

Inuit, Tuberculosis, and Political Determinants of Health

by

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B.Sc. (Hons), Laurentian University, 1983

A thesis submitted in partial fulfillment of the requirements for the degree of

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We acknowledge and respect the lək<sup>w</sup>əŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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## Abstract

Tuberculosis is one of humanity's most ancient and deadly diseases. It is largely curable, but its long co-evolution with humans has given it distinctive characteristics that make it hard to control or eradicate. The persistence of tuberculosis is usually attributed to social determinants of health. Yet, history shows that political determinants are more fundamental to its epidemiology. While tuberculosis is indeed shaped by social factors, along with biomedical and sometimes geographic factors, its distinctiveness makes it an especially expensive disease. This in turn makes it political, as decisions are made on how or even whether to allocate resources to treat it. Political dynamics are clearly seen in the history of tuberculosis among Inuit in Canada. Inuit bear a burden of disease among the highest in the world. The burden has lasted for more than a century, but it has not been uniform. Political factors shaped the history into four periods, each with a distinctive manifestation of tuberculosis. The most clear illustration of underlying forces comes in the most anomalous period, starting in the late 1960s, which centred on a unique project in Frobisher Bay. Inuit were given leading-edge treatments locally, and disease rates dropped dramatically. Yet the project was quickly cancelled. The factors behind the project and its cancellation are examined through a cross-disciplinary approach, drawing on archival records, social science and scientific writing, and recent genomic studies. These demonstrate that political determinants of health are the "determinants of determinants" of tuberculosis.

## Table of Contents

Supervisory committee .....	ii
Abstract .....	iii
Table of Contents .....	iv
Acknowledgements .....	v
Acronyms .....	vi
Glossary .....	vii
Changes in Place Names .....	viii
Map of Nunangat .....	ix
Introduction.....	1
Chapter 1 - Tuberculosis.....	14
Chapter 2 - Historiography .....	28
Chapter 3 - Tuberculosis in Canada.....	41
Chapter 4 - Tuberculosis in Canada's North .....	58
Chapter 5 - The Frobisher Bay Project .....	79
Conclusion .....	104
Works Cited .....	115

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## Acronyms

BCG .....	Bacillus Calmette Guérin
CHR .....	community health representative, a trained Indigenous health worker
COPE .....	Committee for Original People's Entitlement
CPHA .....	Canadian Public Health Association
CTA / CTRDA .....	Canadian Tuberculosis Association (to 1969) Canadian Tuberculosis and Respiratory Disease Association (after 1969)
DNHW .....	Department of National Health and Welfare
DOT .....	directly observed therapy
DOTS .....	directly observed therapy - short course
EMB .....	ethambutol
HBC .....	Hudson's Bay Company
IHS .....	Indian Health Service
INHS .....	Indian and Northern Health Service
INH .....	isoniazid (isonicotinic acid hydrazide)
IPT .....	isoniazid preventative therapy
ITC .....	Inuit Tapirisat of Canada
ITK .....	Inuit Tapiriit Kanatami
IUAT / IUATLD .....	International Union Against Tuberculosis (to 1983) International Union Against Tuberculosis and Lung Diseases (after 1983)
L1 - L8 .....	the eight lineages of <i>Mycobacterium tuberculosis</i>
LAC .....	Library and Archives Canada
LTBI .....	latent tuberculosis infection
MSB .....	Medical Services Branch
Mtb .....	<i>Mycobacterium tuberculosis</i> bacterium
MTC or MTBC .....	Mycobacterium Tuberculosis Complex
NAIB .....	North American Indian Brotherhood
NWMP .....	Northwest Mounted Police
NWT .....	Northwest Territories
PZA .....	pyrazinamide
RMP .....	rifampin, also known as rifampicin
SM .....	streptomycin
TB .....	tuberculosis
TSRU .....	Tuberculosis Surveillance Research Unit
WHO .....	World Health Organization

## Glossary

- comorbidity ..... Effect of multiple conditions on a person's health and wellbeing.
- contagious ..... Transmissible by direct or indirect contact. All contagious diseases are (communicable) infectious, but not all infectious diseases are contagious.
- disease ..... Departure of the state of an organism from its regular condition, defined by clinical, pathological and epidemiological criteria.
- endemic ..... Having a constant presence in a population, usually at a low level.
- epidemic ..... Occurring in a population in higher numbers; having a high number of cases.
- epidemiology ..... Study of occurrence and distribution of health-related events, states, and processes in specified populations, including determinants of the processes.
- health ..... Defined by WHO in 1948 as: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."
- health care ..... Efforts to preserve, protect, or restore health and minimize suffering.
- illness (sickness) ..... Departure from a state of health, defined subjectively or societally.
- incidence ..... New events in a population over a specified time, as a rate or absolute number.
- infection ..... Invasion of a host by a pathogen that can proliferate and may cause disease.
- infectious ..... Transmissible by a pathogen.
- infectious disease ..... Disease caused by a pathogen transmitted to a susceptible host.
- medicine ..... Practice or study concerning with preventing, alleviating or curing disease.
- morbidity ..... State or rate: condition of having a disease; number of cases per number of people in a specified population.
- mortality rate ..... Number of deaths per number of people in a specified population.
- outbreak ..... Cluster of events in a given place, usually of an infectious condition.
- pandemic ..... Epidemic that spans large geographic regions.
- pathogen ..... Microorganism that causes disease.
- prevalence ..... Level of morbidity in a population at a given time.
- reportable ..... Disease that by law or regulation must be reported to designated authorities. (notifiable) disease
- resistance ..... Ability to withstand attack by a pathogen (disease resistance) or a chemical (drug resistance).
- syndemic ..... Overlapping diseases that differ from co-morbidities in interacting with each other and often also with their environments.
- transmission ..... Process by which an infectious agent is spread from one host to another.
- virulence ..... Degree of severity of effects of a disease caused by a pathogen.

Adapted from Miquel Porta and John Last, eds., *Oxford Dictionary of Public Health*, Second edition (Oxford University Press, 2018), <https://doi.org/10.1093/acref/9780191844386.001.0001>.

## Changes in Place Names

### HISTORIC

### CURRENT

#### Communities

Cape Dorset.....	Kinngait
Chesterfield Inlet.....	Igluligaarjuk
Clyde River .....	Kanggiqtugaapik
Coppermine.....	Kugluktuk
Eskimo Point.....	Arviat
Fort Chimo .....	Kuujuuaq
Frobisher Bay.....	Iqaluit
Great Whale River .....	Kuujuaraapik
Pangnirtung .....	Panniqtuuq
Pond Inlet .....	Mittimatalik

#### Regions

Keewatin District .....	Kivalliq region of Nunavut
Eastern Arctic.....	Qikiqtaaluk region of Nunavut
Franklin District, Baffin Zone	
Western Arctic .....	Kitikmeot region of Nunavut
part of Mackenzie District	
Ungava District .....	Nunavik region of Quebec
Northern Labrador .....	Nunatsiavut
partly included in Ungava	

#### Non-Arctic

Caughnawaga.....	Kahnawake
Madras.....	Chennai



## Introduction

In 2020, tuberculosis killed roughly as many people around the world as COVID-19, but only one of these diseases captured global attention. Even in the absence of a pandemic, tuberculosis receives little of the attention given to less deadly infections such as malaria or HIV. World Health Organization (WHO) official Soumya Swaminathan observed that "a person who died of dengue fever in a city would make headlines, whereas you'd have had 1000 deaths due to TB on the same day and they would not feature in any news story at all."<sup>1</sup> Under this cloak of invisibility, tuberculosis has a long history as humanity's most deadly disease, an estimated one billion people killed in the last two hundred years and an unimaginable number in the millennia before that.<sup>2</sup> Beyond the scale of death is the scale of prevalence. Global health experts estimate one quarter to a third of all people on Earth are infected with tuberculosis. In recent decades, during which tuberculosis was almost entirely curable, it regularly killed 1.8 million people a year. Then a joint global campaign against three diseases, AIDS, malaria and tuberculosis, launched in 2015, reduced tuberculosis deaths to an estimated 1.4 million per year by 2019. Even at this lower number, tuberculosis remained the leading cause of death from infectious disease until overtaken by COVID-19 in 2021.<sup>3</sup>

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<sup>1</sup> "First Person: Prepare for the next pandemic, says WHO scientist," UN News: United Nations website, 20 March 2021, <https://news.un.org/en/story/2021/03/1087732>

<sup>2</sup> Tom Paulson, "A mortal foe," *Nature* 502, no. 7470, (10 Oct. 2013): S2+, <https://link.gale.com/apps/doc/A349113905/CPI?u=uvictoria&sid=bookmark-CPI&xid=6d8f11d3>.

This is a widely cited number that is difficult to confirm. Current *Nature* editors cannot track down the source or the author. The number is used here on the assumption previous *Nature* editors did check it.

<sup>3</sup> By the end of 2020, the figures for both diseases were essentially identical, each having great uncertainty. The number for tuberculosis will almost certainly be revised upward as the masking and amplifying effects of COVID-19 are examined. World Health Organization, "Tuberculosis," Newsroom, World Health Organization, 14 October 2021, <https://www.who.int/news-room/fact-sheets/detail/tuberculosis>; "Cumulative confirmed COVID-19 deaths by world region," *Our World in Data*, <https://ourworldindata.org/grapher/cumulative-covid-deaths-region>; Zak Vescera, "Invisible epidemic: Saskatchewan's battle with tuberculosis amid pandemic," *Saskatoon Star Phoenix* (Mar. 29, 2021). <https://thestarphoenix.com/news/saskatchewan/invisible-epidemic-saskatchewans-battle-with-tuberculosis-amid-pandemic>; Lekhika Pathak et al., "Coronavirus Activates an Altruistic Stem Cell-Mediated

The lack of attention to tuberculosis and its steady, staggering mortality rate requires explanation. It may be due to its extremely slow progression; tuberculosis is a slow-motion disease at every level from the molecular to societal. It may be its mundane symptoms and highly adapted, nuanced attack on humans; in the first few years of active disease, people may not show any sign beyond coughing and fatigue. It likely is related to the unevenly distributed burden of suffering and death, though it was not always so. In 1839, at the peak of an English epidemic, Charles Dickens called tuberculosis a disease that "medicine never cured, wealth never warded off, or poverty could boast exemption from; which sometimes moves in giant strides, and sometimes at a tardy sluggish pace, but, slow or quick, is ever sure and certain."<sup>4</sup> Its scope mobilized whole societies to act, and as a result, only vestiges of tuberculosis linger in industrialized countries. In such countries tuberculosis is obscure - almost never experienced, rarely mentioned, and if heard of at all, then mostly in historic accounts of vanquished diseases, or in association with poverty. By contrast, the WHO identifies 20 countries that account for 84 percent of the global burden of tuberculosis.<sup>5</sup>

Canada is in many ways a typical low-incidence industrialized country. Yet even in Canada the burden of disease is unequal. In southern Canada, rates are among the lowest in the world, but only among Canadian-born, non-Indigenous people. The majority of Canada's cases are found among people born in high-burden countries. Incidence is also high among southern

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Defense Mechanism that Reactivates Dormant Tuberculosis," *American Journal of Pathology* 191, no. 7 (July 2021): 1255. <https://doi.org/10.1016/j.ajpath.2021.03.011>.

<sup>4</sup> Charles Dickens, "Chapter 49," *The Life and Adventures of Nicholas Nickleby* (Project Gutenberg etext 1997 [1839]), <http://archive.org/stream/nicholasnickleby00967gut/old/ncklb10.txt>.

<sup>5</sup> World Health Organization, *WHO global lists of high burden countries for tuberculosis (TB), TB/HIV and multidrug/rifampicin-resistant TB (MDR/RR-TB), 2021–2025: background document*, (Geneva: World Health Organization, 2021), 6. <https://apps.who.int/iris/handle/10665/341980>.

Indigenous people, whose rates are 38 times higher than those of other Canadian-born people.<sup>6</sup> In northern Canada the rate is another order of magnitude larger yet. Northern Canada in this context is what Inuit consider their homeland, called Inuit Nunangat. It spans four jurisdictions with a different name in each: Nunavut the territory; Nunavik in northern Quebec, Nunatsiavut in Labrador, and Inuvialuit Settlement Region in the Northwest Territories. Tuberculosis incidence among Inuit across this region is roughly 300 times the rate among Canadian-born, non-Indigenous southerners, and matches disease rates in the high-burden countries.<sup>7</sup> Unlike those countries, tuberculosis in the North is not complicated by HIV or multi-drug resistance. It means the disease is easier to treat and cure. Yet Inuit still die of tuberculosis.

### **Tuberculosis among Inuit**

In January 2017, an Inuk teen died suddenly.<sup>8</sup> She was one of at least four Inuit who died of tuberculosis within a year, but it was her death that triggered action.<sup>9</sup> In March, the news spread outside the territory; in September, former UN HIV/AIDS envoy Stephen Lewis came to Nunavut to investigate;<sup>10</sup> in October, the Inuit Tapiriit Kanatami (ITK) and the federal

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<sup>6</sup> Public Health Agency of Canada, *Tuberculosis in Canada 2018* (Ottawa: Minister of Public Works and Government Services, 2020), 35, <https://open.canada.ca/data/en/dataset/4dbb9bff-022d-4aab-a11d-0a2e1b0afaad>. In 2018, Canada had 1,797 reported cases of tuberculosis, of which 1,313 were among people born outside Canada.

<sup>7</sup> Inuit Tapiriit Kanatami, *Inuit Tuberculosis Elimination Framework* (Ottawa: Inuit Tapiriit Kanatami, November 2018), 9, <https://www.itk.ca/wp-content/uploads/2018/12/FINAL-ElectronicEN-Inuit-TB-Elimination-Framework.pdf>.

<sup>8</sup> Nick Murray, "She was my only girl': Nunavut teen's death sheds light on failures in fighting TB," *CBC News*, (Mar 23, 2017), <https://www.cbc.ca/news/canada/north/tb-nunavut-teen-death-ileen-kooneeliusie-1.4036205>.

<sup>9</sup> Two people died in Nunavut, one in Nunavik and one in Nunatsiavut. M. Patterson, S. Finn and K. Barker, "Addressing tuberculosis among Inuit in Canada," *Canada Communicable Disease Report* 44, no. 3/4 (March 1, 2018):82, <https://doi.org/10.14745/ccdr.v44i34a02>; Sarah Rogers, "Family, community shocked by Nunavik man's TB death," *Nunatsiaq News* (Feb 19, 2018),

[https://nunatsiaq.com/stories/article/65674family\\_community\\_shocked\\_by\\_nunavik\\_mans\\_tb\\_death/](https://nunatsiaq.com/stories/article/65674family_community_shocked_by_nunavik_mans_tb_death/); Ossie Michelin, "We are still here.' How a Labrador community fought a tuberculosis outbreak," *CBC News* (March 24, 2019), <https://newsinteractives.cbc.ca/longform/we-are-still-here-nain-tb>.

<sup>10</sup> Beth Brown, "Global AIDS advocate steps back to fight TB at home, in Nunavut," *Nunatsiaq News* (Sept. 12, 2017),

[https://nunatsiaq.com/stories/article/65674world\\_aids\\_advocate\\_steps\\_back\\_to\\_fight\\_tb\\_at\\_home\\_in\\_nunavut/](https://nunatsiaq.com/stories/article/65674world_aids_advocate_steps_back_to_fight_tb_at_home_in_nunavut/).

government announced a tuberculosis task force;<sup>11</sup> the following March, the task force announced a strategy to fight tuberculosis among Inuit.<sup>12</sup> Then-Indigenous Services minister Jane Philpott linked the teen's death to "nursing shortages, language barriers, medical evacuations, weather delays, delayed diagnoses, and an epidemic that has persisted for more than one century," a discordant framing that links a long continuity of disease with changing and even transient factors.<sup>13</sup> The anti-tuberculosis plan released later that year listed social factors, called social determinants of health, as fueling tuberculosis in the North.<sup>14</sup> Yet social determinants had changed over its history, and not in ways that matched changes in the pattern of disease.

The suffering and death caused by tuberculosis has indeed been a century-long experience for Inuit, but not a uniform one. There were a few relatively abrupt changes in the pattern of this otherwise slow-moving disease, and they coincided with equally abrupt changes in the disease environment. These discontinuities divide the history of tuberculosis among Inuit into four distinct periods.

In the first period, up to the end of World War II (WWII), tuberculosis grew to epidemic levels amid government disregard and almost non-existent health care. In the second period, from the end of WWII to the late 1960s, the federal government responded with mass evacuations of diseased Inuit to southern hospitals. This reduced deaths, but at great societal and individual cost, and incidence remained high. In the third period, from the late 1960s to the end of the 1970s, the government introduced local biomedical treatments and reduced tuberculosis

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<sup>11</sup> Nick Murray, "Inuit, Ottawa launch task force to fight tuberculosis in the North," *CBC News* (Oct 08, 2017), <https://www.cbc.ca/news/canada/north/inuit-tuberculosis-task-force-1.4345734>. Inuit Tapiriit Kanatami is the organization that represents Inuit politically across all jurisdictions in Canada.

<sup>12</sup> Indigenous Services Canada, "The Government of Canada and Inuit Tapiriit Kanatami commit to eliminating tuberculosis across Inuit Nunangat by 2030," News release (March 23, 2018), <https://www.canada.ca/en/indigenous-services-canada/news/2018/03/the-government-of-canada-and-inuit-tapiriit-kanatami-commit-to-eliminating-tuberculosis-across-inuit-nunangat-by-2030.html>.

<sup>13</sup> Murray "Task Force."

<sup>14</sup> ITK, *Elimination Framework*, 14.

incidence. The fourth period, with continued reduced incidence, developed more gradually from the 1980s onward, alongside new philosophies of health care and changing Indigenous-federal relations. Gradually, there was a return of high rates of tuberculosis, and eventually Inuit death.

The third period of this tuberculosis history is brief and anomalous. It started with federal health officials introducing a well-resourced local program of modern measures for treatment and prevention, and approving a special initiative to reduce the extremely high incidence rates that persisted in the eastern Arctic. The special project had several distinctive features. Project leaders were nationally and internationally recognized tuberculosis experts. They explicitly set out to achieve health equity between Inuit and other Canadians with regard to tuberculosis. They had proposed an intensive mass prevention treatment not yet common in Canada, known as multi-drug supervised chemoprophylaxis. It was to start in the largest Inuit community, Frobisher Bay (Iqaluit), then expand to other northern communities. Inuit workers were hired to deliver the treatment. Treatment was explained in advance to prospective participants, and they were asked to consent to treatment. The outcome of the first stage of the project was successful in preventing disease, and contributed to the largest drop in tuberculosis incidence in recorded history.<sup>15</sup> As project leaders prepared to expand the project, senior federal officials cancelled it, even as they acknowledged its medical benefits and lower cost than established measures.

Despite its notable aspects, the Frobisher Bay project seems to have been forgotten, aside from a few scientific citations and references.<sup>16</sup> This is consistent with the thin historiography of tuberculosis in Canada generally. It is also consistent with medical historian Christian McMillen's observation that "discovering and rediscovering tuberculosis has been a feature of

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<sup>15</sup> Stefan Grzybowski, "Natural History of Tuberculosis: Epidemiology," *Bulletin of the International Union Against Tuberculosis* 66, no. 4 (December 1991): 193, <https://pubmed.ncbi.nlm.nih.gov/1687514/>.

<sup>16</sup> Pamela Orr, "Tuberculosis in Nunavut: looking back, moving forward," *Canadian Medical Association Journal* 185, no. 4 (2013 Mar 5): 287-288. <https://doi.org/10.1503/cmaj.121536>.

the twentieth-century history of medicine ... there seems to be no historical consciousness in the world of TB control."<sup>17</sup> McMillen quotes tuberculosis expert Kurt Toman, who, when asked to examine a region of troublesome tuberculosis, said, "to get a full understanding of the present situation ... it would have been probably best to study the project from its beginning."<sup>18</sup> As with Toman's subject, there is benefit in studying the Frobisher Bay project from its beginning to understand its unusual success in this bleak history, and its cancellation.

### **Argument**

The Frobisher Bay project succeeded in reducing tuberculosis incidence, and did so without changing social determinants of health. Similarly, the changes in tuberculosis that marked other periods arrived without changes in social determinants. Rather, disease changes followed political changes. This thesis argues that tuberculosis is primarily a political disease, and that political determinants of health are more fundamental to its epidemiology than social or biomedical determinants. The thesis makes the case for periodizing the history of tuberculosis among Inuit based on this proposition, with attention to the 1970s as a clear illustration of the relationship between politics and disease.

Biomedical determinants were long considered fundamental to health. In the mid-twentieth century, they were superseded by social determinants, which then were seen as fundamental. This reinforced the long-standing view of tuberculosis as a social disease. Similarly, medical history, which began as a biomedical record, is currently dominated by social perspectives. Yet, health matters are most usefully considered through three interacting dimensions: biomedical, social, and political. I define biomedical determinants as factors arising

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<sup>17</sup> Christian McMillen, *Discovering Tuberculosis: A Global History 1900 to the Present*, (New Haven, CT and London: Yale University Press, 2015), 5-6.

<sup>18</sup> McMillen, *Discovering*, 226.

from biology and related technologies; social determinants as individual, community and social factors that affect health; and political determinants as factors involved in the process of making collective decisions that affect health. Most determinants themselves are affected by political decisions, which makes political determinants the "determinants of determinants."<sup>19</sup> It is useful to examine political determinants to illuminate the roots of health circumstances.

