OUR HEALTH COUNTS

Urban Aboriginal Health Database Research Project

Community Report

First Nations Adults and Children

City of Hamilton

Prepared for

De Dwa Da Dehs Ney>s Aboriginal Health Centre,

Ontario Federation of Indian Friendship Centres,

Hamilton Executive Director's Aboriginal Coalition,

and the Our Health Counts Governing Council

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April 2011

ACKNOWLEDGEMENTS

This project was about enhancing *community* ways of gathering urban Aboriginal health information, and as such, could never have existed without the active participation and vital enthusiasm of hundreds First Nations community members living in the City of Hamilton. It is the intention of this report to honour the generosity of your participation and we therefore dedicate this report to members of the First Nations community in Hamilton.

Special thank-you's to all the members of the First Nations community in Hamilton who participated, Donna Lyons, Connie Siedule, Lisa Pigeau, Jessica Hill, Betty Kennedy, Dennis Compton, Mandy Berglund, Chester Langille, the Hamilton Executive Directors Aboriginal Coalition, the Social Planning and Research Council of Hamilton, Gordon Gong, Cindy Sue McCormack, Renee Wetselaar, Crystal Burning, Amye Annett, Ashly MacDonald, Trisha McDonald, Diane Therrien, Alisha Hines, Pat O'Campo, Rick Glazier, Kelly McShane, Roseanne Nisenbaum, Dionne Gesink Law, Cyprian Wejnert, and Brandon Zagorski.

This project was funded by the Ontario Federation of Indian Friendship Centres, the Ministry of Health and Long-Term Care Aboriginal Health Transition Fund, and the Centre for Research on Inner City Health (CRICH) at Saint Michael's Hospital. The Institute for Clinical Evaluative Sciences (ICES) contributed the costs of the in-house ICES data analysis and Dr. Smylie was supported by a Canadian Institutes for Health Research New Investigator in Knowledge Translation award during the course of the project.

This study was supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario MOHLTC is intended or should be inferred.

OUR HEALTH COUNTS
GOVERNING COUNCIL

O.F.I.F.C.

the Métis Nation of Ontario

Tungasuvvingat Inuit

Family Health Team

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ONTARIO NATIVE WOMEN'S ASSOCIATION

St. Michael's

Inspired Care.
Inspiring Science.

We gratefully acknowledge the financial contributions to this project from the Ministry of Health and Long-Term Care, Ontario Federation of Indian Friendship Centres and St. Michael's Hospital.

Ontario

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St. Michael's
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Inspiring Science.

We would like to acknowledge the award given to Dr. Janet Smylie by the CIHR New Investigator Award in Knowledge Translation.

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EXECUTIVE SUMMARY

INTRODUCTION TO THE OUR HEALTH COUNTS PROJECT – ADDRESSING THE GAPS IN URBAN FIRST NATIONS HEALTH DATA IN ONTARIO:

Over 60% of Ontario's Aboriginal population lives in urban areas.[1] Public health assessment data for this population is almost non-existent, despite its size (150,570 persons). This is primarily due to the inability of Ontario's current health information system to identify urban Aboriginal individuals in its health datasets. Health assessment data that do exist are most often program or non-random survey based, not population based. When urban Aboriginal people have been included in census based national surveys (such as the Canadian Community Health Survey (CCHS) these surveys are vastly underpowered and First Nations, Inuit, and Métis data cannot be disaggregated. From a population and public health perspective, this near absence of population based health assessment data is extremely concerning, particularly given the known disparities in social determinants of health. This situation is unacceptable in a developed country such as Canada.

As a result of these deficits in urban Aboriginal health information, policy makers in community organizations, small regions, and provincial and federal governments are limited in their abilities to address urban Aboriginal community health challenges and aspirations. Without Aboriginal health information, effective health policy, planning, program/service delivery, and performance measurement are limited. Moving toward basic population health measures is essential to improve the health status, access to services, and participation in health planning processes affecting Aboriginal people.

For the past three years, the Ontario Federation of Indian Friendship Centres (OFIFC), Métis Nation of Ontario (MNO), Ontario Native Women's Association (ONWA), and Tungasuvvingat Inuit (TI) have been working with a health research team led by Dr. Janet Smylie based at the Centre for Research on Inner City Health (CRICH), Saint Michael's Hospital, on the Our Health Counts Urban Aboriginal Health Database project. For the First Nations arm of the project, the community organizational partner

was De dwa da dehs ney>s Aboriginal Health Access Centre, which represented the interests of the First Nations community in Hamilton on behalf of the broader Hamilton Executive Directors Aboriginal Coalition.

The goal of the Our Health Counts (OHC) project was to work in partnership with Aboriginal organizational stakeholders to develop a baseline population health database for urban Aboriginal people living in Ontario that is immediately accessible, useful, and culturally relevant to local, small region, and provincial policy makers.

The Our Health Counts Urban Aboriginal Health Database project was funded by OFIFC, the Ministry of Health and Long Term Care (MOHLTC) Aboriginal Health Transition Fund, and CRICH. Organizational partners included OFIFC, MNO, ONWA, TI and Saint Michael's Hospital. Community partners included De dwa da dehs ney>s Aboriginal Health Access Centre (on behalf of the Hamilton Executive Directors Aboriginal Coalition), MNO and TI.

There were three project community sites: First Nations in Hamilton, Inuit in Ottawa, and Métis in Ottawa. This report focuses on the First Nations in Hamilton community site, which was chosen as the First Nations project community site because of its significant Aboriginal population (13,735 persons reporting Aboriginal ancestry according to the 2006 Census) and strong infrastructure of Aboriginal community health and social services.

INNOVATIVE METHODS:

Community Based Participatory Research Partnerships:
This project was carried out using community based participatory research methods. Our approach promoted balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination.

This was achieved through the project governing structure including the project Governing Council and research and data sharing agreements described above as well as ensuring that capacity building, respect, cultural relevance, representation, and sustainability were core features of the project's ongoing overall and day to day implementation.

Concept Mapping and Respectful Health Assessment Survey:
Brainstorming and sorting of ideas and topics for the surveys was done using concept mapping with health and social service stakeholders in Hamilton. One hundred and two

statements were sorted into a concept map of ten domains. These domains and statements were used by the research team and to create questionnaires for both adults and children. Surveys were conducted in person by trained interviewers initially with paper-based questionnaires and later on directly on a computer.

Respondent Driven Sampling and ICES data linkage

A respondent driven sampling (RDS) technique was used to recruit individuals to be interviewed for the research. This method involved giving tickets to each First Nation participant who completed an interview, and the participants could give these tickets to other First Nations people they knew, including friends and family. For each participant recruited, the person who made the recruit received $10. The OHC First Nations Hamilton sampling was extremely successful. Over a course of four and a half months a total of 790 persons were recruited, including 554 adults and 236 children. Ninety-two percent of participants gave permission to use their OHIP number to link to their data on health care system usage available through the Institute for Clinical Evaluative Sciences. All the data findings presented in the results section are adjusted for bias using RDS statistics to take into account how spread out different participants are within the social network through which they were recruited.

KEY PROJECT FINDINGS AND IMPLICATIONS FOR HEATH POLICY AND PRACTICE:

Housing, Services for Low Income and Marginalized Populations, and Addressing Inequities in the Social Determinants of Health:

The OHC study identified striking levels of poverty among First Nations residents living in Hamilton. For example, 78.2% of the First Nations persons living in Hamilton earn less than $20,000 per year and 70% of the First Nations population in Hamilton lives in the lowest income quartile neighbourhoods compared to 25% of the general Hamilton population.

This poverty is accompanied by marked challenges in access to housing and food security. For example, 90% of the First Nations population living in Hamilton had moved at least once in the past 5 years and over 50% of the population had moved three or more times in the past 5 years. Furthermore, 13% of the First Nations population living in Hamilton reported being homeless, in transition, or living in any other type of dwelling not listed. In addition, 73.7% of First Nations persons in Hamilton reported that they live in crowded conditions, compared to a rate of 3% general Canadian population. Finally, 63% of First Nations community members in Hamilton had to give up important things (i.e. buying groceries) in order to meet shelter-related [housing]

costs and only 22% of the First Nations population always had enough of the kinds of food that they wanted to eat.

These findings have resulted in the following policy recommendations in the areas of housing, services for low income and marginalized populations and addressing inequities in the social determinants of health:

Housing:

1. That provincial governments that have responsibility for housing and supports (Ministry of Health and Long Term Care and the Ministry of Community and Social Services) engage with urban Aboriginal communities and organizations for the purpose of ensuring that the communities' priorities and critical needs in the areas of affordable rental housing, supportive and transitional housing, and assisted home ownership are addressed in accordance with human rights legislation.

Services for Low Income and Marginalized Populations:

2. That all local and provincial agencies that offer services to significant numbers of low income/marginalized urban Aboriginal populations collaborate directly with urban Aboriginal agencies and organizations and develop and implement mandatory Aboriginal cultural diversity training.

Addressing Inequities in the Social Determinants of Health:

3. That provincial governments engage with urban Aboriginal communities and organizations for the purpose of establishing priorities, resource and funding allocations and action plans to address the critical inequities in all economic and social conditions affecting Aboriginal health including poverty, homelessness, food insecurity, education, employment, health access, gender equality and social safety.

Chronic Disease and Disability:

Another key finding of the OHC study was that First Nations people living in Hamilton are living with a disproportionate burden of chronic disease and disability. For example, the rate of diabetes among the adult First Nations Hamilton population is 15.6%, more than three times the rate among the general Hamilton population, despite a much younger age demographic of the First Nations Hamilton population. Furthermore, the prevalence rate of high blood pressure among the adult First Nations population in Hamilton was 25.8% (compared to a general Hamilton rate of 19.7%) ; the prevalence rate of arthritis was 30.7% (compared to a general Hamilton rate of 19.9%); and the prevalence rate of Hepatitis C was 8.7% (compared to an estimated Ontario prevalence rate of 0.8%). In addition, 52% of the total adult population and over three quarters (77%) of person over 50 years reported often or sometimes experiencing limitations in the kinds or

amount of activity done at home, work or otherwise because of a physical or mental condition or health problem. Finally, 36% of all adults reported fair or poor mental health and 42% reported that they had been told by a health care provider that they had a psychological and/or mental health disorder. These findings have led to the following policy recommendation regarding chronic disease and disability:

4. That municipal and provincial governments commit to long term resources and funding allocations and engages with urban Aboriginal communities and organizations for the purposes of establishing priorities, preventative action and promotion plans towards the reduction of the burden of chronic disease and disability in the urban Aboriginal community.

Health Care Access:

The OHC study findings are compelling with respect to the need to urgently address barriers in accessing health care services across the spectrum of preventative, primary, and tertiary care. For example, 40% of the First Nations population in Hamilton rates their level of access to health care as fair or poor. Identified barriers included long waiting lists (48%), lack of transportation (35%), not able to afford direct costs (32%), doctor not available (29%), and lack of trust in health care provider (24%). Striking differences in emergency room admission rates between for First Nations in Hamilton compared to the general Hamilton and Ontario populations for both acute and non-acute illnesses are linked by participant narrative to the barriers listed above to access of timely preventative and primary health care. Fifty two percent of the First Nations population in Hamilton reported at least one visit to the emergency room over the past 2 years for acute problems compared to 22% of the Hamilton and 20% of the Ontario population. Ten point six percent of the First Nations population in Hamilton reported 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario populations respectively. Notwithstanding this heavy use of emergency room services, 44% of the Hamilton First Nations population rated the quality of the emergency care as fair or poor. These findings have led to the following policy recommendation regarding health care access:

5. That municipal, provincial and federal governments engage with urban Aboriginal communities and organizations for the purposes of eliminating barriers in access to equitable community health care, emergency department services and inpatient hospital services for acute and non-acute conditions.

Aboriginal Specific Services, Cultural Safety, and Aboriginal Self-Determination of Health Care Delivery

Despite the challenges described above, First Nations people living in Hamilton demonstrate remarkable cultural continuity and resilience. Even though resources and

programming for Aboriginal cultural programming in Hamilton have been extremely limited to date and the impacts of colonization have been significant, OHC study measures indicate a strong sense of First Nations identity among the First Nations population living in Hamilton as well as a strong desire to pass culture and language on to the next generation. The OHC pre-survey concept mapping study highlighted the idea that "Our Health Deserves Appropriate and Dedicated Care" and the subsequent respectful health assessment survey documented the desire for more Native health care workers and "prejudice" and "lack of trust and discrimination" as significant barriers in accessing care. In response to these findings we advance the following policy recommendations:

Aboriginal Specific Services for Family Treatment, Mental Health and Maternal Health

6. That municipal, provincial and federal governments ensure the provision of adequate funding to the urban community and organizations directed towards the development and expansion of culturally reflective, community based, long-term traditional family treatment centres, urban Aboriginal child, youth and adult mental health funded strategies and maternal health, programs and services.

Cultural Safety:

7. That municipal, provincial and federal governments and health stakeholders develop and initiate policies towards the implementation of cultural competency and/ or cultural safety programs that are designed and delivered by Aboriginal people that includes the recognition and validation of Aboriginal worldviews and full inclusion of Aboriginal healers, medicine people, midwives, community counselors and health care workers in all collaborative efforts with western medicine.

Aboriginal Self-Determination of Health Care Delivery:

8. That municipal, provincial and federal governments recognize and validate the Aboriginal cultural worldviews (that encompasses the physical, mental, emotional, spiritual, and social well-being of Aboriginal individuals and communities) and that self-determination is fundamental and thus Aboriginal people must have full involvement and choice in all aspects of health care delivery, including governance, research, planning and development, implementation and evaluation.

Children's Health:

Parents and caregivers of First Nations children in Hamilton highly value the transmission of First Nations culture and language to the next generation. For example, the OHC study found that 93% of parents and caregivers felt it was very or somewhat important for their child to learn a First Nations language and 94% of parents and caregivers felt that traditional cultural events were very or somewhat important in their child's life.

Additional key study findings regarding First Nations children's health included the burden of chronic illness facing First Nations children in Hamilton; concerns regarding child development; and long waiting lists as a barrier to accessing health care. Asthma and allergies were the most commonly reported chronic conditions. Rates of asthma were twice as high for Hamilton First Nations children compared to general Canadian rates for children. Rates of chronic ear infections were also high. Twenty-two percent of parents and caregivers were concerned about their child's development. While 83% of participants indicated that their child had seen a family doctor, general practitioner or pediatrician in the past 12 months (compared to 88% for the general Canadian population aged 0-6 years), there were a significant number of reported barriers to accessing care. The number one barrier to receiving health care reported by child custodians was that the wait list was too long. In response to these findings, we recommend the following policies:

9. That municipal and provincial governments, including school boards, recognize the importance of and commit long term funding and resources towards Aboriginal children's language and cultural programming in collaboration with urban Aboriginal organizations and agencies.

10. That municipal and provincial governments work in collaboration with urban Aboriginal agencies and organizations to reduce urban Aboriginal children's health status inequities by eliminating barriers to urban Aboriginal children accessing regular primary health care, reducing long waiting lists and responding to the increased prevalence of health conditions such as asthma in the urban Aboriginal child population with customized culturally appropriate primary health care programming.

11. That municipal and provincial government's work in partnership with urban Aboriginal agencies and organizations to ensure that urban Aboriginal children are accorded their human rights to live in healthy homes and communities and attend day programs/schools in healthy environments that do not exacerbate chronic health conditions such as asthma and allergies.

Research:

Urban First Nations organizations and community members in Hamilton successfully partnered with provincial Aboriginal organizations and academic researchers in the collection, governance, management, analysis and documentation of their own urban First Nations health database. Successful research outcomes included:

- Completion of a community concept mapping project that identified First Nations specific health domains.

- Development and implementation of a customized First Nations adult and child health needs assessment survey which was administered to 554 adults and on behalf 236 children (total 790 community members) living in the city of Hamilton.
- Successful linkage of recruited First Nations cohort to the Institute of Clinical Evaluative Sciences database.
- Statistically rigorous Respondent Driven Sampling (RDS) allowed for successful derivation of population based estimates of survey and Institute for Clinical Evaluative Sciences (ICES) First Nations cohort measures.
- Collaborative production of this project report.

The Our Health Counts research project demonstrates that research can be done by Aboriginal people for Aboriginal community benefit. As a result, we put forward the following policy recommendation regarding research:

12. That municipal, provincial and federal governments and urban Aboriginal organizations recognize the health status inequities and disparities of urban Aboriginal living in the city of Hamilton and advocate for funded urban Aboriginal specific applied health services research.

System Planning:

The above policy recommendations are prefaced on the need for the re-establishment of key relationships between municipal, provincial, and federal governments and urban Aboriginal local and provincial organizations. In particular there is a need to ensure that unresolved jurisdictional accountabilities do not continue to perpetuate unnecessary and resolvable health disparities for urban Aboriginal peoples. Such pressing and significant health inequities are unacceptable given the relative affluence of Ontario and Canada globally. To address these devastating health and social inequities and disparities experienced by urban Aboriginal people today these final policy actions are required:

13. That municipal, provincial and federal governments support interagency collaboration and cooperation amongst urban Aboriginal service providers towards the design and delivery of services and identification of funding and research opportunities.

14. That municipal, provincial and federal governments collaborate with urban Aboriginal agencies and organizations and gain knowledge of the urban Aboriginal health determinants and health inequities and further acknowledge the urban Aboriginal communities right to self-determination in the control of planning, design, development and delivery of culturally specific health services, programs and policy.

PROJECT OVERVIEW

INTRODUCTION

Over 60% of Ontario's Aboriginal population lives in urban areas.[1] Public health assessment data for this population is almost non-existent, despite its size (150,570 persons). This is primarily due to the inability of Ontario's current health information system to identify urban Aboriginal individuals in its health datasets. Health assessment data that do exist are most often program or non-random survey based, not population based. Existing potential sampling frames are either not accessible (ie. Statistic Canada Census) or reflect biased, non-random subpopulations (ie. program/service clients lists, membership lists, and Métis registry). When urban Aboriginal people have been included in census based national surveys (such as the Canadian Community Health Survey (CCHS)) these surveys are vastly underpowered and First Nations, Inuit, and Métis data cannot be disaggregated. We do know from the Canadian Census that First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income security, employment, education, and adequate housing compared to non-Aboriginal Canadians and that these disparities persist with urban residence.[2] From a population and public health perspective, this near absence of population based health assessment data is extremely concerning, particularly given the known disparities in social determinants of health. This situation is unacceptable in a developed country such as Canada.

As a result of these deficits in urban Aboriginal health information, policy makers in community organizations, small regions, and provincial and federal governments are limited in their abilities to address urban Aboriginal community health challenges and aspirations. Without Aboriginal health information, effective health policy, planning, program/service delivery, and performance measurement are limited. Moving toward basic population health measures is essential to improve the health status, access to services, and participation in health planning processes affecting Aboriginal people.

For the past three years, the Ontario Federation of Indian Friendship Centres (OFIFC), Métis Nation of Ontario (MNO), Ontario Native Women's Association (ONWA), and

Tungasuvvingat Inuit (TI) has been working with a health research team led by Dr. Janet Smylie based at Centre for Research on Inner City Health (CRICH), Saint Michael's Hospital, on the Our Health Counts Urban Aboriginal Health Database project. For the First Nations arm of the project, the community organizational partner was De dwa da dehs ney>s Aboriginal Health Access Centre, which represented the interests of the First Nations community in Hamilton on behalf of the broader Hamilton Executive Directors Aboriginal Coalition.

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There were three project community sites: First Nations in Hamilton, Inuit in Ottawa, and Métis in Ottawa. This report will focus on the First Nations in Hamilton community site.

PROJECT OBJECTIVES

Formalizing Intersectoral Partnerships and Establishing Priority Measures

1. To formalize partnerships between the four core urban Aboriginal provincial organizations, the multidisciplinary academic team, the Ontario MOHLTC, and the Institute for Clinical Evaluative Sciences (ICES) for this project through research agreements and data management/governance protocols. This will include the establishment of an Aboriginal Health Data Governance Council comprised of the four core urban Aboriginal provincial organizations.

2. To confirm priority health domains and best indicators for each domain through these partnerships.

Knowledge Development through Establishment of a Population Health Data Base

3. To generate new health data sets reflective of these priorities for a sample of urban First Nations, Inuit, and Métis adults and children using respondent driven sampling, secure data linkage with ICES and a rapid health assessment questionnaire.

Capacity Building, Training and Mentoring

4. To strengthen capacity and leadership among Ontario's urban Aboriginal communities and their policy, program and health service collaborators in the area of Aboriginal health information collection, analysis, and application through: a. the involvement of community representatives as active research team members in all aspects of this project; b: a series of community-based health data use workshops.

5. To provide a scientifically excellent and culturally relevant training and mentorship environment for Aboriginal health researchers at the undergraduate, graduate, post-doctoral and new investigator level.

Knowledge Dissemination, Application, and Contribution to Future Projects

6. To support community-based, small region, provincial, and federal uptake and application of health data generated through 1-3 above to First Nations, Inuit, and Métis health policies, programs, and services. This will include the establishment of an Aboriginal health data users group, which will have open membership and allow diverse stakeholders input and access to data generated by the project.

7. To build on the outcomes of this study to design future longitudinal health studies in partnership with First Nations, Inuit, and Métis governing/organizational stakeholders as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario.

8. To share study results and adaptation processes with First Nations, Inuit, and Métis stakeholders in other provinces and territories and thereby contribute to the development of urban Aboriginal health data enhancement strategies.

PRELIMINARY PROJECT DEVELOPMENT

In the fall of 2007 Sylvia Maracle (OFIFC) approached Dr. Smylie (CRICH) to see if she was interested in collaborating on the improvement of urban Aboriginal health datasets. Over the next few months, TI, MNO and ONWA joined the project team. Of note, Dr. Smylie had a pre-existing research relationship with OFIFC, TI, and MNO. In a previously unfunded project proposal written in partnership with the Tungasuuvingat Inuit Family Resources Centre, Smylie and colleagues had identified respondent driven sampling as a promising method for identifying an urban Inuit cohort for health assessment. A small grant from the Public Health Agency of Canada was used to fund a research planning meeting in March 2008. At this meeting, research principles, partnerships, and methods were further developed. A full research proposal was

submitted by OFIFC on of behalf of the research partners to the Aboriginal Health Transition Fund, MOHLTC Ontario in June 2008.

The project team was tentatively informed of the success of their application in late 2009, however federal and provincial funding delays resulted in no AHTF monies arriving until the end of March 2009. Fortunately both OFIFC and CRICH at Saint Michael's Hospital were able to identify project start-up funds and the project was formally initiated in January 2009.

PROJECT GOVERNANCE

All of the core organizations involved in the Our Health Counts Project (OFIFC, MNO, TI, ONWA, and CRICH) agreed upon the following research principles:

- Aboriginal Leadership
- Research Agreements and Data Management/Governance Protocols
- Capacity Building
- Respect
- Cultural Relevance
- Representation
- Sustainability

The first principle, Aboriginal project leadership, was operationalized by the establishment of the Our Health Counts project Governing Council, which was comprised of representatives from OFIFC, MNO, TI, and ONWA as voting members and Dr. Janet Smylie from CRICH as a non-voting governing council participant who was also identified as the scientific director for the project. Monthly Governing Council meetings were held throughout the length of the project.

The second principle, research agreements and data management and governance protocols, was operationalized in a way that ensured that the OHC Governing Council as well as the First Nations, Inuit, and Métis community project partners were able to exercise their rights to govern and manage project data, including the rights to own, control, have access to and possess project data. To start with, the four Governing Council organizational members developed and signed a project MOU. Next, the OHC project team successfully developed and negotiated community research agreements with each of the three community project sites. The First Nations (OFIFC and DHAC) – SMH research agreement is attached in Appendix A. Finally, a tri-party data sharing agreement was negotiated between the Institute of Clinical and Evaluative Service, the

OHC Governing Council (OFIFC, MNO, ONWA and TI) and the CRICH at St Michael's hospital (Appendix B).

RESEARCH TEAM

Aboriginal Governing Council Members:

Sylvia Maracle (OFIFC), Connie Siedule (TI), Donna Lyons (MNO), Betty Kennedy (ONWA), Janet Smylie (CRICH)

Academic Research Team Members:

Janet Smylie (Scientific Director), Pat O'Campo, Rick Glazier, Marcia Anderson, Kelly McShane, Roseanne Nisenbaum, Dionne Gesink Law, Michelle Firestone

Project Staff:

Cheryl McPherson, Conrad Prince (CRICH); Deborah Tagornak, Colleen Arngna'naaq, Jessica Demeria, Leslie Cochran, Crystal Burning (Community Site Leads); Amye Annett, Ashly MacDonald, Trisha McDonald, Diane Therrien, Alisha Hines (Community Interviewers)

Additional Collaborators:

Vasanthi Srinivasan (Director, Health System Planning and Research Branch, MOHLTC); Fredrika Scarth (Acting Manager, Research, Health System Planning and Research Branch, MOHLTC); Sue Vanstone (Manager, Aboriginal Health Strategy Unit, MOHLTC); Don Embuldeniya (Manager, Health System Information and Management Branch, MOHLTC); Kelly Murphy (Director of Knowledge Translation, CRICH); Leslie McGregor, Director, Noojamawin Health Authority, Paula Stewart (Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada)

HAMILTON SITE

The OFIFC identified the City of Hamilton as a promising First Nations community project site, based on its significant Aboriginal population (13,735 persons reporting Aboriginal ancestry according to the 2006 Census) and strong infrastructure of Aboriginal community health and social services.

In the spring of 2008, OFIFC Executive Director Sylvia Maracle travelled to Hamilton with Dr. Smylie to meet with the Hamilton Executive Directors Aboriginal Coalition (HEDAC) to tell them about the project. The HEDAC agreed to move forward with the project and

identified the De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) as the organizational project lead.

The City of Hamilton is located in southern Ontario, 50 minutes west of Toronto and 1.5 hours east of London. Located on what was traditionally Haudenosaunee (Iroquoian) territory, Hamilton is situated near two First Nations reserves: Six Nations of the Grand River and Mississaugas of the New Credit. The 2006 Census statistics show that the total Aboriginal population in Hamilton is 13,735 by ancestry comprising 2.8% of the overall population of the city (497, 395). The 2006 Census is known to have significant under-representation of the First Nations population in the Hamilton area, including but not limited to: persons who choose not to participate in the Census for personal and/or political reasons; persons who participate in the census but choose not to identify as First Nations or do not identify because the ethnicity questions don't match their self-identify; and persons who are homeless or without a permanent address. Three thousand, two hundred and sixty people living in the City of Hamilton declared they are registered Indians, according to the Indian Act. This number of persons who identified as Registered Indians is likely a gross underestimate as for political and cultural reasons many First Nations persons living in Hamilton may have rejected a notion of self-identification that draws on federal Indian Act legislation even though technically they are recognized by this legislation as Registered Indians. Of note, Six Nations was one of 22 reserves that did not participate in the 2006 census and given the geographic and family ties that many First Nations persons in Hamilton have with Six Nations this boycott would have had an impact on the census.

The DAHC provides primary care, traditional healing and health promotion programs to nearly 6000 Aboriginal people living in both Hamilton and Brantford, Ontario. Its mission is "improving the wellness of Aboriginal individuals and the community by providing services that respect people as individuals with a distinctive cultural identity and distinctive values and beliefs". While DAHC is centrally located and a touchstone for many Aboriginal people living in both Hamilton and Brantford, the Our Health Counts study only collected health information from the First Nations population who were resident to the City of Hamilton.

RESEARCH METHODS

METHODS SUMMARY

- This project was carried out using community based participatory research methods.
- Our approach promoted balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination.
- This was achieved through the project governing structure including the project Governing Council and research and data sharing agreements described above as well as ensuring that capacity building, respect, cultural relevance, representation, and sustainability were core features of the project's ongoing overall and day to day implementation.
- Brainstorming and sorting of ideas and topics for the surveys was done using concept mapping with health and social service stakeholders in Hamilton. One hundred and two statements were sorted into a concept map of ten domains.
- These domains and statements were used by the research team and to create. Questionnaires for both adults and children. Surveys were shortened after pilot testing in the community.
- Surveys were conducted in person by trained interviewers initially with paper-based questionnaires and later on directly on a computer.
- A respondent driven sampling (RDS) technique was used to recruit individuals to be interviewed for the research. This method involved giving tickets to each First Nation participant who completed an interview, and the participants could give these tickets to other First Nations people they knew, including friends and family. For each participant recruited, the person who made the recruit received $10.
- The OHC First Nations Hamilton sampling was extremely successful. Over a course of four and a half months a total of 790 persons were recruited, including 554 adults and 236 children.

- 92% of participants gave permission to use their OHIP number to link to their data on health care system usage available through the Institute for Clinical Evaluative Sciences.
- All the data findings presented in the results section are adjusted for bias using RDS statistics to take into account how spread out different participants are within the social network through which they were recruited.

COMMUNITY BASED PARTICIPATORY RESEARCH

Community-based research takes place in community settings and involves community members in the design, implementation, and documentation of research projects. Its principles and methods ensure that processes are relevant and that the outcomes have tangible benefits for the communities involved. It has been widely used and adapted in research with Aboriginal communities.

Community-based, participatory research (CBPR) was deemed the most appropriate research methodology for the OHC project because it uniquely emphasizes shared decision making among study partners and because it supported the principles of Aboriginal data governance and management. The OHC project's CBPR approach drew on the existing research experiences of the participant core organizations and the project scientific director and successful models of and recommendations regarding community-based participatory Indigenous health research.[3] [4] [5] [6] [7] [8] Our approach promoted balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination. This was achieved through the project governing structure including the project Governing Council and research and data sharing agreements described above as well as ensuring that capacity building, respect, cultural relevance, representation, and sustainability were core features of the project's ongoing overall and day to day implementation.

CONCEPT MAPPING

According to Trochim and Kane, concept mapping is "considered a structured methodology for organizing the ideas of a group or organization, to bring together diverse groups of stakeholders and help them rapidly form a common framework that can be used for planning, evaluation, or both".[9] The OHC research team employed concept mapping in order to create three site specific and culturally appropriate community

health survey questionnaires (First Nations, Inuit, and Métis). The method was identified as promising given the long history of using maps as a tool to document traditional land use and knowledge in Indigenous communities.

The OHC concept mapping method involved three main community participatory steps: (1) Group Brainstorming, (2) Group and/or Online Sorting and Rating and (3) Group Map Interpretation.

Key health and social service stakeholders were identified in partnership with DHAC and invited to attend a group brainstorming session. Participants were purposely selected to ensure a diversity of representation according to organization represented, gender, age, and organizational role (ie. both staff and clients) were included. Sixteen persons participated in two brainstorming sessions and responded to the following question:

Health and health related issues and topics in the Hamilton First Nations community that are prevalent, serious, have the fewest solutions, or otherwise important include….

The result was 102 statements. In a subsequent sorting and rating session, participants sorted these statements into piles that made sense to them and rated each statement according to service availability, need for health information and overall health concern. Concept systems software was used to create preliminary point and cluster maps reflecting the overall group sort and rate. Community stakeholders were then engaged in two further group sessions to refine these preliminary maps. Concept mapping findings are presented in the results section.

RESPECTFUL HEALTH SURVEY

It was determined very early in the research process that the needs assessment survey should be renamed and reconceptualized as “respectful” rather than “rapid” as this would be more fitting with community processes and values.

In March 2009, Governing Council representatives identified priority health and social issues that they wanted to be included in the needs assessment surveys. Drawing on this preliminary list of priority areas and existing survey tools the academic research team developed a bank of questions.

Once the concept mapping processes were complete, the health statements and health domains identified in the First Nations concept mapping were used to develop a community specific adult and child health survey for First Nations in Hamilton. Survey

tools were piloted with First Nations community members who were otherwise ineligible for the survey (i.e. their residence was outside of the city of Hamilton). Two rounds of piloting (which included informed verbal consent) occurred. Each session provided valuable suggestions on how to improve the survey, how to adjust language to become more respectful, and how to promote a logical flow to the questions. The surveys were also subsequently shortened. Academic research team members then incorporated the changes to the survey tool and returned a finished product to the local survey administration team. The final survey tool is attached in Appendix C.

The survey was launched using paper surveys while the academic research team worked on finalizing a computer based version. The Research Team worked with a consultant on the development of a Computer Assisted Personal Interviewing (CAPI); however, this consultant failed to deliver. The Research Team therefore programmed its own CAPI using implemented Statistical Packages for the Social Sciences (SPSS) software. Specifically, the SPSS Data Collection Author Professional was used to develop and program the survey tool and the SPSS Data Collection Interviewer package was used to administer the survey. This presented a significant technical challenge for the research team as well as delays in launching the electronic survey. Upon completion of the computer program, local survey administrators were involved in the piloting process of the SPSS CAPI and contributed, in an on-going manner, to identify issues arising with the electronic survey. The Hamilton team started using the SPSS electronic survey in March 2010 on a go forward basis and worked with the CRICH research team to input over 400 paper files prior to fiscal year end.

RESPONDENT DRIVEN SAMPLING

In the absence of an accessible and accurate population based sampling frame for urban First Nations, Inuit, and Métis communities, the academic team and key Aboriginal stakeholders selected a respondent driven sampling technique (RDS) to generate representative samples. RDS has emerged as a technique for sampling hard to identify populations and has been used in urban centres across the world.[10] [11] [12] It combines a modified snowball or chain referral sample technique with a mathematical system for weighing the sample based on self-reported social nework data to compensate for it not having been drawn as a random sample. Each participant is asked questions regarding their relationship to the person who referred them to the study and the size of their network, which allows the bias in the sampling process to be estimated and unbiased estimates of a population's composition (e.g., age, gender, birthplace), behaviors and disease prevalence to be obtained.[13]

Sample sizes were calculated using the formula provided by Salgunik[11] for RDS, who recommends sample sizes that are twice as large as those that would be needed under simple random sampling. Based on this formulate we originally aimed to recruit 500 First Nations adults and 500 children in Hamilton. This was modified to 500 adults and 250 children as the study progressed as it became apparent that the child sample recruitment was reflecting the age make-up of the Hamilton First Nations population, and that children would make up one-third of the total sample as opposed to one half.

In RDS, the sampling is done by study participants who are given tickets and asked to recruit other study participant by giving out the tickets. In the OHC First Nations Hamilton RDS each participant was given 3 – 5 tickets for recruitment. For each participant recruited, the person who made the recruit received $10. An RDS sample is initiated by providing a limited number of persons (ie. 6-12), who then become known as "seeds" with tickets for recruitment. It is noteworthy that in the past First Nations were at times coerced into participating in harmful colonial processes by the use of incentives, such as cheese or money, which would be dispensed by the Indian agent in return for participation in colonial activites, which at times included health treatments and data collection. Ethically this means that extra caution may be required when considering incentives for participation in a research study, even when the research study is being run by First Nations community members. In this case, even though the use of incentives may have negative historical connotations, the study design is carefully structured to ensure that study results will empower rather than harm community members.

