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Chapter 12: An introductory guide to tuberculosis care to improve cultural competence for health care workers and public health professionals serving Indigenous Peoples of Canada

Jonathan L. Dunn^a, Marlene Larocque^a, Deborah Van Dyk^b, Eduardo Vides^c, Faiz Ahmad Khan^{d,e,f,g}, Tom Wong^h, Richard Longⁱ and Gonzalo G. Alvarez^{j,k}

^aAssembly of First Nations, Ottawa, Ontario, Canada; ^bInuit Tapiriit Kanatami, Ottawa, Ontario, Canada; ^cMétis National Council, Ottawa, Ontario, Canada; ^dDepartments of Medicine, Epidemiology & Biostatistics, McGill University, Montréal, Québec, Canada; ^eTuberculosis Clinic Ungava Tulattavik Health Centre, Kuujuaq, Québec, Canada; ^fInuulitsivik Health Centre, Westmount, Québec, Canada; ^gMcGill International TB Centre, Montreal, Québec, Canada; ^hPublic Health for Indigenous Services Canada; Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada, Ottawa, Ontario, Canada; ⁱTuberculosis Program Evaluation and Research Unit, Department of Medicine, Faculty of Medicine and Dentistry, University of Alberta, Edmonton, Alberta, Canada; ^jDivisions of Respiriology and Infectious Diseases, Department of Medicine, University of Ottawa, The Ottawa Hospital, Ottawa, Ontario, Canada; ^kOttawa Hospital Research Institute, Ottawa, Ontario, Canada

KEY POINTS

Health care workers providing services on Indigenous lands and/or working with Indigenous Peoples to do tuberculosis-related work should:

- educate themselves about the epidemiology of tuberculosis (TB) in the community, recognizing that the community's historical relationship with TB will contextualize present day TB care;
- understand the geography and climate of Indigenous communities, including that many Indigenous communities facing high rates of TB are isolated and not linked by roads to urban centers, with the result that healthcare is less accessible and the diagnosis and treatment of TB potentially delayed;
- acknowledge the Indigenous territory that one is occupying; work toward understanding and practicing cultural safety by self-reflection on power differentials and respecting cultural differences, including language; and incorporate cultural values to promote a safe and inclusive environment;
- recognize the specific social determinants of health affecting distinct Indigenous groups, with the aim of delivering quality TB care and closing the health equity gaps between Indigenous and non-Indigenous Canadians;
- acknowledge the role of on-going colonization, personal and systemic racism, and privilege as they relate to health equity in TB care delivery, and take steps to prevent their harmful effects;

- promote self-resilience, self-advocacy and empowerment by respecting the rights of Indigenous Peoples as outlined in the Patients' Charter of TB care and the United Nations Declaration on the Rights of Indigenous Peoples; and
- understand that each Indigenous group — First Nations, Inuit and Métis — is historically and culturally distinct and may, therefore, have unique TB needs.

Purpose of this document

To provide health workers and public health professionals going to Indigenous lands to do TB work and/or working with Canadian Indigenous Peoples affected by TB, with an introductory platform to learn about the specific epidemiology, historical and cultural context for each of the three Indigenous groups in Canada in an effort to improve cultural competence with respect to providing TB care for Indigenous Peoples in Canada. Note that, in this chapter, First Nations, Inuit, Métis are listed and covered alphabetically.

Disclaimer: this document does not intend to provide a comprehensive cultural safety course to readers but hopes that health workers can connect with specific cultural safety and awareness courses and information to pursue further study in this important area of healthcare as it pertains to the Indigenous group(s) that they are serving.

Leaders' Statements

National Chief of the Assembly of First Nations Statement on Tuberculosis



This featured chapter is a welcome addition to the Canadian TB Standards, as it sheds light on the historical relationship and ongoing struggle First Nations have with TB. Shortly after the establishment of the reserve system, implemented through the Indian Act, First Nations have suffered destructive consequences of TB. This continued when our children were removed from their families and sent to institutions of assimilation and genocide — residential schools. In 1907, Dr. Peter Bryce, an early medical whistleblower documented the horrific conditions that facilitated the spread of TB. The number of TB casualties during the era of residential schools was inhumane and unprecedented. Though First Nations' TB rates fell significantly toward the end of the 20th century, TB rates remain higher than non-Indigenous Canadians — particularly in northern and remote communities. Substantial progress toward national and global TB eradication by the year 2030 will occur once all determinants of TB are addressed. Equitable healthcare at the First Nation community level, with capacity to manage the total transfer of health services supported by sustainable investments and complete jurisdiction, will be strong indicators of progress.