Tuberculosis is best understood as a political disease. It arises from societal disruption, which often comes from large forces with political dimensions. More directly, tuberculosis is a political disease because it is expensive. Many of its traits - massive scale of infection, long duration and treatment, cumbersome diagnosis, complicated response to vaccine and drugs, historic targeting of young, productive adults, and exacerbation by diverse factors - make it costly to prevent or treat, and indirectly costly in its societal burden. High costs trigger political forces, because political decisions are necessary to allocate the resources and sustain the commitment necessary to control the disease. As the American public health physician Hermann Biggs noted around 1911: "Public health is purchasable. Within natural limitations, any community can determine its own death rate."<sup>20</sup> Tuberculosis, especially tuberculosis in the North, demonstrates this statement.

## **Approach**

Medical history has changed over time, and is now divided into two main types. Traditional medical histories are celebrations of biomedical triumphs and achievements, produced as "the

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<sup>19</sup> Daniel Dawes, *Political Determinants of Health*, (Baltimore: Johns Hopkins University Press, 2020), 45.

<sup>20</sup> Quoted in René Dubos and Jean Dubos, *The White Plague: Tuberculosis, Man, and Society* (New Brunswick, NJ: Rutgers University Press, 1996 [1952]), 219. Date is suggested in Howard Markel, "Public Health Is Purchasable," *The Milbank Quarterly* 94, no. 3 (September 2016): 441-7, <https://doi.org/10.1111/1468-0009.12202>.

special province of retiring physicians."<sup>21</sup> By contrast, academically trained historians mainly produce social medical histories. Some such works may touch on political issues but if so, only glancingly and with a sociological view. Some tuberculosis histories, including this paper, are an exception, increasingly acknowledging the evident political nature of the disease, and applying more overt political scrutiny.

This paper takes a cross-disciplinary approach to medical history. For all the benefits of triangulating perspectives across disciplines, the approach has challenges. Medical historian Howard Kushner sees them arising from the structural, cultural and conceptual differences among disciplines, especially between humanities and sciences.<sup>22</sup> In his view, integrating scientific and scholarly historic study is hindered by historians' insistence on the contextual nature of history, and suspicion of those who apply current knowledge to past medical events.<sup>23</sup> Evidence suggests that perceptions of constancy and contingency are indeed barriers to study, but they may be more complex than Kushner portrays. Scientists may see themselves studying immutable laws of nature, yet act in contingent ways in their assumptions and analyses. They may be the most oblivious, however, to inconstancies in their core assumptions, for example, at times disregarding the mutability of the tuberculosis pathogen in its encounters with humans. Conversely, while historians embrace contingency, perhaps because of the evident subjectivity in any interpretation of past events, they tacitly accept essentially unchanging phenomena such as fear or death and desire for relief of suffering. Yet, they too may be oblivious to contradictions within their assumed frameworks. For example, despite the common assumption that the nature of disease is socially constructed, many historians unquestioningly associate tuberculosis with

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<sup>21</sup> Howard Kushner, "The art of medicine: Medical historians and the history of medicine," *Lancet* 372, no. 9640 (August 30, 2008): 710, [https://doi.org/10.1016/S0140-6736\(08\)61293-3](https://doi.org/10.1016/S0140-6736(08)61293-3).

<sup>22</sup> Kushner, "Art," 711.

<sup>23</sup> Kushner, "Art," 710.

poverty, even though this was not always the case. This paper grapples with such issues, starting with the premise that contingency and constancy co-mingle across the scholarly spectrum, and trying to be alert to signs of each anywhere, especially in unexamined assumptions.

Another challenge in integrating disciplines is the application of analytical theories. Each discipline offers any number of potentially useful approaches, which brings its own problems. Economist Albert Hirschman's cautions and advice are useful.<sup>24</sup> While recognizing the value of analytical frameworks, he warns they may hinder understanding. He identifies what he considers their inherent dangers - their potential to essentialize particularities, filter out non-conforming realities, and impose preferred attitudes on real-world complexity.<sup>25</sup> Hirschman's suggested remedy is to maintain an "open cognitive style," and approach research with "a little more 'reverence for life' and less straightjacketing." He advises skepticism toward analyses that offer definitive answers, and urges a recognition that historically notable circumstances are usually a "unique constellation of highly disparate events" which fit theories in only a limited way.<sup>26</sup> It is an attempt to implement this remedy that leads to this cross-disciplinary approach. This history is best illuminated by basic frameworks around decision making from the political science of health, ideas about biological fluidity from genomics, the intersection of epidemiology and ideology from public health, and examination of contingency and context from history.

## **Method**

The small historiography of tuberculosis in Canada requires a piecing together of historic fragments to fill out the history of tuberculosis among Inuit, the Frobisher Bay project, and their

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<sup>24</sup> Albert O. Hirschman, "The Search for Paradigms as a Hindrance to Understanding," *World Politics* 22, no. 3 (April 1970): 329-343, <https://www.jstor.org/stable/2009600>.

<sup>25</sup> Hirschman, "Search," 336-8.

<sup>26</sup> Hirschman, "Search," 338-9.

contexts. This paper first examines the background necessary to understanding the Frobisher Bay project, including the biomedicine of tuberculosis, the relevant historiographies and analytical frameworks. It then examines the histories of tuberculosis in Canada and the North. Finally, it examines the Frobisher Bay project from its roots in the mid-1960s to follow-up in the mid-1970s and discusses the implications of these considerations.

Most of the archival sources examined are used to construct a narrative for the Frobisher Bay project and its context. Core sources come from federal Department of National Health and Welfare, specifically four sets of files: 1960s-'70s records from the Medical Services Branch, which administered healthcare for Inuit from 1945; the mid-1960s to early '70s tuberculosis files from the department's Epidemiology Division; 1960s-'70s files on department budget cuts; and 1970s files from the Policy Review Group, which guided federal health policy through the 1970s.<sup>27</sup> These files comprise correspondence, memoranda, meeting materials, reports, media clippings and reference publications circulated mostly among mid-level bureaucrats. A significant problem with these sources is the use of alphanumeric codes in internal communications in place of people's names.<sup>28</sup> Efforts to learn the codes included online searches, and queries to Library and Archives Canada, Public Service Commission of Canada, and, at their suggestion, the Treasury Board. The effort was not successful. Inferences have been made, with varying degrees of confidence, about who was represented by these codes at any given time. Another challenge is the many gaps resulting from intermittent record retention.

As important as the government records are sources from two of the project leaders. The more significant is the fonds of anti-tuberculosis campaigner George Jasper Wherrett. His

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<sup>27</sup> The Health department sources are in Record Group 29 at Library and Archives Canada. This study did not examine Indian Affairs records, which are in Record Group 85. The single comprehensive history of Inuit tuberculosis, Pat Grygier's *A Long Way from Home*, used records from RG85, not RG29.

<sup>28</sup> These codes appear to represent job positions, but the system and patterns are unclear.

archived papers include a document mix similar to the federal collections, supplemented by sources and materials gathered for his own writing, and his published works. His key works are a tuberculosis report for the 1964 Royal Commission on Health Services (Hall Commission), two Arctic health surveys, one from 1944 in the western Arctic and one from 1969 in the eastern Arctic, and a 1977 book on the history of tuberculosis in Canada.<sup>29</sup> These works bookend the Frobisher Bay project, and help triangulate Wherrett's perspective through the period. Another physician, a federal health consultant associated with the project, John Douglas Galbraith, published a memoir that offers insights into the federal context. Wherrett's papers and Galbraith's memoir fill a few of the gaps in governmental sources.

Other types of sources include historic and current scientific and medical journal articles, health agency reports, and some news stories. A challenge in the use of both scientific and archival sources is changes in terminology, as well as significant changes in epidemiological theories, often masked by unchanging terms. Such changes are navigable, and even illuminating, but all must be checked before being considered in a historic study.

A relatively new source of historic information comes from molecular studies of the tuberculosis pathogen. Most are genomic studies that use what is called a molecular clock. This clock is a calculated rate of genetic mutation in the DNA of the pathogen. The rate is applied to a number of pathogen samples, which all have somewhat different DNA. The degree of DNA divergence is combined with the known rate of change to calculate when in the past all the samples first started to diverge from the same ancestor. Such divergence points mark genomic

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<sup>29</sup> G.J. Wherrett, *Tuberculosis in Canada* (Ottawa: Royal Commission on Health Services, 1965); G.J. Wherrett, "Survey of health conditions and medical and hospital services in the Northwest Territories," 49-60, in H.A. Innis, G.J. Wherrett and Andrew Moore, "Arctic Survey," *Canadian Journal of Economics and Political Science* 11, no. 1 (February 1945): 48-82, <http://www.jstor.org/stable/137379>; G.J. Wherrett, "A Study of Tuberculosis in the Eastern Arctic," *Canadian Journal of Public Health* 60, no. 1 (January 1969): 7-14, <http://www.jstor.org.ezproxy.library.uvic.ca/stable/41984288>; George Jasper Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto: University of Toronto Press, 1977).

events caused by historic events in the organisms' environments, notably, the emergence of new strains under periods of societal disruption, or the spread of the pathogen to new regions. Other types of studies use other techniques simply to indicate the presence of historic tuberculosis infection. Molecular studies have increased in the last decade as techniques have become more robust. Recent work suggests molecular clocks are still speculative in prehistoric timespans, but reliable for studies in historic time under certain conditions.<sup>30</sup> Careful use of these sources adds immensely to knowledge of a disease with few written or oral records, and whose slow development often obscures causal links. In the Canadian context, genomic studies by Caitlin Pepperell's lab and by Marcel Behr and others at McGill University have illuminated historic transmission mechanisms among southern Indigenous people that might plausibly apply in the North. Behr has a useful presentation summarizing some of the tuberculosis genome work in Canada.<sup>31</sup> Genomic analyses in the North are beginning as well. Ethical standards for collection and reporting around human samples used for pathogen analysis are currently being developed.<sup>32</sup>

## Voices

The argument, approach and method outlined above make this paper a history of outsiders acting on Inuit. The argument presupposes that outsiders - bureaucrats and medical experts - are the instigators of events in this history. The approach uses parameters set by outsiders' intellectual frameworks. The method is determined by sources from outsiders. These outsiders have an

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<sup>30</sup> F. Menardo et al., "The molecular clock of *Mycobacterium tuberculosis*," *PLoS Pathogens* 15, no. 9 (Sept 12, 2019): e1008067, <https://doi.org/10.1371/journal.ppat.1008067>.

<sup>31</sup> Marcel A. Behr, "TB in Canada: From Sea to Sea to Sea," Presentation for the Canadian Respiratory Conference (2017), slides 1-24, <https://cts-sct.ca/wp-content/uploads/2018/04/CRC-2017-PRESENTATIONS.pdf>.

<sup>32</sup> The most detailed information is in one paper that indicates ethics approvals by the research institution, local health authority and Inuit village council, but no indication of individual Inuk consent, nor details of how samples were gathered or the process understood by their providers : Robyn S. Lee, et al., "Reemergence and Amplification of Tuberculosis in the Canadian Arctic," *Journal of Infectious Diseases* 211, no. 12 (15 June 2015): 1906, <https://doi.org/10.1093/infdis/jiv011>.

intimate understanding of their own milieux, not of northern circumstances, which means conclusions derived from their perspectives apply more to themselves and their context than to Inuit. Some Inuit interviewed for other purposes, for the 1970s Inuit Land Use study, or the 2000s Qikiqtani Truth Commission, shed light on some matters in this paper. These are few, however, and the paper remains a partial history, one that examines outsiders' actions and their context, as one step in a full history. Medical historian Walter Vanast observes that northern history is heavily shaped by post-contact disease. For this reason, he says northern history needs special attention to its medical aspects, and medical aspects require people's stories to become truly understandable.<sup>33</sup> Thus, a full history requires Inuit experience. This can only come from Inuit. Only Inuit can tell of the impacts of outsiders' actions, Inuit responses, and elements beyond outsiders' awareness.

### **Terminology**

Place names that have changed historically are listed on page viii. In the text, the first appearance of a name is the historic non-indigenous name with the current name in parentheses. The historic name is used subsequently. The exception to this practice is the use of the term 'Inuit.' Up to the mid-1970s, non-indigenous people referred to Inuit as Eskimos. After Inuit established several organizations with 'Inuit' in the name in the early 1970s, non-Inuit people began to use the term 'Inuit' as well. The term "Inuit" is used throughout this study except in direct quotes from historic sources. A similar approach is used for medical terms. On first reference, current names are given in parentheses or footnotes, then the historic terms used afterward.

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<sup>33</sup> Walter J. Vanast, "The death of Jennie Kanajuq: Tuberculosis, religious competition and cultural conflict in Coppermine, 1929-31," *Études/Inuit/Studies* 15, no. 1 (1991), 79, <http://www.jstor.org/stable/42869712>. Vanast says the history of Jennie Kanajug demonstrates the richness of untapped multimedia resources that exist because of the propensity of outsiders and the State to document the Arctic.

## Tuberculosis

Tuberculosis may be humanity's oldest disease, caused by what may be its most successful pathogen. The success is the likely product of its long co-evolution with humans.<sup>1</sup> This co-evolution is a pattern of alternating equilibrium and disruption that extends from prehistoric time to the present. Its product is a distinctive biology and epidemiology, aspects of which apply to this study. A familiarity with some aspects helps to make sense of the tuberculosis history among Inuit. The most relevant aspects are its widespread prevalence, slow progression and long duration, difficult drug therapy, confusing vaccine response, responsiveness to societal change, and centrally, its capacity for latency. It is also useful to consider the distinctions between infection and disease, and between prevalence and incidence.

Disease is often discussed as a generic signifier of social upheaval, but different diseases can signify different things. Smallpox, for instance, caused quick death and decimation, and was a common marker of first contact between two groups. Tuberculosis, by contrast, is mostly a marker of societal change. It may be transmitted in first contacts between groups, but it only becomes a significant disease when certain living conditions change, sometimes long after contact, as may have happened in western Canada, and the North.

### Biology

The tuberculosis pathogen is a bacillus, meaning a rod-shaped bacterium. Tuberculosis bacteria belong to the *Mycobacterium* genus, which has more than a hundred species, mostly living in water or soil, and mostly causing opportunistic lung and skin infections. Eleven species,

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<sup>1</sup> Daniela Brites and Sebastien Gagneux, "Co-evolution of *Mycobacterium tuberculosis* and *Homo sapiens*," *Immunological Reviews* 264, no. 1 (March 2015), 6, <https://doi.org/10.1111/imr.12264>.

however, live only in hosts and propagate by causing active disease in those hosts.<sup>2</sup> Collectively these eleven species are called the Mycobacterium Tuberculosis Complex (MTC or MTBC). Different MTC species can infect humans, or animals or both. By far the most common species to infect humans is *Mycobacterium tuberculosis* (Mtb).

Mtb is transmitted through the air as droplet nuclei from an infected host. It enters the lungs of a new host, and sometimes spreads to other parts of the body. The lungs, however, are so frequently the final destination that tuberculosis is often considered a respiratory disease. The bacteria lodge in the lungs where they are engulfed by specialized white blood cells called macrophages. These normally destroy the invaders they target, but with Mtb, the bacteria take over the macrophage. The hijacked macrophages signal to other immune cells to get involved and together they entrap the bacteria in a casing of cells. The result is a lump or nodule - historically called a tubercle, now called a granuloma - with living bacteria still inside. The walls of these nodules may break down. Usually they never do, and infected people may live with Mtb infection all their lives. This is called latent tuberculosis infection (LTBI). The mechanisms around latency, and its relationship to active disease are complex and continue to be investigated and reinterpreted.<sup>3</sup>

Active disease develops if bacteria escape the nodules. Then there is a struggle between bacterium and human host in which host tissue is destroyed. In the lungs this creates pus, blood, and cavities, as tissue becomes fibrous, shredded and liquified. The inner ravages happen slowly, and on the outside the disease looks mundane. The most common symptom is a phlegmy cough, then night sweats, weakness, fever and weight loss. People waste away slowly, at times coughing

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<sup>2</sup> Another ancient human disease, leprosy (Hansen's disease), is caused by another *Mycobacterium* species, *Mycobacterium leprae*.

<sup>3</sup> Marcel A. Behr et al., "Latent Tuberculosis: Two Centuries of Confusion," *American Journal of Respiratory and Critical Care Medicine* 204, no. 2 (July 15, 2021), 142, <https://doi.org/10.1164/rccm.202011-4239PP>.

blood. Eventually organs fail or blood vessels burst. Without treatment, half of diseased people die within five years, although the rate may have been 80 percent at the peaks of past epidemics.<sup>4</sup>

Distinctive traits of both the pathogen and its human host influence disease outcomes. Each has advantages. The bacterium has thick, fatty cell walls that keep it from drying out during dormant periods, and make it hard for antibiotics to penetrate. It adapts quickly to new conditions, for reasons not yet fully understood given its unusually slow growth. In the lungs, Mtb releases a substance that triggers coughing, helping bacteria travel to new hosts.<sup>5</sup> Mtb's preferred nutrient is fat, and scavenging fat from its hosts causes the body wasting, but it may metabolize carbon monoxide in a pinch, which would give it some advantage in the lungs of smokers and people living with open combustion.<sup>6</sup> Humans also have advantages. Although only a few Mtb cells are needed to cause infection, it takes prolonged contact for transmission to happen. For this reason, it mainly happens when people live or work together for long periods in close quarters. Resistance is increased by a good diet, especially a fatty one. Malnutrition is strongly associated with tuberculosis.

With drug treatment, tuberculosis usually can be cured, but this is complicated by drug resistances and co-morbidities. HIV, which quintuples tuberculosis activation rates, is the most serious co-morbidity, but diabetes and other diseases also amplify tuberculosis. Recovery from tuberculosis does not confer immunity. People may be reinfected, and cured people have lesions with bacteria that may be reactivated. The pool of people with latent tuberculosis represents a

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<sup>4</sup> James E. Gomez and John D. McKinney, "*M. tuberculosis* persistence, latency, and drug tolerance," *Tuberculosis* 84, no. 1–2 (2004): 31, <https://doi.org/10.1016/j.tube.2003.08.003>. 31.

<sup>5</sup> Cody R. Ruhl et al., "*Mycobacterium tuberculosis* Sulfolipid-1 Activates Nociceptive Neurons and Induces Cough," *Cell* 181, no. 2 (2020): 293, <https://doi.org/10.1016/j.cell.2020.02.026>.

<sup>6</sup> Vineetha Zacharia and Michael U. Shiloh. "Effect of carbon monoxide on *Mycobacterium tuberculosis* pathogenesis," *Medical Gas Research* 2, no.30 (December 17, 2012): 1, <https://medicalgasresearch.biomedcentral.com/articles/10.1186/2045-9912-2-30>.

massive global reservoir of disease: about one quarter to one third of all humans are infected, albeit with regional variability. Only five to ten percent of those infected have active disease.

The bacterium's infection mechanism and the human response complicate treatment and prevention. Mtb infection triggers both the innate and adaptive branches of the human immune system. The innate response comes first. It indiscriminately attacks anything considered foreign. In about ten percent of infections, the innate system eliminates Mtb without a trace. Usually, however, Mtb uses the human innate response for its latency mechanism. By contrast, the human adaptive immune system is disease-specific. For Mtb, there is no obvious antibody. The defence appears to come from certain cells that attack Mtb in ways not completely understood. Also poorly understood are changes to response and resistance over time. Human populations seem to develop resistance to a given Mtb strain when they have long enough exposure. Some researchers suggest this takes about two or three hundred years, with peak mortality at fifty years.<sup>7</sup> This suggestion appears based on the epidemic in modern Europe. It is unclear if the pattern holds more widely, or if it is modified by twentieth-century antibiotic treatments. Besides populations' exposure-based resistance, individuals vary in their responses. There is no evidence of differential racial susceptibility, although response to drugs can vary among populations, and different lineages of Mtb prefer to infect the populations with which they co-evolved.

## History

The ancient roots of tuberculosis illuminate the effects of migration, disruption and adaptation on bacteria and humans. Precursors of MTC may have been infecting precursors of human as much

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<sup>7</sup> René Dubos and Jean Dubos, *The White Plague: Tuberculosis, Man, and Society* (New Brunswick, NJ: Rutgers University Press, 1996 [1952]), 197; Katherine McCuaig, *The Weariness, the Fever, and the Fret: The Campaign against Tuberculosis in Canada 1900-1950* (Montreal: McGill-Queen's University Press, 1999), 227, <https://canadacommons-ca.ezproxy.library.uvic.ca/artifacts/1866340/the-weariness-the-fever-and-the-fret/2615335>,

as half a million years ago. The first MTC ancestor appeared several millennia ago, making tuberculosis one of the first human diseases. It likely originated in Africa and spread with the migrations of its human hosts.<sup>8</sup> The oldest tubercular human remains were found in Israel, Syria and Turkey and are 8,000 to 10,000 years old<sup>9</sup>

Successive human migrations are believed to have produced the eight Mtb lineages found in different parts of the world.<sup>10</sup> Lineage 4 (L4), originally called the European lineage, is the most geographically dispersed, and is now often called the Euro-American-African lineage. Lineage 2 (L2), the East Asia lineage, includes the Beijing strain, whose modern variants passed through Eastern Europe as the Soviet Union collapsed and became especially virulent.<sup>11</sup>

The development of tuberculosis from prehistory to the present is a succession of disruption and equilibrium between pathogen and host. Each disruption brings attack and counterattack, until eventually the organisms check each other. Mtb develops strategies to survive and propagate without killing all its hosts, and humans develop defences to dampen virulence, without killing Mtb completely.<sup>12</sup> The disruptions are especially likely after transformations of patterns of human settlement, or food supplies. Genomic studies associate the

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<sup>8</sup> M. Cristina Gutierrez et al., "Ancient origin and gene mosaicism of the progenitor of *Mycobacterium tuberculosis*," *PLoS pathogens* 1, no. 1 (September 2005): e5, <https://doi.org/10.1371/journal.ppat.0010005>; Brites and Gagneux, "Co-evolution," 15; Susanna Sabin et al., "A seventeenth-century *Mycobacterium tuberculosis* genome supports a Neolithic emergence of the Mycobacterium tuberculosis complex." *Genome Biology* 21, no. 1 (2020): 201, <https://doi.org/10.1186/s13059-020-02112-1>. Proposed dates for the origin of a common ancestor diverge widely and are under debate.