In the OHC First Nations Hamilton RDS the DHAC outreach worker as well as members of the research team identified potential seeds who represented a diverse demographic of First Nations people living in Hamilton. Gender, age, family size, occupation, and where in the city a person lived were all factors which were considered seed selection.

Inclusion criteria for participation in the study included adults who were resident within the geographic boundaries of the City of Hamilton and self-identified First Nations/ Native/Indian identity. Adults were defined as persons 18 years of age and older or persons younger than the age of 18 years who were parents. The child survey was completed by parents or custodial relatives/guardians for all children who resided with the adult and were under the age of 14 years. In order not to exclude First Nations children who were living with a non-First Nation biologic or adoptive parent/relative/ guardian we additionally allowed coupons to be given to non-First Nations persons who were the custodial parent/relative/guardian of one or more First Nations children.

Approximately 10 people identified as potential seeds attended a lunch and learn session at DHAC where the community research team explained the study and its potential to

improve First Nations health status and access to services. Of this group, six people agreed to become seeds and completed the survey within a week of their stated commitment. Each seed received three coupons to refer a friend, acquaintance, family member, or stranger into the study. Five of the six seeds produced referrals within the two weeks leading up to the December 2009 holiday closure at DAHC. In February 2010, in order to increase the number of completed child surveys, two additional seeds were added specifically targeting families with children.

The OHC First Nations Hamilton sampling was extremely successful. Over a course of four and a half months a total of 790 persons were recruited, including 554 adults and 236 children. We will further detail in the results section below how long recruitment chains resulted in departure from the original sampling bias and the achievement of a state of "equilibrium" in which the probability of recruitment into the study reflects the demographics of the population. Staff at the health centre verified this successful departure from the original sampling bias by observing study participants who they had never seen before at DHAC.

Using the RDS stat program we used the self-reported social network and referral information to generate population based estimates of the health and social indicators included in the OHC First Nations Hamilton surveys. All the data findings presented in the results section are RDS-adjusted estimates.

ICES DATA LINKAGE

The Institute for Clinical and Evaluative Sciences (ICES) is an independent, not for profit organization whose core business is to contribute to the effectiveness, quality, equity, and efficiency of health care and health services in Ontario. It is able to anonymously link population health information compiled from a number of sources using a participant's health card number. The opportunity to connect with ICES enabled the OHC research team to produce, for the first time, urban Aboriginal population based rates of emergency room use, hospital admission and participation in preventative screening programs, including mammography, Papanicolaou (Pap) testing, and colorectal cancer screening.

Adult participants in the OHC First Nations survey were able to opt in or out of the ICES data linkage for themselves and their children on their consent forms.

First Nations adult and child participants in our sample were identified in the larger ICES database using a deterministic linkage based on their Ontario health card number, date of birth, and name. In order to protect the confidentiality of study participants, this linkage was done internally at ICES, by ICES staff.

A total of 725 First Nations study participants (92% of all study participants) opted into the baseline ICES data linkage and were successfully identified in the ICES database. This included 525 adults (95% of adult participants) and 200 children (85% of children participants).

Tables describing income quintile by census postal code, emergency room admissions, hospital admissions, and participation in preventative care screening by mammography, Papanicolaou (Pap) testing testing and colorectal screening by occult blood were produced for the First Nations cohort, the City of Hamilton and the province of Ontario. The estimates for the First Nations income quintile and health care utilization were adjusted using the RDS stat software program, which was described in the preceding section. RDS uses the self-reported social network and referral information of the OHC First Nations Hamilton cohort to generate population based estimates. These tables are presented in the results section.

COMMUNITY IMPLEMENTATION

The local survey administration team in Hamilton consisted of two site coordinators and five survey administrators. A community research office was established in the DHAC Hamilton facility. A customized training was conducted for all survey staff drawing on a customized project training manual, which was prepared by the CRICH research team. The local team was further supported by monthly larger group research team meetings and weekly RDS work group meetings which included an RDS data analyst. Further details regarding the specifics of community implementation are available upon request.

RESULTS

CONCEPT MAPPING

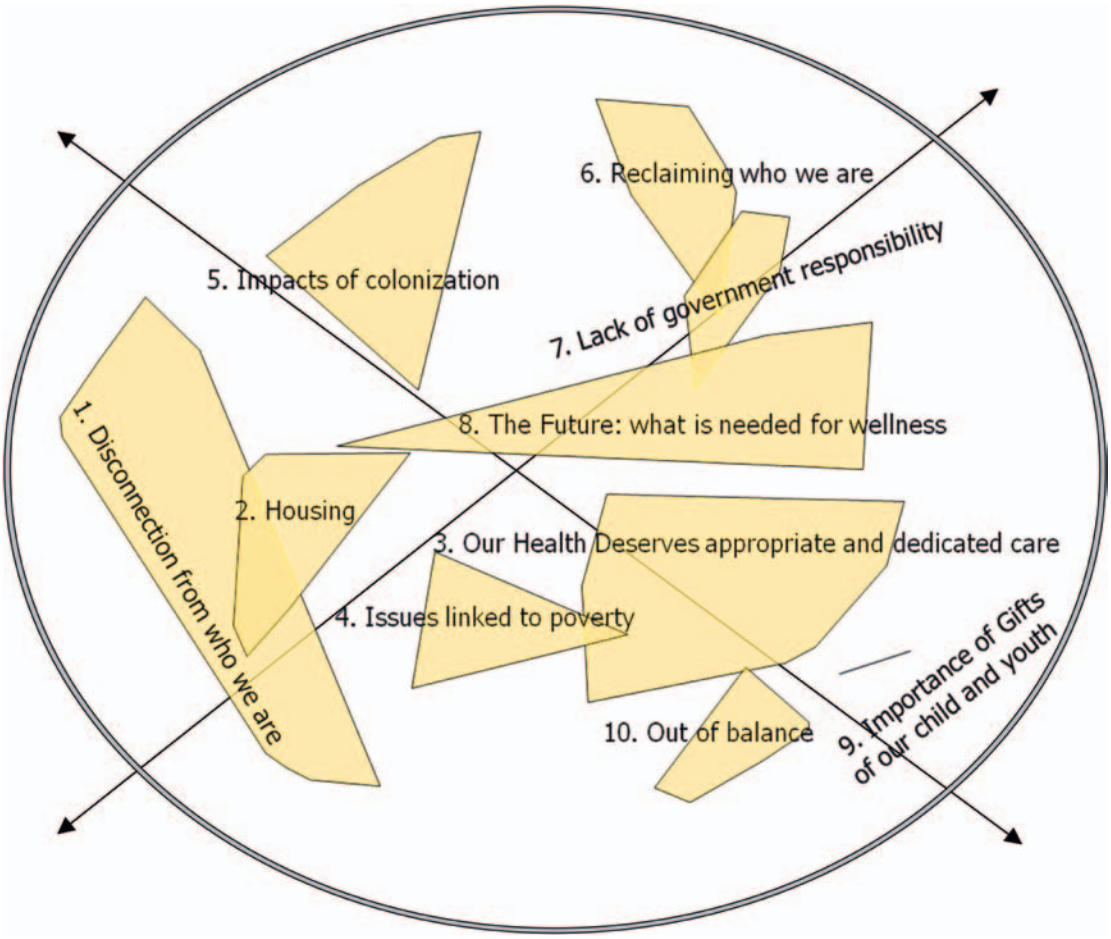


Figure 1: First Nations Hamilton Concept Map

The initial brainstorming session generated 102 statements, which are attached in Appendix D. The concept mapping process revealed the ten interconnected domains that provided the framework for the First Nations health survey.

At the final concept map interpretation meeting the map was placed inside a circle and two perpendicular arrows were drawn across the circle. The first arrow connected the "disconnection from who we are" cluster to the "reclaiming who we are cluster" and the second arrow connected the "impacts of colonization" cluster to the "our health deserves appropriate and dedicated care" cluster. The resulting figure resonated with medicine wheel and Haudenosaunee lodge teachings, figures, and directions. These views reflected traditional ways of interpreting and contextualizing information in a local manner. One key stakeholder gave the research team a teaching of the traditional ways of the Haudenosaunee people and how this map interpretation was in fact reflective of that teaching.

For the purposes of the survey the housing and issues linked to poverty were combined in the first section of the survey, which was titled socio-demographics. Survey domains are as follows:

Socio-demographics: This section addressed housing and mobility, socio-economic status, food security, water quality, and links to poverty.

What happens when we are out of balance: This section addressed physical, mental, and emotional health problems. Questions explored chronic disease, mental health, fetal alcohol spectrum disorder, injury and acute illness, sexual and reproductive health.

Reclaiming who we are: This section addressed aspects of First Nations identity. A series of identity statements were read to survey respondents that spoke to issues of belonging, participation in cultural practices, self-esteem, and understanding.

Disconnection from who we are: This section addressed substance use, including cigarettes, alcohol, illicit and prescription drugs. Perceptions on the level of access and availability of health services were also surveyed, which included traditional medicines and experiences with non-insured health benefits. This section also addressed barriers to health care and use of any Aboriginal specific services in the community.

Impacts of colonization: This section addressed the health impacts of residential schools, child protection agency involvement, and dislocation from traditional lands in the lives of urban First Nations people. Questions about racism, discrimination, violence, and abuse were also included.

Lack of government responsibility: This section asked survey respondents to list the main challenges and strengths of the community. Community services were also assessed for adequacy for particular populations (i.e. youth, single men, Two Spirit Lesbian Gay Bisexual Trans Queer Questioning Identities) and services (i.e. legal, HIV prevention, pandemic planning). This section included open ended questions for respondents to list any areas for which community resources were particularly lacking.

Importance of the gifts of our children and youth: We developed a child specific survey, the results of which will be summarized in a subsequent report.

RESPECTFUL HEALTH SURVEY DATA

Recruitment Dynamics

Among the RDS sample of First Nations in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds (see figure 2). This is quite typical of RDS. The length of both of these recruitment chains is long enough that both chains were able to overcome the original sampling bias. This usually happens after 6 or 7 waves of recruitment. These two recruitment chains had 19 and 32 waves of recruitment each. The relationship between recruiter and recruit (according to recruit) was "friend" in 46% of recruitments, "relative" or "boyfriend/girlfriend" in 42.6% of recruitments, "acquaintance" in 8.6% of recruitments, and "stranger" in 3% of recruitments. The average network size varied among participants, with a mean of 46.6, a median of 20, and a range of [1, 2000]. A total of 49% of respondents recruited others into the sample. The mean number of recruitments for all sample members is .96; the mean number of recruitments among those who recruited is 1.96.

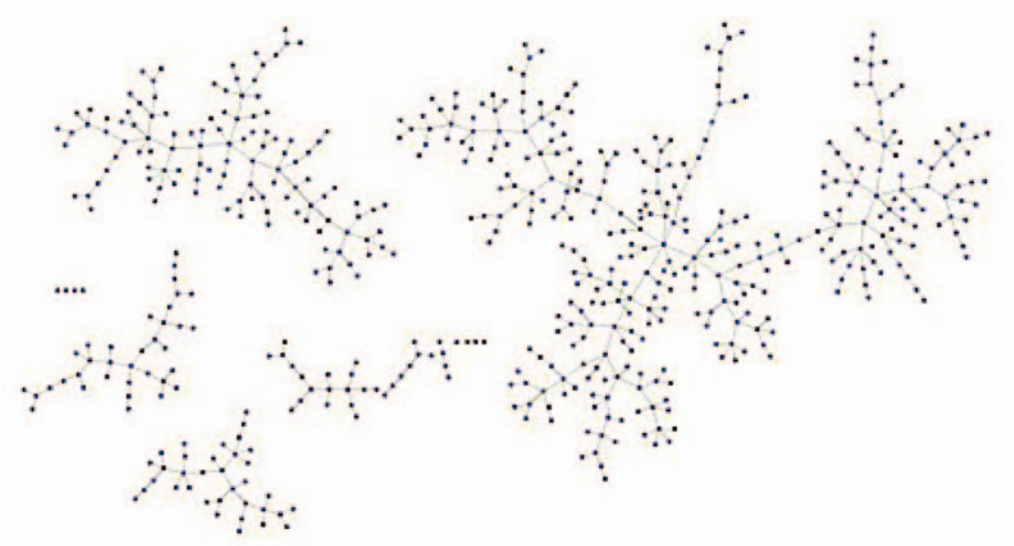


Figure 2. Recruitment Tree of First Nations in Hamilton, Our Health Counts

Methodological Note Regarding the Interpretation of Self-Report Data

It is important to recognize that the cycle of poverty experienced by this population (i.e. reporting of high mobility, overcrowding and very low income) is likely associated with an under-reporting of socio-economic stressors and ill health. This needs to be taken into consideration when interpreting the results of self-report questions such as: having to give up important things to meet shelter related costs; self-reported balanced diet; self-rated health) for a number of reasons. Firstly, there may be some stigma around self-reporting of not having the financial stability to pay rent and meet other needs. Secondly, individuals in a population that has experienced longstanding adverse conditions may have internalized notions of "not being good enough" and therefore accept what others might perceive as hardship. Thirdly, lowering expectations is a strategy for survival when one faces chronic and recurrent hardship. Finally, multi-generational experiences of adversity may result in the normalization of what outsiders living in more prosperous circumstances might consider unmet needs or ill health.

The following results are presented according to the domains of the First Nations health assessment survey tool. As outlined in the Concept Mapping section of this report, the content of each domain and its title reflect the health priorities of First Nation community stakeholders. The results below are for adults. Child survey results are presented in a later section of this report.

DOMAIN 1: SOCIODEMOGRAPHICS

Highlights from Domain 1

- Ninety percent of the First Nations population living in Hamilton had moved at least once in the past 5 years and over 50% of the population had moved three or more times in the past 5 years.
- Thirteen percent of the First Nations population living in Hamilton reported being homeless, in transition, or "living in any other type of dwelling.
- Using the Statistics Canada definition of crowded housing as more than one person per room, 73.7% of First Nations persons in Hamilton live in crowded conditions.
- Sixty-three percent of First Nations community members in Hamilton had to give up important things (i.e. buying groceries) in order to meet shelter-related [housing] costs.
- Twenty-two percent of the First Nations population sometimes or often did not have enough food to eat.

Demographics

The Our Health Counts (OHC) First Nations adult population in Hamilton was comprised of a total 555 participants: 60% men and 40% women. For men, about a third of the population fell in each of the following age categories: 18-34 years (34.5%), 35-49 (35.2%) years and 50+ (30.3%) years. Overall, the female population however was younger, with 47.7% between the ages of 18-34, 36.3% between 35-49 and 16% over the age of 50. Among this First Nations population, 50.8% indicated that they were Status (Registered Indian according to the Indian Act). It is important to note that this figure is likely an underestimate of the proportion of participants who are Registered Indians as for political and cultural reasons some participants may have rejected a notion of self-identification that draws on federal Indian Act legislation even though technically they are recognized by this legislation as Registered Indians. For example, community members from Six Nations may value their nation identity (i.e. Haudenosaunee, Mohawk, Oneida, Onondaga, Cayuga, Seneca and Tuscarora) more than they value 'being Indian'.

When asked what language was spoken most often at home, 95% spoke English only, 3% spoke an Aboriginal language only and 2% spoke French only or English and another language (see figure 3). These numbers clearly reflect the decline of Iroquoian languages due to longstanding contact with colonizers, the impact of residential schools and other challenges. Despite such high numbers of English spoken at home, the importance of children learning a First Nations language at home was rated very high among this population.

As for number of children, 36% of the sample had no children, 18% of the population had either 1 or 2 children, 15% had 3 children, and 13% had 4 or more children.

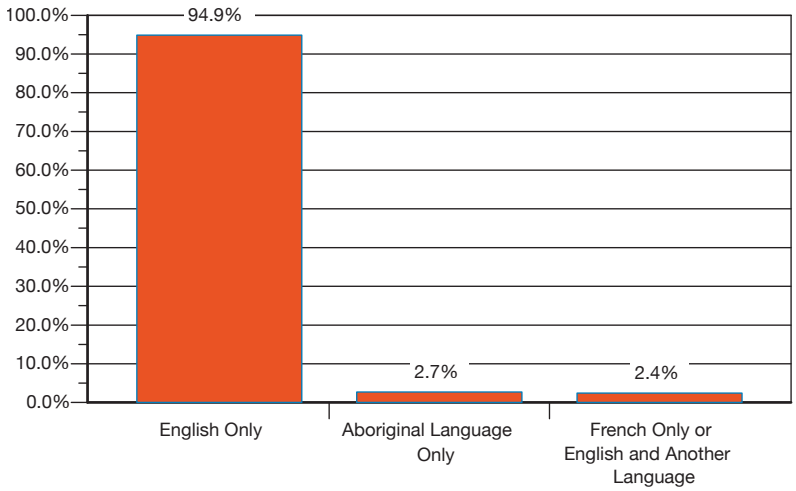


Figure 3. Language spoken at home for First Nations Adults, Our Health Counts

Overall, the OHC First Nations population reported low levels of formal education. When asked the highest level of education completed, the OHC RDS adjusted estimates for First Nations adults over the age of 18 years were: 57% had completed some high school or less and 20% completed high school, 18% had completed some or all of college and only 5% had completed some or all of university. As a comparison, according to the 2006 census, 25% of residents of the city of Hamilton aged 15 and older had some high school or less, 27% had completed a high school diploma, 20% had completed college and 19% had completed university.[14] In the OHC First Nations population, there is evidence to suggest a trend towards more women completing higher levels of education compared to men. For example, 23% of women completed some or all of college compared to 16% of men (see figure 4).

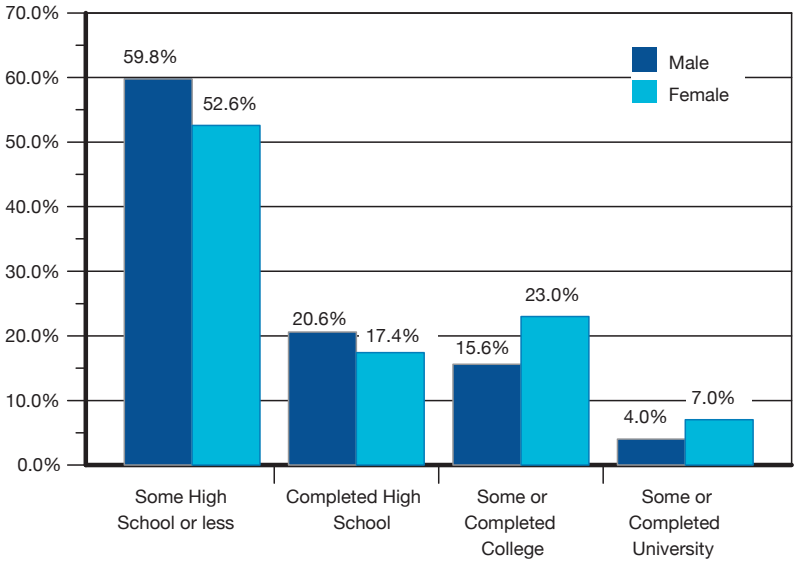


Figure 4. Level of Education by Gender for First Nations Adults, Our Health Counts

When asked to indicate the source(s) of the total income for all household members in the past 12 months, the following results emerged: wages and salaries (28.2%), income from self-employment (7.7%), employment insurance (9.6%), Child Tax Benefits (17%), Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works) (69.2%), child support (3%), any other income source (13.3%). Clearly, this population is relying heavily on social assistance. While more women than men reported child benefits and child support as income sources, more men reported income from self-employment (11% vs. 3%) (see figure 5).

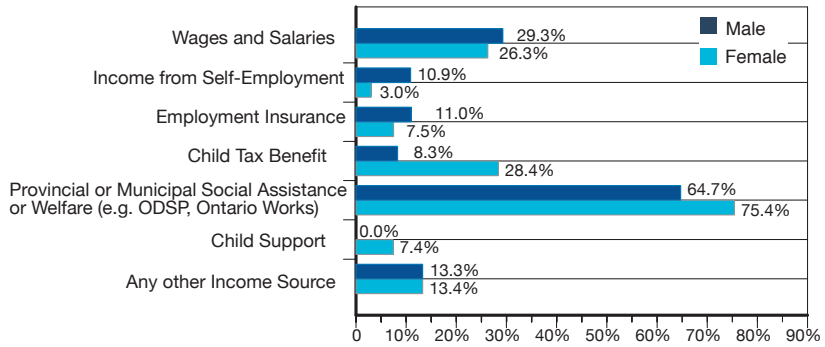


Figure 5. Sources of Income by Gender for First Nations Adults, Our Health Counts

In addition to sources of income, the OHC Hamilton population was also asked to indicate their personal income for the year ending on December 31st, 2008. Based on the answers to this question we determined the following population estimates for income: 18.3% earned less than $4,999, 23.1% earned between $5,000 and $9,999, 21.9% earned between $10,000 and $14,999, 14.8% earned between $15,000 and $19,999 and 21.8% earned over $20,000. As a comparison, according to the 2006 census, 15% of residents of the city of Hamilton aged 15 and older earned less than $5,000, 9% earned between $5,000 and $9,999, 10% earned between $10,000 and $14,999, 9% earned between $15,000 and $19,999 and 57% earned over $20,000.[15]

When the OHC First Nations population was stratified by gender, we observed that more women fell into the lower income bracket with 31.2% of all women who reported earning less than $4,999 compared to 9.3% of men. In terms of higher income, 26.1% of all men reported earning more than $20,000 compared to 16.9% of women, however this difference was not statistically significant (see figure 6). The income differences between men and women are larger in the OHC First Nations population than within the general population in Hamilton.[15]

This income data may be considered a more rigorous representation of the actual income profile of the First Nations population in Hamilton than the 2006 Census data as it was validated and adjusted for bias using RDS statistics, and the Census is known to have significant under-participation by First Nations community members, particularly in Hamilton where many First Nations residents have close ties to the nearby Six Nations First Nations community which did not participate in the 2006 census. The Census is also known to under-represent persons who are homeless, transient or who have low literacy skills, all issues which have higher prevalence in First Nations populations, and all issues that are associated with lower income levels. Finally, the OHC survey income data is also validated by the OHC RDS adjusted ICES income quintile data (reported in the next section), which places over 70% of the OHC cohort into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population.

Clearly, this population is facing high levels of poverty. Poverty is so prevalent in fact that the breakdown of study findings by income categories was not possible due to such high numbers in the lower income brackets and little variation in total earnings.

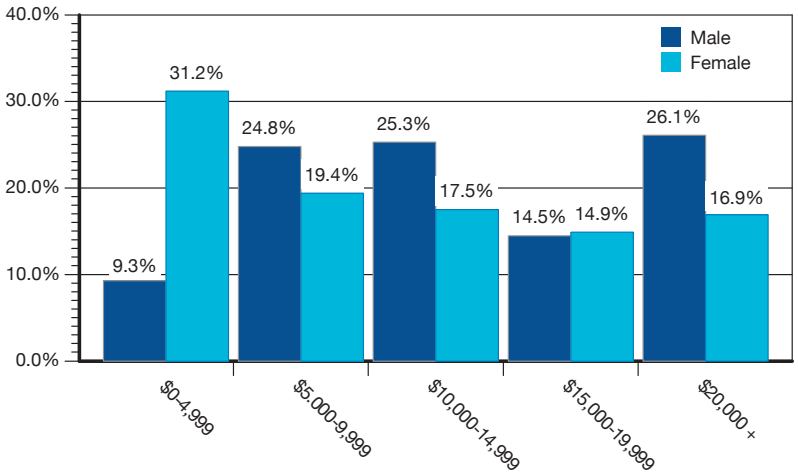


Figure 6. Income Categories by Gender for First Nations Adults, Our Health Counts

Housing and Mobility

With respect to current dwelling type, around 15% of the population lived in each of the following: a single house (not attached to any other dwelling), a semi-detached, duplex house, row house, or townhouse or a self-contained apartment within a single detached house. Most of the population (41%) lived in an apartment or condominium. The distribution of dwelling type across genders was fairly consistent, with the exception that among women, 24% reported living in a semi-detached home or duplex compared to 8.6% of men and these differences were statistically significant. Within the overall dwelling types in the city of Hamilton, 26% of dwellings are apartments,[15] which indicates that the OHC First Nations population is much more likely to be living in apartment buildings than average Hamiltonians.

In addition, 13% of the OHC First Nations population described themselves as homeless, in transition, or living in any other type of dwelling. There is also a trend to suggest that more men in this population are homeless or experience transitional housing compared to women (see figure 7).

There was a strikingly high mobility reported among the study population. Only 10% of the population had no moves over the past 5 years. Over 20% of the population had moved 2 times in the past five years, while 41% had moved between 3 and 5 times in the past 5 years and 10% had moved 6 to 10 times in the past 5 years (see figure 8). These numbers are very high compared to total urban populations in Canada. For example, according to the 2006 Census, among all people living in the city of Hamilton, 60% had

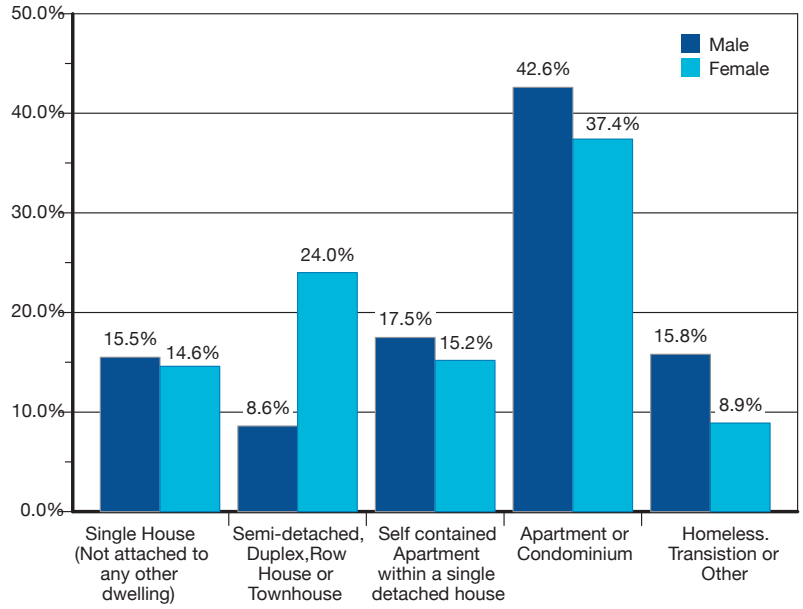


Figure 7. Dwelling Type by Gender for First Nations Adults, Our Health Counts

lived at the same address 5 years ago and 87% had lived at the same address 1 year ago.[14] With respect to the total urban Aboriginal populations in Canada, the 2006 Census revealed that 25% of the total urban Aboriginal population has moved at least once in the year before the census.[16]

This high mobility pattern reflects the cycle of poverty facing this population. Frequent moves puts stress on the family unit; makes it difficult to engage in regular employment and educational programs; and is associated with poor food availability and unstable, overcrowded, inadequate shelter.

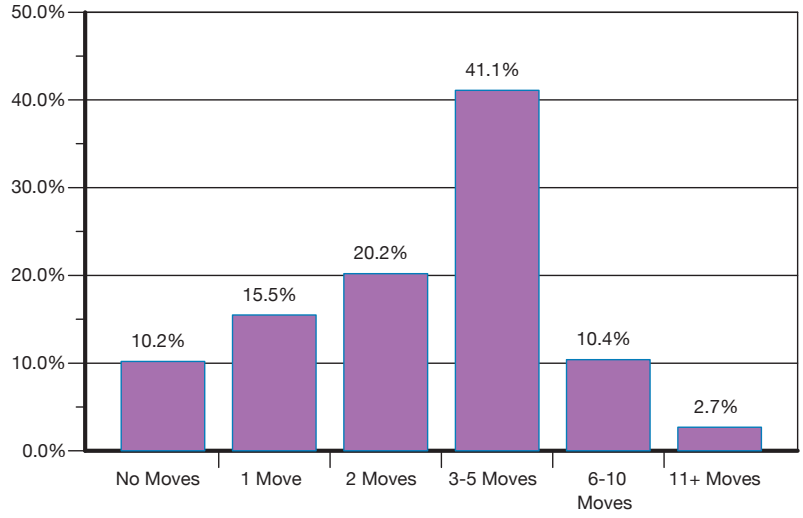


Figure 8. Number of Moves in the Past 5 Years for First Nations Adults, Our Health Counts

Following Statistics Canada standards, we calculated overcrowding in this population by dividing the number of rooms in each household (excluding bathroom) by the number of people residing in the home. Using the Statistics Canada definition of crowded housing as more than one person per room, 73.7% of First Nations persons in Hamilton live in crowded conditions. Specifically, 27.7% of the population were living with less than or equal to 1 person per room, 46% were living with more than 1-2 persons per room and 26.3% were living with more than 2 persons per room. The rate of housing crowding for the general Canadian population according to the 2006 Census was 3%.[17]

Over two thirds (67.2%) of the population felt that their dwelling was not in need of repairs, but only regular maintenance was needed (painting, furnace cleaning, etc.). Over one quarter (26.2%) of the population felt that their dwelling needed minor repairs (missing or loose floor tiles, bricks or shingles, defective steps, railing or siding, etc.) and 6.7% of the population felt that major repairs were needed (defective plumbing or electrical wiring, structural repairs to walls, floors or ceilings etc.). These findings are very close to results from the 2006 census for the overall city of Hamilton population (65% of Hamilton occupants reported that their dwelling only needed regular maintenance, 27% reported dwellings needed minor repairs, and 7% reported dwellings needed major repairs).[15] The similarities may be due to the question being very subjective. As one Hamilton Aboriginal community member stated "housing in Hamilton is great compared to reserve housing". The high proportion of people living in unstable housing in the OHC First Nations population may mean that for many "good housing" is just a roof over their head and a lease in their name. As well, the higher proportion of OHC First Nations population who are tenants of apartment buildings, and lower proportion living in smaller housing types, may be a factor. A recent Social Planning Network of Ontario report noted that tenants of larger buildings may be unaware of the repair needs of their dwellings (e.g. roof, sewage, electricity, etc.) unless these repair issues are immediately obvious to the individual tenant. As such, the extent of apartment buildings dwellings in need of major repair may be undercounted.[18]

With respect to how often First Nations community members in Hamilton had to give up important things (i.e. buying groceries) in order to meet shelter-related [housing] costs, 17.3% had to give up things several things several times a month, about half the population had to give up things between once a month and a few times a year and 37% reported never having to give up important things. While women were pretty evenly distributed across each category, among men, fewer reported having to give up important things with 45% saying they were never faced with this situation. There was also a strong trend of more men who reported never having given up important things to meet shelter-related costs as compared to women (see figure 9). As discussed at the beginning of this section, it is important to recognize that the cycle of poverty experienced by this

population (i.e. reporting of high mobility, overcrowding and very low income) is likely associated with an under-reporting of socio-economic stressors and ill health for reasons that were detailed earlier.

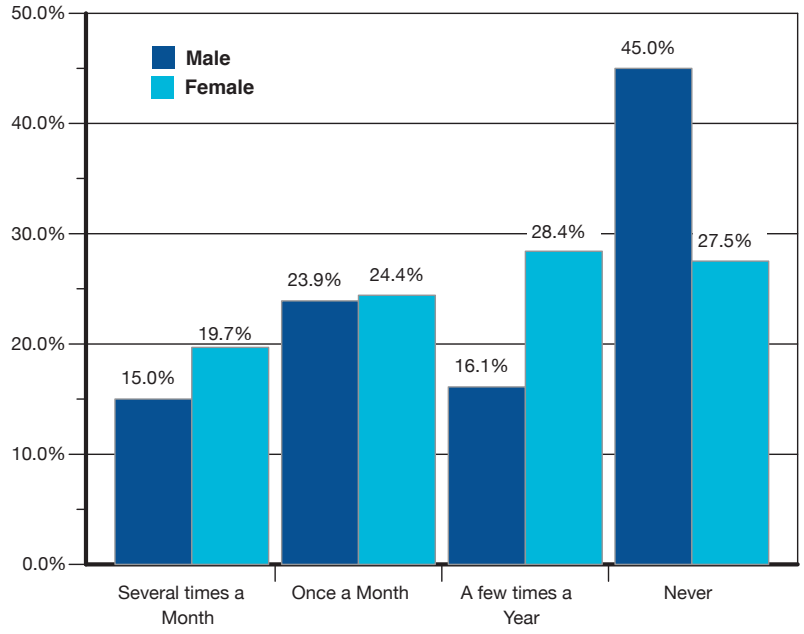


Figure 9. Giving Up Important Things to Meet Shelter-Related Costs by Gender for First Nations Adults, Our Health Counts

Nutrition and Food Security

"I live entirely off of food banks, that's where the nutrition comes in, no choice over food."

"I need access to a doctor to sign my special diet form so I can lower my cholesterol"

"On a fixed income, food money gets short. I find myself binge eating the first two weeks, the other two weeks I am starving. The food bank food isn't fit to eat (expired) and high in sodium…it is depressing."

"When I was on the streets or social assistance, the health workers would tell me that I need to watch what I eat as I am diabetic, it is expensive to eat healthy."

For self-reported nutritious balanced diet, overall, 36% felt that they always or almost always ate a balanced diet, 40% felt they sometimes ate a balanced diet and 24% felt they rarely or never ate a balanced diet. Across gender, we observed a trend towards more men who reported rarely or never eating a nutritious diet compared to women (see figure 10).

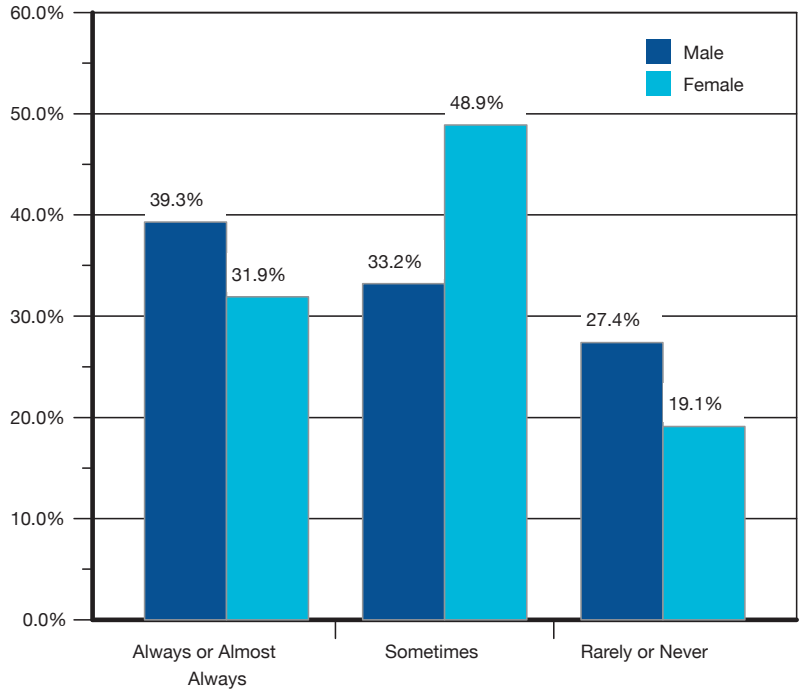


Figure 10. Self-Reported Balanced Diet by Gender for First Nations Adults, Our Health Counts

Regarding food security, a fairly even distribution across the age groups revealed that over 50% of the population, both young and old felt that they and others in their household had enough to eat, but not always the kinds of food they wanted. A similar distribution was revealed for both men and women, again with over 50% of males and females reporting that they and others in their household had enough to eat, but not always the kinds of food they wanted. Twenty-two percent of the population sometimes or often did not have enough to eat (see figure 11). Having enough to eat, but not always the desired type of food may be linked to a higher intake of carbohydrates and sugars, which can lead to feeling full, but not represent a nutritious balanced diet. This higher intake of carbohydrates and sugar in turn is linked to blood sugar problems, including diabetes.

