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Unmet health needs and discrimination by healthcare providers among Indigenous people with multimorbidity

A Respondent-Driven Sampling study of an urban
Indigenous population in Toronto, Canada

Master's thesis in Public Health specializing in Global Health
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Trondheim, May 2017

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Abstract

Background: Inequality in health between Indigenous and non-Indigenous people in Canada persists. Despite the growth in Indigenous peoples of Canada living in urban areas, information on the health of urban Indigenous people is scarce. The “Our Health Counts Toronto” study attempts to fill this knowledge gap for the urban Indigenous population (including First Nations, Inuit and Métis) living in the city of Toronto, Ontario, Canada.

Aim: The aim of this study is to assess factors associated with having unmet health needs including disease burden (multimorbidity), and experience of discrimination by a healthcare provider.

Method: Respondent-Driven Sampling (RDS) methodology, developed specifically to identify hard-to-reach populations, was used for the recruitment of a self-identified adult urban Indigenous population. Health information was collected through a total of 940 interviews conducted, with a final sample of 836 interviews utilized. Respondents were asked if they had ever experienced discrimination by a healthcare provider and if they had an unmet health need in the 12 months prior to the study. Respondents were classified as multimorbid if they indicated two or more conditions from a list of 13 chronic conditions. Data was analysed to assess the relationship between multimorbidity and having unmet health needs and the relationship between experience of discrimination by a healthcare provider and having unmet health needs. Stratified analysis was conducted based on information on: Indigenous identity; gender; age; education; employment; food security; mobility; income; and access to a regular healthcare provider.

Results: The RDS-adjusted prevalence of self-reported unmet health needs in the urban Indigenous population was 27.27% (19.05-35.49 95%C.I.). The RDS-adjusted prevalence of multimorbidity was 61.66% (53.87-69.46 95%C.I.). The RDS-adjusted prevalence of discrimination by a healthcare provider was 28.47% (20.40-36.54 95%C.I.). Both multimorbidity and discrimination by a healthcare provider were independently associated with self-reported unmet health needs, OR 2.45 (1.11-5.41 95%C.I.) and OR 3.05 (1.27-7.34 95%C.I.) respectively.

Conclusion: Unmet health needs are prevalent among urban Indigenous people. Both having multimorbidity and having experienced discrimination by a healthcare provider increase the likelihood of having unmet health needs. The analysis presented reinforces the need for healthcare providers to receive cultural safety training. Measures must be taken to ensure that the needs of urban Indigenous people with multimorbidity are addressed.

Acknowledgments

I would like to take a moment to acknowledge and thank the many people who have made the journey of this master's thesis possible. I would like to thank Dr. Berit Schei, my supervisor at NTNU, for your wonderful dedication, mentorship and continual support (stretching across the Atlantic!) throughout this thesis project. Dr. Janet Smylie and Dr. Michelle Firestone, my co-supervisors in Toronto, Canada, I am profoundly grateful for what you have taught me. I want to thank you for welcoming me to work with the Well Living House team and to share in your incredible knowledge, and passion. I would like to thank Sara Wolfe and Cheryllee Bourgeois, of Seventh Generation Midwives Toronto, for the opportunity to access and learn from the results of the Our Health Counts Survey. Your enthusiastic guidance and mentorship has been so important to my learning and the development of this thesis. I would like to thank Bent-Martin Eliassen for early support and guidance in the development of this project. I would like to give a huge thanks to Kristen, Billie-Jo, Raglan, Gen, Conrad and many others of the Well Living House team for keeping me focused, organized and motivated on this journey. I would also like to thank Dr. Patricia O'Campo, Dr. Michael Rotondi and Dr. Rosane Nisenbaum for your excellent technical support and insight in the development of this thesis.

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Abbreviations

APS	Aboriginal Peoples Survey
CCHS	Canadian Community Health Survey
COPD	Chronic Obstructive Pulmonary Disorder
CPGs	Clinical practice guidelines
LICO	Low-income cut-off
NCDs	Non-communicable Diseases
NHS	National Household Survey
NIHBs	Non-Insured Health Benefits
NPHS	National Public Health Survey
OCAP	Ownership, Control, Access, and Possession
OHC	Our Health Counts (Hamilton)
OHCT	Our Health Counts Toronto
PC-PTSD	Primary Care – Post-Traumatic Stress Disorder (Screeners)
PHAC	Public Health Agency of Canada
RCAP	Royal Commission on Aboriginal People
RDS	Respondent-Driven Sampling
SGMT	Seventh Generation Midwives Toronto
TARP	Toronto Aboriginal Research Project
TRC	Truth and Reconciliation Commission
UAPS	Urban Aboriginal Peoples Study

1 Introduction

1.1 Global Indigenous health

Understanding and addressing Indigenous health is important to the study of global health. A 2016 Lancet Commission on the health of global Indigenous and tribal peoples (estimated at over 302 million spread between 90 countries), found that while the health status varied between Indigenous populations, for the most part Indigenous peoples experienced a lower health status than benchmark populations in countries around the world (1). The commission echoes and emphasizes the importance of colonization as the foundational determinant of Indigenous health and the need to understand health inequalities of Indigenous groups within their specific historical contexts (1,2). As the process of colonization has marginalized First Peoples around the world, there can be no achievement of universal health access or health equity without first understanding the health of Indigenous populations, and empowering them to achieve the best health possible within their cultural contexts and traditional understandings of health and well-being.

1.2 Indigenous peoples of Canada

An internationally accepted definition of ‘Indigenous’ has not been formalized for the United Nations Permanent Forum on Indigenous Issues or for the United Nations Declaration on the Rights of Indigenous Peoples, however self-determination was acknowledged as a key criterion in identification (3). The Indigenous peoples of Canada embody a rich diversity of cultures and languages that can be traced back thousands of years. Prior to European colonization, North America was home to approximately 300 distinct Indigenous languages considered to be from over 50 distinct language families, a diversity approximately tenfold that of Europe at the same time (Goddard 1999 as described by Dr. Janet Smylie in Chapter 19 of the book *Social Determinants of Health: Canadian Perspectives, 3rd Edition* edited by Dennis Raphael (4)). The Indigenous peoples of Canada today come from over 50 distinct cultural groups, each with distinct languages and traditional land bases, and represent themselves in three broad groups, First Nations, Inuit and Métis. *First Nations* peoples of Canada refers to Status and non-Status Indians from more than 50 Nations found in over 630 communities in Canada, according to publicly available information (5). The *Inuit* peoples of Canada are part of a larger circumpolar Inuit population spread across the Arctic in Greenland, Alaska and Russia (6). The *Métis* peoples of Canada refers to a specific group, with a distinct language (Michif) and culture, whose ancestry can be traced to the 17th century

intermarriage of European men and First Nations women in the western provinces of Canada (6). This report will utilize ‘Indigenous’ to recognize the diversity of Indigenous identities in Canada and collectively refer to those who self-identify as either First Nations, Inuit or Métis.

The National Household Survey (NHS), a voluntary census administered by Statistics Canada in 2011, estimated the Indigenous population of Canada to be approximately 1.4 million or 4.3% of the total population (7). The 2011 voluntary NHS has received criticism for its poor data quality and comparability to earlier mandatory National censuses (8,9). This 2011 NHS-based estimate of the Indigenous population of Canada is likely an underestimate of the actual population size due to systematic issues related to identifying and enumerating Indigenous peoples (9,10). According to the 2011 NHS, 49.8% of Indigenous people self-identified as registered or Status First Nations, 15.3% identified as non-Status First Nations, 29.9% as Métis, and 4.2% as Inuit (7). Findings from the 2011 NHS confirm that the Indigenous population is younger than the non-Indigenous population in Canada (7). The urban Indigenous population in Canada has been growing over the last half century with the 2006 National Census estimating 54% of Indigenous people live in urban centres, compared to 50% in 1996 (11).

1.3 Health of Indigenous peoples of Canada

The overabundance of ill-health among Indigenous people in Canada must be understood in the historical context of colonization and the subsequent enforcement of colonial State policies designed to assimilate (discussed in the Background). The Indigenous peoples of Canada have endured over a century of racist policies from the Government of Canada and other colonial institutions, designed to break their connection with their land, their traditional cultures and their social and familial networks (12). As the 2015 Truth and Reconciliation Commission of Canada found after examination of the Residential Schools System, it is a history of cultural genocide (12). In light of these historic and ongoing inequities, the current resurgence of Indigenous culture, language and political empowerment speaks to the incredible resilience and strength of Indigenous peoples.

Research indicates significant health disparities continue to exist between the health of Indigenous and non-Indigenous people in Canada, and critical gaps remain in our understanding of Indigenous health in Canada (13–16). Health data sources that can be used to inform our understanding of Indigenous health, such as national, regional and urban health surveys, are limited in two key areas (discussed in detail in the Background), identifying Indigenous respondents, and ensuring sampling methods do not systematically exclude

population segments (such as those who are homeless) (9,17,18). Métis and urban Indigenous populations are particularly understudied within health research (19).

The Our Health Counts Hamilton study, completed in 2011, examined the health of First Nations people living and accessing services in the city of Hamilton (16). This study was ground breaking in the field of Indigenous health research, for its commitment to community participation at all stages in the research process (through partnership between Dr. Janet Smylie of the Well Living House action research centre and the De dwa da dehs nye>s Aboriginal Health Access Centre in Hamilton), and for its use of Respondent-Driven Sampling (RDS) methodology (discussed in the Background) to enumerate previously under-sampled segments of the population for population-based estimates (16,20). The results of the Our Health Counts Hamilton survey confirmed evidence of health disparities between the urban Indigenous and non-Indigenous populations (16). The results also indicated poor levels of access to primary care and adds evidence to research indicating high levels of discrimination by health care providers (16,21).

Legislative loopholes and jurisdictional ambiguities between levels of government, have been found to result in confusion regarding where and how Indigenous peoples can access health care (22). For many Indigenous people, contact with the health care system is forced to occur at the emergency department, which is neither designed for regular use, nor to provide primary care of non-urgent health needs (14,23). Discrimination by healthcare providers has been found (through analysis of a population-based self-report survey) to increase odds of unmet health needs among minority groups in the United States of America (24). Current research indicates a similar association is likely to be found for Canadian Indigenous populations, particularly for discrimination experienced in healthcare settings (14).

Multimorbidity, referring to the presence of multiple chronic conditions (without one condition being more central than the others), is increasingly recognized as a key public health issue (25–28). Patients with multimorbidity have complex health needs and health risks (discussed in further in the Background) (26,29–31). Their experiences of health care can be considered an indicator of the successful coordination and integration between diverse health providers within a health care system (26,29). Individuals also experience multimorbidity differently, within their own living situation, and multimorbidity has been found to be associated with age, gender, lower socio-economic status (26,32–34). Multimorbidity has been found to be higher in the Indigenous population of Canada, as chronic conditions are overrepresented within this population (28). The increased contact with the health care system

that having multiple chronic conditions necessitates, may make it more likely that Indigenous people with multimorbidity experience discrimination in the health care setting. Due to the health disparities affecting access to care, it is likely that Indigenous people with multimorbidity are more likely to have unmet health needs. This relationship, and potential mediating factors such as having access to a regular healthcare provider or being exposed to discrimination by a healthcare provider, remains an understudied area.

Despite the importance of multimorbidity, no gold standard for its measurement has been determined (which diseases to include and the number considered) and factors affecting this are discussed within the Background of this thesis. For the purpose of this thesis, a definition based on data available and a review of common and comparable indices and disease lists has been developed of 2+ chronic conditions from a list of 13 (arthritis; asthma; cancer; chronic bronchitis, emphysema, or COPD; diabetes; heart disease; hepatitis B; hepatitis C; high blood pressure; liver disease; mental disorder (anxiety and/or depression); PTSD; stroke) (27,35–37).

Using data from the *Our Health Counts Toronto: Developing a Population Based Urban Aboriginal Cohort to Assess and Enhance Individual, Family, and Community Health and Wellbeing* (OHCT) survey, collected using RDS methodology, this thesis seeks to expand our understanding of urban Indigenous health. Understanding the relationship between multimorbidity and unmet health needs could indicate potential health system improvements, and high risk population segments that need specific support. Understanding the relationship between exposure to discrimination by a healthcare provider and unmet health needs could contribute empirical evidence of the negative effect discrimination can have in the health care setting and reinforce calls for training in cultural safety for healthcare providers.

1.4 Community-based participatory research

This thesis seeks to achieve the highest standard of ethical research through both adherence to biomedical research ethics in Canada and Norway, and adherence to Indigenous research ethics standards in Canada. The ethical guidelines used for the research conducted by the Royal Commission on Aboriginal Peoples (RCAP) speak to the importance of ensuring that Indigenous perspectives and understandings are reflected within research into Indigenous experience (38). The principles of OCAP® (Ownership, Control, Access and Possession), critical to ensuring Indigenous control over Indigenous research data, form the basis of the OHCT study (39). The OHCT is a research study designed and implemented in partnership between the Well Living House action research centre based at St. Michael's Hospital in

Toronto, and Seventh Generation Midwives Toronto (SGMT), a midwifery practice group focused on serving the urban Indigenous community (40).

The Well Living House is directed by Métis academic primary investigator Dr. Janet Smylie and co-governed by St. Michael's Hospital, where it is located, and a Counsel of Indigenous Grandparents including elders Jan Longboat, Madeleine Dione Stout, and Carrol Terry. As the Indigenous community partners, Seventh Generation Midwives Toronto are the data *owners* for the Our Health Counts Toronto research project (40). Sara Wolfe and Cheryllee Bourgeois, Indigenous midwives and founding partners of SGMT, are representatives in this research relationship with the Well Living House. While the data is stored on secure servers at the Well Living House action research centre, SGMT maintains control over what data is released, to whom and for what purpose (40). There is also a project reference group comprised of 20 plus local and regional Indigenous and allied health and social service organizations that meets quarterly to help guide the research process. Many stakeholders were involved in the survey design, including survey question development, data analyses, interpretation and sharing of the results. A review of the research results presented within this thesis was conducted by Seventh Generation Midwives Toronto, as data owners and representatives from the urban Indigenous community of Toronto.

1.5 Aims

Key research questions for this thesis are: Is there an association between the two exposures of a. multimorbidity and b. self-identified discrimination by a healthcare provider and the outcome of self-identified unmet health needs in the last 12 months? The available data from the OHCT study, (with a total cohort *n* of 917) and a final thesis sample *n* of 836, corresponding to a much larger population through RDS-weighting, is sufficiently powered (at 90% power) to identify large differences between proportions (more than 20% difference in proportions).

In keeping with these key research questions, the primary objectives of this thesis are to examine: a. the association between having multimorbidity and having an unmet health need in the last 12 months, and b. the association between ever experiencing discrimination by a healthcare provider and having an unmet health need in the last 12 months.

A key secondary aim is to understand the interaction of multimorbidity on the relationship between discrimination by a healthcare provider and having unmet health needs. Further secondary aims are to examine the effects of including additional potential causal factors including regular healthcare provider, age, gender, education, employment, food

security, mobility, income level on the main associations through stratification analysis. Analyses presented here are limited to stratification analysis due to the complexity of multi-variable analysis in RDS samples, which was deemed beyond the scope of this Master's thesis.

2 Background

2.1 Health inequities endured by Indigenous peoples of Canada

Indigenous peoples of Canada experience enormous health disparities compared to the general population of Canada, stemming from current and historical health inequities (13,14). The current health status of Indigenous peoples in Canada must be understood within the context of current and historical colonial policies implemented by the Canadian government and other colonial institutions, from the loss of land and autonomy, the creation of the reserves systems, the historical removal of Indigenous children into residential schools, and to the current removal of Indigenous children by the child welfare system (13,14). There have been 23 successive Canadian governments since Confederation in 1867, each with colonial policies ranging from active assimilation and extermination to a callous unwillingness and ineffectiveness to resolve documented inequities.