<sup>9</sup> Israel Hershkovitz et al., "Tuberculosis origin: The Neolithic scenario," *Tuberculosis (Edinb)* 95, suppl. 1 (June 2015): S122-6, <https://doi.org/10.1016/j.tube.2015.02.021>; Joseph Oussama Baker et al., "New Paleopathological Evidence of Tuberculosis in Child Skeletal Remains from Tell Aswad (8,730-8,290 cal. BC, southern Syria)," *Paléorient online* 47, no. 1 (December 1, 2021): 97-108, <https://doi.org/10.4000/paleorient.926>; J. Kappelman et al., "First Homo erectus from Turkey and implications for migrations into temperate Eurasia," *American Journal of Physical Anthropology* 135, no. 1 (Jan 2008): 110-6, <https://doi.org/10.1002/ajpa.20739>.

<sup>10</sup> J.C.S. Ngabonziza et al., "A sister lineage of the Mycobacterium tuberculosis complex discovered in the African Great Lakes region," *Nature Communications* 11, no. 2917 (June 9, 2020): 1-11, <https://doi.org/10.1038/s41467-020-16626-6>.

<sup>11</sup> M. Senghore et al., "Evolution of Mycobacterium tuberculosis complex lineages and their role in an emerging threat of multidrug resistant tuberculosis in Bamako, Mali." *Scientific reports: Nature Research* 10, no. 327 (15 January 2020): 1-9, <https://doi.org/10.1038/s41598-019-56001-0>.

<sup>12</sup> Brites and Gagneux, "Co-evolution," 11.

disruptions with major societal transformations, such as the Neolithic and industrial revolutions, and upheavals such as war and colonization.

Historic periods produced cultural as well as biological evidence of tuberculosis. Most cultures have a visual or literary record of the disease, and terminology to match. In English alone the prominence of tuberculosis is reflected in its many names: phthisis, scrofula, Pott disease, king's evil, wasting disease, white plague, consumption, galloping consumption, 'the Captain of all these men of death.' and tuberculosis.<sup>13</sup> During the modern European epidemic, tuberculosis caused an estimated 20 to 25 percent of all deaths; in some areas, every person was likely infected.<sup>14</sup> Tuberculosis permeated all demographics, especially teens and young adults, and women over men.<sup>15</sup> In this pervasive phase, the disease became glamourized, the slow wasting seen as a consumption by rarified creative or spiritual forces, and death as an evocative farewell, perhaps an expiring swoon or a final dramatic hemorrhage from the mouth, as famously happened to Molière. By the mid-eighteenth century, however, tuberculosis began to abate, and among privileged people first. It became socially stratified and stigmatized.<sup>16</sup> The decline in the epidemic was gradual. Fear of disease and death remained long after disease started to fall.

MTC species are not rigidly selective of host species. While *Mtb* evolved from soil bacteria to become a human pathogen, other species evolved to prefer other hosts, and most can move among host species. Human settlement may have helped *Mtb* to jump from humans to

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<sup>13</sup> Scrofula is tuberculosis in lymph nodes of the neck. Pott disease is spinal tuberculosis. Galloping or miliary consumption is tuberculosis disseminated throughout the body. 'The Captain of all these men of death' was coined by John Bunyan in 1680, 'tuberculosis' was coined by Johann Lukas Schönlein in the mid-nineteenth century, from I Barberis et al., "The history of tuberculosis: from the first historical records to the isolation of Koch's bacillus," *Journal of Preventative Medicine and Hygiene* 58, no. 1 (March 2017): E10, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5432783>.

<sup>14</sup> Dubos and Dubos, *White Plague*, 9, 122.

<sup>15</sup> John B. Huber, "Dr. Robert Koch, The Father of Preventative Medicine," *Scientific American* 102, no. 24 (June 11, 1910): 483, <http://www.jstor.org/stable/26038539>.

<sup>16</sup> Simon Szreter, *Health and Wealth: Studies in History and Policy* (Rochester, NY: University of Rochester Press, 2005), 24.

domesticated animals, and then to wild animals, making it the reverse of a zoonosis. The most common non-Mtb species to infect humans is *M. bovis*, associated with cows. Bovine tuberculosis was a significant human disease before milk pasteurization and herd management became common. It was transmitted in Canada's residential schools where students were made to drink milk. It is still transmitted to people from ungulates.

### **Biomedicine**

For centuries tuberculosis was considered a hereditary disease, because a theory of family susceptibility fit with patterns of transmission. This made German microbiologist Robert Koch a sensation when he announced in 1882 he had discovered the cause of tuberculosis - the bacillus Mtb. Koch followed this remarkable announcement with even more remarkable news in 1890. He announced he had found a cure. But he was wrong. Koch's mysterious substance, which he called tuberculin, and which turned out to be an extract of proteins from the bacillus, was not only not a cure, it often aggravated illness. It is somewhat useful, however, for diagnosing tuberculosis infection. The tuberculin is applied to the skin, and if the resulting inflammation is large, it indicates infection.<sup>17</sup> Later diagnostics included X-rays, which show internal damage from the disease, and sputum tests (smear tests), which identify the presence of bacteria with microscopes, or now, with automated molecular analysis.

The first widely promoted treatment was the sanatorium, an institution developed in Germany in the 1850s and quickly spreading to countries with affluent populations. It promoted complete rest, fresh air, sunshine and a rich diet, far from insalubrious cities, often at high altitudes, sometimes for years at a time. In the twentieth century less rarified public sanatoria

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<sup>17</sup> Interpreting the resulting reaction requires skill and practice, and the test is unreliable under certain conditions. It is gradually being supplanted by other diagnostic techniques.

arose for more classes of patients, although still only accommodating a small number of those diseased. The effects of fresh air, sunlight, and high altitude are still debated sporadically, but the benefit of isolation within sanatoria seems more clear, as it disrupts disease transmission. The isolation is sometimes cited as a significant cause of the gradual decline of tuberculosis in western industrialized countries, although the argument is sometimes countered by theories of the natural trajectory of tuberculosis epidemics. Surgical treatments were developed in the nineteenth century and became common by the 1920s. This included collapsing lungs to rest them, which in effect denied Mtb the oxygen-rich environment it preferred. The collapses could be temporary, by inflating the chest cavity or abdomen with air, or permanent, by crushing nerves or removing ribs. In 1956, a study in Madras (Chennai) found sanatoria to be only marginally better than home care, and this marked the start of deinstitutionalization.<sup>18</sup>

The only tuberculosis vaccine ever approved for use, the Bacillus Calmette Guérin vaccine (BCG), was introduced a century ago, after a development process barely imaginable today.<sup>19</sup> It was made of live bacteria, with no external oversight, and untested until its first use on a newborn in Paris.<sup>20</sup> Against the odds it was safe. Yet eight years later, a batch of vaccine killed 72 babies in Lübeck, and caused disease in several hundred adults. The fault was contamination and not BCG itself, but the vaccine's reputation was damaged. More testing was done, mostly on people in colonies or former colonies of European countries. This included studies on Indigenous

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<sup>18</sup> Tuberculosis Chemotherapy Centre, "A concurrent comparison of home and sanatorium treatment of pulmonary tuberculosis in South India," *Bulletin of the World Health Organization* 21, no. 1 (1959): 51-144, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2537809/>.

<sup>19</sup> The research was a program of the Pasteur Institute in France, a rival of Koch's laboratory.

<sup>20</sup> The bacteria were attenuated, that is, weakened. Microbiologist Kathryn Loughheed explains it with an analogy to couch potatoes. The vaccine was a batch of Mtb, grown for 239 generations over thirteen years in a mixture of ox bile, glycerine and potato starch. It was "the bacterial equivalent of spending 13 years sitting on a sofa, becoming increasingly out of shape, then attempting to run a marathon." The marathon is injection into a human. Race preparations are made, the race is started (immunological response created), but finishing the race (producing disease) is impossible. Kathryn Loughheed, *Catching Breath: The Making and Unmaking of Tuberculosis* (London: Bloomsbury Sigma, 2017), 83.

infants in Saskatchewan, and non-Indigenous infants in Montreal.<sup>21</sup> Until COVID-19, BCG was the most widely used vaccine in the world, with hundreds of millions of doses given annually, mostly to babies, but mostly not for tuberculosis.<sup>22</sup> BCG trains the innate immune system, which give it a broad protective effect, and it appears to prevent tuberculosis from spreading in children, but it does not work well in adults, and it has stark regional variations, ranging from 0 to 80 percent effective, depending on location.<sup>23</sup> In the century since BCG appeared, only one new vaccine candidate has reached advanced trials, and failed. Health officials consider a new tuberculosis vaccine a global health priority, but development depends on money being made available. Meanwhile, different countries took and continue to take different approaches to BCG for tuberculosis prevention, according to their assessment of its track record.

The discovery of antibiotic treatments for tuberculosis was momentous, yet also complicated.<sup>24</sup> The first widely celebrated drug, streptomycin (SM), discovered in the US in 1944, did cure, but could cause permanent hearing loss, and drug-resistance within weeks.<sup>25</sup> Concurrently in Sweden, para-amino salicylic acid (PAS) was developed, also with side effects and resistance, and more expensive than SM.<sup>26</sup> In 1952 isoniazid (isonicotinic acid hydrazide, INH) appeared. It too had side effects and resistance problems, but much less severe, and it was

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<sup>21</sup> Aro Velmet, *Pasteur's Empire: Bacteriology and Politics in France, Its Colonies and the World* (New York: Oxford University Press, 2020), 144n7, <https://doi.org/10.1093/oso/9780190072827.001.000>; Christian W. McMillen, *Discovering Tuberculosis: A Global History 1900 to the Present* (New Haven, CT and London: Yale University Press, 2015), 5.

<sup>22</sup> UNICEF Supply Division, "Bacillus Calmette-Guérin Vaccine: Supply and Demand Update (Copenhagen: UNICEF Supply Division, August, 2012), 1, [https://www.unicef.org/supply/media/771/file/Bacillus%20Calmette-Gu%C3%A9rin%20\(BCG\)%20Supply%20and%20Demand%20Update.pdf](https://www.unicef.org/supply/media/771/file/Bacillus%20Calmette-Gu%C3%A9rin%20(BCG)%20Supply%20and%20Demand%20Update.pdf). BCG has unambiguous value in preventing infant death from pneumonia and lower respiratory infections, as well as for treating bladder cancer.

<sup>23</sup> Theories for geographic variation include interference from plentiful environmental mycobacteria, and variations in the Mtb strains used by the different manufacturers who supply different countries.

<sup>24</sup> In older literature, antibiotic treatment of tuberculosis is called chemotherapy, a term that simply means a medical treatment using chemicals. The current use of the term chemotherapy is usually more specific, meaning the use of chemicals to treat cancer.

<sup>25</sup> A. Brancker et al., "A Statistical Chronicle of Tuberculosis in Canada: Part I. From the Era of the Sanatorium Treatment to the Present," *Health Reports: Statistics Canada* 4, no. 2 (January 1, 1992): 105; Dubos and Dubos, *White Plague*, 155.

<sup>26</sup> Another PAS advantage was that it could be given as a pill, unlike SM, which must be injected.

much cheaper than SM or PAS. INH quickly became the standard drug. In the 1960s, two other useful drugs were developed: ethambutol (EMB) and rifampin or rifampicin (RMP).

Pyrazinamide (PZA) followed. These five became first-line drugs, and no new drugs have replaced them, despite their serious side effects, contraindications and interactions with other drugs.<sup>27</sup> As with so much about tuberculosis, drug resistance is distinctive because it appears less a product of over-prescription than of *Mtb*'s unique adaptations.<sup>28</sup> Almost from the start, drug combinations were used to overcome resistance, first in pairs, then three at a time, and now usually four drugs at a time.<sup>29</sup> Second- and third-line drugs, more toxic yet, have been developed for multi- and extensively-drug resistant tuberculosis. Such forms of tuberculosis are not significant in Canada, and not a factor in the North.<sup>30</sup> Treatments were initially 24 months long, then 18, then, with different drug combinations and timing, reduced to nine or even six months currently.

The problem of side effects is likely related to widespread patient non-compliance with treatment, which is a likely consequence of treatment length and side effects.<sup>31</sup> The list of side effects for first-line drugs is long: temporary effects such as nausea and rash; and permanent effects such as neuropathy, vision loss and sometimes death. Historic writing rarely mentions side effects, but almost always mentions non-compliance. Patients are faulted for being

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<sup>27</sup> Agencies differ in whether they include streptomycin as a first-line drug; Contraindications that prevent use of these drugs include diabetes and liver disease. Drug interactions include interference with oral contraceptives.

<sup>28</sup> Gomez, "Persistence," 33-4. Some of the resistance appears as tolerance of antibiotics when bacteria are in their latent phase, rather than an ability acquired through mutation after exposure to drugs, as is often implied by public messaging about drug resistance generally.

<sup>29</sup> Wallace Fox, Gordon A. Ellard and Denis A. Mitchison, "Studies on the treatment of tuberculosis undertaken by the British Medical Research Council Tuberculosis Units, 1946–1986, with relevant subsequent publications," *International Journal of Tuberculosis and Lung Disease* 3, no. 10 supplement (October 1999): s231, <https://pubmed.ncbi.nlm.nih.gov/10529902>.

<sup>30</sup> M. LaFreniere, H. Hussain and J. Vachon, "Tuberculosis drug resistance in Canada: 2017," *Canada Communicable Disease Report* 44, no. 11 (November 1, 2018): 291–2, <https://doi.org/10.14745/ccdr.v44i11a04>.

<sup>31</sup> The current term for treatment compliance is adherence.

uncooperative or imagining problems.<sup>32</sup> Frontline workers, however, often observe that mildly symptomatic tuberculosis patients starting drug treatment suddenly change from merely coughing and feeling weak to feeling continually nauseous and sick. It is easy to imagine this is difficult to endure for months after symptoms disappear. The non-compliance problem was highlighted in the 1956 Madras study. To counter it, researchers had health care workers visit patients at home to supervise the drug taking. The worker simply delivered pills and watched the patient swallow them. This supervision technique later became refined and renamed DOT (directly observed therapy), then DOTS (directly observed therapy - short course), which combines drugs in a way that shortens the therapy. DOTS was adopted by the World Health Organization (WHO) in the 1990s as a standard treatment for tuberculosis.<sup>33</sup>

## **Public health**

The historic high mortality of tuberculosis and problematic therapies made prevention important. Nineteenth-century public health was based on the philosophy of the sanitary movement, which sought to improve urban living conditions. Several sanitation interventions were applied in Canada and the North, aimed at both preventing disease outbreak and disrupting transmission. After the major biomedical discoveries, interventionism overtook sanitary approaches.<sup>34</sup>

Vaccination and preventative drug therapy have been the two main preventative treatments in Canada. The drug therapy was known in the past as chemoprophylaxis, and more recently as isoniazid prophylaxis therapy (IPT). Interest in preventative drug use arose in the early 1950s after INH was proven to be effective and cheap. The US Public Health Service led

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<sup>32</sup> Christoph Gradmann, "Treatment on Trial: Tanzania's National Tuberculosis Program, the International Union against Tuberculosis and Lung Disease, and the Road to DOTS, 1977-1991," *Journal of the History of Medicine and Allied Sciences* 74, no. 3 (June 19, 2019): 318, <https://doi.org/10.1093/jhmas/jrz029> 318.

<sup>33</sup> Gradmann, "Treatment "317.

<sup>34</sup> Szreter, *Health*, 25, 222; Velmet, *Pasteur*, 142.

the way with a series of trials, starting in 1955. It targeted people considered at high risk of getting disease. These were contacts of known cases, or people thought to have latent tuberculosis at risk of reactivation. The first trials were with children in families with tuberculosis, then expanded to other high-risk groups.<sup>35</sup> A smaller trial was done in Madras as a follow-up to the watershed sanatorium study.<sup>36</sup> More studies followed in Britain, South Africa, Kenya, Philippines and elsewhere.<sup>37</sup> The WHO concluded chemoprophylaxis worked, and by the 1990s it was recommended by agencies in Canada, Britain and the US. It is now used mainly for people with HIV-TB co-infections, in crowded living situations such as prisons or work camps, and for potentially exposed children.<sup>38</sup> The Frobisher Bay project was an early use of chemoprophylaxis, and played a role in its refinement.

The prelude to treatment or prevention is case finding. The goal is to find active cases early, to improve treatment success and to identify people at risk of reactivation early enough to stop it. Case finding now uses combinations of screening and contact tracing techniques, but it once relied mainly on mass x-ray screening. This started in the US in the 1930s, and was used extensively in Canada's North in the 1950s and '60s.<sup>39</sup> In developing countries, X-ray screening was considered too expensive, so passive screening was developed, essentially collecting sputum from people visiting clinics for other reasons. Passive screening was found to be as effective as

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<sup>35</sup> S.H. Ferebee et al., "The use of chemotherapy as a prophylactic measure in tuberculosis," *Annals of the New York Academy of Sciences* 106, no. 1 (February 1963): 151-156, <https://doi.org/10.1111/j.1749-6632.1963.tb16633.x>.

<sup>36</sup> S. Devadatta et al., "Progress in the second and third years of patients with quiescent pulmonary tuberculosis after a year of chemotherapy at home or in sanatorium, and influence of further chemotherapy on the relapse rate," *Bulletin of the World Health Organization* 24, no. 2 (1961):149-175, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2555497/pdf/bullwho00323-0023.pdf>.

<sup>37</sup> McMillen, *Discovering*, 192,

<sup>38</sup> World Health Organization, *WHO consolidated guidelines on tuberculosis: tuberculosis preventative treatment* (Geneva: World Health Organization, 2020), ix, <https://apps.who.int/iris/bitstream/handle/10665/331170/9789240001503-eng.pdf>.

<sup>39</sup> J. E. Golub et al., "Active case finding of tuberculosis: historical perspective and future prospects," *International Journal of Tuberculosis and Lung Disease* 9, no. 11 (June 19, 2005): 1183-203, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4472641>.

x-ray screening, and, just as home care replaced institutional care, smear tests replaced x-rays.<sup>40</sup>

Yet, even this screening was scaled back in the 1970s to save money.

The development of public health capacity in a society is generally paralleled by the development of public surveillance. This happened in Britain in the nineteenth century, and in Canada in 1921.<sup>41</sup> The Dominion Bureau of Statistics was established after official urgings such as this: "Correct and accurate vital statistics are the basis of modern sanitation; they are the gauge whereby we judge the progress made against disease of all kinds, and whereby we obtain information for further advancement."<sup>42</sup> Behind the scenes there likely were urgings from the life insurance industry also.<sup>43</sup> The type of data collected reflects priorities of the day. In its first few decades, the Bureau's health information comprised only causes of death. Information about illness wasn't collected until after World War II, when the federal government assumed new health responsibilities.<sup>44</sup> Changing public perception of public health surveillance is a sign of its power. Past negative concerns about privacy and the state panopticon have given way to positive views, although this is now complicated by ideologies around COVID-19. Access to surveillance information is seen as a tool to help communities influence official agendas.<sup>45</sup> At the best of times, health information must be "correct and accurate." This was often not the case for

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<sup>40</sup> Golub et al., "Active case finding," 6,

<sup>41</sup> Szreter, *Health*, 9,

<sup>42</sup> Committee on Public Health of the Commission of Conservation, Canada quoted in David A. Worton, *The Dominion Bureau of Statistics: A History of Canada's Central Statistical Office and its Antecedents, 1841-1972* (Montreal: McGill-Queen's University Press, 1998), 25, 106.

<sup>43</sup> Medical Director, The Canada Life Assurance Company, Toronto to John Amyot, Deputy Minister, Dominion Department of Health, May 22, 1925, RG29 v1223 file 311-T7-5 pt.1 Library and Archives Canada; George Jasper Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto: University of Toronto Press, 1977), 28-29; McCuaig, *Fever*, 247. Large insurance companies and the Canadian Life Insurance Officers' Association were active in many aspects of tuberculosis control after World War I.

<sup>44</sup> Worton, *Dominion*, 107.

<sup>45</sup> Kelly Grant, "Inuit group presses Nunavut government for transparency after major tuberculosis outbreak," *The Globe and Mail* (July 3, 2022), <https://www.theglobeandmail.com/canada/article-inuit-group-presses-nunavut-government-for-transparency-on>,

Indigenous people in Canada, which makes it problematic to rest arguments too heavily on general public statistics.

