About Inuit Tapiriit Kanatami

Inuit Tapiriit Kanatami (ITK) is the national representational organization for the 65,000 Inuit in Canada, the majority of whom live in Inuit Nunangat, specifically, the Inuvialuit Settlement Region (Northwest Territories), Nunavut, Nunavik (Northern Québec), and Nunatsiavut (Northern Labrador). Collectively, these four regions make up Inuit Nunangat, our homeland in Canada. It includes 51 communities and encompasses roughly 35 percent of Canada’s landmass and 50 percent of its coastline. Consistent with its founding purpose, ITK represents the rights and interests of Inuit at the national level through a democratic governance structure that represents all Inuit regions.

The comprehensive land claim agreements that have been settled in Inuit Nunangat form a core component of our organization’s mandate. These land claims have the status of protected treaties under section 35 of the Constitution Act, 1982, and we remain committed to fully implementing them in partnership with the Crown. ITK advocates for policies, programs, and services to address the social, cultural, political, and environmental issues facing our people. ITK is governed by a Board of Directors composed of the following members:

- Chair and CEO, Inuvialuit Regional Corporation
- President, Makivik Corporation
- President, Nunavut Tunngavik Incorporated
- President, Nunatsiavut Government

In addition to voting members, the following non-voting Permanent Participant Representatives also sit on the Board:

- President, Inuit Circumpolar Council Canada
- President, Pauktuuit Inuit Women of Canada
- President, National Inuit Youth Council

Vision

Canadian Inuit are prospering through unity and self-determination.

Mission

Inuit Tapiriit Kanatami is the national voice for protecting and advancing the rights and interests of Inuit in Canada.

Copyright © Inuit Tapiriit Kanatami, November, 2018

Issued in print and electronic format (available in English, Inuktut, and French)

ISBN: 978-1-989179-10-9
Acronyms and definitions

Active TB: A term that describes when someone is sick with TB disease. TB disease usually attacks the lungs and airways (chest and throat). TB disease can also develop in other parts of the body such as the brain, lymph nodes or bones.

A person with active TB usually feels unwell and may have symptoms such as feeling very tired, sweating at night, having fevers during the day, and losing weight unexpectedly. A person with active TB in the chest or throat might also have a cough that does not go away after 2 to 3 weeks, chest pain, shortness of breath, or bloody phlegm (sputum). Some people with active TB do not notice any symptoms.

Active TB is caused by bacteria (TB bacteria). TB bacteria spread from one person to another through the air when someone who has TB disease in the chest or throat coughs or sneezes.

Active TB can be cured with specific antibiotics (TB drugs).

DOT: Stands for ‘directly observed treatment’ or ‘directly observed therapy’. DOT is when a health care provider observes (watches) someone with active TB or latent TB infection swallow each dose of TB treatment.


Health Equity: Health equity means all people can reach their full health potential and are not disadvantaged from attaining it because of their race, ethnicity, religion, gender, age, social class, socioeconomic status or other socially determined circumstance.1

Health Inequity: Differences in health associated with social disadvantages that are modifiable and considered unfair.2

IGRA: Stands for ‘interferon gamma release assay’. An IGRA is a blood test to find out if a person is infected with TB bacteria.


2 Ibid.
**LTBI**: Stands for ‘latent TB infection’. LTBI is a term that describes when a person is infected with the bacteria that cause active TB (TB bacteria), but does not have active TB. LTBI is sometimes called ‘sleeping TB’ because the TB bacteria are in a sleep-like or ‘latent’ state. LTBI is not contagious. Treating LTBI can prevent active TB.

**Sputum induction**: A procedure that helps a person to cough out phlegm (sputum) so it can be tested for TB bacteria.

**TST**: Stands for ‘tuberculin skin test’. A TST is a test to find out if a person is infected with the bacteria that cause active TB (TB bacteria). During a TST a small amount of liquid is injected just under the skin of the forearm by a health care worker. The health care worker then checks the test site 48 to 72 hours later for a reaction. Some other names for the TST are: ‘mantoux’, ‘mantoux test’, ‘TB test’, ‘skin test’, and ‘TB skin test’.
# Table of Contents

About Inuit Tapiriit Kanatami........................................................................................................................................ i
Acronyms and definitions ........................................................................................................................................ ii
Letter from the President of ITK ........................................................................................................................... 1
Executive Summary.................................................................................................................................................. 2
Introduction ........................................................................................................................................................ 3
Partnerships ......................................................................................................................................................... 4
Tuberculosis among Inuit...................................................................................................................................... 7
Inuit Tuberculosis Elimination Framework ........................................................................................................ 16
Priority Actions.................................................................................................................................................. 18
Conclusion.......................................................................................................................................................... 30
Appendix A – Tuberculosis Incidence by Inuit Region ..................................................................................... 31
Appendix B – World Care Council Patients' Charter for Tuberculosis Care..................................................... 34
Letter from the President of ITK

The elevated rate of tuberculosis (TB) among Inuit is a public health crisis. TB data from the Public Health Agency of Canada indicate the rate of active TB among Inuit living in Inuit Nunangat in 2016 was over 300 times that of Canadian-born non-Indigenous people.

In March 2018, ITK and the Government of Canada committed to reduce the rate of TB across Inuit Nunangat by 50 percent by 2025, and to eliminate TB by 2030. These are very ambitious goals. Success will require sustained and adequate funding, intense collaboration across all sectors to improve the overall health and wellbeing of Inuit, and very importantly, the involvement of people, families and communities that have been impacted by TB.

With the establishment of the Inuit-Crown Partnership Committee (ICPC) in February 2017, TB among Inuit has become a federal priority, and there is now an opportunity to move forward with the recommendations included in the Inuit-specific Tuberculosis (TB) Strategy released by ITK in 2013. The ICPC initiated the formation of the TB Elimination Task Force in October 2017 to coordinate the elimination of TB across Inuit Nunangat.

The Inuit Tuberculosis Elimination Framework is intended to guide the development of regional action plans to eliminate TB which are holistic, systematic and evidence-based. It highlights strategic actions and investments that we know would create access to high-quality TB care and address long-standing social and economic inequities that are linked to TB transmission and to the high prevalence of TB disease among our people.

The development of the Inuit Tuberculosis Elimination Framework was coordinated by Inuit Tapiriit Kanatami (ITK) in partnership with the Inuit Tuberculosis Elimination Task Force, the Inuit TB Committee and the Inuit Public Health Task Group. Together, these groups include representatives from: the four Inuit Land Claims Organizations (or designates); community representatives from each Inuit region; Pauktuutit Inuit Women of Canada; the National Inuit Youth Council; representatives from federal, provincial and territorial governments; and individuals with expertise in health equity (Janet Hatcher Roberts), TB care and programming (Dr. Anne Fanning) and TB research (Dr. Gonzalo Alvarez).