Ninanaskamon!

Wishing you Peace beyond all understanding,

National Chief RoseAnne Archibald

Opening Statement from President Obed of Inuit Tapiriit Kanatami on Tuberculosis



The history of TB in Inuit Nunangat is one of colonization and loss, but also of resiliency in the face of hardship. The story of eliminating TB from Inuit regions will be told in terms of solidarity and self-determination. Our strength in unity, resilience in the face of hardship, and a strong grip on our traditions have sustained us during challenging periods marked by colonization and disrespect for our human rights. We have our language, our culture and our food. We have the way that we raise our children. We have a love for not only the land but all things that live within it. We know how to hold each other up to persevere through difficult times. We are alive today because of Inuit unity and resilience. These characteristics are still very

evident in our communities. Unfortunately, we have no shortage of challenges upon which to unleash this potential today. The high rates of TB in Inuit regions are a symptom of social inequities that enable the spread of TB, diminishing the health and wellbeing of too many of our people. It is vital that everyone from government leaders to policy-makers to frontline workers understand the conditions contributing to the exceedingly high rates of TB in Inuit communities. Recognizing that TB is directly linked to poverty, insufficient access to healthcare, and overcrowded housing conditions is crucial as we continue to work together to eliminate this disease. All of those who provide health care in Inuit regions have a part in helping Inuit eliminate TB from their communities. TB elimination will be an incredible feat of cooperation and collaboration. We need to work together to ensure TB care for Inuit is evidence-based in design and is Inuit-specific in delivery.

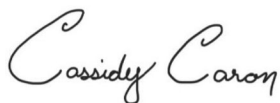
Natan Obed
President

President of Métis National Council's Statement on Tuberculosis



The Canadian Tuberculosis Standards represent a significant step forward in tackling TB within the Métis Nation, and we thank all who contributed to this important work. TB continues to have serious impacts on the health and well-being of Métis Nation individuals, families and communities. Strong and sustained efforts are needed at all levels of government to reduce its harms and to eliminate TB in our population. Increasingly, policy and decision makers and health care workers alike recognize and understand that the Métis Nation is a distinct Indigenous people with unique health challenges and needs. This recognition is essential in ensuring culturally relevant, culturally safe and effective TB prevention, treatment and care for the Métis Nation. Along with the profound and persistent, negative impacts of colonialism, past failed health policies, and the negative impacts of the social determinants of health, ongoing jurisdictional disputes around responsibility for Métis Nation health continue to hamper efforts to reduce TB within the Métis Nation. While Métis Nation citizens have access to mainstream provincial services, these services often do not meet the specific resourcing, cultural, and geographical needs of Métis Nation individuals and families, especially those living in more rural and isolated areas. Federal systems established to address the health needs of Indigenous people in Canada to this day remain exclusive of the Métis Nation, further exacerbating these health disparities. Neither do current data systems have the capacity to accurately assess or track TB in the Métis Nation, and Métis Nation-specific research and

data remain limited and inadequate to the task. It is clear that there is much work to be done to understand and effectively address TB within the Métis Nation. The distinctions-based approach adopted in the development of the new Canadian Tuberculosis Standards makes an important contribution in this collective, ongoing effort.



President Cassidy Caron
Métis National Council

1. Introduction

In Canada, there were 1.67 million Indigenous Peoples, comprising 4.9% of the Canadian population, according to the 2016 Census.¹ The term Indigenous Peoples refers to the original inhabitants of the land, predating the arrival of Europeans. The Canadian constitution recognizes three groups of Indigenous Peoples: First Nations, with a population of 977,230 people; Inuit, with 65,021 people; and Métis with 587,545 people.² In 2017, the incidence rate of TB among Canadian-born Indigenous Peoples was 21.5 cases/100,000 population,³ a rate that has not changed substantially in the past decade. Despite Indigenous Canadians representing only 4.9% of the Canadian population, they represent 19% of all TB cases, with the foreign-born population accounting for the majority of cases in Canada, at 71.8% of all cases in absolute numbers (see [Chapter 1: Epidemiology of Tuberculosis in Canada](#), Figure 5).³