Public health measures can have different goals. Through the twentieth century potential goals came to be considered as control, elimination or eradication. Control was historically the most common goal, broadly defined as the "reduction of disease incidence to some acceptable level."<sup>46</sup> The extreme goal, eradication, is defined as the "reduction of the worldwide incidence of a disease to zero as a result of deliberate efforts." Eradication was the goal of high-profile campaigns against several diseases in the mid-twentieth century. Only the campaign against smallpox succeeded, at a very high cost, while a campaign against malaria failed.<sup>47</sup> Eradication then fell out of favour. Elimination is now a common goal in modern anti-disease campaigns. It is defined as a localized eradication. Traditionally, tuberculosis campaigns aimed for control, to standards set by the World Health Organization. Tuberculosis is considered a poor candidate for eradication, in large part because of the massive global prevalence of latent infection.<sup>48</sup> Increasingly, anti-tuberculosis campaigns aim for elimination by a given date.

The inherently complicated nature of Mtb and the response by its human hosts provides an underlying continuity to the history of efforts to control the disease. Meanwhile, the biology and medical effects of the pathogen and the human response continues to be studied, and the understanding evolves. Historical study of tuberculosis requires awareness of the biomedical understanding operative in the period being examination.

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<sup>46</sup> Nancy Leys Stepan, *Eradication: Ridding the World of Diseases Forever?* (Ithaca, NY: Cornell University Press, 2011), 7.

<sup>47</sup> Smallpox is the only human disease ever eradicated. The only other eradication is rinderpest, a disease of animals.

<sup>48</sup> Stepan, *Eradication*, 11.

## **Historiography**

The field of health is most usefully examined through all its various dimensions, which are here proposed as biomedical, social and political. These dimensions affect all aspects of health, but not always in the same way. Tuberculosis, because of its cost, complexity and burden, is more affected by the political dimension than most health matters. Yet, its politics is often unacknowledged. This omission colours much historical writing on tuberculosis. Political factors determining the course of disease are present in most of the writing, but are mostly unexamined because so rarely acknowledged. The search for insight into these political determinants must cast a wide net, because social determinism dominates thinking and writing about health. It was not always so. The relationship among the health dimensions and their determinants has changed several times since the mid-nineteenth century, each turn a reaction to an imbalance among them. While the dimensions interact - influencing and influenced by one another - undue emphasis on any one of them skews perceptions of health. Changes in the relationships among determinants are reflected in both the history and historiography relevant to this paper.

### **Dimensions of health**

The various turns among dimensions of health were attempts to provide a fuller and more accurate picture of health. In the mid-nineteenth century, the dominance of biomedicine that accompanied advances in science was challenged by the rise of health politics. This was a reaction to biomedicine's relative impotence in the face of health problems caused by urbanization and the industrial revolution. Confusingly called 'social medicine,' but referring to society as a whole, the turn was a call to effect health changes through political action.

Biomedicine continued to have great influence, but it worked alongside political action in public

health matters well into the twentieth century. By the mid-twentieth century, political determinism was overtaken by a social turn. The success of biomedicine and public health measures in eliminating the mass threats of infectious diseases brought to the fore some non-infectious problems such as cancers and cardiovascular disease. It soon became clear these were heavily influenced by individual and cultural factors. The realization produced a social determinants model that was widely adopted and endorsed. Some health analysts have associated the resulting decline of biomedical determinism with the rise of neoliberal approaches to health. They saw social determinism as giving inadvertent cover to small-government neoliberal measures that aggravated health problems. The backlash against neoliberalism brought a revival of political analyses of health that took root in the 2000s.

While there was scattered writing on the politics of health from the late 1960s onward, current work has grown out of a 2005 article by influential policy analyst Ilona Kickbusch, in which she first refers to "political determinants of health," and is given credit for coining the term.<sup>1</sup> Kickbusch characterizes health as a political choice, alluding to a frequent definition of politics as the process of decision making in a collective setting. She calls it a "continuous struggle" shaped by the "distribution of money, power and resources."<sup>2</sup> Kickbusch's framing provides a foundation for subsequent writers, among whom political scientists Nicole Bernier and Carole Clavier usefully propose a political science analysis for use in health. Bernier and Clavier start from the premise that "politically neutral interventions for better public health outcomes are fictitious," and that analytical models used in public health are "naive, idealistic

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<sup>1</sup> Ilona Kickbusch, "Tackling the political determinants of global health," *BMJ* 331 (July 28, 2005): 246-7, <https://doi.org/10.1136/bmj.331.7511.246>.

<sup>2</sup> Ilona Kickbusch, "The political determinants of health - 10 years on," *BMJ* 350 (January 8, 2015): h1, <https://doi.org/10.1136/bmj.h81>.

and narrow."<sup>3</sup> Their alternative analysis identifies variables in the relevant political processes, notably structures and people who constitute centres of power, their positions (interests, attitudes, ideologies and incentives), and the resources at their disposal. Besides frameworks of analysis, ideas about representation are useful for understanding the politics of health and of the North. Political scientist Deborah Stone sees a role for ambiguity in transforming various entities into symbols, which have political power.<sup>4</sup> Symbols present a multiplicity of interpretations that can create broad coalitions of support to overcome political obstacles. The idea of North, and even Inuit, have often been symbols to southern Canadians, which has given them political resonance at various times beyond rational measure. The same can be said of ambiguously defined health concepts, whose interpretation shifts according to what the audience is inclined to perceive. Symbols rarely survive contact with reality, or, in the case of health concepts, implementation into programs, but they can be useful for a time.

Public health scholar Johan Mackenbach uses a framework similar to that proposed by Bernier and Clavier, with timing an added factor. He applies it to what may be the first systematic political analysis of a public health scenario, a Blair government initiative to level social health inequalities in Britain. Mackenbach demonstrates that a misreading of political determinants in the program's timing, policy and implementation led to the program's failures.<sup>5</sup> Health policy advocate Daniel Dawes has adapted Kickbush's and Mackenbach's concepts for use in a detailed analysis of the political determinants of health in America.<sup>6</sup> The specifics of his work are unique to the American system, but his process of customizing general concepts is

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<sup>3</sup> Nicole F. Bernier and Carole Clavier, "Public health policy research: making the case for a political science approach," *Health Promotion International* 26, no. 1 (March 2011): 109-116. <https://doi-org.ezproxy.library.uvic.ca/10.1093/heapro/daq079>.

<sup>4</sup> Deborah A. Stone, *Policy Paradox and Political Reason* (New York: HarperCollins Publishers, 1988).

<sup>5</sup> Johan P. Mackenbach, "Can we reduce health inequalities? An analysis of the English strategy (1997–2010)," *Journal of Epidemiology & Community Health* 65, no. 7 (July 2011): 568-575, <http://dx.doi.org/10.1136/jech.2010.128280>.

<sup>6</sup> Daniel Dawes, *The Political Determinants of Health* (Baltimore: Johns Hopkins University Press, 2020).

applicable to the subject of this paper. The writers in the emerging field of political health almost universally observe a deep reluctance among health professionals to consider politics in health. This is attributed to professional culture, structural barriers, concerns about scholarly integrity, ignorance and personal discomfort.<sup>7</sup> The reluctance may be a factor in the relatively slow emergence of the field, although this may change under the obvious examples of political influences in the COVID-19 pandemic.

### **Tuberculosis and politics**

The historiography of health has lagged the health disciplines in taking up the various determinist frameworks. Until 1962, medical history consisted mainly of the physician-driven biomedical studies referred to by Howard Kushner. Then, a seminal work on cholera by Charles Rosenberg launched a social medical historiography.<sup>8</sup> The social dimension still dominates the field, which raises the possibility that historians of medicine are as reluctant to engage in political matters as people in health fields. Tuberculosis histories, however, are sometimes a special case. The greatest proportion of tuberculosis histories are written by non-historians, and often non-scholars, and while they frequently lack analysis, a few offer insights nonetheless. Tuberculosis histories by historians, by contrast, often usefully reflect the nature of the disease in their content and approach. Like tuberculosis, and its incongruously small footprint in public attention relative to its massive impact, the historiographic attention to tuberculosis is meagre compared to its importance in human history. Also, suggestive of Christian McMillen's theme of historical forgetting of tuberculosis, the few historical works stand alone, paying little attention

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<sup>7</sup> Bernier and Clavier, "Political science," 114; Kickbusch, "10 years on," 1; Johan P. Mackenbach, "Political determinants of health," *European Journal of Public Health* 24, no. 1 (February 2014): 2, <https://doi.org/10.1093/eurpub/ckt183>; Dawes, *Political determinants*, 45.

<sup>8</sup> Charles E. Rosenberg, *The Cholera Years: The United States in 1832, 1849, and 1866* (Chicago: University of Chicago Press, 1987 [1962]).

to one another. More more usefully, tuberculosis histories are sometimes political, at least some global histories.

Three significant works of professionally produced tuberculosis history approach tuberculosis in the context of politics, and also race. Randall Packard examines one of the most infamous regions of racial division, twentieth-century South Africa, to demonstrate the "pathological intersection of political, economic and biological processes" that amplified tuberculosis among black miners.<sup>9</sup> Packard observes similarities between the early stages of epidemics in South Africa and in Britain during the industrial revolution. But the epidemics subsequently diverged, because the interests of British industry and labour overlapped in ways that favoured reforms to control the disease, while in South Africa, the fact of race meant there would never be overlapping interests. The power differential there led to a choice to create and maintain social conditions that amplified disease among the miners, and withheld medical care with the goal of protecting white people. The combination of the political choice, social conditions and the consequent well-established reservoir of latent disease created a stubborn, long continuity of disease, despite availability of medical tools to diminish it. The combination of determinants and their outcome is an uncanny echo of the situation in Canada's North.

Aro Velmet considers the converse case, the deployment of biomedicine to advance political goals, in this case, the bacteriology of the Pasteur Institute to advance French imperialism.<sup>10</sup> Velmet calls his framework 'technopolitics,' which in addition to its biomedical determinants, has three political determinants - money constraints, staff shortages, and ideology - which aligned to induce colonial compliance. The main difference between Velmet's case studies

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<sup>9</sup> Randall Packard, *White Plague, Black Labor: Tuberculosis and the Political Economy of Health and Disease in South Africa* (Berkeley, Los Angeles: University of California Press, 1989), 9.

<sup>10</sup> Aro Velmet, *Pasteur's Empire: Bacteriology and Politics in France, Its Colonies and the World* (New York: Oxford University Press, 2020).

and the experience in Canada's North is the nature of the ideology. The counterpart of France's mission to demonstrate French grandeur by civilizing other races is a Canadian mission to secure sovereignty, national security and resource extraction by maintaining Inuit wellbeing.

Christian McMillen's work is the least explicitly political of the three. In searching for an answer to why tuberculosis is still not under control around the world despite available tools, McMillen highlights a developmental divide.<sup>11</sup> Once tuberculosis was controlled in industrialized countries, political will and money dried up, and the forgetting began, leaving much of the world still scourged by uncontrolled disease. McMillen attributes this to race, pointing to the use of non-white populations around the world to test new treatments. His evidence is not persuasive, given the burden of disease was already disproportionately heavy in these test areas and needed attention. Also, the treatments were benign: BCG had already been proven safe, and chemoprophylaxis drugs were already widely used. Such tests happened in Canada, and except for the earliest BCG tests, were done for the same reasons, to address remaining areas of high burden. Despite the strained evidence, McMillen's initial question about reasons for the inequality of burden is still valid, and his argument worth examining further.

### **Tuberculosis and public health debates**

Inequality of burden of disease is the crux of tensions between a pair of views in the public health of tuberculosis. The opposing positions may be characterized, somewhat incongruously, as laissez-faire ecological and social determinism pitted against social justice delivered through extreme technocratic intervention. More simply, the poles may be termed Dubosian and Soperian, after the most prominent proponents of each view, microbiologist René Dubos and

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<sup>11</sup> Christian W. McMillen, *Discovering Tuberculosis: A Global History 1900 to the Present* (New Haven, CT: Yale University Press, 2015).

arch-eradicationist Fred Soper. Dubos, despite having helped develop some of the earliest antibiotics, was skeptical about their value in treating tuberculosis: "Man can eradicate it without vaccines and without drugs by integrating biological wisdom into social technology, into the management of everyday life."<sup>12</sup> By this he meant preventing transmission, and letting humans develop resistance naturally. His ecological philosophy of co-existence was widely praised in the mid-twentieth century, but now, his somewhat dismissive attitude toward people wanting cures, and the death toll implicit in his suggested strategy would likely be politically unacceptable.<sup>13</sup> Fred Soper's views have had the opposite pattern of attention, for decades dismissed, and now cautiously considered. Soper worked for more than forty years on campaigns to eradicate malaria and yellow fever, initiatives that were environmentally damaging, expensive and only somewhat successful. Soper also paid some attention to tuberculosis, a much different disease than his specialties, but he believed it too needed to be eradicated.<sup>14</sup> He saw this as the only way to achieve health equity: "Eradication cannot sacrifice the minority under the blanket classification - 'no longer of public health importance.' Eradication cannot be made available to part of the people; protection of all the population becomes the only acceptable professional public health standard."<sup>15</sup> Soper espoused the idea of the 'final inch.'<sup>16</sup> This is the most difficult part of a public health campaign, the very end, when interest wanes and per capita costs skyrocket. Soper contrasts the relative ease of large percentage drops in incidence immediately after the peak, when most of a population recovers, to the much more difficult campaign in a low-incidence

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<sup>12</sup> René Dubos and Jean Dubos, *The White Plague: Tuberculosis, Man, and Society* (New Brunswick, NJ: Rutgers University Press, 1996 [1952]), xxxviii, 225.

<sup>13</sup> Dubos and Dubos, *White Plague*, 156.

<sup>14</sup> F.L. Soper, "Problems to be solved if the eradication of tuberculosis is to be realized," *American Journal of Public Health and the Nation's Health* 52, no. 5 (May 1962): 734-48, <https://doi.org/10.2105/ajph.52.5.734>.

<sup>15</sup> Soper, "Problems," 736.

<sup>16</sup> Quote by Alexander Solzhenitzyn from *The First Circle* in John F. Wickett, "The Final Inch: The Eradication of Smallpox and Beyond," *Social Scientist* 30, no. 5-6 (May-June 2002): 62-78, <https://www.jstor.org/stable/351800262>. The term, the 'final inch,' was used in health contexts from 1975.

environment, when cases are few, dispersed, mostly among socially vulnerable people, and the most resource-intensive to trace and treat. Thus the 'final inch' requires large quantities of political will to allocate resources necessary for these final cases.<sup>17</sup>

Another set of opposing views in the public health of tuberculosis has been the subject of even wider debate. The poles are between different views of which are the more fundamental determinants of health - social or political - both sides sharing the view that biomedical determinants are not as important as once thought. On the social side is the McKeown thesis, developed by public health researcher Thomas McKeown. On the political side is a refutation of the thesis by medical historian Simon Szreter. McKeown came to his thesis by examining British vital statistics and concluding that the drop in tuberculosis incidence in the late nineteenth century was the result of improvements in nutrition and standards of living as a result of industrialization.<sup>18</sup> McKeown's work received overwhelming international attention, and policies were developed around his thesis, even into the 2000s. By that time, however, the McKeown thesis was a zombie. Szreter had shown convincingly that McKeown had misinterpreted the data, and misidentified the timing of tuberculosis mortality decline.<sup>19</sup> Szreter argues that rather than benefitting public health, industrialization caused disruption and disease amplification, which only subsided after government interventions improved social conditions and introduced public health measures. Among Szreter's supplementary evidence is the correlation of disease decline with political actions such Birmingham mayor Joseph Chamberlain's "gas and water socialism" which improved public sanitation and public health.<sup>20</sup>

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<sup>17</sup> Nancy Leys Stepan, *Eradication: Ridding the World of Diseases Forever?* (Ithaca, NY: Cornell University Press, 2011), 215.

<sup>18</sup> Thomas McKeown, "Medical issues in historical demography," Reprint in *International Journal of Epidemiology* 34, no. 3 (June 2005 [1971]): 515-520, <https://doi.org/10.1093/ije/dyh195>.

<sup>19</sup> Simon Szreter, *Health and Wealth: Studies in History and Policy* (Rochester, NY: University of Rochester Press, 2005), 113-6.

<sup>20</sup> Szreter, *Health and Wealth*, 224.

### Canadian and northern histories

Canadian medical tuberculosis histories offer little analysis, mainly because almost none are produced by historians, but also because there are so few of them. A few insights may be extracted nonetheless. The only somewhat scholarly history of tuberculosis in Canada, Katherine McCuaig's 1999 study, is a throwback to the era of unexamined biomedical determinism, perhaps because, after her master's level history training, McCuaig became a surgeon.<sup>21</sup> She does try to meld social factors with biomedicine, but unsuccessfully. Her stance becomes clear when she describes proponents of social determinants of health as intellectuals who are "denigrating the role of scientific and bacteriological triumphs" because they are "uncomfortable in and untrained for pure laboratory research."<sup>22</sup> More problematic is her explicit decision to exclude Indigenous people completely from her work, an anachronistic racial segregation that diminishes her work even in her own terms, given that Indigenous aspects of the epidemic did influence tuberculosis control decisions for white Canadians. McCuaig's value is in recognizing, albeit in an unexamined way, that tuberculosis was important to the creation of Canada's public healthcare system, because it was such a "costly disease very few Canadians could afford to deal with themselves."<sup>23</sup> This adds support to the argument that the cost and scope of tuberculosis made it a powerful force in politics.

The most comprehensive history of tuberculosis among Inuit is the 1994 work of a retired federal civil servant, psychologist Pat Grygier.<sup>24</sup> Grygier, more than any writer, conveys the

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<sup>21</sup> Katherine McCuaig, *The Weariness, the Fever, and the Fret: The Campaign against Tuberculosis in Canada 1900-1950* (Montreal: McGill-Queen's University Press, 1999), <https://canadacommons-ca.ezproxy.library.uvic.ca/artifacts/1866340/the-weariness-the-fever-and-the-fret/2615335>.

<sup>22</sup> McCuaig, *Weariness*, 243.

<sup>23</sup> McCuaig, *Weariness*, 257.

<sup>24</sup> Pat Sandiford Grygier, *A Long Way from Home: The Tuberculosis Epidemic among the Inuit* (Montreal: McGill-Queen's University Press, 1994).

callous cruelty of the mass evacuation era. The evacuation period is her focus, even though she purports to examine the entire history of tuberculosis among Inuit. Grygier presents a powerful social history, but her work is hampered by her sympathy for fellow bureaucrats. This leads her to conclude that the treatment of Inuit and the resulting trauma were byproducts of the difficult northern circumstances, and the trauma could have been tempered by better planning. She recognizes colonial attitudes and power imbalances, but glosses over their impacts, excusing most shortcomings by ascribing good intentions and obliviousness. Despite the evidence of harm she herself compiles, she sees good in the evacuations, and concludes they led to the end of the epidemic by the late 1980s, even while noting the continued high incidence rate. Compassion and empathy notwithstanding, Grygier is a northern essentialist. The exotic extremes of northern circumstances, and her "wonder at the ingenuity and spirit that enabled a people to live in and enjoy the Far North" lead her to see intrinsic 'otherness' in Inuit and their experience of tuberculosis, which places it outside the frame of southern standards.<sup>25</sup> Grygier is also a biomedical determinist, crediting biomedical intervention for ending the epidemic, and identifying bureaucrats as its agents. In addition to her ability to create an evocative picture of Inuit experiences, Grygier succeeds in conveying the reality of bureaucrats as the centres of power in the North. This portrayal rounds out similar views in non-medical northern histories, for example, by geographer R. Quinn Duffy and Shelagh Grant.<sup>26</sup> The prevalence of tuberculosis in Arctic history means it pervades almost all historical writing in some way.

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<sup>25</sup> Grygier, *Long Way*, xvii.

<sup>26</sup> R. Quinn Duffy, *The Road to Nunavut: The Progress of the Eastern Arctic Inuit Since the Second World War* (Kingston and Montreal: McGill-Queen's University Press, 1988); Shelagh D. Grant, *Sovereignty or Security? Government Policy in the Canadian North, 1936-1950* (Vancouver: University of British Columbia Press, 1988).

Anthropologist Toby Morantz takes a closer look at the power of northern bureaucrats in her study of James Bay Cree in the twentieth century.<sup>27</sup> Morantz argues that the long presence of Hudson's Bay Company officials caused less upheaval in Cree lives than the 1960s intrusion of southern bureaucrats. She characterizes the impact of the bureaucrats as a distinctive form of state colonialism she calls bureaucratic colonialism, because "the Crees were most affected, not by settlers or capitalists but by the infusion of low-quality versions of Canadian services: education, welfare, health, government management."<sup>28</sup> These were delivered by bureaucrats with a technocratic mission to spread the benefits of modern society, for state self-regard and convenience rather than exploitation. In this the Cree resemble Inuit; the absence of treaties and reserves, and their remoteness created similar relations with bureaucrats and state services.

Morantz reflects on different forms of colonialism in Canada to understand how its operations and impacts vary with circumstances. In this she stands in contrast to writers who accept 'black box' models of colonial harm unmodified by local circumstances. An example is the use of the model of structural violence to study a tuberculosis outbreak in Eskimo Point (Arviat) in the 1960s.<sup>29</sup> The authors, a prolific social work team led by Frank Tester, accept the model in its generalities, which even they acknowledge is a 'black box' that may be applied to factors as wide-ranging as international treaty measures or access to resources. After close examination of bureaucrats' actions, they conclude the epidemic happened because Inuit housing policy violated human rights. They do not explain how the tensions they describe among federal bureaucrats over housing quality arose, why poor quality housing prevailed, or how it was related to human rights and their violation, leaving a large gap in understanding. Medical

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<sup>27</sup> Toby Morantz, *The White Man's Gonna Getcha: The Colonial Challenge to the Crees in Quebec* (Montreal & Kingston: McGill-Queen's University Press, 2002).