One specific example, discussed here to assist readers unfamiliar with Canadian colonial history, to make the connection between historical trauma and current health inequities endured by Indigenous peoples of Canada. The Residential School System implemented by Canada's first prime minister, Sir John A. Macdonald, spanned over 100 years, with the last residential school closing as recently as 1996 (12). For over 100 years Indigenous children were forcibly removed from their families and communities and sent to live for most of their childhood in residential schools where physical and sexual abuse was rampant, and many children died (12). The Truth and Reconciliation Commission (TRC) of Canada was set up as part of a settlement agreement with survivors and involved a six-year process of travelling across Canada to listen and document the experiences of survivors (12). The final report, with the experiences of over 6000 witnesses, most of whom were survivors of the Residential School System, who documented their suffering and the health and social consequences that resulted, was published in 2015 and referred to the Residential School System as an apparatus of cultural genocide (12).

Cultural genocide is the destruction of those structures and practices that allow the group to continue as a group. States that engage in cultural genocide set out to destroy the political and social institutions of the targeted group. Land is seized, and populations are forcibly transferred and their movement is restricted. Languages are banned. Spiritual leaders are persecuted, spiritual practices are forbidden, and objects of spiritual value are confiscated and destroyed. And, most significantly to the issue at hand (The Residential School System), families are disrupted to prevent the transmission of cultural values and identity from one generation to the next. (The Truth and Reconciliation Commission of Canada, Summary of the Final Report, pg. 1) (12)

It is important to highlight the findings of the TRC because of the specific wide-ranging health impacts, both physical and mental, of the Residential School System, through the action of splitting families and disrupting of cultural identity (12,41).

Not only has the TRC shed light on the truth of the Residential School System, it has also pointed to a path of reconciliation for Canada. The TRC made 94 calls to action on wide ranging themes of child welfare, education, language and culture, health, and justice among many others (12). The health-related calls to action include addressing the gaps in health outcomes and health funding, resolving jurisdictional disputes over responsibility, building capacity by increasing the number of Indigenous health professionals, and ensuring that medical and nursing students receive specific training in Indigenous history and health (12).

The Residential School System and the trauma that it caused was made possible by pervasive racism towards Indigenous people by colonizing settlers and their descendants. A 2006 systematic review by Dr. Yin Paradies of empirical epidemiological research on racism and health examined 138 quantitative population-based studies and found research into racism focusing on interpersonal racism (“i.e. racist interactions between people”) and systemic racism (“i.e. racism occurring through societal organizations, institutions, laws, policies, practices etc.”) (42). This review found strong associations between self-reported racism and negative mental health outcomes and health-related behaviours (42). Integral to racism is an inferiority/superiority paradigm with both detrimental effects for those oppressed and also privileges resulting from racism accruing to the perpetrators (42). A 2015 review by Dr. Billie Allan and Dr. Janet Smylie on the role of racism and colonialism in Indigenous health in Canada improved our understanding of racism by including discussion of epistemic racism (the positioning of the knowledge of one racialized group as superior to another and passing judgement on what constitutes knowledge) and internalized racism (the acceptance and internalization of an ideology of racial inferiority) (14). Allan and Smylie indicate that in the Canadian context, perpetuated stereotypes about Indigenous peoples “*serve to justify acts of belittlement, exclusion, maltreatment or violence at the interpersonal, societal and system levels*”, including the stereotyping of Indigenous peoples as “*sick, disorganized and dysfunctional*” (14). The majority of Indigenous people surveyed by the 2010 Urban Aboriginal Peoples Survey in Toronto indicated that they had experienced discrimination through negative behaviours such as insults and unfair treatment (41).

2.2 Indigenous health data

Many of the health data sources to date that can be used to inform our understanding of Indigenous health have received criticism for inadequately identifying Indigenous people and for sampling bias that underestimates the burden of ill-health within this population.

The issue of identifying Indigenous people within health data sources stems from the history of colonial policies designed to disrupt Indigenous identity. Key colonial legislation pertaining to Indigenous identity is discussed here. The original Canadian Constitution Act, 1867 utilizes the colonial term ‘Indians’ to refer to the Indigenous peoples of Canada (43). This was further segregated and confined by the introduction of the concept of registered Status vs non-Status Indians in the Indian Act of 1876 (44). ‘First Nations’ people refers to both Status and non-Status Indians (under the Indian Act, 1876) from more than 50 Nations found in over 630 communities in Canada (5). In April 2016, however, the Supreme Court of Canada upheld a 2013 ruling in the *Daniels v Canada (Indian Affairs and Northern Development)* case that Métis and non-Status Indian people are considered “Indians” within the Canadian Constitution Act, 1867 (45).

‘Indigenous’ peoples of Canada encompass an earlier term ‘Aboriginal’ as introduced in the Canadian Constitution Act, 1982, which included all individuals who self-identify as either Indian, Inuit or Métis people of Canada, irrespective of living on or off a reserve or if they have Status granted from the Indian Act, 1876 (46). The term ‘Aboriginal’ is originally a government imposed, legally defined term, collectively referring to all of the Indigenous peoples of Canada (14). The use of the term ‘Indigenous’ is more appropriate, though there is no legal definition for this term in Canada, and is gaining strength, displacing usage of ‘Aboriginal’ (47).

Indigenous health information available in Canada is limited by the inconsistent, inconclusive and unreliable gathering of Indigenous identity (9). The imposition and segregation of Indigenous identity through colonial policies and the use of identity as a tool for discrimination, has led many Indigenous people to reject identifiers that do not adequately reflect their identity and to lose trust in attempts to identify them. There is also discordance within some health surveys that inadequately address how to identify Indigenous peoples, between those who indicate that they have Indigenous ancestry and those who indicate that they identify as Indigenous (48). An examination of the Canadian Community Health Survey (CCHS) 2009-2010 (self-reported) health status data for diabetes, arthritis and hypertension found no significant difference in prevalence despite these different approaches to identifying Indigenous peoples (48). The Canadian Census has consistently asked about Indigenous

ethnicity, however its questions have only been refined to an adequate level to capture the diversity of Indigenous identity in 1996 (10).

The second key issue affecting Indigenous health data sources is the use of sampling frames that are affected by systematic bias. Smylie and Firestone have identified sources of systematic bias within census-based sampling frames (9). Sources of bias included significant block non-participation, undercounting of housing insecure, homeless, institutionalized, those who struggle with literacy, those who are mobile in their places of residence, and non-participation due to distrust and/or disagreement with federal governmental agencies (9). Statistics Canada identified that 31 on-reserve First Nations communities were not enumerated, including 14 reserves which refused enumeration (49). The overrepresentation of Indigenous people in the homeless community, within institutionalized settings and the high mobility within the population mean that a large proportion of the Indigenous population will not be identified through address-based sampling frames, used by the National Census (9). Health sources regarding urban Indigenous populations are particularly vulnerable to under-sampling of the homeless Indigenous population, a segment of the population that has a higher burden of ill-health (9). Smylie and Firestone have indicated that these systematic biases within the 2011 National Household Survey and within the 2001 and 2006 Canadian Census are likely to underestimate counts and skew results (9). The CCHS and Indigenous specific health assessments, such as the Aboriginal Peoples Survey (APS) conducted by Statistics Canada in 1991, 2001, 2006 and 2012 and, utilize the same census-based sampling frame and are also affected by these biases (9,17,18).

The inconsistent and unreliable gathering of Indigenous identity in health surveys and systematic bias towards the more affluent and healthier segment of the Indigenous community are issues that contribute to the critical gaps in knowledge regarding Indigenous health in Canada. These issues can be mitigated in part by a. vigorous engagement with the Indigenous community to ensure ownership, trust, and participation in the research, b. use of Indigenous identifiers that capture the diversity of Indigenous identity, and c. development and use of sampling methodologies, beyond simple random sampling, that can adequately characterize Indigenous populations.

2.3 Urban Indigenous health

Despite the growing proportion of Indigenous people that live in urban centres in Canada, research on the health of urban Indigenous peoples is limited. The urban Indigenous population in Canada has been growing over the last half century with the 2006 Census

estimating 54% of Indigenous people live in urban centres, up from 50% in 1996 (11). Of the 2006 urban population 50% were First Nations and 43% were Métis (11). This growth of the urban Indigenous population comes despite research indicating that net migration of Indigenous people is from urban communities to reserve communities (50). Growth has been attributed to the lesser impact of a high birth rate and to a greater extent the changing patterns of self-identification over time, termed ethnic mobility (50). Ethnic mobility occurs slowly and may have been influenced by legislative changes such as Bills C-31 and C-3 to the Indian Act in 1985, allowing many previously excluded under the act to seek Status and empowering them to claim their identity (50). The largest growth occurred within the Métis community where growth rates ranged from 6.8% to 8.6% per year from 1996-2006 (50).

Reviews of the research conducted on the Indigenous population within the health sciences and social sciences have found the urban Indigenous population, the Métis, and First Nations living off reserves to be significantly understudied when compared to the general Canadian population or even the non-urban Indigenous population (19,51). In a Medline search of published scientific literature in the health and social sciences covering 1992-2001 which generated 254 citations, Young found only 5 studies that dealt with the health of urban Indigenous peoples (51). Despite the identified dearth of Western scientific research, the urban Indigenous community holds considerable knowledge regarding for example, the size of the urban Indigenous population, the high poverty rate, and ways to improve health within their community. Attempts have been made since 2001 to address this Western scientific research knowledge gap and characterize the health status of the urban Indigenous population. Several key studies on the Indigenous population of Toronto and other urban centres in Canada are discussed here.

The 2010 Urban Aboriginal Peoples Study (UAPS), undertaken by the Environics Institute, utilized mixed-methods to investigate Indigenous populations in 11 cities across Canada, including 250 Indigenous people in Toronto (41). The 2011 Toronto Aboriginal Research Project (TARP) was a mixed methods study, by the Toronto Aboriginal Support Services Council, of 1,424 Indigenous people living in Toronto (52). Health of the Toronto Indigenous population was not the direct focus of either study, however access to health services and experiences of discrimination were discussed among other social determinants of health (41,52). Analysis of the UAPS interviews found participants had significant pride in their Indigenous identity and many stayed connected with their communities of origin (41). The TARP study found persistent widespread poverty and related social challenges despite increases in education level, employment and income level (52). Racism against Indigenous

peoples, not a direct research priority, emerged pervasive within almost all areas of focus (52). A strength of the TARP was its community-based participatory approach with mixed methods and the action-focused recommendations that went beyond simply presenting the data.

In 2013 Senese and Wilson published a qualitative study of in-depth interviews with 36 Indigenous people living in Toronto (53). This study focused on the conceptions of and access to Indigenous rights in Toronto and examined perceived links to Indigenous health (53). Rights identified by the respondents largely focused on rights to specific services and benefits, and to respect for Indigenous cultures and identities (53). While the majority of the sample were First Nations women, their experiences of pervasive discrimination and disrespect to Indigenous rights of culture and identity mirrored earlier findings from the UAPS and TARP (53). Disrespect of Indigenous rights was perceived to have a negative impact on health mediated through socioeconomic factors such as availability of material support and psychosocial factors such as the stress of accessing services and rights within the city (53). Respondents also reported discrimination from healthcare providers such as when trying to pay for services using non-insured health benefits (NIHBs), including being turned away upon presentation of their documentation (53). This report provides unique insight into the experiences of urban Indigenous peoples in Toronto, analyzed through the lens of Indigenous rights as social determinants of health.

The 2011 *Our Health Counts* (OHC) Hamilton comprehensive health study of the urban Indigenous peoples of the city of Hamilton, Ontario, is the predecessor of the *Our Health Counts Toronto* (OHCT) survey analysed in this thesis. The OHC study of Hamilton, conducted in community based partnership with De dwa da dehs nye's Aboriginal Health Access Centre remains arguably the best population based sample available for the health of the urban First Nations population, both adults and children living and accessing services in Hamilton, Ontario (16). What set the OHC apart from studies like the UAPS and TARP was its direct quantitative focus on health, its commitment to community based participation through the involvement of De dwa da dehs nye's Aboriginal Health Access Centre throughout the process of design, implementation, analysis and dissemination, and its use of Respondent-Driven Sampling (RDS) methodology to deal with the absence of an adequate population-based sampling frame (16,54). RDS methodology, also utilized to gather the data analyzed in this thesis, is discussed in depth within Background. The OHC study sampling began with 6 seed respondents, identified through the De dwa da dehs nye's Aboriginal Health Access Centre, with up to five recruitment coupons given to each respondent (16). The

dual incentive system, vital to RDS recruitment, was refined in partnership with Indigenous community members and partner organizations to ensure that incentives were respectful and non-exploitative (16,20). In total 554 First Nations adults were recruited and completed the comprehensive health survey (16). Population-based estimates for the urban First Nations population of Hamilton were derived from this sample through RDS-data specific statistical analyses.

Key findings that were brought to light by the 2011 OHC study confirmed the community understanding of the high levels of poverty among First Nations residents of Hamilton, with 79.2% of First Nations peoples earning less than \$20,000 per year (16). Poverty was accompanied by high mobility (90% of the First Nations had moved at least once in the past 5 years), high levels of homelessness (13% reported being homeless), and overcrowding (73.7% of First Nations reported living in crowded conditions) (16). The First Nations living in Hamilton also reported a disproportionate burden of chronic conditions such as a 15.6% prevalence of diabetes, three times greater than the general Hamilton population (16). Access to health care was indicated to be fair or poor by 40% of the First Nations population (16). The overrepresentation of First Nations peoples in the emergency room for acute and non-acute illness, 52% reported at least one visit over the past two years compared to 22% for the general Hamilton population, provides further evidence of poor access to health care (16). The findings of the OHC provided empirical evidence to support the community understanding of the health and socioeconomic status of First Nations living in Hamilton, while making it clear how egregious the lack of adequate urban Indigenous health data is for other urban centres across Canada.

2.4 Concept of unmet health needs

The prevalence of self-reported unmet health needs constitutes a useful metric of the ability of our health system to function effectively. The 2014 iteration of the CCHS found approximately 11.2% of Canadians reported that they did not receive health care when they felt they needed it (21). Women (12.4%) were more likely than men (10.0%) to report unmet health needs (21). Analysis of CCHS data showed that characteristics associated with higher rates of unmet healthcare needs included Indigenous identity, not having a regular medical doctor, and having at least one chronic condition (21). In the 2014 CCHS, 16.2% of Indigenous survey respondents reported unmet health needs while 18.2% of Indigenous survey respondents who did not have a regular doctor reported unmet health needs (21). Among those with at least one chronic condition, 14.0% reported unmet health needs (21).

2.5 Access to a regular healthcare provider

In her 2005 synthesis, Adelson indicates that general health care service provision for Indigenous peoples began to be addressed systematically only after the second world war, and was paternalistic in nature, with gaps in access persisting (13). An example Adelson raises from an earlier paper by Corinne Hodgson in 1982, describes the intervention treatment of tuberculosis in the 1950s (13). Indigenous people testing positive for tuberculosis were removed to sanatoriums far from their home communities (13). The paternalistic imposition of treatment, stemming from the western biomedical paradigm, constitutes an example of epistemic racism (defined above) against Indigenous knowledge of treatment and concepts of wellness, and Adelson highlights the connection within the Indigenous community to a lingering fear of institutions (13).

Adelson goes on to note the health services gaps currently felt by Indigenous peoples living in urban centres, who find themselves excluded from many of the services and benefits of the First Nations and Inuit Health Branch of Health Canada (13). These gaps in health services are in part the result of the patchwork nature of the Indigenous health legislative and policy framework at federal, provincial and territorial levels (22). A 2013 review by Josée Lavoie of policies and legislation concerning Indigenous health found significant jurisdictional ambiguities that perpetuate confusion regarding where and how Indigenous peoples can access health care (22).