We must eliminate TB among Inuit. The release of this document is an important step in that direction.

Natan Obed
Executive Summary

Tuberculosis (TB) among Inuit is a public health crisis. In 2016, the rate of active TB reported among Inuit living within Inuit Nunangat (Inuvialuit Settlement Region in the Northwest Territories, Nunavut, Nunavik in Northern Quebec, and Nunatsiavut in Northern Labrador) was 38 times the rate for Canada as a whole and more than 300 times the rate for Canadian-born non-Indigenous people.

Persistently high rates of TB across Inuit Nunangat are a symptom of health disparities experienced by Inuit compared with other populations in Canada. Deaths from TB, and increasing TB rates and outbreaks in some regions highlight the urgent need for a coordinated national approach to ending TB among Inuit and to addressing poverty and the gaps in social determinants of Inuit health that have perpetuated it, including: housing, food security and nutrition, mental wellness, and access to health services.

ITK released the *Inuit-specific Tuberculosis (TB) Strategy* in 2013. The Strategy was developed in collaboration with the Inuit Public Health Task Group, which is a sub-committee of the National Inuit Committee on Health (NICoH). The Inuit Tuberculosis Elimination Framework builds on this work.

The Inuit Tuberculosis Elimination Framework will be used by Inuit regions to develop action plans to eliminate TB in every Inuit community in Canada. Success will require substantial resources, ongoing commitment and input from all stakeholders - most importantly Inuit, whose knowledge of the impacts of TB and the opportunities for addressing it are integral to the implementation of impactful and sustainable solutions. In addition, this document provides an overview of the history, context and impacts of TB on our people.

The primary audience for this document is our partners in health and social development, including: Inuit representative organizations and governments, and officials and representatives of federal, provincial and territorial governments and departments. The secondary audience includes health care providers and others who serve Inuit, and whose support for implementation of the regional TB elimination action plans is critical.

ITK will support utilization of the Inuit Tuberculosis Elimination Framework by continuing to coordinate Inuit TB elimination efforts at a national level, and by partnering with public governments and Inuit representative organizations and governments to support the development and implementation of the regional TB elimination action plans. ITK will utilize the Framework in reporting on progress toward TB elimination.
**Introduction**

This document is divided into two main parts: 1) contextual information on the history and impacts of TB across our homeland, and risk factors faced by our people, and 2) information on the TB elimination framework that will be operationalized across Inuit Nunangat through the implementation of region-specific TB elimination action plans.

**Appendix A** presents data on the prevalence and distribution of TB across Inuit Nunangat.

**Appendix B** features *The Patients’ Charter for Tuberculosis Care* as an example of existing tools to support rights-based, person-centred approaches to TB elimination. The *Patients’ Charter* was developed in tandem with the *International Standards for Tuberculosis Care* by the World Care Council. It describes the rights and responsibilities of those with TB and “…sets out the ways in which patients, the community, health providers (both private and public), and governments can work as partners in a positive and open relationship with a view to improving tuberculosis care and enhancing the effectiveness of the healthcare process…It allows for all parties to be held more accountable to each other, fostering mutual interaction and a positive partnership.”

---

Partnerships

ITK will support operationalization of the Inuit Tuberculosis Elimination Framework through partnerships with: Inuvialuit Regional Corporation, Nunavut Tunngavik Inc., Makivik Corporation, Nunatsiavut Government, Pauktuuit Inuit Women of Canada, provincial and territorial governments, the Public Health Agency of Canada, and Indigenous Services Canada. The roles of provincial and territorial governments and federal agencies in eliminating TB across Inuit Nunangat by 2030 are described below.

Government of the Northwest Territories

The Department of Health and Social Services (DHSS) of the Government of the Northwest Territories promotes, protects and provides for the health and wellbeing of the people of the Northwest Territories. This includes:

- Helping people take personal responsibility for healthy lifestyle decisions;
- Protecting people from abuse, violence, preventable disease and unsafe environmental conditions;
- Caring for and/or counseling people when they require support for social or health issues; and
- Treating people when they are sick or suffering from physical, emotional or mental health problems.

TB elimination is an important goal for the DHSS, but this can only be achieved through strong partnership with Indigenous governments and communities. In the Inuvialuit Settlement Region, eliminating TB requires a close working relationship with Inuvialuit Regional Corporation (IRC). A regional action plan for eliminating TB in the Inuvialuit Settlement Region will be jointly produced and implemented by DHSS and IRC.

Government of Nunavut

The Government of Nunavut's Department of Health TB Program is partnering with Nunavut Tunngavik Inc., the federal government and other organizations to eliminate TB in Nunavut by 2030. This is being achieved through: collaborative partnerships, outbreak response, program development, education and training, research, epidemiology surveillance, monitoring and evaluation, community engagement, and communications.
Nunavik Regional Board of Health and Social Services

The Nunavik Regional Board of Health and Social Services (NRBHSS) is incorporated under the James Bay and Northern Québec Agreement. The mission of the NRBHSS is to ensure the provision of health and social services that are adapted to the population’s needs and the region’s realities. NRBHSS is responsible for the development and implementation of the regional action plan for the elimination of TB. The NRBHSS works in collaboration with Makivik Corporation - the land claims organization mandated to manage the rights holding funds of the Inuit of Nunavik provided for under the James Bay and Northern Québec Agreement.

Nunatsiavut Government Department of Health and Social Development and the Government of Newfoundland and Labrador

The Nunatsiavut Government Department of Health and Social Development (DHSD) and the Government of Newfoundland and Labrador collaborate to improve, protect and promote the health and wellbeing of Nunatsiavut communities. In particular, TB clinical care, health protection, education and community engagement are delivered through an integrated model of care by the Nunatsiavut Government DHSD, Labrador-Grenfell Health Authority and the Regional Medical Officer of Health.

The burden of TB is disproportionately high among Nunatsiavut Inuit compared with the rest of the population in the province. All the regional partners are working together to develop a regional strategy towards TB elimination under the leadership of the Nunatsiavut Government.

Public Health Agency of Canada

The Public Health Agency of Canada (PHAC) has a mandate to promote and protect the health of all Canadians through leadership, partnership, innovation, and action in public health. Working with Inuit partners, TB experts, as well as other government partners at the federal and provincial and territorial level, PHAC is actively engaged in meaningful policy and program development in support of the elimination of TB across Inuit Nunangat. Specifically, PHAC’s role in TB elimination includes: national surveillance of active TB, surge capacity support during outbreak events, laboratory support, knowledge transfer and guidance, as well as federal leadership with provinces and territories.
First Nations and Inuit Health Branch (FNIHB), Department of Indigenous Services Canada

The First Nations and Inuit Health Branch (FNIHB) at Indigenous Services Canada:

- Improves access to culturally safe health services for First Nations and Inuit communities;
- Assists First Nations and Inuit communities to address health barriers, disease threats, and attain comparable health outcomes to other Canadians living in similar locations; and
- Builds strong partnerships with First Nations and Inuit to improve the health system.