DOMAIN 2: "WHAT HAPPENS WHEN WE ARE OUT OF BALANCE" PHYSICAL, MENTAL, AND EMOTIONAL HEALTH PROBLEMS

Highlights from Domain 2

- Only one quarter of the First Nations population living in Hamilton reported excellent or very good health. This self-reported health status is much lower than for the general Hamilton population.

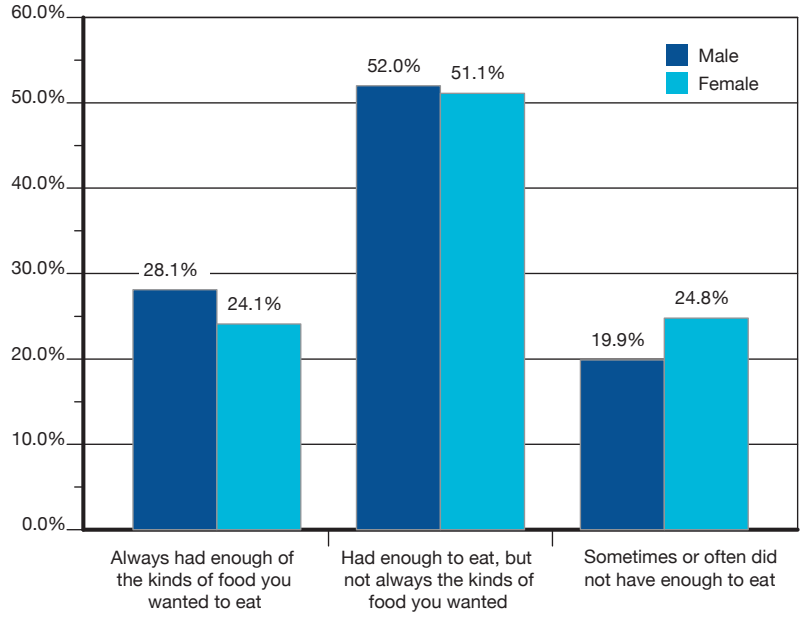


Figure 11. Food Availability by Gender for First Nations Adults, Our Health Counts

- High levels of physical activity were reported, with 42% of the First Nations population in Hamilton reporting having completed 30 minutes or more of moderate or vigorous physical activity 7 days a week.
- The rate of diabetes among the adult population is 15.6%, more than three times the rate among the general Hamilton population, despite a much younger age demographic of the First Nations Hamilton population.
- The rate of high blood pressure among the adult First Nations population in Hamilton was 25.8%.
- The rate of arthritis was 30.7%.
- The rate of hepatitis C was 8.7%.
- Fifty-two percent of the total adult population and over three quarters (77%) of person over 50 years reported often or sometimes experiencing limitations in the kinds or amount of activity done at home, work or otherwise because of a physical or mental condition or health problem.
- Thirty-six of all adults reported fair or poor mental health and 42% reported that they had been told by a health care provider that they had a psychological and/or mental health disorder.

General Health Status and Exercise

One quarter of the First Nations population living in Hamilton reported excellent or very good health. A slightly higher number (33%) reported good health. Twenty-seven percent and 15% reported fair and poor health respectively. These findings show much

lower self-reported health status than has been reported for the overall Hamilton population in the Canadian Community Health Survey.[15] The 2007 CCHS reported that 59% of Hamiltonians over age 20 perceived their health to be excellent or very good.[ibid] These findings also show the First Nations population in Hamilton has a lower self-rated health than First-Nations living on-reserve. The First Nations Regional Longitudinal Health Survey (2002-2003) reported that 40.2% rated their health as excellent or very good[19] (compared to 25% for the OHC First Nations Population).

Self-rated health status varied across age categories and gender. Overall, there was a trend towards persons over 50 years reporting poorer self-rated health status than their younger counterparts with 24% of those above 50 who felt that their physical health was poor compared to 10% of those between 18 and 34 years (figure 12). The differences between the OHC First Nations population and the overall Hamilton population are most striking in the oldest age groups. While 46.6% of the Hamilton population aged 65 years or older considered themselves to be in excellent or very good health,[15] only 12.6% of the OHC First Nations population in Hamilton aged 50 years and older reported themselves in this same category.

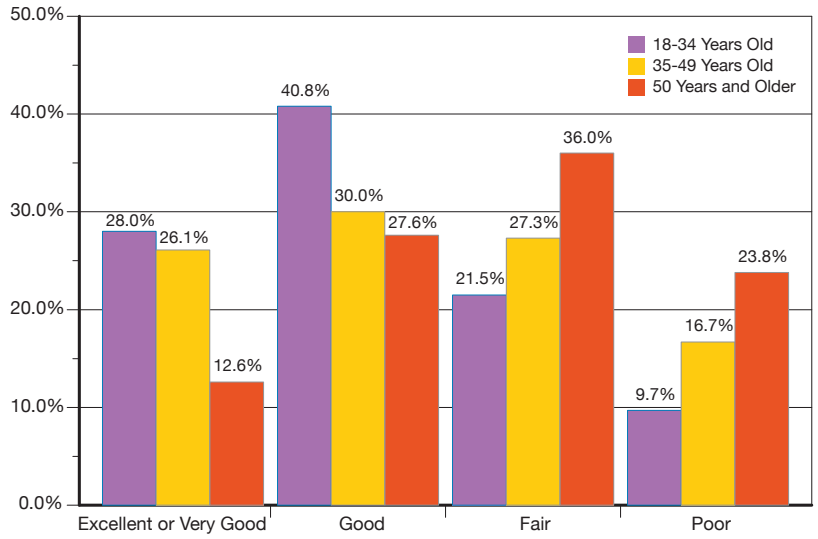


Figure 12. Self-Rated Health by Age for First Nations Adults, Our Health Counts

The gender distribution revealed more men who felt their health was excellent or very good compared to women and fewer men felt their health was poor compared to women (see figure 13). These gender differences were statistically significant. The comparison with the City of Hamilton CCHS data shows that there is a much larger gap for women than for men between the overall Hamilton population and the OHC First Nations

population in Hamilton. While 61.3% of Hamilton's women over age 20 considered themselves to be in excellent or very good health, only 17.9% of OHC First Nations women in Hamilton considered themselves to be in this same category.[15]

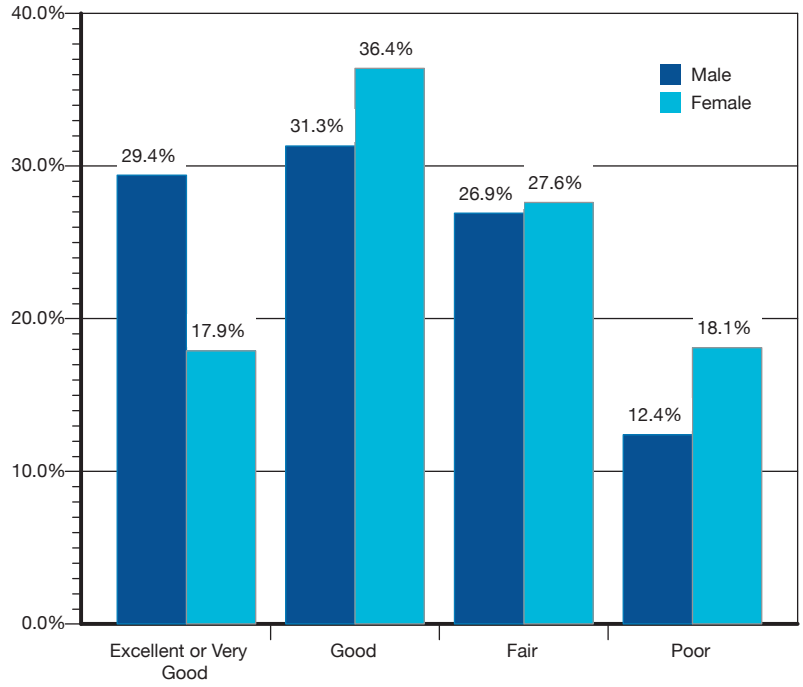


Figure 13. Self-Rated Health by Gender for First Nations Adults, Our Health Counts

For many First Nations individuals and communities, health is considered more than simply physical wellness, but rather a balance of the physical, mental, emotional, and spiritual aspects of self. Regarding whether or not members of the First Nations community in Hamilton feel in balance of the four aspects of life, 43% felt they were in balance all or most of the time, 37% felt they were in balance some of the time and 20% a little or none of the time. Twenty eight point three percent of women compared to 13.9% of men indicated that their life was in balance only a little or none of the time and this difference is statistically significant. Differences in self-reported life balance are not statistically significant across age categories (see figure 14).

Overall, this population reported high levels of physical activity with 42% reporting having completed 30 minutes or more of moderate or vigorous physical activity 7 days a week. Not surprisingly, when asked about physical activity, more older individuals (age 50+) reported zero or one days of activity during the week as compared to younger community members (18-35 years (see figure 15). Across gender, there was a trend towards

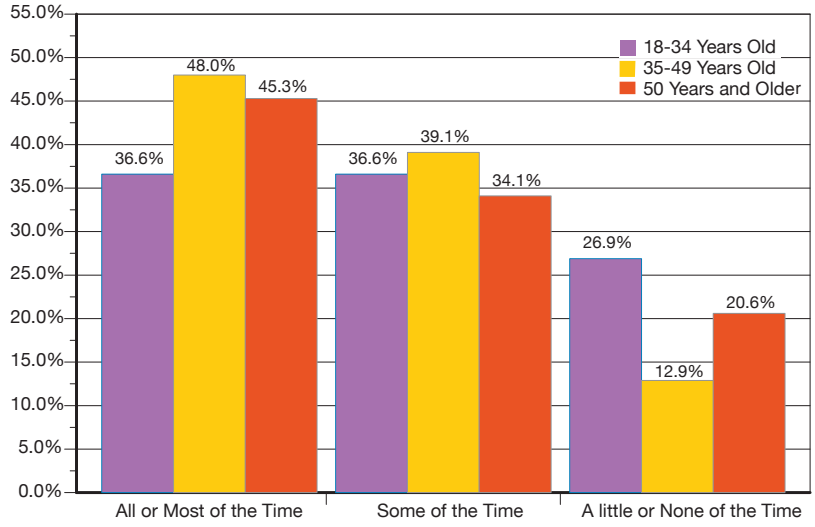


Figure 14. In Balance of 4 Aspects of Life by Age for First Nations Adults, Our Health Counts

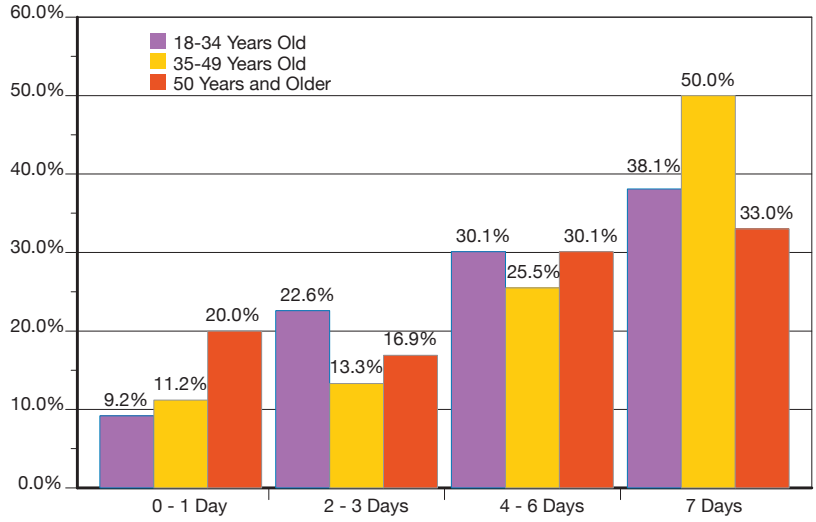


Figure 15. Physical Activity by Age for First Nations Adults, Our Health Counts

more physical activity among men compared to women, with more women than men reporting zero or one days of activity during the week and more men reporting 4, 5, or 6 days of activity during the week (see figure 16). Likely, given the socio-economic conditions reported among this population, the high levels of physical activity reflect a lack of access to transportation and life-based activities that must be conducted by walking.

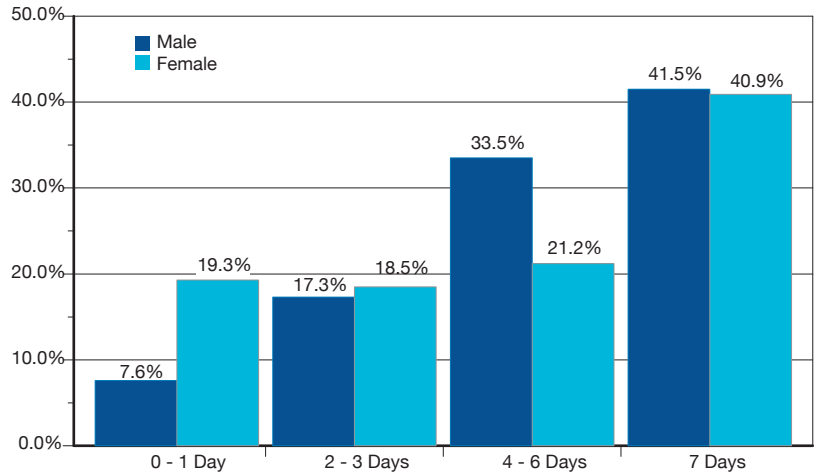


Figure 16. Physical Activity by Gender for First Nations Adults, Our Health Counts

Chronic Health Conditions

Rates of many chronic diseases in the OHC First Nations population are high (see table 1). Among OHC Hamilton population, 19% reported having being told by a health care provider that they have asthma, with similar rates reported by men and women. This is more than twice the asthma rate (9.3%) self-reported by the overall Hamilton population in the 2007 Canadian Community Health Survey.[15]

In total, the self-reported rate of arthritis was 30.7% with similar rates reported by men and women. This is higher than the 19.9% of Hamiltonians who self-reported being diagnosed with arthritis in the 2007 Canadian Community Health Survey.[15]

High rates of blood pressure were reported in this population, with a self-reported prevalence of 25.8%. This compares to 19.7% of the overall Hamilton population that self-reported high blood pressure in the 2007 Canadian Community Health Survey.[15] Within the OHC First Nations population, 28% of men reported having been told by a health care provider that they have high blood pressure compared to 22.5% of women. This difference between men and women was not statistically significant. The self-reported rate of high blood pressure for those over 50 years was higher than that for those between the age of 18 and 34 years with 42.5% of those over 50 who reported blood pressure compared to 14% of persons age 18 to 34 years.

There was a trend towards higher rates of heart disease among men than women (11.5% vs. 3.7%). More specifically, 19.6 % of men 51 years and older reported being told by a health care professional that they had heart disease compared to 9.1% of men 50 years and younger.

In total, the self-reported rate of stroke was 5.9% with no significant difference between men and women. There is no comparable general Canadian rate but the American prevalence of stroke for non-institutionalized adults was 2.6% in 2005.[20]

A total of 15.6% of the adult study population reported having diabetes as diagnosed by a health care provider. This is approximately three times the rate among the general Hamilton population, which was 4.9% in 2007 according to the Canadian Community Health Survey.[15] This is despite a much younger age demographic of the First Nations Hamilton population. For First Nations in Hamilton, over 40% of person who were over 50 years reported having received a diabetes diagnosis compared to 6% of persons 18 to 34 years. This pattern was strongly observed among women, among whom 50% over the age of 50 reported diabetes compared to 5% of women aged 18 to 34. Among those who reported a diabetes diagnosis, 84.4% had been tested for haemoglobin "A-one-C" in the past 12 months, 63.1% reported that a health care professional had checked their feet for any sores or irritations in the past 12 months and 65.5% reported that a health care professional had tested their urine for protein in the past 12 months.

Hepatitis B was not prevalent in the study population (0.7%), however Hepatitis C was highly prevalent with 8.7% of the total population having been told by a health care professional that they had Hepatitis C. This prevalence rate of Hepatitis C is over ten times the estimated Hepatitis C prevalence rate for the province of Ontario (0.8%) and almost three times the estimated Hepatitis C prevalence rate for the total Aboriginal population in Canada (3.0%).[21]

The adjusted rate of chronic bronchitis, emphysema, or COPD (Chronic Obstructive Pulmonary Disease) was 8.4%. The rates for women and men did not differ significantly.

At the time this survey was conducted, 25% of the study population reported having received the H1N1 vaccine. The rate of vaccination appears consistent across income brackets. While this rate of immunization is similar to the immunization rate for the general Hamilton population,[15] it is strikingly low given that First Nations populations were identified as extremely vulnerable to H1N1 infection very early on in the epidemic and experienced much higher morbidity and mortality from H1N1 compared to the general Canadian population.

	RATE
Allergies	9.3%
Arthritis	30.7%
High blood pressure	25.8%
Heart disease	8.4%
Stroke	5.9%
Diabetes	15.6%
Hepatitis B	0.7%
Hepatitis C	8.7%
Chronic bronchitis, emphysema, or COPD (Chronic Obstructive Pulmonary Disease)	8.4%
H1N1 vaccination	25%

Table 1. Rates of Chronic Disease For First Nations Adults in Hamilton, OHC

Breastfeeding

A total of 62% of women in the Our Health Counts study reported having breastfed any of their children. When asked for how many children these women breastfed, over 56% reported breastfeeding for more than two thirds of their children (see figure 17). The average length of time these women breastfed each of their children was as follows: 16% breastfed for less than three months, 33% breastfed for 3 to 6 months, 25% breastfed for 6 to 9 months and 26% breastfed for more than 9 months (see figure 18). The high rates of breastfeeding observed in this population are very consistent with those observed among other Aboriginal datasets, for example the First Nations Regional Health Survey.[19] Improvements in accessible programming and pre-natal care have greatly contributed to an increase in breastfeeding prevalence.

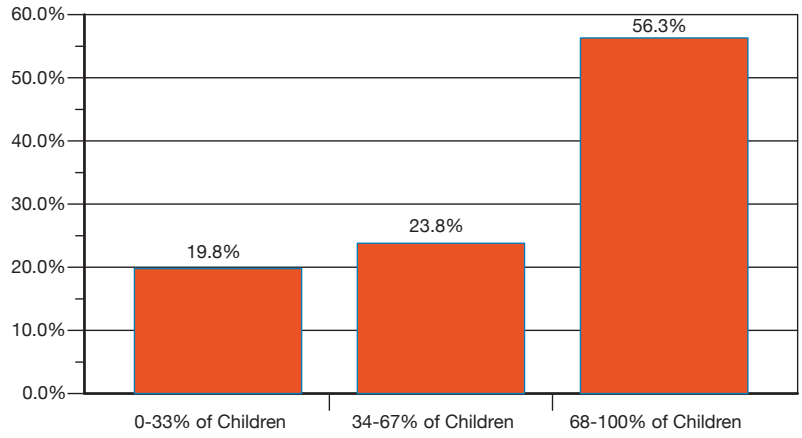


Figure 17. Percent of Children Breastfed for First Nations Women, Our Health Counts

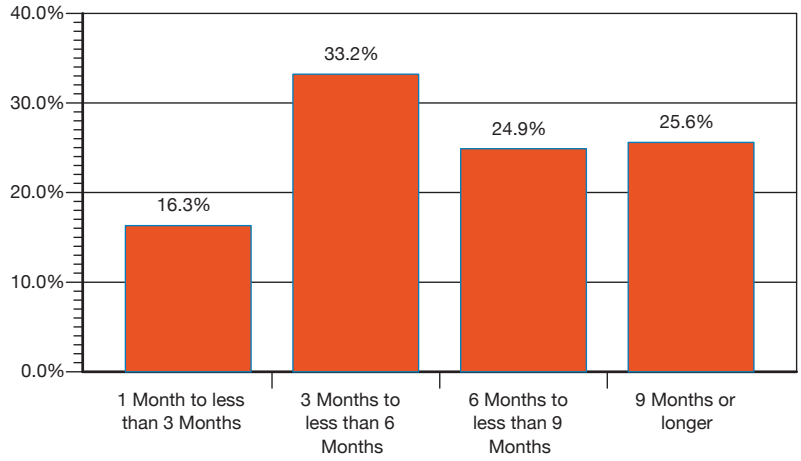


Figure 18. Average Length of Time Breastfed for First Nations Women, Our Health Counts

Preventative Care

Papanicolaou (Pap)

Among First Nations women in the study population, 95.5% reported ever having a Papanicolaou (Pap) test. Of these women, 82.2% reported having received a Pap test in the last 3 years. This rate is about 20% higher than the rate found by the ICES data linkage, which will follow. One reason for the difference in the survey and ICES Pap screening rates is that the questions asked were slightly different. The survey question only reported the three year rate of Pap screening for women who had ever had a Pap test and the ICES linkage allowed examination of participation in Pap screen for the past 3 years for *all women*, whether or not they had ever had a Pap test. This however would only account for approximately 4% of the difference in the survey and ICES rates since this is the self-reported rate of never having had a Pap test for First Nations women in Hamilton, so further exploration of this difference is needed. In the lead researcher's clinical experience as a women's health care provider who has worked in Aboriginal communities for two decades it is common that women assume that every pelvic examination includes a Pap test, when often only swabs for STDs are taken and no Pap test is done. The ICES database does reliably capture all Pap smears that were submitted to community laboratories for analysis, but does not include Pap smears collected and analysed in hospital. However, Pap smears are rarely collected in the emergency department and rates of hospitalization are similar for the Hamilton First Nations and general Hamilton and Ontario population. So unless a large proportion of First Nations women in Hamilton are attending a hospital based outpatient clinic that uses a hospital laboratory for its Pap smear analysis, then the most likely explanation for the difference in the self-report and ICES estimate rates for Pap smear testing for the Hamilton First Nations population is that women are assuming that their health care provider is doing Pap testing during pelvic exams that do not include Pap testing and/or their health care provider is not providing adequate information regarding the actual tests that are being done.

A similar trend is seen in general Hamilton population data. While 72.5% of Hamilton women reported having a Pap smear in the last three years,[15] the rate reported by ICES for women in the City of Hamilton is in 62.6% (see ICES data linkage section).

The OHC survey data indicates a trend towards decreasing participation in Pap screening within the past 3 years with advancing age. This trend is substantiated by the ICES linkage data. It highlights a particular need to better understand and promote cervical cancer screening among First Nations women between the ages of 35 and 70 years of age. Again in the clinical experience of this project's lead researcher, childbearing First Nations women in urban areas have good access to and participation in cervical screening as it is integrated into their prenatal care during their reproductive years, however participation rates in cervical screening are much lower once these Aboriginal women finish having their children. Further efforts regarding improve access to and participation in cervical screening might therefore want to focus on First Nations women who do not have children or who are finished having their children.

HIV testing

The adjusted rate for ever receiving an HIV test was 65%. Further interpretation of this statistic is required, as it appears to be quite high and it may indicate an inappropriately high level of HIV testing given the overall risk in this population. There was a trend of more women receiving an HIV test than men. Sixty nine point five percent of First Nations women in Hamilton received an HIV test, compared to 62.8% of men. Offering HIV tests is often part of routine prenatal care for pregnant women and the large proportion of mothers in the OHC First Nations population may explain in part the higher HIV testing rate in the female population.

Ability

The adjusted rate of limitation in the kinds or amount of activity done at home, work or otherwise because of a physical or mental condition or health problem was 52%. Not surprisingly, the rate of ability limitation was higher for older persons compared to younger persons, with over three quarters (77%) of person over 50 years reporting often or sometimes experiencing limitations. The OHC question regarding activity limitation was slightly different than that of the Canadian Community Health Survey, making direct comparison difficult.

Mental and Emotional Health

"Depression is more common than people are willing to admit. More prevalent in lower income families/households."

"Doctors need to get off their high horse, not just give you the drugs and say, "see you later". The ones [doctors] I am with now actually care about people. They follow up and try and help you solve your disorders."

When asked to rate their mental health compared to other people they knew, 21% reported excellent mental health, 43% reported good mental health and 36% reported fair or poor mental health. There were no significant differences in these rates across gender. Forty-two percent reported that they had been told by a health care provider that they had a psychological and/or mental health disorder. Further analysis into substance use, particularly prescription opioid misuse may reveal a relationship between self-medication and self-reporting of better mental health.

DOMAIN 3: "RECLAIMING WHO WE ARE"

Highlights from Domain 3

- Multi-Group Ethnic Identity Measure scores indicate a strong sense of First Nations identity among the First Nations population living in Hamilton.

In order to explore First Nations identity in our health assessment we used the The Multigroup Ethnic Identity Measure (MEIM) that was originally published by Dr. Jean S. Phinney, at California State University.[22] The measure is comprised of two factors: ethnic identity search (a developmental and cognitive component) and affirmation, belonging, and commitment (an affective component). The measure includes 12 items, which are listed below. Participants were asked how strongly they agreed with the statements on a scale from 1 to 4 with 4 being "strongly agree" and 1 being "strongly disagree". The first factor, ethnic identity search, contains items 1, 2, 4, 8, and 10, while the second factor, affirmation, belonging, and commitment, contains items 3, 5, 6, 7, 9, 11, 12. The preferred scoring is to use the mean of the item scores; that is, the mean of the 12 items for an overall score, and, if desired, the mean of the 5 items for search and the 7 items for affirmation. Thus the range of scores is from 1 to 4.

1. I have spent time trying to find out more about First Nations, such as our history, traditions, and customs.
2. I am active in organizations or social groups that include mostly First Nations people.

3. I have a clear sense of my cultural background as a First Nations person and what that means for me.
4. I think a lot about how my life will be affected because I am First Nations.
5. I am happy that I am First Nations.
6. I have a strong sense of belonging to First Nations community.
7. I understand pretty well what being First Nations means to me.
8. In order to learn more about being First Nations, I have often talked to other people about First Nations.
9. I have a lot of pride in First Nations.
10. I participate in cultural practices, such as pow wows, Aboriginal day events, ceremonies, feasts, drumming, singing etc.
11. I feel a strong attachment towards First Nations.
12. I feel good about my First Nations background.

For the total identity score (range from 1 to 4) for each of the 12 items, we observed that almost three quarters of the sample population scored above 2.875 out of 4 (see figure 19). For the ethnic identity search factor, comprised of 5 items, we calculated that over three quarters of population scored above 2.5 out of 4 (see figure 20). Finally, for the identity affirmation factor, comprised of 7 items, we observed that over 90% of the population scored above 2.5 out of 4 (see figure 21). When we calculated the mean scores for all 12 items, the identity search factor and identity affirmation factor, we generated the following three mean scores: 3.0882, 2.8324, 3.2683 (see figure 22). Clearly these three graphs reflect a strong sense of identity among First Nations adults as we can see that the average ratings on a scale from 1 to 4 is around 3.

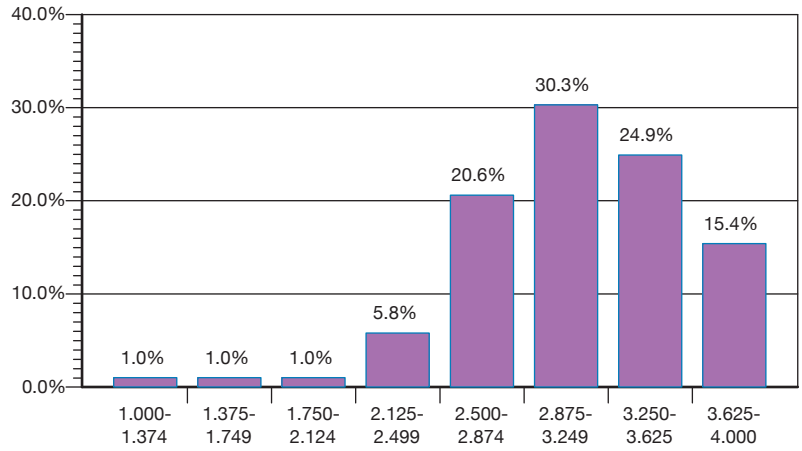


Figure 19. Total MEIM Score for First Nations Adults, Our Health Counts

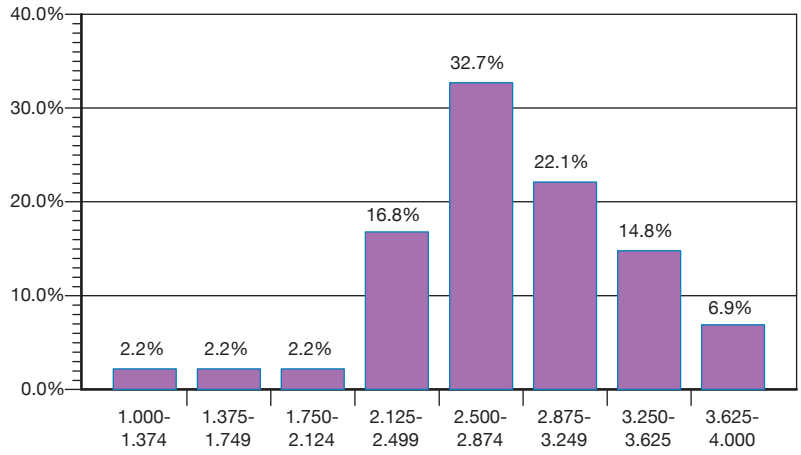


Figure 20. MEIM Search Subscale for First Nations Adults, Our Health Counts

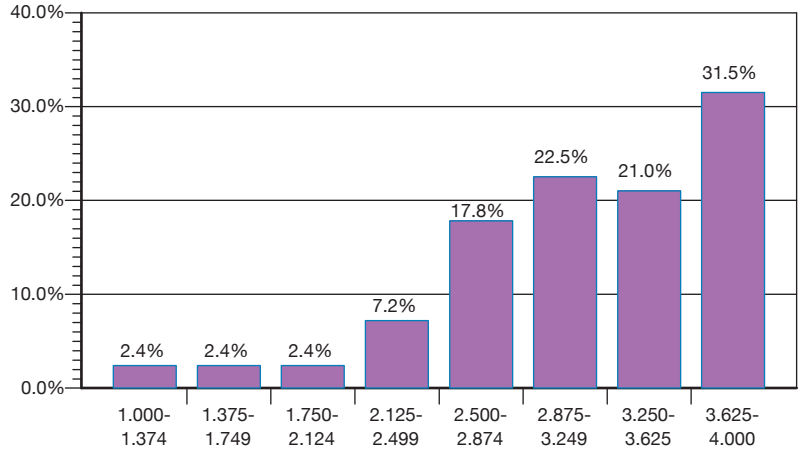


Figure 21. MEIM Affirmation Subscale for First Nations Adults, Our Health Counts

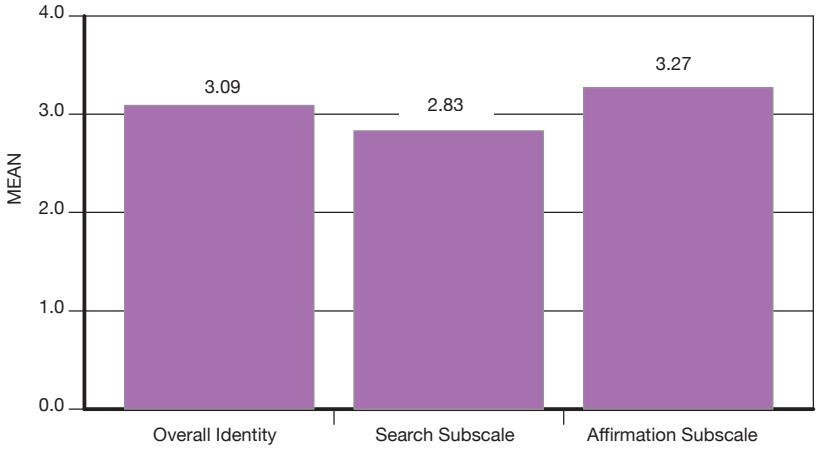


Figure 22. Mean Scores for Overall Identity, Search Subscale and Affirmation Subscale Scores First Nations Adults, Our Health Counts

DOMAIN 4: "DISCONNECTION FROM WHO WE ARE"

Highlights from Domain 4

- Sixty-eight percent of the population reported daily smoking.
- Use of substances in the past 12 months was as follows: 2.1% chewing tobacco; 50% marijuana; 6% ecstasy; 10% sedatives; 19% cocaine; and 19% prescription opioid use, which included Codeine, Morphine, Percodan, Tylenol 3, Fentanyl, Talwin etc.
- Sixty-six percent of the population felt that their level of access was the same as the general Canadian population, while 20% felt they had less access and 14% felt they had better access.
- Forty percent of the First Nations population in Hamilton rated their level of access to health care as fair or poor. Barriers included long waiting lists (48%), lack of transportation (35%), not able to afford direct costs (32%), doctor not available (29%), and lack of trust in health care provider (24%).

Substance Use

When asked if they smoked cigarettes at the present time, 68% of the population reported daily smoking. We observed a trend towards higher rates of smoking under the age of 50 years for both men and women. The rates of smoking between men and women were fairly consistent, with no statistically significant differences (see figure 23). In total, 87.2% of the First Nations population in Hamilton reported that they smoked daily or occasionally, which is more than three times the rate for the general Hamilton population (24.4%) reported in the 2007 Canadian Community Health Survey.

