

# TRAUMA-INFORMED CARE IN THE MANAGEMENT AND TREATMENT OF TUBERCULOSIS IN INDIGENOUS POPULATIONS

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National Collaborating Centre  
for Indigenous Health



Centre de collaboration nationale  
de la santé autochtone

CHRONIC AND INFECTIOUS DISEASES



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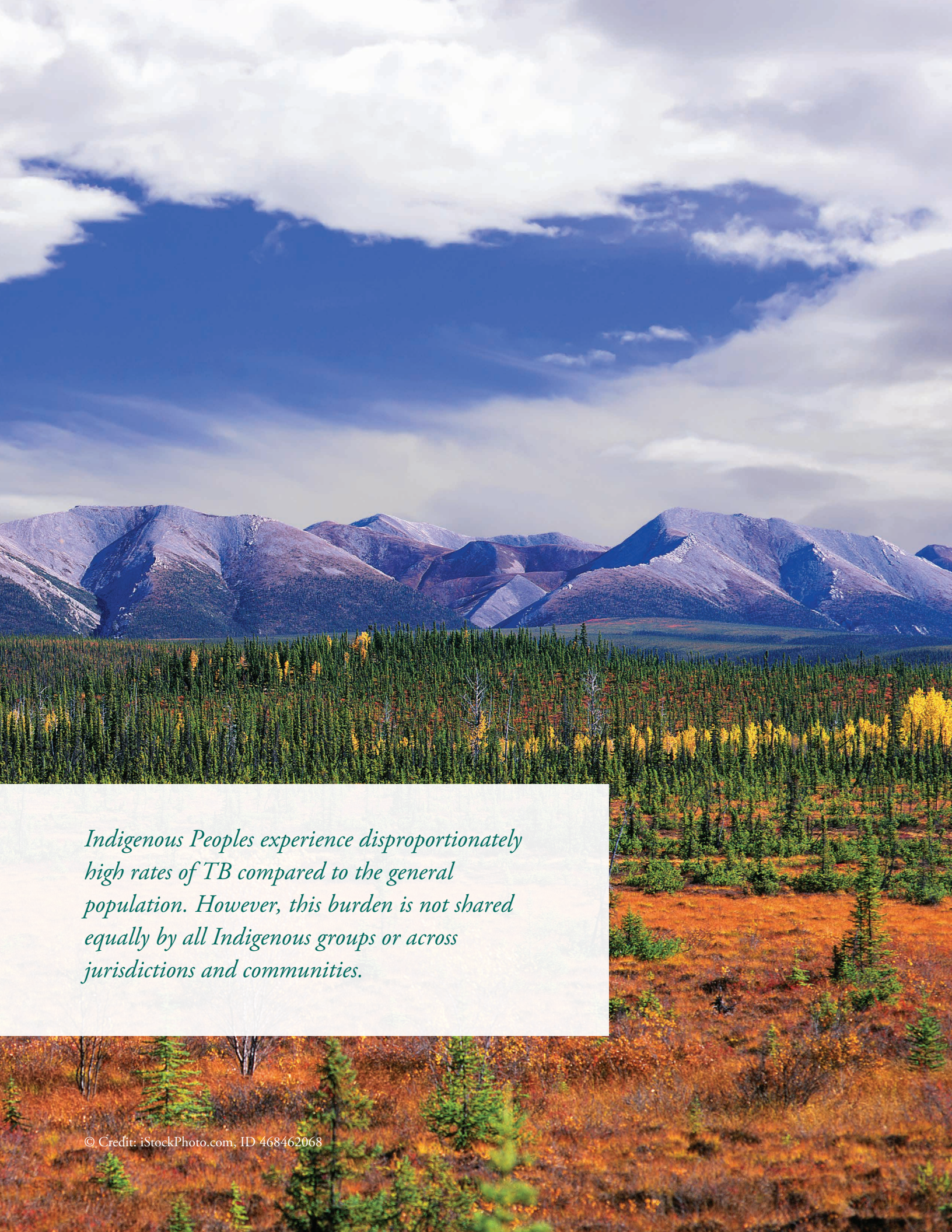


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*Indigenous Peoples experience disproportionately high rates of TB compared to the general population. However, this burden is not shared equally by all Indigenous groups or across jurisdictions and communities.*



# INTRODUCTION



Tuberculosis (TB) is a chronic lung infection caused by an organism called *Mycobacterium tuberculosis* (M.Tb). It primarily infects the lungs, though it may also infect other organs in the body. TB is transmitted via aerosol droplets from people with an active (and contagious) form of the disease. If left untreated, it can result in death; however, not all those infected with TB are contagious, nor will all those exposed become infected. In fact, only 10% of people exposed to the infection will develop active TB within two years, as most people are able to clear the infection on their own (Richardson et al., 2014). Predisposing risk factors that increase the vulnerability of developing active TB after exposure include young age (children less than 5 years) and impaired immunity (i.e., HIV/AIDS, immunosuppressive drugs, alcoholism, diabetes, and pre-existing lung disease). Other factors like poverty, homelessness,

malnutrition, and poor or overcrowded housing can also increase the risk of developing TB (Fox et al., 2015). Many of these conditions are prevalent among Indigenous Peoples<sup>1</sup> and their origins can be traced to the traumatic conditions they have experienced historically and continue to face today.

Indigenous Peoples experience disproportionately high rates of TB compared to the general population. However, this burden is not shared equally by all Indigenous groups or across jurisdictions and communities. In 2020, Inuit had the highest incidence rate for active TB in Canada (72.2 per 100,000 population). This rate represents a significant decline from the previous year, when the incident rate was 188.7 cases per 100,000 population yet is still 15 times the overall Canadian rate (Mouchili et al., 2022b). Given the relatively small Inuit population

in Canada,<sup>2</sup> any community outbreak can translate into a high TB incidence rate. Incident rates of active TB have also trended downward for First Nations and Métis peoples over recent years. In 2020, the incident rate of active TB among status First Nations was 13.6 per 100,000 (down from 22.2 cases per 100,000 population in 2010), while the Métis rate declined from 5.8 per 100,000 population in 2010 to 2.8 per 100,000 in 2020 (Mouchili et al., 2022a, 2022b). In contrast, over the period 2010 to 2020, the incidence rates for Canada as a whole ranged from a high of 5.1 per 100,000 population in 2019 to a low of 4.6 per 100,000 in 2014 and 2015 (Mouchili et al., 2022a, 2022b). Geographically, Nunavut<sup>3</sup> has had the highest rates of TB in Canada, while the Maritime Provinces, Ontario, and Quebec have had rates equal to or lower than the Canadian rate (LaFreniere et al., 2019).

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<sup>1</sup> The term “Indigenous Peoples” is used throughout this report to refer to First Nations people (regardless of location of residence or status), Inuit, and Métis people inclusively.

<sup>2</sup> In 2022, the number of Inuit in Canada was approximately 70,545 (Statistics Canada, 2022a).

<sup>3</sup> Approximately 84% of Nunavut’s population identifies as Inuit (Statistics Canada, 2022b).





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*Despite the availability of effective medications, TB continues to persist in Indigenous communities, driven largely by Indigenous Peoples' long history of enduring trauma, which continues to influence their contemporary experiences with TB and its treatment*

(Abonyi et al., 2017).

Despite the availability of effective medications, TB continues to persist in Indigenous communities, driven largely by Indigenous Peoples' long history of enduring trauma, which continues to influence their contemporary experiences with TB and its treatment (Abonyi et al., 2017). Applying a trauma-informed model of care is recommended, in addition to other TB elimination strategies, to help eradicate TB (British Columbia Centre for Disease Control [BCCDC], 2016).

This paper reviews literature focused on trauma-informed models of care for Indigenous populations and suggests ways of improving TB care for Indigenous Peoples through principles of trauma-informed care (TIC).

Some of this literature is a subset of a more comprehensive literature review undertaken by the National Collaborating Centre for Aboriginal Health (NCCAHA), now the National Collaborating Centre for Indigenous Health (NCCIH),<sup>4</sup> focused on TB and Indigenous populations in Canada (see Halseth & Odulaja, 2018). Literature to inform this review was identified from three academic databases (PubMed Central, Medline, and Google Scholar), using the search terms Aboriginal/Indigenous/Inuit/Métis/First Nation/Native Indian/North American Indian in combination with “tuberculosis.” The search terms “trauma-informed care,” “trauma-informed practice,” and “cultural safety” were subsequently added in conjunction with population-

specific terms and “tuberculosis” to identify literature focused specifically on TIC in this context. The review includes literature published up to 2022. In preliminary searches, we found there is a limited body of literature focused specifically on trauma-informed approaches to TB care in the context of Indigenous populations in Canada. Thus, to fill information gaps, this paper also draws on TIC literature in relation to Indigenous populations in other contexts, such as mental health, HIV/AIDS, and/or social work, incidentally reflecting the multiple and intersecting manifestations of trauma for Indigenous Peoples.

This review is organized into four sections. The paper begins with an overview of what trauma is and its origins for Indigenous Peoples in Canada, followed by a discussion of how trauma influences the transmission of TB in Indigenous populations and what the contemporary context of TB care looks like for this population. The paper then discusses what trauma and trauma-informed care are and examines how a trauma-informed model of care can be applied to the management of TB in Indigenous populations. The paper ends with some concluding statements and suggestions for tools that may inform the implementation of TIC principles in this context.

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<sup>4</sup> This name change occurred in 2019.



# THE ORIGINS OF TRAUMA FOR INDIGENOUS PEOPLES



## Trauma defined

According to the Trauma-Informed Practice Guide (TIP-Guide), trauma is defined as “experiences that overwhelm an individual’s capacity to cope” (TIP Project Team, 2013, p. 6). Trauma can result from events experienced by individuals that are or were physically or emotionally harmful (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). These events can include adverse childhood experiences such as “child abuse, neglect, witnessing violence and disrupted attachment,” as well as later life experiences, such as “violence, accidents, natural disaster, war, sudden expected loss and other life events that are out of one’s control” (TIP Project Team, 2013, p. 6).

Trauma can affect one person individually or groups of people collectively. When experiences of trauma involve large groups of individuals directly or indirectly, either through their shared experiences or recollections

of a traumatic event, this is often referred to as “collective trauma” (Saul, 2013). When large groups of people are exposed to chronic trauma over long periods of time, this trauma can accumulate and be transmitted to future generations, leaving intergenerational impacts on health and well-being. This has been referred to as either “historic(al)” or “intergenerational trauma” (see for example, Bombay et al., 2009; Denham, 2008; Mohatt et al., 2014; and Wesley-Esquimaux & Smolewski, 2004). If left unresolved, trauma can cause victims to feel helpless and lose a sense of control, connection, and meaning (Herman, 1997), which in turn can undermine their psychological, social, and physical health and well-being (Sotero, 2006).

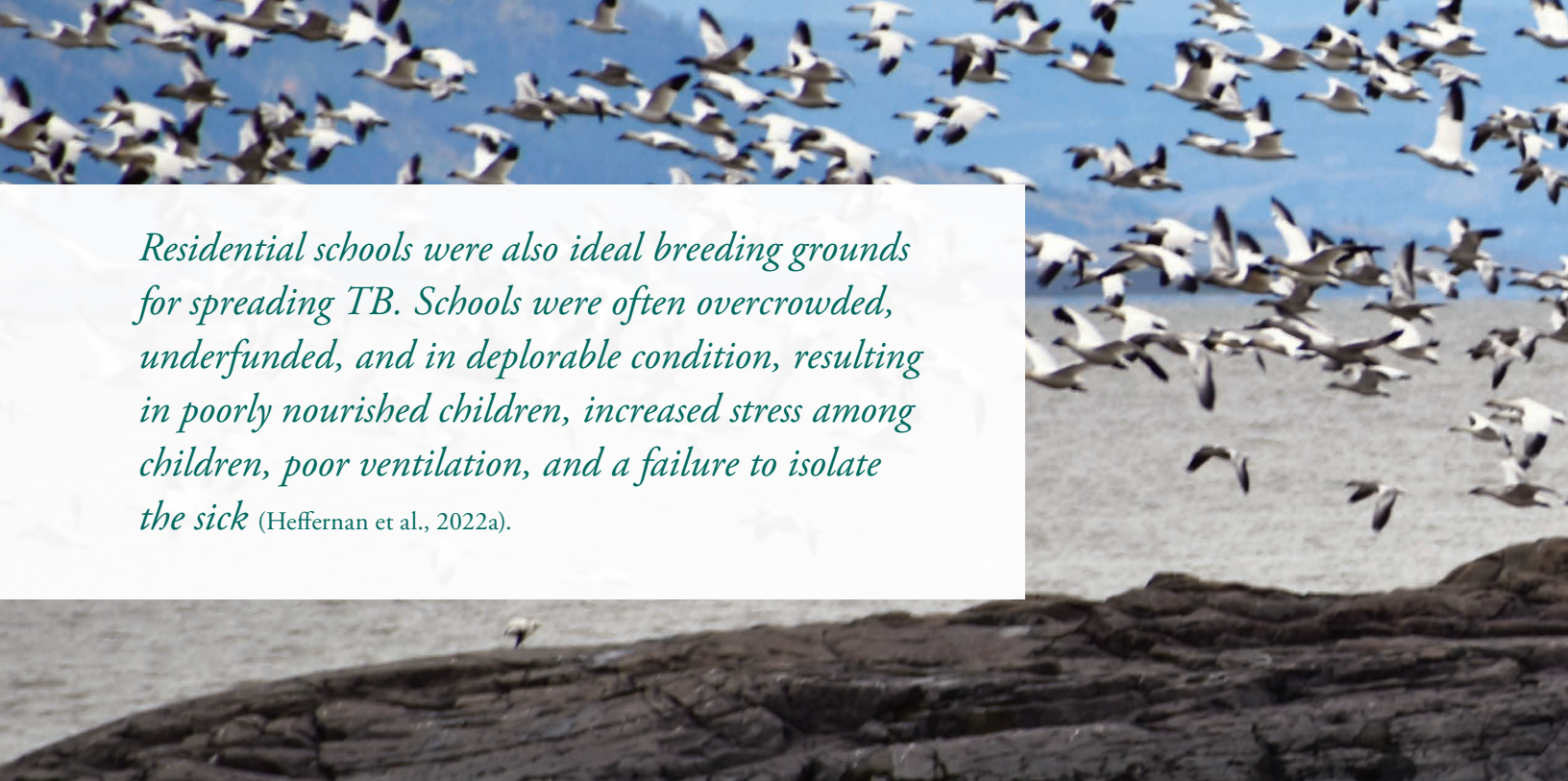
Trauma can manifest in a number of emotional, psychological, and physical symptoms, including: self-blame and self-hatred; fatigue, depression, panic attacks, emotional numbness, dissociative symptoms, withdrawal from normal routine and relationships,

memory lapses (especially about the traumatic experience[s]), substance abuse and/or addictions; self-harming, risk-taking, and abusive behaviours; difficulty concentrating or making decisions; and feelings of despair, anxiety, hopelessness, fearfulness, irritability, or anger (Chansonneuve, 2005; Santa Barbara Graduate Institute Center for Clinical Studies and Research & L.A. County Early Identification and Intervention Group, 2005).