Primary health care services are most often the first point of contact patients have with the Canadian health care system, received through meeting with a regular health care provider (55). A consequence of not having access to primary care through a regular health care provider is an increased dependency on emergency departments (ED) for stable and non-urgent health issues. Annette Browne et al. in 2011 published an exploration of the perspectives of Indigenous and non-Indigenous patients who presented to an ED in an urban centre in western Canada (23). The sample included 44 patients who presented with stable non-urgent health needs with 34 self-identifying as Indigenous (Status First Nations, non-Status First Nations, and Métis) (23). The analysis within this report focused primarily on the open-ended interviews lasting 30-60 minutes conducted with the Indigenous patients within the sample (23). Three themes were discussed within the analysis a) patient's anticipation of provider's assumptions, b) seeking help for chronic pain, and c) use of the ED for primary care as a reflection of social suffering (23). Brown and colleagues identify the paradox of, both Indigenous and non-Indigenous, patient's descriptions of reliance on ED services due to absence of alternatives or expectation of poor services elsewhere, and their descriptions of

dissatisfying experiences at the ED due to unmet health needs (23). Authors note that EDs are not designed to respond fully and effectively to the complex health and social issues that require longitudinal and interdisciplinary care and support (23). False perceptions of misuse of EDs for primary care may perpetuate racist assumptions within healthcare providers. The boundaries that force those caught in conditions of social suffering into EDs for primary care, include geographic (social boundary lines between inner city and gentrified neighbourhoods), historic (anxiety when talking to people in positions of authority or power stemming from historic abuse and trauma in institutions) and people's lived experiences of racialization and marginalization (primary care providers who screen out patients who have complex mental health problems, addictions, or related health and social issues) (23). The 2011 OHC Hamilton study found higher rates of emergency room admissions for First Nations people for both acute and non-acute health needs (16). Among the First Nations population of Hamilton, 10.06% reported six or more emergency room visits in the previous two years compared to 1.6% for the general Hamilton population (16). Barriers to care identified by respondents included long wait lists (48%), lack of transportation (35%), unable to afford out-of-pocket health expenditures (32%), doctor was unavailable (29%) and lack of trust in health care provider (24%) (16). The barriers found in the OHC Hamilton have led to increased resources and expanded services provided by the Indigenous health service provider, De dwa da dehs nye's Aboriginal Health Access Centre (16). Access to a regular healthcare provider affects unmet health needs and may be impacted by discrimination by healthcare providers and increased patient complexity (represented by multimorbidity status).

2.6 Discrimination by healthcare providers

Annette Brown and colleagues discuss experiences of discrimination by health professionals in the urban Indigenous population in their 2011 report (23). Within the qualitative interviews conducted, Indigenous patients expressed concern about how health care providers may respond to them, through dismissal or diminishment of their health issues, based on appearances of poverty and inner-city residence status (23). Among Indigenous respondents, these concerns included being treated differently based on their visibility as an Indigenous person (23). Analysis indicated that many Indigenous patients were attuned to negative body-language and non-verbal communication from health care providers (23). Within the context of chronic pain relief, Indigenous patients were concerned with how they would be judged and whether their chronic pain issues would be dismissed or devalued (23). As Brown and colleagues note, assumptions regarding drug seeking behaviour, are key

determinants in health care provider decision-making around chronic pain relief medication (23). Indigenous respondents were concerned about the intersection of these assumptions with discriminatory assumptions regarding their Indigenous identity (23). In this way past experiences of discrimination by health professionals grow into assumptions regarding the potential for future discrimination by other health professionals. This may create delays in seeking health care and impact a person's likelihood of having unmet health needs.

One population-based study of 1,699 White, African American, Mexican and Puerto Rican respondents in the United States found discrimination in health care settings was associated with poorer perceived quality of care and more unmet health care needs (24). Under an adjusted logistic regression model those discriminated against in health care settings had 2.48 (95%C.I. of 1.57-3.90) odds of ever having unmet health care needs and 0.43 (95%C.I. of 0.28-0.66) odds of indicating they received excellent quality care (24).

Self-identification or perceived racism has served as the benchmark method for research in discrimination (14). Discrimination within the healthcare system can also be indirectly identified through analysis of medical records, such as the 2009 retrospective medical record review conducted in Townsville, Australia (56). Richard Brown and Jeremy Furyk examined the records of 276 (76 Indigenous (Aboriginal and/or Torres Strait Islanders) and 200 non-Indigenous) patients presenting to the Townsville Tertiary hospital who received ICD-10 diagnoses for minor head injury over a three year period (56). Brown and Furyk found statistically significant evidence that Indigenous patients in Australia waited on average 13.5 minutes more than non-Indigenous patients (56). Indigenous patients also had higher odds 2.6 OR (1.26-5.42 95%C.I.) of receiving a serum ethanol test, despite authors noting this test to be irrelevant to clinical decision-making related to the diagnosis (56). The 2011 OHC Hamilton study found prejudice, lack of trust, and discrimination to be frequent barriers to accessing care for the First Nations population of Hamilton (16). Policy recommendations stemming from these findings included a. adequate support for Indigenous specific services, b. implementation of cultural competency and safety programs, and c. recognition and validation by all levels of government, of Indigenous cultural worldviews and self-determination in health care delivery (16). Understanding the impact of discrimination by healthcare providers on the urban Indigenous population could assist in its elimination.

2.7 Concept and impact of multimorbidity

Comorbidity was first defined by Feinstein in 1970 as “any distinct additional clinical entity that has existed or may occur during the clinical course of a patient who has the index

disease under study” (57). While this is a useful term in understanding patients whose index disease is significantly more severe than their additional conditions, it does little for those whose conditions overlap or whose clinical care plan fails to account for potentially synergistic disease relationships. To address this, the term multimorbidity has developed to refer to the situation when a patient has multiple chronic conditions, where one is not necessarily more central than the others (25,26). Multimorbidity is distinct from comorbidity because it refers to situations where there is no primary or index disease (25,27).

As Boyd and Fortin highlight in their 2010 review regarding our understanding of multimorbidity and patient complexity, the patient experiences multimorbidity within their social, educational, cultural, economic and environmental context (26). Disease impact has also been found to increase with age and differ between genders, with women having a higher prevalence (32,33). Socio-economic status and quality of life was found to be inversely associated with multimorbidity (33,34). The Boyd and Fortin review in 2010 found research to indicate multimorbidity affected quality of life, ability to work, and employability, increased mortality, increased probability of hospitalization and more nights spent in hospital, increased out-of-pocket health expenditures, and contributed to higher risk of hospital-acquired infections (26,30,31). A 2005 review by Vogeli et al. found evidence that patients with multiple chronic conditions had a significantly greater association with disability than for the diseases in isolation, indicating a potential synergistic interaction resulting from multimorbidity (29).

Boyd and Fortin go on to stress the importance, for patients with multimorbidity, of patient-centred care that is coordinated between multiple care sites such as emergency rooms, hospitals, outpatient settings, speciality clinics and community health centres (26). The 2005 Vogeli review found the increased coordination required for patients with multimorbidity creates greater potential for suboptimal quality care (29). The complexity of multimorbid patient care has been attributed in part to the research focused on single disease treatments that make it unclear for physicians how best to treat multiple diseases simultaneously (58). Boyd and Fortin warn of the increased risk patients with multimorbidity face from the hazards of hospitalization, polypharmacy, and post-operative complications (26). Boyd and Fortin also found limited applicability of clinical practice guidelines (CPGs) to cases of multimorbidity and included within their review a noteworthy example of applying current CPGs to a theoretical elderly multimorbid patient (26). The pharmacologic and non-pharmacologic regime suggested was complex: overlapping, contradictory and with potential drug-drug interactions, possibly dangerous (26).

2.8 Measuring multimorbidity

No common consensus, or gold standard, exists regarding the measurement of multimorbidity (27). Researchers and clinicians have used tools to capture multimorbidity ranging from simple disease counts to indexes which draw upon disease severity to examine disease burden (27). A 2011 systematic review Diederichs *et al.* found 59% of the 39 population-based studies included did not give specific criteria for the selection of chronic conditions investigated, which ranged from four to over 100, suggesting pragmatic reasons for selection, such as availability of data, are common (35). Within these 39 articles included, diabetes mellitus was the most commonly included disease followed by stroke and cardiovascular diseases (35). Confounding the creation of a gold standard tool is the wide variation in scientific opinion over what constitutes a chronic condition (27). Comorbidity of two diseases can fit within several etiological models of association: no association, direct causation, associated risk factors, heterogeneity, and independence (59). Researchers have also identified chronological issues with the concept of multimorbidity, specifically examining the sequence of chronic conditions (59). Diseases can positively and negatively interact affecting diagnosis, treatment and prognosis of a second disease (59). In an example identified by Valderas *et al.* in 2009, a patient with established diabetes who is diagnosed with depression may be different from patients with depression who are later diagnosed with diabetes, though through a cross-sectional lens both would be identified as patients with diabetes and depression (59). In this way, equal priority is given to each disease, which can hide differences in disease severity. Severity or the notion of burden of illness is a key concept of multimorbidity and a multitude of indices have been developed attempting to include measures of severity or burden (25,59–62).

Another factor in the choice of chronic conditions considered, or case definition for multimorbidity, is the available data. Depending on the population under investigation and the study design, researchers examine data from self-reported chronic conditions, medical charts and other administrative sources. Alternative data sources lead to separate approaches as patients may not recall their exact diagnosis and find it easier to identify broader disease groups such as ‘heart disease’ and ‘arthritis’. The diagnostic codes used in medical charts and in health system reimbursement allow for a detailed approach to examining specific diseases, including the use of detailed indices (25,59–62). Comparisons between self-reported and administrative data sources for chronic disease and multimorbidity surveillance found mixed results. The Canadian population data sources, the self-reported Canadian Community Health Survey and administrative records from the Manitoba Health Services Insurance Plan, were

compared for arthritis, asthma, diabetes, heart disease, hypertension and stroke (63). Hypertension and diabetes had the greatest level of agreement between the two data sources, while arthritis had the lowest agreement (63). Lix et al. suggest their findings are consistent with previous research and conclude that the difficulty in diagnosing arthritis and its identification with non-specific diagnostic codes may contribute to the low agreement between data sources (63). These findings were supported by another Canadian study which found high agreement between self-report and administrative data for diabetes and hypertension, with lower agreement for stroke (64). Another study of Montreal Emergency Department patients found limited agreement between self-reported multimorbidity and administrative records for calculation of the Charlson Comorbidity Index, though both indices had similar predictive validity (65).

Dr. Michael Fortin, an editor-in-chief of the *Journal of Comorbidity*, has contributed significant work towards measuring and understanding the complexity of multimorbidity (36,66). With others, he reported in 2012 that any 12 highly prevalent conditions, based on population level prevalence, should suffice to measure multimorbidity accurately and comparably (36). Four to seven diseases, it was suggested, would be vulnerable to bias in comparability between prevalences and provide an underestimation of the burden of multimorbidity in a given population (36,67). This claim was examined further in 2014 by Harrison et al. who found that studies defining multimorbidity as two or more (2+) chronic conditions could be compared between studies with different multimorbidity classifications (37). Utilizing the 12 most prevalent chronic conditions provided an estimate that was reasonably close to the estimate when utilizing two or more of 'all' chronic conditions (37).

The Public Health Agency of Canada (PHAC) developed a definition of multimorbidity at a technical meeting, held on December 14, 2012, of experts in the field of multimorbidity, including a presentation from Dr. Michael Fortin (68). From the summary report for this technical meeting it is clear that Dr. Fortin presented current research, including his own analysis that a final list of diseases should include at least 12 highly prevalent diseases, based upon population-based prevalences (36,68). Despite this, the resulting case definition devised by PHAC included only 10 diseases (asthma, arthritis, COPD, diabetes, heart disease, mental disorders (mood disorder and/or anxiety), Alzheimer's disease (and related dementias), cancer, and stroke). While Alzheimer's disease had a low prevalence within the population, its inclusion at the technical meeting was attributed to the high-impact of the disease (68). This definition designed by PHAC is likely to systematically underrepresent the burden of multimorbidity, as it includes 10 diseases, versus the suggested

12 most prevalent conditions, and included Alzheimer's disease with a low population prevalence. Treating depression and anxiety as a single disease entity, under mental disorder (depression and/or anxiety) may serve to underrepresent the burden of mental health in the population, though co-occurrence is common.

2.9 Chronic conditions and multimorbidity in the Indigenous population

The 2015 WHO global status report indicates non-communicable diseases (NCDs), including many chronic conditions, were responsible for 38 million (68%) of the world's 56 million deaths in 2012 (69). In her 2005 synthesis of health disparities, Naomi Adelson touches on the historic disease profile of Indigenous peoples in Canada, noting that current disease burden is in stark contrast to the historic, pre-contact disease burden of Indigenous peoples (13). While the pre-contact period was not disease free, Indigenous people coped with cyclical famines, parasitic infections, accidents among other diseases, Adelson indicates that chronic conditions such as diabetes and cancer are emerging threats (13). For example, Adelson points out non-insulin-dependent diabetes mellitus was previously unknown to Indigenous populations (13).

The findings of the 2011 OHC Hamilton study described earlier found First Nations living in Hamilton reported a disproportionate burden of chronic conditions such as diabetes (15.6%), high blood pressure (25.8%), arthritis (30.7%), Hepatitis C (8.7%), and mental health disorders (42%), despite having a younger population (16,70). A recent report from Cancer Care Ontario entitled '*Path to Prevention: Recommendations for reducing chronic disease in First Nations, Inuit and Métis*' utilizes combined 2007-2010 CCHS data to estimate chronic condition disease burden in off-reserve First Nations and Métis populations (71). In the off-reserve First Nations population 19.4% reported cardiovascular disease, 8.7% reported diabetes, 15.6% reported asthma, 4.3% reported chronic obstructive pulmonary disease (COPD), 1.5% reported cancer and 12.4% reported high blood pressure (71). In the Métis population 18.1% reported cardiovascular disease, 4.9% reported diabetes, 12.1% reported asthma, 3.2% reported chronic obstructive pulmonary disease (COPD), 0.6% reported cancer and 12.1% reported high blood pressure (71). The discrepancy between the CCHS disease burden for diabetes and high blood pressure, and the prevalences found within the OHC study may in part be reflective of the systematic sampling bias that affects the census based sampling frame used in the CCHS, discussed earlier.

Despite initially conflicting reports, most recent evidence indicates the prevalence of multimorbidity is higher within the Indigenous population versus the non-Indigenous

population in Canada, consistent with the greater disease burden observed for individual chronic conditions (28,71,72). Analysis of the 2011/2012 cycle of the CCHS indicated the prevalence of 2+ chronic conditions (from a list of 9 chronic illnesses developed by a technical meeting of the Public Health Agency of Canada, discussed earlier) was 17.3% for those who self-identified as Indigenous (on-reserve Indigenous communities were not included within the CCHS) versus 13.5% for the non-Indigenous population (28). A knowledge gap remains in our understanding of the prevalence of multimorbidity in the urban Indigenous population, as 17.3% is likely an underestimate due to a. the limited number of conditions included and b. systemic bias in the CCHS towards under-sampling of Indigenous peoples with a lower socio-economic status, a segment likely to suffer a higher burden of multimorbidity.

2.10 Respondent-Driven Sampling methodology

RDS methodology was developed since the 1990's, to collect data from 'hidden' or marginalized populations, populations for which no adequate sampling frame exists (simple random sampling is inadequate) and where identifying as a member of the population may carry real or perceived repercussions (20,73,74). In his initial presentation of the methodology in 1997, Heckathorn showed, using Markov-chain theory and analysis of incentive systems, that as recruitment progresses, a sample selected via modified chain-referral develops a random character distinct from the characteristics of the initial seed respondents (20). Conceptually, recruitment within an RDS chain can be considered a finite Markov Chain whereby the social characteristics of each recruiter probabilistically affect who they recruit (20). These characteristics can be considered the states of the chain, and the transition between states is governed by transition probabilities. The next state is only dependent on the previous state and not on the states prior to it. With sufficient recruitment waves, the characteristics of the sample recruited reaches an equilibrium, approximate to a random sample of the general population (20,73). The equilibrium state, or convergence, is estimated to be reached after 4-6 waves of participants (75). More than 6 waves are necessary to minimize the non-random selection of the seed (76). Limiting the number of coupons each participant receives, a maximum of five, ensures that recruitment trees can grow without becoming too dispersed.