Specifically, Indigenous Services Canada is working with Inuit partners and provincial/territorial counterparts in addressing the high rates of TB in Inuit communities, for example by: providing financial and human resources to address social determinants of health and outbreak response, investing in the acquisition of rapid TB diagnostic technology, and sharing a TB high incidence monitoring tool.

The Department supports Inuit partners in each of the four Inuit regions through ITK’s Inuit Public Health Task Group in the development of region-specific action plans to work towards the elimination of TB across Inuit Nunangat by 2030, with reduction of at least 50% of active TB cases by 2025.

Through Budget 2018 the Government of Canada is investing $27.5 million over 5 years to help eliminate TB in Inuit Nunangat and $400 million over 10 years to support an Inuit-led housing plan in the Inuit regions of Nunavik, Nunatsiavut and Inuvialuit. This is in addition to the $240 million over 10 years announced in Budget 2017 to support housing in Nunavut.
Tuberculosis among Inuit

This section describes how TB has impacted Inuit. It compares the current burden of TB disease among Inuit with other Canadian-born populations, and describes some of the key influences on TB prevalence and transmission within Inuit communities today.

Historical context

TB, or “consumption” as it was then called, was among many infectious diseases brought to Inuit communities by early European explorers and whalers, with particularly lethal consequences. By 1861, C.F. Hall noted, “…consumption had killed more Inuit than all other diseases put together.”

The extent of the impacts of various epidemics on Inuit began to garner attention from government officials in Canada in the 1920s when physicians started coming to the Arctic more regularly. Throughout the 1930s, medical officers reported concerns about the high rates of TB in their areas and the need for improved services. The situation had not improved by 1945, when the problem of TB among Inuit in the McKenzie Delta was described in a report by Dr. G.J. Wherrett as ‘staggering’.

Subsequent efforts to address TB among Inuit included community-wide screening, removal of people with active TB disease for treatment and to interrupt transmission, and immunization of as much of the rest of the population as feasible with bacille Calmette-Guérin (BCG) vaccine. Initially, these interventions were undertaken as part of summertime patrols by ship-board medical clinics to communities and Inuit camps along Arctic coastlines.

Figure 1. Inuit boarding the CD Howe ship for medical examination by the Eastern Arctic Patrol Officers. July 1951.

---


5 Ibid.

By the 1950s, it was estimated that one in seven Inuit was living in a southern sanatorium. At that time, the incidence rates of TB among Inuit in Canada and Alaska were in the 1500-2900 cases/100,000 range.

The magnitude of the impact the TB evacuations had on our people and communities cannot be overstated. Mothers and fathers were separated from their spouses and children; children were separated from their parents, siblings and extended families; and communities were left without the guidance and support of elders. The separations were immediate, without opportunity for those found to have active TB to return home to collect belongings and make arrangements for their families, or to even say goodbye.

The separations were also lengthy, often lasting years. Many families were not informed where their loved ones were taken, or when or if they would return. Those who did return, particularly the children, faced new challenges including reduced physical capacities related to their illness or its treatment (e.g. removal of diseased portions of the lungs), and the loss of language and other aspects of Inuit culture.

In the years before effective anti-TB drugs became available, death rates from TB among Inuit were high. Many of those taken away died, and until very recently, their fates and final resting places remained unknown to family and friends. Over time, new approaches to the TB epidemic in the north were introduced. Alaska began a mass testing and treatment program for latent TB infection in 1955. A similar campaign was started in Inuit Nunangat in the late 1960s, under the leadership of Dr. Stefan Gryzbowski.

Gryzbowski’s approach saw 15 percent annual reductions in the incidence of active TB among Inuit in Canada. TB testing and treatment was integrated into routine programming at northern health centres in Canada during the late 1970s. By 1997, the TB incidence rate among Inuit had fallen to 31/100,000.

Since 1997, the overall TB incidence rate for our people has risen substantially, although the resurgence of TB within Inuit Nunangat is largely confined to the Eastern Arctic. Contributing factors include poverty and ongoing challenges with social determinants of Inuit health including: housing, food security, mental wellness, and availability of health services (see Risk factors for TB among Inuit).

---

9 Ibid.
Inuit carry an exceptionally high burden of TB disease (Figure 2). In 2016, the overall TB incidence rate among Inuit living in Inuit Nunangat was 182.9 cases per 100,000 population. That same year, the TB incidence rate was 4.8 cases per 100,000 for Canada overall and 0.6 cases per 100,000 for the Canadian-born non-Indigenous population. Recent years have also seen TB outbreaks in three of the four Inuit regions and deaths from TB among Inuit youth. Additional information on the epidemiology of TB across Inuit Nunangat is provided in Appendix 1.

---

10 Canadian Tuberculosis Reporting System – March 2018 (Contact: W. Siu)
11 Ibid.
Figure 2. Incidence rate of TB disease among Inuit living in Inuit Nunangat compared with Canadian-born non-Indigenous populations and all of Canada, 2006-2016\textsuperscript{12}

The overall TB incidence rate among Inuit living in Inuit Nunangat and elsewhere (170.1 per 100,000 in 2016) was also substantially higher than for other Indigenous groups in Canada (Figure 3).

Figure 3. Incidence rate of TB disease by Indigenous group compared with Canadian-born non-Indigenous, 2006-2016\textsuperscript{13}

\textsuperscript{12}Ibid.
\textsuperscript{13}Canadian Tuberculosis Reporting System – February 2018 (Contact: W. Siu)
Risk factors for TB among Inuit

The Stop TB Partnership’s *Global Plan to End TB* and other guiding documents on TB care and elimination identify risk factors for TB that, when present among individuals, families or communities increase the chances of individuals developing TB disease. These include poverty, gaps in the social determinants of health, and health inequities that contribute to conditions that put people and communities at greater risk for developing TB disease.\(^{14,15,16}\) Additional influences on incidence rates of active TB among Inuit described in the *Inuit-specific Tuberculosis (TB) Strategy* (2013) include post-colonization TB epidemics, early efforts to control TB disease across Inuit Nunangat, and acculturation. Eliminating TB among our people will clearly require holistic approaches and multisectoral collaboration.