## Colonialism and intergenerational trauma

Indigenous Peoples’ contact with European settlers was one of conquest and devastation. From the 1600’s to the establishment of treaties and colonization in the 1800’s, Indigenous Peoples were introduced to diseases like TB, smallpox, and measles, for which they had no prior immunity, resulting in waves of epidemic disease and decimation of Indigenous populations across North America (Daschuk et al., 2006).





*Residential schools were also ideal breeding grounds for spreading TB. Schools were often overcrowded, underfunded, and in deplorable condition, resulting in poorly nourished children, increased stress among children, poor ventilation, and a failure to isolate the sick* (Heffernan et al., 2022a).

With the adoption of the *Indian Act* in 1876, the colonial government made clear its intention to assimilate Indigenous populations into the dominant Western culture. The *Indian Act* empowered various legislative agencies of the Crown with the legal authority to undertake wide-ranging social, economic, and political actions affecting all aspects of Indigenous Peoples' lives. This highly invasive and paternalistic federal law allowed the federal government to implement policies that led to the forceful displacement of Indigenous communities from their traditional lands; the apprehension of Indigenous children into residential schools; the continued disproportionate removal of Indigenous children from their families and into the child welfare system; persistent inadequate funding for housing,

transportation infrastructure, and health care at both community and individual levels; and the deprivation of Indigenous communities of their right to self-determination – that is, the ability to control decisions regarding their lands, health, economy, trade, and governance (Falk, 2019; First Nations & Indigenous Studies, 2009; Hick, 2019; Hodgson, 1982; Patterson et al., 2018; Smith et al., 2021). Collectively, these colonial policies have contributed to high rates of poverty, poor housing, unemployment, and inaccessible health care services, leading to increased stress, mental and physical health issues, and in turn, greater likelihood of developing active TB (Greenaway et al., 2022; Heffernan et al., 2022a). They have also increased the likelihood of Indigenous people experiencing trauma in

their lives, including physical violence and sexual assault (Heidinger, 2021, 2022; Long, 2021).

The imposition of the Indian Residential School system is one of the leading sources of intergenerational trauma among Indigenous Peoples. This system of education was adopted by the federal government, in collaboration with religious institutions, for the purpose of assimilating Indigenous Peoples into mainstream society. It led to the forced removal and separation of Indigenous children from their homes, families, and communities, and the denigration of Indigenous languages and cultures. For far too many Indigenous children, the quality of education received was poor and treatment was harsh, exposing many to multiple





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types of abuse and trauma (Truth and Reconciliation Commission [TRC], 2015). The residential schools contributed to feelings of isolation, shame, and anger, and left “long lasting and intergenerational effects on the physical and mental well-being of Indigenous populations in Canada” (Wilk et al., 2017, p. 1). Many families continue to experience poor general and self-rated health, and high rates of chronic and infectious diseases, mental distress, depression, substance abuse, and suicidal behaviours. The intergenerational effects of residential schools were, and continue to be, experienced at individual, family, and community levels through high rates of family violence, child abuse, apprehension of children into the child welfare system, and incarceration (Bombay et al., 2009; Partridge, 2010; TRC,

2015). These effects, in turn, have fostered environments in which additional trauma can multiply.

Residential schools were also ideal breeding grounds for spreading TB. Schools were often overcrowded, underfunded, and in deplorable condition, resulting in poorly nourished children, increased stress among children, poor ventilation, and a failure to isolate the sick (Heffernan et al., 2022a). Evidence drawn from five southern Alberta residential schools revealed that in 1908, more than 70% of 175 students had TB (ranging from a low of 51% in one school to a high of 100% in two other schools) (Hackett, 2014). In 1922, a former Medical Inspector for the Department of Indian Affairs, Dr. Peter Bryce, reported on the alarmingly high TB mortality rates among children in western

Indian Residential Schools, yet attendance was compulsory under federal law (Bryce, 1922) and no comprehensive efforts seem to have been made to eradicate TB from these schools until the 1940s (Komarnisky et al., 2016). As it was, the high rates of TB in residential schools contributed to a TB epidemic simultaneously occurring within Indigenous, especially northern, First Nations and Inuit communities.



## The trauma of historic TB treatment

When European colonizers began to arrive in large numbers during the 1600s and 1700s in what is now known as Canada, they created an environment of material deprivation in which infectious diseases like TB could flourish (Hoepfner & Marciniuk, 2000; Kulmann & Richmond, 2011). TB spread rapidly from east to west in conjunction with European settlement through to the construction of the Canadian Pacific Railway in the 1800s, then moved into the northern territories in the 20<sup>th</sup> century (Grzybowski & Allen, 1999; Hoepfner & Marciniuk, 2000). The TB epidemic reached a crisis during the 1940s and 1950s, particularly among Inuit who had

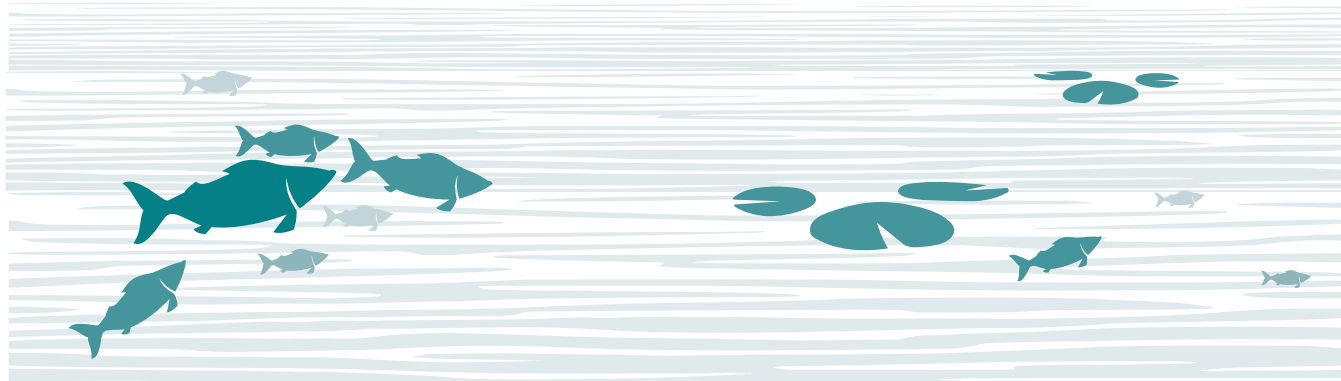
incidence rates ranging between 1500-2900 cases per 100,000 (Demmer, 2011; Kulmann & Richmond, 2011; Orr, 2013). At the height of the epidemic, an estimated 7-10% of the Inuit population was hospitalized with TB (Olofsson et al., 2008). Indigenous people were often blamed by medical professionals for spreading the disease (Kelm, 1998).

The Canadian government adopted a heavy-handed response to the TB epidemic in the early twentieth century, which further contributed to the trauma experienced by Indigenous Peoples. During the 1940s, they implemented an aggressive TB strategy involving mass TB screening in northern Indigenous communities,

forced Bacille Calmette-Guèrin (BCG) vaccinations<sup>5</sup> for Indigenous children in high-risk communities, and large-scale evacuations of Indigenous patients suspected of having TB from their communities to southern sanatoriums where they were quarantined (Grzybowski & Dorken, 1983; Nixon, 1988; Olofsson et al., 2008). By 1960, there were about 22 Indian hospitals and sanatoria operating in Canada (Komarnisky et al., 2016). Before the discovery of antibiotics, treatment for TB consisted of a lengthy stay in these sanatoriums (sometimes for years), with plenty of bed rest, good nutrition, and fresh air. Once the use of antibiotics became widespread, this time was reduced to 7-8 months (Moffatt et al., 2013).

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<sup>5</sup> BCG is a widely administered vaccine made with an attenuated strain of the M.tb virus. It has been routinely administered in newborns of high-risk populations, including First Nations on reserve and Inuit. Use of the vaccine is controversial because it does not entirely prevent infection, it has no impact on more serious forms of the disease such as military and meningeal TB, its protective effects wane with time, it can impact the accuracy of TB skin tests, and there have been reports of disseminated BCG infection in children with severe congenital or acquired immunodeficiency syndromes, resulting in death (Cook & Elwood, 2004). Forceful compliance with the vaccine also aroused suspicions that Indigenous patients were being used as test “guinea pigs,” causing mistrust in the healthcare system (Jacklin et al., 2017).







The federal government's TB strategy took a heavy toll on Indigenous individuals, families, and communities. Non-Indigenous public health officials often used coercive tactics to force Indigenous people to be admitted to the nearest sanatorium, such as arresting them when symptoms of TB were present or withholding federal funding to First Nation reserves (Lux, 2010, Shedden, 2011). Individuals suspected of having TB faced a frightening experience of being

forcibly removed and placed for extended periods of time in a foreign hospital environment without their consent, or that of their families, where they experienced alienation from friends and family (Moffatt et al., 2013; Selway, 2016). Many Indigenous patients found the forced treatments distressing and isolating (Dunn et al., 2022; Pelley, 2018). These hospitals were generally characterized by their lack of capacity and language to explain TB and its

treatment to Indigenous patients, inability to practice traditional healing methods, delivery of anonymous TB care,<sup>6</sup> and failure to notify family members when their loved ones died (Crawford et al., 2021; Jonathan, 2017; Mayan et al., 2017; Selway, 2016). Many Indigenous patients were also subject to abuse and neglect, including medical experimentation, in these Indian hospitals (Geddes, 2017).

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<sup>6</sup> Anonymous TB care refers to the system of numbers in place at that time used to identify TB patients rather than names.





*Many Indigenous patients died of the disease, some returned to the wrong communities because of poor record keeping, others lost connection to their communities and never returned, while still others returned to their communities but faced challenges reintegrating or rejection from community members*

(Mayan et al., 2017; Moffatt et al., 2013; Smith et al., 2021).

The foreign medical practices, language, and culture Indigenous people were forced to endure in the sanatoria environment resulted in communication barriers, as well as apprehension and uncertainty about the disease, its treatment, and when patients would be able to return to their home communities (Moffatt et al., 2013). Many Indigenous patients died of the disease, some returned to the wrong communities because of poor record keeping, others lost connection to their communities and never returned, while still others returned to their communities but faced challenges reintegrating or rejection from community members (Mayan et al., 2017; Moffatt et al., 2013; Smith et al., 2021). Some



Indigenous children were also sent directly to residential schools after recovering from TB, compounding the trauma of their TB treatment (Jetty & FNIM Health Committee, 2020).

The physical, spiritual, and cultural separation from families and communities that Indigenous TB patients experienced left long-lasting impacts on their psyche (Moffatt et al., 2013). In a study aiming to understand the contemporary effects of past TB treatment on First Nations, participants from the prairie provinces reflected on the impacts of TB treatment in sanatoriums (Komarnisky et al., 2016). They spoke about the hopelessness, anger, and fear they experienced in relation to their own TB treatment and about their loved ones being airlifted to unfamiliar places for treatment and finding out years later they had died. These types of narratives have been transmitted orally through generations and continue to shape Indigenous Peoples' contemporary perspectives and understandings about TB, which in turn, has limited the effectiveness of contemporary TB treatment (Hackett, 2005; Moffatt et al., 2013; Tester et al., 2001).

The legacy of historic TB control practices endures today through stigma and discrimination towards those with the disease, fear and mistrust of Western healthcare providers and institutions within Indigenous

communities, as well as fear of being diagnosed with TB (Greenaway et al., 2022; Jetty, 2021; Moffatt et al., 2013; Robinson, 2015; Smith et al., 2021). As a result, Indigenous people with TB are at increased risk of further traumatization. Being diagnosed with TB and undergoing treatment can be a traumatic experience because of the social stigma attached to the disease, the many side effects from the treatment itself, and the potential impacts of a diagnosis on individuals and families. This can be demoralizing and raise a host of mental health issues, including depression, anxiety (Venkatraju & Prasad, 2013), and a high degree of psychological distress (Louw et al., 2016; Orhan Aydin & Uluşahin, 2001; Tola et al., 2015). Additionally, people diagnosed with TB are less likely to find work, be able to work, or care for their families due to the associated stigma and isolation requirements, aggravating pre-existing conditions of poverty and causing further psychological distress (Westaway & Womorans, 1994).