The impacts of historical traumas and systematic inattention paid to the upstream social determinants of health and comorbidities among Indigenous populations of Canada have shaped the TB epidemics seen over the past century. Available evidence suggests that TB did occur sporadically among Canadian Indigenous populations,^{4,5} as well as other Indigenous populations in the Americas, prior to European contact.^{6–8} However, genomic evidence suggests that TB was further dispersed into Canadian Indigenous populations as a result of contact between European fur traders with First Nations Peoples during the 18th century.⁹ Large-scale TB epidemics would unfortunately follow in the 19th and 20th centuries, propagated by ecologic, political and economic factors. The epidemic spread of TB in Indigenous populations was accelerated by the forced relocation of individuals who were separated from their families and sent to reserves, hamlets and residential schools.¹⁰ Forced relocation disrupted the relationship of Indigenous Peoples with their lands, the ancestral place where the totality of life occurred.^{11,12} These forced relocations caused malnutrition, as hunters and fisherman did not know the new territories where they were moved, making subsistence difficult or impossible.^{13–15} Once relocated, families lived in crowded conditions, which favored transmission of TB, while malnutrition fostered the progression of infection to disease.^{16–20} The death rate among

Indigenous children in residential schools in Canada was exceedingly high at the turn of the last century and TB was a significant cause of death.²¹ All three Canadian Indigenous groups experienced significant disruption in their families and communities as those with TB were sent to sanatoria in southern Canada for treatment throughout the 1930s–1960s for long periods of time, sometimes never to return. The magnitude of the impact of evacuations to southern sanatoria, relocations and residential schools cannot be overstated. Survival was often accompanied by a legacy of emotional, psychological and physical scars. The history of TB in First Nations, Inuit and Métis communities speaks of transgenerational loss and suffering.^{16–20} Those who work in TB prevention and care in the 21st century must be aware of the existence of a collective memory of the suffering of individuals, families and communities associated with prior TB epidemics.

1.1. Methods

The chair of the committee (GGA) was appointed by the editor of the Canadian TB Standards to generate a position statement on TB prevention and care among Indigenous Peoples of Canada. The chair asked each of the three major Canadian Indigenous groups to appoint representatives to the writing committee. The committee first began by reaching a consensus on the purpose of the chapter, followed by reaching a consensus on an outline. Each Indigenous organization representative then produced their section according to the outline. A TB expert physician supported each Indigenous organization representative in drafting the document. The role of the TB expert physicians was to provide clinical content expertise and to support the arguments made by the Indigenous representatives, to ensure the voices of these representatives were central to the document. In addition, as much as possible, committee members were encouraged to add the voices of Indigenous Peoples to this document so that these voices could directly speak to health workers to help educate them. To this end, the committee members did a scoping review of the literature²² to support the concepts put forward by Indigenous partners. A search for published and unpublished articles (grey literature) and video testimonials by Indigenous Peoples to highlight the oral traditions used to convey history common to all three groups was also undertaken.²³

It is important to note that, although the 3 Indigenous groups recognized by the Constitution of Canada commonly experience the process of colonization and have other areas of overlap, their cultures are distinct. As a result, while their experiences with TB are similar in some ways, there are important differences reflected in the three population-specific sub-sections of this chapter.

2. First Nations

Sporadic cases of TB almost certainly occurred in the Americas before European contact, but significant exposure

and the introduction of possibly more virulent strains of *Mycobacterium tuberculosis* (*M. tuberculosis*) occurred post-contact,²⁴⁻²⁶ with dispersal following trade routes and encroaching settlements.⁹ The gradient of TB in First Nations can reflect the serial stages of European colonization, with the lowest rates in the Atlantic region and the highest rates reported in the North, consequently mirroring the earliest and latest encounters.^{27,28} Since the mid-20th century, when Health and Welfare Canada began implementing serious TB prevention and care measures among the First Nations of Canada, and when the first effective anti-TB drugs were discovered, rates of TB in Indigenous Canadians have been slowly falling.²⁹ The rate of decline, however, has been slower than the rate of decline in the Canadian-born, non-Indigenous population, such that the relative rate (Indigenous/non-Indigenous rate) has been increasing,^{29,30} highlighting a continuous inequity in health indicators for First Nations.