**Poverty**

Inuit communities face the highest cost of living in Canada. Despite this, the incomes of Inuit living in Inuit Nunangat tend to fall far below those of non-Indigenous people living in our homeland. The before tax median individual income for Inuit adults living in Inuit Nunangat is almost $70,000 less than that of non-Indigenous people living in the area.\(^{17}\) This disparity in earnings relative to cost of living contributes to other social and economic inequities in Inuit Nunangat, as described in Figure 5.

---


\(^{17}\)Heather Tait (Analyst/Researcher, Health Canada), e-mail message to author (March 27, 2018) *Median Total Income for the Population Aged 15 and over, 2016 Census.*
Figure 4  Equality versus equity
Figure 5. Social and economic inequity in Inuit Nunangat

<table>
<thead>
<tr>
<th>Inuit Nunangat</th>
<th>All Canadians</th>
</tr>
</thead>
<tbody>
<tr>
<td>52% of Inuit in Inuit Nunangat live in crowded homes*†</td>
<td>9% of all Canadians live in crowded homes*†</td>
</tr>
<tr>
<td>34% of Inuit aged 25 to 64 in Inuit Nunangat have earned a high school diploma</td>
<td>86% of all Canadians aged 25 to 64 have earned a high school diploma³</td>
</tr>
<tr>
<td>70% of Inuit households in Nunavut are food insecure²</td>
<td>8% of all households in Canada are food insecure³</td>
</tr>
<tr>
<td>$23,485 The median before tax individual income for Inuit in Inuit Nunangat¹</td>
<td>$92,011 The median before tax individual income for non-Indigenous people in Inuit Nunangat¹</td>
</tr>
<tr>
<td>30 The number of physicians per 100,000 population in Nunavut⁴</td>
<td>119 The number of physicians per 100,000 population in Urban Health Authorities⁴</td>
</tr>
<tr>
<td>47.5% of Inuit in Inuit Nunangat are employed¹</td>
<td>60.2% of all Canadians are employed¹</td>
</tr>
<tr>
<td>72.4 years The projected life expectancy for Inuit in Canada⁵</td>
<td>82.9 years The projected life expectancy for non-Indigenous people in Canada⁵</td>
</tr>
<tr>
<td>12.3 The infant mortality rate per 1,000 for Inuit infants in Canada.⁶</td>
<td>IMR 4.4 The non-Indigenous infant mortality rate per 1,000 for Canada.⁶</td>
</tr>
</tbody>
</table>

---

* Should not be compared with crowding data for previous years. Based on the suitability definition (whether the dwelling has enough bedrooms for the size and composition of the household). The previous figure was based on the number of persons per room definition.
† Should not be compared with previous life expectancy data. The figure is a national 2017 projection of life expectancy for Inuit. Previous figures were for 2004-2008 for all residents of Inuit Nunangat, including non-Inuit.
4 Canadian Institute for Health Information, Supply, Distribution and Migration of Physicians in Canada, 2014 (Ottawa, ON: Canadian Institute for Health Information, September 2015).
5 Custom table based on Statistics Canada’s Projections of the Aboriginal Population and Households in Canada, 2011 to 2036.
Social determinants of Inuit health

TB has long been referred to as a social disease with a medical aspect due to the tendency of populations with poorer social and economic conditions to be disproportionately affected by the disease. Reductions in TB incidence, mortality and morbidity have been observed historically as populations experienced improvements in social and economic conditions, also known as social determinants of health.

The eleven social determinants of Inuit health (SDOIH) are presented in Figure 6. SDOIH are described in detail in the ITK report, *Social Determinants of Inuit Health in Canada* (2014).18

Figure 6. Social determinants of Inuit health

Until relatively recently, organized TB prevention and control efforts in Canada and elsewhere have tended to focus on medical (clinical) interventions. However, interest in meeting the World Health Organization’s *End TB Strategy* milestones and 2050 global TB elimination target19 have contributed to

---


increasing interest in understanding and addressing health determinants that are referred to by some as ‘social determinants of TB’.\textsuperscript{20}

SDOIH identified in the \textit{Inuit-specific Tuberculosis (TB) Strategy} (2013) as particularly relevant to TB are: housing, food security and nutrition, mental wellness, income distribution, and availability of health services. In addition, factors such as colonialism, systemic racism and social exclusion (discrimination toward individuals or families experiencing TB) may also contribute to the context of SDOH for Inuit and other Indigenous communities, families and individuals.\textsuperscript{21}

**Health inequities**

Variability in access to health services (discussed above) is one example of the myriad of health inequities faced by Inuit compared to most other Canadians, and a gap that needs to be closed. Variability in the nature of services – for example, regional differences in protocols for clinical and public health TB management - is another.

As portrayed in Figure 4, equal provision of support (e.g. programmatic funding) does not ensure an equitable outcome. Adapting policies, programs and initiatives to the needs of Inuit is essential for creating social and economic equity, and is emphasized in the WHO action framework for TB elimination in low-incidence countries.\textsuperscript{22}

\begin{flushleft}


\end{flushleft}
Inuit Tuberculosis Elimination Framework

This section describes the Inuit Tuberculosis Elimination Framework. Region-specific TB elimination action plans will be developed to operationalize the Framework across Inuit Nunangat. The plans will be tailored to the priorities, needs and strengths of each region to ensure interventions and activities are informed by local TB epidemiology and health systems. This approach aligns with the principles of the Stop TB Partnership’s Global Plan to End TB 2016-2020 and the Inuit-specific Tuberculosis TB Strategy (2013).

Alignment with key global guidance

The Inuit Tuberculosis Elimination Framework aligns with the following key global guidance documents on TB care and elimination:

- The International Standards for Tuberculosis Care (2006)
- The Patients’ Charter for Tuberculosis Care (2006)
- The World Health Organization End TB Strategy (2014)

Purpose and vision

The Inuit Tuberculosis Elimination Framework has two purposes:

1. To provide strategic direction for Inuit regions and their partners as they develop and implement region-specific TB elimination action plans; and

2. To provide an evidence-based, transparent tool for ensuring accountability and measuring progress toward TB elimination.

The vision of the Framework is elimination of TB in every Inuit community in Canada.
2025 milestone and 2030 TB elimination target

Together with stakeholders and partners, Inuit regions have committed to working together to reduce the reported incidence rate of active TB disease across Inuit Nunangat by at least 50% by 2025. This will require a drop in the rate from 182.9 cases per 100,000 population (2016) to no more than 91.5 cases per 100,000.

ITK, in collaboration with the Inuit Public Health Task Group, will coordinate reporting on progress toward the 2025 milestone and 2030 TB elimination target. Progress will be monitored over two phases: phase one (2018-2023) and phase two (2024-2030).