Indigenous people also continue to endure negative encounters with mainstream healthcare systems, including racism, discrimination, and negative stereotypes, which can lead to re-traumatization and further mistrust in the healthcare system (Abonyi et al., 2017). Collectively, these experiences can contribute to a reluctance to undergo TB

screening and seek treatment, which poses a significant barrier to accessing timely and effective TB care (Anderson, 2019; Brassard et al., 2008; Gibson et al., 2005; LaVallee, 2014; Macdonald et al., 2010; Marra et al., 2004; Møller, 2010; Smith et al., 2021). In turn, delays in diagnoses and treatment are instrumental in contributing to the ongoing persistence of TB in Indigenous communities.

Colonial policies and historic TB treatment, coupled with socio-economic marginalization and ongoing racism and discrimination in the healthcare system and society generally, have exposed many Indigenous people to multiple traumatic events over the life course, resulting in intergenerational impacts to the health and well-being of individuals, families, and communities. Notably, any adult, child, or descendent who has suffered loss of land, culture, family, language, and/or ways of life due to colonization and its numerous institutions is a victim of trauma (Chansonneuve, 2005).





*The high prevalence of TB among Indigenous populations in Canada is a consequence of the historical and ongoing effects of colonialism, which have resulted in chronic and intergenerational trauma.*



# THE INFLUENCE OF TRAUMA ON THE TRANSMISSION OF TB AMONG INDIGENOUS POPULATIONS



The high prevalence of TB among Indigenous populations in Canada is a consequence of the historical and ongoing effects of colonialism, which have resulted in chronic and intergenerational trauma. Past traumatic experiences can leave “lifelong devastating impacts on a person’s sense of self, safety, attachment, relationships, ability to regulate emotions, and physical or mental health” (Anderson, 2019, p. 27). In the context of Indigenous populations, these impacts can affect the transmission of TB through physical, environmental, and social pathways.

## Physical pathways

Research has shown that traumatic experiences not only leave mental and physical scars on individuals for life but also weaken the immune system, leaving individuals more vulnerable to disease infection and progression (Segerstrom &

Miller, 2004). When individuals experience traumatic events, they are exposed to high levels of stress. Chronic stress alters the body’s response to invading organisms like viruses and bacteria. In individuals who are exposed to chronic stimuli, including stress and traumatic experiences, the number and function of two types of cells that are critical for the immune system – the Natural Killer Cells and the cytotoxic T cells – become depressed (Schnurr, & Green, 2004). While both cell types can kill foreign pathogens, they belong to different immune systems.

Natural Killer Cells belong to the innate immune system and serve as a first line of defense against any foreign pathogens, including bacterial or virus particles or virus infected cells, responding quickly and killing them before they can do harm (Vivier et al., 2008). With repeated exposure

to the same pathogen, a memory response is induced and the adaptive immune system initiates a more rapid and heightened immune reaction targeting this one specific pathogen (Andersen et al., 2006). Cytotoxic T cells belong to the adaptive part of the immune system. An intact cell-mediated immunity is necessary to contain TB infection early, thus as these immune systems become weakened through chronic stimuli, they become a potential pathway for TB to invade and proliferate in individuals exposed to the organism. Presently, much of the research on immune response and chronic stress focuses on mental illnesses, particularly post-traumatic stress syndrome. There is a need for more research on the immune system’s response to TB infection in people who are also chronically stressed, like Indigenous people with historical and intergenerational experiences of trauma.



*Indigenous Peoples' historic and contemporary experiences with colonialism have not only contributed to increased exposure to trauma but have also led to social and cultural marginalization, which is at the root of many of the health inequities Indigenous Peoples face today.*

## Environmental pathways

Indigenous Peoples' historic and contemporary experiences with colonialism have not only contributed to increased exposure to trauma but have also led to social and cultural marginalization, which is at the root of many of the health inequities Indigenous Peoples face today. As a result, Indigenous people are more likely than the non-Indigenous population to live in poverty, which increases the risk of being in poor health or malnourished (Beedie et al., 2019; MacDonald & Wilson, 2016). This can impair the body's ability to fight off infectious organisms (Gupta et al., 2009). Indigenous people are also more likely to live in poorly ventilated

or overcrowded housing or be homeless compared to non-Indigenous people (National Collaborating Centre for Aboriginal Health [NCCAHA], 2017a). This increases the risk of contracting TB infection and progressing to active TB disease due to close contact with those who may carry the infection (Narasimhan et al., 2013). Lower levels of or inequitable access to education may also result in reduced health literacy about TB prevention, management, and treatment, leading to delayed diagnosis and treatment (NCCAHA, 2017b). Additionally, the health care environment, including negative experiences with mainstream healthcare systems, mistrust of healthcare providers, and culturally

inappropriate healthcare, can be barriers to TB diagnosis and treatment, allowing TB to spread to others (Gibson, et al., 2005; Jenkins, 1977; Møller, 2005; Orr, 2011).

As a result of colonialism and socio-economic marginalization, Indigenous Peoples have higher rates of chronic conditions than the non-Indigenous population. The rapid lifestyle changes that many Indigenous communities have experienced,<sup>7</sup> from a traditional way of life on the land to a more sedentary one, coupled with limited access to affordable and nutritious market-based foods in northern and remote areas, have led to reduced physical activity and less nutrient dense diets (Egeland et al., 2011;

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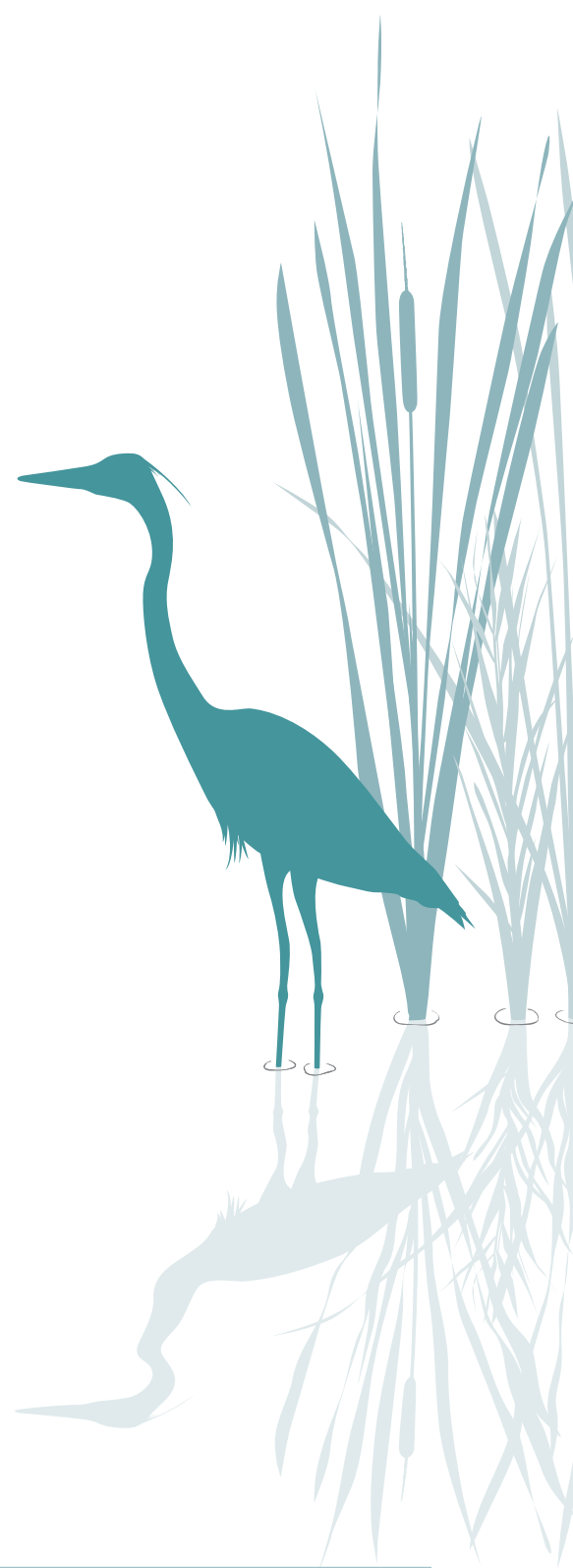
<sup>7</sup> It is important to note that many Indigenous communities maintain or have revitalized (or are in the process of revitalizing) their traditional practices and lifestyles.



Halseth, 2015; Rice et al., 2016; Wilson, 2021). This has resulted in high rates of diabetes mellitus, especially among First Nations who have rates of diabetes that are approximately 3-5 times greater than in the general population (Chief Public Health Officer, 2013; Walker et al., 2020). Diabetes mellitus is considered one of the main factors that can increase the risk of developing active TB infection once exposed to the TB organism (Cormier et al., 2019; Narasimhan et al., 2013). Inequities in the social determinants, including traumatic childhood experiences, poverty, unstable housing, mental health and addictions, and food insecurity, also contribute to the disproportionately high rates of HIV/AIDS among Indigenous populations in Canada (Public Health Agency of Canada [PHAC], 2014; Woodgate et al., 2017). This is particularly concerning, as HIV/AIDS also increases the risk of progressing from latent TB infection<sup>8</sup> (LTBI) to active TB disease (Menzies et al., 2014).

Historic and contemporary experiences of trauma, including loss of identity and culture, violence in families and communities, hopelessness, and despair, contribute to unhealthy coping mechanisms, including smoking, alcohol, and drug use.

These coping mechanisms can increase the risk of TB infection and progression to active TB disease because they can weaken the immune system and/or are associated with other risk factors for TB infection and progression, such as homelessness or HIV/AIDS (Deiss et al., 2009; Narasimhan et al., 2013; Rehm et al., 2009). As a result of trauma, Indigenous people are more prone to smoke, use marijuana and other illicit drugs, and engage in binge drinking (First Nations Information Governance Centre, 2012; Kelly-Scott & Smith, 2015; Sikorski et al., 2019; Statistics Canada, 2015). Substance abuse can present challenges in the identification and treatment of TB because it can mask its symptoms, resulting in delayed care, or pose difficulties for adhering to treatment for LTBI or TB disease (Abonyi et al., 2017; Hirsch-Moverman et al., 2008; Robinson, 2015). In the face of multiple competing challenges, including substance abuse, comorbidities like diabetes and HIV/AIDS, and having basic needs like food and housing being unmet, some Indigenous people may consider dealing with TB to be a lower priority, causing them to ignore the disease until their deteriorating health becomes too obvious (McMullin et al., 2012).



<sup>8</sup> Latent TB infection (LTBI) is when individuals have been infected with *M.tb* tuberculosis but have not (yet) developed active TB. Identifying individuals with LTBI and having them complete antiretroviral therapy are key components of strategies to eradicate the disease.

*The social stigma attached to having TB creates a general silence about the disease in Indigenous communities and prevents individuals from talking about it with others*

(Smith et al., 2021).



## Social pathways

One of the adverse outcomes of Canada's historical TB strategy is the stigma tied to the infection (Smith et al., 2021). Stigma is shaped by the health care experiences of Indigenous Peoples, including racism, discrimination, stereotyping, and negative encounters with healthcare providers who may judge or dismiss patients' concerns (Smith et al., 2021). Stigma can perpetuate Indigenous identities as "being poor and lacking self-care" (Mayan et al., 2019, p. 11; see also Westaway & Womorans, 1994), which can reinforce racist beliefs among mainstream healthcare providers, lead to discrimination, and enhance feelings of mistrust by Indigenous patients toward mainstream healthcare systems. In a study of Inuit perceptions about TB in two Nunavut communities, TB was perceived as afflicting

those who broke moral codes of conduct (Møller, 2010). Stigma can leave individuals with TB feeling unworthy (Jetty, 2021), compromise their mental health (Jetty, 2021; Jetty & FNIM Health Committee, 2020) and invoke feelings of fear in relation to infecting others or the repercussions of a TB diagnosis<sup>9</sup> (Robinson, 2015). Stigma can lead to internalized self-blame (Craig et al., 2017; Jacklin et al., 2017; Robinson, 2015), self-imposed emotional and physical isolation from sources of support (Jetty, 2021; Jetty & FNIM Health Committee, 2020), and the normalization of poor health (Brassard et al., 2008). Stigma is amplified when other intersecting forms of stigma are present, including stigma towards persons with mental health conditions, substance use disorders and HIV, as well as stigma related to gender, sexual orientation, age, and race (Erickson et al., 2022; Long,

2021; Murney et al., 2020; Smith et al., 2021; Smye et al., 2023).

The social stigma attached to having TB creates a general silence about the disease in Indigenous communities and prevents individuals from talking about it with others (Smith et al., 2021). As a result of stigma, individuals may be reluctant to seek a diagnosis for their symptoms, leading to more advanced forms of TB upon diagnosis (Craig et al., 2017; Mayan et al., 2019; Robinson, 2015). They may also be reluctant to disclose their TB diagnosis to anyone, leaving them isolated and without the support they need to adhere fully to isolation requirements and antiretroviral therapy, compromising treatment and enabling the further spread of TB (Erickson et al., 2022; Robinson, 2015).