In 2015, the last year in which all provinces and territories reported disaggregated data, there were 155 Registered Indian cases (Registered Indians or Status Indians are persons who are eligible to be registered as an “Indian” under the *Indian Act*, and who therefore are able to use services and benefits that are offered by federal departments) reported in Canada; all were reported in the provinces west of Quebec and in the territories. The prairie provinces alone reported 127 (81.9%) cases. Most cases (101, or 65.2%) were living on-reserve at the time of diagnosis.³¹ The on- and off-reserve crude rates of disease were 19.3 and 10.7 per 100,000 persons, using population estimates from Aboriginal Affairs and Northern Development Canada (AANDC)/Indigenous Services Canada (ISC). On the prairies in 2004-2008, again using AANDC/ISC population estimates, the age- and sex-adjusted rates in Registered Indians were 52.6 (95% confidence interval 49.2-56.0) per 100,000 person-years (37.6 times the rate in Canadian-born “others”), with rates on- and off-reserve being 62.2 (57.3-67.0) and 40.0 (35.4-44.6) per 100,000 person-years, respectively.³² Rates on the Prairies increased incrementally with age, with males having higher rates in each age group.³² In 2007-2008, the distribution of pulmonary TB cases according to community-of-residence on the prairies was highly focal; only 47 (23.6%) of 199 reserve communities reported a case and most of these communities were in the northern latitudes. In Alberta, where near-universal opt-out human immunodeficiency virus (HIV) testing of TB patients has been performed since 2003, being Indigenous was an independent risk factor for HIV seropositivity.³³

After European exposure, multiple diseases decimated the First Nations population, which negatively affected communities’ social and economic infrastructures.³⁴ The rise of TB that occurred in the latter half of the 19th century resulted from events related to the decline of the fur trade and the destruction of the bison-based economy. These changes jeopardized many First Nations’ political and economic autonomy, thus forcing many to ratify treaties with the Canadian government. The treaty terms and the eventual introduction of the *Indian Act* (the Act) of 1876, led to mandatory relocations onto reserves, loss of liberties and land claims, even though the initial agreements were based

on shared land management principles, in exchange for crucial living essentials needed to survive.^{35,36} Despite the allocation of food rations and basic living infrastructures, the rations were subpar and used as a means of coercion, leading to malnutrition and impoverished living conditions in many communities^{34,35} and culminating in TB outbreaks on reserves.³⁷

Prairie First Nations faced extraordinarily high TB death rates, which peaked shortly after they were placed on reserves, with 9,000 deaths per 100,000 persons in 1886; that rate fell to approximately 800 deaths per 100,000 persons in 1926.³⁸ Off-reserve, TB outbreaks were appearing in Indian residential schools across the prairie provinces, with up to one-quarter of students dying from TB.^{39,40} Residential schools were an assimilation tactic to incorporate Indigenous children into Canadian society, starting in the 1880s, and with the last school closing in 1996. In the early days of Indian Residential Schools, the common themes of poor ventilation, poor construction design, overcrowding, lack of basic medical treatment and malnutrition contributed to the propagation of TB, unseen in the general public.³⁷ The epidemic of TB on reserves concerned non-Indigenous Canadians; due to public outcry, the Canadian government funded sanatoria treatment for First Nations Peoples, beginning in the late 1930s.^{37,41} In general, sanatoria were established on the idea that treatments of “open air,” bed rest and a balanced diet would cure TB. However, designated First Nations sanatoria were racially segregated, underfunded, understaffed and First Nations patients often found the forced treatments distressing and isolating.⁴¹⁻⁴⁴

Recorded TB incidence declined considerably during the 1940s to 1960s, due to the expansion of medical interventions to combat the disease,⁴⁵ including Bacille Calmette-Guérin (BCG) vaccinations, mass radiography, tuberculin surveys and anti-TB drugs.⁴⁶ However, many of the interventions were coerced on nonconsensual First Nations children and adults.⁴¹ These negative experiences have been harbored and passed on to each generation, creating even further resentment, suspicion and distrust toward the government and the medical system in general.

Regardless of these medical advances, there are numerous structural barriers that impede TB elimination in remote First Nations populations. First, isolated clinics provide inadequate healthcare, due to understaffing, insufficient supplies of practical diagnostic equipment (digital chest radiography, interferon-gamma release assays and sputum testing), the inconvenience of transporting samples to external laboratories and limited local human resources to ensure patients’ adherence to treatment and unsatisfactory documentation of HIV rates, prevalence of TB drug resistance and BCG vaccination within the community. When these clinics cannot provide the necessities, the inconvenient transportation of patients to a larger health facility, thousands of kilometers away, is the subsequent step. Additionally, widespread discrimination and implicit bias from health care providers means patients become reluctant to seek, or travel for, care.⁴⁷ Too often, Indigenous Peoples’ medical cases are mismanaged, overlooked and

misdiagnosed. Inconsistent access to culturally safe health services is a modern and prominent structural barrier. Furthermore, living conditions on reserves continue to mirror the past. The low socioeconomic situation for many communities continues to be reflected in substandard conditions. Overcrowded, multigenerational homes, lack of access to clean water, high rates of unemployment and food insecurity contribute to the continuity of TB transmission.^{48,49}