Principles

The Framework is grounded in a number of principles that build upon those described in the Inuit-specific Tuberculosis (TB) Strategy (2013). They are:

- Efficient, effective and fair use of resources;
- Meaningful involvement of Inuit and Inuit communities;
- Respect for Inuit values, language, knowledge, culture, and the historical context of TB across Inuit Nunangat;
- Commitment to health equity for Inuit, and recognition that this will require both biomedical interventions and improvements to the social determinants of Inuit health across Inuit Nunangat;
- Valuing youth perspectives and the potential for youth to lead and champion meaningful change;
- Appreciation of the importance of tailoring TB care and prevention approaches to meet the needs of Inuit and to reduce stigma and discrimination associated with TB;
- Transparency and accountability; and
- Collaboration and shared decision making.
Priority Actions

The Framework identifies six priority areas for action and investment to guide TB elimination efforts that build upon the core TB action plan components proposed in the *Inuit-specific Tuberculosis (TB) Strategy* (2013). These are:

1. Enhance TB Care and prevention programming
2. Reduce poverty, improve social determinants of health and create social equity
3. Empower and mobilize communities
4. Strengthen TB care and prevention capacity
5. Develop and implement Inuit specific solutions
6. Ensure accountability for TB elimination

This section provides an overview of the priority action areas along with recommendations on how to incorporate and/or reflect them within the regional TB elimination action plans.

Requirements

Coordinated approaches, founded on partnership and collaboration will be critical, given the interrelated, interdependent nature of the priority areas and the number of stakeholders and partners involved. Other requirements include:

- Transformative changes in TB care and prevention programming, social determinants of health and health equity for Inuit, and community ownership of and involvement in TB elimination efforts;

- Strong and enduring commitment to achieving and maintaining TB elimination from all levels of government and leadership, Inuit communities, partners, and health care providers; and

- Substantial initial and ongoing investments to: improve social determinants of health and health equity for Inuit; strengthen key areas of TB programming and health service delivery; develop, implement, monitor and evaluate strategic short-, medium- and longer-term interventions that enable communities and health systems to work together; and sustain elimination by developing and supporting capacity at the community level.
Ensuring that TB programming across Inuit Nunangat is consistent with the principle activities, clinical standards and care and prevention service capacities set out in Canadian and international guidelines is critical to providing high-quality care and to achieving the 2025 milestone and 2030 TB elimination target.

**Recommendation:** *Strengthen regional health service delivery systems and build capacity for robust, consistent, evidence-based, Inuit-informed and sustainable TB prevention and care interventions with an emphasis on public health.*

**Key Elements for Regional TB Elimination Action Plans:**

1. **Political commitment** from all levels of government, along with sustained and consistent financing to enhance TB care and prevention programming across Inuit Nunangat including strengthening health and information technology infrastructures

2. **Program leadership** (e.g. designated physician and nursing leads for regional TB programs with clearly defined roles and responsibilities)

3. **Adequate and consistent health human resourcing and diagnostic/treatment supplies** (see Priority Action 4 for information on building capacity)

4. **Health providers sensitized to TB and standardized competencies** for health providers responsible for delivering TB care (see Priority Action 4 for information on education/training)

5. **Equitable access to high-quality and new/emerging diagnostic tools** including digital radiology and sputum induction, GeneXpert and interferon gamma release assay (IGRA) and whole genome sequencing - supported with adequate infrastructure and laboratory, radiology and pharmacy personnel - and standardized protocols for use

6. **Equitable access to new TB/LTBI drugs/treatment options across Inuit Nunangat** such as 3HP and fixed-dose combinations for the treatment of TB in children, supported with adequate infrastructure and standardized protocols for use
1.7 Baseline data and information to inform core program development (e.g. establishing ideal standards of care protocols) and comprehensive regional TB elimination action plans to provide starting points against which progress can be measured (e.g. regional SWOT analyses)

1.8 Data management systems, processes and indicators to monitor the impact of existing and new program interventions and activities

1.9 Epidemiologist support for TB within each region and Inuit Nunangat as a whole

1.10 Structures and mechanisms to monitor and evaluate program performance and progress toward routine goals and objectives, and elimination milestones and targets (e.g. regional advisory bodies with relevant representation to annually review program performance)

1.11 Consistent, evidence-based and equity-sensitive clinical care guidelines for case finding, treatment and prevention that incorporate social support and protection, are tailored to the epidemiology of TB and health delivery systems across Inuit Nunangat, and reflect principles of people-centred care

1.12 Access to clinical technical assistance to minimize diagnostic/treatment delays and to assist with management of complex cases, contact investigations and outbreak detection/response

1.13 Coordination of care/discharge planning with referral centres that supports continuity of care (e.g. use of treatment/follow-up protocols consistent with those used where the client is returning to)

1.14 Interventions and activities to strengthen TB programming and reduce impacts of TB and improve the overall health of Inuit (e.g. integration of tobacco cessation and diabetes management)

1.15 Collaboration across regions and with others (e.g. International Circumpolar Surveillance Tuberculosis Working group) to: identify and share best and evolving practices in TB care and elimination, build strategic partnerships, create synergies, increase integration of TB screening into existing programs, and reduce barriers to early detection/treatment of LTBI/TB across the health system
1.16 **Partnerships** with local health and social service officials, public health practitioners, implementing partners, researchers, correctional facility services, occupational health departments, and special health and social service organizations who serve especially vulnerable groups.

1.17 **Designated regional TB elimination leads to coordinate elimination efforts**

1.18 **Coordination to support activities that require surge capacity** (e.g. whole community screening, outbreak response) including health human resourcing, diagnostic/treatment supplies/infrastructure and technical assistance (clinical).

1.19 **Inuit-led research** to:

- Strengthen the care cascade for TB/LTBI/contact investigation;
- Identify highest risk and hardest to reach groups;
- Fill gaps in knowledge about the impact/feasibility/sustainability of TB programming interventions/activities (e.g., ‘pop-up’ community screening clinics, deployment of portable GeneXpert machines during contact investigations);
- Evaluate TB programming policies/processes;
- Explore the utility of virtual clinic models, given geographic and health human resourcing challenges;
- Test, monitor and disseminate findings from interventions/activities;
- Implement/scale-up access to new diagnostic tools and drug/treatment options;
- Increase understanding of the impacts of TB on Inuit, and risk factors for TB that may be unique to Inuit and/or Inuit Nunangat; and
- Enhance prevention strategies and interventions.
Recommendation: Initiate system-wide and cross-government commitment, partnerships and action toward improving social determinants of Inuit health and health equity with particular focus on reducing poverty and the effects of social determinants of Inuit health and health inequities known or expected to contribute to TB.