<sup>9</sup> The repercussions of a TB diagnosis can include loss of friends, loss of acceptance in communities, loss of employment and related socio-economic impact, concerns over who will care for one's children if hospitalized, and associated negative impacts to quality of life (Robinson, 2015).



Many urban medical professionals do not fully understand the transmission of TB and lack experience diagnosing and treating the disease (Mayan et al., 2019; Robinson, 2015). This contributes further to the stigma urban Indigenous people experience when seeking TB treatment, which in turn contributes to the ongoing transmission of the disease.

## The intersecting pathways of TB transmission in Indigenous communities

Collectively, the multiple pathways by which TB can be transmitted among Indigenous populations complicate the eradication of this disease. Ghanem et al. (2019) utilize a framework based on predisposing, enabling, and reinforcing factors to show how the multiple factors interact to contribute to an ongoing TB outbreak in the Inuit community of Qikiqtarjuaq, Nunavut. The community was predisposed to the TB outbreak by their historical experiences with the federal government's TB eradication efforts and sustained impacts of colonialism, which rooted a deep mistrust towards government institutions and TB control and treatment policies. The TB outbreak was enabled by inadequate housing and sanitation infrastructure, lack of access to healthcare services, food insecurity and malnutrition, and poor observance of TB recommendations. Finally, the outbreak was reinforced by fear and

stigma around TB, contributing to delayed diagnosis and evacuation from the community for treatment. These factors impeded efforts to eradicate TB from the community.

Likewise, a study by Abonyi and colleagues (2017) highlights the many ways that colonization and colonialism, with its resulting intergenerational trauma and influences on the social determinants of health, affect the way First Nations people experience and give meaning to TB and access TB care. They sought to identify the factors that contributed to the persistence and advanced state of TB in First Nations communities in Manitoba, Saskatchewan, and Alberta. Most of the study participants had low levels of educational attainment and were unemployed, and many reported experiences of crowded housing conditions with perceived poor air quality, as well as incarceration within the past two years, one or more chronic health conditions, and smoking. Study participants identified a number of barriers attributable to the social determinants of health that prevented them from accessing timely TB care, including: worries about who would care for their children if they were hospitalized, fear of losing their jobs, fear of being diagnosed with TB and associated stigma; general apprehension in accessing mainstream health care due to mistrust, racism,

and discrimination; poverty; not noticing their declining health due to other influences like chronic conditions, substance use, and recent personal losses; and a general sense of hopelessness and despair. Collectively, these social determinants so influenced health seeking behaviours that individuals were literally “falling down” due to their deteriorating health before they sought treatment, at which point TB symptoms were very advanced.

Robinson (2015) revealed similar findings in his graduate research on the value of connections for Indigenous people in Alberta, Saskatchewan and Manitoba who were navigating their TB experiences. His study highlighted how poverty and unhealthy lifestyle choices took an emotional and psychological toll on the well-being of study participants and helped mask their TB symptoms, contributing to the normalization of TB and the downplaying of its symptoms. As a result, study participants lived longer with the disease before seeking a diagnosis and treatment, increasing the spread of the disease to others.



# CONTEMPORARY TB CARE FOR INDIGENOUS POPULATIONS



The persistence of TB in many Indigenous communities suggests that prevention and control measures are insufficient. Canada has committed to meeting global<sup>10</sup> and national<sup>11</sup> TB elimination targets for low incidence countries, as well as to eliminating TB across Inuit Nunangat by 2030,<sup>12</sup> yet so far has failed to meet these goals (Abdollahi et al., 2022). To meet its commitments, a coordinated national strategy, with targeted and innovative interventions, is needed (Basham et al., 2019a). These interventions must account for the ongoing barriers that Indigenous patients may face in accessing timely TB care. This section describes Indigenous

Peoples' contemporary experiences with and barriers to TB care, including their knowledge and understanding of TB and its treatment.

## TB control strategies

Current strategies to control and treat TB continue to bear some resemblance to past TB management in the sanatorium system, thus have the potential to be re-traumatizing. This includes relocation from home communities into hospital settings for isolation and treatment of active TB cases, uncertainty about the time frame for treatment, and now – the invasive practice of contact tracing.

The isolation requirements for infectious cases of TB vary across Canada. Saskatchewan has a patient-centred approach that allows TB patients to be isolated in their own home with the support of a community-based team (Mayan et al., 2017). For patients who are particularly ill, some hospitalization may still be required but stays are typically short in duration, based on the assumption – increasingly supported by research evidence – that patients without drug resistant TB will be rapidly rendered non-infectious after initiating 'directly observed treatment' (DOT)<sup>13</sup> (Mayan et al., 2017). The province makes some effort to provide stimulation for

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<sup>10</sup> The global target, set by the World Health Organization, is < 1 case per 1,000,000 annually by 2050 (Amaratunga & Alvarez, 2016).

<sup>11</sup> National targets have been set at < 3.6 per 100,000 annually by 2015 (Amaratunga & Alvarez, 2016) and a 90% reduction of new incident cases by 2036 (Heffernan et al., 2022b).

<sup>12</sup> It also announced its commitment to reduce active TB in this region by at least 50% by 2025 (Indigenous Services Canada, 2018).

<sup>13</sup> Directly observed treatment (DOT) refers to the visual observance that TB patients have taken their antiretroviral drugs. This method is considered more effective than self-administered therapy in improving medication adherence and health outcomes of TB patients (Pradipta et al., 2020).



hospitalized patients in isolation and foster social and cultural connections, such as through allowing family visitations, supplementing hospital food with home cooking, and providing access to an Aboriginal Liaison Worker who can perform ceremonies and support family members (Mayan et al., 2017). In comparison, Alberta allows for some home isolation, although this option is typically not made available to on-reserve First Nations patients with infectious pulmonary TB.<sup>14</sup> These patients are generally required to remain in isolation in a hospital setting until they are proven to be non-infectious (Mayan et al., 2017). Meanwhile, Manitoba mandates isolation in a hospital setting only. In fact, patients in Manitoba who are not compliant with isolation requirements may be apprehended by a peace officer and detained, a scenario that closely resembles the trauma experienced by Indigenous people with historic TB treatment (Mayan et al., 2017; Robinson, 2015).



For Indigenous patients, many of whom are from communities with local health centres that lack isolation capacity, the requirement to isolate in a hospital setting entails separation from families, communities, and support networks, leading to disconnection from cultural and social ties (Mayan et al., 2017). While current TB policies regarding home isolation for TB patients may not single-handedly eliminate TB transmission in Indigenous communities, the lower TB rates found in Saskatchewan compared to Manitoba<sup>15</sup> provide

some evidence that traumatizing approaches that mirror historic TB treatment may be less effective in eradicating TB (Robinson, 2015).

Contact tracing is also a key feature of contemporary TB management. This practice requires patients with TB to identify their close contacts and can be a fearful and stigmatizing experience, very much reminiscent of historical TB practices (Komarnisky et al., 2016).

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<sup>14</sup> Tuberculosis can be classified as either respiratory or non-respiratory and can come in multiple forms, based on site of infection. Pulmonary TB is the most common form and includes “tuberculosis fibrosis of the lung, tuberculous bronchiectasis, tuberculous pneumonia and tuberculous pneumothorax, isolated tracheal or bronchial TB, and tuberculous laryngitis” (Mouchili et al., 2022b, pp. 5-6).

<sup>15</sup> For example, in 2017 the incidence rates of TB were 94 per 100,000 in Saskatchewan compared to 187 per 100,000 for Manitoba (LaFreniere et al., 2019).

*Indigenous people in Canada face numerous barriers to accessing healthcare services at individual, societal, and health system levels, which can influence their TB experiences and health outcomes.*



## Barriers to health care

Indigenous people in Canada face numerous barriers to accessing healthcare services at individual, societal, and health system levels, which can influence their TB experiences and health outcomes. Some of these barriers occur across Indigenous populations regardless of geographic location, while others are unique to urban or remote/isolated areas. Challenges may exist across the cascade of care<sup>16</sup> and may include long wait times for physicians and health specialists, the complexities of a highly mobile lifestyle or homelessness, the absence of a personal health card (Brassard et al., 2008), and the side effects of TB drugs (Macdonald et al., 2010). These barriers can delay health seeking behaviour, diagnosis, treatment, and adherence to treatment.

As noted earlier, the shame and stigma associated with TB can also be a significant barrier to receiving a timely diagnosis and treatment (Brassard et al., 2008; Gibson et al., 2005; LaVallee, 2014; Macdonald et al., 2010; Marra et al., 2004; Møller, 2010). When health care providers are not mindful of Indigenous Peoples' psychosocial and historical experiences with TB, they can consciously or unconsciously re-enact past negative experiences. For example, a participant in Brassard et al.'s (2008) study on the TB experiences of urban Indigenous people in Montreal described the intense shame he felt when a health worker made him wear a face mask home from the TB clinic. Actions like this – though needed – can cause poor adherence to treatment and emphasize the need for cultural

sensitivity and competence in practice (discussed in later sections).

Studies suggest that Indigenous people's access to a timely TB diagnosis and treatment and the quality of care they receive can differ greatly by whether they live in remote and isolated communities or in urban and non-remote settings (Mayan et al., 2017; Robinson, 2015). Rural, remote, and isolated First Nations, Inuit, and Métis communities face significant barriers to accessing health care, including precarious transportation infrastructure, chronic vacancies and high turnover of health care staff, inequitable access to supplies and resources, lack of isolation capacity at local health centres, and lack of diagnostic services (Abonyi et al., 2017; Greenaway et al., 2022; Jacklin

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<sup>16</sup> The cascade of care refers to the various steps involved in health care, from testing, to receiving a diagnosis, to referrals, to treatment initiation and completion.





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*Studies suggest that Indigenous people's access to a timely TB diagnosis and treatment and the quality of care they receive can differ greatly by whether they live in remote and isolated communities or in urban and non-remote settings*

(Mayan et al., 2017; Robinson, 2015).

et al., 2017; Mayan et al., 2017; Patterson et al., 2018; Robinson, 2015). Federal policies contribute further to these inequities across First Nations communities by providing smaller communities with less funding for services, creating challenges in the coordination and funding of health care across jurisdictions (Falk, 2019). Consequently, Indigenous TB patients are often removed from their homes and communities for treatment in more urban centres.

Research has shown that extended periods of isolation can take an emotional and mental toll on Indigenous TB patients. This can include exacerbated feelings of imprisonment, isolation, and social disconnection, as well as heightened levels of depression, anxiety, and anger due to loss of social connections with friends and family and inability to go outside and engage with nature (Mayan et al., 2017; Robinson, 2015). Mayan et al. (2017) argue that Indigenous people's feelings

of confinement and disconnection in TB isolation must be understood through the lens of their historical TB treatment and experiences in sanatoriums, the role of family in their lives, and their strong connection to their communities and the land. Negative experiences in accessing TB care and treatment are subsequently shared with others, potentially impacting other people's desire to get tested (Robinson, 2015).

Despite the additional health resource challenges faced in rural, remote, and isolated First Nations, Inuit, and Métis communities, individuals in these communities may have a greater likelihood of having their cases of TB diagnosed and treated more quickly compared to those living in urban and off-reserve communities. This is because individuals know exactly where to access health services and TB information in these communities due to the limited number of health services and health

practitioners. As such, there is increased potential for patients to access a consistent health care provider – one who is embedded in the local community, knows community members, has a good relationship with them, provides culturally sensitive care, and has knowledge about and familiarity with TB due to previous experience with the disease (Mayan et al., 2019; Robinson, 2015). However, patients with TB from rural, remote, and isolated communities may have greater concerns about lack of confidentiality, shame, and fear of contagion compared to their urban counterparts, which may pose barriers to TB care (Mayan et al., 2019).

In contrast, urban and non-remote Indigenous populations face unique challenges in accessing health services, which can cause delays in obtaining an accurate TB diagnosis and lead to more advanced presentations of the disease (Mayan et al., 2019). Indigenous people in these



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settings often do not know where to go for TB information and generally access care in hospital emergency rooms and walk-in clinics. These settings are often characterized by a lack of access to a consistent family physician, negative health care encounters (including dismissive treatment, indifference, racism, and stereotyping), as well as health care providers who are unfamiliar with TB. This can result in misdiagnoses, numerous repeat visits with a health care provider, and unnecessary prescriptions for medications (Mayan et al., 2019; Robinson, 2015). By the time patients receive a TB diagnosis, their condition may have worsened.

Jurisdictional fragmentation can further complicate access to health services. Access to

federally funded health services on reserve is limited by rules around First Nations status, band membership, and residency<sup>17</sup> (Browne et al., 2009). Health services for off-reserve individuals are under provincial and territorial jurisdiction, with each government having different rules and policies. For First Nations people, who often move between urban centres and their home communities (Murdock, 2023; Snyder & Wilson, 2012), jurisdictional fragmentation can present challenges for continuity of care and funding across jurisdictions and lead to potential miscommunication when jurisdictional lines must be crossed to access health services, which in turn can complicate TB control (Falk, 2019; Robinson, 2015; Vidanaral et al., 2022).