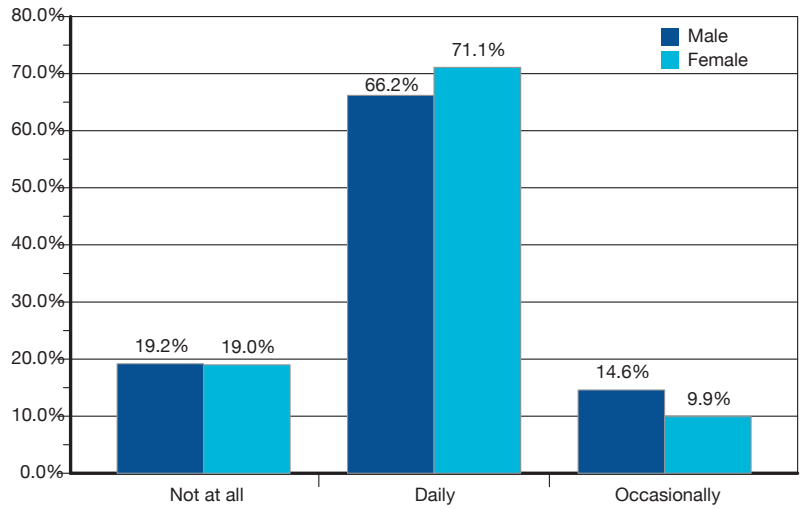


Figure 23. Frequency of Smoking Cigarettes by Gender for First Nations Adults, Our Health Counts

Participants were asked how often they had 5 or more drinks on one occasion in the past 12 months. The adjusted population distribution was as follows: 26% answered never, 18.5% answered less than once per month, 14% answered once per month, 17.5% answered 2–3 times per month, 7% answered once per week and 17% answered more than once per week or everyday. Differences in the rates between men and women were not statistically significant, however the data suggests a trend towards more men consuming more than 5 drinks on one occasion more than once per week compared to women (19% vs. 12%) and more women never consuming over 5 drinks in one occasion compared to their male counterparts (30% vs. 24%). Still, a high number of women reported consumption of 5 or more drinks on one occasion 2-3 times a week (see figure 24). In total, 55.4% of the First Nations population in Hamilton reported that they had 5 or more drinks on one occasion at least once per month, which is more than twice the rate for the general Hamilton population (26.6%) reported in the 2007 Canadian Community Health Survey.[15]

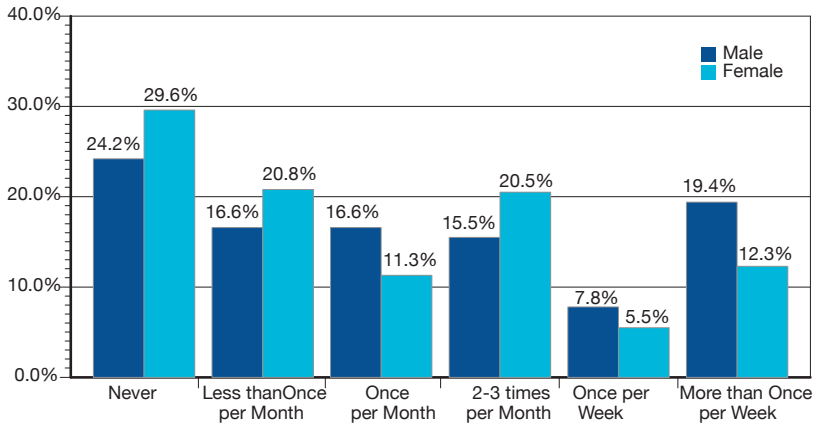


Figure 24. Consumption of 5 or More Drinks on One Occasion by Gender for First Nations Adults, Our Health Counts

The First Nations Our Health Counts participants were asked to report on substance abuse in the last 12 months, including abuse of illicit and prescription drugs. Adjusted self-reported rates were: 2.1% for chewing tobacco; 50% for marijuana use; 6% for ecstasy; 10% for sedatives; 19% for cocaine; and 19% for prescription opioid use, which included Codeine, Morphine, Percodan, Tylenol 3, Fentanyl, Talwin etc. For all of these substances there were no statistically significant differences in rates of use between men and women.

As mentioned above, higher rates of marijuana and prescription opioid misuse may reflect mechanisms by which people are managing their poverty and stress/mental emotional health issues. This is preliminary, descriptive data, however a more in-depth analysis in the future will help to build a more in-depth understanding.

In addition to the drugs listed above, we also asked participants about PCP/Angel dust, Acid/LSD/Amphetamines, Inhalants and Ritalin, but the numbers were too small to report. For the majority of drugs, the prevalence of use did not vary substantially across age groups, except for the case of ecstasy where we observed much higher use for persons under 35 years of age.

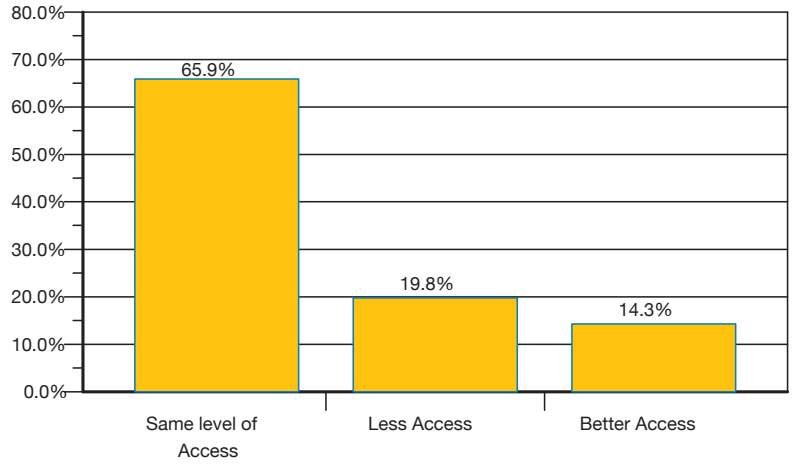
Health Services

"We need more Aboriginal people in health care, education, places where people are looking up to other people. More native role models."

"Life just gets harder and harder and the government is not helping, they seem to backwards, dealing with mental health issues…they dictate and nothing gets done, you don't get counselling or prevention. You get lip service."

"I wish I had someone to talk to when my husband died. I need closure. I've been trying to get an appointment with a psychiatrist and it has been difficult."

Study participants were asked to rate the level of access to health services available to them as compared to Canadians generally. Our adjusted rates were: 66% felt that their level of access was the same as the general Canadian population, while 20% felt they had



less access and 14% felt they had better access (see figure 25).

Figure 25. Level of Access to Health Services for First Nations Adults, Our Health Counts

When asked to rate the availability of health services in their community, 17% felt availability was excellent, 43% felt availability was good in their community, 29% felt

availability was fair and 11% felt availability of services was poor (see figure 26). The fact that 40% of the population felt their level of access to health care was fair or poor, despite the geographic proximity to extensive health and social services that the City of Hamilton provides, substantiates the idea that just because the services are geographically proximate, does not mean that they are accessible to First Nations people.

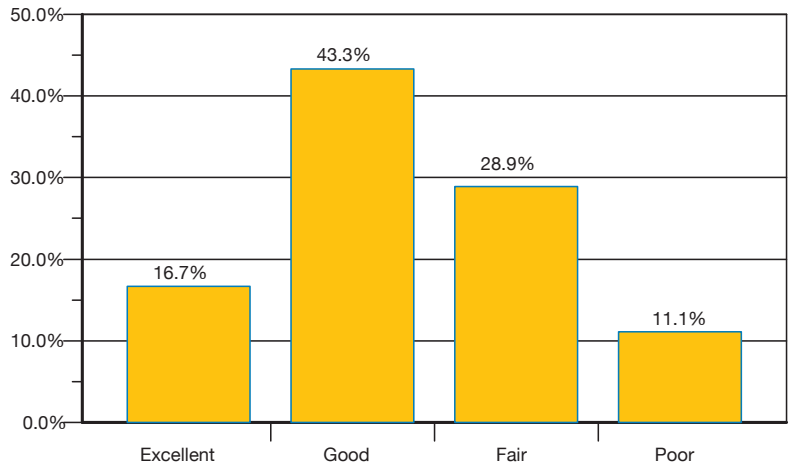


Figure 26. Availability of Health Services for First Nations Adults, Our Health Counts

Participants were asked to indicate any barriers they may have experienced to receiving health care in the past 12 months. The list of barriers included the following: Doctor not available in my area, Nurse not available, Lack of trust in health care provider, Waiting list too long, Unable to arrange transportation, Difficulty getting traditional care, Not covered by NIHB, Prior approval for services under NIHB was denied, Could not afford direct cost of care, Could not afford transportation costs, Could not afford childcare costs, Felt health care provided was inadequate, Felt health care provided was not culturally appropriate, chose not to see health professional, service was not available in my area and other. The distribution of percentages reported for each of these barriers is displayed in the graph below (see figure 27).

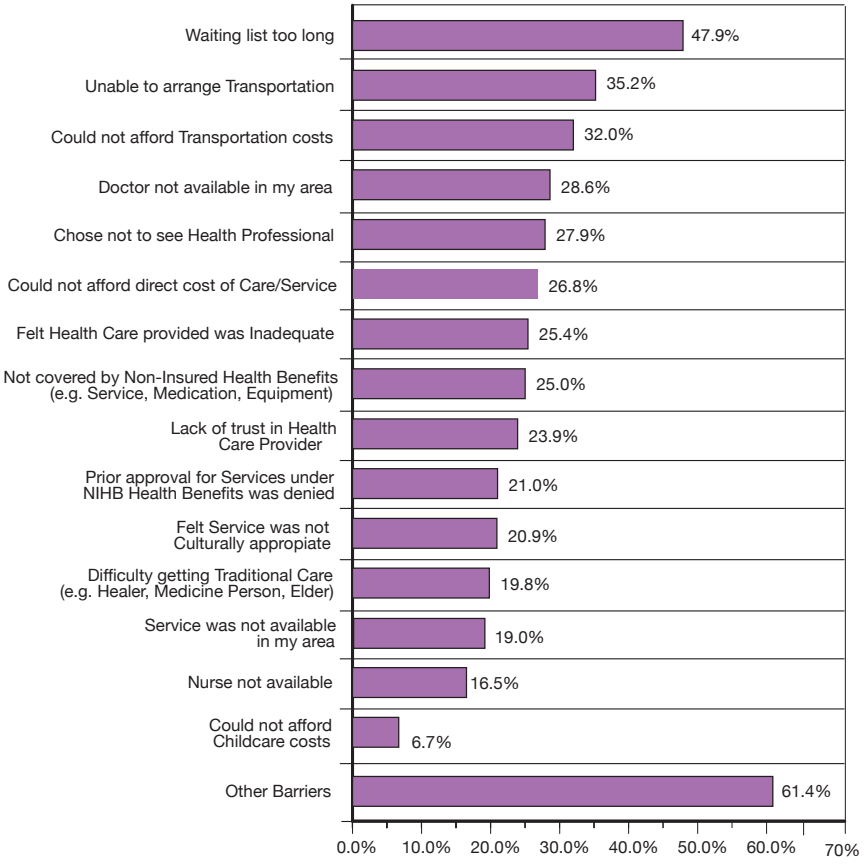


Figure 27. Barriers to Receiving Health Care in Past 12 Months for First Nations Adults, Our Health Counts

Other Barriers to Receiving Health Care Included:

"No sweats in the city [Hamilton]."

"Prejudice"

"Lack of trust and cultural understanding"

"Not a fan of doctors or hospitals. I feel judged before being treated."

"Lack of specialists [including psychiatrist]"

Our population-based self-report estimate is that 33% of First Nations adults in Hamilton have accessed emergency care in the past 12 months. There were no statistically significant differences across gender, age and income categories. This result is consistent with the ICES data linkage results reported in the next section. Specifically, the ICES linkage included

emergency room admissions over the past two years, rather than past year, and found that approximately 68.5% of the study participants had accessed the ER over the past 2 years.

When asked to rate the quality of emergency care accessed in the past 12 months, 55% felt it was excellent or good, while 44% felt it was fair or poor. Little variation was observed between men and women.

Study participants were asked if they had ever been treated unfairly by health professionals because of being First Nations. Our adjusted rate was 13% yes with similar rates reported by men and women. Reporting of unfair treatment also appeared to increase with age as 19% of persons over 50 reported unfair treatment as compared to 8% of persons between the age of 18 and 34 years, however these differences were not statistically significant. Questions regarding discrimination as a result of being First Nations more generally as well as experiences of ethnically or racially motivated attack were asked in a later section of the survey. The results for these questions are reporting in the following section on Impacts of Colonization. Further interpretation of the OHC discrimination data is required, as the interpretation of self-report data regarding experiences of racism is complex. Under-reporting is common and the need for validated, multiple measures has been identified in working class African and Latino American populations.[23] There is a paucity of validated tools to measure discrimination in Aboriginal groups.

Access to Traditional Medicine

Use of traditional medicine was quite common among the study population with one third of the First Nations study population reported use of traditional medicine. It should be noted, however, that the survey itself did not provide a definition of traditional medicine in this context, so there may have been some inconsistency with reporting. Specifically, those who answered, 'Can't afford it' may have been thinking of other non-Western services such as visiting a naturopath or chiropractor as traditional medicine. Of those who had difficulty accessing traditional medicine, we observed the following breakdown of specific barriers (see figure 28).

Participants who had Non-Insured Health Benefits (NIHB) were asked if they had experienced any difficulty accessing any of the health services provided through the Non-Insured Health Benefits Program (NIHB) provided to status First Nations and Inuit persons through Health Canada. Our population based estimate is that 61% report no difficulties accessing the NIHB program.

Of those who had difficulty accessing services provided through NIHB, we observed the following breakdown of specific barriers (see figure 29).

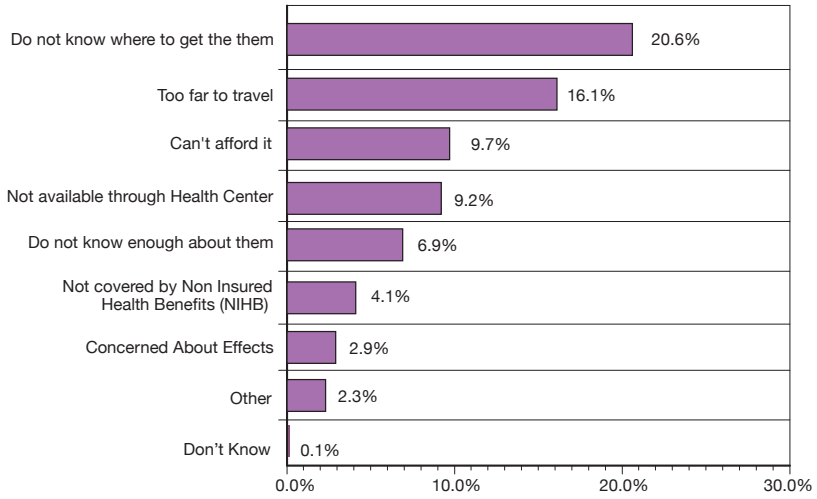


Figure 28. Difficult Accessing Traditional Medicine for First Nations Adults, Our Health Counts

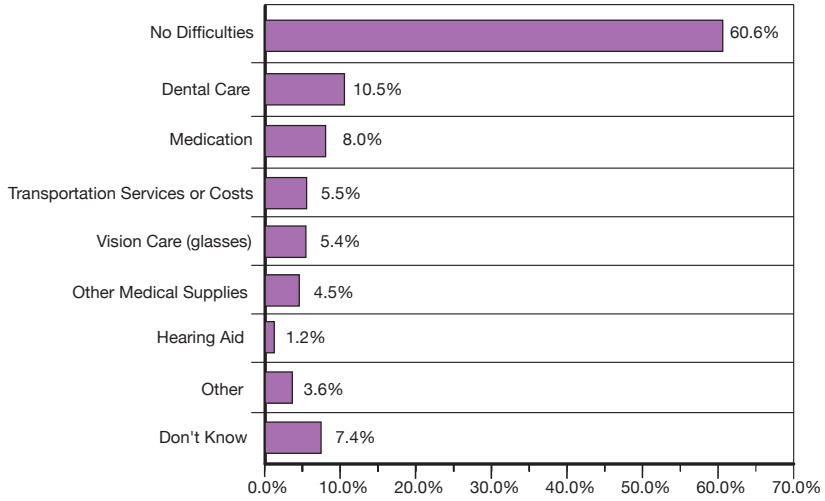


Figure 29. Difficulty Accessing NIHB For First Nations Adults, Our Health Counts

DOMAIN 5: "IMPACTS OF COLONIZATION"

Highlights from Domain 5

- Six point one percent of the study population reported that they had been a student at a federal residential school, or a federal industrial school. Of those, 65% felt that their health and well-being had been negatively affected by this experience.
- Forty percent of participants reported that a child protection agency was involved in their own personal care as a child.
- A total of 41.5% of First Nations adults in Hamilton reported that their home community had one or more land claim.

- Half of the study population reported ever receiving unfair treatment because they are First Nations.
- High rates of community and family violence were also reported.

Residential School

Six point one percent of the study population reported that they had been a student at a federal residential school, or a federal industrial school. Of those, when asked if their overall health and well-being had been affected by their attendance at a residential school, 65% felt that their health had been negatively affected. Clearly, these numbers indicate that the legacy of residential school continues persists in urban areas and is not something observed only on reserve or in Northern communities.

Forty percent of First Nations in Hamilton reported that a family member had been a student at a federal residential school or a federal industrial school. Of these, 24% had a grandparent who attended, 17% had a parent who attended, 6.5% had a sibling who attended, 15% had an aunt or uncle who attended and 10% had another family member who attended. Of those who had a family member who attended residential school, 34% felt it had a negative impact and 63% felt it had no impact on their overall health.

Child Protection Agency Involvement

Study participants were asked if a child protection agency was involved in their own personal care as a child. Our adjusted rates indicated that in total, 40% answered yes. The rate for men was 38% and the rate for women was 44%. Such a high number of men reporting their own experience with child protection agencies speaks to the need for services targeting men in this community. We observed that more younger persons reported child protection agency involvement in their care compared to older persons. When asked if a child protection agency had ever been involved in the care of one of their children, 34.5% reported yes, of whom 62% were women. While there was not much variation across age, we did observe higher rates of child protection involvement in participants' children among those individuals who were more economically marginalized. Over 62% of the population who earn less than $4,999 a year reported child protection agency involvement in the care of their children. Finally, of those who reported the involvement of a child protection agency in their family (either as a child or for the care of one of their children), 49% felt that childcare protection agency involvement had a negative affect on their overall health and well-being.

Dislocation from Traditional Lands

A total of 41.5% of First Nations in Hamilton reported that their home community had one or more land claim. The rate for men was 43% and the rate for women was 39%. When asked if their overall health and wellbeing was affected by dislocation from traditional lands, 68% felt there was no impact and 29% felt there was a negative impact.

Discrimination

"The only discrimination that I have received was from First Nations people. Being urban and not being on reserve, not being from this area. Not being respectful of my Ojibway culture."

When asked how their overall health and well-being have been affected by racism, some of the responses included:

"…in high school, being off the reserve and finding out how white people treat native people. Calling us wagon burners, telling us to go live in our teepees and that we don't belong here. And it is still going on to this day."

"people get racist against me and it just makes me stronger. I get stronger when I come on to people like that."

"…distrust of people. Programs aren't functional for Natives because we are never asked for input."

"…less opportunities and because of not having, you can't provide the way you would like to for your family. Its always about survival."

Participants of the OHC study were asked if they were ever treated unfairly because they are First Nations. Half the population, including slightly more men (55%) reported that they had experienced unfair treatment. Trends in the data suggest that discrimination was reported more among persons over the age of 34 years and was prevalent among both lower and higher income brackets (60% of the lowest and highest income groups reported unfair treatment).

When asked if they had ever been the victim of an ethnically or racially motivated verbal or physical attack, we observed the following: 60% reported no experience of a verbal or physical attack, 34.9% had been a victim of a verbal attack (14% within the past 12 months) and 15.1% had been the victim of a physical attack (5% had been the victim of a physical attack within the past 12 months). Differences in rates of ethnically or racially motivated attack between men and women were not statistically significant. The following figure illustrates the breakdown of physical and verbal attack in less than 12 months and more than 12 months by gender (see figure 30).

A total of 21% of the study population believed that their overall health and wellbeing was affected by racism. This rate was similar for men and women.

Further examination of the First Nations OHC self-reported discrimination rate data to better understand the links between reported experiences of discrimination and health status outcomes is ongoing.

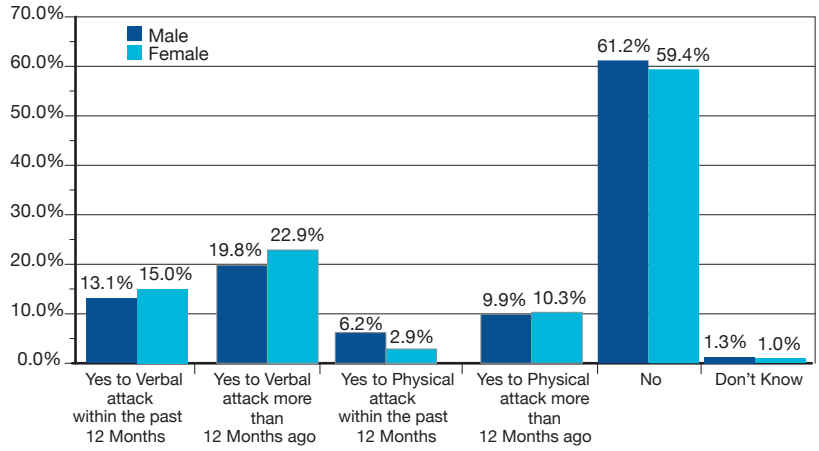


Figure 30. Victim of Physical and Verbal Attack by Gender for First Nations Adults, Our Health Counts

Violence and Abuse

The following data presents descriptive RDS-adjusted frequencies on violence and neglect in the community. More analysis of this data set and additional focussed data collection in the future will further our understanding of these issues and their impact. When asked if any types of violence occur in the community, 58% answered yes. In terms of specific kinds of violence, 60% of those reporting violence, reported family violence in the community, 95% reported violence related to crime and criminal behaviour in the community, 67% reported violence related to racism and discrimination, and 81% reported lateral violence in the community. Among those who reported family violence specifically, 96% felt that family violence included mental or emotional abuse, 90% felt that family violence included physical abuse and 52% felt that family violence included sexual abuse. The breakdown of types of family violence reported by those who reported family violence in the community by gender is illustrated in the following figure. The differences between men and women were not statistically significant (see figure 31).

One gap in the current study is it doesn't ask about the incidence of and types of abuse that are perpetrated by persons outside of the family.

When asked to rate the impact of violence and neglect in their community, 7.4% felt it had an extremely high impact, 24% felt it had a high impact, 35% felt it had a moderate impact, 20% felt it had little impact, and 14% felt it had no impact. Differences between men and women and their rating of the impact of violence in their community can be observed in the following figure (see figure 32). Overall women rated the impact of violence in the community as having a higher impact than men, with a significantly higher number of women rating the impact as "high" compared to men and a significantly higher number of men rating the impact as "little" compared to women.

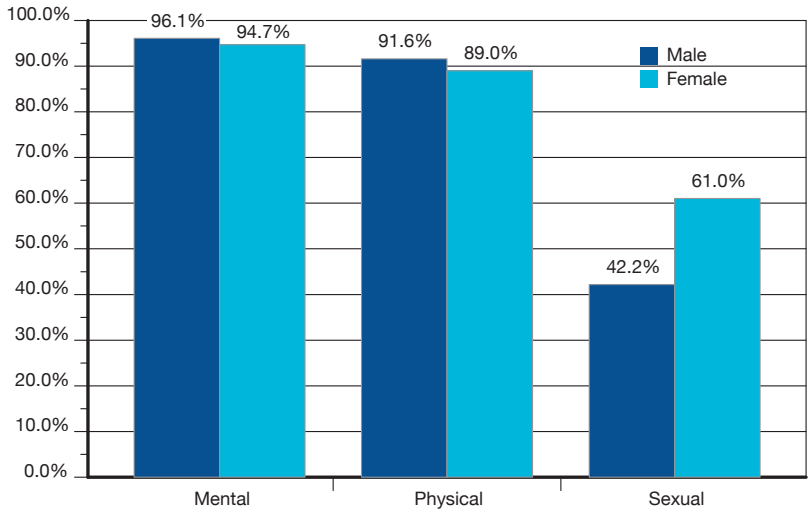


Figure 31. Types of Family Violence Identified as Occurring in the Hamilton First Nations Community by Gender for First Nations Adults, Our Health Counts

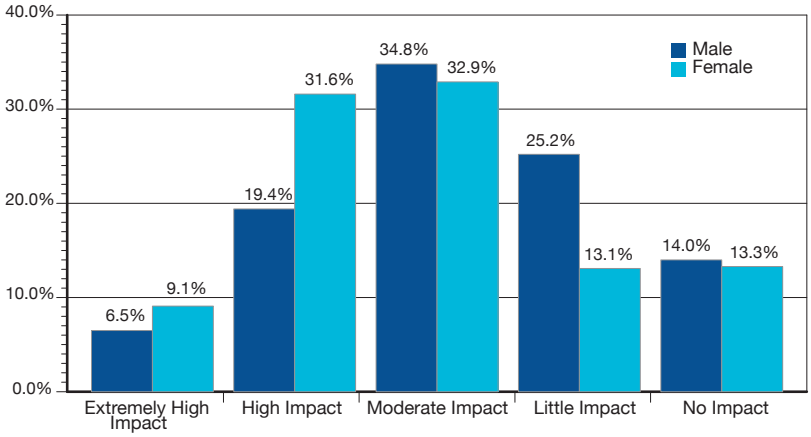


Figure 32. Perceived Impact of Community Violence and Neglect by Gender for First Nations Adults, Our Health Counts

When asked to list the impacts of violence and/or neglect in the community, many participants described youth violence specifically and neglect of youth and children:

"The young people (teenagers), I see them on the street being violent to each other. You can't step in and say something."

"…unattended children, young children smoking cigarettes and doing drugs…"

"Younger children are not receiving adequate food, supervision and examples of family values."

Among those who felt comfortable sharing their experiences about conflict in their own household, 27.5% reported that someone in their household had physically hurt them, 45% reported being insulted or talked down to, 27% reported being threatened with harm, 61% reported being screamed or cursed at, 27% reported having their actions restricted by someone in the household and finally, 10% reported having sex when they didn't feel like it. The breakdown by gender for each type of household conflict are presented in the figure below. Overall there is a trend towards women reporting all types of violence more frequently than men. This difference between women and men is statistically significant for physical harm (see figure 33).

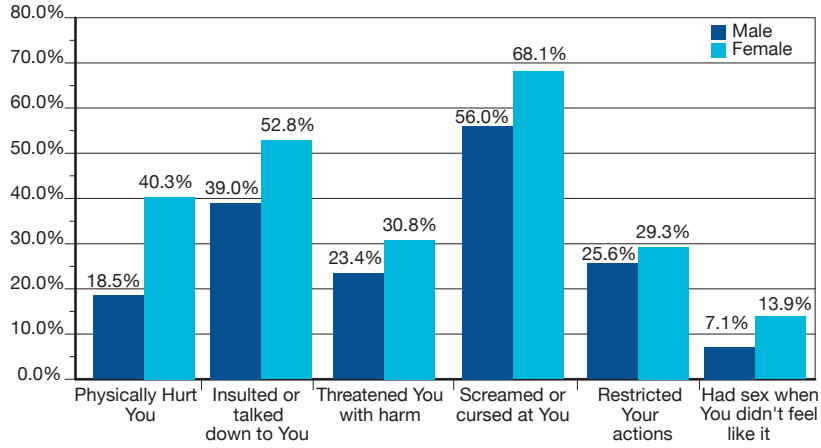


Figure 33. Types of Household Conflict by Gender for First Nations Adults, Our Health Counts

DOMAIN 6: "LACK OF GOVERNMENT RESPONSIBILITY"

"There are more services available to women then men (gender based….i.e. belly dancing, sewing, quilt making) Would like more social activities geared toward men (cards, exercise)"

When asked what the main challenges were facing their community, 68% felt that alcohol and drug abuse were a main challenge, 61% felt that housing was a main challenge, 60.5% felt that crime was a main challenge, 60% felt poverty was an issue, and 60% also felt that employment and number of jobs was an issue.

In terms of strengths of the community, 52.5% felt family values were a strength, 36% felt that Elders were a strength of the community, 41% felt awareness of First Nations culture was a strength, 38% felt that community health programs and traditional ceremonial activities were a strength and 35% felt social connections were a strength in their community.

When asked if they felt there were adequate resources for community services, the following results were revealed: 41% felt there were adequate resources for family violence, 45.4% felt there were enough services for HIV prevention, 56% felt there were adequate

services for pregnant women, 49% felt there enough legal services, 17.4% felt there were enough LGBTTQQI services, 56% felt there were enough services for youth, 32.5% felt there were enough services for single men, 40% felt there were enough suicide prevention services and 55% felt there adequate resources for pandemics such as H1N1.

ICES DATA LINKAGE

Highlights from ICES Linkage

- OHC survey income data is validated by the ICES linkage, which places over 70% of the OHC cohort into the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population.
- Fifteen percent of Hamilton residents and 20% of Ontario residents fell into the highest income quartile while only 2% of the OHC cohort were in this highest income quartile.
- Fifty percent of the First Nations population in Hamilton reported at least one visit to the emergency room over the past 2 years for acute problems compared to 22% of the Hamilton and 20% of the Ontario population.
- Ten point six percent of the First Nations population in Hamilton reported 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario populations respectively.

Using health card numbers provided by Our Health Counts study participants, a successful link to data at the Institute for Clinical Evaluative Sciences was completed. The data estimates generated through this linkage consist of the following: neighbourhood income quintiles (based on the 2006 Census and participant postal codes listed in their OHIP record), Pap smear in the previous 3 years, emergency room admissions over the previous 2 years and hospitalization over the past 5 years. The data presented here for income and health care utilization compare the Our Health Counts population estimates with the total Hamilton population and a random subset of 10% of the Ontario provincial population. Again, it should be noted that the Our Health Counts First Nations Hamilton income and health care use numbers reflect RDS-adjusted estimates.

Sociodemographics

The study population was very similar to that of the total Hamilton population and the Ontario population with respect to the gender breakdown. In terms of age, the Our Health Counts (OHC) sample was much younger than the general Hamilton and Ontario populations. Overall, this pattern is consistent with what we know about the demography of the Aboriginal population in Hamilton from the Census, with the exception that the OHC First Nations sample appears to be somewhat under-represented in the over 65 age category. 1.5 % of the OHC First Nations Hamilton sample was over the age of 65 years compared to 5.3% of the Aboriginal identity population (includes First Nations, Métis, and Inuit) in Hamilton over the age of 65 years according to the 2006 Census.[24]

In terms of income quartiles, we observed that over 70% of the OHC population fell into the lowest quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. While 15% of Hamilton residents and 20% of Ontario residents fell into the highest income quartile, only 2% of the First Nations adults sampled for OHC were in the highest income quartile. Clearly, these data highlight the poverty experienced by this community.

		OHC		OHC RDS-ADJUSTED		HAMILTON		ONTARIO-10%	
		N	COL%	COL %	95% C.I.	N	COL%	N	COL%
ADULTS									
Age on	18-34	196	37.4	41.9	[34.4, 49.9]	125,189	28.18	307,751	28.15
2010-04-01	35-49	197	37.6	36.6	[29.9, 43.1]	124,857	28.11	322,730	29.52
	50-64	120	22.9	20.7	[14.7, 26.9]	110,332	24.84	271,028	24.79
	65+	11	2.1	0.8	[0.3, 1.6]	83,829	18.87	191,904	17.55
Sex	F	259	49.43	37.6	[29.6, 43.6]	226,269	50.94	560,690	51.28
	M	265	50.57	62.4	[56.4, 70.4]	217,938	49.06	532,723	48.72
Income	1-Low	376	71.76	73	[66.5, 79.2]	111,468	25.09	213,212	19.5
Quintile	2	85	16.22	11.8	[7.7, 16]	101,200	22.78	216,461	19.8
	3	33	6.3	7.4	[3.6, 10.5]	90,069	20.28	216,614	19.81
	4	13	2.48	4.9	[2.5, 9.8]	75,704	17.04	223,113	20.41
	5-High	7	1.34	3	[1.1, 5.4]	65,375	14.72	220,665	20.18
	Missing	10	1.91	na	na	391	0.09	3,348	0.31
Total		**524**	**100**	**100**	**na**	**444,207**	**100**	**1,093,413**	**100**
CHILDREN									
Age on	0-5	89	45.88	48.74	[42.5, 55]	34,662	37.66	88,182	38.2
2010-04-01	6-14	105	54.12	51.27	[45, 57.5]	57,384	62.34	142,646	61.8
Sex	F	88	45.36	45.42	[39.2, 51.6]	44,575	48.43	112,435	48.71
	M	106	54.64	54.58	[48.4, 60.8]	47,471	51.57	118,393	51.29
Income	1-Low	144	74.23	75.25	[69.9, 80.6]	23,741	25.79	46,102	19.97
Quintile	2	30	15.46	15.58	[11.1, 20.1]	18,857	20.49	42,636	18.47
	3	9	4.64	5.4	[2.6, 8.2]	19,030	20.67	46,192	20.01
	4	< /=5	1.03	1.26	[0.01, 2.7]	16,363	17.78	49,563	21.47
	5-High	8	4.12	2.52	[0.6, 4.5]	13,975	15.18	45,675	19.79
	Missing	< /=5	0.52	na	na	80	0.09	660	0.29
Total		**194**	**100**	**100**	**na**	**92,046**	**100**	**230,828**	**100**

Table 2. Gender, Age and Income Quartiles for Hamilton and Our Health Counts Adults

Preventative Screening

Pap Smear

Overall, First Nations women in Hamilton had similar levels of having received a Pap smear in the previous 3 years, compared to women in Hamilton and Ontario. With

increasing age, however, the rates of reported Pap smear tests among the First Nations study population dropped significantly compared to both the Hamilton and Ontario populations. The majority of First Nations women were receiving adequate cervical cancer screening before the age of 35 years, however among older women, and particularly in the over 50 age group, rates of participation were much lower. In the clinical experience of the lead researcher, childbearing First Nations women have good access to and participation in cervical screening as it is integrated into their prenatal care, however women who are finished childbearing are less likely to participate in cervical screening. This may be one reason that participation rates drop with advancing age. Screening programs that focus on older First Nations women are indicated. Also further investigation regarding participation in cervical screening for First Nations women who do not have children is also required.

As noted earlier in the survey data section of this report (Page 48), self-reported rates of Pap smear testing among the First Nations population in Hamilton were about 20% higher than these ICES estimates. This is partly due to subtle differences in how the question was asked (the survey data 3 year participation question was only asked for the subset of 96% of participants that ever had had a Pap test). However this would only account for 4% of the difference. Further investigation is therefore required to better understand this different in self-report and ICES linked estimates of Pap smear testing. Given that the ICES database reliably gathers all Pap tests that are submitted to community laboratories for analysis; that it is common in the clinical experience of the lead investigator for Aboriginal women to understand that they have had a Pap test during a pelvic exam when in fact they have not had a Pap test, but rather just swabs for STDs, and that there is no known difference between rates of hospital based Pap testing for First Nations women living in Hamilton and the general Hamilton population, the ICES estimates will be considered the more rigorous estimates at this time.