Key Elements for Regional TB Elimination Action Plans:

2.1 Political commitment from all levels of government, along with sustained and consistent financing to reduce poverty, improve social determinants and create health equity across Inuit Nunangat

2.2 Input, engagement and advocacy from civil society, communities and other stakeholders

2.3 Structures and mechanisms across Inuit organizations, Federal and provincial/territorial governments, and other stakeholders that foster partnership, dialogue and action toward TB elimination

2.4 Data management systems, processes and indicators for mapping and monitoring of key populations and their socioeconomic conditions

2.5 Interventions and activities to raise awareness with communities and partners on the connections between TB and poverty, SDOIH and health equity, and that provide equitable access to social protection during TB care

2.6 Collaboration with others to identify and share best and evolving practices for reducing poverty, improving SDOIH and creating health equity

2.7 Employment and income distribution that is respectful of Inuit culture and environmental concerns, given the critical importance of diet and nutrition to Inuit health – which indirectly depends upon the preservation of Inuit culture, and the land and sea mammal habitat
2.8 Inuit-led research to:

- Fill gaps in knowledge about the impact of poverty, SDOIH and health inequity on TB in Inuit Nunangat;
- Evaluate policies and processes that affect health equity; and
- Test, monitor and disseminate findings from interventions to address poverty, SDOIH, and health equity

Priority Action 3: Empower and mobilize community

Although TB is diagnosed in health centres and hospitals, it impacts individual people, their families and the communities they live in. Those affected and threatened by TB are the best informed on how to raise awareness, reduce risk and increase uptake of screening and treatment in ways that are culturally appropriate and culturally safe. They also have valuable insights about the influence local people and structures have on the persistence of TB in Inuit communities and the important contributions individuals and communities could make to TB elimination.

Recommendation: Implement community ownership and competency building initiatives to engage, educate and empower local people and structures.

Key Elements for Regional TB Elimination Action Plans:

3.1 Participation of Inuit in the formulation, implementation, and evaluation of approaches and interventions, and the ability to hold those with a duty to act accountable

3.2 Approaches and interventions that recognize and reflect social factors that are important to Inuit communities

3.3 Approaches and interventions that empower and mobilize individuals and communities, and reduce stigma and discrimination associated with TB

3.4 Data management systems, processes and indicators for mapping and monitoring of the impact of community empowerment and mobilization on TB elimination efforts
3.5 Inuit-led research to:

- Fill gaps in knowledge about the impact of community empowerment and mobilization, and stigma and discrimination associated with TB on TB elimination efforts;

- Evaluate policies and processes that affect community empowerment and mobilization (e.g. policies on volunteering); and

- Evaluate interventions aimed at reducing stigma and discrimination associated with TB

Priority Action 4: Strengthen TB care and prevention capacity

Adequate and appropriate health human resourcing (HHR) is an essential component of a tuberculosis prevention and control program. Regions have been facing serious challenges meeting HHR requirements to deliver effective TB prevention and care in some Inuit communities, particularly those in remote locations and those experiencing large or protracted TB outbreaks. There is a critical need to increase HHR capacity and to ensure those responsible for TB prevention and care are adequately prepared to do so – both to protect the integrity of foundation-level programming and to prepare for and support the transformations needed to meet the 2025 milestones and 2030 elimination target.

Some factors identified as important to delivery of high quality TB care and prevention services in Inuit communities include:

- Adequate HHR to support all sectors/components of health care (i.e. not just public health/TB);

- Clear delineation of roles and responsibilities for staff (e.g., Community Health Nurses versus TB Nurses, TB Nurses versus DOT workers);

- Adequate/appropriate recognition of contributions/roles of Inuit para-professionals within health service delivery systems;

- Role-appropriate TB competencies;

---

Centers for Disease Control and Prevention. Essential components of a tuberculosis prevention and control program; and Screening for tuberculosis and tuberculosis infection in high-risk populations: recommendations of the Advisory Council for the Elimination of Tuberculosis. MMWR 1995;44 (No. RR-11)
• Good communication between service components and between clinical and public health staff;

• Baseline, pre-requisite sensitization/training on TB and cultural safety/competence for all health care providers working in Inuit Nunangat and more advanced TB education/training for health care providers whose responsibilities include TB care and prevention;

• Consistency in care providers, particularly for staff working directly with patients and families;

• Adequate support for staff at all levels of the care pathway, particularly those working in remote communities without physicians;

• Adequate and appropriate support/supervision for para-professional staff (e.g. DOT workers);

• Ongoing professional development/education/training opportunities;

• Adequate and appropriate housing for health staff;

• Remuneration and benefits equity (e.g. between staff/contracted nurses and ‘agency’ nurses);

• Adequate and appropriate occupational health and safety programming/support; and

• Adequate communication capacity at the community level

**Recommendation:** Fortify health human resourcing and implement health care provider awareness and competency strengthening initiatives to ensure culturally and equity-sensitive care and facilitate timely detection and treatment of active TB and latent TB infection (LTBI).

**Key Elements for Regional TB Elimination Action Plans:**

4.1 **Political commitment** from all levels of government along with sustained and consistent financing to ensure adequate and appropriate routine and surge capacity HHR for TB care and prevention programs/services

4.2 **Data management systems, processes and indicators** for mapping and monitoring of HHR needs and **structures and mechanisms** to respond promptly and effectively when gaps are identified

4.3 **Engagement with community** on how to increase the number of Inuit health care workers and expand the role of community health workers in public health programs including TB prevention and care
4.4 **Interventions and activities** to educate/train, recruit and retain adequate and appropriate HHR, with a particular emphasis on increasing the number of Inuit health care workers and expanding the role of community health workers (e.g., Community Health Aides, Public Health Assistants) to support TB and other public health activities in each community.

4.5 **Engagement with staff** at all program levels on job satisfaction.

4.6 **Collaboration** with others to identify and share best and evolving HHR and competency strengthening practices.

4.7 **New/strengthened partnerships** to find innovative and sustainable solutions to HHR challenges (e.g., with Indigenous Services Canada, provincial/territorial TB programs, professional regulatory bodies, laboratory accreditation bodies, post-secondary educational institutions).

4.8 **Inuit-led research** to:

- Evaluate policies and processes that affect HHR.

---

**Priority Action 5: Develop and implement Inuit-specific solutions**

In keeping with the World Health Organization’s *End TB Strategy*, strengthening TB care and prevention across Inuit Nunangat, and reaching the 2025 milestone and 2030 elimination target will require improvements in TB tools as well as transformative changes in how TB services are delivered. Working in collaboration with governments, partners and research institutions, and guided by the *National Inuit Strategy on Research* (2018), Inuit can use research to develop and implement solutions that are appropriate, equitable, acceptable, and sustainable.