Cultural and linguistic barriers can further impede access to health care. When health services are offered in a culturally and linguistically foreign and unwelcoming environment, Indigenous patients may feel unsafe when accessing care (Macdonald et al., 2010). Cultural safety is essential for patients accessing health services so they do not deny the severity of their health problems, experience low self-worth, develop mistrust when interacting with health care professionals, and subsequently avoid utilizing health services. Culturally safe services do not denigrate or threaten the cherished values, goals, language, identity, and ways of life of patients and do not ask them “to venture into a foreign culture without knowing how

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<sup>17</sup> The ability of First Nation persons to access federal Indigenous-specific services is dependent on whether they have First Nations status, live on or off reserve, and have membership in a band. This is due to the federal government’s long-standing position that it has responsibility solely for registered (status) First Nations living on reserve and Inuit in Inuit communities. leaving non-registered First Nations people living on-reserve and Indigenous Peoples living off-reserve at a significant disadvantage in terms of access to federally funded health programs and services.



to function in it and without positive accompaniment” (Page, 2021, p. 1). Rather, they entail communication of health information in one’s own language and effective cross-cultural communication techniques, and they make patients feel respected and heard (Ladha et al., 2018; Page, 2021). Culturally safe care is thus also key to avoiding misdiagnoses, repeated health care visits, and poor adherence to TB treatment.

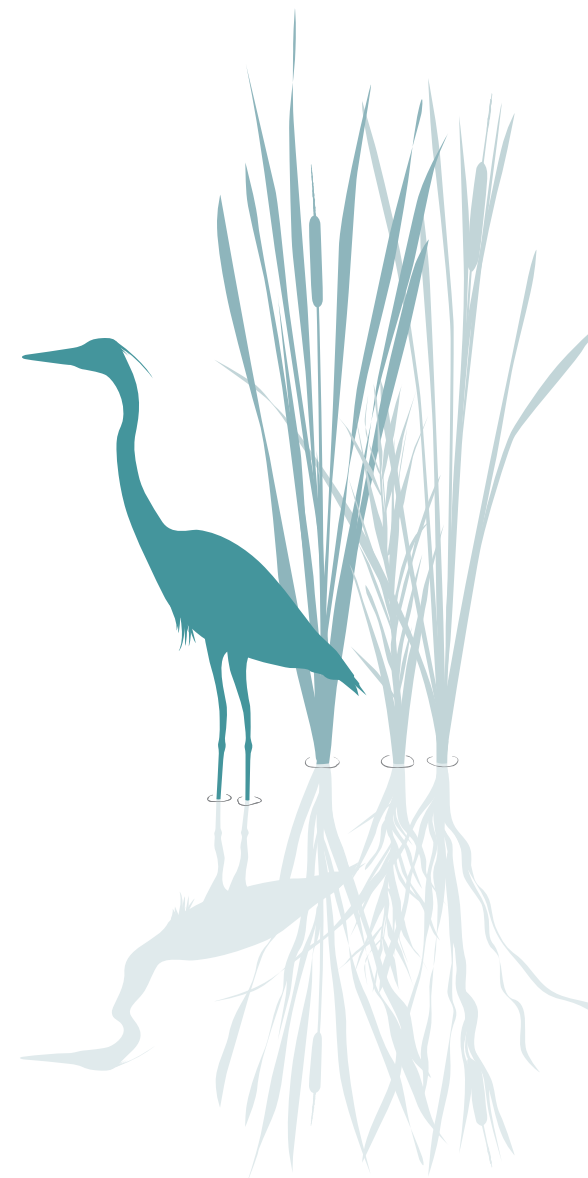
At present, Canadian mainstream healthcare systems are not well equipped to meet the linguistic and cultural needs of Indigenous populations. While there have been improvements (e.g., setting aside spaces for Indigenous ceremonies), mainstream healthcare systems continue to ignore aspects of Indigenous cultures that do not fit within boundaries considered acceptable by Western standards, including a failure to offer services in Indigenous languages or incorporate spiritual health and community healing (Hick, 2019). As noted by Jacklin et al. (2017), there continues to be strong institutional resistance for allowing Indigenous family members to visit patients, a disregard for family supports, and largely inaccessible access to Indigenous ceremonies for those confined to hospital beds or in isolation. These shortcomings of mainstream healthcare systems can contribute to the sense of isolation and cultural

disconnection that Indigenous TB patients may experience, which in turn may impact their motivation to adhere to isolation and TB treatment (Robinson, 2015; Mayan et al., 2017).

There also remains the ongoing issue of racist and discriminatory practices within mainstream healthcare systems, such as those documented by the Independent Reviewer of Indigenous-specific racism in British Columbia’s health system contained in the *In plain sight* report (Turpel-Lafond, 2020) and by the Viens Commission (2019) in its public inquiry on relations between Indigenous Peoples and certain public services in Quebec. Systemic racism exposes Indigenous people to further harms when they access health services and reinforces TB stigma, which in turn can cause delays in the uptake of TB screening and treatment (Smith et al., 2021).

In the absence of access to culturally appropriate health services, Indigenous TB patients can be further traumatized, leading to poorer health outcomes. There is a need to improve Indigenous Peoples’ engagement with TB services and address the ongoing structural issues that contribute to the spread of TB infection.

*Systemic racism exposes Indigenous people to further harms when they access health services and reinforces TB stigma, which in turn can cause delays in the uptake of TB screening and treatment*  
(Smith et al., 2021).



## Indigenous Peoples' knowledge and understanding of Tuberculosis

Health literacy regarding TB and its management can help reduce the stigma associated with the disease and any fear or apprehension individuals may have about its treatment. However, at present, there is limited knowledge and awareness of TB among many Indigenous people, which is likely contributing to the stigma associated with the disease, feelings of shame, fears of a TB diagnosis, and psychological

distress regarding long-term TB treatment (Robinson, 2015; Theron et al., 2015).

Research with select Indigenous populations has shown strikingly low knowledge about the symptoms, transmission, causes, and risk factors of TB (Alvarez et al., 2014; Brassard et al., 2008; Gibson et al., 2005; Jenkins, 1997; Møller, 2005). Urban Indigenous TB patients in Montreal generally lacked a biomedical awareness and knowledge about the disease, how they acquired it, how it could be passed on, and where to go for testing and diagnosis, with increased knowledge

among individuals who had previous contact with a TB clinic (Brassard et al., 2008; Macdonald et al., 2010). In a study examining the experiences and knowledge of Indigenous TB patients in different locales, Robinson (2015) found a gap in knowledge about TB among younger generations compared to older ones, attributing this gap to a lack of interest in available TB information among younger generations who did not view TB as a contemporary problem. Lack of knowledge about TB has resulted in several popular misconceptions among Indigenous people surrounding TB. Examples include that TB no





longer exists (Brassard et al, 2008; Macdonald et al., 2010), that previous treatment guarantees immunity from infection (Kormanisky et al., 2016), and that health clinics are places to go and die or to separate the sick from their families (Brassard et al., 2008; Gibson et al., 2005).


As noted earlier, studies have also shown differences between urban Indigenous people and their counterparts living in rural, remote, and northern community settings in the level of knowledge and awareness they have about TB and its treatment (Mayan et al., 2017; Robinson, 2015). With more

limited access to health services and greater familiarity with TB among health professionals working in rural, remote, and northern communities, individuals accessing TB services in these settings may have more timely access to TB information than their urban counterparts. Nurses in rural, remote, and northern communities are able to screen patients for TB early through annual checkups and local nursing stations serve as TB information sharing hubs that coordinate community information sharing events and conduct outreach. Nevertheless, despite having more readily accessible TB information,

encouraging people to access the available information in these settings remains an ongoing challenge (Robinson, 2015). Limited access to TB information can pose challenges to improving health literacy about the disease for urban Indigenous people, with impacts across the cascade of care (Gibson et al., 2005; Mayan et al., 2017; Robinson, 2015). As a result, efforts to eliminate TB among Indigenous populations are undermined (Castro-Sanchez, 2016; Courtwright & Turner, 2010).







*Given Indigenous Peoples' past experiences with trauma and the traumatizing nature of a TB diagnosis and its treatment, a trauma-informed model of care is an important tool for addressing the high prevalence of TB among Indigenous populations (BCCDC, 2016).*



# TRAUMA AND TRAUMA-INFORMED TB CARE: PUTTING PRINCIPLES INTO ACTION FOR INDIGENOUS POPULATIONS



Trauma is a key barrier to engagement with the healthcare system and completion of disease treatment (see for example, Erickson et al., 2021; López et al., 2020; Mugavero et al., 2006; Selwyn et al., 2021; Sikkema et al., 2022). Given Indigenous Peoples' past experiences with trauma and the traumatizing nature of a TB diagnosis and its treatment, a trauma-informed model of care is an important tool for addressing the high prevalence of TB among Indigenous populations (BCCDC, 2016). This section identifies key principles of trauma-informed care (TIC) and describes elements of a TIC approach to TB management in the context of Indigenous populations in Canada, utilizing a framework of four key principles:

1. trauma awareness,
2. safety and trustworthiness,
3. opportunities for choice, collaboration, and connection; and
4. strengths-based skill building techniques.

## Trauma-Informed Care

Trauma-informed care accounts for the many barriers that may impact client's access to and engagement with the healthcare system, including gender identity, history, culture, and past traumatic experiences (Erickson et al., 2021; TIP Project Team, 2013). TIC involves understanding the whole person, as opposed to focusing only on specific health conditions (Menschner & Maul, 2016). It recognizes that patients with experiences of severe trauma may exhibit certain behaviours, such as fear, hesitation, or anger, that can undermine the quality and effectiveness of the care they receive (Anderson, 2019; Withers, 2017). Recognizing the impact of trauma on individuals can help shift the blame for health conditions away from the individual and onto their social history (Weaver, 2022). This enables healthcare providers to treat patients with compassion and sensitivity to how their life experiences may affect their health behaviours and health status and respond better to their needs, which in turn reduces the risk of intensifying patients' trauma. TIC incorporates acknowledgment and sensitivity to trauma in all aspects of service delivery to ensure patients follow through and complete each step of their cascade of care (Greenaway et al., 2022).



TIC models share some common features. Harris and Fallot (2001) identify five guiding principles that underscore a trauma-informed environment: safety, trustworthiness, choice, collaboration, and empowerment (as cited in Anderson, 2019). The model used by SAMHSA (2014) includes most of these principles, but also addresses cultural, historical, and gender issues. Its principles are:

1. ensuring the physical and emotional safety of patients and staff;
2. building and maintaining trust and transparency among patients, staff, and family members;
3. fostering peer support and mutual self-help as a vehicle for building trust, establishing safety, and empowerment;
4. levelling power differentials between staff and clients and meaningfully sharing decision-making practices;
5. recognizing and building on the strengths of individuals in order to empower clients and give them voice and choice in their health decision-making; and
6. moving past cultural stereotypes and biases, offering gender responsive services, leveraging the healing value of traditional cultural connections, and recognizing and addressing historical trauma (p. 11).

It is important to acknowledge that while TIC contributes to improved individual care and interactions with clients, it is based on a narrow definition of violence and trauma – one that emphasizes individual experiences; thus, can have limited effectiveness for clients who experience disproportionately high levels of trauma due to deeply entrenched structural determinants (Befus et al., 2019). As such, some researchers have advocated for a trauma- and violence-informed care (TVIC) approach that emphasizes the intersections of interpersonal and structural forms of violence (including racism and poverty) and acknowledges that these structural forms are often ongoing and historical (Befus et al., 2019). TVIC approaches are systems-level approaches that focus on actions that promote equity and social justice. While there is no doubt that trauma for Indigenous Peoples is rooted in both interpersonal and structural violence, which requires a systems-level approach to address, given this paper's focus on trauma in the context of TB care, emphasis will be placed henceforth on TIC approaches that aim to prevent re-traumatization of Indigenous TB patients in their interactions with healthcare providers.

Principles of TIC overlap with the concepts of “cultural safety” and patient-centred care (Crawford et al., 2021; Smith et al., 2021).

Cultural safety can be defined as an outcome based on respectful engagement and collaboration that recognizes and strives to address power imbalances, racism, and institutional discrimination inherent in health services delivery (Cultural Safety Attribute Working Group, 2019; First Nations Health Authority, 2022; Winnipeg Regional Health Authority [WRHA], 2022). Cultural safety means providing services in a way that shows respect for culture and identity (WRHA, 2022). It produces an environment where patients are treated with dignity and respect and their concerns are taken seriously. Cultural safety enhances client's self-determination and empowerment, and is defined by the recipient of care, not the provider (Nelson et al., 2014; Schill & Caxaj, 2019; Williams, 1999). When individuals with a history of trauma experience racism and discrimination in their health care encounters, as many Indigenous people do, these unsafe environments have the potential to amplify trauma and act as a significant barrier to accessing health care safely. Implementing principles of a trauma-informed approach can enhance cultural safety for Indigenous clients and improve their health outcomes.

Patient-centred care calls for “professionals to adopt the patient's perspective, rather than seeing them as just another



manifestation of pathology” (Odone et al., p. 133). A patient-centred approach is comprised of several key attributes. At the individual level, it considers patients holistically while addressing their multiple needs and understanding the contexts of their lives. It is individualized to reflect the patient’s unique needs, preferences, personality, and health concerns. Patient-centred care also shows respect for the patient and focuses on empowerment, encouraging patients to make informed decisions and exercise individual self-determination. At the health system level, patient-centred care involves the coordination and integration of health services to enhance continuity of care across diverse settings, with patients actively involved in the process (Odone et al., 2018). This latter point is especially pertinent for rural, remote, and isolated Indigenous populations, who face considerable health service challenges that often require them to travel to urban centres for care.