Although TB rates have significantly decreased since the unprecedented highs in the late 1800s and early 1900s, the disease is by no means close to being eliminated. In fact, these unacceptable rates remain high in relative terms and have been so for the past decade. The practical steps to ameliorate the current situation must involve the federal government resuming annual TB reports that would acknowledge the present inequitable health status, implement measurable goals and establish accountability. The Truth and Reconciliation Commission provided eight recommendations specific to health (#18-24, 55), outlining realistic targets to lessen disparities in health outcomes our people face across Turtle Island (a First Nation term to denote the North American continent). To date, active TB incidence rates are thirty-two times higher for First Nations Peoples than the general non-Indigenous, Canadian-born population.⁵⁰ It is evident that the devastating rates of TB were historically parallel with the height of Canada's racist legislation against First Nations Peoples. Yet, as efforts slowly begin to recognize reconciliation for First Nations, TB persistently remains an indicator of colonialism.

3. Inuit

TB among Inuit is a public health crisis. In 2019, the rate of active TB reported among Inuit living within Inuit Nunangat was 40 times the rate for Canada as a whole (189/100,00 vs 4.7/100,000) and more than 400 times the rate for the Canadian-born, non-Indigenous population (189/100,000 vs 0.4/100,000) (see [Chapter 1: Epidemiology of Tuberculosis in Canada](#)). There are 65,000 Inuit in Canada, the majority of whom live in four regions that comprise Inuit Nunangat (the Inuit homelands): the Inuvialuit Settlement Region (in the Northwest Territories), Nunavut, Nunavik (in northern Quebec) and Nunatsiavut (in northern Labrador). It includes 51 communities and encompasses roughly 35% of Canada's landmass and 50% of its coastline. Regular, reliable airline and seasonal supply ship services are critical, as access to most communities is by air and water in summer and by air only in other seasons. All communities have a health center, the majority of which are staffed by registered nurses with advanced training. Referrals out of community to a regional hospital or to care facilities in southern urban centers are frequently required. Emergency medical evacuation services are available,⁵¹ although geography and weather conditions can affect response times.

Historical traumas from earlier efforts by the Canadian government to address TB epidemics among Inuit continue to have an impact on the current context of TB in Inuit

communities.⁵²⁻⁵⁵ As the Canadian Arctic was colonized in the first half of the 1900s, it became a time of rapid social changes and disease epidemics for Inuit. Before effective TB drugs became available, TB death rates among Inuit were high.¹⁸ Many were sent to TB hospitals in southern Canada during the 1940s-1960s.^{56,57} Families were not informed of where loved ones were taken or where those who died were buried.⁵⁸ Inuit who returned, particularly children, faced new challenges, including reduced physical capacities related to their illness or treatment, and the loss of language, family attachments and other aspects of Inuit culture. In 2019, the Prime Minister delivered an apology on behalf of the Canadian government for the treatment of Inuit with TB during this time,⁵⁹ and the Nanilavut Initiative began helping Inuit locate, visit and mark the graves of family members who did not return home.^{58,60-62}

In 2019, the incidence rate of TB disease varied across Inuit regions, from 0 in the Inuvialuit Settlement Region to 139/100,000 in Nunavut, 517/100,000 in Nunavik, and 112/100,000 in Nunatsiavut.⁶³ TB rates also vary dramatically within regions, with some communities experiencing recurrent TB outbreaks. There is also a large pool of latent TB infection across all regions in Inuit Nunangat that creates a high risk for future outbreaks. The BCG vaccine is given to neonates in all regions except Nunatsiavut. While the BCG vaccine is important for preventing disseminated TB among children, it may have a confounding effect on screening programs for latent TB infection among young children (see [Chapter 9: Pediatric Tuberculosis](#)).