Potential areas for TB-related research described within the Framework’s Priority Actions include:

- Epidemiological research and surveillance to understand the causes and patterns of health and illness;

- Operational and implementation research to enhance programming to make evidence-based decisions by identifying service delivery problems, testing service delivery innovations, and testing service delivery costs;
• Health policy and health system research to understand how health care is financed, organized, delivered and used, and how health policies are prioritized, developed and implemented; and

• Social science research and research on social determinants of Inuit health.

**Recommendation**: Facilitate Inuit-specific TB surveillance and research to inform development of evidence-based, equity-oriented and Inuit-informed approaches to achieving and sustaining TB elimination.

**Key Elements for Regional TB Elimination Action Plans:**

5.1 **Political commitment** from all levels of government along with sustained and consistent financing to expand and strengthen Inuit-led research, and the research and human resources infrastructure needed to support it

5.2 **Alignment with the National Inuit Strategy on Research**

5.3 **Interventions and activities to engage individuals and communities** in efforts/research toward developing/implementing Inuit-specific solutions to achieve and maintain TB elimination

5.4 **Research partnerships and knowledge translation** to strengthen TB care and prevention programming for Inuit, to achieve and maintain TB elimination, and to contribute to national and international efforts to end TB

5.5 **Data management systems**

**Priority Action 6: Ensure accountability for TB elimination**

Infrastructure, processes and capacity for TB reporting, surveillance and data management vary across Inuit regions. This variability has contributed to challenges in understanding TB epidemiology across Inuit Nunangat and within individual regions. Gaps in infrastructure, process and capacity have limited potential for making evidence-based decisions on TB program priorities and development. Such gaps can also contribute to missed opportunities for TB prevention, and delays in identifying case clusters and other potential indicators of ongoing TB transmission and TB outbreaks.
Moving forward, improving and (where possible) standardizing strategies and systems for monitoring and evaluation will benefit principal TB program activities. It will also make it possible to monitor and evaluate progress toward reaching the 2025 milestone, achieving and sustaining TB elimination, and ensuring Inuit have equitable access to high-quality TB care and prevention services.

It may not be necessary for all Inuit regions to use the same approaches to monitoring and evaluation (e.g. a single information technology system), however it is critical that comprehensive baseline (2016) and yearly TB epidemiology reports be produced for each Inuit region and for Inuit Nunangat as a whole.

Regions will also need to work with communities and partners to determine measurable, equity-sensitive TB program goals and objectives, and work individually with their communities to identify region-specific program performance and other progress measurements (indicators) that align with the goal and objectives of their TB programs. They must collaborate to identify a set of standardized pan-regional indicators, and develop the infrastructure, tools and processes needed to collect, monitor, evaluate, and report on the indicators. Information sharing agreements and other requirements will be put in place to enable individual regions to monitor, evaluate and interpret their own data, and to share findings and progress toward elimination in timely and appropriate ways.

**Recommendation:** Implement monitoring and evaluation strategies and systems.

**Key Elements for Regional TB Elimination Action Plans:**

- **6.1 Political commitment** from all levels of government, along with sustained and consistent financing to ensure the 2025 milestone is met, and that TB elimination is achieved by 2030 and sustained afterward

- **6.2 Input, engagement and advocacy** from civil society, communities and other stakeholders

- **6.3 Structures and mechanisms** across Inuit organizations, rights holders, Federal and provincial/territorial governments departments, and other stakeholders that ensure accountability for achieving and sustaining TB elimination

- **6.4 Partnerships** to identify pan-regional and region-specific program performance indicators for monitoring and evaluating progress
6.5 **Baseline data, data management systems and processes** for monitoring and evaluating progress toward achieving and sustaining TB elimination

6.6 **Monitoring and evaluation** of interventions and activities to ensure they are contributing to achieving and sustaining TB elimination and remain effective, efficient and equitable

6.7 **Collaboration** with others to identify and share best and evolving practices for achieving and sustaining TB elimination (e.g., Inuit Circumpolar Council, International Circumpolar Surveillance Tuberculosis Working Group, Canadian Tuberculosis Elimination Network, World Health Organization, International Union Against Tuberculosis and Lung Disease)

6.8 **Oversight and coordination** to ensure TB elimination efforts align with and leverage other initiatives to improve/protect the health and wellbeing of Inuit (e.g., ITK national strategies, federal investments in housing)

6.9 **Inuit-led research** to:

- Fill gaps in knowledge about TB epidemiology/impact across Inuit Nunangat and within each Inuit region; and

- Evaluate public health and TB program policies, processes, interventions and activities that can influence/impact achieving and sustaining TB elimination (e.g. implementation and/or outcomes from regional TB elimination action plans)
Conclusion

On March 23, 2018, the Government of Canada made a commitment to work with Inuit to reduce TB rates across Inuit Nunangat by 50% before 2025 and eliminate TB across Inuit Nunangat by 2030. These targets are very ambitious and will be challenging to meet, but we have a collective responsibility to do so – for ourselves and for future generations.

It is high time that governments work in partnership with Inuit to end TB across Inuit Nunangat. Inuit have unnecessarily carried a disproportionate burden of TB for far too long and our families and communities continue to experience the shameful toll of TB even as the disease has become virtually unknown in most other parts of Canada.

Reducing poverty and improving social determinants of Inuit health are critical to ending TB. So too is ensuring Inuit are fully committed to the vision of eliminating TB. Through the development and implementation of regional TB elimination action plans guided by the Inuit Tuberculosis Elimination Framework, Inuit and our partners will collectively approach this problem with new energy, new ideas and new resources.

We will work together to transform TB care to better meet the needs of our people; to incorporate the most effective and appropriate methods for diagnosing, treating and preventing TB; and to ensure our access to care is equitable and fair.

We will change the way we think about TB; to not see it as a disease but instead as a symptom of social inequities that enable the spread of TB, diminishing the health and wellbeing of too many of our people. Most importantly, we will recognize that the goal of building strong and sustainable TB care programs is not managing illness; it is achieving and protecting wellness.
Appendix A – Tuberculosis Incidence by Inuit Region

TB incidence rates vary among Inuit regions (Figure A1). Although Nunavut reported the most TB cases during this time period (670 cases), its TB incidence rate is also less volatile than those of the other regions because it has the largest Inuit population. In regions with fewer Inuit residents, even small changes in the number of TB cases reported can cause sizable variations in TB incidence rates.

Figure A1. Incidence rates of TB disease among Inuit individuals living in Inuit regions, 2006-2016

Note: Differences between the data published in this report and the data published in previous national, provincial and territorial surveillance reports may be due to reporting delays or differences as to when the data were extracted from various surveillance databases. The reporting province or territory may update its published data on a more regular basis. Should differences exist between this report and provincial or territorial reports, readers are encouraged to contact the provincial/territorial jurisdiction for clarification.