A trauma-informed approach can consume much time and energy, leading to compassion fatigue and/or burnout (Anderson, 2019). Implementing a TIC approach thus requires changes not only to clinical practice in order to transform health care settings in ways that empower patients, provide choice, enhance physical and emotional safety, build trust, and maximize collaboration, but also requires widespread changes

to organizational policy and culture so that frontline health care professionals feel supported in doing this work (Anderson, 2019; Manitoba Trauma Information and Education Centre, 2013; Menschner & Maul, 2016; SAMHSA, 2014). Brown and colleagues (2022) identify three potential types of interventions that can be adopted in a trauma-informed approach:

1. educational interventions aimed at increasing health care providers’ comfort and knowledge of TIC;
2. collaborations across allied professions, community organizations, patients, and others to ensure success of each TIC intervention; and
3. interventions that make staff and patients feel safe, including cultural safety interventions, trauma screening and assessment, development of standardized TIC protocols and programs, and safety assessments and planning for patients identified as victims of violence.







## Applying TIC principles to TB care for Indigenous populations

The benefits of a TIC approach have been demonstrated in relation to mental health services, where the practice is widely employed. In 2008, the Center for Addiction and Mental Health in Toronto, Ontario adopted a TIC approach for in-patient psychiatry clients (TIP Project Team, 2013). This led to a reduction in the use of chemical and physical restraints; as well as reductions in the seclusion of and improved relationships with clients through incident debriefs. Trauma-informed principles were also implemented in 2008 by the Victoria Women's Sexual Assault Centre in British Columbia to respond to the experiences of clients who divulged traumatic information to health care

providers in a bid to prepare and train staff to offer holistic and appropriate care to their clients (TIP Project Team). While TIC principles have been applied in other contexts, including mental health, HIV/AIDS, and social work, they have not yet been investigated in TB case management.

Due to the lack of information on this important subject matter, this section draws on trauma-informed guidelines used in other Indigenous health contexts to inform recommendations for a trauma-informed approach to TB care for Indigenous populations in Canada. For instance, a general framework which may be used to inform recommendations in a TB context is British Columbia's Mental Health and Substance Use Group's (BCMHSUG) model of four TIC principles (TIP Project Team, 2013). This model

identifies trauma awareness as the first step to implementing a trauma-informed approach because care providers must be able to recognize trauma and the various adaptive responses to trauma (i.e., substance use disorders, avoidance of health clinics, not wanting to divulge contact tracing information). This awareness helps care providers respond to trauma in ways that avoid re-traumatizing patients. Recommendations for a TIC framework in TB care for Indigenous populations offered here will be organized into the four core principles of the BCMHSUG's model of TIC. This includes:

1. trauma awareness;
2. safety and trustworthiness;
3. choice, collaboration, and connection; and
4. strengths-based and skills building interventions.



## Trauma awareness

It is well recognized that trauma has an impact on the utilization of health services (Esmaili, 2021). Indigenous Peoples' contemporary experiences with TB and its treatment must be understood from the lens of past traumatic experiences, including historic TB control measures and "past colonial violence and cultural genocide" (Smith et al., 2021, p. 6). To reduce the fear Indigenous people may have about TB diagnosis and treatment, there is a need to address the stigma associated with TB and improve Indigenous Peoples' experiences and engagement with the healthcare system generally. Given the potential for Indigenous people to experience re-traumatization in their encounters with the healthcare system, the three

intersecting approaches of TIC, cultural safety, and patient-centred care should guide TB care and management in Indigenous communities. A logical first step is to ensure health care providers and policy makers have the knowledge and skills they need to provide this type of care.

The literature identifies several areas where knowledge and skills among healthcare providers and policy makers need to be improved. Educational interventions are needed to increase knowledge about trauma and TIC among healthcare providers, health administrators, and policy makers. They must be aware of the specific context of trauma and TB in the communities they serve and the role of trauma in health care so that they can better support TIC approaches (Hoeppner &

Marciniuk, 2000; Inuit Tapiriit Kanatami, 2013; Komarnisky et al., 2016). This includes awareness of the traumatic experiences of Indigenous Peoples with historic TB management, the impacts of colonization on Indigenous Peoples' health and well-being, and the present social determinants of health in communities affected by TB that reinforce trauma (Inuit Tapiriit Kanatami, 2013). It is important that clinicians learn skills for recognizing the symptoms and manifestations of trauma and understand the principles of TIC so they can become more comfortable in applying this approach (Collins, 2021). This includes understanding and respecting the mental, social, and financial impacts of a TB diagnosis on Indigenous individuals (Jetty, 2021; Jetty & FNIM Health Committee,



*Given the potential for Indigenous peoples to experience re-traumatization in their encounters with the healthcare system, the three intersecting approaches of TIC, cultural safety, and patient-centred care should guide TB care and management in Indigenous communities.*



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*Interventions must be decolonized; that is, they must be strengths-based approaches that resonate with aspects of Indigenous identities, reflect traditional values, and emphasize resilience and empowerment*

(Crawford et al., 2021; Greenaway et al., 2022; Weaver, 2022).

2020; Venkatraju & Prasad, 2013). Health practitioners and policy makers also need to be aware of and apply appropriate approaches and interventions for addressing trauma when working with Indigenous clients. While not every Indigenous client who requires TB treatment will have a traumatic story, many do live with trauma.

Current research suggests that health care providers may be aware of trauma and its role in health care but lack knowledge on how to apply TIC in practice (Li et al., 2019; Stokes et al., 2017). As such, there is a need to integrate TIC guidelines and data into health studies curricula (Li et al., 2019; Collins, 2019). Reid et al. (2022) argue that context relevant approaches targeted at the population being served are more effective than generic training. They call for

TIC training to be required in the inductions processes of the health care workforce, regularly updated, and offered as part of ongoing training opportunities.

It is the responsibility of health administrators to ensure all health care staff have TIC and Indigenous cultural safety training (discussed later) and to support TIC approaches through appropriate policy actions. Structural barriers may exist in primary health care, particularly in rural and remote settings, which may inhibit implementation of a TIC approach (Reid et al., 2022). These challenges may consist of a lack of local support services and continuity of care, local stigma, and human resource challenges. Policy makers must know what tools should be put in place to enable a TIC approach and ensure its sustainability. A

TIC implementation strategy is one example of effective action (Reid et al.). Such a strategy should focus on how to increase recognition and understanding of trauma among health care providers; innovative ways to address service gaps through multidisciplinary and collaborative approaches; methods of reducing fragmented services and avoiding re-traumatization; and strengths-based and outcome-focused approaches. The strategy should also be responsive to cultural, historical, and gender issues.

Health practitioners and policy makers must also be aware of strategies for minimizing the risk of intensifying trauma for Indigenous people. Interventions must be decolonized; that is, they must be strengths-based approaches that resonate with aspects of Indigenous



identities, reflect traditional values, and emphasize resilience and empowerment (Crawford et al., 2021; Greenaway et al., 2022; Weaver, 2022). The importance of culture must be acknowledged as an important part of the healing process for Indigenous clients in providing personalized and appropriate health services (Hick, 2019). TB interventions must therefore resonate with Indigenous people's strong connections to families, communities, and the land (Mayan et al., 2017). Some suggestions for a decolonized approach to TB care include:

- learning to work with Indigenous families in the co-development of TB care plans that meet patients' needs;
- finding ways to involve families and loved ones in the process of healing to reduce stigma and negative attitudes towards TB treatment;
- incorporating Indigenous healing pathways into TB care;
- developing and sharing culturally appropriate health information;

- providing time and space to develop sustainable models of Indigenous-focused care; and
- linking patients with community resources and supports upon discharge (Jetty, 2021; Jetty & FNIM Health Committee, 2020; Mayan et al., 2017; Robinson, 2015).

A patient-centred approach to care is considered less traumatic for TB patients (Robinson, 2015). An example of this type of approach in TB care is home-based isolation. Emerging evidence suggests that TB patients are rendered non-infectious quite rapidly once placed on effective treatment; thus, policy makers should examine isolation policies with respect to Indigenous populations and facilitate home-based isolation as an option whenever possible (Mayan et al., 2017). As seen in Saskatchewan, home-based isolation can be supported by community-based teams. For Indigenous patients who must isolate in a hospital setting for any period of time, their isolation experiences should be as short and positive as possible to keep them optimistic and motivated to

complete treatment. This requires implementing policies that allow for more flexible family visitation and outdoor experiences; providing activities for mental, social, and emotional stimulation; and taking actions to enhance social connections between patients and their families, friends, and other TB patients. For example, creating TB clubs<sup>18</sup> is a good way to reduce feelings of stigma and shame and keep patients, particularly those without family connections, supported as they undergo treatment (Mayan et al., 2017).

A TIC approach commits organizations to move past cultural stereotypes and biases and embed understanding of the impacts of historical trauma within policies, procedures, and practices to ensure they are tailored to respond to the racial, ethnic, and cultural needs of clients (Anderson, 2019; Harris & Fallot, 2001). To achieve service change, understanding of trauma must be integrated into all levels of care and supported by “system engagement, workforce development, agency policy and interagency work” (BC Ministry of Children and Family Development, 2017, p. 15).

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<sup>18</sup> TB clubs are groups of individuals with active TB who meet regularly to support each other in adhering to TB treatment, share information about the course of the disease and possible drug side effects, provide social support, arrange transportation to clinics, and encourage TB screening among other at-risk community members (Courtwright & Turner, 2010; Demissie et al., 2003). These clubs are often organized by health workers, who serve as points of contact for the TB club leader (Demissie et al., 2003), and may be led by people who are cured of TB, patients under treatment, or community leaders (World Health Organization, 2007).

## Safety and trustworthiness

Patient and staff safety interventions are important for the success of any TIC interventions. In the context of health organizations, safety refers to the physical and psychological safety of both health care staff and the clients they serve (SAMHSA, 2014). A key part of patient safety for Indigenous Peoples is the need to ensure their emotional and physical well-being. This entails interventions that aim to overcome any fear or mistrust Indigenous people may have with mainstream healthcare systems and ensure they feel safe in their encounters with health care staff. One way to facilitate safety and trust is through health programs and services that are culturally appropriate for the population being served. Health care providers need to understand the influence of culture on an individual's perception about illness and disease (New Jersey Medical School Global Tuberculosis Institute, 2008). For example, some Indigenous populations believe a lack of balance between the physical and

spiritual domains is a leading cause of illness. Therefore, there is a need to be culturally aware,<sup>19</sup> humble,<sup>20</sup> sensitive,<sup>21</sup> responsive, competent,<sup>22</sup> and safe with clients living with TB (Baba, 2013; New Jersey Medical School Global Tuberculosis Institute, 2008). In fact, some researchers have argued that Indigenous cultural safety is the cornerstone of trauma-informed care, as without cultural safety, there is a risk of triggering further trauma (Crawford et al., 2021).

Requiring all health service providers working directly or indirectly with Indigenous clients living with TB to undergo Indigenous anti-racism and cultural safety training is an important tool for enhancing the safety and trustworthiness of health services. Such training can enable service providers to see the impact of their own personal histories and biases on Indigenous patients and their families and improve the quality of services they provide. This training is especially needed for non-Indigenous health care providers who work in off reserve and urban settings or are not embedded

within Indigenous communities to prevent the types of negative encounters that Indigenous people have experienced with the mainstream healthcare system that have acted, and continue to act, as barriers to a timely TB diagnosis and adherence to treatment completion (Robinson, 2015). Indigenous anti-racism and cultural safety training typically includes learning about:

1. the concept of culture and cultural diversity of Indigenous Peoples;
2. the context and legacy of colonization;
3. health disparities of Indigenous Peoples, including the social determinants of health;
4. the importance of cultural safety in reducing health disparities;
5. the potential role of culture and Indigenous healing in patient care; and
6. one's own cultural assumptions, beliefs, and attitudes about Indigenous Peoples (WRHA, 2022, para. 4).

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<sup>19</sup> Cultural awareness is the acknowledgement of differences between culture but does not consider how political or socio-economic differences influence differences in culture (Baba, 2013).

<sup>20</sup> Cultural humility is the acknowledgement that there are differences in cultures and no culture is superior to others (Baba, 2013).

<sup>21</sup> Cultural sensitivity is the exhibition of a behavior considered to be polite and respectful by people of other cultures (Baba, 2013).

<sup>22</sup> Cultural competence is a self-reflexive action where individuals are aware of their culture and the cultures of others, and the corresponding action taken to function in a multicultural environment (Baba, 2013).



There is also a need to teach health care providers about how racism is embedded at the systemic level in Canada – in the structures, systems, policies, and institutions that uphold racism and continue to oppress Indigenous Peoples.

There are several ways that culture can specifically be incorporated into the care of Indigenous TB patients to enhance cultural safety. While focused on the context of palliative care, Falk (2019) identifies five key aspects of health care for First Nations in British Columbia. First is the need to recognize the cultural and spiritual diversity of First Nations, and the role of family, community, and ceremony in the provision of personalized care. Second, health care providers must acquire baseline knowledge about local First Nations and their cultures so they can engage in conversation and understand their values and perspectives of health. Third, health care providers must understand differing First Nation's conceptions of family and be flexible in accommodating large numbers of visitors. Fourth, it is important that health

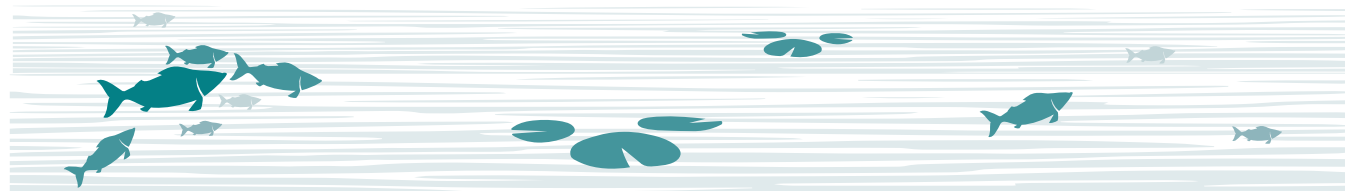
care providers inquire about and respect the importance of ceremony for First Nations clients. Finally, recognizing the influence of trauma and colonialism on First Nations health care experiences is important. These same principles apply just as strongly in the context of TB care, as well as to other Indigenous populations, including Inuit and Métis.