<sup>28</sup> Morantz, *White Man*, 242.

<sup>29</sup> Frank James Tester, Paule McNicol and Quyen Tran, "Structural violence and the 1962-1963 tuberculosis epidemic in Eskimo Point, N.W.T.," *Études/Inuit/Studies* 36, no. 2 (2012): 165-185, <https://doi.org/10.7202/1015983ar>.

historian Maureen Lux grapples with colonialism in her look at Canada's Indian hospitals, which were homes for many Inuit tuberculosis patients, often for years at a time.<sup>30</sup> Lux's strength is in documenting the widespread racist practices in Indigenous healthcare. Her work is less useful in explaining what drove those practices. Lux's view of white authority figures is the opposite of Grygier's, but the effect is the same. Lux talks about the varieties of colonial interactions, and varying forms of Indigenous agency, but in the end she applies a broad brush of racism, hypocrisy and cruelty. Sometimes the outcome is misleading, for example, her framing of BCG vaccinations and tuberculosis surgeries as practices especially directed at Indigenous people, even though they were used widely on non-indigenous people when the epidemic among them was at its height. Lux's blanket approach flattens the forces behind the history being examined.

A final perspective from environmental historians Liza Piper and John Sandlos is a reminder of the importance of the distinctive northern environment to northern health history.<sup>31</sup> Among the geographic determinants of health are the North's distances, remoteness, sparse population, extremes of climate, distinctiveness of marine and land environments and their associated ecosystems. All affected and continue to affect colonial interactions, and often cause distinctive trajectories of disease, which Piper and Sandlos examine. It is a reminder that any similarities notwithstanding, the experience of tuberculosis in the North and elsewhere do differ, and the particularities of the North must be considered in any analysis. A similar theme is addressed by historian Renée Fossett in her examination of 400 years of post-contact history of Inuit in the central Arctic.<sup>32</sup> Fossett proposes a rehabilitation of the idea of geographic

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<sup>30</sup> Maureen K. Lux, *Separate Beds: A History of Indian Hospitals in Canada, 1920s-1980s* (Toronto: University of Toronto Press, 2016).

<sup>31</sup> Liza Piper and John Sandlos, "A Broken Frontier: Ecological Imperialism in the Canadian North." *Environmental History* 12, no. 4 Special Issue on Canada (Oct. 2007): 759-795, <https://www-jstor-org.ezproxy.library.uvic.ca/stable/25473161>.

<sup>32</sup> Renée Fossett, *In Order to Live Untroubled: Inuit of the Central Arctic, 1550-1940* (Winnipeg: University of Manitoba Press, 2001), 19.

determinism, rescuing it from the essentialism with which it was associated in earlier, apparently ideologically motivated histories. She argues the importance of acknowledging that people living in regions of environmental extremes faced distinctive constraints and instabilities, which made basic survival loom large in their stories, and that their choices for achieving security and stability were determined by that context.

## Tuberculosis in Canada

The history of tuberculosis in Canada has several political aspects. At Confederation, tuberculosis was an epidemic across all parts of Canadian society, affecting the wealthy and influential along with the poor. The prevalence, widespread fear, and the high cost of treatment challenged political ideologies and created pressures for governments to act, which then shaped people's views on the role of government in healthcare. Eventually stark divides developed. Among Indigenous people, tuberculosis amplified the damaging effects of colonial policies, while policies meant to address tuberculosis hardened racial divides. Among non-Indigenous people, large mobilizations of people and resources led to widespread availability of treatment, and measures to mitigate the high costs became the precursors of Canada's publicly funded healthcare system. This history of tuberculosis in southern Canada, has some connection to tuberculosis in the North, but mostly it illuminates the northern experience through contrast.

### Americas

Little is known about tuberculosis in the Americas before the mid-nineteenth century, but some patterns can be inferred. Discoveries in the late-twentieth century disproved long-standing views that the Americas were virgin soil for tuberculosis, that is, a region never exposed to a disease where people had unprepared immune systems. The continents had indigenous forms of tuberculosis, but of unknown strains, and likely different from post-contact strains. Physical evidence has been found at several dozen sites ranging from Chile to Canada, the oldest one from 700 CE in Peru.<sup>1</sup> In Wyoming, 17,000-year-old tubercular remains of an animal raise the

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<sup>1</sup> Janet W. McGrath, "Social networks of disease spread in the Lower Illinois Valley: A simulation approach," *American Journal of Physical Anthropology* 77, no. 12 (December 1988): 484, <https://doi.org/10.1002/ajpa.1330770409>; P. Charlier and P.D. Deps, "Possible new evidence of pre-Columbian tuberculosis in America: Pott disease in a prehistoric Mexican statue," *Tuberculosis* 116 (May 2019): 35,

possibility of much older human infection in the Americas, given the frequent exchanges of MTC bacteria between humans and animals.<sup>2</sup> There are also prehistoric cultural representations consistent with Pott disease that are suggestive of early tuberculosis presence.<sup>3</sup>

After Europeans arrived, strains of the European L4 lineage began to trace pathways of European colonization. For example, genomic analyses of *Mtb* samples from the Caribbean have found four L4 strains: one originating in the Haarlem area of the Netherlands, one in Spain, one in Britain, and one less well-defined, but now common in western Africa. Since indigenous people of the Caribbean had been mostly displaced by newcomers, there is no evidence of pre-contact indigenous tuberculosis or indigenous responses to L4.<sup>4</sup>

### **Tuberculosis increase**

In Canada, evidence of tuberculosis predating European contact has been found at four sites, in areas associated with agriculture: one in Saskatchewan from about 1000 CE, and three in Ontario near the Great Lakes from 1300 to 1600 CE.<sup>5</sup> The sites are likely to have had settled communities practicing forms of agriculture. All samples show tuberculosis in bones, usually a small fraction of tuberculosis infection. This suggests tuberculosis may have been endemic.

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<https://doi.org/10.1016/j.tube.2019.03.011>; Wilmar L. Salo et al., "Identification of *Mycobacterium tuberculosis* DNA in a pre-Columbian Peruvian mummy," *Proceedings of the National Academy of Sciences USA* 91, no. 6 (15 March 1994): 2091, <https://doi.org/10.1073/pnas.91.6.2091>; Kristen I. Bos et al. "Pre-Columbian mycobacterial genomes reveal seals as a source of New World human tuberculosis," *Nature* 514, no. 7523 (27 August 2014): 494, <https://doi.org/10.1038/nature13591>. The Peruvian tuberculosis appears to have been caused by a species of MTC usual associated with sea mammals.

<sup>2</sup> I. Buzic and V. Giuffra, "The paleopathological evidence on the origins of human tuberculosis: a review," *Journal of Preventive Medicine and Hygiene* 61, no. 1 suppl.1 (30 April 2020): E4, <https://doi.org/10.15167/2421-4248/jpmh2020.61.1s1.1379>.

<sup>3</sup> Charlier, "Pre-Columbian," 35.

<sup>4</sup> Véronique Duchêne et al., "Phylogenetic reconstruction of *Mycobacterium tuberculosis* within four settings of the Caribbean region: tree comparative analyse and first appraisal on their phylogeography," *Infection, Genetics and Evolution* 4, no. 1 (March 2004): 5-14, <https://doi.org/10.1016/j.meegid.2003.09.001>

<sup>5</sup> Jordi Gómez Prat and Sheila MF Mendonça de Souza, "Prehistoric Tuberculosis in America: Adding Comments to a Literature Review," *Memórias do Instituto Oswaldo Cruz* 98 suppl. 1 (January 2003): 155, <https://doi.org/10.1590/S0074-02762003000900023>.

Seventeenth-century Jesuit missionaries reported widespread tuberculosis among agricultural Haudenosaunee people settled around the Great Lakes.<sup>6</sup> It is unclear if this was in fact tuberculosis, and if so if it was pre-existing or a sign that L4 strains had already spread. Among eastern Indigenous people, who first had contact with Europeans, the course of tuberculosis either before or after contact is unclear, but molecular studies of the disease in western provinces suggest a pattern that could plausibly apply in the East, a pattern of endemic disease that later intensified as people moved to more densely settled communities around European settlements.

Two genomic studies of Mtb among Indigenous people in western Canada show dispersal is separate from epidemic development. The former came from simple contact, the latter from societal disruption. One of the studies found that an L4 strain long established in francophone Quebec is also the most common strain found in Indigenous people in Ontario, Saskatchewan and Alberta.<sup>7</sup> Combining genomic dating with historic evidence, researchers conclude that dispersal of the Quebec strain happened through the Montreal fur trade, which brought about 5,000 people west from Quebec starting in 1710. The Quebec strain spread from the fur traders to Indigenous people, but only as sporadic infections until the late nineteenth century. At that point tuberculosis suddenly became a widespread epidemic killing whole families.<sup>8</sup>

The other study analyzed Mtb samples from Indigenous people in Saskatchewan. These samples fell into two groups. The larger group showed an epidemic peak between 1870 and

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<sup>6</sup> Christian W. McMillen, *Discovering Tuberculosis: A Global History 1900 to the Present* (New Haven, CT and London: Yale University Press, 2015), 22.

<sup>7</sup> Marcel A. Behr "TB in Canada: From Sea to Sea to Sea." Presentation at Canadian Respiratory Conference (April 2017), slide 2, <https://cts-sct.ca/wp-content/uploads/2018/04/CRC-2017-PRESENTATIONS.pdf>; Caitlin S. Pepperell et al., "Dispersal of *Mycobacterium tuberculosis* via the Canadian fur trade," *Proceedings of the National Academy of Sciences U.S.A.* 108, no.16 (April 4, 2011): 6528, <https://doi.org/10.1073/pnas.1016708108>.

<sup>8</sup> Pepperell, "Dispersal," 6529.

1920, the second group peaked around the 1940s.<sup>9</sup> Historian James Daschuk describes the time of the first peak as one of federal officials forcing Indigenous people onto reserves, using starvation as a tool of coercion after the collapse of bison herds. At the same time, they were institutionalizing Indigenous children.<sup>10</sup> Both overcrowding and malnutrition are strong tuberculosis determinants, which meant conditions enabled endemic Mtb to become epidemic.<sup>11</sup> The second peak was found among people in remote northern Saskatchewan, who were settled and had children institutionalized later in the twentieth century. European immigrants arriving on the Prairies in those periods from high-tuberculosis regions did not contribute significantly to the Mtb pool among Indigenous people, indicative of the social divide between the groups.<sup>12</sup>

As the epidemic was starting among Indigenous people, Canada's leaders, colonial and then federal, were focussed on cholera, typhus and smallpox.<sup>13</sup> These high-profile diseases were arriving with immigrants, but immigrants were also bringing tuberculosis from epidemic Europe. By Confederation, tuberculosis had become the leading cause of death in Canada among all populations, and grew worse in subsequent decades.<sup>14</sup> Gradual urbanization amplified the disease and resulting fear. Tuberculosis was called a "national disease," and doctors worried about population collapse.<sup>15</sup> As fears grew, so did the number of charlatans offering hope, and the number of rumours. One rumour accused Britain of emptying its tuberculosis sanatoria and sending patients to Canada. The chief federal medical officer, Peter Bryce, responding to such

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<sup>9</sup> Caitlin Pepperell et al., "Bacterial Genetic Signatures of Human Social Phenomena among *M. tuberculosis* from an Aboriginal Canadian Population," *Molecular Biology and Evolution* 27, no.2 (February 2010): 432, <https://doi.org/10.1093/molbev/msp261>.

<sup>10</sup> James Daschuk, *Clearing the Plains: Disease, Politics of Starvation, and the Loss of Aboriginal Life* (Regina: University of Regina Press, 2013), 100, 176.

<sup>11</sup> Sarah Ackley et al., "Modeling historical tuberculosis epidemics among Canadian First Nations: effects of malnutrition and genetic variation," *PeerJ* 3, e1237 (24 September 2015): 5.

<sup>12</sup> Pepperell, "Bacterial signatures," 6530.

<sup>13</sup> Christopher Rutt and Sue C. Sullivan, *This is Public Health: A Canadian History* (Ottawa: Canadian Public Health Association, 2010), 1.1, [https://cpha.ca/sites/default/files/assets/history/book/history-book-print\\_all\\_e.pdf](https://cpha.ca/sites/default/files/assets/history/book/history-book-print_all_e.pdf).

<sup>14</sup> George Jasper Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto: University of Toronto Press, 1977), 18.

<sup>15</sup> Wherrett, *Miracle*, 12.

concerns, said it was not possible to catch all tuberculosis among immigrants because of the large numbers involved and need for speed in their medical examinations.<sup>16</sup>

Overall numbers were unclear, as only cities collected statistics, but even those limited numbers showed an intense epidemic. In 1880, the mortality rate in Montreal was 300 deaths per 100,000 people. In Toronto, it was 200 deaths, increasing to 250 by 1900.<sup>17</sup> National statistics were finally introduced in 1921, in response to decades of pressure from public health officials and industry.<sup>18</sup> Local authorities were the original collectors of statistics because they were the ones responsible for public health, a responsibility delegated by the provinces. The only health responsibility the federal government kept for itself after Confederation was continued immigration quarantines for cholera and typhus. For the rest, "one notes a certain absurdity in the granting of administrative powers to the provinces for education, health, hospitals and social welfare in the British North America Act without provision of financing."<sup>19</sup>

Tuberculosis was an expensive disease. The large number of people needing treatment combined with high costs of illness - direct costs of supporting years spent at home or in sanatoria - were compounded by indirect costs to the economy. Most patients were working-age adults, and illness usually meant their families lost their incomes. In 1908, the Canadian Medical Association estimated the cost of tuberculosis to the economy was \$70.4 million per year, compared to \$5.5 million for typhoid.<sup>20</sup> The physicians accused the federal government of spending more on controlling agricultural disease than human. Tuberculosis created widespread needs for healthcare and financial support. Municipalities had a mandate to support both public

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<sup>16</sup> Wherrett, *Miracle*, 4.

<sup>17</sup> Wherrett, *Miracle*, 249. For comparison, the most recent Canadian mortality is 0.19, and in the fifty highest burden countries it is 25 to 250. "Death rate from tuberculosis," *Our World in Data*, <https://ourworldindata.org/grapher/tuberculosis-death-rates>.

<sup>18</sup> David A. Worton, *The Dominion Bureau of Statistics: A History of Canada's Central Statistical Office and its Antecedents, 1841-1972* (Montreal: McGill-Queen's University Press, 1998), 25.

<sup>19</sup> Wherrett, *Miracle*, 4.

<sup>20</sup> Rutty and Sullivan, *Public Health*, 1.14

health and 'indigent' people, people who were poor or became poor through disease, but the need for support far outstripped municipalities' capacities and resources.

### **Tuberculosis control**

By the turn of the twentieth century, public health advocates were describing anti-tuberculosis efforts in military language: a crusade, campaign or fight against an enemy disease. Yet the metaphor does not completely fit the actual situation. Among Indigenous people, the mission was to have a voice and receive the health care promised by treaties. Among authorities, the goal was to do as little and spend as little as possible, so the resulting care was grudging and parsimonious to the point of cruelty. Among non-Indigenous people, the foremost mission was for influence decision makers and find funding to advance treatment.

For Indigenous people at the turn of the twentieth century, continuing settlement restrictions and institutionalizations was prolonging the tuberculosis epidemic. Peter Bryce, the physician who supervised immigration inspections, was also responsible for Indigenous healthcare for a time. In 1907 he reported on conditions at 35 residential schools, and when his report appeared to have been suppressed, he famously reported it publicly in 1922<sup>21</sup>. Bryce found that during the first 15 years of the schools' existence, a quarter of all students were known to be dead, and at one school three-quarters of all students had died.<sup>22</sup> In 1907, all children at the schools were infected with tuberculosis, while a survey 14 years later showed 93 percent infected.<sup>23</sup> Some of the disease was likely bovine tuberculosis transmitted by cow's milk served

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<sup>21</sup> Peter Henderson Bryce, *The Story of a National Crime: An Appeal for Justice to the Indians of Canada* (Ottawa: James Hope & Sons, Limited, 1922), 1-14. <https://ia802705.us.archive.org/20/items/storyofnationalc00brycuoft/storyofnationalc00brycuoft.pdf>. This report was published after Bryce had been let go from his position, allegedly a reaction to his efforts to improve tuberculosis care and residential school conditions. Some of his language, however, supports a theory that he was bitter at being denied a promotion he felt he deserved.

<sup>22</sup> Bryce, *National Crime*, 4.

<sup>23</sup> Bryce, *National Crime*, 4, 14.

in the schools.<sup>24</sup> Infected children returning to their communities added to the problem. Bryce reported Indigenous tuberculosis death rates of more than eight times those non-Indigenous people, and spending on tuberculosis control for all Indigenous people across Canada at less than a third of tuberculosis spending in the city of Ottawa alone.<sup>25</sup>

This treatment of Indigenous people - callous indifference, or racist cruelty - was based on an official rejection of a treaty responsibility to provide Indigenous healthcare.<sup>26</sup> Federal officials consistently aimed to do and spend as little as possible. The office responsible for Indians was tacked onto five different federal departments between Confederation and the end of World War II.<sup>27</sup> Parsimony may have reached a low point with an infamous memo written by the federal director of Indian Affairs Harold McGill in 1937, in which he instructed Indian agents to restrict medical services for Indigenous people "to those required for the safety of limb, life or essential function," similarly restricting hospital services, and allocating no money for tuberculosis measures, so his office could meet its goal of cutting spending in half.<sup>28</sup>

Even without the 1937 directive, the federal government refused to pay for sanatorium care for Indigenous people, or paid reduced rates, so hospitals refused to take Indigenous patients. This refusal, combined with pressures to segregate Indigenous people to prevent them infecting white people, led administrators to set up separate "Indian hospitals." First they took over mission hospitals, then creating their own facilities.<sup>29</sup> Parsimony extended to the new hospitals. Their operating costs were half those of non-Indigenous sanatoria, which themselves

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<sup>24</sup> Maureen K. Lux, *Separate Beds: A History of Indian Hospitals in Canada, 1920s-1980s* (Toronto: University of Toronto Press, 2016), 26.

<sup>25</sup> Bryce, *National Crime*, 10, 13.

<sup>26</sup> Wherrett, *Miracle*, 108.

<sup>27</sup> Responsibility remains in this department, except for instances of devolution under self-governance provisions of various modern treaties and agreements. The first instance was to the James Bay Cree, and the largest to the British Columbia First Nations Health Authority.

<sup>28</sup> Wherrett, *Miracle*, 110-112.

<sup>29</sup> Lux, *Separate Beds*, 33.

had operating costs well below those of non-Indigenous hospitals.<sup>30</sup> The best that could be said about the Indian hospitals was that they may have helped disrupt disease transmission in communities, and Indigenous people felt they were not nearly as bad as residential schools.<sup>31</sup>

Institutions were not the only problem. In 1940, Doug Galbraith, a young physician then working with Indigenous people in Bella Coola, felt compelled to write to Prime Minister Mackenzie King, "appalled by the incidence of tuberculosis and lack of any treatment or prevention," and struck by "a gap in the treatment of our Indians. The prevention and cure of tuberculosis has gone ahead in the last twenty years in tremendous strides under Provincial organizations which have in almost every instance excluded our Canadian Indians."<sup>32</sup> Galbraith later became one of the officials who helped initiate the Frobisher Bay project.

Non-institutional tuberculosis services were rarely offered to Indigenous people, except to reduce a perceived threat to non-Indigenous people. An example was BCG vaccination. After BCG's introduction in France in 1921, the National Research Council (NRC) became interested in using it in Canada, and funded two studies in 1925. In Alberta, one large study used BCG on cattle to control bovine tuberculosis. In Montreal, researchers began vaccinating newborns in families with tuberculosis-infected members. The question was vaccine effectiveness, not safety, as BCG had already been used widely in Europe, especially on infants. The Montreal newborn study lasted twenty years, was judged effective, and Quebec adopted universal BCG vaccination. In 1933, the NRC funded another study, somewhat controversial at the time, and more so in recent years. Robert Ferguson, director of Saskatchewan's anti-tuberculosis program, led the

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<sup>30</sup> Lux, *Separate Beds*, 26, 34; G.J. Wherrett, *Tuberculosis in Canada* (Ottawa: Royal Commission on Health Services, 1965), 47.

<sup>31</sup> J. Douglas Galbraith and W. David Galbraith, *From Slate to Computer: A Memoir of Dr. J. Douglas Galbraith* (Victoria: Trafford Publishing, n.d. [2003?]), 91; Lux, *Separate Beds*, 101; "In Focus: The dark past and injustices of tuberculosis sanatoria in Canada," Broadcast program, APTN National News. November 1, 2017. <https://www.aptnnews.ca/infocus/infocus-4/>.