High rates of TB among Inuit are a symptom of the health disparities they experienced. Social and economic inequities faced by many include: poverty; crowded and inadequate housing;⁶⁴ food insecurity;⁶⁵ low academic achievement; and high rates of unemployment.⁶³ These inequities assert themselves beyond TB; collectively, the 4 Inuit regions have rates of suicide that range from 5 to 25 times the rate of suicide for Canada as a whole and are among the highest rates in the world.⁶⁶ There is also high overall prevalence of other respiratory illnesses, including asthma, chronic obstructive pulmonary disease, lung cancer^{67,68} and respiratory syncytial virus (RSV), as well as smoking and use of harmful substances that cause or exacerbate these diseases.

Inuit experience challenges in accessing health services that most Canadians do not face.⁶⁹ Historical experiences continue to affect how individuals, families and communities perceive the potential consequences of being diagnosed with TB. Many diagnostic services are not available in Inuit communities, requiring extensive travel for simple tests and procedures. Inadequate telecommunications services limit access to virtual care. Frequent turnover of health care providers,⁷⁰ particularly in smaller and more remote communities, and language and cultural differences between clients and providers are recognized as important ongoing obstacles to health services for Inuit.⁷¹ These barriers may cause delays in TB diagnosis and treatment. Delays can increase the severity of illness, perpetuate ongoing transmission and amplify the prevalence of latent TB infection in Inuit communities.

In 2018, Inuit leadership and the Government of Canada jointly committed to eliminating TB from Inuit communities

by 2030.⁷² Inuit Tapiriit Kanatami (ITK), the national organization representing Inuit, released the Inuit Tuberculosis Elimination Framework in December of 2018 to guide this work.⁶³ Priority areas for action and investment highlighted in the framework include: enhancements to TB care and prevention programming; reductions in poverty; improvements in social determinants of health; creation of social equity; empowerment and mobilization of communities; strengthening of TB care and prevention capacity; developing and implementing Inuit-specific solutions; and ensuring accountability for TB elimination. Each Inuit region has developed its own TB elimination action plan. The TB elimination action plans are tailored to the needs and strengths of each region to ensure investments and activities are informed by local TB epidemiology and health systems. Meaningful involvement of Inuit and Inuit communities in TB programming and planning is the foundation of eliminating TB from Inuit Nunangat.

Respect for Inuit values, language, knowledge, culture and the historical context of TB across Inuit Nunangat is integral to providing TB care in Inuit communities. TB care is a partnership between the healthcare provider and the patient, their family and their community. The goal of building strong and sustainable TB care programs and eliminating TB is not managing illness; it is achieving and protecting wellness.

4. Métis

The Métis are a distinct group of Indigenous Peoples, with their own unique culture, traditions, language (Michif), way of life and nationhood.⁷³ The Métis Nation emerged in the historic Northwest during the 18th century, when European fur traders established relationships with local Indigenous women.⁷⁴ The offspring of these relations form the Métis Nation.⁷⁴ According to the 2016 population census, 587,545 people identified as single-identity Métis in Canada, accounting for 1.7% of the total population.¹ The majority of the Métis population lives in Ontario and the western provinces.¹ Alberta is the only province to have land-based Métis settlements. That said, there are many communities across the western provinces containing $\geq 25\%$ Métis residents, based on Statistics Canada census data.³²

Citizens of the Métis Nation are not homogenous. Métis health outcomes and experiences with the healthcare system writ large, and specifically TB treatment, differ across the country and according to age, gender and socioeconomic status. There are significant social and economic differences, for instance, between remote northern Métis communities and Métis living in urban areas. As of 2016, Métis are a predominately urban population; 62.6% of Métis people live in an area of at least 30,000 people.¹ Métis residing in rural areas tend to face more challenges accessing consistent and high-quality healthcare.

According to the most recent statistics, there were 313 cases of TB reported among Canadian-born Indigenous persons in 2017. Of these Indigenous cases, 5.4% ($n=17$) were Métis.³ Among Métis, the incidence rate of TB was 3.5 cases per 100,000 population, which is lower than the overall

Canadian rate (4.9 per 100,000) but higher than the Canadian-born, non-Indigenous rate (0.5 per 100,000).³ Métis in the prairie provinces are disproportionately affected by TB, with cases largely concentrated (excluding Winnipeg) in a relatively small number of Métis settlements/communities in the northern portion of each province.³² The higher prevalence of TB relative to the Canadian-born, non-Indigenous population is mainly due to social determinants of health, which cannot be understood in isolation from the historical processes of colonization, forced assimilation and social exclusion.

