGC, 2012; Pelletier et al., 2015; Young et al., 2000), a number of health system-level changes are recommended to ensure that Indigenous patients are receiving culturally appropriate

care in a welcoming and safe environment. As we have learned from UAHCs, combining conventional and traditional Indigenous approaches to health and wellbeing are necessary to ensure that urban Indigenous people are given the opportunity to develop a culturally relevant care plan that suits their needs. Similarly, incorporating the concept of *Two Eyed Seeing* to health care and specifically to diabetes services would ensure that Indigenous perspectives and approaches to health and wellbeing would be valued and accommodated. This would allow Indigenous patients with diabetes to be more comfortable in the medical environment because they would have the opportunity to engage in more than just conventional medicine, which could also influence their involvement in developing their own culturally relevant care plan and making them more willing to seek health care when needed.

In addition to incorporating the *Two-Eyed Seeing* concept to health care services, health care workers should be mandated to undergo cultural safety training specific to Indigenous nations and cultures. As aforementioned, cultural safety training does not necessarily change behaviours of health workers immediately. Instead, it is a longer process that takes time and reflection of current practice and behaviours but does have the potential to change health disparities (Majumdar et al., 2004). All health care professionals should be mandated to participate in training if they are practicing in Canada, as called for by the TRC (2015). In addition, cultural safety training should be introduced at earlier stages in a medical professional's career. As recommended by the TRC (2015), all medical and nursing students studying in Canada should be mandated to participate in Indigenous history courses that teach students about the detrimental effects of the colonial legacy that Indigenous peoples still face today. Such courses should focus on and incorporate Indigenous Knowledge as a fundamental practice to medicine. This may mean revamping medical school curriculum in many universities and colleges across Canada but is a necessary step to ensuring that future health care workers are culturally competent enough to take care of Canada's first peoples, which has been successfully done in Australia and New Zealand (Bozorgzad, Negarandeh, Raiesifar, & Poortaghi, 2016). Another approach to ensuring cultural competence among health care workers in Canada is increasing the number Indigenous health care professionals in Canada, as recommended by the TRC (2015). In addition to having more Indigenous health care professionals across the board, there is a need for more Indigenous patient navigators to assist patients in navigating the health care system and facilitating access to

needed services (Allan & Smylie, 2015). Furthermore, an increase in the number of Indigenous professionals working in diabetes-specific programs and services is needed given the high prevalence of diabetes affecting the Indigenous population in Canada. All of these proposed recommendations are meant to be established nationally to facilitate access to culturally-relevant diabetes programs and services for both urban Indigenous people and Indigenous people that live in rural and remote areas.

5.6 Limitations

RDS is still an emerging and expanding sampling method in research. Introduced over two-decades ago (Heckathorn, 1997), a number of studies have successfully employed RDS methodologies (Ramirez-Valles et al., 2005; Smylie et al., 2011). However, there are a number of challenges surrounding statistical analysis of RDS data. To date, there is no gold standard for analyzing RDS data to account for all the inherent biases associated with such complex methods. RDS relies on social network sizes of participants to recruit a large sample and those with larger network sizes are more likely to be included in the study, whereas those with smaller network sizes are less likely to be included (Heckathorn, 1997; Magnani et al., 2005). This method of sampling also has no way of monitoring response rates, therefore making us unable to take biases associated with low response rates into consideration throughout analysis.

As displayed in the network diagram in Figure 1, there is evidence that First Nations participants were over-sampled due to the low prevalence of Métis and Inuit participants in the *OHC Toronto* study, despite efforts to engage and reach out to the Métis and Inuit communities in Toronto. This could be due to the larger population of First Nations peoples residing in Toronto, when compared to Métis and Inuit populations. Additionally, Métis and Inuit people may be less networked to First Nations people and/or other Métis and Inuit people living in Toronto. RDS-II methods were employed throughout data analysis, which gave more weight to potentially “under-sampled” and less weight to potentially “over-sampled” individuals in the study as a means of decreasing non-random sampling bias. Additionally, homogeneous samples arise due to the fact that participants are likely to recruit individuals with similar characteristics as their own (Ramirez-Valles et al., 2005). This can create non-independence among recruitment chains. Having a variety of seeds and a quota on the number of coupons each participant is given

increases heterogeneity across the sample (Magnani et al., 2005; Ramirez-Valles et al., 2005); however, clustering by recruiter id was adjusted for throughout analysis to account for the non-independence among recruitment chains.

The determinants of Indigenous peoples' health were measured using an Indigenous framework. Reading (2015) explains that colonialism is one of the most significant determinants of Indigenous peoples' health. There is no explicit way to measure colonialism, so proxy measures were used in its place. While generational and inter-generational residential school attendance seem like reasonable measures of colonialism, we were unable to make conclusions on the full effect of colonialism based on the information asked and provided in the *OHC Toronto* survey. Experiences of discrimination by a service provider was also used as a proxy measure for colonialism. The full effect of colonialism cannot be measured because there are so many other colonial legacies, therefore using only these three proxy measures of colonialism actually underestimates the influence of colonialism on Indigenous peoples' health. Use of conventional services was also not captured in the *OHC Toronto* survey. It was assumed that participants who reported seeking a doctor in the past 12 months were those who were regularly using conventional services. Furthermore, it was also assumed that participants who sought a doctor in the past 12 months and also reported using traditional Indigenous medicines were using both services. While these are not direct measures of conventional medicine and a combination of services, this was the closest measure given the information provided.