Integral to RDS estimate calculation is the size of each participant's social network. Those with large social networks are more likely to be recruited to the sample than those who have a small network size of potential recruits (20). As a result, network size is utilized to

calculate probabilistic weights for each participant (20). RDS recruitment rests on several basic assumptions about the sampling and network structure including: sampling is ‘with’ replacement, the relationship between a recruiter and a recruit is reciprocal, respondents can accurately report their network size, and that respondents recruit randomly from within their network (20,77). In a 2014 study, Gile et al. examined these assumptions and developed basic diagnostic tests to assess their validity and impact within a sample (77). Reciprocal ties can be examined by asking respondents about their relationship to their recruiter. The ‘with’ replacement assumption was analysed by Gile and Handcock in 2012 as many RDS based studies do not actually follow ‘with’ replacement sampling (76). Discrepancy between ‘with’ and ‘without’ replacement was identified to particularly affect samples that include a large fraction of the population, though specific bias is only introduced if this differentially favours one characteristic or group within respondents (76,78).

A short description of an RDS recruitment process is presented here to help understand how RDS functions. Non-random seed respondents are selected, from locations where members of the target population are abundant. After completing the survey, seed respondents are provided with up to 5 recruitment coupons each, to distribute to people they know within the target population under study. The seed respondent hands out recruitment coupons to their network of peers within the target population, and receives an incentive for each of the coupons that leads to the successful recruitment of a new respondent. Each of the new respondents recruited are given an incentive to complete the survey. The new respondents are also provided up to 5 new recruitment coupons with instructions to recruit further respondents with incentives for successful recruitment. Each wave of subsequent respondents recruited receives this dual incentive, a. to complete the survey and b. to successfully recruit further respondents (20). This strategy helps to reduce non-response bias in RDS surveys (79). Altruistic motives for participation are also emphasized including the importance of health data to policy formation and the health of friends and family within their network. In this way respondents themselves exert social pressure on their recruits which provides additional incentive to the monetary reward (79). With coupon tracking, the referral pattern can be mapped to create recruitment trees which can help indicate to researchers when characteristics have reached equilibrium state, representative of proportions found in the total population (20).

By examining the social network of respondents in the recruitment chain and developing post-sampling weights related to the probability of recruitment, RDS methodology limits the bias introduced by the non-random selection of initial respondents or ‘seeds’ and

start locations (20,54,73). This distinguishes RDS from typical traditional chain referral sampling methods such as convenience and snowball sampling, and gives the potential to calculate accurate population-based estimates for characteristics of interest (20). The statistical grounding of the methodology has developed since 1997 for use with continuous variables, improvements to post-sampling weight estimators for unbiased population proportions and effect measures, along with respective confidence intervals using bootstrapping and variance recovery approaches (73–75,79,80). Studies utilizing RDS have successfully examined hidden populations such as HIV positive populations, injection drug users, men who have sex with men, the homeless, and with the 2011 OHC study, urban Indigenous peoples (54,75,80–82).

3 Methodology

3.1 Community-based participatory research methods used

The *Our Health Counts Toronto: Developing a Population Based Urban Aboriginal Cohort to Assess and Enhance Individual, Family, and Community Health and Wellbeing* (OHCT) is a comprehensive urban Indigenous health study, conducted using an Indigenous community-based participatory research method. This method is based upon principles of capacity building, respect, cultural relevance, representation, sustainability and OCAP® (Ownership, Control, Access and Possession) (39). The OHCT survey was conducted by the Well Living House in partnership with Seventh Generation Midwives Toronto (40). Many stakeholders were involved in the survey design, data analyses, interpretation and sharing of the results. A “respectful health assessment survey tool” was developed, building on the concept of a rapid health assessment tool through incorporation of domains of relevance to the Indigenous community identified through concept mapping and discussions with community partners, Seventh Generation Midwives of Toronto. Previous research has shown that Indigenous community members are willing to spend over an hour in interview with a trained Indigenous community surveyor, allowing a respectful transfer of information, considerably longer than the 20 minutes typical of a standard rapid health assessment survey (16). As the Indigenous community partner, Seventh Generation Midwives Toronto, owns the data and has complete control over what data is released, to whom and for what (40). Well Living House is an action research centre focused on Indigenous health within the Centre for Urban Health Solutions (C-UHS), a part of the Li Ka Shing Knowledge Institute of St. Michael’s Hospital. The Well Living House is directed by Métis academic primary investigator Dr. Janet Smylie and co-governed by SMH and a Counsel of Indigenous Grandparents with elders Jan Longboat, Madeleine Dione Stout, and Carrol Terry. Seventh Generation Midwives Toronto, is the founding midwifery practice at the Toronto Birth Centre. Sara Wolfe and Cherylle Bourgeois, Indigenous midwives and founders of the Toronto Birth Centre, are key representatives of SGMT in the research relationship with the Well Living House. There is also a project reference group comprised of 20 plus local and regional Indigenous and allied health and social service organizations that meets quarterly to help guide the research process.

The OHCT study received ethical clearance from the St. Michael’s Hospital Research Ethics Board. Ethical approval for the project has also been provided by the Well Living House Counsel of Grandparents and the Seven Generations Midwives Toronto. The specific analysis presented in this thesis received ethical approval from the Sør-Trøndelag Regional

Committee for Medical and Health Research Ethics (REK) in Trondheim, Norway. A review of the research results presented within this thesis was conducted by Seventh Generation Midwives Toronto, as data owners and representatives from the urban Indigenous community of Toronto.

3.2 RDS Survey methods used

All data in the OHCT survey was collected between March 2015 and March 2016 using RDS methodology to recruit Indigenous survey respondents. The target sample size for the OHCT survey was over 900 adults based upon recommendation and previous successful experience researchers at the Well Living House have had conducting RDS health surveys of urban Indigenous populations and the desired precision of population-based estimates (16,73). Inclusion criteria for the sample included self-identified Indigenous adults (aged 15+ years) residing in the census metropolitan area of Toronto. 20 initial seed participants were selected from diverse Indigenous identity, socioeconomic, educational, occupational, geographic, gender, and age backgrounds. Each participant was able to recruit up to five additional participants until the sample size was attained. There were three main sites where interviews were conducted: the Queen West Central Toronto Community Health Centre, Seventh Generation Midwives Toronto practice at the Toronto Birth Centre, and the Native Canadian Centre of Toronto. Several home visits were also made to conduct interviews with individuals who were less mobile. One-on-one interviews were used to complete a respectful health survey lasting approximately 90 minutes. All interviewers were Indigenous community members which contributed to creating culturally safe spaces for the interviews. Interview respondents were generous with their time and the stories they related, which speaks to their desire to share and the safe space successfully created by the interviewers.

The incentives utilized within the Our Health Counts Toronto Survey were developed through discussion and dialogue with Seventh Generation Midwives Toronto and agencies and organizations in the reference group. Incentives were set at \$20 CAD for completion of the survey and \$10 CAD for every successful participant a respondent recruits, up to a maximum of five. Respondents who were parents and guardians of Indigenous children received further compensation if they were willing to also complete a children's health survey (\$10 CAD per child). Social network size, integral to the post-weight estimation for RDS population estimates, was determined by self-report in answer to the question: "Approximately how many Aboriginal people do you know (i.e. by name and who know you by name) who currently live, work or use health and social services in Toronto?".

3.3 Statistical calculations conducted

Existing univariate and multivariate analysis methods for examining associations between factors are not directly transferable to RDS samples as random sampling assumptions are not maintained with RDS samples. Multivariable analysis methods for RDS samples are being developed and tested but were beyond the scope of this thesis. The association between exposures of a. multimorbidity and b. discrimination by a healthcare provider and the outcome of an unmet health need in the last 12 months were explored using cross tabulation. 2-way crosstabs were utilized to calculate an odds ratio of the effect of each exposure on the outcome. The 2-way crosstabs were then separately stratified by each potential covariate (i.e. 3-way cross tabs). Covariates included in the stratified analysis were access to a regular healthcare provider and sociodemographic factors (gender, age, education level, employment status, food security, mobility, and income level).

Responses from 45 of the questions in the OHCT study were used for the analysis (Table 4). The majority of these questions have been validated in previous surveys of Indigenous populations. The total number of participants included in the OHCT study cohort (of all surveyed Indigenous individuals (as determined by survey question q2_1) was 917. For the purpose of this analysis a final sample was drawn from this total cohort of 917. Exclusion from this final sample was based on missing data and data that lay outside of the categories developed for outcomes, exposures and potential covariates examined. The final sample size was 836 for the total Indigenous population. Analysis was not adequately powered to generate First Nations, Métis or Inuit specific results for the unstratified and stratified interaction of multimorbidity or exposure to discrimination by a health care provider, and unmet health needs.

A disease list of 13 chronic conditions, with high population based prevalences in Canada, was used to determine multimorbidity. Respondents were considered multimorbid with 2+ of the following conditions: arthritis; asthma; cancer; chronic bronchitis, emphysema, or COPD; diabetes; heart disease; hepatitis B; hepatitis C; high blood pressure; liver disease; mental disorder (diagnosed/undiagnosed anxiety and/or depression); PTSD (diagnosed/undiagnosed); stroke. Participants were considered to have a mental disorder if they had either received a diagnosis of depression or anxiety, or they had a high or very high score on the Kessler 10 scale, included within the OHCT survey. Participants were considered to have Post-Traumatic Stress Disorder (PTSD) if they had either received a diagnosis of PTSD or they had a positive score in the Primary Care – Post-Traumatic Stress Disorder (PC-PTSD) screener included within the OHCT survey. The other exposure was determined by

survey question regarding any experience of discrimination by a health care provider. The outcome examined was a self-identified unmet health need within the past 12 months.

New modified variables utilized in the analysis were developed using the Statistical Package for Social Scientists (SPSS) (83). RDS weights and wave number were calculated for each eligible participant through the RDS Analyst program which is powered by the statistical package R (84). The sample was weighted using the RDS.II weighting estimator developed by Volz and Heckathorn (76,85). For multimorbidity, data present in question q5_1o, a string question concerning other chronic conditions, was evaluated and where possible, added to the 13 chronic conditions included in the analysis (see Table 4). Data for employment was identified in question q3_2a, a string question concerning other employment. This data was added to the three categories developed for employment (see Table 4). The variable created for income presents a dichotomous measure, above or below the low-income cutoff (LICO) based on the 2014 Statistics Canada LICO cutoffs (86). PTSD included as a chronic condition was based on those who had received a diagnosis of PTSD (q18_6a_8) or those answering 'yes' to at least three of the four questions in the PC-PTSD screener scale (q18_12a – q18_12d) (87). Mental disorder was informed by several variables including self-reported diagnoses of depression and anxiety (q18_6a_1 and q18_6a_2) and a post-coded dichotomous variable 'depression_dicot' based on a cumulative K10 score from the Kessler scale (q18_9a – q18_9j, and derived K10Score). Individuals could rate the 10 questions of the Kessler scale (see Table 4) about how they have been feeling over the past 30 days with values of 1(none of the time), 2 (a little of the time), 3(some of the time), 4(most of the time), and 5(all of the time), with total scores ranging from 10-50. K10 scores can be broken into four categories: 10-15 (considered low), 16-21 (considered moderate), 22-29 (considered high) and 30-50 (considered very high) (70). Respondents who score over 22 would likely receive a diagnosis of anxiety and/or depression (70). Respondents with missing information in the Kessler Scale were examined for the degree of difference in final category if they had responded with 1 or 5. 15 respondents were completely missing responses and 12 gave partial answers to questions on the K10 score. Of the 12 partial missing respondents, those whose category could change based on the response were coded as missing. Respondents whose final category could not change regardless of scoring missing items with 1-5, were left as valid. This process left 4 partial missing respondents with K10 scores that could be used and 8 respondents who were post-coded as missing.

Initially RDS-weighted frequencies were used to build weighted crosstabs for unstratified and stratified odds ratio calculations. These crosstabs were evaluated for small

cell sizes and categories that included cells with fewer than 15 were combined into larger categories or left out of the analysis. Every attempt was made to preserve the original categories and to create categories that were meaningful for stratification. Table 4 indicates the questions that were utilized within each of the final categories used in the analysis. Initially two strategies for stratification were investigated: a. the odds of having unmet health needs for covariates, exposures and social determinants of health under investigation, stratified by presence of multimorbidity and by exposure to discrimination; and b. the associations between multimorbidity and exposure to discrimination and having unmet health needs, stratified by covariates, exposures and social determinants of health under investigation. The final stratification strategy presented within the results was the second (b.) strategy.

Frequencies and weighted frequencies for unmodified original variables and modified variables were calculated in SAS® University Edition (88). Odds ratios, unstratified and stratified, for the associations of interest were also calculated using SAS® University Edition (88). 95% confidence intervals were calculated in SAS® University Edition for each weighted frequency and odds ratio (88). Wald Chi-square tests were conducted to determine whether associations existed between exposures, potential confounders and the outcome (p-values were reported).

4 Results

4.1 Overview

A total of 940 complete interviews were conducted, with the final number of survey respondents eligible for inclusion at 917, those left out were deemed duplicates or were incomplete due to non-eligibility (i.e. non-Indigenous or significant missing data) discovered through the course of the interview. One non-Indigenous respondent with Indigenous children was kept for the RDS calculations, to ensure recruitment chains were not disrupted, however they were excluded from the final sample. A network diagram of the cohort of 917 was developed by Well Living House Data Analyst Kristen O'Brien and included as Figure 1 to present the recruitment trees within the sample. The cohort of 917 participants was further narrowed to a final sample of 836 by removal of participants who were missing data from key questions under investigation. The classification of inclusion in the sample for analysis is laid out in Figure 2. Two participants were removed for missing information on unmet health needs; 16 were missing information on discrimination by a health care provider; 17 were removed due to being underpowered in the subsequent analysis of their gender identities (Transgendered/Other gender) (the experiences of transgendered people of discrimination and the health care system are unique and need further study with a sufficiently powered sample); two were missing information on education level; one was missing information on employment; six were missing information on their food security; 28 were missing information on mobility in the last 12 months; and nine were missing information on income level. The sample of 836 included were spread over up to 19 waves of recruitment. Basic socio-demographic frequencies for the sample, with RDS-weighted population prevalence estimates, are presented in Table 1a. The RDS-weighted population prevalences of the sample of 836 approximate the RDS-prevalences derived from the full cohort of 917 respondents, with significant overlap of 95% Confidence Intervals. The mean absolute difference between RDS-prevalences for the full cohort ($n=917$) and sample ($n=836$) was $\pm 0.49\%$ for factors presented in Tables 1a and 1b. The largest difference (1.53%) was found between final cohort and sample prevalences of being below the low-income cut-off (i.e. the RDS-prevalence estimate for being below LICO in the final sample was 1.53% higher than in the total cohort). Figure 3 presents a simple model representing the associations under investigation. Figure 4 presents a complex model of proposed relationships and interactions between the exposures, outcomes, and potential covariates. Many of the proposed relationships and interactions in Figure 4 are beyond the scope of this thesis to examine.

4.2 Characteristics of the sample

After RDS weight calculation and incorporation, the Indigenous population of Toronto is estimated to include 85.70% (79.72-91.67 95%C.I.) First Nations, 0.40% (0.11-0.69 95%C.I.) Inuit, 13.19% (7.25-19.14 95%C.I.) Métis, and 0.44% (0.00-0.97 95%C.I.) identifying as both First Nations and Métis. While the sample included 52 more women than men (sample percentage of 53.11% versus 46.89%), the final population estimate is 49.26% (40.95-57.58 95%C.I.) women (female) and 50.74% (42.42-59.05 95%C.I.) men (male). The age of respondents indicates that 30.16% (21.94-38.38 95%C.I.) of the adult population (those above 15) were between the ages of 15-29. The population prevalence for education level indicated that 50.49% (42.17-58.80 95%C.I.) had not completed high school. Unemployment within the population was estimated at 62.21% (54.41-70.02 95%C.I.). The majority of the population, 55.03% (46.90-63.16 95%C.I.), had enough food but it was not always of the desired type, and 7.05% (3.98-10.13 95%C.I.) of the population often did not have enough food. Based on the sample, the Indigenous population of Toronto moves frequently with 22.09% (13.99-30.19 95%C.I.) of the population moving two or more times within the past 12 months. In the Indigenous population of Toronto, 87.37% (83.98-90.77 95%C.I.) live below the low-income cut-off.