Indigenous cultural safety can also be enhanced through other means, including cross-cultural communication techniques, patient-centred care, and actions that build respectful and therapeutic relationships with clients and their family members (Greenwood et al., 2017; Neubauer et al., 2016; Nguyen, 2008; Saha et al., 2008). Cross-cultural communication encompasses overcoming language barriers, learning to interpret and use nonverbal communication tools, and understanding cultural differences in communication styles, and aims to prevent miscommunication, enable the exchange of information, and strengthen relationships

(MasterClass, 2022). In Indigenous contexts, cultural safety can be enhanced by relationship-building actions such as taking time to involve family and partners in care plans, establishing rapport, exercising humility, being empathetic, exercising good listening skills, and showing interest in and incorporating Indigenous cultural practices (Esmaili, 2021; Halovic, 2016; Jacklin et al., 2017). Providing physical spaces that are welcoming and inclusive can contribute to Indigenous patients' comfort and safety (Blanchet-Cohen & Richardson, 2017; Parrella et al., 2022; Schill & Caxaj, 2019). Indigenous cultural safety can also be facilitated by having local Indigenous healthcare workers or community health representatives provide culturally appropriate TB education to improve screening in Indigenous communities and monitor adherence to directly observed therapy (DOT)<sup>23</sup> rather than using non-Indigenous healthcare workers or 'outsiders' (Alvarez et al., 2014; Heuvelings et al., 2017; Orr, 2011).

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<sup>23</sup> DOT by definition means watching clients swallow each dose of anti-TB medication (BCCDC, 2011).



Indigenous cultural safety must be supported through actions that demonstrate commitment to principles of cultural safety by health administrators and policy makers. Indigenous Peoples' knowledge and experiences must be reflected in the provision of health services (Heffernan et al., 2022a). As such, there must be meaningful sharing of power and decision-making with Indigenous communities and service organizations at all stages and levels of the health system (Cultural Safety Attribute Working Group, 2019; Jacklin et al., 2017; SAMHSA, 2014). This includes working collaboratively to co-develop mechanisms, organizational strategies, and policies that help create conditions for equity in TB care, such as those that integrate Indigenous approaches and healing practices into TB prevention and enhance the Indigenous health workforce. An equity-based commitment to providing health care to Indigenous people should be part of the mission statement of organizations providing TB care to Indigenous populations, which may require organizational restructuring to provide care

based on principles of social justice<sup>24</sup> (Browne et al., 2016).

Organizational transparency and accountability mechanisms must also be implemented to ensure cultural safety within health care settings and foster trust with Indigenous populations (Heffernan et al., 2022a). This includes performance reviews of cultural safety education and training initiatives for health care practitioners and staff and tracking measures to assess progress on cultural safety initiatives (Cultural Safety Attribute Working Group, 2019). These types of actions work to ensure that health services are more responsive to the needs and concerns of Indigenous patients, which in turn, can help rebuild trust in mainstream healthcare systems.

Brown et al. (2022) identify several other interventions that aim to address safety in emergency medicine and are equally important for ensuring the success of TIC interventions. These include: interventions to ensure staff safety, safety assessments and planning for individuals identified as victims

of violence, trauma screening and assessment, leadership buy in, and the development of standardized TIC protocols and programs for vulnerable patient populations, among others (p. 341). There are also ways to make health care environments culturally safe and welcoming for Indigenous clients. Some tips, provided by the Southwest Ontario Aboriginal Health Access Centre, include:

- displaying Indigenous art in waiting areas and meeting rooms;
- making medicines and resources available for Indigenous clients;
- having food and beverages available for clients;
- being aware of clients' mood and body language for stress reactions, suggesting an alternate location if they seem anxious, or offering smudging or grounding techniques;
- taking time to introduce yourself;
- being mindful of your own body language;

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<sup>24</sup> Social justice is “a philosophy that everyone deserves equal rights and opportunities” and is considered a fundamental prerequisite for health (BCCDC Foundation for Public Health, 2023, para. 3). Social justice entails actions to redress inequalities based on gender, race, religion, age, and other characteristics, including training nurses to ensure they are culturally competent, can advocate for patients' rights, and provide the highest level of care to all individuals; creating diverse care delivery models, including technology, to enhance access to care; increasing diversity in health care staff; providing health information in languages that communities can understand; and ensuring equity in access to health care services through health policies (Regis College, 2021; Health & Community Services Workforce Council & CheckUp Australia, n.d.).



- being aware of lighting, noises, and smells;
- asking clients for their feedback;
- allowing flexibility in schedules to accommodate late arrivals and multiple ‘no shows’ at no cost, but exploring barriers to help reduce such no shows;
- avoiding preconceived assumptions, biases, and hearsay about clients;
- explaining everything you do, in language that is plain, simple, and understandable; and
- responding appropriately and apologizing when needed (George et al., n.d.).

### Opportunities for choice, collaboration, and connection

The TIP Project Team (2013) identified the importance of trauma-informed services to “foster a sense of efficacy, self-determination, dignity, and personal control for receiving care” (p. 14). This can be achieved by prioritizing patient choice and control, promoting collaboration, and emphasizing connections. In TB care with Indigenous patients, this can include having traditional ceremonial practices incorporated alongside Western based treatment, creating a friendly and welcoming environment (Browne et al., 2016), having the opportunity to establish safe

connections with care providers and others who can support TB patients (TIP Project Team, 2013), and letting clients have options and say in decisions about their care (George et al., n.d.). Health care professionals should embark on a quest to understand their client by asking questions like: “what do you think will help to cure your TB? Apart from me, and the [nurses] and [doctors], who *else* do you think can help you get better? Are there things that make you feel better, or give you relief, that [nurses] or [doctors] don’t know about?” (Pffifferling [1981] as cited in New Jersey Medical School Global Tuberculosis Institute, 2008, p.10).



*To promote greater choice in urban centres, there is a need to support more health services that are provided by organizations working specifically with Indigenous populations*

(Mayan et al., 2019).



To promote greater choice in urban centres, there is a need to support more health services that are provided by organizations working specifically with Indigenous populations (Mayan et al., 2019). These types of services are generally preferred by Indigenous clients (Kurtz et al., 2008; Wendt & Gone, 2012). They consider the client holistically, incorporate Indigenous cultural values and practices into care, and are typically staffed by either Indigenous-identified staff or staff who share a commitment to Indigenous cultural safety (Lemchuk-Favel & Jock, 2004; Maxwell, 2011; Pomerville et al., 2021). Given the overwhelmingly negative experiences that urban Indigenous people have had with mainstream health services

(Benoit et al., 2003; Kurtz et al., 2008; Mayan et al., 2017, 2019; Robinson, 2015) and the role these types of experiences play in delaying TB diagnosis and treatment, being able to choose services from an Indigenous-specific care provider offers considerable potential to improve health outcomes for Indigenous people living with TB. However, funding for urban Indigenous health services is often insufficient for meeting the needs of clients due to proportionally lower levels of federal funding for urban compared to on-reserve services, as well as the nature of that funding.<sup>25</sup> This makes it challenging to compete for a limited supply of qualified Indigenous health professionals (Maxwell, 2011). Additionally, urban Indigenous health services

may not be as comprehensive as those provided in the mainstream healthcare system, in part because they are not mandated to do so (Kurtz et al., 2008; Lemchuk-Favel & Jock, 2004). It is thus imperative that the funding and mandate of urban Indigenous health centres be revised so they can better meet the needs of their clients.

There is also a need for greater flexibility and choice in the way DOT is monitored to promote better adherence to antiretroviral treatment<sup>26</sup> among Indigenous people and reduce the trauma of TB treatment. Some options may include home-based isolation with community health workers monitoring adherence to treatment (Mayan et al., 2017; Robinson, 2015), video

<sup>25</sup> Urban Indigenous health services rely heavily on multiple short-term programme funding sources, including provincial and federal governments, and non-governmental sources (Collier, 2020; Maxwell, 2011).

<sup>26</sup> See for example Macalino et al. (2004) in the case of HIV antiretroviral therapy.





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*Partnerships across governments, allied professions, community organizations, patients, and others are important for enhancing health equity and ensuring the success of TIC interventions*

(Brown et al., 2022).

monitoring, devices for time-registering when pill bottles are opened, and ingestible or on-body wearable sensors (Belknap et al., 2013; Lam et al., 2018).

TIC approaches work to create a treatment culture of non-violence, learning, and collaboration (Crawford et al., 2021). Collaboration must occur at the patient-provider level, across organizations, and across governments. This requires building strong relationships with Indigenous Peoples and communities, based on trust and respect. At the patient-provider level, health practitioners must take the time to listen to their patients and be less time conscious, as strict observance of schedules can lead to poor engagement with patients (Reid et al., 2022). At the organizational level, collaboration requires better integration and co-location of health services to promote better engagement of Indigenous people with those services, particularly

for individuals with substance use disorders, HIV/AIDS, and other competing health priorities (Altice et al., 2010; Sylla et al., 2007).

Given that “top-down” paternalistic TB programs have historically not been very effective in eradicating TB in Indigenous communities, the nature of the relationship between Indigenous communities and federal and provincial/territorial governments must change in terms of how TB programs are designed and delivered (Long et al., 2019). The inequitable power dynamic that currently exists between Indigenous populations and various levels of non-Indigenous governments must be dismantled and replaced with an approach that recognizes Indigenous rights to self-determination in the design and delivery of TB prevention and care programs and services. Indigenous people with TB should be invited to participate in the evaluation of treatment services and serve

on advisory councils to provide advice on program/service design (TIP Project Team, 2013). Meaningful participation and engagement of Indigenous Peoples in TB program planning and operation is needed to ensure that barriers to TB care are overcome in ways that reflect local cultures, languages, values, and needs (Basham et al., 2020). This requires political commitment to work in partnerships with Indigenous Peoples, leaders, agencies, and communities (Orr, 2013).

Partnerships across governments, allied professions, community organizations, patients, and others are important for enhancing health equity and ensuring the success of TIC interventions (Brown et al., 2022). Such partnerships are needed to help overcome the challenges of providing coordinated services in rural and remote settings, where access to a full range of health services may be limited,



and to prevent re-traumatization (Reid et al., 2022). They are also needed to address jurisdictional barriers to health care access that affect a timely diagnosis and continuity of care, particularly in the context of inter-jurisdictional migration to access health services (Robinson, 2015; Vidanaral et al., 2022). Strong intergovernmental collaboration is needed to establish appropriate TB guidelines<sup>27</sup> and develop funding mechanisms to support the development of Indigenous-led collaborative TB programming and accommodate inter-jurisdictional migration (Long et al., 2019; Vidanaral et al., 2022). It is also needed to support the expansion of urban Indigenous-specific health services, clarify the respective

responsibilities of various levels of government in administering and funding those services, and ensure the long-term sustainability of those services (Collier, 2020; Maxwell, 2011). Collaborations with Indigenous-led health organizations, Elders, leaders, and scholars will also be helpful in developing trauma-based protocols for the care of Indigenous persons or communities living with TB.

Based on Indigenous Peoples' historic experiences with trauma and the socioeconomic impacts of that trauma (including poor housing, overcrowding, malnutrition, and poverty) that are root causes of TB in Indigenous communities, multisectoral collaboration is

also required to address these socioeconomic determinants of health. Increasing funding and cooperation on initiatives that address the determinants of health should be regarded as trauma-informed approaches (Inuit Tapiriit Kanatami, 2013; Health Canada & PHAC, 2014).

Finally, patient connections can be facilitated by developing TB policies and protocols that enable Indigenous TB patients to receive treatment in their home communities and when isolation in a hospital setting is required, enabling patients to visit with family and friends and go outdoors and experience nature. Establishing TB clubs can help patients who lack social and family supports to establish supportive connections and help keep them motivated in completing their treatment. Patient connections can also be supported by the expansion of telehealth and mobile TB clinics, such as those offered in Alberta, Saskatchewan, and Manitoba (Robinson, 2015). These types of tools can enable patients to receive follow-up care without needing to travel to urban centres, keeping them more socially connected to friends, families, and communities (Mayan et al., 2017).

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<sup>27</sup> In some contexts, community-based guidelines may be more appropriate than establishing federal or provincial/territorial guidelines (Vidanaral et al., 2022).



## Strengths-based skill building techniques

It is important that First Nations, Inuit, and Métis individuals and communities be characterized as adaptive and resilient, in the face of the trauma communities have endured (Crawford et al., 2021). To address the adverse effects of historic TB control measures, TB programs must be community driven and community focused. To be successful in such efforts, local knowledge and capacity must be built in two key areas:

1. enhancing knowledge about TB and its prevention among Indigenous community members to address stigma and enhance support; and
2. building capacity among the health workforce to provide TB services and treat Indigenous patients locally.