<sup>32</sup> Galbraith and Galbraith, *From Slate to Computer*, 73.

trial, which vaccinated Indigenous babies at the Fort Qu'Appelle Indian hospital. The trial was a scientific success: it was well designed, definitive in its results, proved excellent effectiveness, and became widely cited. It was socially controversial; it came only a few years after the Lübeck trial that had killed 72 babies, when confidence in BCG had been badly undermined. One of Ferguson's family members later wrote that Ferguson proposed it because he had confidence in his own experience preparing typhoid vaccines.<sup>33</sup> Despite Ferguson's self-confidence and a previous decade of essentially safe use, the Lübeck tragedy did raise risk, and Ferguson exposed Indigenous children to that risk without parental consent.<sup>34</sup>

Indigenous people lobbied for better tuberculosis care on their own behalf, but these efforts are rarely recorded by historians. Lux identifies two examples, one by the British Columbia Indian Anti-Tuberculosis League in 1923, and one by people on the Pasqua reserve in southern Saskatchewan in 1928.<sup>35</sup> John Leslie reports on concerns about tuberculosis raised at the 1939 Toronto Indian Conference of white and Indigenous representatives.<sup>36</sup> Another instance comes from the North American Indian Brotherhood (NAIB), formed in 1943 to advocate for Indigenous concerns. It persuaded the federal government to form a joint Senate-House committee to review the *Indian Act*, and the end of the committee's work coincided with NAIB's 1948 Indian Convention in Ottawa. One of the convention executives, Edward Beauvais, a member of the Caughnawaga band (Mohawk Council of Kahnawake), was interviewed by CBC

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<sup>33</sup> Bill Barrable, "Sheelagh Barrable inspired others with her compassion," *Globe and Mail*, March 14, 2018, Life section, Lives Lived, <https://www.theglobeandmail.com/life/sheelagh-barrable-inspired-others-with-her-compassion-and-humility/article38205263>.

<sup>34</sup> Lux, *Separate Beds*, 111; E.D. Zwick and C.S. Pepperell, "Tuberculosis sanatorium treatment at the advent of the chemotherapy era," *BMC Infectious Diseases* 20, no. 1 (2020-11-01): 1-11, <https://doi.org/10.1186/s12879-020-05539-w>.

<sup>35</sup> Lux, *Separate Beds*, 25-26.

<sup>36</sup> John F. Leslie, "Assimilation, Integration or Termination? The Development of Canadian Indian Policy, 1943-1963," (PhD Thesis, Carleton University, 1999), 72. [https://www.collectionscanada.gc.ca/obj/s4/f2/dsk1/tape9/PQDD\\_0013/NQ42797.pdf](https://www.collectionscanada.gc.ca/obj/s4/f2/dsk1/tape9/PQDD_0013/NQ42797.pdf).

Radio News at the time. Beauvais said the concerns of greatest importance were land and health, which Beauvais raised in the context of the promise of new federal money:

**Mr. Beauvais:** "As far as I can see, most of the money will be spent trying to cure the Indians of TB. There is a lot of TB amongst Canadian Indians. Well, the idea is all right up to a point, but I think it would be a better idea if more money was spent on the prevention of TB."

**Mr. Sanderson:** And how do you suggest that that should be done?

**Mr. Beauvais:** By improving the conditions in which some of the Indians live. I've traveled quite a lot, especially around the province of Quebec, and the housing conditions of some of the Indians are pitiful. There are houses without floors, others with mud roofs, and in some of these, the lighting is poor and sanitation. That sort of thing breeds TB.

**Mr. Sanderson:** I see. And you think that some of the money from the health project should be spent on housing for these people?

**Mr. Beauvais:** That's right. We should aim at preventing TB in the next generation instead of concentrating entirely on curing it in this generation. I think the best method would be to make low interest loans available to the Indians, so that they can build new roof houses. They could pay back the loans in the form of rent over a period of years.

**Mr. Sanderson:** And you think that the scheme would work?

**Mr. Beauvais:** It does work. It has been proven by the fact that TB is almost wiped out on the reservations where the housing conditions are good. And, anyway, it's certainly a better idea than spending millions of the taxpayer's money on prolonged health schemes. This they never get back.<sup>37</sup>

NAIB leaders wanted Indigenous people to have a say in how the money would be spent. They met with Prime Minister Mackenzie King, who said he was "most anxious to see that right and justice was done Indians."<sup>38</sup> He agreed to let NAIB delegates review the bill arising from the committee report and to suggest changes "which in their opinion would be necessary for the welfare of our race."<sup>39</sup> Yet the bill released in 1950 failed to incorporate Indigenous suggestions,

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<sup>37</sup> Yale D. Belanger, "CBC Indian Convention, Broadcast 29 May 1948," *Native Studies Review* 20, no.2 (2011), 190, <https://search-ebSCOhost-com.ezproxy.library.uvic.ca/login.aspx?direct=true&db=a9h&AN=82910975&site=ehost-live&scope=site>

<sup>38</sup> Belanger, "CBC Indian Convention," 188.

<sup>39</sup> Belanger, "CBC Indian Convention," 194.

even after revisions.<sup>40</sup> Tuberculosis care for Indigenous people continued as before, except with more Indian hospitals and support for dependents of tuberculosis patients.

Through this half-century of half-measures for Indigenous people, tuberculosis care for non-Indigenous people was on a completely different path. The need for care was first filled by many volunteers and charities, mobilized by tuberculosis disease and death crossing class lines and ages, especially among young people, and young women most of all.<sup>41</sup> When the son of Toronto businessman Hart Massey became ill in 1895, Massey and others set up the National Sanitarium Association, which opened the first sanatorium in Canada in 1897, Muskoka Hospital near Gravenhurst, Ontario, and soon afterward a nearby 'free hospital' for indigents.<sup>42</sup> Similar groups - leagues, associations, orders, societies, councils - arose provincially and in communities across Canada. Most groups were founded to raise money for sanatoria, and many later fundraised for preventoria (institutions for children from tuberculous families), dispensaries (clinics to diagnose and track patients and their contacts), public health nurses (often defacto social workers), and eventually research.<sup>43</sup> They also provided services. Most fundamental was public education, with basic messages, such as the need to pasteurize milk, or that tuberculosis was infectious not hereditary. Until at least the 1930s and in some places later, volunteer groups provided almost all tuberculosis services, including running dispensaries and case finding.

A key volunteer group was formed in 1901. First called the Canadian Association for the Prevention of Consumption and Other Forms of Tuberculosis, it was later renamed the Canadian Tuberculosis Association (CTA), and it was the first disease-based organization in Canada. The

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<sup>40</sup> Belanger, "CBC Indian Convention," 198.

<sup>41</sup> A. Brancker et al., "A Statistical Chronicle of Tuberculosis in Canada: Part I. From the Era of the Sanatorium Treatment to the Present," *Health Reports: Statistics Canada* 4, no.2 (January 1, 1992): 117.

<sup>42</sup> Note two different spellings. 'Sanitarium' is derived from *sanitas*, health, was associated with the sanitary public health movement, while 'sanatorium,' derived from *sanare*, to cure, and became the preferred term in Canada. René Dubos and Jean Dubos, *The White Plague: Tuberculosis, Man, and Society* (New Brunswick, NJ: Rutgers University Press, 1952, 1996), 173n1.

<sup>43</sup> Wherrett, *Tuberculosis*, 71.

CTA became the backbone of nation-wide anti-tuberculosis efforts, and its roles grew over time to include support for the many provincial and local groups, eventually coordinating with official agencies and funding many activities. From the start, however, the core activity of the CTA, and other groups, was lobbying. The CTA's first full-time director, William Moore, spent his first two years visiting every town on major rail lines to lecture and meet community leaders to build support for anti-tuberculosis efforts. Most lobbying was directed at senior governments. In 1905, the House of Commons and the Senate were each persuaded to pass a resolution calling on the state to "take some active steps to lessen the widespread suffering and great mortality among the people of Canada from consumption."<sup>44</sup> The only immediate result for the resolutions was an annual grant to the CTA, which nonetheless may have been the earliest federal funding for public health.<sup>45</sup> The CTA also lobbied other groups, the most influential being the Canadian Life Insurance Officers' Association (CLIOA). Insurance companies and CLIOA began donating to tuberculosis programs in 1924 and by 1945 had contributed almost half a million dollars.<sup>46</sup>

Another key group was the Canadian Public Health Association (CPHA), created in 1910 over concerns about tuberculosis and water-borne infections. Its mission was to promote disease prevention and social welfare.<sup>47</sup> It too lobbied Ottawa, for example, in 1941 it appealed for more money because the expense of tuberculosis control and sanatoria, "closely approximates or even exceeds the expenditure of the Health Department for all other services."<sup>48</sup>

One barrier to government involvement was a commonly held laissez-faire view of governance, in which individuals were responsible for their own health and government assistance was, in the words of economist and historian Adam Shortt, "an illegitimate function of

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<sup>44</sup> Wherrett, *Miracle*, 21.

<sup>45</sup> Wherrett, *Miracle*, 21-22.

<sup>46</sup> Wherrett, *Miracle*, 26, 28-29.

<sup>47</sup> Rutty and Sullivan, *Public Health*, 2.6. The CPHA's conception of social welfare at the time included eugenics.

<sup>48</sup> Rutty and Sullivan, *Public Health*, 5.2

a government ... in forcing one portion of the people to contribute to the support of another."<sup>49</sup> As the toll of disease continued and lobbying continued along with it, resistance to government participation diminished. This was expressed by Clifford Sifton, former federal cabinet minister, and later a federal commission chair, who observed in 1914 that "the individual was no longer left to kill or cure himself by patent medicines," with little thought to disease prevention, as "there has been a revolution since that time. Public Health is the new gospel."<sup>50</sup> After World War I, the federal government felt compelled to offer returning soldiers tuberculosis care, rehabilitation, and welfare. This was quickly followed by calls to extend the service to civilians, as in this 1917 *Hamilton Times* editorial calling on the federal government to "recognize their responsibility to tuberculous civilians as well as to the soldiers" and establish permanent tuberculosis treatment facilities.<sup>51</sup>

Saskatchewan led the way in government-supported care from the time it became a province in 1905, pushed in part by its first commissioner of public health, Maurice Seymour. In 1906 Seymour's son was diagnosed with tuberculosis and treated in a sanatorium. It so impressed Seymour he became an advocate and promoter of many tuberculosis initiatives.<sup>52</sup> The government granted official status to the Saskatchewan Anti-Tuberculosis League, and gave more than \$100,000 toward a new sanatorium in 1914. It was the first province to create enough sanatorium beds for every tuberculosis patient, and led the way in mass screenings. In 1929, Saskatchewan became the first province to offer tuberculosis treatment free to all residents, covered by taxpayers. By 1937 it had the lowest incidence of tuberculosis in Canada.<sup>53</sup>

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<sup>49</sup> Wherrett, *Miracle*, 7.

<sup>50</sup> Wherrett, *Miracle*, 3; Ruddy and Sullivan, *Public Health*, 2.1

<sup>51</sup> Wherrett, *Miracle*, 125.

<sup>52</sup> Wherrett, *Miracle*, 183

<sup>53</sup> Wherrett, *Tuberculosis*, 183.

Alberta followed Saskatchewan with tuberculosis care funding in 1933, and by 1961, eight provinces were funding all tuberculosis treatments; British Columbia and Ontario were the exceptions.<sup>54</sup> In 1948, as part of its overhaul of health department services, the federal government instituted the Federal Health Grants program to provinces. Tuberculosis control was one of the five areas funded, receiving about \$4 million per year.<sup>55</sup> By then, provincial and local governments had taken over tuberculosis services previously provided by charities, and expanded them. The priority was increasing sanatorium beds to meet demand, since sanatoria were still considered the best treatment available.

### **Tuberculosis decline**

From 1939 to 1944, tuberculosis killed almost as many Canadians as enemy action: 36,000 tuberculosis deaths, mostly young adults, compared to 38,000 in war.<sup>56</sup> Traditional treatments expanded, but within a decade, new tuberculosis antibiotics were becoming available. At peak traditional treatment, in 1953, there were 117 sanatoria and 19,000 tuberculosis beds, while sanatorium stays were just over a year long, and surgeries were still being used to collapse lungs.<sup>57</sup> A decade later, the number of beds had been cut in half and surgeries were rare - except among Indigenous people. From the 1950s, Indigenous people continued to get outdated care. They were increasingly occupying sanatorium beds vacated by non-Indigenous people, even though the 1956 Madras study had shown sanatorium care was barely better than home care;

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<sup>54</sup> Wherrett, *Tuberculosis*, 36.

<sup>55</sup> The other four areas were cancer, mental health, rehabilitation, and child and maternal health.

<sup>56</sup> Pat Sandiford Grygier, *A Long Way from Home: The Tuberculosis Epidemic among the Inuit* (Montreal: McGill-Queen's University Press, 1994), 3.

<sup>57</sup> Brancker et al., "Statistical Chronicle," 109.

their stays in the institutions grew longer; and surgeries on Indigenous people were increasing, and including experimental techniques.<sup>58</sup>

BCG vaccination policy varied across Canada, depending on whether officials were influenced by opinions from the US (against BCG), or Britain or Quebec (both for BCG).<sup>59</sup> While there was global geographic variation in BCG effectiveness, its use in Canada was shown to be effective. Both Quebec and Newfoundland had province-wide vaccination programs. Other provinces used it selectively for high-risk groups, such as medical students, nurses, tuberculosis patient contacts, schoolchildren in high-risk areas, and Indigenous people. By the 1970s BCG use was discontinued in most cases, with sporadic use among Indigenous people in southern Canada, but more common among Inuit.

Meanwhile, case finding, begun in the 1920s, also peaked in the late 1950s to mid-1960s. This was screening with tuberculin and sputum tests, and chest x-rays, the latter used in mass campaigns, often with mobile units. The earliest screenings were of specific groups: schoolchildren, university students, miners, Indigenous people in BC, and nurses. Mass campaigns began in the 1940s, surveying whole communities, immigrants, and in World War II, recruits and discharged soldiers. In the 1950s, chest x-rays became routine in admissions to other institutions. Combining screenings with drug therapy allowed early detection and effective treatment, and by the end of the 1960s, tuberculosis deaths among Canadian-born non-Indigenous people was so low, mass campaigns were no longer useful.<sup>60</sup> The drop in mortality was different from the drop in incidence. Mortality started to decrease from about 1900, albeit very

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<sup>58</sup> Zwick and Pepperell, "Tuberculosis sanatorium," 2.

<sup>59</sup> Wherrett, *Miracle*, 63.

<sup>60</sup> Wherrett, *Miracle*, 35-37.

slowly at first and more rapidly by 1950. Incidence, on the other hand, increased steadily to a peak in the late 1940s, the likely the result of increased case finding.<sup>61</sup>

It is still not entirely clear why tuberculosis incidence and death declined before drug cures became available. There are several suggested theories. One is that the disease changed over time, either *Mtb* infectivity, or human immune response. The McKeown thesis, that improved quality of life reduced mortality, is still advanced, despite being rebutted. Another plausible explanation is that disrupting *Mtb* transmission through isolation, hygiene campaigns, and better building ventilation prevented new infections and shrank the disease reservoir. Supporting this theory is the death rate being reduced by half in the two decades of peak sanatorium use just before antibiotics became available.<sup>62</sup> Screening and earlier treatments also may have contributed to pre-antibiotic declines.

After antibiotics, not only did tuberculosis mortality and incidence drop dramatically, the epidemiology also changed. Instead of being a disease of young people, predominantly women, it became a disease of the old, predominantly men.<sup>63</sup> Societal stratification also became more apparent as disease numbers and rates were tracked separately for Canadian-born non-Indigenous people, foreign-born residents, Indigenous people, and Inuit. Incidence rates between lowest and highest burden groups spanned two orders of magnitude, setting societal and racial inequality in stark relief.

Based on this history, there are grounds to argue that changes in tuberculosis prevalence and incidence in different groups was most closely related to the resources invested in its control for these groups. The example of Saskatchewan suggests a strong correlation between sufficient

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<sup>61</sup>Public Health Agency of Canada. *Tuberculosis in Canada 2012* (Ottawa: Minister of Public Works and Government Services, 2015), 7, <https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/tbpc-latb/pubs/tbcan12/assets/pdf/tbcan12-eng.pdf>.

<sup>62</sup> Brancker et al., "Statistical Chronicle," 111.

<sup>63</sup> Brancker et al., "Statistical Chronicle," 115.

funding for public health measures and reduction of morbidity and mortality. The drop in disease rates introduced the possibility of new goal for tuberculosis public health. The previous goal to control the disease, "reducing it to the point where it would be possible to provide free diagnostic and treatment service for all who require it," now included the possibility of eradication.<sup>64</sup>

Among the groups with continuing high incidence, however, eradication was barely imaginable. In these groups, the problem of tuberculosis was being shaped by new government health policy that left tuberculosis behind. The effectiveness of antibiotics meant infectious disease were no longer a leading cause of death in Canada, and they were not reflected in government priorities.<sup>65</sup> The new policy introduced in the early 1970s in the Lalonde report and called health promotion, was one of the first in the world to be based on the soon to be discredited McKeown thesis. It introduced the idea of an integrated health field that incorporated a full spectrum of health determinants, which it grouped into four categories: human biology, environment, lifestyle, and health care organization. Actions to address the components were health promotion. The Lalonde approach became widely adopted across Canada and the world. When it was adopted in northern Canada, within a newly restructured government health administration, it introduced a new barrier to tuberculosis control for Inuit.

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<sup>64</sup> Wherrett, *Tuberculosis*, 49.

<sup>65</sup> Marc Lalonde, *A New Perspective on the Health of Canadians: A working document* (Ottawa: Minister of Supply and Services Canada, 1981 [1974]), 77, <https://www.phac-aspc.gc.ca/ph-sp/pdf/perspect-eng.pdf>.

## Tuberculosis in Canada's North

Inuit span the North American continent above the tree line. In Canada, they are bordered by Dene people along the Mackenzie River and in the sub-Arctic zones above the Prairies, and by Cree and Innu east of Hudson's Bay.<sup>1</sup> In 1931, the Inuit population was near its low point, at around 6,000 people, spread over half a million square kilometres but concentrated in the eastern Arctic.<sup>2</sup> Inuit were usually considered distinct from other Indigenous people, and legally not even Indians until 1939.<sup>3</sup> Nonetheless Inuit also faced essentializing, racist attitudes. While they were often referred to more positively than other Indigenous people, and were praised for having almost uncanny capacities for survival, they were simultaneously considered child-like and in need of saving. A common view was that they were especially susceptible to tuberculosis, but some medical opinions considered them especially resilient.<sup>4</sup>

The history of tuberculosis in northern Canada differs from that in southern Canada in every way but its most general biological features. Most differences arise from differences in geography and government approach. The geography dictated Inuit

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<sup>1</sup> In the period of early contact, Inuit presence extended southward to the north shore of the St. Lawrence River, and into the high Arctic islands.

<sup>2</sup> Anatole Romaniuc, "Aboriginal Population of Canada: Growth Dynamics under Conditions of Encounter of Civilisations," *Canadian Studies in Population* 30, no. 1 (2003): 115, <https://doi.org/10.25336/P6B605>; G. C. L. Bertram, "The Eskimo Population of the Canadian Eastern Arctic," *Polar Record* 4, no. 30 (July 1945): 282. <https://doi.org/10.1017/S0032247400042108>; This was the first Inuit census. Reports suggest Inuit populations were far higher a century earlier. Currently, about 66,000 Inuit live in Canada.

<sup>3</sup> Richard Diubaldo, *The Government of Canada and the Inuit, 1900-1967* (Ottawa: Indian and Northern Affairs Canada, 1985), 35-36. [https://publications.gc.ca/collections/collection\\_2017/aanc-inac/R5-407-1985-eng.pdf](https://publications.gc.ca/collections/collection_2017/aanc-inac/R5-407-1985-eng.pdf); Supreme Court of Canada, *Dominion Government v. Government of the Province of Quebec: Reference as to whether "Indians" includes in s. 91 (24) of the B.N.A. Act includes Eskimo in habitants of the Province of Quebec*, [1939] S.C.R. 104 (June 17, 1938; April 5, 1939), 105, <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/8531/index.do>; Richard Diubaldo, "The Absurd Little Mouse: When Eskimos Became Indians," *Journal of Canadian Studies/Revue d'Études Canadiennes* 16, no. 2, (Summer 1981): 34, <https://doi.org/10.3138/jcs.16.2.34>.

<sup>4</sup> G. J. Wherrett, "A Study of Tuberculosis in the Eastern Arctic," *Canadian Journal of Public Health* 60, no. 1 (January 1969): 9, <https://www.jstor.org/stable/41984288>; R. Quinn Duffy, *The Road to Nunavut: The Progress of the Eastern Arctic Inuit Since the Second World War* (Kingston and Montreal: McGill-Queen's University Press, 1988), 68.

settlement patterns and the nature of contact with outsiders. These shaped transmission patterns and made the epidemic hit much later in the North than the South.<sup>5</sup> The federal government approach was shaped by Southern ideas of and goals for the North, which produced forms of colonialism that amplified the epidemic. Government approach, settlement patterns, and outsider contact all changed over time, sometimes abruptly. The abrupt changes divide the epidemiology of tuberculosis in the North into four periods.

The first period of tuberculosis in the North, lasting almost 400 years, started with the first outsider arrivals and ended after World War II. It was marked by mostly unchecked escalation of outsider activity and tuberculosis, with essentially no public health response. The period ended with a confrontation among outsiders about Inuit wellbeing. The second period started with the epidemic at, or near, its peak and ended in the late 1960s. This period was marked by mass medical evacuations of tuberculous Inuit to southern hospitals, which eventually reduced tuberculosis deaths, but at an immense social cost, and without substantially reducing disease incidence. The third, relatively brief period followed the evacuations, and ended gradually in the 1980s. It was anomalous in offering local tuberculosis services for Inuit that were more advanced than those for other Canadians. It was an effort to raise Inuit health to the levels of other Canadians, and it did bring a radical decline in incidence, in large part the result of the early 1970s project in Frobisher Bay. The fourth period gradually established itself alongside a change in government health policy, which shifted resources away from tuberculosis, and integrated those that remained into general healthcare. By the 1990s, tuberculosis rates began to climb again, and by 2002, alarms were being raised. By 2009,

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<sup>5</sup> Liza Piper and John Sandlos, "A Broken Frontier: Ecological Imperialism in the Canadian North," *Environmental History* 12, no. 4 Special Issue on Canada (Oct. 2007): 764, <https://www-jstor-org/stable/25473161>.

deaths returned, making the fourth historical period one of resurging tuberculosis.<sup>6</sup> This chapter discusses the first two epidemiological periods as context for the third period and the Frobisher Bay project.

