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Manitoba Inuit Association's Rapid Response to Include an Inuit Identifier within Manitoba COVID-19 Diagnostic Tests

Wayne Clark, Josée Gabrielle Lavoie, Nathan Nickel, and Rachel Dutton

As of 2016, there were approximately 47,330 Inuit living in Canada, mainly in Inuit Nunangat (which includes Nunavut, Nunatsiavut, Nunavik, and Inuvialuit, the four Inuit regions located in the Canadian Arctic), and 17,690 Inuit living outside the land claim territories, mainly in southern Canada.¹ Inuit move to southern centers to seek training, health care, advanced education, or other opportunities, sometimes for shorter periods as well as more permanently. The Nunavut healthcare system is the most geographically dispersed north-to-south health system in Canada, leaving it

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disjointed, both administratively and operationally.² Supports offered to Indigenous populations in Manitoba tend to be focused primarily on First Nation or Métis populations, depending on the program or service delivery context. Despite a north-to-south corridor for health services that has existed for more than five decades, a lack of Inuit-centric and/or Inuit-responsive services persists in Manitoba.

This commentary utilizes an Inuit-specific approach to discuss key issues related to data, inequities, monitoring, and future research opportunities that will occur as a result of the system-wide mobilization created by the COVID-19 pandemic. Established in 2008, the mission of the Manitoba Inuit Association (MIA) is to improve the lives of Inuit in Manitoba by promoting Inuit values, community, and culture.³ MIA recognizes and promotes the realization of the right of self-determination for Inuit in Manitoba and throughout Inuit Nunangat and Canada.⁴ Inuit health is one of the key areas that MIA supports, consulting with partners such as the Winnipeg Regional Health Authority and University of Manitoba on cultural awareness training for healthcare providers, and through programs and outreach, supporting Inuit coming from Nunavut to Winnipeg for health care to navigate systems or social networks in support of their well-being. MIA is also a partner of Ongomiizwin Research at the University of Manitoba and was involved in co-designing a process for health research engagement.⁵

For Inuit, equitable access to health care across Canada has been shown to be problematic. This is in part due to a substandard infrastructure across the north, which includes housing shortages and crowding.⁶ Access to care beyond basic primary health care at the community level is limited, largely because of diseconomies of scale and recruitment and retention issues. This can result in delays in diagnoses, and worse outcomes.⁷ Still, a major factor is the legacy of colonialism, which undermines local economies, culture, and language.⁸ This impact, which is still felt today, has led to the high rate of suicides.⁹ As a result, the life expectancy of Inuit is the lowest in Canada. In 2011, life expectancy at age one for the male household population was 70.0 years for Inuit and 81.4 years for non-Indigenous people. Among the female household population, life expectancy at age one was 76.1 years for Inuit and 87.3 for non-Indigenous people.¹⁰

According to the Canadian Census, there are 600 Inuit living in Manitoba;¹¹ however, other estimates are slightly higher.¹² MIA has approximated as many as 1,000 Inuit, some of whom who are living temporarily in Manitoba, mainly to access health-care services.¹³ Approximately 15,000 other Inuit travel from Nunavut to Manitoba frequently for health services.¹⁴ These statistics indicate a need for more effective tracking of Inuit within health information systems, particularly to ensure equity and public health surveillance. Historically, there has been no mechanism to identify Inuit in health systems, both at the point-of-care, and within administrative data. Identification is essential to ensure that universal coverage to responsive health services exists. This includes the ability to monitor and evaluate health systems to identify gaps and inform on how best to improve coverage. However, developing a mechanism for tracking Inuit service utilization in health information systems can be a formidable task. This undermines Manitoba Health's ability to track inequities which might be

related to service delivery, and for the Government of Nunavut to plan health service delivery and purchasing (from Manitoba Health) more purposefully. It also limits MIA's ability to track Inuit needs, and to advocate for services to address these needs.

Manitoba Health's administrative data has been made accessible to researchers for decades. Access is through the Manitoba Centre for Health Policy at the University of Manitoba, which hosts the most comprehensive data repository in Canada and beyond, with data linkage capability across the health, justice, child protection, and education systems. Indigenous organizations govern and oversee research that intends to use data specific to the populations they represent. Manitoba First Nations have been actively engaged in this research and led the co-development of evidence-based innovations. Manitoba Métis have also benefited, albeit to a lesser extent, but until recently, Inuit had been left behind.