Table 1b presents the frequency of unmet health needs, exposures, discrimination by a health care provider and multimorbidity, and the covariate of access to a regular health care provider. The prevalence of self-reported unmet health needs in the past 12 months in the urban Indigenous population is 27.27% (19.05-35.49 95%C.I.). Based on the sample 28.47% (20.40-36.54 95%C.I.) of the urban Indigenous population have experienced discrimination by a healthcare provider. The most prevalent chronic conditions within the Indigenous community of Toronto, were found to be diagnosed anxiety at 24.73% (17.23-32.23 95%C.I.), high blood pressure at 24.01% (17.23-30.80 95%C.I.), and asthma at 23.87% (16.62-31.11 95%C.I.). When mental illnesses were compiled into one chronic condition ‘mental disorder’, representing diagnosed anxiety and/or depression and those who would likely receive a diagnosis of anxiety and/or depression (as indicated by the Kessler scale), the prevalence reaches 60.37% (52.85-67.89 95%C.I.). Similarly, when PTSD includes both those with a diagnosis and those who have the symptoms (as indicated by the PC-PTSD screener), the prevalence of PTSD rises to 35.86% (27.73-43.99 95%C.I.). The prevalence of multimorbidity in the Indigenous population of Toronto is 61.66% (53.87-69.46 95%C.I.). Based on the sample, 36.93% (28.42-45.44 95%C.I.) of the Indigenous population does not have access to a regular healthcare provider.

4.3 Unmet health needs

Table 2a and Table 2b provide the frequencies of unmet health need outcomes for Indigenous women (females) and men (males) by factors under investigation and social determinants of health. Access to a regular healthcare provider was found to have a statistically significant association with unmet health needs (i.e. the X^2 -test null-hypothesis of independence can be rejected) for women, but not men. Among Indigenous women with access to a healthcare provider 33.56% (20.15-46.97 95%C.I.) had unmet health needs while among Indigenous women without access to a healthcare provider 13.11% (4.36-21.88 95%C.I.) had unmet health needs. The majority of exposures and social determinants of health under investigation were not found to have a statistically significant association with unmet health needs for Indigenous women or men (i.e. the X^2 -test null-hypothesis of independence could not be rejected). Among Indigenous women who have experienced discrimination 34.00% (17.84-50.17 95%C.I.) have an unmet health need. Discrimination by a healthcare provider was found to be significantly associated with unmet health needs for Indigenous men (i.e. the X^2 -test null-hypothesis of independence can be rejected). Half of Indigenous men who have experienced discrimination, 52.93% (23.86-82.00 95%C.I.) reported an unmet health need, compared to 16.06% (8.84-23.27 95%C.I.) among Indigenous men who had not experienced discrimination. One in three Indigenous women (33.51% (18.86-48.15 95%C.I.) and men (33.67% (15.46-51.88 95%C.I.) who have multimorbidity reported an unmet health need, compared to one in five Indigenous women (16.77% (3.19-30.34 95%C.I.) and men (17.41% (6.94-27.89 95%C.I.) who do not have multimorbidity who reported an unmet health need. Indigenous women between the ages of 30-39 had the highest proportion reporting an unmet health need, 43.56% (26.27-86.61 95%C.I.), among age groups. Indigenous women who had high food insecurity (often did not have enough food) had the highest proportion reporting an unmet health need in the past 12 months, 35.70% (4.83-66.58 95%C.I.) among different food security categories. Mobility was found to be significantly associated with unmet health needs for Indigenous men (i.e. the X^2 -test null-hypothesis of independence can be rejected). Even one move within the last 12 months was associated with a higher proportion, 42.54% (19.52-65.56 95%C.I.), of unmet health needs in the past 12 months compared to the proportion, 10.45% (4.73-16.17 95%C.I.), among Indigenous men who did not move at all.

4.4 Multimorbidity and unmet health needs

Table 3a presents the odds ratio results of unstratified (2X2) cross tabulations between exposure to multimorbidity and the outcome unmet health needs, and (3X3) cross tabulations stratified by potential covariates. In the unstratified analysis, having multimorbidity was associated with significantly higher odds of unmet health needs, 2.45 Crude OR (1.11-5.41 95%C.I.), when compared to those who were not suffering from multimorbidity. When the association between multimorbidity and unmet health needs was stratified by potentially covariates significant odds ratios were identified. When the association between multimorbidity and having unmet health needs was stratified by discrimination, both OR point-estimates were below the unstratified OR point-estimate, 1.98 OR (0.47-8.38 95%C.I.) for those exposed to discrimination by a healthcare provider and 2.31 OR (0.93-5.70 95%C.I.), for those unexposed to discrimination by a healthcare provider. When stratified by age, among Indigenous people who are 30-39 years of age, those with multimorbidity have significantly higher odds of having unmet health needs, 4.79 OR (1.26-18.25 95%C.I.), than those without multimorbidity. Among the oldest age group (50+ years of age) of Indigenous people examined, those with multimorbidity also have significantly higher odds of having unmet health needs, 6.20 OR (1.59-24.19 95%C.I.), than those without multiple chronic conditions. When stratified by education level, among Indigenous people who did not complete high school, having multimorbidity was associated with significantly higher odds of having unmet health needs, 7.09 OR (2.33-21.57 95%C.I.), compared to those without multimorbidity. Among Indigenous people who were unemployed, having multimorbidity was associated with significantly higher odds of having unmet health needs, 3.48 OR (1.18-10.28 95%C.I.), than those without multimorbidity. When stratified by food security, among Indigenous people who reported always having enough food, those with multimorbidity had significantly higher odds of having unmet health needs 11.69 OR (1.85-73.94 95%C.I.) when compared to those who were not multimorbid. Among Indigenous people who sometimes did not have enough food, those with multimorbidity had significantly higher odds of having unmet health needs 3.63 OR (1.04-12.61 95%C.I.) compared to those who were not multimorbid. Among Indigenous people who did not move within the last 12 months, those with multiple chronic conditions had significantly higher odds of having unmet health needs, 4.21 OR (1.76-10.03 95%C.I.), compared to those without multimorbidity. Comparatively, among Indigenous people who were highly mobile (moved two or more times) in the last 12 months, having multimorbidity was associated with significantly higher odds of having unmet health needs, 10.43 OR (2.65-41.05 95%C.I.), when compared to those who were not

multimorbid. Among Indigenous people who are above the low-income cut-off, those with multimorbidity had significantly higher odds of having unmet health needs, 3.40 OR (1.02-11.29 95%C.I.) compared to those without multimorbidity.

4.5 Discrimination by a healthcare provider and unmet health needs

Table 3b presents the odds ratio results of unstratified (2X2) cross tabulations between exposure to discrimination by a healthcare provider and the outcome unmet health needs, and (3X3) cross tabulations stratified by potential covariates. In the unstratified analysis, exposure to discrimination was associated with significantly higher odds of unmet health needs, 3.05 Crude OR (1.27-7.34 95%C.I.), when compared to those who had not been discriminated against by a healthcare provider. When the association between discrimination by a healthcare provider and unmet health needs was stratified by potentially modifying factors significant odds ratios were identified. Among Indigenous people who do not have access to regular health care provider, those exposed to discrimination by a healthcare provider have significantly higher odds of having unmet health needs, 5.20 OR (1.21-22.32 95%C.I.), compared to those unexposed to this discrimination. Among Indigenous people who are multimorbid, discrimination by a healthcare provider was associated with 2.68 (0.89-8.09 95%C.I.) higher odds of having unmet health needs. Among those who were not multimorbid, the point estimate of the increased odds of having unmet health needs with exposure to discrimination by a healthcare provider is 3.13 OR (0.85-11.46 95%C.I.). Among male Indigenous people, being discriminated against by a healthcare provider was associated with significantly higher odds of having unmet health needs, 5.88 OR (1.63-21.22 95%C.I.), compared to those unexposed to this discrimination. Among Indigenous people over the age of 50 years old, being discriminated against by a healthcare provider was associated with significantly higher odds of having unmet health needs, 7.00 OR (1.32-37.24 95%C.I.), compared to those who have not discriminated against by a healthcare provider. When stratified by education level, among Indigenous people who did not complete high school, exposure to discrimination by a healthcare provider was associated with significantly higher odds of having unmet health needs, 3.87 OR (1.12-13.34 95%C.I.), than those who were unexposed to this discrimination. Among those who had completed high school or more, discrimination by a healthcare provider was associated with significantly higher odds of unmet health needs, 3.41 OR (1.10-10.58 95%C.I.) compared to those who were not discriminated against by a healthcare provider. Among Indigenous people who were unemployed, being discriminated against by a healthcare provider was associated with

significantly higher odds of having unmet health needs 4.33 OR (1.39-13.46 95%C.I.) compared to those who did not experience this discrimination. Among Indigenous people in Toronto who have enough food but not of the desired type, discrimination by a healthcare provider was associated with significantly higher odds of having the outcome of unmet health needs, 5.20 OR (1.61-16.79 95%C.I.), compared to those who have not faced this discrimination. Among Indigenous people who are living below the low-income cut-off, exposure to discrimination by a healthcare provider is associated with significantly higher odds of having unmet health needs, 3.24 OR (1.24-8.45 95%C.I.) compared to those who have not experienced this discrimination.

5 Discussion

The findings discussed here confirm existing Indigenous community and stakeholder concerns and underscore the disproportionate burden of chronic illness experienced by this population. This discussion chapter examines the results of the unstratified and stratified association between multimorbidity, self-reported exposure to any discrimination by a health care provider and the outcome of self-reported unmet health needs in the last 12 months. Significant results are interpreted within the context of the current scientific and community understanding of Indigenous health in Canada and within the city of Toronto.

5.1 Multimorbidity

To date there is an absence of studies conducted examining the prevalence of multimorbidity in an urban Indigenous population in Canada, or examination of the relationship those with multimorbidity have with the health care system. This study provides useful insight into the prevalence of multimorbidity in the Indigenous population of Toronto and provides initial evidence of a strong association between being multimorbid and having unmet health needs in this population.

Multimorbidity, as defined by 13 highly prevalent chronic conditions, had a prevalence of 61.66% (53.87-69.46 95%C.I.) in the urban Indigenous population of Toronto. This prevalence is significantly higher than the 17.3% estimate, from 2011/2012 CCHS data for the off-reserve self-identified Indigenous population, made using the PHAC multimorbidity definition (28). While the increased number of diseases included within definition (13 compared to 9) likely contributed to the discrepancy between estimates, the sequential addition of a disease to the list considered has a diminishing effect on the prevalence (36). The inclusion of individuals who would likely receive a diagnosis of anxiety and/or depression (evaluated through the Kessler Scale) and individuals who would likely receive a diagnosis of PTSD (evaluated through the PC-PTSD screener) would likely account for some of the discrepancy, however including this information provides a more accurate reflection of the burden of chronic illness within the Indigenous community. The large discrepancy between estimates is also likely the result of successful enumeration of segments of the urban Indigenous population with high disease burdens, previously under-enumerated. Previous critiques of systematic biases affecting the generalizability of CCHS Indigenous data discussed within the Background, such as poor enumeration of those who are highly mobile, homeless, or illiterate, may account for the discrepancy between these estimates. Utilizing the

PHAC definition of multimorbidity for the analysis of the associations between multimorbidity and unmet health needs is unsatisfactory due to likely underestimation associated with this definition. As discussed within the background, definitions including at least 12 highly prevalent diseases (reported by self-report) have been found to be adequate and comparable for measurement of multimorbidity and for assessment of associations with multimorbidity (36,37). The inclusion of 13 diseases, rather than the identified minimum of 12, ensures comparability with other studies (37).

On average, the population based estimates for prevalence of each individual chronic condition in the urban Indigenous community of Toronto, for those conditions listed in the PHAC definition of multimorbidity, were over two times larger than the population based prevalence estimates for the diseases based on the national 2011/2012 CCHS data. The largest gap between the national prevalence and the urban Indigenous prevalence was observed for mental health disorders. From the 2011-2012 CCHS data, the national prevalence of mental disorder (mood disorder and/or anxiety) was estimated at 11.2% (10.8-11.5 95%C.I.) (28). From the estimates presented in Table 1b, the prevalence of self-reported diagnoses of anxiety is 24.73% (17.23-32.23 95%C.I.) and depression is 23.37% (15.81-30.93 95%C.I.). The prevalence of mental disorder (categorized by a high or very high score on the Kessler 10 Scale which would most likely present symptoms of clinical anxiety and/or depression) was estimated at 48.18% (39.80-56.56 95%C.I.). The disproportionate burden of mental illness within the urban Indigenous population of Toronto mirrors findings from the earlier Our Health Counts study of the urban Indigenous population of Hamilton (70). First Nations adults in Hamilton had prevalence rates of 39% for mental disorder (those with a high or very high Kessler 10 Score) and 34% for PTSD (70). The significantly higher rates of mental illness within the urban Indigenous population identified through Respondent-Driven Sampling points to the under sampling within the census-based CCHS of the most marginalized and at risk within the Indigenous population. The disproportionate burden may also be related to systemic under diagnosis of mental health issues across Canada (89). In a 2016 report by Pelletier et al., analysis conducted on the data from the 2011-2012 CCHS found only half of all who expressed symptoms of mental disorder had received a formal diagnosis (89). Indigenous people living in cities may be at increased risk of mental health issues due to separation from the land and social networks, and increased contact with non-Indigenous people who have limited understanding of their historical and contemporary context and relationships (70). As discussed earlier, colonial policies implemented by the Government of Canada, such as the Residential Schools System, have caused trauma both to

direct survivors of these policies, and to their children and extended family networks (12). From the results, the population prevalence estimate for diagnosis of post-traumatic stress disorder in the urban Indigenous population is 11.76% (6.33-17.18 95%C.I.) however the prevalence of symptoms of PTSD is 31.19% (23.56-38.82 95%C.I.) based on those who answered positive to three to four questions from a four-question primary care post-traumatic stress disorder (PC-PTSD) screen. It is likely that this screen is including individuals who have been exposed to complex trauma (from recurrent and multiple traumas, including historical trauma). In their 2014 discussion of the intergeneration impacts of Indian Residential Schools, Bombay et al. examine ways that familial history of Indian Residential School can interact and accumulate with contemporary stressors to affect current well-being, providing evidence for the concept of historical trauma (90). The PC-PTSD screen was initially designed for veterans of war, exposed to discrete episodic traumas, however use of this screener has been validated for primary care (87). While use of this screen has limitations it represents a useful reflection of trauma in the community with greater scope than considering only those who have received a clinical diagnosis. The high prevalence and intergenerational impact of mental health disorders and symptoms of PTSD in the urban Indigenous population of Toronto presents a critical need for well-resourced mental health and healing services, including counselling, therapy and traditional healing practices.

The findings of this study confirm the community and stakeholder understanding that unmet health needs are prevalent within the Indigenous community of Toronto. Approximately 27% of the population have a self-reported unmet health need in the last 12 months. In comparison, the 2014 iteration of the CCHS found approximately 11.2% of the total national population and 16.2% of the Indigenous population surveyed self-reported that they did not receive health care when they felt they needed it (21). This divergence from the 2014 CCHS estimate indicates that more respondents identified through RDS methodology had unmet health needs. This may reflect a selection bias towards those who have unmet health needs, however it may alternatively signify a more accurate reflection of the burden of unmet health needs in the urban Indigenous population, with better representation of those who are homeless or highly mobile. Multimorbidity, having multiple chronic conditions, was found to be significantly associated with unmet health needs, including when stratified by potential covariates such as gender, age and other social determinants of health. Stratified analysis indicates subgroups of Indigenous people with multimorbidity that may be at particular risk of having an unmet health need. These specific groups include those who are 50+ years of age, those who did not complete high school, and those who are unemployed.