### **First period: to post-World War II**

Environmental historian Alfred Crosby attributes the historic devastation of disease epidemics to first contact between isolated populations and outsiders, but other historians link epidemics to societal disruption, which is not always coincident with outsider contact.<sup>7</sup> In the North, Inuit were exposed to outsiders for about 250 years before their ways of life started to change, and tuberculosis took hold. As in southern Canada, genomic studies suggest that the disruption and disease followed concentration of populations, which in the North was associated with establishment of fur trade posts. These drew Inuit who faced scarcity of game. Studies in the eastern Arctic have found a few bacterial strains that belong to the European L4 lineage, which likely came from a single introduction in the early twentieth century when most trading posts in the area were established.<sup>8</sup> A Nunavik study places the main introduction there around 1919, and a smaller one around 1976.<sup>9</sup> That first date coincides with the arrival of Hudson's Bay Company posts in the region. The second coincides with the negotiation and signing of

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<sup>6</sup> Jim Bell, "Report: Nunavummiut get sick more often, die younger," *Nunatsiaq News*, October 4, 2002, Health section 4-5, [https://nunatsiaq.com/stories/article/report\\_nunavummiut\\_get\\_sick\\_more\\_often\\_die\\_younger](https://nunatsiaq.com/stories/article/report_nunavummiut_get_sick_more_often_die_younger); Annie-Claude Bourgeois, *Report on the epidemiology of tuberculosis in Nunavut, 1999 to 2011* (Iqaluit: Department of Health and Social Services, Government of Nunavut, 2013), 42.

<sup>7</sup> Piper and Sandlos, "Broken Frontier," 764; Nancy Leys Stepan, *Eradication: Ridding the World of Diseases Forever?* (Ithaca, NY: Cornell University Press, 2011), 26.

<sup>8</sup> Robyn S. Lee et al., "Population genomics of *Mycobacterium tuberculosis* in the Inuit," *Proceedings of the National Academy of Sciences USA* 112, no. 44 (3 Nov 2015): 13612; Peter J. Usher, *Fur Trade Posts of the Northwest Territories, 1870-1970* (Ottawa: Northern Science Research Group, Department of Indian Affairs and Northern Development, 1971), 125; The discontinuity from an earlier set of fur trade posts around Fort Chimo (Kuujuuaq) in the 1830s bears investigation. The tuberculosis reported afterward was likely connected to those posts, but the current absence of strains from that time invites speculation.

<sup>9</sup> Lee, "Population Genomics," 13610.

the first Inuit land claim with the federal government, the James Bay and Northern Quebec Agreement in 1975, which involved increased travel and interaction with outsiders.<sup>10</sup> After introduction, transmission was mainly within rather than between the distant villages, indicating their isolation and establishment of a disease reservoir. Earlier contacts between Inuit in the region and outsiders, some of whom almost certainly were diseased appears to have left no *Mtb* infection.<sup>11</sup>

Traditionally, Inuit lived in small, mobile, dispersed groups, which Inuit themselves recognized as limiting their exposure to illness.<sup>12</sup> The only evidence of pre-contact tuberculosis is in bones from Alaska that suggest endemic disease of some unknown lineage.<sup>13</sup> The first reported encounters between Inuit and outsiders were with explorers and fishermen around Labrador and Baffin Island in the mid-sixteenth century. Reports suggested the encounters triggered new diseases, but they did not appear to be tuberculosis.<sup>14</sup> The question is whether the absence reflects small incidence of disease, or simply few outsiders to record it. At least two scenarios are plausible. Either contact was too brief and distant for tuberculosis transmission, or some Inuit did become infected and brought tuberculosis to their group, who all died without leaving evidence, onward transmission, or disease reservoir. The early absence of predisposing conditions -

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<sup>10</sup> "Makivik Corporation," Online Website, 2021, <https://www.makivik.org/corporate/history/makivik-corporation/>. The agreement also included Cree and later Naskapi people.

<sup>11</sup> Lee, "Population Genomics," 13612.

<sup>12</sup> Milton M.R. Freeman, ed., *Report: Inuit Land Use and Occupancy Project, Volume 1 Land Use and Occupancy* (Ottawa: Printing and Publishing Supply and Services Canada, Government of Canada, 1976), 230, <https://publications.gc.ca/collections/collection-2018/aanc-inac/R2-46-1976-1-eng.pdf>.

<sup>13</sup> Robert Fortune, *Must We All Die? Alaska's Enduring Struggle with Tuberculosis* (Fairbanks, AK: University of Alaska Press, 2005), 2-3; James B. Waldram, D. Ann Herring and T. Kue Young, *Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives*, Second edition (Toronto: University of Toronto Press, 2006), 31. Only a few of the rare finds of pre-contact human bones in the Arctic have been studied. Some show lesions and evidence of respiratory infection, but this cannot be attributed to a specific disease.

<sup>14</sup> Stefan Grzybowski, J.D. Galbraith and E. Dorken, "Tuberculosis in Eskimos," *Tubercule* 57, no. 4 supplement (December 1976): S1, [https://doi.org/10.1016/0041-3879\(76\)90059-3](https://doi.org/10.1016/0041-3879(76)90059-3).

prolonged close contact, co-morbidities, malnutrition - suggests that there were sporadic infections among Indigenous people after fur traders arrived, but no major outbreaks let alone epidemics until much later.<sup>15</sup>

In the late eighteenth century, outsiders moved onto the land: Moravian missionaries in northern Labrador; and fur traders northwestward from Hudson's Bay. Through the nineteenth century, whalers and fur traders established a patchwork of areas of prolonged contact with Inuit.<sup>16</sup> At first, they reported Inuit in excellent health, only noting some gastrointestinal, lung and eye trouble.<sup>17</sup> Then imported diseases took hold, but with patchwork incidence. Inuit remained healthy in many places, but where traditional ways of life were being modified, deadly diseases tore through populations.<sup>18</sup> The Moravians in Labrador regularly recorded tuberculosis incidence, but not epidemics, except when other diseases erupted.<sup>19</sup> Elsewhere, the first record of an Inuk suffering what may have been tuberculosis was in 1823.<sup>20</sup> Through the rest of the century, local outbreaks of tuberculosis developed where regular outsider contact had depleted game and changed living conditions.<sup>21</sup> By the 1860s, tuberculosis was the leading cause of death around the whaling areas of Hudson's Bay and southern Baffin.<sup>22</sup> By the late 1880s, a report from Ungava said half of all Inuit were dying of pulmonary troubles, which

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<sup>15</sup> Caitlin S. Pepperell, et al., "Dispersal of *Mycobacterium tuberculosis* via the Canadian fur trade." *Proceedings of the National Academy of Sciences USA* 108 (April 4, 2011): 6526–6531. <https://doi.org/10.1073/pnas.1016708108>.

<sup>16</sup> Grzybowski, "Tuberculosis in Eskimos," S1; Renée Fossett, *In Order to Live Untroubled: Inuit of the Central Arctic, 1550-1940* (Winnipeg: University of Manitoba Press, 2001), 134; Anne Keenleyside, "Euro-American Whaling in the Canadian Arctic: Its Effects on Eskimo Health," *Arctic Anthropology* 27, no. 1 (1990): 2-3, <http://www.jstor.org/stable/40316193>.

<sup>17</sup> Grzybowski, "Tuberculosis in Eskimos," S1; Waldram, *Aboriginal Health in Canada*, 39-41. This view is challenged on the grounds that outsiders would not have encountered those suffering serious diseases.

<sup>18</sup> Piper and Sandlos, "Broken Frontier," 765.

<sup>19</sup> Pat Sandiford Grygier, *A Long Way from Home: The Tuberculosis Epidemic among the Inuit* (Montreal: McGill-Queen's University Press, 1994), 159.

<sup>20</sup> Grzybowski, "Tuberculosis in Eskimos," S1. It is not clear where this happened.

<sup>21</sup> Fossett, *In Order to Live Untroubled*, 171.

<sup>22</sup> Piper and Sandlos, "Broken Frontiers," 767.

raised concerns about extinction of Inuit in the area."<sup>23</sup> In the western Arctic, tuberculosis, infrequently reported at mid-century, became catastrophic by the end of it. Tuberculosis and other diseases may have caused complete population collapse in the Mackenzie delta, which was later repopulated by Inuit from Alaska.<sup>24</sup>

Disruption and disease intensified after 1870 and 1880, when Canada gained jurisdiction of the mainland North and the Arctic archipelago respectively. Nothing much happened at first. Canada let the Hudson's Bay Company (HBC) deliver nominal governance, justifying its neglect on the North's small, scattered population. The North became essentialized in southern myths that ranged from beckoning to forbidding, but all assuming a *terra nullius* in which northern people were part of the landscape along with wildlife.<sup>25</sup> By the twentieth century, Canada's sovereignty claim was threatened by increasing incursions by foreigners, mainly American, and the Alaska boundary dispute, which Canada lost in 1903. Canada began to express ambitions for the North: to solidify sovereignty and increase resource extraction, but at minimal cost. This reflected southern priorities and awareness rather than consideration of Inuit or other northern people.

Yet, Inuit did have value to the state. Sovereignty claims could be strengthened only by establishing Canada's 'effective occupation' of lands with no previous connection to the state. Inuit, as northern residents and putative Canadians, were central to Canada's claim. This was supplemented by trivial state actions, for example, overseas advertising asserting sovereignty, declarations at whaling stations, cairns of possession, and scientific and ethnographic expeditions. More substantive was the introduction of southern law

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<sup>23</sup> Walter J. Vanast, "Hastening the day of extinction: Canada, Québec, and medical care of Ungava's Inuit, 1867-1967," *Études/Inuit/Studies* 15, no. 2 (1991): 64 <http://www.jstor.org/stable/42871953>.

<sup>24</sup> Shelagh D. Grant, *Sovereignty or Security? Government Policy in the Canadian North, 1936-1950* (Vancouver: University of British Columbia Press, 1988), 32. Piper and Sandlos, "Broken Frontier," 765. Piper and Sandlos suggest it is difficult to estimate the degree of population loss in the north.

<sup>25</sup> Duffy, *Road to Nunavut*, 74.

enforcement. In contrast to Denmark, which first sent teachers and medical staff to Greenland, Canada sent police to the North. Northwest Mounted Police (NWMP) arrived in the Arctic in 1903, setting up three posts where whaling activity was most intense.<sup>26</sup>

Anthropologist Diamond Jenness called the police posts the first sign that Canada was accepting the responsibilities of sovereignty, "but what plans had she entertained, if any, for the welfare of its Eskimos, she wrapped in silence. Presumably she had no plans, since otherwise she would have devised some more constructive method ... than the setting up of police posts, after the manner of a military occupation."<sup>27</sup> There was in fact a plan for Inuit welfare, expressed by O.S. Finnie, who was considered the most enlightened of the early northern officials:

the Canadian government subsidizes the Territories, not altogether in a spirit of philanthropy, but as an investment from which it will draw ample dividends. The value of the natural resources of the country is undoubted. To develop them to the best advantage, the coöperation of the native population is most essential, and the expense incurred in their care and improvement will be amply repaid.<sup>28</sup>

Notwithstanding the language of "care and improvement," and in contrast to the Canadian policy of Indigenous assimilation in the South, the federal aim in the North was to 'keep the native, native.' Inuit were encouraged to maintain their traditional lifestyles as much as possible, which had the benefit of costing the government almost nothing.<sup>29</sup> Inuit were not even Indians subject to the fiduciary care of the *Indian Act* until 1939. Up to that point they were technically full citizens of Canada, although receiving almost none

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<sup>26</sup> These were the first posts in the Northwest Territories and the first in the Arctic. The NWMP had been established in the Yukon Klondike since 1895.

<sup>27</sup> Diamond Jenness, *Eskimo Administration: II. Canada. Technical Paper No. 14* (Montreal: Arctic Institute of North America, 1964), 20.

<sup>28</sup> O.S. Finnie, "Canada's Land of the Midnight Sun," *Natural History* 28 (1928): 366, <http://www.archive.org/details/naturalhistory2816newy>.

<sup>29</sup> Diubaldo, *Government of Canada*, 71, 79, 86, 93.

of the benefits. Investments in Inuit were aligned with northern priorities, that is, support for resource extraction, game conservation, sovereignty and related public relations.<sup>30</sup>

This approach was fraught with inconsistencies: the government repeatedly refused to fund hospitals, but did pay churches to care for the elderly and disabled so hunters could remain free to hunt fur; the government was concerned about Inuit starvation, yet relocated some Inuit groups away from caribou to conserve the herds; other Inuit were relocated to new areas to streamline oversight or enhance the perception of effective occupancy, yet the government wanted Inuit to continue their traditional lives without interference.<sup>31</sup> Whatever was spent on Inuit was widely recognized as inadequate to need. Services were rudimentary and available only haphazardly. These included piecemeal schooling, first aid, and emergency food rations, delivered by missions or the HBC in exchange for small fees, or by police when they had time.

The first small change in this approach was the hiring of a physician who visited HBC settlements on the annual sailing of the Eastern Arctic Patrol, itself a sovereignty exercise. Even the hiring, however, showed a low standard for Inuit services. The doctor, Leslie Livingstone, was not a fully qualified physician, and only received an honorary medical degree years later based on his experience in the North.<sup>32</sup> In 1928, another four doctors were hired to serve the entire Arctic after an influenza epidemic had threatened Inuit capacity to hunt. The improvement was short lived. In 1931, the Depression led to service cuts, tensions over fees, and elimination of the entire territorial administration

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<sup>30</sup> Finnie, "Canada's Land," 206-207; Diubaldo, *Government of Canada*, 15, 32. Public relations and sovereignty overlapped in government sponsorships of northern expeditions and travel for prominent southerners who would communicate their experiences.

<sup>31</sup> Grant, *Sovereignty or Security*, 88; Diubaldo, *Government of Canada*, 40, 72; John Kurt Sandlos, "Northern Wildlife, Northern People: Native Hunters and Wildlife Conservation in the Northwest Territories, 1894-1970," PhD thesis, York University, 2004, 28.

<sup>32</sup> Dudley Copland, *Livingstone of the Arctic* (Lancaster, ON: Canadian Century Publishers, 1967), 8, 98.

office, including Finnie's job. Southern interest in the North waned, with the exception of resource exploration. By the start of World War II, the North had two hospitals run by mining companies alongside nine run by missions, two mission-run care homes, and eight doctors.<sup>33</sup> As in southern Canada, fees to missions were low and the hospitals primitive. Calls for change were ignored. The war, however, changed everything.

In the fall of 1938 a federal publication told Canadians that Inuit were in good health. This did not reflect field observations, which came to light during the war.<sup>34</sup> The wartime observers were part of the American army, which arrived in northern Canada after 1942 in such massive numbers it called itself the 'Army of Occupation.'<sup>35</sup> The Americans engaged with Indigenous people, hired them, tolerated their foraging in military dumps, and treated them medically. US medical staff sent out reports of their "shock and outrage" at the state of Indigenous health and the care provided by the Canadian government.<sup>36</sup> The immediate Canadian response was defensive. The eastern Arctic official called the Americans "itinerant, inexperienced doctors" with no knowledge of Inuit nor of the government's financial limits, which had produced these types of rules:

Incurable tubercular Eskimo patients have never been admitted [to hospitals] except under exceptional circumstances. Moreover, when death was imminent from any cause, patients were removed from the hospital to die in tents or snow houses. I doubt if ... the U.S. army doctors temporarily stationed in the Arctic are familiar with these well-known departmental regulations and practices.<sup>37</sup>

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<sup>33</sup> Diubaldo, *Government of Canada*, 102.

<sup>34</sup> Diubaldo, *Government of Canada*, 98.

<sup>35</sup> Grant, *Sovereignty or Security*, 112. By 1943, there were about 43,000 Americans in the North, a region whose regular population ranged between 11,000 and 17,000, Grant, *Sovereignty or Security*, 111; Statistics Canada, "Population of Canada, by Province, Census Dates, 1851-1976" (Ottawa: Statistics Canada, 1983), <https://www150.statcan.gc.ca/n1/pub/11-516-x/sectiona/4147436-eng.htm#1>.

<sup>36</sup> Diubaldo, *Government of Canada*, 100.

<sup>37</sup> Diubaldo, *Government of Canada*, 101.

Inuit engagement with Americans had mixed effects. Along with the benefits, Inuit were exposed to more disease. It amplified the tuberculosis epidemic that was being fueled by hunger and poor housing. Hunger made Inuit more susceptible to disease. Game fluctuations and Inuit starvation had almost certainly always existed, but by the twentieth century, Inuit hunger had become common. The reasons likely include game laws, introduction of fur hunting, and increased hunting overall by both outsiders and Inuit.<sup>38</sup> Tuberculosis was found to be more prevalent among Inuit dependent on caribou than among those dependent on seal, which was a more stable food source.<sup>39</sup> Meanwhile, changes in Inuit housing increased tuberculosis transmission. In areas of intense outsider activity Inuit began to gather for longer periods around outsiders' posts, living in densities they had never experienced before, in collections of tents and scrap-built structures that were colder and more damp than their traditional homes. Inuit appeared aware of the trade-offs in their choices. This is seen in their use of terms like 'boat colds', or 'boat sickness' for the phenomena that followed visits of outsiders' supply ships, and in the debates recorded between groups who stayed close to posts and those who avoided them.<sup>40</sup> The debates suggest that Inuit who chose to gather around posts did so because outsiders' presence decreased traditional food supplies and the benefits of access to food and supplies outweighed the dangers of sickness.

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<sup>38</sup> Liza Piper, "From Subsistence to Nutrition: The Canadian State's Involvement in Food and Diet in the North, 1900-1970." In *Ice Blink: Navigating Northern Environmental History*, eds. S. Bocking and B. Martin (Calgary: University of Calgary Press, 2017), 186-186, 188, [https://prism.ucalgary.ca/bitstream/handle/1880/51791/9781552388556\\_chapter6.pdf](https://prism.ucalgary.ca/bitstream/handle/1880/51791/9781552388556_chapter6.pdf); Diubaldo, *Government of Canada*, 130.

<sup>39</sup> Sandlos, "Northern Wildlife," 25-27; Vanast, "Hastening the day," 57; Stefan Grzybowski and E. Dorken, "Tuberculosis in Inuit," *Ecology of Disease* 2, no.2 (1983): 147, <https://www.ncbi.nlm.nih.gov/pubmed/6332010>.

<sup>40</sup> *Coppermine*. Film. Directed by Ray Harper. Edmonton: National Film Board of Canada, 1992. 00:09:18, <https://www.nfb.ca/film/coppermine/>

The most obvious factor that amplified the epidemic was the application of southern law, as demonstrated by two outbreaks in the 1920s. The first was in the eastern Arctic, in Pond Inlet (Mittimatalik) on northern Baffin Island. Its roots were in the 1920 imprisonment of Nuqallaq, in a penitentiary known for its high incidence of tuberculosis.<sup>41</sup> Less than two years into a ten-year sentence Nuqallaq was sent home with tuberculosis and died. Months later, tuberculosis had spread throughout northern Baffin Island, where it had not been recorded before.<sup>42</sup> The evidence for Nuqallaq as the trigger is circumstantial but strong, supported by the predisposing factors of disruption and starvation. The second example was in the western Arctic in Coppermine (Kugluktuk). It came with the return of Uloqsaq, who, after serving sentences in Calgary and elsewhere, was diagnosed with galloping consumption. He was sent home to die in 1929. On his return he lived in a crowded tent for a month, infecting all those who lived with him before he died.<sup>43</sup> Uloqsaq had returned on a ship carrying a doctor, who recorded and filmed the subsequent path of the disease.<sup>44</sup> The doctor had found no tuberculosis on his arrival, but in just over a year, it had killed one quarter of all Inuit in the area, and more deaths were expected in coming years.<sup>45</sup> The ship carrying Uloqsaq and the doctor brought other outsiders who drastically transformed life in the region, perhaps

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<sup>41</sup> Shelagh D. Grant, *Arctic Justice: On Trial for Murder, Pond Inlet, 1923* (Montreal & Kingston: McGill-Queen's University Press, 2002), 191, <https://ebookcentral-proquest-com.ezproxy.library.uvic.ca/lib/uvic/detail.action?docID=3330504>.

<sup>42</sup> Grant, *Arctic Justice*, 210, 244.

<sup>43</sup> Walter J. Vanast, "The death of Jennie Kanajuq: Tuberculosis, religious competition and cultural conflict in Coppermine, 1929-31," *Études/Inuit/Studies* 15, no.1 (1991): 90, <http://www.jstor.org/stable/42869712>.

<sup>44</sup> In a remarkable coincidence, the doctor's footage was one of three collections shot in the region within a decade, all of which are used in a historic documentary of the Arctic with multi-media primary sources, the film cited above, *Coppermine*.