In 2017, a group of researchers from the University of Manitoba and the MIA began to work on creating a pathway to identify Inuit in health administrative data. This project has been successful, and is now at the data analysis and writing stage. The method developed is documented in a forthcoming publication. ¹⁷ Building on this work, MIA began working with Manitoba Health, Shared Health Manitoba, the First Nations Health and Social Secretariat of Manitoba and University researchers in March 2020 to develop a mechanism to identify Inuit living in Manitoba or from Nunavut accessing services in the province, when being tested for COVID-19 (whether the results are positive or negative). Table 1 summarizes the mandate of each agency involved.

In Manitoba, diagnostic testing for COVID-19 began in late January 2020, through Cadham Provincial Laboratory in collaboration with the National Microbiology Laboratory, with further support from the Public Health Agency of Canada. The first positive COVID-19 case in Manitoba was confirmed on March 12, 2020. After following the pandemic closely through its incident command structure established earlier in the year, the Manitoba Government declared a province-wide state of emergency on March 20, 2020. Regular communication and daily public briefings were made by the chief public health officer and chief nursing officer at Manitoba Health and Shared Health Manitoba, respectively. Evidence of social transmission emerged on April 1, 2020. 20

Indigenous communities in Manitoba had previous experience responding to a pandemic in 2009 during the outbreak of the influenza A virus H1N1.²¹ Lessons learned from this event caused Indigenous populations to take a different approach with COVID-19. When the Government of Manitoba declared a state of emergency under the Emergency Measures Act on March 20, 2020, it already had held extensive consultation with Indigenous community leaders and stakeholders. Indigenous leaders, government officials, healthcare administrators, health researchers, and Indigenous community members were able to work together for efficient decision-making and communication that resulted in highly synchronized planning. The Nunavut Government declared a territory-wide state of emergency on March 18, 2020, to allow for coordinated efforts within Inuit Nunangat, provinces, territories, and federal government partners. As of March 24, 2020, all residents were required to undergo a

Table 1
Agencies Supporting an Inuit Identifier within Manitoba COVID-19
Diagnostic Tests

Organization Name	Mandate
First Nations Health and Social Secretariat of Manitoba	First Nations in Manitoba to have increased opportunities to participate in: the planning & development of a unified health system in Manitoba, the influence of regional and national health policy, health systems and program development in areas including, but not limited to, health consultation, maternal child health, electronic health and surveillance, youth suicide, mental health, inter-governmental health, health and social determinants of health, health research, web-based home and community care training, health governance, and infrastructure support.
Indigenous Institute of Health and Healing	Provide leadership and advance research excellence in education and health services in collaboration with First Nations, Metis, and Inuit communities. Its work is guided by Knowledge Keepers and Elders and helps to achieve health and wellness of Indigenous peoples.
Manitoba Centre for Health Policy (MCHP)	Conduct world class population-based research on health, and the social determinants of health. It develops and maintains a comprehensive population-based data repository on behalf of the Province of Manitoba for use by the local, national and international research community.
Manitoba Inuit Association	Enhance the lives of Inuit in Manitoba by promoting Inuit values, community, and culture while connecting to services that meet evolving needs.
Ongomiizwin Research	Build and maintain productive and respectful partnership-based relationships with First Nations, Metis, Inuit and Indigenous communities, to recruit Indigenous students and scholars, to provide effective support and mentorship, and to share and build knowledge internationally.
Shared Health Manitoba	Bring Manitobans together to create equitable, safe, accessible, trusted, and sustainable pathways to care.
Winnipeg Regional Health Authority	Deliver quality, caring services that promote health and well-being of its patients, clients, and community stakeholders.

two-week isolation period prior to returning to the territory aimed at preventing the spread of COVID-19 in the local population. Self-isolation accommodations were set up at a Winnipeg hotel at the end of March and in July a second hotel was opened for medical travelers in order to keep up with the demand.

In March 2020, when MIA was asked to participate in ongoing provincial work to add Inuit identifiers in Manitoba's provincial COVID-19 testing sites, the MIA board of directors approved a motion to ensure that Inuit-specific COVID-19 data would be collected. From MIA's perspective, requirements for a COVID-19 testing strategy that responds to Inuit needs are threefold. First, it requires a testing process that is culturally safe and equitable for Inuit to access and ensures appropriate messaging targeted to Inuit in official communications related to COVID-19. Second, data derived from

test results must inform public health officials in Manitoba and Nunavut to make decisions related to screening, contact tracing, and other pandemic management protocols. Third, the data generated must be available, with appropriate permissions, to help inform research related to COVID-19 and identify potential gaps in healthcare delivery. MIA entered into an agreement with the Government of Manitoba to identify and protect Inuit in health data and systems as a result of the COVID-19 pandemic. As a result, Manitoba is able to capture positive COVID-19 cases for Inuit tests in Manitoba, whether they are residents of Nunavut or Manitoba.