24 Canadian Tuberculosis Reporting System – May 2018 (Contact: J. Vachon)
TB incidence rates by year and Inuit region for 2006-2016 are presented in Table A1. Three Inuit regions have experienced significant TB outbreaks in the last 10 years.

Table A1. TB case numbers and incidence rates of TB disease among Inuit individuals living in Inuit regions, 2006-2016

<table>
<thead>
<tr>
<th></th>
<th>Inuvialuit</th>
<th>Nunatsiavut</th>
<th>Nunavik</th>
<th>Nunavut</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>TB cases</td>
<td>TB rate/100,000</td>
<td>TB cases</td>
<td>TB rate/100,000</td>
</tr>
<tr>
<td>2006</td>
<td>1</td>
<td>16.7</td>
<td>5</td>
<td>203.5</td>
</tr>
<tr>
<td>2007</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>40.0</td>
</tr>
<tr>
<td>2008</td>
<td>0</td>
<td>0.0</td>
<td>2</td>
<td>78.4</td>
</tr>
<tr>
<td>2009</td>
<td>0</td>
<td>0.0</td>
<td>14</td>
<td>536.2</td>
</tr>
<tr>
<td>2010</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>37.8</td>
</tr>
<tr>
<td>2011</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>37.1</td>
</tr>
<tr>
<td>2012</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>2013</td>
<td>0</td>
<td>0.0</td>
<td>5</td>
<td>184.5</td>
</tr>
<tr>
<td>2014</td>
<td>0</td>
<td>0.0</td>
<td>2</td>
<td>73.9</td>
</tr>
<tr>
<td>2015</td>
<td>0</td>
<td>0.0</td>
<td>24</td>
<td>887.2</td>
</tr>
<tr>
<td>2016</td>
<td>0</td>
<td>0.0</td>
<td>17</td>
<td>628.2</td>
</tr>
<tr>
<td>Totals</td>
<td>1</td>
<td>-</td>
<td>72</td>
<td>354.9</td>
</tr>
<tr>
<td>5-year average</td>
<td>0</td>
<td>0.0</td>
<td>10</td>
<td>-</td>
</tr>
</tbody>
</table>

Inuvialuit Settlement Region

No cases of active TB were reported in the Inuvialuit region between 2007 and 2016.

Nunavut

In Nunavut, the average rate of TB per 100,000 population for the years 2006-2016 was 181.1. Outbreaks have occurred in communities in the years 2010, 2012, 2014 and 2017. Activity is highest in the Qikiqtaaluk region, with an average crude rate of 305.1 from 2006-2016. However, in the past 2 years outbreaks have also occurred in the other two regions of Nunavut. In 2017, 11 of 25 communities had active TB cases reported. Teenagers and young adults between the ages of 15 and 24 have the highest rates of active TB in the territory. Contributing factors to the continued transmission of TB in Nunavut include the housing crisis affecting the entire territory and the challenges of delivering health care services over a large, remote geographical area.

25 Canadian Tuberculosis Reporting System – April 2018 (Contact: J. Vachon)
26 Canadian Tuberculosis Reporting System – May 2018 (Contact: J. Vachon)
Nunavik

In Nunavik, the incidence of active tuberculosis declined steadily from the 1960s to the mid-2000s. The subsequent years saw an increase of the incidence of the disease, which reached a rate of 350 per 100,000 for the period 2011-2015. The highest incidence rates are found amongst children, adolescents and adults under 34 years of age. From 2008 to 2017, 11 of the 14 communities had active cases reported. Since 2012, three of these communities experienced major outbreaks, requiring mass screening interventions.

Nunatsiavut

The average rate of TB per 100,000 population for the years 2006-2016 in Nunatsiavut was 248.4 cases per 100,000; the highest of all four Inuit regions. This high rate has been masked by the usual reporting of rates by province or territory (i.e. the Labrador Inuit numbers get lost in the larger provincial population, which has fewer cases). Since 2006, outbreaks occurred in the years 2006-07, 2009-10, 2015, 2016-17 and 2018 with TB deaths associated with three outbreaks occurring in two of five Nunatsiavut communities.
Appendix B – World Care Council Patients' Charter for Tuberculosis Care

Patients’ Rights
You have the right to:

Care
- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness
- The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis human immunodeficiency virus (HIV) coinfections and preventative treatment for young children and others considered to be at high risk
- The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs

Dignity
- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities
- The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community

Information
- The right to information about what healthcare services are available for tuberculosis and what responsibilities, engagements, and direct or indirect costs are involved
- The right to receive a timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments
- The right of access to medical information which relates to the patient’s condition and treatment and to a copy of the medical record if requested by the patient or a person authorized by the patient
- The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion

Choice
- The right to a second medical opinion, with access to previous medical records
- The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease
- The right to choose whether or not to take part in research programs without compromising care

Confidence
- The right to have personal privacy, dignity, religious beliefs, and culture respected
- The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient’s consent
Justice

- The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly
- The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome

Organization

- The right to join, or to establish, organizations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society
- The right to participate as “stakeholders” in the development, implementation, monitoring, and evaluation of tuberculosis policies and programs with local, national, and international health authorities

Security

- The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment
- The right to nutritional security or food supplements if needed to meet treatment requirements

Patients’ Responsibilities

You have the responsibility to:

Share Information

- The responsibility to provide the healthcare giver as much information as possible about present health, past illnesses, any allergies, and any other relevant details
- The responsibility to provide information to the health provider about contacts with immediate family, friends, and others who may be vulnerable to tuberculosis or may have been infected by contact

Follow Treatment

- The responsibility to follow the prescribed and agreed treatment plan and to conscientiously comply with the instructions given to protect the patient’s health, and that of others
- The responsibility to inform the health provider of any difficulties or problems with following treatment or if any part of the treatment is not clearly understood

Contribute to Community Health

- The responsibility to contribute to community well-being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis
- The responsibility to show consideration for the rights of other patients and healthcare providers, understanding that this is the dignified basis and respectful foundation of the tuberculosis community

Show Solidarity

- The moral responsibility of showing solidarity with other patients, marching together towards cure
- The moral responsibility to share information and knowledge gained during treatment and to pass this expertise to others in the community, making empowerment contagious
- The moral responsibility to join in efforts to make the community tuberculosis free
75 Albert Street, Suite 1101
Ottawa, ON Canada K1P 5E7
613-238-8181
@ITK_CanadaInuit
InuitTapiriitKanatami
www.itk.ca