The Métis Nation's history, especially in the context of TB, is often left out of the mainstream narrative of Canadian history. Like other Indigenous Peoples, the Métis Nation was devastated by the smallpox epidemic and later, TB infection.³⁵ Many Métis children also attended residential schools designed to remove children from their families and to assimilate them into European culture.⁷⁵ Often, Métis children suffered physical, emotional and sexual abuse in these schools.⁷⁵ Conditions in residential schools were considered "breeding grounds" for TB.⁷¹ In 1907, Dr. Peter Bryce, the first Chief Medical Officer of the Department of the Interior, released a report stating that roughly one-quarter of all Indigenous children attending residential schools at that time had died from TB.³⁹ From the 1940s through to the 1960s, doctors confined infected Métis Nation members in TB sanatoria, cutting patients off from their family and communities.⁷¹ After long periods of confinement in the sanatoria, those who survived found it challenging to re-integrate into their home communities.⁴² The stigma of a TB diagnosis only compounded the feelings of isolation by patients. Contemporary physicians reinforced the stigma of TB by arguing that it was Métis morality, personality and social behaviors that were responsible for the elevated rates of TB among the Métis population.⁷⁶ Many adults and Elders of the Métis Nation today lived through the sanatorium age. These experiences continue to affect how the Métis perceive the consequences of a TB diagnosis.⁷¹ Across the Métis Nation population, there remains a profound mistrust of medical institutions, due to colonial medical policies and continued racial discrimination in the healthcare system.⁷¹ Medical staff working with Métis should complete cultural safety training so that they understand the historical and current context of TB.⁷¹

Today, many Métis are at a higher risk of TB due to poverty and health inequity rooted in colonialism and the marginalization of the Métis population. Crowded, poor-quality housing, food insecurity, barriers to healthcare access, coinfections with HIV and diabetes and malnutrition are all risk factors for TB in Métis communities. Métis youth are more likely to live in low-income households; in 2016, 21.5% of Métis under 18 years were living in low-income households, compared to 16% of non-Indigenous youth.⁷⁷ Métis individuals are also more likely to live in houses that are in disrepair; in 2016, 14% of Métis homes needed major repairs, compared to 7% nationally.⁷⁷ Métis are more likely to live in a food-insecure household, particularly within the urban population.⁷⁸

In terms of accessing healthcare, jurisdictional disputes exclude the Métis Nation population to a certain degree from both mainstream and Indigenous-specific health systems. First Nations and Inuit people access some of their programming through the First Nations and Inuit Health Branch (FNIHB) of Health Canada, which does not have a mandate to work with the Métis.⁷⁹ While the Métis must access mainstream provincial services as a result, these services often do not meet the specific cultural or geographical needs of Métis communities.⁷⁹ To date, there is no agreed strategy for addressing TB among the Métis Nation with the federal government. Métis living in rural areas have more severe challenges in accessing healthcare. Métis individuals often have to find the money to pay for their transportation to see specialists and to get directly observed therapy (DOT) for TB in larger urban centers.⁷¹ For example, a Métis individual living in Northern Saskatchewan who is diagnosed with TB has to travel to Saskatoon for specialized treatment.⁸⁰

There is an urgent need for Métis-specific information and complete TB surveillance among the Métis population. Relative to other Indigenous groups and the non-Indigenous population, there is limited Métis-focused research on TB, which means there is an incomplete picture of TB in Métis communities. The current identification of Métis TB incidence is likely to be underreported. For example, Saskatchewan has particularly high rates of TB; the province is also distinct in that the majority of cases are in First Nations, Métis, and northern populations, rather than foreign-born populations.⁸⁰ However, TB reporting often conflates Métis TB cases with First Nations TB cases, due to mixed family ancestry or intermarriage, similar geographic location and the same disparities in social determinants of health.⁷¹ With improved TB reporting and research, the Métis Nation and health workers can develop a Métis-specific TB strategy designed by and for Métis people to meet their unique needs and realities.