The ability to identify Inuit in health data is significant. While it was technically possible to add Indigenous identifiers in health administrative data systems, previously provincial political will was somewhat tepid. Provincial COVID-19 pandemic planning became the perfect time to finally move ahead to include Indigenous identifiers in a diagnostic test. With the expected benefits of improved health reporting and health planning for Indigenous populations, Shared Health Manitoba had already started planning a process of collecting Indigenous identifiers. In a pilot project at one teaching hospital located in the capital, Health Sciences Centre of Winnipeg, patients self-identify at the point of registration. Discussions related to this strategy brought heightened awareness of the need to increase opportunities for Indigenous identifiers throughout the healthcare system in Manitoba. In these discussions, some raised issues of accuracy of ethnicity data through self-identification. This method requires a health professional to ask patients about ethnicity, at times when patients may feel particularly vulnerable, and despite a long history of discrimination at the hands of service providers, that patients be willing to disclose their ethnicity to providers accurately.²² The identifier strategy was led by Marcia Anderson, MD (Cree-Anishinaabe), head of First Nations, Métis and Inuit Health at the University of Manitoba Rady Faculty of Health Sciences. The risk of misclassification and nonresponse was seen as a considerable problem,²³ requiring ethnicity identification using a complementary process of verification through an algorithm utilized in and/or derived from previous work.

MIA also began to participate in a biweekly teleconference to troubleshoot COVID-19 related issues led by Shared Health Manitoba. These teleconferences brought together Indigenous health leadership from across Manitoba, representatives from the Regional Health Authorities and municipalities, and high-level officials from Manitoba Health and Manitoba Indigenous and Northern Affairs. Issues raised included, for example, the unmet needs of Inuit who had come from Nunavut to access care in Manitoba and were required to self-isolate for fourteen days before returning to Nunavut. Those Inuit reported urgent needs and felt isolated and lonely. Stories of young Inuit women who had come to Manitoba to give birth emerged, with new mothers expressing distress when isolated from support systems while caring for a new baby. Officials were able to respond appropriately to support Government of Nunavut nurses deployed to assist Nunavummuit (Inuit from Nunavut) who were in self-isolation.

COVID-19 reports are being provided weekly for tests conducted within the previous week. Each report template includes placeholders for data around COVID-19 infections reported for Inuit, the rate of the Inuit case count in relation to all cases in

Manitoba, the number of Inuit cases that have been hospitalized and discharged, intensive care unit admissions, and deaths. In addition, the report template provides the total number of Inuit cases that are travel-related and how cases may be linked to another known case. At the time of writing, there were 26 positive cases out of 1062 tests conducted. Finally, the report distinguishes between Inuit living in Manitoba, and Nunavut Inuit tested while accessing services in Manitoba. MIA offered to share the reports with Inuit stakeholders in Nunavut, including the Government of Nunavut, Nunavut Tunngavik Incorporated, and Kivalliq Inuit Association. Each of these organizations has a vested interested in the processes designed in Manitoba by MIA representatives, government, researchers, and healthcare providers given the responsibility Manitoba has in providing services to Nunavummuit.

It is important to note that strategies put in place by public health officials to contain the virus require access to housing, water, food, and income, which are often in short supply in Indigenous communities. Inuit social determinants of health have been identified as acculturation, self-determination, education, quality of life, productivity, income, food security, healthcare services, social safety net, housing, and environment.²⁴ In other planning efforts early in the pandemic, MIA and others began advocating for pathways to address the social challenges that the pandemic would clearly impose on Inuit populations. The challenges do not stop with the determinants of health. The requirement for Inuit to self-isolate, while prudent, created considerable hardship for patients eager to go home. Inuit living in Manitoba found their opportunity to visit loved ones in Nunavut closed, sources of traditional food brought by those who travel to Manitoba from Nunavut gone, and fear of food security and social distress increased.