Across almost all stratified categories multimorbidity was more likely to increase odds of having unmet health needs, though in many cases wide confidence intervals obscure potentially significant effects indicated by large point estimates. Among those who had experienced discrimination by a healthcare provider, having multimorbidity was associated with higher odds of unmet health needs compared to those without multimorbidity, however the result was not significant indicating a larger sample is needed to explore this relationship adequately. As described earlier, multimorbidity is experienced differently by each individual within their social, educational, cultural, economic and environmental context (26). Unmet health needs can be considered a metric for how successful the health care system is at supporting these complex patients. The evidence from the stratified analysis presented here on the odds of having unmet health needs provides evidence for the concept of the Inverse Care Law, that those with the greatest health care needs receive the least health care services and are most vulnerable to health care disparities (91). The analysis presented also provides indirect evidence to support previous findings of an inverse relationship between multimorbidity and socio-economic status (33,34).

An Australian retrospective cohort study by Brett *et al.* of patients using a mobile outreach health clinic found overrepresentation of multimorbidity within the homeless population and specifically among homeless Aboriginal people (92). In the urban Indigenous population of Toronto that is highly mobile, moving more than twice in the last year, multimorbidity was significantly associated with higher odds of having unmet health needs (10.43 OR (2.65-41.05 95%C.I.)). As discussed in the Australian survey, homelessness can cause earlier onset of multimorbidity and increased disease severity, particularly among Aboriginal patients (92). The significantly higher odds of unmet health needs among mobile Indigenous people with multimorbidity in Toronto is indicative of a serious need for resources to address this specific population. The ability of the Our Health Counts survey, utilizing Respondent-Driven Sampling methods in concert with strong community participation throughout, to identify Indigenous people who are moving frequently or are homeless provides a unique snapshot into their health and interactions with the health care system. This is a hidden population, likely unidentified using standard simple random sampling (census-based) frameworks, and from the results it is clear that within this population the health needs of those who have the heaviest burden of illness are not being met.

5.2 Discrimination by a health care provider

The pervasive experiences of discrimination by health care providers, with 28.47% (20.40-36.54 95%C.I.) of the urban Indigenous population of Toronto having ever experienced this, must be addressed. The need for cultural safety training in medical and nursing schools in Canada, particularly “skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism” has been identified within the 94 Calls to Action of the Truth and Reconciliation Commission (12). Cultural safety training programs, such as the San’yas Indigenous Cultural Safety Training programme developed in British Columbia, which has been adapted for Ontario (provincial Indigenous Cultural Safety program) and Manitoba provide an opportunity for health care providers to learn about their internalized biases that cause them to make discriminatory assumptions (93). Biases, such as ‘Indigenous people do not feel pain’, lead to racist assumptions that when an Indigenous person requests pain medication it is more likely to be drug-seeking behaviour related to addictions (23). As previous research indicates, assumptions made by health care providers modifies the care Indigenous people receive (23,56).

Urban Indigenous people may be at a higher risk of not receiving health care when they felt they needed it, due to increased risk of discrimination when living within a dense concentration of non-Indigenous people, and increased risk of falling through the cracks due to systemic issues in health service provision for Indigenous people living outside their community or reserve (22). An important aspect of unmet health needs is the lack of adequate Indigenous specific services, including services that are perceived as intrinsic to the Indigenous community. As research on prenatal and infant-toddler health promotion programs has shown, services and programs that are intrinsic to, and involve Indigenous community investment and ownership can trigger community activation and participation (94). Concurrent research based on the Our Health Counts Toronto data indicates that the total Indigenous population of Toronto is significantly larger than previously estimated from the Census. Anishnawbe Health Toronto, an Indigenous specific community health service in Toronto, provides a model for Indigenous-led health service provision. Despite multiple service provision sites across the city, geographic barriers to access for Indigenous specific health services in Toronto remain. New and greater resources are needed to address the revised population estimate.

Experience of discrimination by a healthcare provider increased the odds of unmet health needs by 3.05 times (1.27-7.34 95%C.I.). This finding contributes evidence to the significant broad negative impact of discrimination in the health care setting, previously

identified in a population based study in the United States (24). The adjusted logistic regression model developed for this US study found those discriminated against in health care settings had 2.48 OR (1.57-3.90 95%C.I.) times higher odds of ever having unmet health needs (24). Discrimination by a healthcare provider was also found to be significantly associated with unmet health needs among Indigenous males. This relationship was identified both for the frequencies presented in Table 2b and in the stratified analysis presented in Table 3b. Discrimination by a healthcare provider may be an added barrier to addressing unmet health needs for men. It may contribute to the male paradigm of not needing health care until later in life, such that men present with more advanced conditions. Previous research from data collected in the 2014 CCHS indicate that women are more likely to report unmet health needs (21). Among Indigenous people with multimorbidity, those who experienced discrimination by a healthcare provider had higher odds of having unmet health needs compared to those who had not been discrimination against, but the result was non-significant indicating a larger sample is needed to understand this relationship.

The results presented in this report confirm community and stakeholder understanding that poor access to primary care is widespread within the Indigenous population of Toronto. Over 36% of this population is without access to a regular health care provider, such as a doctor or nurse practitioner. In Table 2a, the frequencies of unmet health needs for women with and without a regular healthcare provider present a distinct pattern. Among women with a regular healthcare provider, a higher proportion have unmet health needs (33.56% (20.15-46.97 95%C.I.)) compared to women without a regular healthcare provider (13.11% (4.36-21.88 95%C.I.)). The difference in proportions may be related to a number of contributing factors. For those who do not have a regular healthcare provider, there may be a higher level of undiagnosed health conditions, and lower health literacy to identify health needs as unmet rather than considering these needs to be unavoidable aspects of ill health. Denial of illness due to the stigma associated with suffering from a disease may also contribute to lower expressions of unmet health needs. Having a regular healthcare provider does not mean all health care needs are met, among these women other unmet health needs may arise from barriers to fulfilling prescriptions, or barriers to accessing specific services such as dental care.

With a high proportion of urban Indigenous peoples reporting they do not have a regular health care provider, this is an indicator of systemic failures by the health care system. As discussed earlier, this may be related to discrimination by health care providers resulting in health care spaces that are not safe for Indigenous peoples. From the stratified analysis of

Indigenous people who did not have access to a regular healthcare provider, those who had been discriminated against by a healthcare provider had over five times higher odds of reporting unmet health needs (5.20 OR (1.21-22.32 95%CI)). This finding provides empirical evidence for the increased impact that not having a regular healthcare provider can have on the relationship between discrimination by a healthcare provider and unmet health needs. Without a regular healthcare provider, and the potential relationship of trust and empathy that can build up between patient and a consistent healthcare provider, patients may resort to finding care in walk-in clinics and emergency departments, ill-suited to providing long-term non-emergency primary care (23). A shortage of culturally safe health service providers and an increase in short term interactions with healthcare providers at walk-in clinics and emergency departments may increase risk of exposure to discrimination by healthcare providers. Attending walk-in clinics and visiting hospital emergency departments for primary care may also affect continuity of care for Indigenous patients, found to be of critical importance for the management of chronic diseases in people with multimorbidity (95).

5.3 Limitations of this study

A limitation of this RDS study is that the analysis was often underpowered to adequately show significant relationships. This manifested itself in wide confidence intervals which in many cases could not exclude the possibility of no significant association, despite large effect size point estimates. RDS methodology requires large sample sizes because design effects are greater. The data from the OHCT survey is also cross-sectional, so no causal relationships between variables can be inferred. Inherent in the cross-sectional design of this survey is the inability to address exposure and lag time (14). Associations between multimorbidity and unmet health needs and exposure to discrimination and unmet health needs for Indigenous people living in Toronto can be identified but causal links cannot be concluded. It may be possible to address this issue of time, using information obtained from longitudinal ICES administrative database linkages, to determine a portrait of health service access over time.

The inability to use multivariable analysis methods on this RDS sample necessitated using a sequential stratification approach to including relevant covariates. Using stratification in lieu of multivariable modelling resulted in limiting the inclusion of covariates to one sociodemographic variable at a time.

RDS sampling methods have other inherent limitations. One example arises from attempting to recruit specific Indigenous subpopulations including Métis and Inuit within a larger inclusive Indigenous sample. RDS is dependent on the social networks of respondents for recruitment. Some groups may be under-sampled if they have fewer social network ties to other groups within the larger sample (54). In the Our Health Counts Toronto there is evidence of this under sampling of Métis in that they represented only 9.57% of the total sample and 13.19% (7.25-19.14 95%C.I.) of the total Indigenous population, which was below the expected amount of 30% found in the 2006 Census and 2011 NHS consistent with community estimations (7,96). The distribution of Métis within the recruitment chains indicate little presence of separate Métis social networks, i.e. individuals were well distributed throughout the chains rather than clustered. It is possible that despite the rigorous preparation and dissemination of information regarding the study that this subpopulation was not adequately represented. It is possible only a subpopulation of Métis was recruited, Métis who have ties to the larger Indigenous community or were connected to the Indigenous and allied health and social services where the recruitment took place. There may be a substantive additional subpopulation of Métis who were excluded from the RDS sampling. The social isolation of Métis from each other and from the larger Indigenous community could be explained by historic and current policies including exclusion of Métis from Indigenous services (structured to preferentially serve First Nations people with Status), disruptions of Métis kin-networks, and the historic vilification of Métis in Ontario which resulted in it becoming unsafe for Metis to reveal their identity (22).

While it is difficult to measure discrimination empirically, self-identification or perceived racism has served as the benchmark method for research in discrimination (14). Under-reporting is common in many populations experiencing racism and is dependent upon the context of the question (14). As a result, the rate of discrimination by healthcare providers may be higher than the prevalence estimate of 28%. It is also possible that healthcare providers may provide differential treatment without either the patient or the healthcare provider being aware of this, through implicit bias. Similarly, measuring unmet health needs is a non-specific way of determining gaps in the health system. Individuals experience their own health differently, such that what one may consider to be an unmet health need, another may consider to be a normalized burden. It is probable that decades of racial and colonial history have made it less likely that Indigenous people will indicate an unmet health need, a manifestation of internalized racism (14). This may particularly affect those suffering mental health issues and PTSD who find it difficult to recognize their own disease state, or fear

stigmatization. The question regarding unmet health needs is also complicated by differing concepts of health between the Indigenous concepts of holistic well-being and the Western biomedical tradition. Indigenous people may recognize and report unmet health needs from the perspective of known traditional healing and healthy living practices, or from a disease specific treatment paradigm.

The decision to examine Indigenous individuals with two or more chronic conditions has its own limitations. The inclusion of those who had the symptoms of anxiety and depression within the mental disorder category of chronic condition, and those who had the symptoms of PTSD within the PTSD category of chronic conditions may be a considered a limitation of the analysis presented. Attempting to address the potential level of undiagnosed chronic conditions adds useful information regarding the true burden of multimorbidity, particularly considering the high level of undiagnosed mental health issues within the Indigenous population and general population of Canada (89). Diagnostic scales such as the Kessler 10 and PC-PTSD screener, have been used previously, for both physical and mental disorders, within classifications of multimorbidity (97).

The severity of the chronic disease may be a confounder and create internal variation within the health user profile of patients with multimorbidity. The health needs of someone suffering from non-invasive cervical cancer may be significantly different than someone suffering from metastatic ovarian cancer for example. While this is a limitation, it is important to note the potential for negative synergies arising from multiple chronic conditions. Patients with multimorbidity often receive fragmented, incomplete, inefficient and ineffective care and are at increased risk from the hazards of polypharmacy, and post-operative complications (26). Disaggregating particular combinations of multiple chronic conditions is difficult and requires large or specific survey samples to maintain adequate statistical power. Treating patients with multimorbidity as a single group can still provide useful insight, despite the limitations, into issues within the healthcare system and potential areas for improvement.

5.4 Conclusions

In conclusion, the results presented in this report constitute analysis of a successful Indigenous owned and led RDS health survey of the urban Indigenous community of Toronto. As the results indicate, there is a high prevalence of unmet health needs within the urban Indigenous population of Toronto. A large majority of this population suffer from multiple chronic conditions and a high proportion have experienced discrimination from a healthcare

provider. Both having multimorbidity and exposure to discrimination by a healthcare provider were found to be significantly associated with having unmet health needs.

Stratified analyses indicate subgroups of urban Indigenous people with multimorbidity that are at particular risk of having an unmet health need. These specific groups include those who are 50+ years of age, those who did not complete high school, and those who are unemployed. The effect of mobility on the odds of having unmet health needs for those with multimorbidity is of particular concern. Identifying highly mobile urban Indigenous people confirms the strength of the RDS and community-based participatory methods integral to the Our Health Counts study, and sets this study apart from previous census-based studies.

Stratified analysis also indicates that discrimination by a healthcare provider is associated with increased odds of having unmet health needs for urban Indigenous people who do not have access to a regular healthcare provider, who are male, who are 50+ years of age, who are unemployed and who live below the low-income cut-off.

Cultural safety training programmes, such as San'yas Program in B.C and the Indigenous Cultural Safety Training Program in Ontario, can help to create a safer space for Indigenous people within the health care system. Care focused on addressing the complex burden of multimorbidity in the urban Indigenous community must be developed to ensure non-siloed treatment and continuity of care, especially for urban Indigenous people who are moving frequently. Efforts must be made to ensure that every urban Indigenous person has a regular health care provider with targeted efforts to ensure those who are highly mobile maintain access to regular primary care.

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Appendix A: Figures

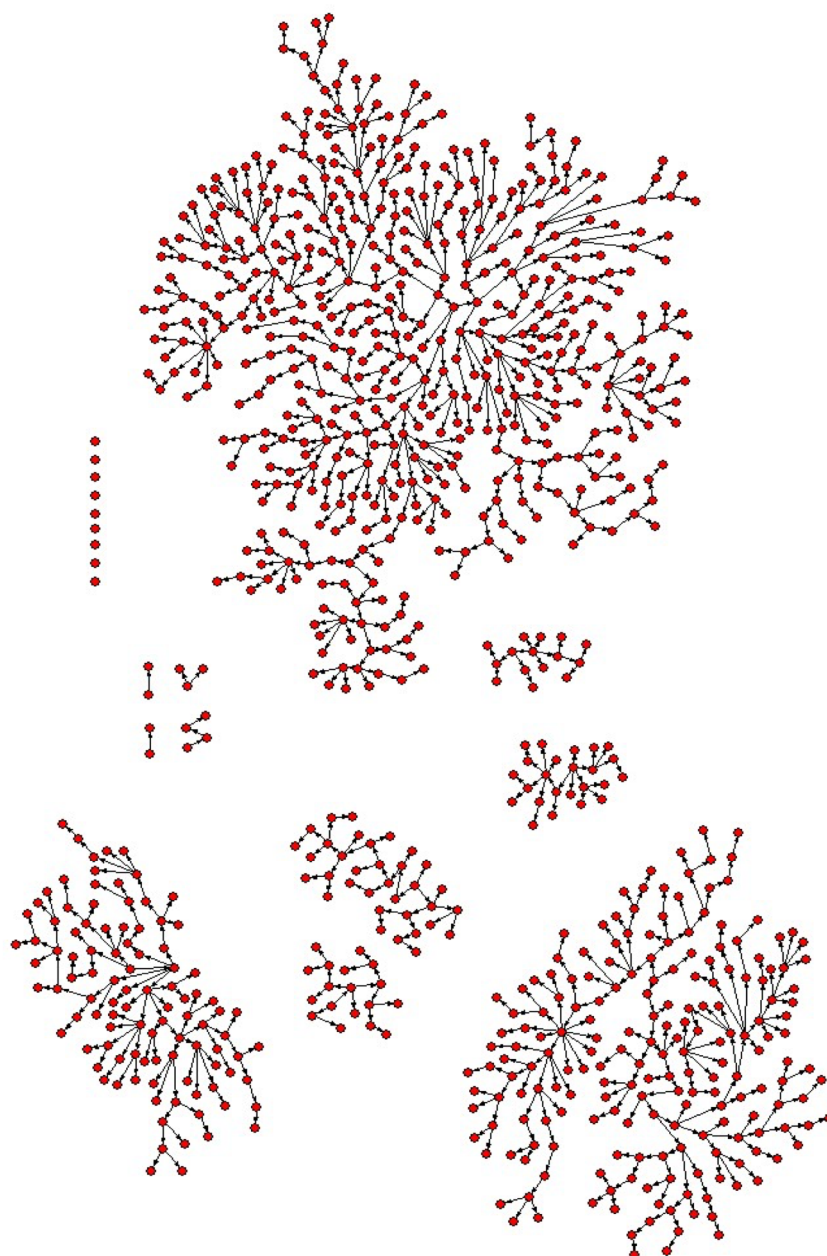


Figure 1. Network diagram for OHCT study cohort

This network diagram was developed by Well Living House Data Analyst, Kristen O'Brien. Red nodes indicate a recruit