There was a high prevalence of participants who identified as having an unmet need. To get a better understanding of the unmet health needs that have been or continue to affect Indigenous people today, the question should not have been limited to having an unmet need in the past 12 months. Therefore, this question does not represent participants that have not used services in the past 12 months or participants who avoid services altogether. Among participants who did identify as having an unmet health need, a number of respondents selected "other" when given the list of 23 unmet need options. A number of the "other" responses expressed an unmet need that was already in a pre-determined category in the list of 23 options. For example, wait list was one of the pre-determined categories and a number of participants selected "other" and verbally expressed that they had an issue with waiting lists and wait times for services. This also occurred

among some of the other pre-determined categories. Therefore, the “other” option in the unmet needs section is over-represented due to potentially losing attention of the interviewee when listing out the 23 options, overlapping of answers and/or not properly categorizing responses.

Associations between the determinants of health and unmet health needs and between the determinants of health and diabetes diagnosis have been identified. While these associations are valid, we are unable to make causal inferences about these relationships due to the cross-sectional nature of the *OHC Toronto* study. Since the sample was targeted using the original seed’s and recruited participant’s personal networks, the associations identified in this study are not necessarily generalizable to all Indigenous people in Toronto, but rather only able to be generalized to the networked Indigenous adult population living in Toronto.

5.7 Conclusion

National statistics present Indigenous peoples in Canada as a homogeneous population of peoples with ill health. This thesis and the overall *OHC Toronto* study have demonstrated that there are unique health and health care access issues for urban Indigenous populations, that are not captured in the national data sources. Through partnering with Toronto’s urban Indigenous community and the results from *OHC Toronto*, a unique urban context has been explored and the need for Indigenous-specific health and social service improvements in urban settings has been identified. There is a need for more studies like *OHC* to take place in other urban cities across Canada in order to get more accurate regional-level health assessment data on urban Indigenous peoples. Given that the Canadian government relies heavily on Census data to fund health and social programs for Indigenous peoples, updated and accurate health assessment data that is owned and governed by Indigenous peoples is necessary to ensure that funds and resources are being allocated appropriately and sufficiently to support urban Indigenous people, in addition to their other Indigenous counterparts. This would mean increasing the amount of funding for Indigenous peoples’ health and developing a new funding model that is Indigenous governed and inclusive of urban First Nations, Inuit and Métis peoples because Indigenous people have a human right to health care in Canada and the current funding model is inadequate in supporting all the unique Indigenous populations in Canada.

As the results indicate, there is a high prevalence of diabetes and unmet health needs experienced among Indigenous adults in Toronto. While this research has highlighted some of the gaps in care related to unmet health needs, more research is needed to determine how to address the gaps that were identified in this research. This study showed that Indigenous adults that attended residential schools were more likely to develop diabetes. More research is needed to understand the depth of the effect that the different determinants of Indigenous peoples' health have on the development of diabetes in Indigenous communities. This is also necessary for understanding the relationship between the determinants of Indigenous peoples' health and unmet health needs. Experiences of discrimination and consumption of traditional Indigenous foods were predictors for experiencing an unmet health need. Whereas, use of traditional medicine was associated with a decreased likelihood of experiencing an unmet health need. Due to the contrary findings specific to cultural continuity factors, more research is needed to further understand these associations and why they may exist.

Based on the findings from this study, it is recommended that diabetes prevention programming that is specific to urban Indigenous populations should focus on combining traditional Indigenous and conventional approaches to medicine as well as targeting the specific determinants of health that predict a diabetes diagnosis among urban Indigenous people. A number of policy-level recommendations based on the direct findings from this study including increasing the number of Indigenous health care professionals, mandating cultural safety training for all health care workers in Canada and incorporating Indigenous perspectives and approaches to medicine into mainstream health care settings are viewed and believed to be useful approaches to combat the existing health disparities faced by urban Indigenous people in Canada.

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Appendix 1 – OHC Toronto Unmet Health Needs Survey Questions

Question 12.4

In the previous 12 months, was there a time you felt you needed health care services but did not receive them?

- Yes (Go to 12.4a)
- No
- Interviewer Use Only*

Question 12.4a

Why was this need unmet?

- Doctor not available
- Nurse not available
- Lack of trust in health care provider
- Waiting list too long
- Unable to arrange transport
- Could not afford transport
- Difficulty accessing traditional healer and/or medicines
- Do not have health benefits from my work
- Do not have non-insured health benefits
- Not covered by non-insured health benefits
- Prior approval for services under non-insured health benefits was denied
- Could not afford direct cost of care/services
- Felt health care provided was inadequate
- Felt service was not culturally appropriate
- Chose not to see health professional
- Service not available in my area
- Could not get time off work
- Did not have safe or reliable childcare option
- Could not afford childcare
- Was referred to a specialist but have difficulty getting an appointment
- Was referred to a specialist and got an appointment but missed it
- Was excluded because I was under the influence of alcohol or other substances
- Other

Appendix 2 – *OHC Toronto* Conventional Medicine Use Survey Questions

Question 12.3

When did you last see a doctor or nurse practitioner?

- Less than 1 year ago
- 1 year to less than 2 years ago
- 2 years to less than 3 years ago
- 3 years to less than 4 years ago
- 4 years to less than 5 years ago
- 5 years ago or more
- Never
- Interviewer Use Only*

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