	OVERALL		PAP SMEAR IN PREVIOUS 3 YEARS NO		YES	
AGE	N	COL%	N	ROW% RDS ADJUSTED [CI]	N	ROW% RDS ADJUSTED [CI]
All	243	100	98	40.1 [30.6, 51.2]	145	59.9 [48.8, 69.1]
18-34	106	43.6	27	28.1 [15.7, 40.0]	79	71.9 [60.0, 84.3]
35-49	93	38.3	46	46.7 [31.7,67.1]	47	53.3 [32.9, 68.3]
50-69	44	18.1	25	56.8[46.9,88.9]	19	31.6 [11.1,53.1]

Table 3. Pap Smear in Previous 3 Years by Age for Adult Women, Our Health Counts

	OVERALL		PAP SMEAR IN PREVIOUS 3 YEARS NO		YES	
AGE	N	COL%	N	ROW%	N	ROW%
All	179,134	100	66,963	37.4	112,171	62.6
18-34	61,857	34.5	23,505	38	38,352	62
35-49	58,710	32.8	18,865	32.1	39,845	67.9
50-69	58,567	32.7	24,593	42	33,974	58

Table 4. Pap Smear in Previous 3 Years by Age for Adult Women in Hamilton

OVERALL			PAP SMEAR IN PREVIOUS 3 YEARS NO		YES	
AGE	N	COL%	N	ROW%	N	ROW%
All	456,729	100	171,998	37.7	284,731	62.3
18-34	154,208	33.8	62,425	40.5	91,783	59.5
35-49	155,030	33.9	51,042	32.9	103,988	67.1
50-69	147,491	32.3	58,531	39.7	88,960	60.3

Table 5. Pap Smear in Previous 3 Years by Age for Adult Women in Ontario (10%)

Emergency Room Visits

Emergency room visits were much more frequent among the First Nations population in Hamilton as compared to the general Hamilton and Ontario populations, overall and for both acute and non-acute illnesses. These differences are statistically significant and striking, particularly with respect to the relative percentages of multiple ER visits for the First Nations OHC, Hamilton, and Ontario populations. Ten point six of the First Nations adult population in Hamilton reported 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario adult populations respectively. Fifty percent of the First Nations adult population in Hamilton had at least one recorded visit to the emergency room for acute problems compared to 22% of the Hamilton and 20% of the Ontario adult populations.

Rates of emergency room use were similar for men and women in the OHC First Nations population with no significant differences in access rates detected. This similarity across gender in ER use was also found in the Hamilton and Ontario populations. The OHC First Nations sample wasn't adequately powered to detect differences in ER access across adult age strata.

Rates of emergency room use were also significantly higher for First Nations children between the ages of 2 and 14 years of age compared to Hamilton and Ontario children from the same age group. For example, 50% of First Nations children aged 2-14 years had one or more recorded visits to the emergency room over the past two years, compared to 36% of Hamilton and 37% of Ontario children in the same age groups.

These high rates of emergency room usage by First Nations persons living in Hamilton may be linked to the problems in accessing non-emergent health care that are revealed by the survey data and described in the preceding section of this report. For example, 40% of the First Nations population rated their access to health care as poor or fair and 48% indicated that "waiting lists too long" was a barrier in accessing health care. In addition, in at least some cases, primary care reform may have increase emergency room usage, since rostered primary care patients may be told by their primary care providers to go to the emergency department rather than a walk-in clinic when their primary care team is not available.

	EMERGENCY ROOM VISITS (ALL)			
	NONE	1	2-5	6+
OHC	31.5 [25.8,37.5]	26.2 [20.7,32.8]	31.7 [25.9,37.8]	10.6 [6.2,14.5]
Hamilton	66.3	18.7	13.4	1.6
Ontario – 10%	69.1	16.8	12.3	1.9

Table 6. All Emergency Room Visits – Percentage of Population with 0,1,2-5 or 6+ total ER visits in the Previous 2 Years for adults aged 18 – 64 years, OHC First Nations Cohort (RDS adjusted with confidence intervals), Hamilton and Ontario

	EMERGENCY ROOM VISITS (ACUTE)			
	NONE	1	2-5	6+
OHC	50.2 [43.9, 57.5]	24.7 [18.7,30.1]	20.7 [15.3,26.1]	4 [1.6,6.9]
Hamilton	78.4	14.2	6.8	.6
Ontario – 10%	80.1	13.1	6.3	.6

Table 7. Acute Emergency Room Visits – Percentage of Population with 0,1,2-5 or 6+ Acute ER visits in the Previous 2 Years for adults aged 18 – 64 years, OHC First Nations Cohort (RDS adjusted with confidence intervals), Hamilton and Ontario

	EMERGENCY ROOM VISITS (NON-ACUTE)			
	NONE	1	2-5	6+
OHC	54.3 [47.6,61.2]	22.4 [17.3,28.5]	20.4 [14.5,25.4]	2.9 [1,5.6]
Hamilton	79.4	14.0	6.3	.4
Ontario – 10%	81.2	12.2	6.0	.6

Table 8. Non-Acute Emergency Room Visits – Percentage of Population with 0,1,2-5 or 6+ non-Acute ER visits in the Previous 2 Years for adults aged 18 – 64 years, OHC First Nations Cohort (RDS adjusted with confidence intervals), Hamilton and Ontario

Hospitalizations

Rates of hospitalization appear to be similar between the First Nations adult population in Hamilton based on the OHC adjusted rates and the general adult Hamilton and Ontario populations, with a slightly higher frequency of hospitalization among the First Nations population compared to the Hamilton and Ontario populations. Overall, 74% (68.3, 79.2) of the First Nations population between the ages of 18 and 64 years in Hamilton had not been

hospitalized at all over the past five years compared to 82.9% of the general Hamilton population and 85% of the Ontario population in the same age group. This is partly explained by the higher birth rate among the First Nations population in Hamilton which is reflected by slightly higher rates of obstetrics hospitalization for this group compared to the general Hamilton and Ontario population. Eighty-nine point one percent (84.4, 92.9) of the First Nations population between the ages of 18 and 64 years in Hamilton had not been hospitalized for obstetrical reasons compared to 94.1 of the general Hamilton and 94.2 of the Ontario population in the same age group. However, given the high rates of chronic diseases such as diabetes and stroke and the much higher rates of emergency room use among the OHC First Nations population compared to the Hamilton and Ontario populations an even higher rate difference of hospital admissions between the OHC First Nations population and Hamilton and Ontario population could be anticipated.

With respect to the hospitalization of children ages 5 to 14, rates of hospitalization for First Nations children living in Hamilton are significantly lower than rates of hospitalization for the general population of children living in Hamilton and Ontario. Two point four percent (0.01, 4.9) of First Nations children had been hospitalized one or more times over the past five years compared to 6.1% and 6.0% of all children living in Hamilton and Ontario respectively.

Further examination of this data and additional study is therefore required to better understand whether or not there is a systematic bias in hospital admission practices which prioritizes the admission of non-First Nations community members over First Nations community members.

Because hospitalization is less frequent event than emergency room use, the study was not adequately powered to detect differences in other types of hospitalizations (i.e. mental health, surgical, and medical hospitalizations) between the First Nations Hamilton population and the general Hamilton and Ontario populations.

RESPECTFUL HEALTH CHILD SURVEY DATA

Highlights from the Child Health Survey

- Ninety-three percent of parents and caregivers felt it was very or somewhat important for their child to learn a First Nations language
- Ninety-four percent of parents and caregivers felt that traditional cultural events were very or somewhat important in their child's life
- Asthma and allergies were the most commonly reported chronic conditions. Rates of asthma were twice as high for Hamilton First Nations children compared to general Canadian rates for children.

- Rates of chronic ear infections were high
- Twenty-two percent of parents and caregivers were concerned about their child's development
- Eighty-three percent of participants indicated that their child had seen a family doctor, general practitioner or pediatrician in the past 12 months (compared to 88% for the general Canadian population aged 0-6 years)
- The number one barrier to receiving health care reported by child custodians was that the wait list was too long

As explained above, the child survey was completed by parents or custodial relatives/guardians for all children who resided with the adult and were under the age of 14 years. In order not to exclude First Nations children who were living with a non-First Nation biologic or adoptive parent/relative/guardian we additionally allowed coupons to be given to non-First Nations persons who were the custodial parent/relative/guardian of one or more First Nations children.

Among the total child surveys that were completed (N=222), 51% were male children and 49% were female children. Forty-four percent of the children were 5 years and younger, while the remaining 56% were over 6 years old. A fairly even distribution across genders was observed in both of the age categories.

Language

When participants were asked how important it is for the child to learn a First Nations language, 49% said it was very important, 44% said it was somewhat important, while the remaining 7% felt it was not very important or not important (see figure 34).

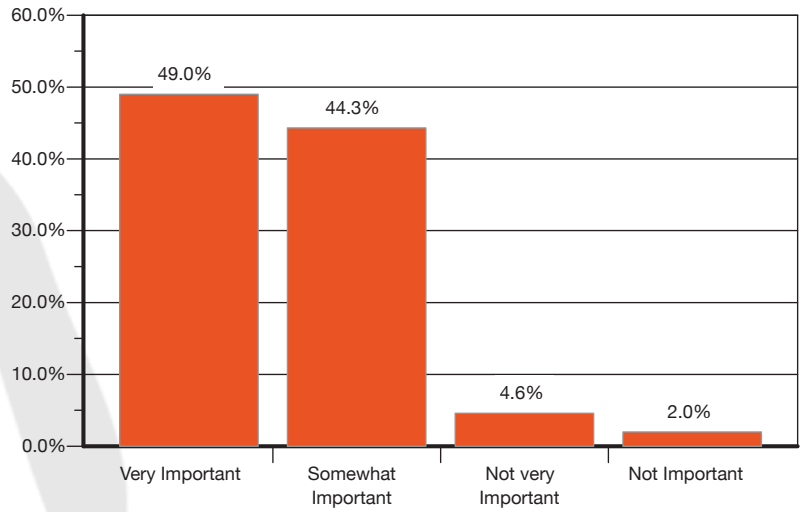


Figure 34. Importance of the Child Learning a First Nations Language for First Nations Children, Our Health Counts

When asked how important traditional cultural events were in the child's life, 54% felt they were very important, 40% felt they were somewhat important and the remaining 6% felt that they were not very important or not important.

Parents (75%) and grandparents (57%) were reported most often as the family members responsible for helping the child to understand Firs Nations culture, followed by aunts and uncles (34%), other relatives (32%) and friends (24%).

General Health

Child custodians were asked to rate their child's health on a 5-point scale from excellent to poor. Overall, children's health in this population was rated quite high, with 43% who reported that their child's health was excellent and over 51% who reported that their child's health was either very good or good. These rates are very similar to the self-rated health findings of the Aboriginal Children's Survey and the National Longitudinal Survey of Children and Youth.[25] Variation across gender was not substantial, however there does appear to be a trend with more guardians of male children reporting very good health as compared to guardians of female children (see figure 35). Similarly, across age groups, the data was fairly consistent, although we did observe a trend towards guardians of younger children (0-5 years) reporting better overall health of their children as compared to guardians of children over 6 years (see figure 36).

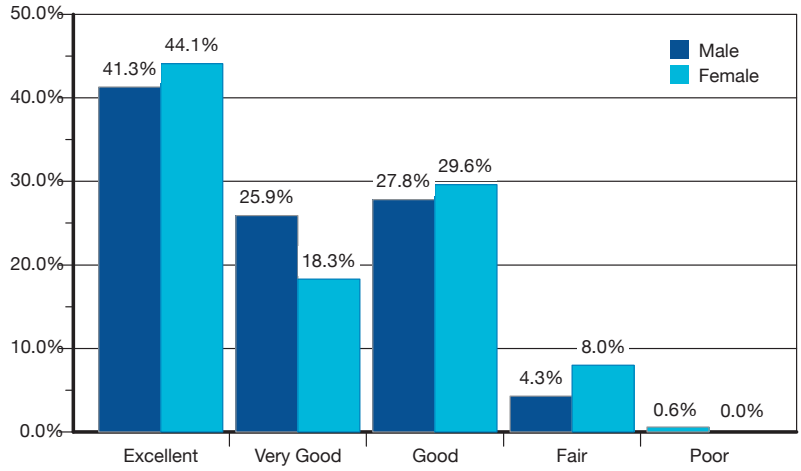


Figure 35. Overall Health by Gender for First Nations Children, Our Health Counts

Participants who completed the child survey were asked about a number of commonly reported chronic conditions. The following table displays the most prevalent conditions and the percentages across gender and age. Conditions that were also included in the survey, but are not presented here due to very small numbers included:

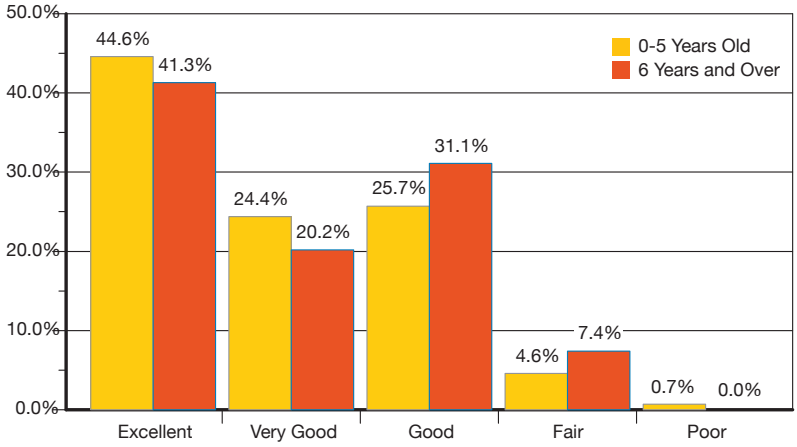


Figure 36. Overall Health by Age for First Nations Children, Our Health Counts

anxiety and depression, ADD/ADHD, autism, blindness or serious vision problems, cancer, chronic bronchitis, cognitive or mental disability, fetal alcohol disorder, hearing impairment, hepatitis, kidney disease, learning disability, speech/language difficulties, physical disability (other than visual and/or hearing impairment) and tuberculosis.

	OVERALL REPORTED RATE	AMONG MALE CHILDREN	AMONG FEMALE CHILDREN	AMONG CHILDREN AGED 0-5 YEARS	AMONG CHILDREN 6 YEARS AND OLDER
Allergies	10.3%	11.7%	9.1%	3.5%	15.7%
Asthma	18.1%	22.6%	13.7%	14.9%	20.5%
Heart Condition	4.0%	5.6%	2.4%	1.3%	6.1%
Diabetes	0.7%	0.0%	1.3%	1.5%	0.0%
Anemia	1.7%	1.6%	1.8%	2.1%	1.4%
Dermatitis	6.1%	11.3%	1.0%	7.2%	5.2%
Hearing Impairment	4.0%	4.3%	3.6%	4.2%	3.8%

Table 9. Commonly Reported Chronic Conditions by Gender and Age for First Nations Children in Hamilton, Our Health Counts

The rate of allergies reported among the First Nations population in Hamilton (10.3%) is very similar to the overall rate in Canadian children (10.0%) reported in the National Longitudinal Survey of Children and Youth (2004/2005).[26]

Eighteen percent of child custodians reported that their child had asthma. This rate is higher than rate of 8.8% rate reported for Canadian children (2004/2005 National Longitudinal Survey of Children and Youth).[25]

Rates of chronic ear infections were high in this population. A total 60% of child custodians reported that their child had had an ear infection since birth, and of those 30% reported one ear infection in the past 12 months (15% reported 2 or more in the past 12 months). Finally, when specifically asked if they had been told by a health care professional that their child had chronic ear infections or ear problems, 14% reported yes.

Injury

When asked if the child required medical attention for a serious injury in the last 12 months, 10% responded yes. When asked to describe the type of injury, 18% reported broken or fractured bones, 14% reported a dental injury and 3% reported minor cuts, scrapes or bruises.

Access

Eighty-three percent of participants indicated that their child had seen a family doctor, general practitioner or pediatrician in the past 12 months and 63% reported that their child had seen a dentist, dental therapist, or orthodontist in the past 12 months. This compares to a rate of 88% for the general Canadian population aged 0-6 years.[27]

Participants were asked if they had experienced any barriers to receiving health care for the child in the past 12 months (see figure 37). The number one barrier reported by child custodians was that the wait list was too long (32%). Next, participants reported being unable to arrange transportation (22.5%), that they could not afford transportation (18%), that a doctor was not available (15.3%), that a nurse was not available (15.1%) and that they could not afford direct cost of care/services (15.1%). The full list of barriers to receiving health care for children are displayed in the figure below.

When asked if their child had participated in any Aboriginal community programs, 27% said they had been to an Ontario Early Years Centre, 14% reported that their child had participated in the Niwasa Aboriginal Head Start Program and 6% reported that their child had participated in Aboriginal Health Babies or Health Children Program. For each of the other programs listed, the numbers were very small. A total of 55% reported that their child had not participated in any of the community programs listed (see figure 38).

Child Development

When adults were asked if they had any concern about the progress of their child's physical, mental, emotional, spiritual and/or social development, 22% answered yes. Among those who indicated they had concern, when asked to specify the area of development they were concerned about, the following results emerged: 56% reported

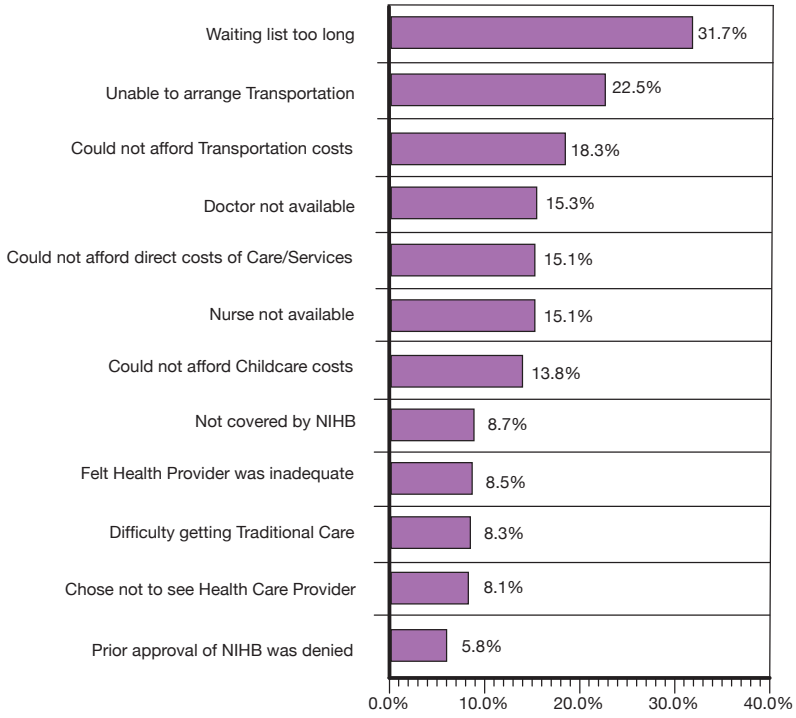


Figure 37. Barriers to Receiving Health Care for Child in Past 12 Months for First Nations Children, Our Health Counts

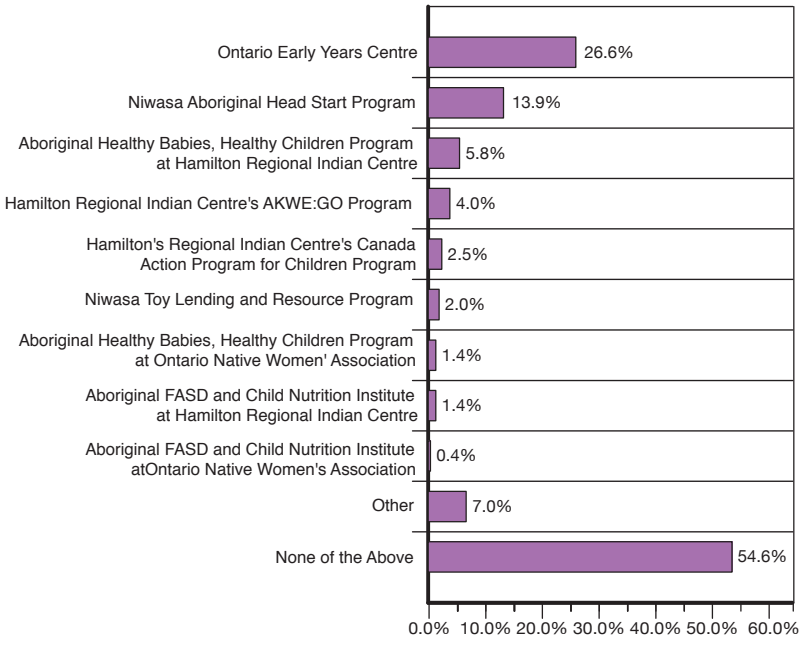


Figure 38. Participation of Child Aboriginal Community Programs for First Nations Children, Our Health Counts

that this was a concern about their child's physical health, 54% were concerned about emotional development, 41% were concerned about the child's speech/language, 38% were concerned about the child's mental/intellectual development, and 25% were concerned about social development (see figure 39).

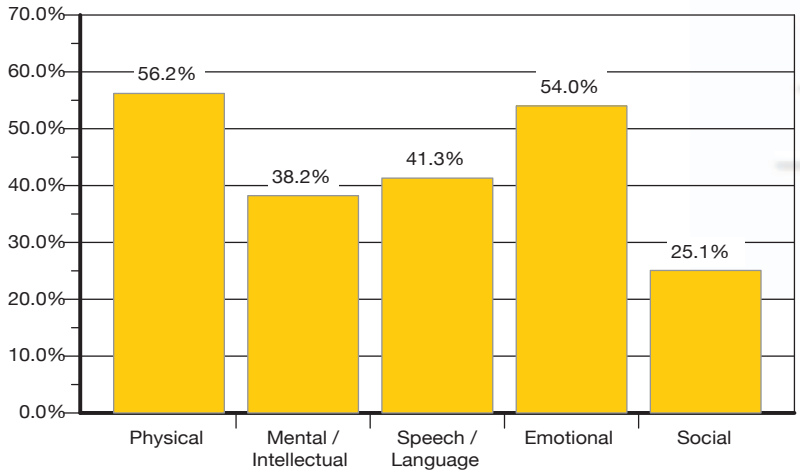


Figure 39. Area of Concern for Child's Development for First Nations Children, Our Health Counts

IMPLICATIONS FOR URBAN ABORIGINAL HEALTH POLICY AND PRACTICE

INTRODUCTION

Through the development of a sustainable infrastructure of partnerships, data governance and management of protocols/agreements between four core urban Aboriginal provincial organizations, the Centre for Research on Inner City Health – Saint Michael's Hospital, the Ministry of Health and Long-Term Care, Institute for Clinical and Evaluative Services and the Hamilton community, *the Our Health Counts – Urban Aboriginal Health Database project* has successfully established a First Nations Urban Health Database. With limited public health data available for Ontario's urban First Nations populations, the increasing disparities in social determinants of health for urban Aboriginal peoples, and jurisdictional complexities, policy makers in small regions, and provincial and federal governments and urban Aboriginal stakeholders were restricted in their abilities to address such inequitable health challenges.

The Our *Health Counts – Urban Aboriginal Health Database project* is now able to provide for the first time, First Nations health data that clearly demonstrates alarming inequities in areas such as housing, income, services for low income and marginalized populations, chronic disease, health care access, culture-based programmes and services, health empowerment and self-determination, research and system planning, and child and family health. The project's findings also indicate that the First Nations Hamilton community maintain remarkable cultural continuity, resilience and hope, in the light of such alarming inequities. With this new urban Aboriginal health data and health measures, all health stakeholders will now be able to work together in intersectoral partnerships to improve the health status, access to services, and participation in health planning processes affecting urban Aboriginal people in Ontario. In order to drive systemic policy changes towards the improvement of the health and

social status of urban Aboriginal people living in Ontario, the development of an urban Aboriginal specific, cultural based community driven strategy is essential. Such a strategy would incorporate the urban Aboriginal community's leadership and governance structures in all health planning, programme and service development and resource allocation at a local, provincial and federal level.

Immediate action is required by local, provincial and federal governments to re-establish key relationships with urban Aboriginal local and provincial organizations to address the policy actions required to address the devastating health and social inequities and disparities experienced by urban Aboriginal people today. Unresolved jurisdictional accountabilities and systemic disparities in access to care for Aboriginal people are far too often illustrated by the fate of Aboriginal children. Such cases should not exist, as in the example of Jordan River Anderson of Norway House Cree Nation, a chronically ill and disabled First Nations child, who died far away from his family, because of jurisdictional conflicts between the federal and provincial government, over the cost of his home health care. In honour of Jordan River Anderson, the *Jordan's Principle* was established with the goal of ensuring equitable access to government services for First Nations children. *Jordan's Principle* is consistent with government obligations set out in the United Nations Convention on the Rights of the Child, the Charter of Rights and Freedoms and many federal, provincial and territorial child focused statutes. While *Jordan's Principle* arose from a jurisdictional conflict over on-reserve health care costs, the principle is relevant and required with respect to ensuring timely and equitable access to health care for all Aboriginal children, including Aboriginal children living in urban areas in Ontario who are often also left behind due to debates between municipal, provincial and federal stakeholders regarding accountability. To date, no provincial/territorial government has fully implemented *Jordan's Principle*.[28]

The Royal Commission on Aboriginal Peoples identified the need to negotiate and reconcile Aboriginal governments within Canada as one key step towards resolving the concerns of Aboriginal peoples and building a new relationship between Aboriginal and non-Aboriginal peoples based on mutual respect, recognition and sharing.[29] The establishment of a commitment, by all levels of governments to establish collaborative policies and planned principled approaches, to work across local, regional and national jurisdictions with urban Aboriginal health stakeholders will ensure that all governments meets their judicial obligations and Aboriginal people in Canada are afforded their full human rights as set out in the United Nations Declaration on the Rights of Indigenous People[30] and the 1982 Constitution Act of Canada[31] and international law.

The First Nations Hamilton community project participants have demonstrated their resilience in the light of extreme adversity in many areas of the social determinants of

health and now through their participation in the Health *Counts – Urban Aboriginal Health Database project* we can now illustrate, through a newly established First Nations health database, clear data and measures towards making strategic directions towards the improvement of the health and social status of urban Aboriginal people in Ontario.

POLICY RECOMMENDATIONS:

Housing, Services for Low Income and Marginalized Populations, and Addressing Inequities in the Social Determinants of Health:

The OHC study identified striking levels of poverty among First Nations residents living in Hamilton. For example, 78.2% of the First Nations persons living in Hamilton earn less than $20,000 per year and 70% of the First Nations population in Hamilton lives in the lowest income quartile neighbourhoods compared to 25% of the general Hamilton population.

This poverty is accompanied by marked challenges in access to housing and food security. For example, 90% of the First Nations population living in Hamilton had moved at least once in the past 5 years and over 50% of the population had moved three or more times in the past 5 years. Furthermore, 13% of the First Nations population living in Hamilton reported being homeless, in transition, or living in any other type of dwelling not listed. In addition, 73.7% of First Nations persons in Hamilton reported that they live in crowded conditions, compared to a rate of 3% general Canadian population. Finally, 63% of First Nations community members in Hamilton had to give up important things (i.e. buying groceries) in order to meet housing costs and only 22% of the First Nations population always had enough of the kinds of food that they wanted to eat.

These findings have resulted in the following policy recommendations in the areas of housing, services for low income and marginalized populations and addressing inequities in the social determinants of health:

Housing:

1. That provincial governments that have responsibility for housing and supports (Ministry of Health and Long Term Care and the Ministry of Community and Social Services) engage with urban Aboriginal communities and organizations for the purpose of ensuring that the communities priorities and critical needs in the areas of affordable rental housing, supportive and transitional housing, and assisted home ownership are addressed in accordance with human rights legislation.

Services for Low Income and Marginalized Populations:

2. That all local and provincial agencies that offer services to significant numbers of low income/marginalized urban Aboriginal populations collaborate directly with urban Aboriginal agencies and organizations and develop and implement mandatory Aboriginal cultural diversity training.

Addressing Inequities in the Social Determinants of Health:

3. That provincial governments engage with urban Aboriginal communities and organizations for the purpose of establishing priorities, resource and funding allocations and action plans to address the critical inequities in all economic and social conditions affecting Aboriginal health including poverty, homelessness, food insecurity, education, employment, health access, gender equality and social safety.

Chronic Disease and Disability:

Another key finding of the OHC study was that First Nations people living in Hamilton are living with a disproportionate burden of chronic disease and disability. For example, the rate of diabetes among the adult First Nations Hamilton population is 15.6%, more than three times the rate among the general Hamilton population, despite a much younger age demographic of the First Nations Hamilton population. Furthermore, the prevalence rate of high blood pressure among the adult First Nations population in Hamilton was 25.8% (compared to a general Hamilton rate of 19.7%) ; the prevalence rate of arthritis was 30.7% (compared to a general Hamilton rate of 19.9%); and the prevalence rate of Hepatitis C was 8.7% (compared to an estimated Ontario prevalence rate of 0.8%). In addition, 52% of the total adult population and over three quarters (77%) of person over 50 years reported often or sometimes experiencing limitations in the kinds or amount of activity done at home, work or otherwise because of a physical or mental condition or health problem. Finally, 36% of all adults reported fair or poor mental health and 42% reported that they had been told by a health care provider that they had a psychological and/or mental health disorder. These findings have led to the following policy recommendation regarding chronic disease and disability:

4. That municipal and provincial governments commit to long term resources and funding allocations and engages with urban Aboriginal communities and organizations for the purposes of establishing priorities, preventative action and promotion plans towards the reduction of the burden of chronic disease and disability in the urban Aboriginal community.

Health Care Access:

The OHC study findings are compelling with respect to the need to urgently address barriers in accessing health care services across the spectrum of preventative, primary,

and tertiary care. For example, 40% of the First Nations population in Hamilton rates their level of access to health care as fair or poor. Identified barriers included long waiting lists (48%), lack of transportation (35%), not able to afford direct costs (32%), doctor not available (29%), and lack of trust in health care provider (24%). Striking differences in emergency room admission rates between for First Nations in Hamilton compared to the general Hamilton and Ontario populations for both acute and non-acute illnesses are linked by participant narrative to the barriers listed above to access of timely preventative and primary health care. Fifty percent of the First Nations population in Hamilton reported at least one visit to the emergency room over the past 2 years for acute problems compared to 22% of the Hamilton and 20% of the Ontario population and 10.6% of the First Nations population in Hamilton reported 6 or more emergency room visits in the previous 2 years compared to 1.6% and 1.9% of the Hamilton and Ontario populations respectively. Notwithstanding this heavy use of emergency room services, 44% of the Hamilton First Nations population rated the quality of the emergency care as fair or poor. These findings have led to the following policy recommendation regarding health care access:

5. That municipal, provincial and federal governments engage with urban Aboriginal communities and organizations for the purposes of eliminating barriers in access to equitable community health care, emergency department services and inpatient hospital services for acute and non-acute conditions.

Aboriginal Specific Services, Cultural Safety, and Aboriginal Self-Determination of Health Care Delivery

Despite the challenges described above, First Nations people living in Hamilton demonstrate remarkable cultural continuity and resilience. Even though resources and programming for Aboriginal cultural programming in Hamilton have been extremely limited to date and the impacts of colonization have been significant, OHC study measures indicate a strong sense of First Nations identity among the First Nations population living in Hamilton as well as a strong desire to pass culture and language on to the next generation. The OHC pre-survey concept mapping study highlighted the idea that "Our Health Deserves Appropriate and Dedicated Care" and the subsequent respectful health assessment survey documented the desire for more Aboriginal health care workers and "prejudice" and "lack of trust and discrimination" as significant barriers in accessing care. In response to these findings we advance the following policy recommendations:

Aboriginal Specific Services for Family Treatment, Mental Health and Maternal Health

6. That municipal, provincial and federal governments ensure the provision of adequate funding to the urban community and organizations directed towards the development and expansion of culturally reflective, community based, long-term

traditional family treatment centres, urban Aboriginal child, youth and adult mental health funded strategies and maternal health, programs and services.

Cultural Safety:

7. That municipal, provincial and federal governments and health stakeholders develop and initiate policies towards the implementation of cultural competency and/ or cultural safety programs that are designed and delivered by Aboriginal people that includes the recognition and validation of Aboriginal worldviews and full inclusion of Aboriginal healers, medicine people, midwives, community counselors and health care workers in all collaborative efforts with western medicine.

Aboriginal Self-Determination of Health Care Delivery:

8. That municipal, provincial and federal governments recognize and validate the Aboriginal cultural worldviews (that encompasses the physical, mental, emotional, spiritual, and social well-being of Aboriginal individuals and communities) and that self-determination is fundamental and thus Aboriginal people must have full involvement and choice in all aspects of health care delivery, including governance, research, planning and development, implementation and evaluation.

Children's Health:

Parents and caregivers of First Nations children in Hamilton highly value the transmission of First Nations culture and language to the next generation. For example, the OHC study found that 93% of parents and caregivers felt it was very or somewhat important for their child to learn a First Nations language and 94% of parents and caregivers felt that traditional cultural events were very or somewhat important in their child's life.

Additional key study findings regarding First Nations children's health included the burden of chronic illness facing First Nations children in Hamilton; concerns regarding child development; and long waiting lists as a barrier to accessing health care. Asthma and allergies were the most commonly reported chronic conditions. Rates of asthma were twice as high for Hamilton First Nations children compared to general Canadian rates for children. Rates of chronic ear infections were also high. Twenty-two percent of parents and caregivers were concerned about their child's development. While 83% of participants indicated that their child had seen a family doctor, general practitioner or pediatrician in the past 12 months (compared to 88% for the general Canadian population aged 0-6 years), there were a significant number of reported barriers to accessing care. The number one barrier to receiving health care reported by child custodians was that the wait list was too long. In response to these findings, we recommend the following policies:

9. That municipal and provincial governments, including school boards, recognize the importance of and commit long term funding and resources towards Aboriginal children's language and cultural programming in collaboration with urban Aboriginal organizations and agencies.

10. That municipal and provincial governments work in collaboration with urban Aboriginal agencies and organizations to reduce urban Aboriginal children's health status inequities by eliminating barriers to urban Aboriginal children accessing regular primary health care, reducing long waiting lists and responding to the increased prevalence of health conditions such as asthma in the urban Aboriginal child population with customized culturally appropriate primary health care programming.

11. That municipal and provincial governments work in partnership with urban Aboriginal agencies and organizations to ensure that urban Aboriginal children are accorded their human rights to live in healthy homes and communities and attend day programs/schools in healthy environments that do not exacerbate chronic health conditions such as asthma and allergies.

RESEARCH:

Urban First Nations organizations and community members in Hamilton successfully partnered with provincial Aboriginal organizations and academic researchers in the collection, governance, management, analysis and documentation of their own urban First Nations health database. Successful research outcomes included:

- Completion of a community concept mapping project that identified First Nations specific health domains.
- Development and implementation of a customized First Nations adult and child health needs assessment survey which was administered to 554 adults and on behalf 236 children (total 790 community members) living in the city of Hamilton.
- Successful linkage of recruited First Nations cohort to the Institute of Clinical Evaluative Sciences database.
- Statistically rigorous Respondent Driven Sampling (RDS) allowed for successful derivation of population based estimates of survey and Institute for Clinical Evaluative Sciences (ICES) First Nations cohort measures.
- Collaborative production of this project report.