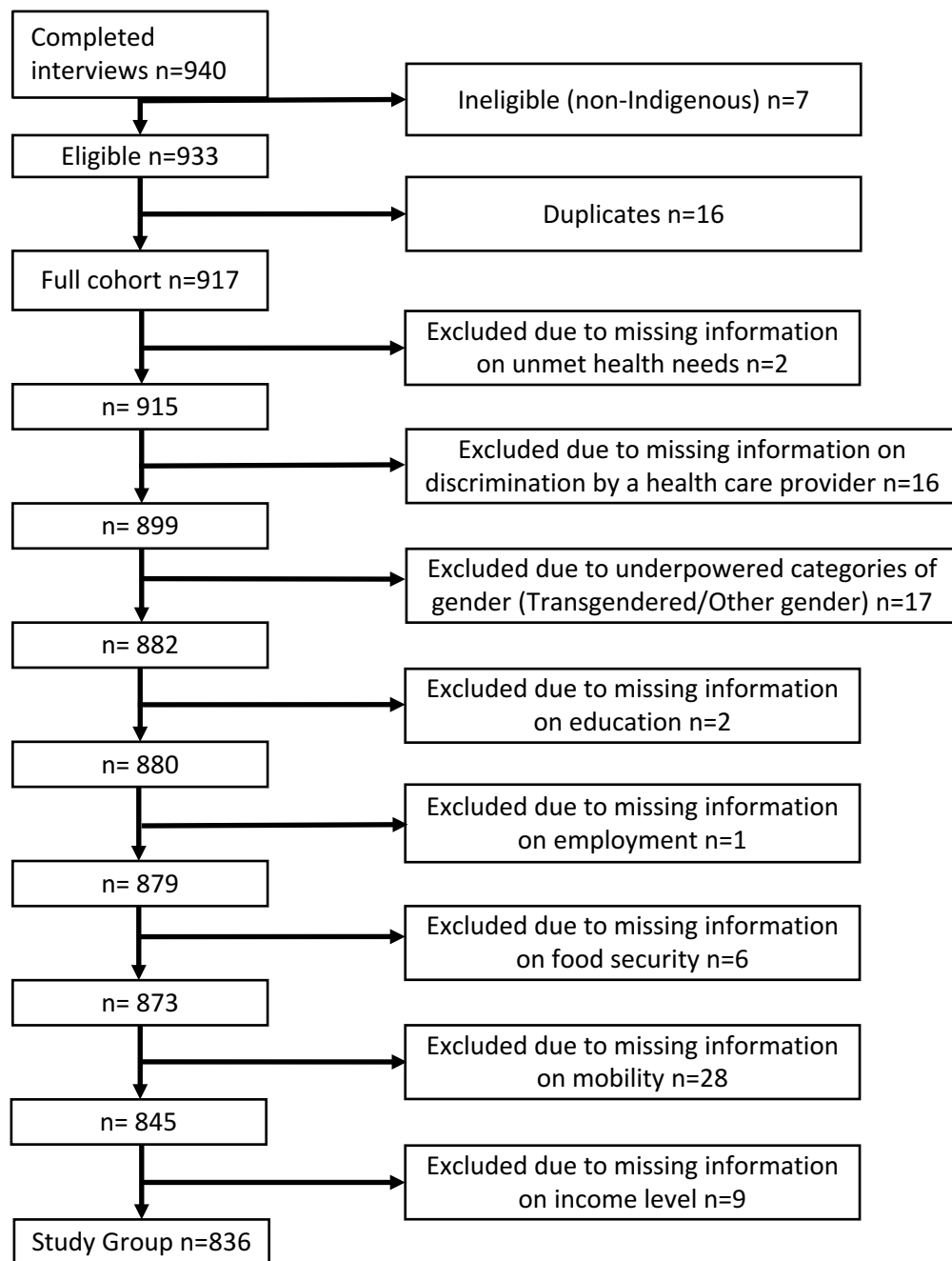


Figure 2. Flow chart of inclusion in the study sample

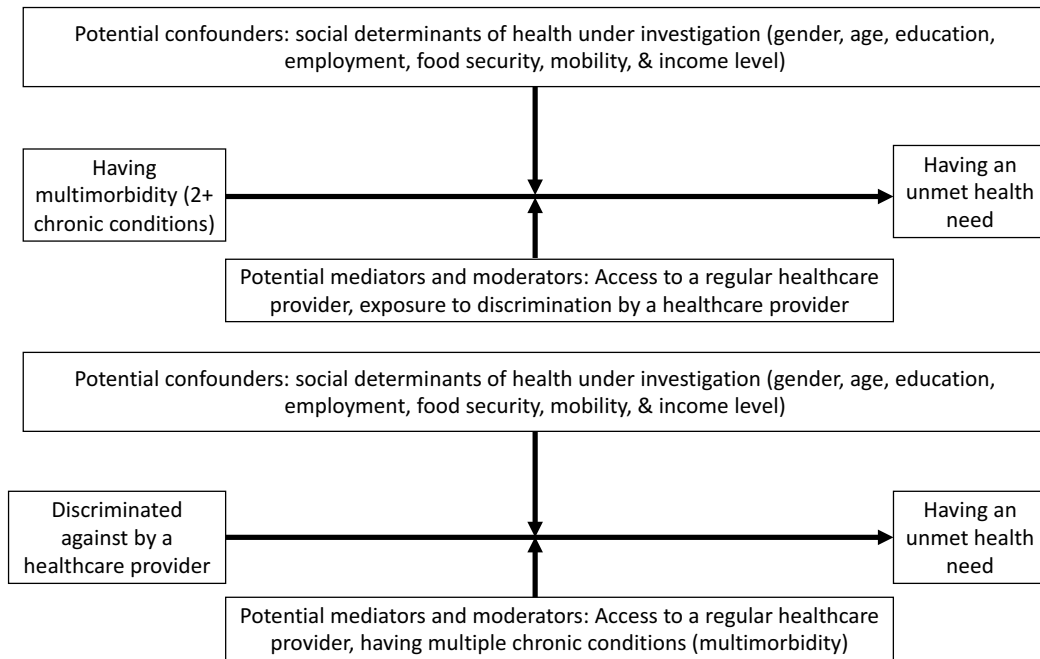


Figure 3. Logic model for the analysis conducted

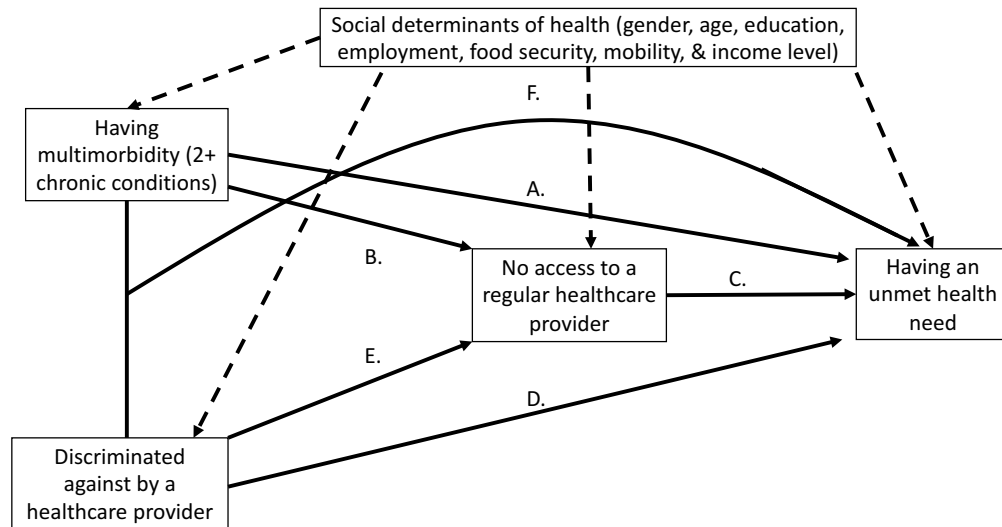


Figure 4. Proposed complex logic model of potential associations between the covariates under investigation

Having multimorbidity can be directly associated with having an unmet health need (A). Having multimorbidity can lead to not having access to a regular healthcare provider, (B) (ex. Due to reluctance by some service providers in accepting complex patients) a mediator that can lead to having an unmet health need (C). Being discriminated against by a healthcare provider can directly result in having an unmet health need (D). Being discriminated against by a health care provider can lead to not having access to a regular healthcare provider, (E) (Ex. Due to not feeling comfortable with or trusting the regular healthcare provider) a mediator that can lead to having an unmet health need (C). Having multimorbidity can also be a moderator of the association between discrimination by a healthcare provider and having an unmet health need (F) (Ex. Increased contact between people with multimorbidity and the health care system increases their potential for exposure to discrimination). Dashed arrows indicate how social determinants of health confound associations between factors under investigation. Social determinants of health under investigation (gender, age, education, employment, food security, mobility, and income level) can affect each factor separately.

Appendix B: Tables

Table 1a. Characteristics of the study sample

	Sample n=836 (%)	RDS-adjusted estimate of Prevalence (95% C.I.)
Gender		
Female	444 (53.11)	49.26 (40.95, 57.58)
Male	392 (46.89)	50.74 (42.42, 59.05)
Indigenous Identity		
First Nations	735 (87.92)	85.70 (79.72, 91.67)
Inuit	11 (1.32)	0.40 (0.11, 0.69)
Métis	80 (9.57)	13.19 (7.25, 19.14)
First Nations and Métis	7 (0.84)	0.44 (0.00, 0.97)
Other	X	0.27 (0.00, 0.75)
Age		
15-29	174 (20.81)	30.16 (21.94, 38.38)
30-39	181 (21.64)	22.03 (14.71, 29.35)
40-49	186 (22.24)	17.78 (13.11, 22.46)
50+	295 (35.32)	30.03 (22.52, 37.53)
Education		
Did not complete high school	357 (42.70)	50.49 (42.17, 58.80)
Completed high school or more	479 (57.30)	49.51 (41.20, 57.83)
Employment		
Employed	261 (31.22)	17.80 (13.44, 22.16)
Not in labour Force	140 (16.75)	19.99 (12.65, 27.34)
Unemployed	435 (52.03)	62.21 (54.41, 70.02)
Food Security		
Always enough food	177 (21.17)	20.06 (12.98, 27.14)
Enough but not of desired foods	434 (51.91)	55.03 (46.90, 63.16)
Sometimes not enough	150 (17.94)	17.85 (12.85, 22.86)
Often not enough	75 (8.97)	7.05 (3.98, 10.13)
Mobility		
0	508 (60.77)	48.18 (39.93, 56.43)
1	177 (21.17)	29.73 (22.12, 37.34)
2 or more moves	151 (18.06)	22.09 (13.99, 30.19)
Income		
Below Low-Income Cut-off	662 (79.19)	87.37 (83.98, 90.77)
Above Low-Income Cut-off	174 (20.81)	12.63 (9.23, 16.02)

X indicates suppressed cell (5 or less respondents).

Table 1b. Unmet health needs, access to a regular health care provider, exposure to discrimination by health care providers and prevalence of chronic conditions for the sample under analysis

	Sample n=836 (%)	RDS-adjusted estimate of Prevalence (95%C.I.)
Unmet health needs in the past 12 months		
Yes	197 (23.56)	27.27 (19.05, 35.49)
No	639 (76.44)	72.73 (64.51, 80.95)
Access to a regular healthcare provider		
Yes	572 (68.42)	63.07 (54.56, 71.58)
No	264 (31.58)	36.93 (28.42, 45.44)
Discrimination by a healthcare provider		
Yes	263 (31.46)	28.47 (20.40, 36.54)
No	573 (68.54)	71.53 (63.46, 79.60)
Chronic Conditions		
Arthritis	240 (28.71)	21.94 (16.43, 27.46)
Asthma	204 (24.40)	23.87 (16.62, 31.11)
Cancer	37 (4.43)	6.93 (1.47, 12.39)
COPD	93 (11.12)	9.09 (3.91, 14.27)
Diabetes	147 (17.58)	14.75 (8.92, 20.59)
Heart Disease	75 (8.97)	7.13 (4.13, 10.13)
Hepatitis B	18 (2.15)	2.10 (0.68, 3.53)
Hepatitis C	94 (11.12)	11.46 (5.93, 16.98)
High Blood Pressure	204 (24.44)	24.01 (17.23, 30.80)
Liver	71 (8.49)	8.20 (3.00, 13.39)
Mental disorder (Diagnosed (a/b) / Undiagnosed (c) Anxiety and/or Depression)	416 (49.76)	60.37 (52.85, 67.89)
PTSD (Diagnosed (d) / Undiagnosed (e))	293 (35.05)	35.86 (27.73, 43.99)
Stroke	42 (5.02)	4.01 (1.35, 6.67)
a. Anxiety (Diagnosed)	193 (23.09)	24.73 (17.23, 32.23)
b. Depression (Diagnosed)	180 (21.53)	23.37 (15.81, 30.93)
c. Symptoms of Anxiety and/or Depression (Kessler Score High or Very High)	324 (38.76)	48.18 (39.80, 56.56)
d. PTSD (Diagnosed)	113 (13.52)	11.76 (6.33, 17.18)
e. Symptoms of PTSD (PC-PTSD screener)	263 (31.46)	31.19 (23.56, 38.82)
Multimorbidity (2+ of 13 listed chronic conditions)		
Yes	493 (58.97)	61.66 (53.87, 69.46)
No	343 (41.03)	38.34 (30.54, 46.13)

Table 2a. Female, frequencies of unmet health needs stratified by covariates, exposures and social determinants of health under investigation (row percentages). Statistically significant (95%) P-values are bolded.