*Currently, the lack of knowledge about TB and how to prevent the disease among Indigenous populations is contributing to ongoing shame and stigma, and subsequently to delays in TB diagnosis and treatment.*

Education is vital for raising awareness about TB, not only for individuals with direct experience with the disease and their close contacts, but also for community members and the general public at large, particularly for youth who are less likely to perceive TB as a major health concern (Abonyi et al., 2017; Alvarez et al., 2016; Brassard et al., 2008; Mayan et al., 2019; Robinson, 2015). Currently, the lack of knowledge about TB and how to prevent the disease among Indigenous populations is contributing to ongoing shame and stigma, and subsequently to delays in TB diagnosis and treatment. Culturally appropriate TB education interventions are needed to enhance knowledge about TB prevention, TB symptoms, where to go for a diagnosis, how TB can be transmitted and treated, and to address any misconceptions

Indigenous people may have about the disease. As Robinson (2015) argues, seeking treatment is a social process. It is often those around us who first notice our deteriorating health, encourage us to seek medical help, and then support us through the treatment process. A universal one-size fits all approach is unlikely to be successful due to differences across specific settings (Smith et al., 2021). To ensure TB diagnoses are received earlier, TB education interventions must resonate with Indigenous Peoples (Abonyi et al., 2017) and be delivered in a culturally appropriate way (Brassard et al., 2008; Mayan et al., 2017, 2019; Robinson, 2015). As such, it must incorporate Indigenous perspectives on causation and care, avoid messages of blaming individuals for their condition, and be conveyed in culturally appropriate mediums and by



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trusted individuals like Elders or by individuals with lived experiences of TB. Suggestions from the literature on culturally appropriate TB education include:

- promoting educational activities among Elders and youth that are informed by local input, especially the knowledge and experiences of TB survivors; using innovative methods to reach target audiences; and prioritizing public health programs and prevention (i.e., establishing routine testing) (Mayan et al., 2019);
- conducting a community-wide TB awareness campaign with community involvement at all levels, including the introduction, design, implementation, and delivery of subsequent educational programs, taking into consideration the regional cultures, languages and TB history (Alvarez et al., 2014);
- implementing educational interventions by local implementation teams at community celebration events (Alvarez et al., 2016);
- involving Indigenous community members to present information on TB prevention in videos (Pease et al., 2019);
- improving promotion of TB workshops (Robinson, 2015); and

- incorporating Indigenous communities' cultural beliefs about health in educational TB programs (Houston et al., 2002).

Given the role that lack of knowledge of and experience with TB plays in perpetuating stigma and the ongoing transmission of the disease, it is imperative that health care providers in all settings, including those in settings where TB is not prevalent, have knowledge about the symptoms of TB and appropriate treatment. They must also have anti-racism and cultural safety training so they can better understand the root causes of ill health among Indigenous people and improve the quality of health services they provide to this marginalized population. There is also a need to identify and support health care professionals who are interested in working with urban Indigenous people and willing to work towards building therapeutic relationships with Indigenous clients and offer culturally safe environments (Mayan et al., 2019).

In addition, there is a need to address the lack of consistent and culturally appropriate health services for Indigenous Peoples. Canadian healthcare systems are not well-equipped to meet the needs of Indigenous populations, as they ignore aspects of Indigenous cultures that are important for health and healing (Hick, 2019). TB prevention,

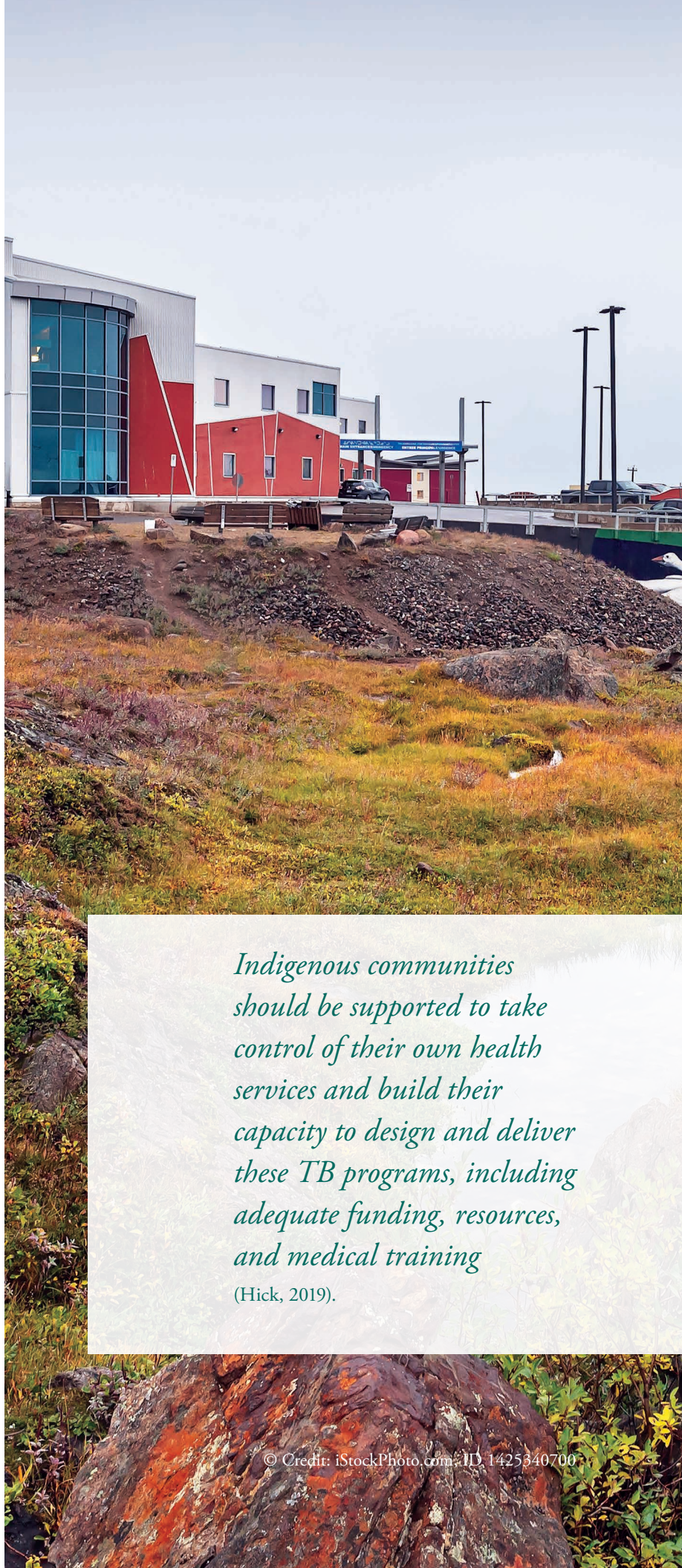
screening, and treatment measures should be community driven and community focused to avoid paternalistic TB programs that run counter to the principle of Indigenous self-determination and have been shown to be ineffective in eliminating TB and its upstream determinants (Long et al., 2019). Such interventions may also help to overcome the deeply rooted mistrust many Indigenous people have with TB control measures and the continued lack of two-way communication (Ghanem et al., 2019; Hick, 2019). TB programs and services should be strengths-based, incorporate Indigenous beliefs about causation and approaches to achieving wellness, adopt strategies that draw on the support of friends and family to facilitate health care seeking behaviour; and address the social determinants of health, including the intergenerational legacy of colonization, so that Indigenous people are better able to recognize TB symptoms as being 'unusual' rather than normal (Abonyi et al., 2017).

Indigenous communities should be supported to take control of their own health services and build their capacity to design and deliver these TB programs, including adequate funding, resources, and medical training (Hick, 2019). This requires addressing federal policies currently seen as leading to inequity between communities, such as those that provide smaller



reserves with fewer resources (Jacklin et al., 2017) or those that contribute to inequitable TB diagnosis and care (Long & Ellis, 2015). It also requires training health workers who can conduct community-wide TB testing and monitor antiretroviral adherence, as well as training of lab scientists in communities with limited access to TB diagnostic resources (Alvarez et al., 2015).

Strengths-based approaches to TB prevention and care services can also be applied in the collection and use of relevant data (Love et al., 2022). Community relevant data can help identify what is working in the community in terms of TB management, the community assets and resources that can be drawn upon to improve access to health services and TB supports, and what may be built upon to address any gaps. Regular performance measurement of TB services within communities is needed to ensure transparency and accountability, for without this, communities may not know which programs are effective (Basham et al., 2019b).



*Indigenous communities should be supported to take control of their own health services and build their capacity to design and deliver these TB programs, including adequate funding, resources, and medical training*

(Hick, 2019).



*Long-term investment is needed to support initiatives that address mental health and addictions, food insecurity, and chronic diseases to reduce the conditions that increase the risk of TB among Indigenous populations and act as barriers to TB treatment adherence* (Cormier et al., 2019).



Given that the high rates of TB among Indigenous populations in Canada are driven by inequities in the social determinants of health, locally driven strategies are also needed to promote healthy lifestyles and address the underlying root causes of TB disease (Ghanem et al., 2019; Kilabuk et al., 2019; Robinson, 2015; Uppal et al., 2021). Long-term investment is needed to support initiatives that address mental health and addictions, food insecurity, and chronic diseases to reduce the conditions that increase the risk of TB among Indigenous populations and act as barriers to TB treatment adherence (Cormier et al., 2019). There is also a need to address Indigenous-specific determinants of health related to colonization, migration, loss of languages and cultures, and connections to family, community, and the land (Cormier et al., 2019; Long &

Ellis, 2015). Addressing these determinants of health can lead to improved general physical and mental health of Indigenous Peoples, thus reducing the risk of being infected by TB and progressing to active TB, while also creating conditions where the declining health of individuals with TB can be noticed more readily and brought to attention sooner.

As noted earlier, TB treatment can be traumatizing with its many side effects and social and cultural isolation. Novel approaches to TB management can be seen as TIC approaches since ensuring patient engagement with health care services and patient-centred care are at the core of TIC. In remote and isolated Indigenous communities, where access to sputum microscopy and culture (the gold standard for TB diagnosis) is limited, improving access to and capacity to utilize

other investigation modalities that offer rapid diagnosis and prompt treatment of TB, such as using the X-pert MTB/RIF test, can improve engagement with TB services and thus help reduce the likelihood of TB transmission in the community (Alvarez et al., 2015; Pai et al., 2014). Shorter treatment regimens, such as a weekly dose of Isoniazid and Rifampentine, to treat latent TB infection (LTBI) can also be an effective TIC strategy in Indigenous communities, as it can address the trauma of a lengthy treatment and numerous side effects (Alvarez et al., 2020; Pease et al., 2017, 2019; Richardson et al., 2014; Sterling, 2011; Taima TB, n.d.). These novel approaches to TB management should be the minimum standard of care for Indigenous Peoples who have been victims of historical, intergenerational, and ongoing multiple traumatic events.



# CONCLUSION



Given Indigenous Peoples' history of TB treatment in Indian hospitals and sanatoria, one would assume that a model approach – one that is trauma-informed, patient-centred, and culturally safe – would have been developed for the control of TB among First Nations, Inuit, and Métis populations. Surprisingly, this review identified no such blueprints for trauma-informed TB care. More research is needed to understand the psychological effects of TB diagnosis and treatment on Indigenous populations, how TB services can address the historic experiences of Indigenous Peoples with TB, and the effectiveness of present-day engagement strategies and influence on adherence to TB treatments.

Due to the disproportionately high rates of TB in many Indigenous communities and the role that a long history of trauma has played in contributing to those rates, there is a clear need for a trauma-informed approach to TB care to improve Indigenous Peoples' engagement with TB services. While there is a paucity of literature on trauma-informed

approaches in this specific area, literature in other contexts can inform the development and implementation of such an approach. This review identified educational, collaborative, and health system interventions needed to address the stigma and trauma associated with TB in Indigenous communities. It emphasized the need to decolonize TB interventions to minimize the risk of further traumatization for Indigenous people (Crawford et al., 2021; Greenaway et al., 2022; Weaver, 2022). As such, a trauma-informed approach to TB care for Indigenous populations acknowledges trauma in all aspects of service delivery and emphasizes cultural safety, trust, choice, empowerment, patient-centred care, strengths-based approaches, and Indigenous self-determination. A TIC approach requires that knowledge and capacity be built among Indigenous Peoples and communities to reduce the stigma associated with TB, enhance community support for TB patients, enable Indigenous communities to provide TB services and treat

Indigenous patients locally, reduce the trauma of a lengthy TB treatment regimen, and address the underlying root causes of TB disease.

This report highlighted strategies that may be effective in combatting trauma in TB services. TIC should be incorporated not only into the treatment of individuals with active TB, but also in other TB elimination strategies, such as early-identification of cases, prompt treatment of TB, screening, contact tracing, treatment of LTBI among high-risk individuals, and TB education and prevention interventions (BCCDC, 2011; Health Canada & PHAC, 2014). It should be regarded not only as an engagement strategy, but as a way of changing current practice and adapting established protocols to better meet the needs of communities and patients with TB.

# TRAUMA-INFORMED TOOLS



While no tools exist for trauma-informed practice in the context of tuberculosis care for Indigenous Peoples, the tools provided below can inform practitioners working with Indigenous patients on the application of TIC principles in diverse health care settings.

**Indigenous Continuing Education Centre. (2022). *Trauma-informed care through an Indigenous lens.***

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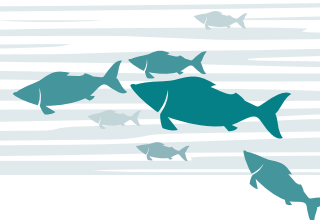
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