5. Colonization, racism, privilege and health equity in TB care

Persistently high rates of TB among Canadian Indigenous Peoples are a symptom of health disparities rooted in colonization. Colonization is systemic dominance of one group over another, often resulting in racial and cultural inequities.^{81–83} Colonial approaches to healthcare continue to endure in Canada, preventing Indigenous Peoples from making decisions about their own health and the health of their communities. The effects of colonization continue to plague how Canadian Indigenous populations experience TB care.⁸⁴ Health workers are not immune to the propagation of the effects of colonization,⁸⁵ which are often driven by unperceived and unintended racism and privilege that continue to permeate healthcare delivery in Canada. Racism in this context is defined as an organized system that distributes power, resources and opportunities unequally and inequitably across racial or ethnic groups; historically, racism has gone hand-in-hand with

colonization.⁸¹ This may be seen in inequity in access to, or quality of, healthcare, dominance of colonial language and culture in healthcare systems and a lack of opportunities to improve social determinants of health.⁸¹ As part of the decolonization movement, the Truth and Reconciliation Commission of Canada outlined several key Calls to Action that pertain to health, including the education of health workers working with Indigenous populations (Call to Action #24).²¹ Achieving health equity in TB care can come from understanding and redressing the power dynamics between health workers and Indigenous patients.⁸⁵ The foundation of effective TB care is positive partnerships between health care workers, public health professionals, patients and governments.

6. TB patients' charter of rights

Engaging patients, their families and their communities in TB care is critical for health workers delivering such care among Indigenous populations. Central to this approach is to promote decolonization by seeing individuals in Indigenous communities as rights holders with human rights rather than passive recipients of government-driven healthcare.³⁰ The World Health Organization (WHO) has developed a charter for TB care that outlines the rights and responsibilities of people affected by TB.⁸⁶ The charter outlines, in a concise one-page document, ways that patients, communities, health care providers and governments can work as partners in a positive and open relationship to improve TB care. It outlines roles and responsibilities of all partners, allowing for more accountability for all involved in TB care. Partnership between patients, their families and communities, health workers and governments lie at the heart of eliminating TB in Canada.

7. Path forward

In order to achieve TB elimination in Canada, any plan must address the significant disparities between Indigenous and non-Indigenous Canadians with respect to social determinants of health that are well known drivers of TB. Along with sustained programmatic and research investments, elimination will require tremendous leadership and participation from Indigenous Peoples and governments at all levels to work together to ensure equitable care that not only recognizes the continued effects of colonization but actively promotes decolonization and strives to eliminate all forms of racism and privilege in order to achieve health equity for all Canadians on the path to reconciliation.

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9. Further study

Health workers are encouraged to use this document as an invitation to further educate themselves on Indigenous health as it pertains to TB in order to walk further on the path to reconciliation. Health workers need to commit to lifelong learning in cultural awareness, sensitivity, competency, humility and safety when it comes to achieving strong relationships with TB patients and families.

Suggested websites

- United Nations Declaration on the Rights of Indigenous Peoples
https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf
- Royal College of Physicians and Surgeons of Canada
<https://www.royalcollege.ca/rcsite/health-policy/indigenous-health-e>
- BC Center for Disease Control, Culturally Safe Care
<http://www.bccdc.ca/health-professionals/clinical-resources/covid-19-care/education-and-training/culturally-safe-care>
- CHEO Nunavut Cultural Competency Modules
<https://www.cheo.on.ca/en/clinics-services-programs/nunavut-program.aspx>
<https://www.qhrc.ca/cases/health-nu-app/>
- National Collaborating Center for Determinants of Health Indigenous cultural safety training program - Online course
<https://nccdh.ca/resources/entry/indigenous-cultural-safety-training-program-online-course>
- Association of Ontario Midwives Indigenous Cultural Safety Training and the EQUIP Equity in Health Care TOOLKIT
<https://www.ontariomidwives.ca/indigenous-cultural-safety>
- Cancer Care Ontario Indigenous Relationship and Cultural Safety Courses
<https://www.cancercareontario.ca/en/resources-first-nations-inuit-metis-first-nations-inuit-metis-courses>
- San'yas Indigenous Cultural Safety Training Core Indigenous Cultural Safety Health Training
<https://sanyas.ca/core-training/british-columbia>
- Northern Health Indigenous Health Webinar Series
<https://www.indigenoushealthnh.ca/resources/local-cultural-resources>
- Winnipeg Regional Health Authority

<https://wrha.mb.ca/indigenous-health/cultural-initiatives/micst/>

- Indigenous Cultural Safety (ICS) Learning Series
<https://www.icscollaborative.com/>
- National Collaborating Center for Indigenous Health
<https://www.nccih.ca/34/Publication.nccih?type=6&search=racism>
<https://www.nccih.ca/docs/emerging/RPT-CulturalSafetyPublicHealth-Baba-EN.pdf>
- Government of Canada Indigenous Learning Series
<https://www.csps-efpc.gc.ca/ils-eng.aspx>

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