The Our Health Counts research project demonstrates that research can be done by Aboriginal people for Aboriginal community benefit. As a result, we put forward the following policy recommendation regarding research:

12. That municipal, provincial and federal governments and urban Aboriginal organizations recognize the health status inequities and disparities of urban Aboriginal peoples living in the city of Hamilton and across the province and advocate for funded urban Aboriginal specific applied health services research.

SYSTEM PLANNING:

As highlighted in the introduction of this section, all of the above policy recommendations are prefaced on the need for the re-establishment of key relationships between municipal, provincial, and federal governments and urban Aboriginal local and provincial organizations. In particular there is a need to ensure that unresolved jurisdictional accountabilities do not continue to perpetuate unnecessary and resolvable health disparities for urban Aboriginal peoples. Such pressing and significant health inequities are unacceptable given the relative affluence of Ontario and Canada globally. To address these devastating health and social inequities and disparities experienced by urban Aboriginal people today these final policy actions are required:

13. That municipal, provincial and federal governments support interagency collaboration and cooperation amongst urban Aboriginal service providers towards the design and delivery of services and identification of funding and research opportunities.

14. That municipal, provincial and federal governments collaborate with urban Aboriginal agencies and organizations and gain knowledge of the urban Aboriginal health determinants and health inequities and further acknowledge the urban Aboriginal communities right to self-determination in the control of planning, design, development and delivery of culturally specific health services, programs and policy.

REFERENCES

1 Information, Policy and Integration Unit, Ontario Ministry of Community and Social Services. Aboriginal Population, 2006 Census Data Release. Info Notes, 2008; Volume 6 (March). Accessed April 30th, 2011: http://www.trilliumfoundation.org/User/Docs/PDFs/research/InfoNote_Aboriginal.pdf

2 Statistics Canada. 2006 Census: Aboriginal Peoples of Canada. [CD-ROM] Ottawa : Statistics Canada, 2006

3 Smylie J., Nili Kaplan-Myrth, Kelly McShane, Métis Nation of Ontario – Ottawa Council, Pikwakanagan First Nation, Tungasuvvingat Inuit Family Resource Centre. Indigenous Knowledge Translation: Baseline Findings in a Qualitative Study of the Pathways of Health Knowledge in Three Indigenous Communities in Canada. Journal of Health Promotion Practice (in press)

4 First Nations Centre, National Aboriginal Health Organization. First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities. Ottawa: First Nations Centre; 2005

5 Smylie Janet, Kelly McShane, Tungasuvvingat Inuit Family Resource Centre. Understanding Knowledge Translation in an Urban Inuit Community. CIHR- IPPH Knowledge Translation Casebook – Moving population and public health knowledge into action. Ottawa – CIHR, 2006

6 Royal Commission on Aboriginal Peoples. Appendix B: *Ethical Guidelines for Research*. Ottawa: RCAP, 1993

7 CIHR. CIHR Guidelines for Health Research Involving Aboriginal Peoples. CIHR, Ottawa: 2007. http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf (accessed June 8th, 2007)

8 Kahnawake Schools Diabetes Prevention Project. Code of Research Ethics. Kahnawake Schools Diabetes Prevention Program. 1996

9 Kane M and Trochim WMK. Concept Mapping for Planning and Evaluation. Thousand Oaks, California: Sage Publications, 2007

10 Abdul-Quader A., Heckathorn DD., Sabin K., Saidel T. Implementation and Analysis of Respondent Driven Sampling: Lessons from the Field. Journal of Urban Health: Bulletin of the New York Academy of Medicine, 2006; 83(7):1-5

11 Salganik MJ. Variance Estimation, Design Effects, and Sample Size Calculations for Respondent-Driven Sampling. Journal of Urban Health: Bulletin of the New York Academy of Medicine, 2006; 83(7):98-112

12 McKnight C., Des Jarlais D., Bramson H., Tower L., Abdul-Quader A., Nemeth C., Heckathorn DD. Respondent-Driven Sampling in Study of Drug Users in New York City: Notes from the Field. Journal of Urban Health: Bulletin of the New York Academy of Medicine, 2006; 83(7):54-59

13 Heckathorn D. Respondent-driven sampling II: Deriving Valid Population Estimates from Chain referral Samples of Hidden Populations. Social Problems 49, 2002;11-34 (2002)

14 Statistics Canada. Community Profiles. Ottawa, ON: Statistics Canada. 2006. Accessed April 30th,2011: http://www12.statcan.ca/census-recensement/2006/dp-pd/prof/92-591/details/Page.cfm?Lang=E&Geo1=CSD&Code1=3525005&Geo2=PR&Code2=35&Data=Count&SearchText=hamilton&SearchType=Contains&SearchPR=35&B1=All&Custom=

15 Social Policy and Research Council of Hamilton, Internal Data

16 Indian and Northern Affairs Canada. Fact Sheet – Urban Aboriginal Population in Canada. Ottawa, ON: INAC 2009. Accessed April 30th, 2011: http://ainc-inac.gc.ca/ai/ofi/uas/fs/index-eng.asp

17 Statistics Canada. Aboriginal Peoples in Canada in 2006: Inuit, Métis, and First Nations, 2006 Census. 2008. Ottawa: Ministry of Industry. Statistics Canada catalogue number 7-558-XIE Accessed April 30th 20011: http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/pdf/97-558-XIE2006001.pdf

18 Social Planning Network of Ontario. Ontario's Social Landscape: Socio-demographic trends and conditions in communities across the province. 2010. Accessed February 7 2011: http://www.spno.ca/images/stories/pdf/reports/ontario-social-landscape-2010.pdf

19 First Nations Information Governance Committee. First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities, Second Edition. Ottawa: Assembly of First Nations; 2007. Accessed February 28th, 2009: http://www.rhs-ers.ca/english/pdf/rhs2002-03reports/rhs2002-03-technicalreport-afn.pdf

20 Neyer JR et al. Prevalence of Stroke – United States 2005. MMWR. 2007; 56(19):469-474. Accessed April 30th, 2011: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5619a2.htm

21 Remis R. Modelling the Incidence and Prevalence of Hepatitis C Infection and its Sequelae in Canada, 2007 Final Report. Ottawa: Community Acquired Infections Division Centre for Communicable Diseases and Infection Control Infectious Disease and Emergency Preparedness Branch Public Health Agency of Canada, 2007.
Accessed April 30th, 2011 : http://www.phac-aspc.gc.ca/sti-its-surv-epi/model/index-eng.php#t1

22 Phinney, J. The Multi-group Ethnic Identity Measure: A new scale for use with adolescents and young adults from diverse groups. *Journal of Adolescent Research, 7, 156-176.*

23 Krieger N, Smith K, Naishadham D, Hartman C, Barbeau EM.
Experiences of discrimination: validity and reliability of a self-report measure for population health research on racism and health. Social Science and Medicine 2005;61(7):1576-96. Epub 2005 Apr 21.

24 Statistics Canada. Aboriginal Population Profile. Ottawa, ON, 2006. Accessed April 30th ,2011: http://www12.statcan.ca/english/censuso6/data/profiles/aboriginal/Index.cfm?Lang=E

25 McShane K, Smylie J, Adomako P. Health of First Nations, Inuit, and Métis Children in Canada In: Smylie J, Adomako P (eds). Indigenous Children's Health Report: Health Assessment in Action. Toronto: Saint Michael's Hospital, 2009.

26 Human Resources and Social Development Canada, Public Health Agency of Canada and Indian and Northern Affairs Canada. Well Being of Canada's Young Children – Government of Canada report 2008. Ottawa: 2008. Accessed April 30th, 2011: http://www.socialunion.gc.ca/well_being/2008/en/page04.shtml

27 Statistics Canada, National Longitudinal Survey of Children and Youth 2006/2007, special data run for Dr. Janet Smylie, February 2009

28 First Nations Child and Family Caring Society of Canada. Joint Declaration of Support for Jordan's Principle To Resolving Jurisdictional Disputes Affecting Services to First Nations Children. Ottawa, 2011. Accessed March 17th, 2011: http://www.fncfcs.com/jordans-principle

29 Canada. Royal Commission on Aboriginal Peoples.People to people, nation to nation: Highlights from the report of the Royal Commission on Aboriginal Peoples. Ottawa: Minister of Supply and Services, 1996

30 United Nations General Assembly. United Nations Declaration on the Rights of Indigenous Peoples. Geneva: United Nations. Accessed March 17th, 2011: http://www.un.org/esa/socdev/unpfii/en/drip.html.

31 Canada. Constitution Act 1982. Accessed March 17th, 2011: http://www.constitutionofcanada.com/constitution-act-1982.shtml

APPENDIX A

COMMUNITY—SMH RESEARCH AGREEMENT

Research, Data, Statistics, and Publication Agreement
Between
Ontario Federation of Indian Friendship Centres (OFIFC)
and
De dwa da dehs ney>s – Aboriginal Health Access Centre (AHAC)
and
Centre for Research on Inner City (CRICH)/ Michael's Hospital ("SMH")

Project: "Our Health Counts": *Development and Application of a Baseline Population Health Database for Urban Aboriginal People in Ontario*

THIS AGREEMENT MADE IN DUPLICATE this day (11/30/2009)
WITNESSETH AS FOLLOWS:

PURPOSE OF AGREEMENT:

The purpose of this agreement is to ensure that the project "*Our Health Counts*": *Development and Application of a Baseline Population Health Database for Urban Aboriginal People in Ontario* is respectful to the cultures, languages, knowledge, values, and rights to self-determination of OFIFC and AHAC. This agreement will also provide a framework for the use of data collected during the Research Project. This agreement supports principles of Aboriginal collective and self-determined data management and governance. This is not a financial agreement. The agreement supports the information needs of OFIFC and AHAC, as well as acknowledging the desire of Dr. Janet Smylie and the OHC research team to conduct this collaborative research. It defines the opportunity(ies) to develop research capacity at OFIFC and AHAC. OFIFC and AHAC anticipates this research project will assist to enhance capacity and leadership among OFIFC and AHAC communities and their policy, program and health service collaborators in the area of First Nation urban health information collection, analysis, and application through:

a. the involvement of community representatives as active research team members in all aspects of this project;
b. a series of community-based health data use workshops in program and service policy making, planning, delivery, and evaluation.

AGREEMENT PRINCIPALS:

- Maintain mutual respect and accountability between the parties;
- Recognize the complementary and distinct expertise, responsibilities, mandates, and accountability structures of each party;
- Ensure the highest standards of research ethics, including the acknowledgement of OFIFC and AHAC specific principles of self-determined data management;
- Respect the individual and collective privacy rights of OFIFC and AHAC staff;
- Recognize the value and potential of research that is scientifically and culturally validated;
- Recognize the value of capacity building at all levels;
- Support OFIFC and AHAC processes, including the analysis and dissemination of survey results.

PROJECT DESCRIPTION (see page 91)

AGREEMENT:

AND WHEREAS OFIFC and AHAC are developing a policy framework of principles for data collection, self-determined data management, analysis, and dissemination;

AND WHEREAS the OFIFC and AHAC principles will be articulated in a written format as a result of the gap in legislation applicable to OFIFC and AHAC clients and staff with respect to the collective ownership and possession of data, statistics, and information;

AND WHEREAS OFIFC and AHAC wish to use this opportunity to build research capacity and/or provide research opportunities to its members and staff by working in collaboration with SMH and ICES;

AND WHEREAS OFIFC and AHAC would like to maintain a positive and good faith relationship with SMH and ICES;

NOW THEREFORE CRICH/SMH covenants and agrees as follows for the consideration of the sum of One ($1.00) dollar paid to CRICH/SMH by OFIFC and AHAC, and other valuable consideration, the receipt and sufficiency of which is hereby acknowledged;

3. SMH and ICES acknowledges that any and all data collected by OFIFC and AHAC as a result of this research project is rightfully owned by OFIFC and AHAC on behalf of the Hamilton First Nation community. Utilization of the data collected for the purpose and by the means outlined in the research proposal is acknowledged and granted by OFIFC and AHAC to CRICH/SMH in accordance with the terms and conditions contained in this agreement.
4. OFIFC and AHAC agree to undertake the research roles, responsibilities and activities described in Appendix B. Funding for these activities will be provided by Ontario Federation of Indian Friendship Centres as per their agreement with AHAC.
5. SMH and ICES agrees to the inclusion of project team representative(s) from OFIFC and AHAC as co-investigators and they will be acknowledged in any and all publications, reports, documents, or other written material from which this data is utilized. The representative(s) from OFIFC and AHAC will be included by CRICH/SMH in the complete research process or to the level the representative(s) is directed by OFIFC and AHAC to be involved. Any presentations, workshops or conferences where SMH Project Team members wish to attend for purposes of discussing Our Health Counts shall involve OFIFC and AHAC representatives.
6. The OFIFC and AHAC Research Project Representative(s) shall be able to provide a dissenting opinion of findings. Any dissenting opinions will be included as part of the overall report in all publications and/or pertinent published or produced materials.
7. Utilizing the data gathered from this research project by CRICH/SMH for secondary publishing will require specific written permission of OFIFC and AHAC. CRICH/SMH is to protect the data and act as stewards of this data on behalf of the rightful owner.
8. OFIFC and AHAC are the rightful owners of all data collected from the Hamilton First Nation community. CRICH/SMH will require OFIFC and AHAC consent to maintain a copy of the data set with Drs. Smylie's databank. CRICH/SMH will be required to protect the data from unauthorized use and act as stewards on behalf of the rightful owner. OFIFC and AHAC have provided prior consent to Dr. Janet Smylie of the Centre for Research on Inner City Health at St. Michael's Hospital to maintain a copy of the data sets generated by this project in accordance with the Study Protocol reviewed and approved by CRICH/SMH research ethics board and OFIFC and AHAC management for the purpose of publishing research reports as set out herein and having access to a copy of the source data of such research reports
9. This agreement is in force from the date of the last authorizing signature and CRICH/SMH agrees that this agreement is irrevocable and shall ensure to the benefit of and be binding upon CRICH/SMH its employees, administrators and legal and personal representatives.
10. CRICH/SMH represents that they understand and agree to the terms contained within this agreement and such performance will not be unreasonably withheld.
11. CRICH/SMH declares that it has been given the opportunity to obtain independent legal advice with respect to the details of the terms evidenced by this Agreement and confirms that they are executing this Agreement freely and voluntarily.
12. CRICH/SMH will provide OFIFC and AHAC the opportunity for review of any approved research reports before the submission of reports for

publication. OFIFC and AHAC will be provided 4 weeks to review the research results and accompanying manuscript. In the event that OFIFC and AHAC and Drs. Smylie cannot agree on the content of the written report, OFIFC and AHAC will be invited to write an editorial to accompany the report to be submitted for publication.

13. OFIFC and AHAC, and CRICH/SMH agree to perform their respective study activities in accordance with the research proposal as approved by the SMH REB, participant consent forms, and all applicable laws, regulations and guidelines, including without limitation, the Tri-Council Policy Statement, "Ethical Conduct for Research Involving Humans" and the Canadian Institutes of Health Research Guidelines, "Guidelines for Health Research Involving Aboriginal People", all as amended from time to time

14. OFIFC and AHAC, and CRICH/SMH confirm their respect for the privacy of individual participants in the research project. OFIFC and AHAC, and CRICH/SMH agree to follow applicable privacy laws and regulations and to notify each other if either receives a complaint about breach of privacy

15. Neither party shall use the name of the other party or its staff in any publication, news release, promotion, advertisement, or other public announcement, whether written or oral, that endorses services, organizations or products, without the prior written consent of the party whose name is to be used

16. OFIFC and AHAC, the Releasor, confirms that if they transmit this Agreement by facsimile or such device, that the reproduction of signatures by facsimile or such similar device will be treated as binding as if originals and undertakes to provide all parties with a copy of this Agreement bearing original signatures forthwith by courier.

17. Notices to each Party shall be sent to:

CRICH/SMH:
70 Richmond Street East
Toronto, ON
M5C 1N8

Ontario Federation of Indian Friendship Centre
Sylvia Maracle
219 Front St. East
Toronto, ON
M5A 1E8

De dwa de dehs ney>s Aboriginal Health Centre:
Denis Compton678 Main St. East. Hamilton, ON
L8M 1K2

18. This agreement may be executed in counterpart. Copies collectively bearing the signatures of all parties shall constitute the fully executed agreement.

SIGNATURES:

ST. MICHAEL'S HOSPITAL

.....
For, Dr. Arthur S. Slutsky

.....
Dr. Janet Smylie

Ontario Federation of Indian Friendship Centres

.....
OFIFC Authorized Signature

Name and Title: .....

De dwa de dehs ney>s Aboriginal Health Centre

.....
AHAC Authorized Signature

Name and Title: .....

PROJECT DESCRIPTION

Background:

Dr. Janet Smylie is a Métis family doctor and public health researcher with an interest in improving health services and programs in First Nations Inuit and Métis communities by providing health workers, program managers, and policy makers with useful and relevant information. As a result of her experiences providing medical care to young Aboriginal families, she is especially interested in the health and wellbeing of infants, children, and families. Dr. Smylie believes that health services and programs may be improved by enhancing Ontario's health information system in order to provide accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, and provincial policy makers.

Key Adaptations:

In order to meet our goal of improving Ontario's health information system in order to provide accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, and provincial policy makers, we have designed several key adaptations, which will be implemented and evaluated during this two year adaptation program. These include:

1. Community-based participatory action approaches to health data collection
2. Respondent driven sampling
3. Longitudinal linkages to the ICES database
4. Respectful health assessment survey
5. Data governance and management protocols

Goal:

To work with provincial urban First Nations, Inuit, and Métis organizations and the Ontario Ministry of Health and Long Term Care to adapt Ontario's health information collection system so that it provides accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, provincial and federal policy makers.

Objectives:

Formalizing Intersectoral Partnerships and Establishing Priority Measures

1. To formalize partnerships between the four core urban Aboriginal provincial organizations, the multidisciplinary academic team, the Ontario Ministry of Health and Long Term Care (MOHLTC), and the Institute for Clinical Evaluative Sciences (ICES) for this project through research agreements and data management/governance protocols. This will include the establishment of an Aboriginal Health Data Governance Council comprised of the four core urban Aboriginal provincial organizations.
2. To confirm priority health domains and best indicators for each domain through these partnerships.

Knowledge Development through Establishment of a Population Health Data Base

3. To generate new health data sets reflective of these priorities for a sample of urban First Nations, Inuit, and Métis adults and children using respondent driven sampling, secure data linkage with ICES and a respectful health assessment questionnaire.

Capacity Building, Training and Mentoring

4. To strengthen capacity and leadership among Ontario's urban Aboriginal communities and their policy, program and health service collaborators in the area of Aboriginal health information collection, analysis, and application through: a. the involvement of community representatives as active research team members in all aspects of this project; b: a series of community-based health data use workshops.
5. To provide a scientifically excellent and culturally relevant training and mentorship environment for Aboriginal health researchers at the undergraduate, graduate, post-doctoral and new investigator level.

Knowledge Dissemination, Application, and Contribution to Future Projects

6. To support community-based, small region, provincial, and federal uptake and application of health data generated through 1-3 above to First Nations, Inuit, and Métis health policies, programs, and services. This will include the establishment of an Aboriginal health data users group, which will have open membership and allow diverse stakeholders input and access to data generated by the project.
7. To build on the outcomes of this study to design future longitudinal health studies in partnership with First Nations, Inuit, and Métis governing/organizational stakeholders as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario.
8. To share study results and adaptation processes with First Nations, Inuit, and Métis stakeholders in other provinces and territories and thereby contribute to the development of urban Aboriginal health data enhancement strategies.

Team:

This adaptation program brings together representatives from Ontario's four key urban Aboriginal health policy and service delivery stakeholder organizations (Ontario Federation of Indian Friendship Centres (OFIFC), Métis Nation of Ontario (MNO), Tungasuvvingat Inuit (TI), Ontario Native Women's Association (ONWA) and multidisciplinary biomedical and social science academics from five different institutions (Centre for Research on Inner City Health (CRICH) - St. Michael's Hospital; University of Toronto – Department of Public Health Sciences; ICES; University of Manitoba; and the Indigenous Peoples Health Research Development Program). The four urban Aboriginal organizations will work together as a coalition, with OFIFC taking the lead as signatory and acting as delivery agent for OFIFC, MNO,

and ONWA and CRICH, supporting the interests and financing for Tungasuvvingat Inuit. The team will build on existing longstanding research partnerships between the research director (Smylie) and the core Aboriginal organizational partners –Dr. Smylie has been engaged in community based partnership research with TI and MNO (Ottawa Council) since 2002 and OFIFC since 2004. The multidisciplinary academic research team brings together experts from the disciplines of public health, family medicine, epidemiology, health database research, biostatistics, psychiatry, internal medicine, and psychology. All of the academic team members have experience in community based Aboriginal health research and several have dedicated their careers to this area.

Core Aboriginal Organizational Partners: Ontario Federation of Indian Friendship Centres (OFIFC), Métis Nation of Ontario (MNO), Tungasuvvingat Inuit (TI), Ontario Native Women's Association (ONWA)

Academic Research Team Members: Janet Smylie, Pat O'Campo, Rick Glazier, Marcia Anderson, Kelly McShane, Roseanne Nisenbaum, Dionne Gesink Law, Cornelia Wieman, Sanjeev Sridharan

Aboriginal Organizational Research Team Members: Sylvia Maracle (OFIFC), Connie Siedule (TI), Donna Lyons (MNO), Marianne Borg (ONWA)

APPENDIX B

ICES DATA SHARING AGREEMENT

DATA SHARING AGREEMENT

THIS AGREEMENT made this 20th January, 2010

BETWEEN:

INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES
a corporation having its head office at
2075 Bayview Avenue, in the City of Toronto

[hereinafter referred to as "ICES"]

-AND-

THE OUR HEALTH COUNTS GOVERNING COUNCIL
ONTARIO FEDERATION OF INDIAN FRIENDSHIP CENTRE
ONTARIO NATIVE WOMEN'S ASSOCIATION
TUNGASUVVINGAT INUIT
MÉTIS NATION OF ONTARIO

[hereinafter referred to as the "GOVERNING COUNCIL"]

-AND-

CENTRE FOR RESEARCH ON INNER CITY HEALTH/ST. MICHAEL'S HOSPITAL
70 Richmond Street East
Toronto, ON M5C 1N8

[hereinafter referred to as "CRICH"]

WHEREAS ICES was established in 1992 in order to carry out research with respect to physicians' services and related health services on behalf of the Ministry of Health and Long Term Care (MOHLTC) and the Ontario Medical Association;

WHEREAS ICES' mandate now includes the conduct of clinical evaluative studies and health services research in order to improve the efficiency and effectiveness of physicians' services and related health care services;

WHEREAS MOHLTC has entered into an agreement with ICES to provide annual funding to ICES for the purpose of conducting such research;

WHEREAS ICES has entered into a data sharing agreement with the MOHLTC for access to information, including personal health information, that is in the custody or control of MOHLTC for the purpose of conducting clinical evaluative studies and health services research;

WHEREAS ICES is a prescribed entity under section 45(1) of the *Personal Health Information Protection Act,* S.O. 2004, c. 3 Sched. A (the Act) and O. Reg. 329/04 section 18(3) and warrants and represents that the personal health information requested in this agreement is necessary to conducting clinical evaluation studies and health services research;

WHEREAS pursuant to section 45(1) of the Act, the Health Information Custodian may disclose to a prescribed entity personal health information for the purpose of clinical evaluation studies and health services research if the entity meets the requirements under subsection (3). 2004, c. 3, Sched. A, s.45 (1);

WHEREAS ICES has in place the practices and procedures necessary under subsection (3). 2004, c. 3, Sched. A, s.45 (1) to protect the privacy of individuals and the confidentiality and security of personal health information it receives;

WHEREAS the Information & Privacy Commissioner/ Ontario has reviewed the privacy, confidentiality and security practices and procedures of ICES and approved them in October 2008;

AND WHEREAS the First Nations, Métis, and Inuit people in Canada have inherent rights to self-government, specific rights as negotiated in the numbered Treaties and rights as outlined and enshrined in the Constitution Act of Canada (1982);

NOW THEREFORE in the consideration of the promises and the mutual covenants hereinafter contained, the parties hereto agree as follows:

1.0 PURPOSE OF THE AGREEMENT

The purpose of this agreement is:

1.1 to set out the terms and conditions governing the provision of data, including personal health information, to ICES to enable it to conduct clinical evaluative studies and health services research on behalf of the GOVERNING COUNCIL and CRICH.

2.0 INFORMATION TO BE PROVIDED

2.1 CRICH and GOVERNING COUNCIL have agreed to provide to ICES a copy of the Our Health Counts Respectful Health Survey dataset, (henceforth the OHC RHS dataset). The database will contain the name, gender, date of birth, OHIP number, and Respectful Health Survey response data of self-identified First Nations people living in Hamilton and Inuit and Métis people living in Ottawa (see Schedule A for variables list). There will be three linkages of the OHC RHS Database to the ICES database at baseline (2010) and in 2 (2012) and 5 (2015) years from baseline. Following the completion of the project, in 2017 the OHC RHS Database will be permanently erased from ICES files.

3.0 USE OF THE INFORMATION

ICES shall use the personal health information collected under this agreement only as necessary for the following purposes:

3.1. To link the OHC RHS Database with the Registered Person Database (RPDB) to create a cohort of First Nations people living in Hamilton and Inuit and Métis people living in Ottawa. This cohort will be linked with the other administrative data, and a variety of measures will be determined and analyses will be conducted for the First Nations cohort in Hamilton and the Inuit and Métis cohort in Ottawa. These may include, but will not be limited to:

- **3.1.1.** The incidence and prevalence of chronic diseases such as diabetes, cardiovascular disease, arthritis, COPD, cancer, and stroke.
- **3.1.2.** Emergency care
- **3.1.3.** Physician care (visits with and continuity of primary care, visits with specialists)
- **3.1.4.** Age and gender specific hospitalization rates
- **3.1.5.** Medication use (glucose-lowering medications, cardioprotective medications)
- **3.1.6.** Participation in preventative care activities (as defined by ICES)
- **3.1.7.** Access to mental health care (as defined by ICES)
- **3.1.8.** The relationship between social determinants of health and acute and chronic health status outcomes
- **3.1.9.** The relationship between social determinants of health and access to health services
- **3.1.10.** Chronic disease complications (myocardial infarction, bypass surgery/angioplasty, heart failure, stroke, amputation, dialysis)

3.2 ICES will only release requested measures and analyses to CRICH and the GOVERNING COUNCIL in an aggregated format that prevents the identification of individuals. This does not preclude the release of First Nations, Inuit, Métis specific datasets.

3.3 At the request of Tungasuvvingit Inuit, ICES may release Inuit specific measures and analyses.

3.4 At the request of Métis Nation of Ontario, ICES may release Métis specific measures and analyses.

3.5. Research reports and publications, including peer reviewed scholarly manuscripts, will be created at the discretion of the GOVERNING COUNCIL and CRICH.

3.6 All research reports and publications will credit the GOVERNING COUNCIL, relevant CRICH staff and the relevant ICES scientists/staff with authorship.

3.7 The GOVERNING COUNCIL will have the opportunity to review all research reports and publications that

are prepared by CRICH before they are made public, submitted to the MOHTLC as per 3.6 below, or submitted for publication. The GOVERNING COUNCIL will be provided a minimum of 30 days for this review unless otherwise agreed by GOVERNING COUNCIL Representatives shall be able to provide a dissenting opinion of findings and any dissenting opinions will be included as part of the overall report in all publications and/or pertinent published or produced materials.

3.8 Under its contractual obligation to the MOHLTC, ICES will provide the MOHLTC with copies of all reports that have required the use of health care data obtained from the MOHLTC for the purposes of compiling the information 30 days prior to submitting such reports for publication or making such reports public, as the case may be. The MOHLTC shall keep all such reports confidential.

4.0 MECHANISMS FOR TRANSMISSION

4.1 The parties shall mutually determine the method, medium, frequency and timetable to be used with respect to the provision of information under this agreement. These parameters shall enable ICES to meet its IPC-approved standards, must fit with available technology, and with availability of staff to effectively and securely manage the PHI.

5.0 CONFIDENTIALITY

5.1 The personal information disclosed under this agreement is confidential and mechanisms for maintaining the confidentiality of this information are described in Article 5.4.

5.2 Before disclosing any personal health information under this agreement, CRICH, the GOVERNING COUNCIL and ICES shall exercise due caution in providing only that personal health information that is determined to be necessary for the purpose set out in Article 3.1.

5.3 ICES, in requesting personal information under this agreement, warrants and represents that the personal information is necessary for the purposes set out in Article 3.1.

5.4 ICES agrees to the following precautions and safeguards in handling confidential personal information and personal health information:

5.4.1 ICES will give access to personal health information in a form in which the individual to whom it relates can be identified only to the following persons: Mr. Don DeBoer, Director, Data Management, Mr. Nelson Chong, Health Data Administrator, and Mr Nicholas Gnidziejko, Analyst.

5.4.2 ICES will keep the personal health information in a physically secure location to which access is given only to the persons mentioned in Section 5.4.1, above.

5.4.3 Identifying numbers on linked OHC RHS Database will be encrypted immediately after the data are first read, and all working files will have only the encrypted number on them.

5.4.4 The data from CRICH, the GOVERNING COUNCIL and MOHLTC with identifying information about an individual will be copied by ICES to electronic media and stored separately in a locked safe in a room with security locks. The original media will be returned to the source or destroyed.

5.4.5 ICES linked working files will not contain identifying information about an individual.

5.4.6 Other than the individuals named in Article 5.4.1, the staff in ICES Information Systems, the members of ICES' Programming and Biostatistics team and ICES Scientists will be accessing the working files only in an anonymized form and will be producing analyses required for reports from such files.

5.4.7 All personnel of ICES shall sign a confidentiality agreement to ensure that they do not disclose personal health information to any other person. In so doing, each person working for ICES acknowledges that the disclosure of personal health information is grounds for immediate dismissal or termination.

5.4.8 In accordance with its privacy policy, ICES

will only present aggregated data in its reports so as to prevent the indirect identification of individuals. This will not preclude the presentation of First Nations, Inuit, and/or Métis specific datasets. Information in the cells will be suppressed when they contain five (5) observations or less. Information in sparse cells may be combined with other cells to avoid cell counts of five (5) observations or less.

5.5 Where a person specified in Article 5.4 .1 no longer has access to identifying information, ICES shall notify CRICH and the GOVERNING COUNCIL of the substitute for that person.

5.6 ICES will not contact any individual to whom personal health information relates, directly or indirectly.

5.7 ICES will ensure that no information regarding the cohort of First Nations people in Hamilton and Métis and Inuit people in Ottawa will be used or disclosed to any other party without the prior written authority of the GOVERNING COUNCIL except to ICES employees identified in Article 5.4.1 who are responsible for encrypting the identifying numbers, doing linkages and storing, retrieving or destroying the data.

5.8 ICES will notify CRIHC and the GOVERNING COUNCIL as soon as it has become aware of a breach of the terms and conditions set out in this agreement and ICES will advise CRICH and the GOVERNING COUNCIL of the steps
taken to correct any such default and to prevent any recurrence.

6.0 FINANCIAL ARRANGEMENTS

6.1 Each party shall bear its own cost of implementing this agreement.

7.0 AMENDMENTS

7.1 This agreement may be amended if the parties agree to such amendments in writing. Any amendments so made shall be consistent with the requirements of the Personal Health Information Protection Act and the CIHR Guidelines for Research with Aboriginal Peoples and shall not be contrary to any laws regarding confidentiality of health information.

9.0 TERMS, COMMENCEMENT AND TERMINATION OF AGREEMENT

9.1 This agreement shall take effect on the date set out on page 1.

9.2 This agreement shall continue in effect for as long as the DATA CUSTODIAN provides data identified in this agreement, unless there is an amendment or termination, subject to Article 10.1.

9.3 CRICH and the GOVERNING COUNCIL may cease disclosing any one or more data elements, without cause, by giving ICES notice in accordance with Article 11.

9.4 If CRICH and the GOVERNING COUNCIL cease disclosing of personal information under Article 9.3, the entire agreement is not terminated but continues with respect to the remaining data elements which CRIHC and the GOVERNING COUNCIL are willing to continue to disclose.

9.5 This agreement may be terminated by either party without cause on at least three months notice and on breach by the other party immediately on notice.

9.6 This agreement may be amended or terminated on mutual agreement by the parties.

9.8 On termination the CRICH and the GOVERNING COUNCIL shall cease
disclosing data and ICES shall cease using data.

9.9 On termination, ICES shall destroy all the data and all copies immediately, in accordance with ICES procedures

10.0 SURVIVAL OF OBLIGATIONS

10.1 Terms and conditions relating to
- **(a)** use and destruction of the information
- **(b)** confidentiality; and
- **(c)** indemnification shall survive the termination of this agreement.

11.0 NOTICE

11.1 Notice of intention to terminate shall be given in writing to the other party at least three months before the date on which this agreement, or any part of this agreement, as the case may be, is to be terminated.

11.2 Notice shall be deemed to have been sufficiently given seventy-two hours after it has been mailed, postage prepaid, or on the date of receipt where the notice has been delivered by hand or by facsimile transmission.

11.3 Any notice or other communication required or permitted to be given by either party to the other shall be sent to the following addresses:

If for **ICES**:
Dr. David A. Henry
Chief Executive Officer
G Wing, Room 106,
2075 Bayview Avenue,
Toronto, ON M4N 3M5
Phone: 416-480-4297

If for the **GOVERNING COUNCIL**:
Sylvia Maracle
Executive Director
Ontario Federation of Indian Friendship Centres
219 Front St.
Toronto, ON M5A 1E8

Connie Siedule
Health Director
Tungasuuvingat Inuit
ADD IN ADDRESS

Donna Lyons
Health Director
Métis Nation of Ontario
500 Old St. Patrick Street, Unit #3
Ottawa, ON K1N 9G4

Cora Lee McGuire-Cyrette
Executive Director
Ontario Native Women's Association
ADD IN ADDRESS

AND

If for **CRICH**
Janet Smylie
Research Scientist
Centre for Research on Inner City Health
70 Richmond St.
Toronto, ON M5C 1N8

12.0 INDEMNIFICATION

12.1 ICES shall indemnify and save harmless the GOVERNING COUNCIL and CRICH and the GOVERNING COUNCIL and CRICH's Custodian's directors, officers, employees, independent contractors, subcontractors, agents, and assigns from all costs, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature based on or attributable to any disclosure of personal health information to whom it relates can be identified by ICES or its directors, officers, employees, independent contractors, subcontractors, agents or assigns in contravention of this agreement. This provision survives the termination of this agreement.

12.2 CRICH and the GOVERNING COUNCIL shall indemnify and save harmless ICES and ICES' directors, officers, employees, independent contractors, subcontractors, agents, and assigns from all cost, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature based on or attributable to any inaccuracy of the information provided by CRICH and the GOVERNING COUNCIL to ICES under this agreement. This provision survives the termination of this agreement.