With the support of funding through Government of Canada's Community Support Fund and COVID-19 funding from Nunavut Tunngavik Incorporated, MIA developed its COVID-19 Emergency Response Plan for Inuit residing in Manitoba to address urgent needs around food security and community capacity. MIA has been providing Inuit families and street-involved Inuit with emergency food, personal hygiene, and cleaning supply hampers customized to families' immediate needs. MIA has also been providing elder support, transportation, and emergency accommodation for Inuit women and children/youth at risk as regional shelter capacity has been limited due to COVID-19 public health restrictions. Furthermore, MIA is providing support to Nunavummuit who come to Winnipeg to access healthcare services, and are self-isolating prior to returning to Nunavut.

As MIA was not engaged with Manitoba Health during the H1N1 outbreak, the COVID-19 pandemic is the first instance in which Manitoba Health recognizes the unique needs of Inuit living and/or accessing services in Manitoba and made overtures to MIA to ensure Inuit perspectives are represented. Overall, Manitoba was able to mobilize with Indigenous communities quickly as the pandemic was advancing toward North America. With a secured agreement in place, MIA is able to commence with research being undertaken by the Manitoba Centre for Health Policy to review its whole-population health data infrastructure to provide real-time testing rates. Data will be analyzed to ensure the availability of high-quality data that can help to meet

the testing needs of the Inuit community while the pandemic unfolds. Among all the provinces, Manitoba is uniquely positioned to conduct this type of research, as it is home to a large population of Indigenous peoples and has the capacity to conduct studies of this nature due to the extensive population-based administrative health data holdings and relationships among MIA and Ongomiizwin Research team members and public health system.

MIA and representatives from the University of Manitoba recently received funding from the Canadian Institutes for Health Research and Research Manitoba to increase understanding and awareness of Inuit access to COVID-19 testing, and identify opportunities for removing barriers to timely and efficient testing among Inuit living in Manitoba. Using the health administrative data housed at the Manitoba Centre for Health Policy, researchers will identify where testing is occurring geographically, identify individual (e.g., income, residential mobility, physical and mental health comorbidities) and system-level (e.g., region of residence, urbanicity) barriers to accessing testing, and monitor trends in testing as the pandemic unfolds. Researchers will also be able to develop analytic algorithms to automate these data queries, monitor the trends in real time throughout the pandemic, and report back to stakeholders and the public health system in timely fashion.

The pandemic highlighted areas where social and other support for Inuit have been lacking. Beyond issues of testing and treatment, the Manitoba and Nunavut responses to the pandemic have resulted in considerable hardship for Inuit, such as restricted access to healthcare services, and previously available social programs. While policy responses aimed at protecting Inuit from the pandemic were necessary, nevertheless they were imposed on a population that navigates a highly fragmented north-south healthcare system, resulting in complexities that might be experienced by other populations, but not to the same extent. COVID-19 has dramatically changed the landscape of health care for Inuit in Manitoba and Inuit Nunangat in an already stretched health system. The onset of self-isolation requirements needed in order to access medical care outside the territory resulted in considerable hardships that were somewhat unavoidable, but might have been better mitigated. For Inuit living outside their traditional boundaries in the south, lower population levels and pan-Indigenous programs and services have caused increased loss of social and familial connection, cultural isolation, systemic invisibility, housing insecurity, and economic marginalization.

Collaborative research is currently underway between MIA, a Council of Inuit Elders, and researchers affiliated with Ongomiizwin Research to document service gaps and unmet needs. This work will support the development of a more integrated, culturally appropriate safety net for Inuit living in Manitoba or traveling to Manitoba to access care. Still, additional work will be required to carefully map Inuit needs during the pandemic, met and unmet, as well as to advise on service development should this or other pandemics require the mobilization implemented during the current COVID-19-response time line.

The overall experience to date highlights persistent policy and planning gaps, and the increased need to ensure equitable access to healthcare services. The need for Manitoba-Nunavut protocols to ensure equity in access to services is equally crucial.

The inclusion of an Inuit identifier to COVID-19 provides an exceptional tool for public health officials in Manitoba and Nunavut. The inclusion of the identifier also highlights the importance of the notion of an Inuit right to universal healthcare coverage. The ability for the MIA to access Inuit-centric real time data provides an unprecedented opportunity to act as an active partner in providing Inuit-centric services to Inuit. While the process for collecting and maintaining Inuit data in this context is still very preliminary, opportunities exist for establishing further mechanisms for partnerships in public health, healthcare delivery, and research. The work undertaken by MIA further supports the notion of Inuit self-determination over health as the health system becomes increasingly more complex as a result of the COVID-19 pandemic.

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