Significant (>5%) P-values are bolded.					
Female n=444 (100%)	Crude Frequency among all n (% of 444)	Crude Frequency with unmet health needs n (% of row total)	Crude Frequency without unmet health needs n (% of row total)	RDS-Adjusted Row proportion with unmet health health needs % (95%C.I.)	P- value
Access to a regular healthcare provider					
Yes	334 (75.23)	82 (24.55)	252 (75.45)	33.56 (20.15, 46.97)	0.05
No	110 (24.77)	37 (33.64)	73 (66.36)	13.11 (4.36, 21.88)	
Discrimination by a healthcare provider					
Yes	168 (37.84)	68 (40.48)	100 (59.52)	34.00 (17.84, 50.17)	0.41
No	276 (62.16)	51 (18.48)	225 (81.52)	25.02 (11.38, 38.65)	
Multimorbidity					
Yes	286 (64.41)	90 (31.47)	196 (68.53)	33.51 (18.86, 48.15)	0.11
No	158 (35.59)	29 (18.35)	129 (81.65)	16.77 (3.19, 30.34)	
Age					
15-29	88 (19.82)	25 (28.41)	63 (71.59)	30.02 (10.77, 49.27)	0.45
30-39	101 (22.75)	30 (29.70)	71 (70.30)	43.56 (26.27, 86.61)	
40-49	93 (20.95)	28 (30.11)	65 (69.89)	20.73 (7.20, 34.26)	
50+	162 (36.49)	36 (22.22)	126 (77.78)	16.45 (3.39, 29.52)	
Education					
Did not complete high school	173 (38.96)	43 (24.86)	130 (75.14)	17.46 (7.56, 27.37)	0.08
Completed high school or more	271 (61.04)	76 (28.04)	195 (71.96)	36.64 (20.23, 53.04)	
Employment					
Employed	138 (31.08)	27 (19.57)	111 (80.43)	20.74 (3.83, 37.66)	0.32
Not in labour Force	90 (20.27)	32 (35.56)	58 (64.44)	41.25 (17.53, 64.96)	
Unemployed	216 (48.65)	60 (27.78)	156 (72.22)	23.37 (7.81, 38.93)	
Food Security					
Always enough food	97 (21.85)	11 (11.34)	86 (88.66)	26.56 (0.00, 58.33)	0.96
Enough but not of desired foods	234 (52.70)	66 (28.21)	168 (71.79)	26.96 (14.28, 39.65)	
Sometimes not enough	73 (16.44)	25 (34.25)	48 (65.75)	25.69 (8.68, 42.69)	
Often not enough	40 (9.01)	17 (42.50)	23 (57.50)	35.70 (4.83, 66.58)	
Mobility					
0	299 (67.34)	80 (26.76)	219 (73.24)	23.46 (12.70, 34.21)	0.63
1	82 (18.47)	18 (21.95)	64 (78.05)	24.38 (6.70, 42.07)	
2 or more	63 (14.19)	21 (33.33)	42 (66.67)	46.91 (11.16, 82.65)	
Income					
Below LICO	359 (80.86)	100 (27.86)	259 (72.14)	29.02 (16.95, 41.08)	0.09
Above LICO	85 (19.14)	19 (22.35)	66 (77.65)	14.31 (4.87, 23.76)	

Table 2b. Male, frequencies of unmet health needs stratified by covariates, exposures and social determinants of health under investigation (row percentages). Statistically significant (95%) P-values are bolded.

Male n=392 (100%)	Crude Frequency among all n (% of 392)	Crude Frequency with unmet health needs n (% of row total)	Crude Frequency without unmet health needs n (% of row total)	RDS-Adjusted Row proportion with unmet health health needs % (95%C.I.)	P- value
Access to a regular healthcare provider					
Yes	238 (60.71)	43 (18.07)	195 (81.93)	21.73 (6.67, 36.80)	0.34
No	154 (39.29)	35 (22.72)	119 (77.27)	34.05 (14.11, 53.98)	
Discrimination by a healthcare provider					
Yes	95 (24.23)	32 (33.68)	63 (66.32)	52.93 (23.86, 82.00)	0.05
No	297 (75.77)	46 (15.49)	251 (84.51)	16.06 (8.84, 23.27)	
Multimorbidity					
Yes	207 (52.81)	50 (24.15)	157 (75.85)	33.67 (15.46, 51.88)	0.15
No	185 (47.19)	28 (15.14)	157 (84.86)	17.41 (6.94, 27.89)	
Age					
15-29	86 (21.94)	13 (15.12)	73 (84.88)	13.26 (1.74, 24.77)	0.24
30-39	80 (20.41)	18 (22.50)	62 (77.50)	41.01 (11.93, 70.08)	
40-49	93 (23.72)	22 (23.66)	71 (76.34)	35.97 (16.80, 55.14)	
50+	133 (33.93)	25 (18.80)	108 (81.20)	24.00 (1.44, 46.56)	
Education					
Did not complete high school	184 (46.94)	31 (16.85)	153 (83.15)	23.01 (5.75, 40.27)	0.49
Completed high school or more	208 (53.06)	47 (22.60)	161 (77.40)	31.72 (14.26, 49.19)	
Employment					
Employed	123 (31.38)	23 (18.70)	100 (81.30)	18.67 (8.87, 28.47)	0.13
Not in labour Force	50 (12.76)	9 (18.00)	41 (82.00)	6.91 (0.00, 14.89)	
Unemployed	219 (55.87)	46 (21.00)	173 (79.00)	34.03 (17.31, 50.74)	
Food Security					
Always enough food	80 (20.41)	10 (12.50)	70 (87.50)	10.96 (1.60, 20.31)	0.16
Enough but not of desired foods	200 (51.02)	38 (19.00)	162 (81.00)	32.80 (14.05, 51.54)	
Sometimes not enough	77 (19.64)	20 (25.97)	57 (74.03)	27.33 (7.53, 47.14)	
Often not enough	35 (8.93)	10 (28.57)	25 (71.43)	10.22 (0.86, 19.58)	
Mobility					
0	209 (53.32)	31 (14.83)	178 (85.17)	10.45 (4.73, 16.17)	0.03
1	95 (24.23)	22 (23.16)	73 (76.84)	42.54 (19.52, 65.56)	
2 or more	88 (22.45)	25 (28.41)	63 (71.59)	37.10 (8.50, 65.70)	
Income					
Below LICO	303 (77.30)	64 (21.12)	239 (78.88)	27.28 (13.16, 41.39)	0.92
Above LICO	89 (22.70)	14 (15.73)	75 (84.27)	26.14 (10.66, 41.62)	

Table 3a. The association between multimorbidity and having unmet health needs, with stratified analysis of this association among respondents within each stratum. Significant RDS-adjusted associations are bolded.

All (n=836)	Non-multimorbidity by Unmet health needs OR (Reference)	Multimorbidity by Unmet health needs OR (95%C.I.)
Unstratified analysis of the total sample:	1 (Reference)	2.45 (1.11, 5.41)
Stratified analysis of respondents within each stratum:		
Access to a regular HCP		
Yes	1 (Reference)	2.85 (1.00, 8.15)
No	1 (Reference)	1.93 (0.52, 7.15)
Discrimination by HCP		
Yes	1 (Reference)	1.98 (0.47, 8.38)
No	1 (Reference)	2.31 (0.93, 5.70)
Gender		
Female	1 (Reference)	2.50 (0.77, 8.09)
Male	1 (Reference)	2.41 (0.81, 7.19)
Age		
15-29	1 (Reference)	0.88 (0.23, 3.46)
30-39	1 (Reference)	4.79 (1.26, 18.25)
40-49	1 (Reference)	2.99 (0.56, 16.03)
50+	1 (Reference)	6.20 (1.59, 24.19)
Education		
Did not complete high school	1 (Reference)	7.09 (2.33, 21.57)
Completed high school or more	1 (Reference)	2.11 (0.78, 5.75)
Employment		
Employed	1 (Reference)	2.35 (0.76, 7.30)
Not in labour Force	1 (Reference)	0.98 (0.18, 5.26)
Unemployed	1 (Reference)	3.48 (1.18, 10.28)
Food Security		
Always enough food	1 (Reference)	11.69 (1.85, 73.94)
Enough but not of desired foods	1 (Reference)	1.42 (0.49, 4.14)
Sometimes not enough	1 (Reference)	3.63 (1.04, 12.61)
Often not enough	1 (Reference)	X
Mobility		
0	1 (Reference)	4.21 (1.76, 10.03)
1	1 (Reference)	0.78 (0.20, 3.11)
2 or more	1 (Reference)	10.43 (2.65, 41.05)
Income		
Below LICO	1 (Reference)	2.29 (0.95, 5.55)
Above LICO	1 (Reference)	3.40 (1.02, 11.29)

X indicates RDS-adjusted OR calculation included at least one cell less than 15.

Table 3b. The association between exposure to discrimination by a health care provider and having unmet health needs, with stratified analysis of this association among respondents within each stratum. Significant RDS-adjusted associations are bolded.

All (n=836)	No discrimination by HCP by Unmet health needs OR (Reference)	Discrimination by HCP by Unmet health needs OR (95%C.I.)
Unstratified analysis of the total sample:	1 (Reference)	3.05 (1.27, 7.34)
Stratified analysis of respondents in each stratum:		
Access to a regular HCP		
Yes	1 (Reference)	2.29 (0.79, 6.64)
No	1 (Reference)	5.20 (1.21, 22.32)
Multimorbidity		
Yes	1 (Reference)	2.68 (0.89, 8.09)
No	1 (Reference)	3.13 (0.85, 11.46)
Gender		
Female	1 (Reference)	1.54 (0.55, 4.30)
Male	1 (Reference)	5.88 (1.63, 21.22)
Age		
15-29	1 (Reference)	1.84 (0.38, 8.83)
30-39	1 (Reference)	2.76 (0.48, 15.82)
40-49	1 (Reference)	2.02 (0.61, 6.62)
50+	1 (Reference)	7.00 (1.32, 37.24)
Education		
Did not complete high school	1 (Reference)	3.87 (1.12, 13.34)
Completed high school or more	1 (Reference)	3.41 (1.10, 10.58)
Employment		
Employed	1 (Reference)	0.70 (0.25, 1.96)
Not in labour Force	1 (Reference)	2.50 (0.40, 15.68)
Unemployed	1 (Reference)	4.33 (1.39, 13.46)
Food Security		
Always enough food	1 (Reference)	X
Enough but not of desired foods	1 (Reference)	5.20 (1.61, 16.79)
Sometimes not enough	1 (Reference)	3.45 (0.84, 14.21)
Often not enough	1 (Reference)	0.73 (0.10, 5.21)
Mobility		
0	1 (Reference)	1.79 (0.81, 3.94)
1	1 (Reference)	3.41 (0.89, 13.07)
2 or more	1 (Reference)	2.14 (0.29, 15.91)
Income		
Below LICO	1 (Reference)	3.24 (1.24, 8.45)
Above LICO	1 (Reference)	1.53 (0.48, 4.89)

X indicates RDS-adjusted OR calculation included at least one cell less than 15.

Table 4. Categories developed for analysis with survey questions used

Category	Question	Question Number	Possible responses	Values utilized
Multimorbidity (2+ of these 14 chronic conditions)	Have you been told by a health care provider that you have any of the following chronic health conditions?	Asthma q5_1a	Yes/No	Yes/No
		Arthritis q5_1b	Yes/No	Yes/No
		Heart Disease q5_1c	Yes/No	Yes/No
		Stroke q5_1d	Yes/No	Yes/No
		Liver q5_1e	Yes/No	Yes/No
		High Blood Pressure q5_1f	Yes/No	Yes/No
		Hepatitis B q5_1g	Yes/No	Yes/No
		Hepatitis C q5_1h	Yes/No	Yes/No
		COPD q5_1j	Yes/No	Yes/No
		Cancer q5_1m	Yes/No	Yes/No
		Other q5_1o	'Brain tumor', 'Cardio-vascular', 'High cholesterol and osteoarthritis' and 'Osteoarthritis, Tendinitis', 'Anxiety', 'Anxiety-panic attacks', 'anxiety, depression', 'Anxiety/Depression', 'Panic attacks', 'Diabetes' and 'Diabetes, Low Iron, Schizophrenia'	'Brain tumor', 'Cardio-vascular', 'High cholesterol and osteoarthritis' and 'Osteoarthritis, Tendinitis', 'Anxiety', 'Anxiety-panic attacks', 'anxiety, depression', 'Anxiety/Depression', 'Panic attacks', 'Diabetes' and 'Diabetes, Low Iron, Schizophrenia'
	Do you have diabetes as diagnosed by a health care provider?	q5_2	Yes/No	Yes/No
	Have you ever been told by a health care worker that you have a psychological and/or mental health disorder(s)?	q18_6	Yes/No	Yes/No

Category	Question	Question Number	Possible responses	Values utilized
Multimorbidity (2+ of these 14 chronic conditions)	If yes, which psychological and/or mental health disorders have you been told that you have?	Anxiety	Yes/No	Yes/No
		Depression	Yes/No	Yes/No
		PTSD	Yes/No	Yes/No
	...feel depressed?	q18_9a	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel so depressed that nothing could cheer you up?	q18_9b	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	In the last 30 days, how often did you...	q18_9c	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel so nervous that nothing could calm you down?	q18_9d	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel restless or fidgety?	q18_9e	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
			None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)

Category	Question	Question Number	Possible responses	Values utilized
Multimorbidity (2+ of these 14 chronic conditions)	...feel so restless that you could not sit still?	q18_9f	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel without hope?	q18_9g	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	In the last 30 days, how often did you... ...feel everything was an effort?	q18_9h	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel worthless?	q18_9i	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	...feel tired out for no good reason?	q18_9j	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)	None of the time (1), A little of the time (2), Some of the time (3), Most of the time (4), All of the time (5)
	In your life, have you ever had any experience that was so frightening, horrible, or upsetting that in the past month, you...	q18_12a	Yes/No	Yes/No

Category	Question	Question Number	Possible responses	Values utilized
Multimorbidity (2+ of these 14 chronic conditions)	...tried hard not to think about it or went out of your way to avoid situations that reminded you of it?	q18_12b	Yes/No	Yes/No
	In your life, have you ever had any experience that was so frightening, guard, watchful, or horrible, or upsetting that in the past month, you... easily startled?	q18_12c	Yes/No	Yes/No
	...felt numb or detached from others, activities, or your surroundings?	q18_12d	Yes/No	Yes/No
	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?	q12_7	Yes/No	Yes/No
Discrimination by a healthcare provider				
Unmet health needs	In the previous 12 months, was there a time you felt you needed health care services but did not receive them?	q12_4	Yes/No	Yes/No
Access to a regular healthcare provider	Do you have a regular family doctor and/or nurse practitioner?	q12_2	Yes/No	Yes/No
Indigenous Identity	How do you self-identify?	q2_1	First Nations/Métis/Inuit/Other Indigenous Female (a woman)/Male (a man)/Trans (e.g. Transgender, Transsexual, Gender Queer)/Other/You do not have a category that applies to me	First Nations/Métis/Inuit/Other Indigenous Female (a woman)/Male (a man)
Gender	What is your gender?	q2_6		
Age	What is your date of birth	1_1	15+	15-29/30-39/40-49/50+

Category	Question	Question Number	Possible responses	Values utilized
Education	What is the highest level of schooling you have ever completed? Please choose one from the following categories.	q3_1	Less than grade 9/Some high school/Completed high school/Some college or specialized training (i.e. trades)/Completed college or specialized training (i.e. trades)/Some university/Completed university/Some post-graduate education (i.e. Masters, PhD, MD, LLB)/ Completed post-graduate education	Completed high school or less/Completed some or all of a college or university degree
Employment	Which of the following best describes your current employment status? Please choose one from the following categories.	q3_2a	Part-time/Full-time/Seasonal/Self-employed/Homemaker/Any other informal paid work such as babysitting, housekeeping/Student/Retired/Unemployed	Employed (Full time/Part time/Seasonal/Self-employed/Homemaker/Any other informal work); Not in labour Force (Retired/Student/Unable to work); Unemployed Employed: 'Casual – Relief Worker', 'Contractual', 'Occasionally work', 'ON ODSP BUT IS WORKING FULLTIME AND SUBMITS HOURS ACCORDINGLY', 'Ontario works', 'Paid volunteer work', 'Seasonal', 'Sick leave', 'Works a little bit handing out flyers.', and 'Year-round occasional work'; Not in Labour Force: 'Can't work bc of a hernia', 'Disability', 'Disability/Pension', 'Disabled', 'Disabled and unable to work due to', 'Medically retired', 'Odsp', 'ODSP', 'On disability', 'short term disability', 'Student placement for school', 'Unable to work', 'Unemployed due to having a stroke', and 'Works throughout school year as well as summer'; Unemployed: 'Out of contract', 'Starting work soon.', 'volunteer', 'Volunteer', and 'Volunteer, outreach'

Category	Question	Question Number	Possible responses	Values utilized
Food Security	Which of the following statements best describes the food eaten in your household in the past 12 months?	q3_9	You and others always had enough of the kinds of food you wanted to eat/You and others had enough to eat, but not always the kinds of food you wanted/Sometimes you or others did not have enough to eat/Often you or others did not have enough to eat	Always enough food/Enough but not of desired foods/Sometimes not enough/Often not enough
Mobility	How many times, if any, have you moved in the past 1 year?	q3_13	0-15	0/1/2+
	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?	q23_1	\$ value 0 or above 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/More than \$100,000	
Income	Can you estimate in which of the following groups your household income falls? Was the total household income from all sources...	q23_2		Below LICO/Above LICO
	Including yourself, how many people rely on this income?	q23_3	# of people 1 or above	