IN WITNESS WHEREOF THE PARTIES hereto have executed this Agreement:

ONTARIO FEDERATION OF INDIAN FRIENDSHIP CENTRES
SYLVIA MARACLE

Per:
.....
Authorized Signing Officer *Witness*
.....
Print Authorized Signing Officer Name *Date*

ONTARIO NATIVE WOMEN'S ASSOCIATION
CORA LEE MCQUIRE

Per:.....
Authorized Signing Officer *Witness*
.....
Print Authorized Signing Officer Name *Date*

TUNGASUVVINGAT INUIT
MORGAN HARE

Per:

.....

Authorized Signing Officer *Witness*

.....

Print Authorized Signing Officer Name *Date*

MÉTIS NATION OF ONTARIO
DOUG WILSON
Per:

.....

Authorized Signing Officer *Witness*

.....

Print Authorized Signing Officer Name *Date*

CENTRE FOR RESEARCH ON INNER CITY HEALTH/ ST. MICHAEL'S HOSPITAL
DR. ARTHUR S. SLUTSKY

Per:

.....

Authorized Signing Officer *Witness*

.....

Print Authorized Signing Officer Name *Date*

INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES
DR. DAVID A HENRY

Per:

.....

David A. Henry *Witness*
Chief Executive Officer

.....

Print Authorized Signing Officer Name *Date*

APPENDIX C

FIRST NATIONS ADULT AND CHILD SURVEY TOOL

QUESTIONNAIRE: HAMILTON FIRST NATIONS

RDS Screening Questions

1. Coupon # Presented: .....

2. Do you self-identify as being First Nations?
   - ☐ YES
   - ☐ NO [end interview]
   - ☐ DON'T KNOW [end interview]
   - ☐ NO RESPONSE [end interview]

3. Do you live in Hamilton?
   - ☐ YES
   - ☐ NO [end interview]
   - ☐ DON'T KNOW [end interview]
   - ☐ NO RESPONSE [end interview]

4. OHIP # .....

5. DOB .....

6. Participant Name
   .....

7. Do you have First Nation children that are under your care and reside with you?
   - ☐ YES
   - ☐ NO [SKIP TO NEXT SECTION]

8. Would you be willing to complete the child portion of the survey? (inform them it will take an additional 20 minutes ask we will be asking for all their children under the age of 14)
   - ☐ YES
   - ☐ NO [Skip to next section]

9. How many children do you have?
   .....

RDS Questions

These next questions are about gathering information on your personal network. We will use this information to determine how long we will continue to recruit research participants.

1. How many First Nations people do you know by name who currently live in the city of Hamilton [Not including those who live on-reserve]
   - ☐☐☐☐ # of people
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. What is your relationship to the person who gave you the coupon? (read out list)
   - ☐ Relative
   - ☐ Girlfriend/boyfriend; partner or spouse
   - ☐ Friend
   - ☐ Acquaintance
   - ☐ Stranger
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

Introduction

The Respectful Health Assessment Survey (RHAS) for Urban First Nation people living in Hamilton Ontario is directed, operated, controlled and owned by De dwa da dehs nye >s and the Ontario Federation of Indian Friendship Centres on behalf of the First Nations people living in Hamilton.

The main objective of the RHAS is to obtain accurate, useful health data for the First Nations population living in Hamilton. This data will be used by First Nations organizations and services in Hamilton to advocate for enhanced resources and better The survey consists of two sections:

- Adult survey
- Children survey (14 and Under)

The RHAS is collected using a Computer Assisted Personal Interview system. The data is gathered by trained community survey interviewers. The RHAS was developed in partnership with Hamilton First Nation service providers and community members. The RHAS has been reviewed and approved by De dwa da dehs nye >s and the Our Health Counts Governing Committee.

SECTION 1: SOCIODEMOGRAPHICS
(INCLUDING HOUSING, SOCIOECONOMIC STATUS, AND FOOD SECURITY)

A. Demographics

1. What is your gender?
- ☐ MALE
- ☐ FEMALE
- ☐ TRANSGENDER
- ☐ OTHER

2. In what year were you born?
- ☐ DON'T KNOW
- ☐ NO RESPONSE

3. How do you self-identity?

a. Are you First Nations?
- ☐ YES
- ☐ NO [SKIP TO END]
- ☐ DON'T KNOW [SKIP TO END]
- ☐ NO RESPONSE [SKIP TO END]

b. Are you:
- ☐ Status (Registered Indian according to the Indian Act)
- ☐ Non-status
- ☐ DON'T KNOW
- ☐ NO RESPONSE

c. What is your Nation (e.g. Ojibway, Cree, Mohawk?)

.....

d. What is your reserve and or band affiliation if any?

.....

4. What language do you speak most often at home?

..... *(please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

5. What is your marital status? (*Show Card 1*).
- ☐ Married
- ☐ Separated
- ☐ Divorced, marriage annulment
- ☐ Widowed
- ☐ Cohabiting, common law
- ☐ Never married
- ☐ DON'T KNOW
- ☐ NO RESPONSE

6. Have you had any children?
- ☐ YES
- ☐ NO [SKIP TO 10]
- ☐ DON'T KNOW [SKIP TO 10]
- ☐ NO RESPONSE [SKIP TO 10]

7. How many children do you have?

..... *(please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

8. How old are your children?
- #1 ☐
- #2 ☐
- #3 ☐
- #4 ☐
- #5 ☐
- #6 ☐
- #7 ☐
- #8 ☐

OTHERS: .....

..... *(please specify all ages)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

9. How many of these children currently live in your household?
- ☐☐ # of children
- ☐ DON'T KNOW
- ☐ NO RESPONSE

10. What is the highest level of schooling you have ever completed? Please choose one from the following categories. (*Show Card 2*).

- ☐ Less than grade 9
- ☐ Some high school
- ☐ Completed high school
- ☐ Some trades or technical training (college)
- ☐ Completed trades or technical training (college)
- ☐ Some university
- ☐ Completed university
- ☐ Some post-graduate education
- ☐ DON'T KNOW
- ☐ NO RESPONSE

11. Which of the following best describes your current employment status? Please choose one from the following categories. (*Show Card 3*)

- ☐ Part-time
- ☐ Full-time
- ☐ Seasonal
- ☐ Self-employed
- ☐ Homemaker
- ☐ Any other informal paid work such as babysitting, housekeeping
- ☐ Student
- ☐ Retired
- ☐ Unemployed
- ☐ DON'T KNOW
- ☐ NO RESPONSE

12. Thinking about the total income for all household members, from which of the following sources did your household receive any income in the past 12 months? Please select all that apply. (*Show Card 4*)

- ☐ Wages and salaries
- ☐ Income from self-employment
- ☐ Employment insurance
- ☐ Worker's compensation
- ☐ Child Tax Benefit
- ☐ Provincial or municipal social assistance or welfare
- ☐ Child support
- ☐ Alimony
- ☐ Money from family on a regular basis
- ☐ Benefits from Canada or Quebec Pension Plan
- ☐ Retirement pensions, superannuation and annuities
- ☐ Old Age Security and Guaranteed Income Supplement
- ☐ Dividends and interest (e.g., on bonds, savings)
- ☐ OTHER (e.g., rental income, scholarships, Indian Affairs support for school)

..... *(please specify)*

- ☐ DON'T KNOW
- ☐ NO RESPONSE

13. Do you have any additional thoughts/comments?

.....
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.....

B. Housing and Mobility

1. Which of the following best describes the type of dwelling you live in? Please choose one from the following categories. (*Show Card 5*)

- ☐ Single house (not attached to any other dwelling)
- ☐ Semi-detached, duplex house, row house, or townhouse
- ☐ Self-contained apartment within a single detached house
- ☐ Apartment or condominium in a **low** rise building or apartment block (< 5 storeys)
- ☐ Apartment or condominium in a **high** rise building or apartment block (> 5 storeys)
- ☐ Homeless [Skip to 16]
- ☐ Transition (ie. Couch surfing, shelter, welfare residence, drug treatment centre) [Skip to 16]
- ☐ Other:

..... *(please specify)*

- ☐ DON'T KNOW [Skip to 16]
- ☐ NO RESPONSE [Skip to 16]

2. For how long have you lived in your current home?

- ☐☐ YEARS ☐☐ MONTHS
- ☐ DON'T KNOW
- ☐ NO RESPONSE

3. For how long have you lived in the city of Hamilton? *(if the participant has lived in Hamilton more than once, specify that this refers to the time since the respondent last moved to Hamilton).*

- ☐☐ YEARS ☐☐ MONTHS
- ☐ DON'T KNOW
- ☐ NO RESPONSE

4. How many times have you moved in the past 5 years?

- ☐☐ TIMES
- ☐ DON'T KNOW
- ☐ NO RESPONSE

5. Is your home: *(Show Card 6)*

- ☐ Owned without a mortgage by your household
- ☐ Owned with a mortgage by your household
- ☐ Rented by your household
- ☐ Native Housing (ie.Urban Native Homes Inc.) other social housing
- ☐ Occupied rent-free by your household where no member owns and no rent is charged
- ☐ Other

..... *(please specify)*

- ☐ DON'T KNOW
- ☐ NO RESPONSE

6. How many rooms are there in your home? (We would like to know the total number of rooms, including the kitchen, bedrooms, finished rooms in attic or basement, etc. Do not count bathrooms, hallways and rooms used solely for business purposes.)

- ☐☐ ROOMS
- ☐ DON'T KNOW
- ☐ NO RESPONSE

7. Including yourself, how many people currently live in your household?

- ☐ 1 PERSON
- ☐ 2 PEOPLE
- ☐ 3 PEOPLE
- ☐ 4 PEOPLE
- ☐ 5 PEOPLE
- ☐ 6 PEOPLE
- ☐ 7 PEOPLE
- ☐ 8 PEOPLE
- ☐ 9 PEOPLE
- ☐ 10 OR MORE PEOPLE
- ☐ DON'T KNOW
- ☐ NO RESPONSE

8. Which of the following best describes your household? Please choose one from the following categories. (*Show Card 7*)

- ☐ One adult person living alone
- ☐ One adult with children
- ☐ One adult with children and additional family (ie. parents, grandparents, sisters, brothers, aunties, uncles, cousins etc.)
- ☐ A married or common law couple with NO children
- ☐ A married or common law couple with NO children and additional family (ie. parents, grandparents, sisters, brothers, aunties, uncles, cousins etc.)
- ☐ A married or common law couple with children
- ☐ A married or common law couple with children and additional family (ie. parents, grandparents, sisters, brothers, aunties, uncles, cousins etc.)
- ☐ Two or more unrelated persons
- ☐ Other:

..... *(please specify)*

- ☐ DON'T KNOW
- ☐ NO RESPONSE

9. Is your dwelling in need of any repairs? (Not including desirable remodeling or additions) (*Show Card 8*)

- ☐ No, only regular maintenance is needed (painting, furnace cleaning, etc.)
- ☐ Yes, minor repairs are needed (missing or loose floor tiles, bricks or shingles, defective steps, railing or siding, etc.)
- ☐ Yes, major repairs are needed (defective plumbing or electrical wiring, structural repairs to walls, floors or ceilings, etc.)
- ☐ DON'T KNOW
- ☐ NO RESPONSE

10. In the last 2 years, have you had a problem in your home with mice, rats or roaches?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

11. In general, how do you rate the day-to-day comfort provided by your home's heating system? Is it: (*Show Card 9*)

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ DON'T KNOW
- ☐ NO RESPONSE

12. How concerned are you about poor air quality in your home due to things like dampness, mold, pollution, or bad air exchange/venting? Are you: (*show card 10*)

- ☐ Very concerned
- ☐ Somewhat concerned
- ☐ A little concerned
- ☐ Not concerned at all
- ☐ DON'T KNOW
- ☐ NO RESPONSE

13. How much do you spend monthly on shelter costs [including rent/mortgage, utilities, repair, upkeep]?

$ .....

- ☐ DON'T KNOW
- ☐ NO RESPONSE

14. How often do you have to give up important things (ie. buying groceries) in order to meet shelter-related [housing] costs? (read list)

- ☐ Several times a month
- ☐ Once a month
- ☐ A few times a year
- ☐ Never [Skip to 16]
- ☐ DON'T KNOW [Skip to 16]
- ☐ NO RESPONSE [Skip to 16]

15. How long has this been going on? (*show card 11*)

- ☐ Less than 1 month
- ☐ 1-3 months
- ☐ 3 months to 1 year
- ☐ 1 year to 5 years
- ☐ More than 5 years
- ☐ DON'T KNOW
- ☐ NO RESPONSE

16. It has been shown that financial hardship can have an impact on health. Do you believe that your overall health and well-being has been affected by financial hardship?

- ☐ Yes
- ☐ No [Skip to 18)
- ☐ DON'T KNOW [Skip to 18)
- ☐ No Response [Skip to 18)

17. How long has this been going on? (show card 12)

- ☐ Less than 1 month
- ☐ 1-3 months
- ☐ 3 months to 1 year
- ☐ 1 year to 5 years
- ☐ More than 5 years
- ☐ DON'T KNOW
- ☐ NO RESPONSE

18. Do you believe that your ability to engage in preventative health activities (i.e. regular exercise, going to the doctor or nurse for health screening tests, accessing preventative dental care) has been affected by financial hardship?

- ☐ Yes
- ☐ No (Skip to Next Section)
- ☐ DON'T KNOW (Skip to Next Section)
- ☐ NO RESPONSE (Skip to Next Section)

19. How long has this been going on? (show card 13)

- ☐ Less than 1 month
- ☐ 1-3 months
- ☐ 3 months to 1 year
- ☐ 1 year to 5 years
- ☐ More than 5 years
- ☐ DON'T KNOW
- ☐ NO RESPONSE

C. Nutrition, Water Quality, and Food Security

1. Do you eat a nutritious balanced diet? (*show card 14*)

- ☐ Always
- ☐ Almost always
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ DON'T KNOW
- ☐ NO RESPONSE

2. Which of the following statements best describes the food eaten in your household in the past 12 months: *(Show Card 15)*

- ☐ 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
- ☐ DON'T KNOW
- ☐ NO RESPONSE

3. **Do you have a place to go if you or your family doesn't have enough to eat? [This could be to a family member or friends place, a food bank, or any other place]**
   - ☐ YES
   - ☐ NO
   - ☐ I have never needed to go to such a place
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

4. **Does anyone in your household grow food—that is vegetables, fruit, berries, nuts, or** herbs—in your yard, on your balcony or in a community garden?
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

5. **Do you consider the tap water in your home safe for drinking year round?**
   - ☐ Yes
   - ☐ No
   - ☐ Don't have running water/tap water
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

6. **Do you have any additional thoughts/comments about the issues we have discussed so far?[open end]**

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SECTION 2: "WHAT HAPPENS WHEN WE ARE OUT OF BALANCE"

PHYSICAL, MENTAL, AND EMOTIONAL HEALTH PROBLEMS

A. General Health Status and Exercise

1. **Please rate your health. Compared to other people your age, would you say your health is: (*show card 16*)**
   - ☐ Excellent
   - ☐ Very Good
   - ☐ Good
   - ☐ Fair
   - ☐ Poor
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **How often do you feel that you are in balance in the four aspects of your life? (Physical, emotional, mental and spiritual) (*Show Card 17)***
   - ☐ All of the time
   - ☐ Most of the time
   - ☐ Some of the time
   - ☐ A little of the time
   - ☐ None of the time
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **On average, how many days per week do you do 30 minutes or more of moderate or vigorous physical activity? This activity can be part of work, transportation, or recreation, and need not be all at once, but is a total of at least 30 minutes per day. Moderate activity includes brisk walking, for example; and vigorous activity makes you work up a sweat. Based on this definition, how many days per week do you at least do 30 minutes of moderate or vigorous activity? (*show card 18*)**
   - ☐ 0 DAYS
   - ☐ 1 DAY / WEEK
   - ☐ 2 DAYS / WEEK
   - ☐ 3 DAYS / WEEK
   - ☐ 4 DAYS / WEEK
   - ☐ 5 DAYS / WEEK
   - ☐ 6 DAYS / WEEK
   - ☐ 7 DAYS / WEEK
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

B. Chronic Health Conditions

I would now like to ask you about certain chronic health conditions that you may have. We are interested in "long-term conditions" which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health care provider.

1. Have you been told by a health care provider that you have any of the follow health conditions? If Yes, Please answer follow-up questions

Read through the entire list of conditions and answer 'yes' or 'no'

List conditions that have lasted at least 6 months or are expected to last at least 6 months.
Yes = Y
No = N
DON'T KNOW = DK
No response = R

CONDITION	TOLD THAT YOU HAVE OR BEEN DIAGNOSED WITH:				IF YES:				
Asthma	N	Y	DK	R	Have you had any symptoms or attacks in the last 12 months? In the past 12 months have you taken medication for asthma (i.e. inhalers, nebulizers, pills, liquids or injections)	N N	Y Y	DK DK	R R
Arthritis	N	Y	DK	R	In the past 12 months, did you ever have pain in your joints (i.e. hips, knees, hands) that limited the amount or type of activity that you were able to do?	N	Y	DK	R
Heart disease	N	Y	DK	R					
Stroke	N	Y	DK	R					
Liver disease	N	Y	DK	R					
High Blood Pressure	N	Y	DK	R	In the past month have you taken medication for high blood pressure	N	Y	DK	R
Hepatitis B	N	Y	DK	R					
Hepatitis C	N	Y	DK	R					
Allergies	N	Y	DK	R					
Chronic bronchitis, Emphysema, or COPD (Chronic Obstructive Pulmonary Disease)	N	Y	DK	R					
Attention Deficit Disorder/ Attention Deficit-Hyperactivity Disorder (ADD/ADHD)	N	Y	DK	R					
Learning disability	N	Y	DK	R					

2. Do you have diabetes (as diagnosed by a health care provider)

- ☐ YES
- ☐ NO [SKIP TO question # 10]
- ☐ DON'T KNOW [SKIP TO question # 10]
- ☐ NO RESPONSE [SKIP TO question # 10]

3. Do you currently take insulin for your diabetes?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

4. In the last month, did you take pills to control your blood sugar?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

5. In the past 12 months, has a health care professional tested you for haemoglobin "A-one-C"? (An "A-one-C" haemoglogin test measures the average level of blood sugar over a 3 month period.)

- ☐ YES
- ☐ NO

- ☐ DON'T KNOW
- ☐ NO RESPONSE

6. In the past 12 months, has a health care professional checked your feet for any sores or irritations?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

7. In the past 12 months, has a health care professional tested your urine for protein (i.e. Microalbumin)?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

8. Have you ever had an eye exam where the pupils of your eyes were dilated? (This procedure would have made you temporarily sensitive to light.)

- ☐ YES
- ☐ NO [SKIP TO NEXT SECTION]
- ☐ DON'T KNOW [SKIP TO NEXT SECTION]
- ☐ NO RESPONSE [SKIP TO NEXT SECTION]

9. When was the last time? (*show card 19*)

- ☐ Less than one month ago
- ☐ 1 month to less than 1 year ago
- ☐ 1 year to less than 2 years ago
- ☐ 2 or more years ago
- ☐ DON'T KNOW
- ☐ NO RESPONSE

10. Did your mother consume alcohol during any part or all of her pregnancy with you?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

C. INJURY AND ACUTE ILLNESS

1. Were you injured in the past 12 months?

- ☐ YES
- ☐ NO [Skip to question 3]
- ☐ DON'T KNOW [Skip to question 3]
- ☐ NO RESPONSE [Skip to question 3]

2. For your most serious injury in the past 12 months, please indicate which of the following was the cause of this injury? *Show Card 20)*

- ☐ Fall
- ☐ Burn
- ☐ Poisoning
- ☐ Near-drowning
- ☐ Animal bite
- ☐ Road traffic crash as a passenger
- ☐ Road traffic crash as a driver
- ☐ Road traffic crash as a pedestrian
- ☐ Other

..... *(please specify)*

- ☐ DON'T KNOW
- ☐ No response

3. In the past 12 months, how many times have you had an upper respiratory tract infection (ie. cough, cold, bronchitis, ear infection, sore throat, sinus infection)? (read list)

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ More than 3
- ☐ DON'T KNOW
- ☐ NO RESPONSE

4. In the past 12 months, how many times have you had a lower respiratory tract infection (ie. pneumonia)? (read list)

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ More than 3
- ☐ DON'T KNOW
- ☐ NO RESPONSE

5. Have you received the H1N1 flu vaccine?

- ☐ YES
- ☐ NO [Skip to next section]
- ☐ DON'T KNOW
- ☐ NO RESPONSE

6. **What was the reason(s) you did not receive the vaccine? (Check all that apply) (Show card 21)**
   - ☐ I was not a member of the listed 'at risk' groups
   - ☐ I was worried about the side-effects of the vaccine
   - ☐ My health care provider (ie. doctor/nurse/clinic) did not have the vaccine or ran out of the vaccine
   - ☐ The wait to get the vaccine was too long
   - ☐ I didn't have time in my schedule to go and get the vaccine
   - ☐ I didn't have transportation to go and get the vaccine
   - ☐ I don't trust my health care provider
   - ☐ I already had the flu
   - ☐ DON'T KNOW
   - ☐ No Response
   - ☐ Other

   ..... *(please specify)*

D. Sexual and reproductive health.

For Women:

1. **Have you ever had a Pap test?** (A Pap test is a test performed by a doctor, nurse, or nurse practitioner where a sample of cells is taken from the cervix.)
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 3]
   - ☐ DON'T KNOW [SKIP TO QUESTION 3]
   - ☐ NO RESPONSE [SKIP TO QUESTION 3]

2. **When was that last time you had a Pap test?**
   - ☐ Months ago
   - ☐ Years ago
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

For Women with children:

3. **Did you breastfeed any of your children?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 6]
   - ☐ DON'T KNOW [SKIP TO QUESTION 6]
   - ☐ NO RESPONSE [SKIP TO QUESTION 6]

4. **If yes, for how many children?**
   - ☐☐ # of children
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

5. **For each child, how long did you breastfeed?**
   Child 1: ☐☐ months ☐☐ years
   Child 2: ☐☐ months ☐☐ years
   - ☐ Up to 20 Children
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

For Men and Women:

6. **Without revealing test results, have you ever been tested for HIV?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

7. **Have you ever had a sexually transmitted infection?**
   - ☐ Yes
   - ☐ No [SKIP TO NEXT SECTION]
   - ☐ DON'T KNOW
   - ☐ No Response

8. **Have you ever been diagnosed and treated for: (show card 22)**
   - ☐ Chlamydia
   - ☐ Genital herpes
   - ☐ Genital warts
   - ☐ Gonorrhea
   - ☐ Syphilis
   - ☐ Other

   ..... *(please specify)*

E. Ability

1. **Are you limited in the kinds or amount of activity you can do at home, work or otherwise because of a physical or mental condition or health problem? (read list)**
   - ☐ Yes, often
   - ☐ Yes, sometimes
   - ☐ No
   - ☐ DON'T KNOW
   - ☐ No response

2. **Do you suffer from blindness or serious vision problems that can't be corrected?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **Do you suffer from hearing impairment (i.e. need a hearing aid or have problems hearing when there is background noise)?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

F. Mental and Emotional Health

The next section asks about your personal mental and emotional health. Please remember you do not have to answer any questions you do not want to answer. The reason why we are asking these questions is that we want to ensure that there are adequate and appropriate services for First Nations in Hamilton. Anything you say will remain completely confidential.

1. **Compared to other people you know, how would you rate your mental health? (Show card 23)**
   - ☐ Excellent
   - ☐ Good
   - ☐ Fair
   - ☐ Poor
   - ☐ Unsure
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **Have you ever been told by a health care worker that you have a psychological and/or mental health disorder? (i.e. Depression, anxiety)**
   - ☐ YES
   - ☐ NO [SKIP TO 3]
   - ☐ DON'T KNOW [SKIP TO 3]
   - ☐ NO RESPONSE [SKIP TO 3]

   a. **At what age were you first told?**
      - ☐☐ Years
      - ☐ DON'T KNOW
      - ☐ NO RESPONSE

   b. **Are you currently taking medication for this condition?**
      - ☐ YES
      - ☐ NO
      - ☐ DON'T KNOW
      - ☐ NO RESPONSE

   c. **Are you currently undergoing treatment (other than medication) for this condition?**
      - ☐ YES
      - ☐ NO
      - ☐ DON'T KNOW
      - ☐ NO RESPONSE

   d. **Has this condition limited the amount or kinds of activities you can do?**
      - ☐ YES
      - ☐ NO
      - ☐ DON'T KNOW
      - ☐ NO RESPONSE

3. **Have you ever experienced discrimination because of an emotional or mental health problem?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 5]
   - ☐ DON'T KNOW [SKIP TO QUESTION 5]
   - ☐ NO RESPONSE [SKIP TO QUESTION 5]

4. **Did this prevent or delay you from getting health care for it?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

The following questions ask about how you have been feeling during the past 30 days.

5. About how often during the past 30 days did you feel [Insert A through J here]. Would you say all of the time, most of the time, some of the time, a little of the time, or none of the time?

[If A THRUOUGH J are 'None of the time', then skip to next section]

	ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME	DON'T KNOW	NO RESPONSE
A Tired out for no good reason?							
B Nervous?					Skip to D		
C So nervous that nothing could calm you down?							
D Hopeless?							
E Restless or fidgety?					Skip to G		
F So restless you cannot sit still?							
G Depressed					Skip to I		
H So depressed that nothing could cheer you up?							
I That everything is an effort?							
J Worthless?							

6. During the past 30 days, how many days out of 30 were you unable to work or carry out your normal activities because of these feelings?

- ☐ # of days
- ☐ DON'T KNOW
- ☐ NO RESPONSE

G. Post-Traumatic Stress Disorder

1. In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, in the past month, you:

a. Have had nightmares about it or thought about it when you did not want to?
- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

b. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

c. Were constantly on guard, watchful, or easily startled?
- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

d. Felt numb or detached from others, activities, or your surroundings?
- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

H. Suicide

The following section may have questions that may be upsetting. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at any time. The reason why we are asking these questions is that we want to ensure that there are adequate and appropriate services for First Nations in Hamilton.

1. **Has a close friend or family member ever committed suicide?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **Have you ever harmed yourself on purpose?** (e.g. cut yourself, burned yourself, taken poison or overdosed on medications)
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **Have you ever thought about committing suicide?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 5]
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

4. **Have you ever attempted suicide?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

5. **Do you have any additional thoughts/comments about the issues we have discussed so far?[open end]**

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SECTION 3: "RECLAIMING WHO WE ARE"

A. Now, I am going to read you several statements about your First Nations identity. After each statement, please tell me if you:

(4) Strongly agree (3) Agree (2) Disagree (1) Strongly disagree

		4	3	2	1	DN	NR
1	I have spent time trying to find out more about First Nations, such as our history, traditions, and customs.						
2	I am active in organizations or social groups that include mostly First Nations people.						
3	I have a clear sense of my cultural background as a First Nations person and what that means for me.						
4	I think a lot about how my life will be affected because I am First Nations.						
5	I am happy that I am First Nations.						
6	I have a strong sense of belonging to First Nations community.						
7	I understand pretty well what being First Nations means to me.						
8	In order to learn more about being First Nations, I have often talked to other people about First Nations.						
9	I have a lot of pride in First Nations.						
10	I participate in cultural practices, such as pow wows, Aboriginal day events, ceremonies, feasts, drumming, singing etc						
11	I feel a strong attachment towards First Nations.						
12	I feel good about my First Nations background.						

SECTION 4: "DISCONNECTION FROM WHO WE ARE"

Substance Use

The following section may have questions that may cause mild distress. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at anytime.

1. At the present time, do you smoke cigarettes? (read list)
   - ☐ Not at all
   - ☐ Daily [Go to question 3]
   - ☐ Occasionally [Go to question 3]
   - ☐ No response

2. Have you ever smoked cigarettes? (Current non-smokers only)
   - ☐ Yes, daily
   - ☐ Yes, occasionally
   - ☐ No [SKIP TO QUESTION 6]
   - ☐ DON'T KNOW
   - ☐ No response

3. **On average, how many cigarettes do you currently smoke each day?**
   Approximate if necessary
   #☐ ☐

4. **At what age did you begin smoking cigarettes? (Age in years)** ☐ ☐

5. **In the past 12 months, how many times have you tried to quit smoking? (For current smokers and ex-smokers) (Show card 24)**
   - ☐ 0 (never tried to quit)
   - ☐ 1 – 2 tries
   - ☐ 3 – 4 tries
   - ☐ 5 or more tries
   - ☐ DON'T KNOW
   - ☐ No response

6. **Do you have a smoke free home? (Show card 25)**
   - ☐ YES – COMPLETELY SMOKE FREE
   - ☐ YES – THERE ARE SMOKERS LIVING IN THE HOME, BUT THEY SMOKE OUTSIDE ONLY
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

7. **During the past 30 days, have you had a drink of beer, wine, liquor or any other alcoholic beverage?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 10]
   - ☐ DON'T KNOW [SKIP TO QUESTION 10]
   - ☐ NO RESPONSE [SKIP TO QUESTION 10]

8. **On how many days of the 30 did you drink?** ☐ ☐

9. **What was the average number of drinks per day on those days that you drank?** *One drink includes one beer, one glass of wine or one shot (ounce) of hard liquor.*
   # of drinks ☐ ☐
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

10. **During the past 12 months, how often have you had 5 or more drinks on one occasion?** One drink *includes one beer, one glass of wine or one shot (ounce) of hard liquor.* **(Show card 26)**
    - ☐ Never
    - ☐ Less than once per month
    - ☐ Once per month
    - ☐ 2-3 times per month
    - ☐ Once per week
    - ☐ More than once per week
    - ☐ Every day
    - ☐ DON'T KNOW
    - ☐ NO RESPONSE

B. Substance Use - Illicit Drugs and Prescription Drugs

The following questions are about substance abuse that includes both illicit and prescriptions drugs. The questions may not apply to you. We are asking all research participants these questions. Our intent is to use the information collected to ensure there are adequate resources and services in the community. Remember anything you say will remain completely confidential. Answering questions honestly will assist us to bring about change.

1. **Have you used any of the following substances in the last 12 months (Includes prescription drugs if they were used without a prescription or out of keeping with how they were prescribed)? For each, please select the answer that best describes your frequency of use.**

   For the substances you selected in #1, what is the drug or combination of drugs you are currently using the most? [Choose only one drug or one combination of drugs.]

ITEM	ABOUT 2-3 TIMES/ YEAR	ABOUT ONCE A MONTH	2-3 TIMES A MONTH	ABOUT 2-3 TIMES A WEEK	ABOUT ONCE A DAY	CURRENTLY USING THE MOST
Chewing tobacco	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Marijuana (weed, grass)/Hash	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
PCP/ Angel dust	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Acid/ LSD/ Amphetamines	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Ecstasy	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Inhalants (glue, gas, paint)	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Sedatives/ Downers (Valium etc.)	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Cocaine/Crack/ Freebase	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Codeine/ Morphine/ Opiates (Percodan, Tylenol 3, Fentanyl, Talwin etc.)	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Ritalin	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Combination Specify:	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE
Other	☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE					☐ YES ☐ NO ☐ DON'T KNOW ☐ NO RESPONSE

2. Have you ever used a needle to inject any illicit drug?

- ☐ YES
- ☐ NO [SKIP TO NEXT SECTION]
- ☐ DON'T KNOW [SKIP TO NEXT SECTION]
- ☐ NO RESPONSE [SKIP TO NEXT SECTION]

3. Have you ever shared needles with anyone including your spouse, partner, or close friend?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

C. Health Services

The following section asks questions about access to health services. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at anytime

1. **How would you rate the level of access to health services available to you compared to Canadians generally? (please read list)**
   - ☐ Same level of access
   - ☐ Less access
   - ☐ Better access
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **Overall, how would you rate the availability of health services in your community? (Show card 27)**
   - ☐ Excellent
   - ☐ Good
   - ☐ Fair
   - ☐ Poor
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **During the past 12 months, have you experienced any of the following barriers to receiving health care?** *Read each item and mark all that apply.*

	YES	NO	DON'T KNOW	NO RESPONSE
Doctor not available in my area				
Nurse not available				
Lack of trust in health care provider				
Waiting list too long				
Unable to arrange transportation				
Difficulty getting traditional care (e.g. healer, medicine person or elder)				
Not covered by Non-insured Health Benefits (e.g. service, medication, equipment)				
Prior approval for services under Non-Insured health benefits (NIHB) was denied				
Could not afford direct cost of care/service				
Could not afford transportation costs				
Could not afford childcare costs				
Felt health care provided was inadequate				
Felt service was not culturally appropriate				
Chose not to see health professional				
Service was not available in my area				
Other				

4. **Have you accessed emergency care for yourself in the last 12 months?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 6]
   - ☐ DON'T KNOW [SKIP TO QUESTION 6]
   - ☐ NO RESPONSE [SKIP TO QUESTION 6]

5. **How would you rate the quality of the emergency care you received at that time? Would you say it was… (show card 28)**
   - ☐ Excellent
   - ☐ Good
   - ☐ Fair
   - ☐ Poor
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

6. In the past 12 months, have you seen or talked on the telephone about an emotional or mental health issue or problem to any of the following: Answer 'yes' or 'no' for each person/professional. **(Show card 29)**

YES	NO	
☐	☐	Immediate family member
☐	☐	Other family member
☐	☐	Friend
☐	☐	Traditional healer
☐	☐	Family doctor
☐	☐	Psychiatrist
☐	☐	CHR (community health representative)
☐	☐	Nurse
☐	☐	Counselor
☐	☐	Psychologist
☐	☐	Social worker
☐	☐	Crisis line worker
☐	☐	DON'T KNOW
☐	☐	NO RESPONSE

7. Have you spent one night or more as a patient in a hospital at any time in the past 5 years?

- ☐ Yes
- ☐ No [SKIP TO QUESTION 9]
- ☐ DON'T KNOW [SKIP TO QUESTION 9]
- ☐ NO RESPONSE [SKIP TO QUESTION 9]

8. Thinking of your most recent hospital stay, how would you rate the quality of the hospital care you received at that time? Would you say it was … (Show card 30)

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ DON'T KNOW
- ☐ NO RESPONSE

9. Have you ever been treated unfairly (e.g. treated differently, kept waiting) by a health professional (e.g. doctor, nurse, dentist, etc.) because you are First Nations?

