Executive Summary
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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 Tungsuvvingat 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 offc, the Ministry of Health and Long Term Care (Mohltc) Aboriginal Health Transition Fund, and crich. Organizational partners included offc, 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 Metis 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.

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**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 OHP 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.

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**KEY PROJECT FINDINGS AND IMPLICATIONS FOR HEALTH 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 ONC 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 resiliency. 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, the 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 HS 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 HS 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 of 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 preaced 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.
Prepared for

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