- ☐ YES
- ☐ NO [SKIP TO 12]
- ☐ DON'T KNOW [SKIP TO 12]
- ☐ NO RESPONSE [SKIP TO 12]

10. How long ago did this happen? (show card 31)

- ☐ Within the past 3 months
- ☐ Within the past 6 months
- ☐ Within the past 12 months
- ☐ Longer than a year ago
- ☐ DON'T KNOW
- ☐ NO RESPONSE

11. Has this stopped or delayed you from returning to a health service?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

12. In the past 12 months have you participated in any of the following programs: (check all that apply)

Hamilton Regional Indian Centre

- ☐ Employment Services
- ☐ Alternative Education (SHAY)
- ☐ Court Worker
- ☐ Alcohol Worker
- ☐ Lifelong care program
- ☐ Arts, Dance and Craft courses
- ☐ Food and Clothing bank
- ☐ Other program
  ..... *(Please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

De dwa da dehs ney>s Aboriginal Health Centre

- ☐ Primary Health Care (physician, nurse practitioner and/or traditional healer)
- ☐ Advocacy Services (for issues with income, health care, education, housing)
- ☐ Complementary Services (naturopath, needle exchange)
- ☐ Mental Health (Counseling and addictions)
- ☐ raditional Health program (women's/men's circles, drumming, teaching, healers, grief recovery program)
- ☐ Outreach (transportation services)
- ☐ Other program
  ..... *(Please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

Native Women's Centre

- ☐ Community Counselling
- ☐ Woman Abuse Education Program
- ☐ Transitional Housing and Supports
- ☐ Emergency Outreach (food and clothing)
- ☐ Aboriginal Healing and Outreach Program (AHOP)
- ☐ Other program
  ..... *(Please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

Southern Ontario Aboriginal Diabetes Imitative

- ☐ Foot care program
- ☐ Diabetes Prevention program
- ☐ Other program
  ..... *(Please specify)*
- ☐ DON'T KNOW
- ☐ NO RESPONSE

D. Access to Traditional Medicine

1. **Do you use traditional medicine?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 3]
   - ☐ DON'T KNOW [SKIP TO QUESTION 3]
   - ☐ NO RESPONSE [SKIP TO QUESTION 3]

2. **Have you had any of the following difficulties accessing traditional medicines?** Read list. Mark all that apply. **Show Card 32**
   - ☐ No Difficulties
   - ☐ Do not know where to get them
   - ☐ Can't afford it
   - ☐ Too far to travel
   - ☐ Concerned about effects
   - ☐ Do not know enough about them
   - ☐ Not available through health centre
   - ☐ Not covered by non-insured health benefits (Health Canada)
   - ☐ Other program
     ..... *(Please specify)*
   - ☐ DON'T KNOW
   - ☐ No response

3. **Have you had any difficulty accessing any of the health services provided through the Non-Insured Health Benefits Program (NIHB) provided to status First Nations and Inuit persons through Health Canada.**
   Read all options and check all that apply. Note: "Other Medical Supplies" includes: wheelchair, magnifying aid, walker, crutches, cane, artificial limb, modified kitchen utensils, modified clothing or shoe, special cushions. ***Show Card 33***
   - ☐ No Difficulties
   - ☐ Medication
   - ☐ Dental Care
   - ☐ Vision Care (glasses)
   - ☐ Hearing aid
   - ☐ Other Medical Supplies
   - ☐ Transportation services or costs (air or road)
   - ☐ Other
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

SECTION 5: "IMPACTS OF COLONIZATION"

The following section may have questions that may cause mild distress. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at anytime.

A. Residential School

1. **Were you ever a student at a federal residential school, or a federal industrial school?** (federal industrial schools were schools for young men that mostly operated in the prairie provinces and the United States)
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 3]
   - ☐ DON'T KNOW [SKIP TO QUESTION 3]
   - ☐ NO RESPONSE [SKIP TO QUESTION 3]

2. **Do you believe that your overall health and well-being has been affected by your attendance at residential school?** ***Show Card 34***
   - ☐ YES, negatively impacted
   - ☐ YES, positively impacted
   - ☐ NO impact
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **Were any of the following members of your family ever a student at a federal** residential school or a federal industrial school? Select all that apply. ***Show Card 35***
   - ☐ Your grandmothers
   - ☐ Your grandfathers
   - ☐ Your mother
   - ☐ Your father
   - ☐ Your current spouse or partner
   - ☐ Your brothers or sisters
   - ☐ Your aunts or uncles
   - ☐ Your cousins
   - ☐ Other relatives
   - ☐ NO [SKIP TO NEXT SECTION]
   - ☐ DON'T KNOW [SKIP TO NEXT SECTION]
   - ☐ NO RESPONSE [SKIP TO NEXT SECTION]

4. **Do you believe that your overall health and well-being has been affected by a member of your family attending residential school?** ***Show Card 36***
   - ☐ YES, negatively impacted
   - ☐ YES, positively impacted
   - ☐ NO impact
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

B. Child Protection agency involvement

1. **Was a child protection agency (i.e. Children's Aid Society, Catholic Family Services) ever involved in your care when you were a child?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **Has a child protection agency (ie. Children's Aid Society, Catholic Family Services) ever been involved in the care of one of your children?**
   - ☐ YES
   - ☐ NO [Skip to next section if No to 1 & 2]
   - ☐ DON'T KNOW [Skip to next section]
   - ☐ NO RESPONSE [Skip to next section]

3. **Do you believe that your overall health and wellbeing has been affected by the involvement of child protection agencies in your family?** ***Show Card 37***
   - ☐ YES, negative impact
   - ☐ YES, positive impact
   - ☐ NO impact
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

C. Dislocation from Traditional Lands

1. **Does your home community have one or more land claims?**
   - ☐ Yes
   - ☐ No [SKIP TO 3]
   - ☐ DON'T KNOW
   - ☐ No response

2. **What is the current status of your home community's land claim(s)?**
   - ☐ Settled
   - ☐ Unsettled (i.e. in negotiation, awaiting decision)
   - ☐ DON'T KNOW
   - ☐ No response

3. **Do you believe that your overall health and wellbeing has been affected by dislocation from your traditional lands?** ***Show Card 38***
   - ☐ YES, negative impact
   - ☐ YES, positive impact
   - ☐ NO impact
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

D. Discrimination

1. **Have you ever been treated unfairly because you are First Nations?**
   - ☐ YES
   - ☐ NO [SKIP TO 4]
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

2. **How long ago was your last experience of this type of unfair treatment? (Show card 39)**
   - ☐ Within the past 3 months
   - ☐ Within the past 6 months
   - ☐ Within the past 12 months
   - ☐ Longer than a year ago
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

3. **Has that experience negatively affected your self-esteem?** ***Show Card 40***
   - ☐ No effect
   - ☐ Little effect
   - ☐ Some effect
   - ☐ Strong effect
   - ☐ Very strong effect
   - ☐ DON'T KNOW
   - ☐ No response

4. **Have you ever been the victim of an ethnically or racially motivated attack (verbal or physical abuse to person or property)?** Response options: **(show card 41)**
   - ☐ Yes, verbal – within the past 12 months
   - ☐ Yes, verbal – more than 12 months ago
   - ☐ Yes, physical – within the past 12 months
   - ☐ Yes, physical – more than 12 months ago
   - ☐ No
   - ☐ DON'T KNOW
   - ☐ Refuse

5. **Do you believe that your overall health and wellbeing have been affected by racism?**
   - ☐ YES
   - ☐ NO [SKIP TO QUESTION 7]
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

6. **If so, how? Can you share an example with me?** [OPEN ENDED?]

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   .....
   .....
   .....
   .....
   .....

7. **Have you ever been treated unfairly because of your gender?**
   - ☐ YES
   - ☐ NO
   - ☐ DON'T KNOW
   - ☐ NO RESPONSE

8. **Do you have any additional thoughts/comments about the issues we have discussed so far?[open end]**

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   .....

E. Violence and Abuse

The next section asks you about experiences about family violence. You may encounter questions that you cause mild distress. Please remember that you do not have to answer any questions you do not want to answer and you can take a break at anytime. Again we would like to remind you that anything you say will remain completely confidential.

1. **Do any types of violence occur in your community?**
   - ☐ Yes
   - ☐ No [SKIP TO QUESTION 4]
   - ☐ DON'T KNOW [SKIP TO QUESTION 4]
   - ☐ NO RESPONSE [SKIP TO QUESTION 4]

2. **What kinds of violence occur in your community (check all that occur)?**

	YES	NO	DON'T KNOW	NO RESPONSE
Family Violence	If YES, proceed to questions 3 to 5.			
Violence related to crime and criminal behaviour in the community				
Violence related to racism/discrimination				
Lateral violence (violence directed laterally from one community member to another as a result of rage, anger and frustration from being constantly put down).				

3. What kinds of family violence occur in your community?

	YES	NO	DON'T KNOW	NO RESPONSE
Mental/emotional				
Physical				
Sexual				

4. Sometimes abuse includes neglect. Are there people in your community who are neglected?

- ☐ Yes
- ☐ No [SKIP TO QUESTION 6
- ☐ DON'T KNOW [SKIP TO QUESTION 6]
- ☐ NO RESPONSE [SKIP TO QUESTION 6]

5. Who are the people who are neglected?

	YES	NO	DON'T KNOW	NO RESPONSE
Husband/Male partner				
Wife/Female Partner				
Children				
Elders				
Wife/Female partner and children				
Husband/Male Partner and children				
Elders and children				
Other Relatives				
Others				

6. Can you list some of the impacts of violence and/or neglect in your community?

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7. Overall, how would you rate the impact of violence and/or neglect in your community? (show card 42)

- ☐ EXTREMELY HIGH IMPACT
- ☐ HIGH IMPACT
- ☐ MODERATE IMPACT
- ☐ LITTLE IMPACT
- ☐ NO IMPACT
- ☐ DON'T KNOW
- ☐ NO RESPONSE

The following questions ask you about stress and even conflict you may have experienced in your household. It is important to remember that this is not a test, so there are no right or wrong answers. Please remember that all your answers will remain completely confidential and that you do not have to answer any question you do not want to answer.

8. We are wondering if you can share experiences about conflict in your household. We think it is of concern in the community. Do you feel comfortable sharing your experiences today?

- ☐ YES
- ☐ NO [skip to end of section]
- ☐ DON'T KNOW [skip to end of section]
- ☐ NO RESPONSE [skip to end of section]

Answer each item as carefully and as accurately as you can. Please remember that all of your answers are strictly confidential. If you require assistance in dealing with the following issues, we can provide you with a list of appropriate resources and emergency contacts in your neighbourhood.

9. Has anyone in your household…..

	YES	NO	DON'T KNOW	NO RESPONSE	IF YES	YES	NO	DON'T KNOW	NO RESPONSE
Physically hurt you?					Has this				
Insulted or talked down to you?					happened				
Threatened you with harm?					in the				
Screamed or cursed at you?					last year?				
Restricted your actions?									
Had sex when they didn't feel like it?									

10. Is there anything you would like add about personal violence in your house hold? [open ended]

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11. What kinds of support are needed in your community to address personal violence?[open ended]

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12. Are you interested in seeking personal violence services if they are available in your community? [open ended]

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SECTION 6: "LACK OF GOVERNMENT RESPONSIBILITY"

A. Lack of Government responsibilty

1. What are the main challenges your community is currently facing (check all that apply)? *Show Card 43*

- ☐ Education and training opportunities
- ☐ Housing
- ☐ Culture
- ☐ Poverty
- ☐ Control over decisions
- ☐ Natural environment
- ☐ Recognition of treaty rights off-reserve
- ☐ Funding
- ☐ Health
- ☐ Crime
- ☐ Employment/number of jobs
- ☐ Legal problems including incarceration
- ☐ Family breakdown including apprehension of children
- ☐ Alcohol and drug abuse
- ☐ Shortage of community health and/or social service workers
- ☐ Disregard for First Nations needs
- ☐ Other program .....
- ☐ DON'T KNOW
- ☐ NO RESPONSE

2. What are the main strengths of your community? (Show card 44)

- ☐ Family values
- ☐ Awareness of First Nations culture
- ☐ Social connections (community working together)
- ☐ Community/health programs
- ☐ Traditional ceremonial activities (e.g powwow)
- ☐ Low rates of suicide/crime/drug abuse
- ☐ Good leisure/recreation facilities
- ☐ Elders
- ☐ Use of First Nation language
- ☐ Education and training opportunities
- ☐ Natural environment
- ☐ Strong economy
- ☐ Strong leadership
- ☐ Other: .....
- ☐ DON'T KNOW
- ☐ NO RESPONSE

B. Community Services

1. Do you think there are adequate community resources available for:

Please answer yes or no for each of the following

YES	NO	DK	NR	
☐	☐	☐	☐	Family violence
☐	☐	☐	☐	HIV prevention
☐	☐	☐	☐	Pregnant women
☐	☐	☐	☐	Legal services
☐	☐	☐	☐	The LGBTTQQI community (Lesbian, Gay, Bisexual, Transgender, Two-Spirited, Queer and questioning
☐	☐	☐	☐	Youth
☐	☐	☐	☐	Single men
☐	☐	☐	☐	Suicide prevention
☐	☐	☐	☐	Pandemics such as H1N1 (swine flu)

2. Can you list areas for which community resources/ services are particularly lacking?:

.....
.....

We are almost finished the survey and you are doing really well. There are only a few questions left.

C. INCOME AND POVERTY

1. **For the year ending December 31, 2008, please think of your total personal income, before deductions, from all sources. Please look at these categories and tell me which range it falls into (Show Card 45)**

Check only one category

- ☐ No personal income
- ☐ $1 to $4,999
- ☐ $5,000 to $9,999
- ☐ $10,000 to $ 14,999
- ☐ $15,000 to $19,999
- ☐ $20,000 to $24,999
- ☐ $25,000 to $29,999
- ☐ $30,000 to $39,999
- ☐ $40,000 to $49,999
- ☐ $50,000 to $59,999
- ☐ $60,000 to $69,999
- ☐ $70,000 to $79,999
- ☐ $80,000 and over
- ☐ DON'T KNOW ➔**1a**
- ☐ NO RESPONSE

IF YOU DON'T KNOW OR YOU ARE UNSURE...	YES	NO	DK	NR
1 a …would it amount to $30,000 or more?	➔1b	➔1e		
1 b If YES, would it amount to $50,000 or more?	➔1c	➔1d		
1 c If YES, would it amount $80,000 or more?	➔check box for #1 and proceed to next section	➔ check box for #1 and proceed to next section		
1 d If NO, would it amount to $40,000 or more?	➔ check box for #1 and proceed to next section	➔1e		
1 e If NO, would it amount to $15,000 or more?	➔1f	➔1g		
1 f If YES, would it amount to $20,000 or more?	➔ check box for #1 and proceed to next section	➔1g		
1 g If NO, would it amount to $10,000 or more?	➔ check box for #1 and proceed to next section	➔ check box for #1 and proceed to next section		

D. HEIGHT AND WEIGHT

Finally, with your permission, we would like to measure your height and weight. Will be using this information to measure your Body Mass Index (BMI). The BMI is a measure of body fat based on a formula that calculates the ratio of your height and weight. Your BMI is an indicator of your appropriate weight for your height and is a more reliable indicator of body fat than just weight alone.

If your BMI is above the normal range then you are at greater risk for developing type 2 diabetes. If you already have diabetes, losing weight and trying to keep your weight as near to normal as possible can help you manage the disease more effectively.

To make you feel more comfortable, there is a scale in the private area where you can weigh yourself and then write the number down on a piece of paper.

1. **How tall are you without your shoes on?**

☐☐☐ CENTIMETRES

OR

☐☐☐ FEET ☐☐ INCHES

☐ DON'T KNOW

☐ NO RESPONSE

2. **How much do you weigh?** *[IF RESPONDENT IS PREGNANT, ASK HER WHAT WAS HER PRE-PREGNANCY WEIGHT?]*

☐☐☐ KILOGRAMS

OR

☐☐☐ LBS.

☐ DON'T KNOW

☐ NO RESPONSE

Participant Education Section (adult survey)

Survey will now educate the participant to recruit here.

Coupons given:

Coupon # .....
Coupon # .....
Coupon # .....
Honorarium Provide **Yes** ☐
Amount given .....

INTERVIEWER IMPRESSION ITEMS
(To be completed by the interviewer after completion of the survey adult survey complete)

1. **Please rate the participant's orientation to the interview on a scale of 1 to 5,where 1 is very poor and 5 is very good on the following items:**
   Interest .....
   Cooperation .....
   Ability to understand .....
   Ability to recall .....
   Ability to formulate/articulate a response .....
   Sincerity/truthfulness .....

2. **Did the participant show any signs of difficulty in reading the response cards?**
   ☐ No
   ☐ Some
   ☐ A lot

3. **How confident are you in the overall validity of the information collected in this interview?**
   ☐ Completely Confident
   ☐ Some Doubts
   ☐ No Confidence

4. **Other Comments:**
   .....
   .....
   .....
   .....
   .....
   .....

OUR HEALTH COUNTS: CHILDREN'S RESPECTFUL HEALTH SURVEY

"IMPORTANCE OF GIFTS OF OUR CHILDREN AND YOUTH"

NB: Survey should be administered to adults who have current custody of the child for whom the survey is being completed

Section A: Personal

1. **What is the name of the child?**
   If no answer, write in 'the child'. (This information is used for the CAPI version and is deleted before the survey is saved.)
   .....

2. **What is your relationship to the child? (Choose one)** ***[Read List]***
   - ☐ Birth parent
   - ☐ Grandparent
   - ☐ Step parent (including common-law step parent)
   - ☐ Sister or brother
   - ☐ Adoptive parent
   - ☐ Foster parent
   - ☐ Other program

   ..... *(Please specify)*

3. **What is the child's date of birth?**
   Child # 1
   Day ..... Month ..... Year .....
   Child # 2
   Day ..... Month ..... Year .....
   Child # 3
   Day ..... Month ..... Year .....
   Child # 4
   Day ..... Month ..... Year .....
   Child # 5
   Day ..... Month ..... Year .....

4. **Is your child male or female?** [***Read List***]
   Child # 1
   - ☐ Male
   - ☐ Female

   Child's OHIP Number
   .....

Section B: Language

6. **Which language(s) does the child use in his or her day-to-day life? (please choose only one)** [***Read List***]
   - ☐ English
   - ☐ French
   - ☐ First Nations Language
   - ☐ Other .....

7. **Can the child understand or speak a First Nations language?** [***Read List***]
   - ☐ Yes
   - ☐ No [Skip to 10]
   - ☐ DON'T KNOW [Skip to 10]
   - ☐ No Response [Skip to 10]

8. **Please list all First Nations Languages spoken:**
   .....
   .....
   .....
   .....

9. **How well can the child understand and speak the language?** [***Read Definitions***]
   A few words: understand or can speak a few words (hello, goodbye, etc)
   Basic: understand basic phrases, ask simple questions ('where am I?'), and write basic sentences
   Intermediate: understand main idea of everyday speech (TV, radio), engaged in conversations, write paragraphs/text
   Fluent: no difficulty understanding spoken word, carrying on complex conversations, write complex reports/letters/etc.

FIRST NATION LANGUAGE	UNDERSTAND					SPEAKING				
	FLUENT	INTERMEDIATE	BASIC	A FEW WORDS	N/A	FLUENT	INTERMEDIATE	BASIC	A FEW WORDS	N/A

10. How important is it for the child to learn a First Nations language? ***[Read List]***

- ☐ Very important
- ☐ Somewhat important
- ☐ Not very important
- ☐ Not important
- ☐ DON'T KNOW
- ☐ No Response

11. How important are traditional cultural events in the child's life? ***[Read List]***
(Cultural events vary, but may include powwows, sweat lodges, and community feasts)

- ☐ Very important
- ☐ Somewhat important
- ☐ Not very important
- ☐ Not important
- ☐ DON'T KNOW
- ☐ No Response

12. Who helps the child understand their culture? ***[Read List]***
(Check all that apply)

- ☐ Grandparents
- ☐ Parents (mother and/or father)
- ☐ Aunts and uncles
- ☐ Other relatives (siblings, cousins, etc.)
- ☐ Friends
- ☐ School teachers
- ☐ Community Elders
- ☐ Other community members
- ☐ No one
- ☐ DON'T KNOW
- ☐ No Response
- ☐ Other program

..... *(Please specify)*

Section C: Education

13. Has the child ever attended an Aboriginal Head Start Program? ***[Read List]***

- ☐ Yes
- ☐ No
- ☐ DON'T KNOW
- ☐ No Response

Section D: General Health

14. Does the child live in a smoke-free home? [***Read List***]

- ☐ Yes, completely smoke free
- ☐ Yes, smoke outside
- ☐ No
- ☐ DON'T KNOW
- ☐ No Response

15. In general, would you say that the child's health is: [***Read List***]

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ DON'T KNOW
- ☐ No Response

Section E: Health Conditions

16. Have you been told by a health care professional that the child has any of the follow health conditions?

If yes, what age was the diagnosis given?

If Yes, are you currently undergoing treatment(s) or taking medication(s) for these conditions?

Read through the entire list of conditions and answer 'yes' or 'no'
List conditions that have lasted at least 6 months or are expected to last at least 6 months.

Yes = Y
No = N
DON'T KNOW = DK
No Response = R

CONDITION	16. TOLD THAT YOU HAVE:				17. AGE WHEN DIAGNOSED	18. IF YES, UNDER-GOING TREATMENT			
Allergies	Y	N	DK	R		Y	N	DK	R
Anemia	Y	N	DK	R		Y	N	DK	R
Anxiety/Depression	Y	N	DK	R		Y	N	DK	R
Asthma	Y	N	DK	R		Y	N	DK	R
Attention Deficit Disorder/ Attention Deficit-Hyperactivity Disorder	Y	N	DK	R		Y	N	DK	R
Autism	Y	N	DK	R		Y	N	DK	R
Blindness or serious vision problems	Y	N	DK	R		Y	N	DK	R
Cancer	Y	N	DK	NR		Y	N	DK	NR
Chronic Bronchitis	Y	N	DK	NR		Y	N	DK	NR
Cognitive or Mental Disability	Y	N	DK	NR		Y	N	DK	NR
Dermatisit, atopic ecxema	Y	N	DK	NR		Y	N	DK	NR
Diabetes	Y	N	DK	NR		Y	N	DK	NR
Fetal Alcohol Disorder (FASD, FASE, FAS)	Y	N	DK	NR		Y	N	DK	NR
Hearing impairment	Y	N	DK	NR		Y	N	DK	NR
Heart Condition	Y	N	DK	NR		Y	N	DK	NR
Hepatitis (If yes what type: Type A Type B Type C DK	Y	N	DK	NR		Y	N	DK	NR
Kidney Disease	Y	N	DK	NR		Y	N	DK	NR
Learning Disability	Y	N	DK	NR		Y	N	DK	NR
Speech/Language difficulties	Y	N	DK	NR		Y	N	DK	NR
Physical Disability (other than visual and/or hearing impairment)	Y	N	DK	NR		Y	N	DK	NR
Tuberculosis (if yes is it Active Inactive DK)	Y	N	DK	NR		Y	N	DK	NR

17. Since Birth, has the child ever had an ear infection? [*Read List*]

- ☐ Yes
- ☐ No [SKIP TO 20]
- ☐ DON'T KNOW [SKIP TO 20]
- ☐ No Response

18. How many ear infections has the child had in the past 12 months?

.....

19. Have you been told by a health care professional that the child has chronic ear infections or ear problems? (Chronic ear infections happen frequently and/or last a long time) [*Read List*]

- ☐ Yes
- ☐ No
- ☐ DON'T KNOW
- ☐ No Response

20. Does the child take the following medications? (check all that apply) *[Read List]*

	Y	N	DK	NR
Asthma Drugs (inhalers, puffers, ventolin)				
Antibiotics				
Antihistamines				
Ritalin (or other ADD meds)				
Vitamins				
Traditional Medicines				

Section F: Injury

21. Has the child required medical attention for a serious injury in the last 12 months? [*Read List*]

- ☐ Yes
- ☐ No (If no go to section G).
- ☐ DON'T KNOW
- ☐ No Response

22. What type of injury(ies) did the child have? For example, was it a burn, a broken bone, etc. (Please select all that apply) [*Read List*]

- ☐ Broken or fractured bones
- ☐ Poisoning
- ☐ Burns or scalds
- ☐ Injury to internal organ
- ☐ Dislocation
- ☐ Dental injury
- ☐ Major sprain or strain
- ☐ Hypothermia, frost bite
- ☐ Minor cuts, scrapes or bruises
- ☐ Repetitive strain
- ☐ Concussion
- ☐ Other program

..... *(Please specify)*

- ☐ DON'T KNOW
- ☐ No Response

Section G: Access

23. Has your child seen a family doctor, general practitioner or pediatrician in the past 12 months? [*Read List*]

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

24. Has your child seen a dentist, dental therapist, or orthodontist in the past 12 months? [*Read List*]

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

25. During the past 12 months, have you experienced any of the following barriers to receiving health care for the child? (please answer for each question) *[Read List]*

Note: NIHB or non-insured health benefits is the Health Canada program that provides support to help cover health care costs – medications, dental care, vision care, medical supplies/equipment, etc.

A. ACCESS BARRIER	Y	N	DK	NR
B Doctor not available				
C Nurse not available				
D Waiting List is too long				
E Unable to arrange transportation				
F Difficulty in getting traditional care (e.g. healer Medicine person, or Elder)				
G Not covered by non-insured Health Benefits(NIHB)				
H Prior approval of non-insured Health Benefits was denied				
I Could not afford direct cost of care/services				
J Could not afford transportation costs				
K Could not afford childcare costs				
L Felt health provider was inadequate				
M Chose not to see health care professional				
N Service was not available in my area				

26. Has your child participated in any of the following programs: (check all that apply)

- ☐ Niwasa Aboriginal Head Start Program
- ☐ Ontario Early Years Centre
- ☐ Aboriginal Healthy Babies, Healthy Children Program
  - ☐ at Hamilton Regional Indian Centre
  - ☐ at Ontario Native Women's Association

- ☐ Hamilton Regional Indian Centre's Canada Action Program for Children Program
- ☐ Hamilton Regional Indian Centre's AKWE:GO program
- ☐ Niwasa Toy Lending and Resource Program
- ☐ Aboriginal FASD and Child Nutrition Initiative
- ☐ Other program

..... *(Please specify)*

27. Has your child been referred by their family doctor, general practitioner or program worker to see a specialist in the past 12 months?

- ☐ YES
- ☐ NO [Skip to next section]
- ☐ DON'T KNOW
- ☐ NO RESPONSE

28. Did your child attend this specialist appointment?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW
- ☐ NO RESPONSE

29. Did you encounter any of the following barriers in getting your child to this specialist appointment?

	Y	N	DK	NR
Transportation not available Trouble getting through to the specialist office to make the appointment				
Trouble getting messages from the referring doctor and/or specialist doctor regarding the appointment time				
Trouble finding time in my schedule to attend the specialist appointment				
Trouble finding the specialist's office				
Referral letter didn't get to the specialist				
Could not afford transportation				
Could not afford childcare				
Felt specialist was inadequate				
Chose not to see specialist				
Other (please specify)				

Section H: Child Immunizations

1. Has the child received his/her routine (regular) vaccinations/immunizations? [*Read List*]

- ☐ Yes
- ☐ No
- ☐ DON'T KNOW
- ☐ No Response

Section I: Child development

1. Have you ever had a concern about the progress of your child's physical, mental, emotional, spiritual and/or social development? [*Read List*]

- ☐ Yes
- ☐ No (FINISH CHILD SURVEY)
- ☐ DON'T KNOW
- ☐ No Response

2. What areas of development were you concerned about? (check all that apply) [*Read List*]

- ☐ Physical
- ☐ Mental/Intellectual
- ☐ Speech/Language
- ☐ Emotional
- ☐ Social
- ☐ Other program

..... *(Please specify)*

- ☐ DON'T KNOW
- ☐ No Response

3. Did you access any of the following supports? (check all that apply) [*Read List*]

- ☐ Family member
- ☐ Doctor
- ☐ Nurse
- ☐ Traditional healer
- ☐ Psychologist
- ☐ Physiotherapist
- ☐ Occupational therapist
- ☐ Speech Language therapist
- ☐ Teacher
- ☐ Head Start Program Staff
- ☐ Healthy babies, health children program staff
- ☐ Ontario Early Years Centre program staff
- ☐ CAP-C program staff
- ☐ Other program staff

..... *(Please specify)*

- ☐ Other program

..... *(Please specify)*

- ☐ DON'T KNOW
- ☐ No Response

4. Did you encounter any of the following barriers? *Remember, that we are talking about barriers you might have encountered when seeking support for any developmental concerns you may have had about your child.* **(check all that apply) [*Read List*]**

A. ACCESS BARRIER	Y	N	DK	NR
B Health provider not available				
C Waiting List is too long				
D Unable to arrange transportation				
E Difficulty in getting traditional care (e.g. healer, Medicine person, or Elder)				
F Assessment (ie. developmental standards/scales) were culturally inappropriate				
G Service was otherwise culturally inappropriate				
H Not covered by non-insured Health Benefits (NIHB)				
I Prior approval of non-insured Health Benefits was denied				
J Could not afford direct cost of care/services				
K Could not afford transportation costs				
L Could not afford childcare costs				
M Felt health care provided was inadequate				
N Chose not to see health care professional				
O Service was not available in my area				

5. Is there anything else about your child's health that you feel is important and would like to mention? [open ended]

.....
.....
.....
.....
.....
.....

Participant Education Section (Children Survey)

Survey will now educate the participant to recruit here.

Coupons given:

Coupon # .....
Coupon # .....
Coupon # .....
Honorarium Provide **Yes** ☐
Amount given .....

INTERVIEWER IMPRESSION ITEMS
(To be completed by the interviewer after completion of the survey child survey complete)

1. Please rate the participant's orientation to the interview on a scale of 1 to 5,where 1 is very poor and 5 is very good on the following items:

Interest .....
Cooperation .....
Ability to understand .....
Ability to recall .....
Ability to formulate/articulate a response .....
Sincerity/truthfulness .....

2. Did the participant show any signs of difficulty in reading the response cards?

☐ No
☐ Some
☐ A lot

3. How confident are you in the overall validity of the information collected in this interview?

☐ Completely Confident
☐ Some Doubts
☐ No Confidence

4. Other Comments:

.....
.....
.....
.....
.....
.....

APPENDIX D

CONCEPT MAPPING STATEMENTS

- Access to mental health services, including psychiatrists and mental health assessments
- Suffering from multiple chronic diseases at the same time
- Stress
- Concurrent disorders (i.e. suffering from both a mental health and addiction issue)
- Obesity
- High incidence of HIV and AIDS
- Mental illness (including depression and schizophrenia)
- High Blood Pressure
- Cancer
- Heart Disease and Stroke
- Hepatitis C
- Diabetes
- Environmental allergies
- Arthritis
- Fetal Alcohol Spectrum Disorder/Fetal Alcohol Syndrome/Fetal Alcohol Effects
- Discrimination against and stereotyping of First Nations people who are in need of health care
- Negative impacts on clients of short term program funding (i.e. needed programs disappear, poor continuity of service providers, resultant discouraging of program attendance)
- Education as a determinant of health
- Need for holistic definitions and approaches to health
- Need for increased awareness of alternate ways of receiving care (i.e. naturopath, traditional healing)
- Enhanced funding for health promotion workers to upgrade their skills
- Need for training and education at hospitals regarding First Nations communication and culture
- The need to enhance evaluation of services and programs
- Community level suicide prevention and intervention with clients, health workers, and caregivers
- Need for increased services and employment opportunities for people with illness and/or disabilities
- Inadequate resources for and inclusion of two-spirited/lesbian/gay/bisexual/transgendered/transexual/queer/questioning community
- Inadequate coverage of medication and health services by non-insured health benefits/Indian Affairs
- Shortage of doctors and nurses
- Need to increase funding for health professionals and equipment in Aboriginal Health Centre
- Health funding systems that marginalize Aboriginal health needs (ie. Local health integration networks)
- Lack of trust by First Nations individuals in their health care providers
- Waiting time for ambulance and emergency department services
- Waiting times for medical tests and operations
- Shortage of HIV/AIDS workers
- Lack of direct response for First Nations health workers who are seeking assistance for their clients
- Lack of transportation to and from health services and programs
- Youth health (13-18 years)
- Child health (6-12 years)
- Child health (2-5 years)
- Infant Health (0-1 years)
- Access to information regarding nutrition and food additives
- Pre-prenatal, prenatal and postnatal health promotion
- Inappropriate family assessment tools and culturally incompetent lawyers and judges leading to the high

incidence of apprehension of First Nations children by child protection services
- Disruption and loss of positive First Nations identity
- Disproportionate number of children under the care of and/or apprehended by child protection agencies and the impact of this on family and community
- Low self-esteem
- Lack of understanding of First Nations culture by mainstream
- Development of identity and self-awareness
- Disconnection from family and community and its impacts on mental and physical health
- Dealing with social isolation in urban areas
- Need to understand our children as gifts from the creator that we need to take care of
- Need to improve the ability of individuals to engage in stable relationships
- Need to move away from a victim mentality towards self-efficacy
- Impacts of dislocation from traditional lands and unresolved land claims, including overcrowding, inadequate housing and spiritual impacts
- Need for recognition by persons living on-reserve that persons living off- reserve are still part of the community
- The failure of government to recognize First Nations and to accept fiduciary responsibilities/inherent rights
- The need for enhanced ability of First Nations individuals to self-advocate
- Need for recognition of the cultural differences between First Nations
- Mobility of First Nations and the challenges this creates for tracking
- Spiritual awareness/spiritual health
- Lack of recognition of First Nations community knowledge and experience (i.e. Too much emphasis instead on non-Aboriginal academic systems)
- Access to traditional spirituality and culture
- Community impacts of community workers and board members in need of personal growth
- Lack of funding for traditional art, drawing and language
- The need to return to traditional culture and lifestyles (i.e. traditional roles, ceremonies, parenting skills)
- The need to care for land/environment in order to have human health
- Work overload for community service workers
- Need for government to understand First Nations culture in order to appropriately allocate funds and programs
- Enhanced funding and training for holistic and spiritual healing
- The need for enhanced services and supports for youth
- The importance of kinship systems/extended family to health
- The need for urban specific pandemic preparedness that builds on traditional First Nations worldviews
- Impact of domestic violence on individuals, families, and communities
- Intergenerational trauma, including the impact of residential schools
- Lateral violence (i.e. Violence between peers in First Nations community and/or organizations)
- Disproportionate rates of incarceration
- Inadequate services for domestic violence
- Intergenerational abuse
- Elder Neglect and Abuse

- Need for improved legal services
- Poverty facing female single parents and their families
- Impact of inadequate social assistance and minimum wage on access to services
- Need for improved access to health and social services for inmates and past inmates
- Inadequate housing for First Nations seniors
- Inadequate/overcrowded housing
- The need to provide a supportive foundation in addition to housing for the «hard to house»
- Lack of programs and supports for single men (i.e. housing, talking circles)
- Houses in need of repair/Inadequate home maintenance
- Increasing number of female sex trade workers as a result of increasing poverty
- Alcohol addiction
- Drug addiction (non prescription)
- Addiction to prescription drugs
- Too much or too many prescription medication(s)
- Smoking
- Cycle of poverty (i.e. poverty leads to stress leads to mental health issues leads to inability to work leads to poverty)
- Food security
- The impact of homelessness and/or transience on health (i.e. inability to care for self, inability to see the same health care provider)
- Healthy and safe water
- Focus on survival rather than preventative health
- Culturally inadequate assessment processes for children and youth resulting in missed/wrong diagnosis
- Mental health stigma as a barrier to accessing mental health care


De dwa da dehs nye7s
Aboriginal Health Centre