<sup>45</sup> *Coppermine* 8:46, 22:27; *Coppermine* 49:16. Federal parsimony also made the doctor a coroner, commissioner of oaths and distributor of relief rations for Inuit in extreme need.

introducing other sources of tuberculosis besides Uloqsaq, and certainly introducing factors that amplified the effects of Uloqsaq's disease.<sup>46</sup>

Federal officials were told of these outbreaks and of the growing epidemic, but refused to offer aid or spend money. At the same time, they spent \$25,000 on Uloqsaq's prosecution in 1917 in the midst of a war, and a million dollars to recreate the Nuqallaq case "to show Denmark that Canada was actively administering the Arctic Islands."<sup>47</sup> It was just one more example of government inconsistency. Another was government policy on Inuit employment. The government vocally supported Inuit earning a wage, but worried about creating dependence on jobs. First the government warned US wartime employers against hiring Inuit, which the Americans resisted, and then it limited the amount of time each Inuk could spend on a job.

The incoherence and callousness of Canada's policy toward Inuit had many roots, but it was shaped by a few underqualified men facing almost no accountability.<sup>48</sup> The bubble was made possible by political leaders whose attitude to the North was later described by Prime Minister Louis St. Laurent as "an almost continuing state of absence of mind."<sup>49</sup> The top northern bureaucrat, Roy Gibson, was assistant deputy minister who had charge of the territories for 29 years without sign of ever having visited them. He was described as hardworking but "a dictator and an autocrat, the North was his kingdom and he ruled it."<sup>50</sup> Of his two assistants, the western Arctic superintendent was described as "an older man ... who didn't seem to know what was going on," and the eastern Arctic

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<sup>46</sup> Ten of the first sixteen deaths that winter were among three families, one of may have been Uloqsaq's, as it was the first infected.

<sup>47</sup> Grant, *Arctic Justice*, 209-210.

<sup>48</sup> Administrative units for the North and for Inuit shifted from the Department of Interior in 1936 to Mines and Resources. Northern personnel were shifted also and retained their roles.

<sup>49</sup> Diubaldo, *Government of Canada*, 113.

<sup>50</sup> Grant, *Sovereignty or Security*, 27.

superintendent was variously called "bombastic," a "talkative bully who was not very bright," "a very stupid man," "the fatuous major" and someone who was laughed at by "everyone in the Eastern Arctic."<sup>51</sup> These men not only controlled the North, they controlled what outsiders knew about it, refusing access to information, or censoring others' materials.<sup>52</sup> For example, in 1931 they insisted on reviewing a draft of a Maclean's magazine article on a tuberculosis fact-finding trip. By "invoking censorship rules instituted in 1922," they removed all references to tuberculosis.<sup>53</sup>

Eventually, critics penetrated the censorship and control. Americans' concerns were made public and added force to those of others familiar with the North. Jenness later wrote on how the revelations "convulsed" the North: "It bared to the world the ineptitude of [Canada's] administration and the degradation of her Eskimos, many of whom it dragged out of their isolation and caught up in its turmoil."<sup>54</sup> A multi-part study was commissioned to investigate conditions in the western Arctic. It was led by Harold Innis, overseen by the Canadian Social Sciences Research Council, and funded by the Rockefeller Foundation, with the health component conducted by George Wherrett, the head of the Canadian Tuberculosis Association. Wherrett's report, released in 1945, was one of the factors that ended the period of neglect of Inuit tuberculosis care. He had delivered an indictment of northern healthcare services that required a response.

The Indian problem is on the conscience of the Canadian people until more action is taken. It is high time that the Department formulated a health policy founded on

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<sup>51</sup> Grant, *Sovereignty or Security*, 27; Vanast, "Hastening the day," 64n16.

<sup>52</sup> Grant, *Sovereignty or Security*, 143.

<sup>53</sup> Grant, *Arctic Justice*, 212-213.

<sup>54</sup> Diamond Jenness, *Eskimo Administration: V. Analysis and Reflections. Technical Paper No. 21* (Montreal: Arctic Institute of North America, 1968), 25.

the needs of the people, rather than the meagre sum that "Treasury Board" will allow it to put in the estimates.<sup>55</sup>

### **Second period: post-WWII to the late 1960s**

Postwar 'convulsions' extended beyond the North and transformed parts of the federal government. Changes related to defence, northern development, Indian affairs and health all enabled a new approach to Inuit health care. The new tuberculosis policy was a complete reversal of the old, a swing from extreme neglect to extreme intervention. It centred on a program of mass medical evacuations of Inuit to southern hospitals, on the assumption that hospital treatment for all who needed it would end the epidemic. While it was radically different from neglect, it shared with the old policy a lack of understanding of what would work best under the actual circumstances. The new program did succeed in ending tuberculosis deaths, but the achievement came with great psychological and social costs that are still felt half a century later. Despite the high costs, incidence remained high, which sustained a disease reservoir that could trigger future outbreaks.

The postwar environment gave new prominence to the world's circumpolar regions, including Canada's North. Canada responded with new goals and administration to show it was in charge. The main goal was to remove the American presence, and take a larger role in defence.<sup>56</sup> A lesser goal, but useful for public sentiment, was to give northern people what amounted to "pale versions of southern institutions" and an economy to sustain them.<sup>57</sup> The work required to do all this kept the government heavily

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<sup>55</sup> G.J. Wherrett, "Survey of health conditions and medical and hospital services in the Northwest Territories," in Innis, H.A., G.J. Wherrett and Andrew Moore, "Arctic Survey," *Canadian Journal of Economics and Political Science* 11, no. 1 (February 1945): 59.

<sup>56</sup> Diubaldo, *Government of Canada*, 108.

<sup>57</sup> Toby Morantz, *The White Man's Gonna Getcha: The Colonial Challenge to the Crees in Quebec* (Montreal & Kingston: McGill-Queen's University Press, 2002), 176; Jean Lesage, "Enter the European,"

engaged in the North. To manage the main goal of external relations, Ottawa put veteran diplomat Hugh Keenleyside in charge of territorial administration. Keenleyside brought with him an additional agenda, to improve the lives of northern people.<sup>58</sup> In his three years as territorial administrator, Keenleyside dispelled secrecy and established a more activist policy. The resulting changes were complex, and took the better part of two decades to reach a workable state. The process was marked by frequent jurisdictional shifts, and a change of the guard among senior officials. It brought new bureaucratic cultures into Inuit affairs and health care, diminishing racist, colonial attitudes, and replacing them with a belief in technocracy to spread the benefits of post-war advances.

The 1939 legal decision that had turned Eskimos into Indians began to be implemented after the war, just as Inuit living circumstances were at their most bleak.<sup>59</sup> The 'Eskimo problem' entered the government lexicon alongside the 'Indian problem' - issues for governments to decide about Indigenous futures.<sup>60</sup> Despite some overlap between Inuit and other Indigenous matters, northern officials did not want Inuit to fall under the jurisdiction of the Indian Affairs Branch, whose inadequacy was being highlighted in postwar Indigenous activism and parliamentary attention.<sup>61</sup> Senior officials' desire to keep Indian Affairs out of the North was a factor in moving responsibility for Indigenous health care to the new Department of National Health and

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*The Beaver* (Spring 1955), 4, <https://canadashistory.partica.online/canadas-history/the-beaver-spring-1955/flipbook/2>.

<sup>58</sup> Grant, *Sovereignty or Security*, 189, 191, 198.

<sup>59</sup> Diubaldo, "Absurd Little Mouse," 108.

<sup>60</sup> Diubaldo, *Government of Canada*, 109; Peter Clancy and P. Whitney Lackenbauer, eds., *Shaping Inuit Policy: The Minute of the Eskimo Affairs Committee, 1952-62* (Calgary and Waterloo, ON: Centre for Military, Security and Strategic Studies; Arctic Institute of North America; Centre on Foreign Policy & Federalism, 2019), i.

<sup>61</sup> Clancy and Lackenbauer, *Eskimo Advisory Committee*, xi; John F. Leslie, "Assimilation, Integration or Termination? The Development of Canadian Indian Policy, 1943-1963." (PhD Thesis, Carleton University, 1999), 13. [https://www.collectionscanada.gc.ca/obj/s4/f2/dsk1/tape9/PQDD\\_0013/NQ42797.pdf](https://www.collectionscanada.gc.ca/obj/s4/f2/dsk1/tape9/PQDD_0013/NQ42797.pdf). The 1946 Special Joint Committee on the Indian Act was the first national examination of Indigenous experiences.

Welfare in 1945.<sup>62</sup> Some staff moved with the office, notably Percy Moore, who became director of Indian Health Services within the health department.<sup>63</sup> Moore was the main architect of the mass medical evacuation program, and a controversial and transitional figure in the culture shift within federal Indigenous health administration.

Moore was a public health physician who had joined Indian Affairs just before the war. He appeared to share with his Indian Affairs colleagues an apparent willingness to subjugate Indigenous interests to the service of departmental goals and his own racial biases. One example was his leadership of what are now recognized as highly unethical and damaging nutrition experiments on Indigenous children in residential schools.<sup>64</sup> He considered hygiene more important than nutrition in the spread of disease.<sup>65</sup> He also generated controversy by advocating Indigenous assimilation.<sup>66</sup> In the new federal health department, he was named director of Indian Health Services (IHS) and given responsibility for addressing Wherrett's damning report.<sup>67</sup> Moore was described as "outgoing and aggressive and well able to make his demands known to his minister and in turn to officials of the Treasury Board for increased funds required," although the same aggression and strong views made him criticized.<sup>68</sup> The Indian Health Services budget,

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<sup>62</sup> Grant, *Sovereignty or Security*, 162.

<sup>63</sup> In 1955 this office became Indian and Northern Health Services, and oversaw health of all Indigenous, Inuit and Métis people in Canada, and all residents of the territories.

<sup>64</sup> Ian Mosby, "Administering Colonial Science: Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools, 1942–1952," *Histoire Sociale / Social History* 46, no. 1 (May 2013): 146, <https://doi.org/10.1353/his.2013.0015>.

<sup>65</sup> Clancy and Lackenbauer, *Eskimo Advisory Committee*, 44.

<sup>66</sup> News clippings, Calgary Herald, Montreal Star, Montreal Gazette, Canadian Press, 1953, George Jasper Wherrett fonds, LAC, MG30-B138 vol 5 section 7, series: Correspondence, Research Data, Printed material, 1968-1970.

<sup>67</sup> The branch name was changed to Indian and Northern Health Services in 1956.

<sup>68</sup> P.G. Nixon, "Percy Elmer Moore (1899-1987)," *Arctic* 42, no. 2 (June 1989): 167, <http://www.jstor.org/stable/40510800>; George Jasper Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto: University of Toronto Press, 1977), 114.

which was \$1.3 million in 1943, increased to \$11 million in 1949.<sup>69</sup> A great deal of money was needed to pay for Moore's agenda.

The centrepiece of the new Inuit tuberculosis policy was a program of mass screening, transportation and hospitalization, supplemented by universal BCG vaccination. An effort was made to assess all Inuit, which was done mainly with a shipboard x-ray program in the area covered by the Eastern Arctic Patrol, and by air elsewhere. All Inuit with active tuberculosis were taken to southern hospitals, where they stayed on average more than two years.<sup>70</sup> Of the 1500 Inuit screened during the first medical patrol in 1947, one observer found that almost six percent had active tuberculosis and another five percent had what was considered latent infection; another noted elsewhere that almost every person tested was infected.<sup>71</sup> This suggests a barely imaginable rate of disease in the eastern Arctic, and statistics that varied among sources. Incidence also varied among communities. Those that were extensively screened had higher rates. For example, in Clyde River (Kanggiqtugaapik), about 70 percent of all adults over the age of 25 were hospitalized with active disease, and only two males had never been hospitalized.<sup>72</sup> From 1953 to the early 1960s, between 4,800 and 5,200 Inuit had been sent south, which was about half of the Inuit population of the North at that time.<sup>73</sup> Death rates were better documented, but no more accurate. In 1950, Statistics Canada reported a rate of 411 deaths per 100,000, while the health department reported 718 deaths per 100,000, either figure being among the highest recorded in the world at

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<sup>69</sup> Nixon, "Moore," 167.

<sup>70</sup> P.G. Nixon, "Early Administrative Developments in Fighting Tuberculosis among Canadian Inuit," *Northern Review* 2 (1988): 67.

<sup>71</sup> Wherrett, *Miracle*, 118; Wherrett, "Eastern Arctic," 9.

<sup>72</sup> Nixon, "Early Administration," 67.

<sup>73</sup> Bob Weber, "Where is she buried?" Database on Inuit tuberculosis graves offers some answers, but is 'imperfect'," *National Post* (September 24, 2017), <https://nationalpost.com/news/canada/where-is-she-buried-government-prepares-database-on-inuit-tuberculosis-graves>.

the time.<sup>74</sup> By 1969, no deaths were reported, but the infection rate in the eastern Arctic was still a world-leading 1,300 per 100,000.<sup>75</sup> The prevalence of latent infection was unclear.

The intensive treatment and declining death rate were often taken as evidence that the evacuation program was a success.<sup>76</sup> Criticisms of the program suggested otherwise. When evacuations started, neither Inuit nor hospitals in the South were prepared for it. Inuit were sent on their journeys straight from the screening without being allowed to return home to make arrangements; mothers and children were often separated with no notice, even those who were nursing.<sup>77</sup> At the hospitals they faced racism and a language barrier with no support.<sup>78</sup> Families received no news of patients, nor notice if they died. Inuit were identified only by a government-issued pulp identification disk, usually worn on a string. If the disk were lost, there might be no way to identify the person.<sup>79</sup> Many people, especially children, were simply lost, fates unknown.<sup>80</sup> Those who recovered and went home also faced a lack of preparation. Children were deposited in Iqaluit or remote areas with no one being notified.<sup>81</sup> The widespread concerns did lead to some changes over time, notably the hiring of interpreters and support workers, and the creation of Inuit

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<sup>74</sup> Grygier, *Long Way from Home*, 84.

<sup>75</sup> Wherrett, "Eastern Arctic," 8.

<sup>76</sup> Bill Cockman, "Inuit patients go south for tuberculosis treatment." *CBC Digital Archives: Assignment*, (May 15, 1959). <http://www.cbc.ca/archives/entry/inuit-go-south-for-tuberculosis-treatment>.

<sup>77</sup> Grygier, *Long Way from Home*, 118, 120, 123.

<sup>78</sup> Grygier, *Long Way from Home*, 76.

<sup>79</sup> Grygier, *Long Way from Home*, 75-76.

<sup>80</sup> Raj Ahluwalia, "Tuberculosis treatment in south takes Inuit from families." *CBC Digital Archives: Midday* [television program], (January 30, 1989) <http://www.cbc.ca/archives/entry/tuberculosis-tb-treatment-in-south-takes-inuit-from-their-families>: Weber, "Where is she buried?" In September 2017, the federal government announced a program called Nanilavut to find Inuit who had disappeared. In March 2019, Prime Minister Justin Trudeau apologized to Inuit for the evacuation program.

<sup>81</sup> Grygier, *Long Way from Home*, 124.

hospital wards rather than dispersing Inuit among English-speakers or other Indigenous people.<sup>82</sup> Even so, Inuit were angry at the brutality of the program, and resisted.<sup>83</sup>

The overriding criticism during the whole span of the program was that it was based on evacuations at all. From the start, most federal officials and most outsiders familiar with the North called for more northern hospitals, and to have them run by the state instead of churches. Moore strongly resisted northern hospitalization, but strongly pushed for the end of church-run northern health care. He won both points in the face of stiff resistance, but his motivations are unclear. It may have been cost. Moore noted that the northern hospitals received much higher patient subsidies than southern hospitals, with extra payments toward nursing and other costs. Yet it was not enough to cover proper operations. Moore argued that the high hospital costs more than offset the high cost of evacuations.<sup>84</sup> He avoided construction costs by negotiating to have redundant military hospitals handed over to the department, and to use the beds in southern sanatoria that were no longer needed by white southerners. Alternatively, Moore may have been motivated by a campaign against the churches. He argued that patients had to go South because they needed the care of specialists, and that the mission-run hospitals were very poor. Many observers noted problems with these hospitals, but Moore made his case with skewed evidence; more tuberculosis patients died in the North because those most likely to die were kept in the North.<sup>85</sup> Moore got the changes he wanted, but he was not able to silence the critics. Along with his arguments about costs and specialists, he was made to repeat through the 1950s that disease rates had peaked and were about to

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<sup>82</sup> Grygier, *Long Way from Home*, 94-95.

<sup>83</sup> Grygier, *Long Way from Home*, 78, 98;

<sup>84</sup> Grygier, *Long Way from Home*, 74.

<sup>85</sup> Grygier, *Long Way from Home*, 73.

fall.<sup>86</sup> As the toll of the evacuation program became more well known, the pressure to change intensified. Concerns were raised in meetings, in media, and in direct approaches to federal politicians.<sup>87</sup> Aside from social concerns, the biomedical recovery itself was fragile. A tuberculosis outbreak in Eskimo Point (Arviat) in 1963 sent 91 people to hospital, 45 of them children.<sup>88</sup> There had been outbreaks of measles and other viral infections just before the tuberculosis outbreak, lowering resistance and illustrating how opportunistic tuberculosis was, and how easily it still could grow out of control.

Mass evacuations ended in 1969 with the last maritime patrol. Seriously ill Inuit were still sent south for treatment, but by aircraft in small numbers. Beside responding to continuing criticisms, the end of evacuations reflected federal budget cuts and the end of tuberculosis as a government priority. While officials had previously resisted investing in northern health services, they found southern-based treatment wasn't cheap either. In one ten-year span of the evacuation program, the government had spent \$12.5 million on hospital care, with another half million dollars for the Eskimo Point outbreak.<sup>89</sup> These figures were on top of medical salaries, and administration and travel costs. The end of Inuit tuberculosis deaths justified a shift to a new and cheaper direction.

Although deaths had ended, a disease-amplifying environment ensured that active and latent disease remained high. Along with co-infections, Inuit still faced hunger and

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<sup>86</sup> Clancy and Lackenbauer, *Eskimo Advisory Committee*, 61, 193.

<sup>87</sup> Clancy and Lackenbauer, *Eskimo Advisory Committee*, 211; Stanley Westall, "Eskimo's Smile Often Conceals Resentment Over Health Measures," *Globe and Mail* (May 18, 1956), 10. <http://search.proquest.com.ezproxy.library.uvic.ca/historical-newspapers/eskimos-smile-often-conceals-resentment-over/docview/1291289396/se-2>; G.J. Wherrett to Director General, Medical Services, May 7, 1968 re psychiatrist report on harms of southern hospitalization, LAC, MG30-B138 vol 5, Section 7 Correspondence 1965-1968; Grygier, *Long Way from Home*, 77-78.

<sup>88</sup> P.E. Moore, "Puvalluttuq: An Epidemic of Tuberculosis at Eskimo Point, Northwest Territories," *Canadian Medical Association Journal* 90, no. 21, (May 23, 1964): 1193, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1927161/>.

<sup>89</sup> Moore, *Puvalluttuq*, 1193.

starvation through the 1950s and poor nutrition after that, the result of poor alternative food sources. Federal officials tried to fix housing through the 1960s, but the new homes were expensive and poorly designed for northern conditions.<sup>90</sup> Healthcare staffing was also a problem. Even relatively high salaries did not tempt many outsiders, and programs to train Inuit health workers were not considered until well into the 1960s.<sup>91</sup> The presence of such amplifying factors meant tuberculosis continued to be a serious problem for Inuit, and set the stage for a new approach to northern tuberculosis control

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<sup>90</sup> A.B. Yates, "Housing Programmes for Eskimos in Northern Canada," *Polar Record* 15, no. 94 (1970): 45, <https://doi.org/10.1017/S0032247400060381>.

<sup>91</sup> Ethel G. Martens, "Culture and Communications - Training Indians and Eskimos as Community Health Workers," *Canadian Journal of Public Health* 57, no. 11 (Nov. 1966): 495, <http://www.jstor.org/stable/41984757>.

## **The Frobisher Bay Project**

The third period in the history of tuberculosis among Inuit lasted roughly a decade, from the end of the mass evacuations in 1969 to a slackening of tuberculosis measures at the end of the 1970s. It was a rare time in Canadian medical history when services offered to Indigenous people were more advanced than those offered Canadians generally. This was mainly because Inuit and other Indigenous people were in greater need. Nonetheless, it was better than the past imposition of outdated services, and it aimed to close the gap between Indigenous and non-Indigenous health.

The core initiative of this period was a plan to use an innovative combination of techniques to treat people who had latent infections (LTBI), to reduce their risk of developing active disease. The assumption was that an intensive, systematic, mass prevention program would reduce the reservoir of infection in the region, and disrupt its transmission and activation. This would eventually reduce disease incidence to rates as low as in the rest of Canada. Implementation in Frobisher Bay was to be the start. If the program worked as expected, it was to be extended across the North. The first stage did work, beyond expectations, but the political climate had already changed. Plans for future work were cancelled, and a compromise approach implemented. Even this, however, was eased through the 1970s and '80s, and health care moved away from targeted tuberculosis treatment.

### **Context**

The 1960s was a time of adjustment to new medical and political realities around tuberculosis. With the success of antibiotics in radically decreasing disease rates, especially among white southerners, administrators debated what to do with unnecessary treatment capacity. Hospitals were closed or converted, and new mandates were adopted by the tuberculosis organizations and

programs that had been a feature of Canadian life since the turn of the century. Few new physicians were specializing in tuberculosis, or other infectious diseases, and medical research in this field was decreasing. What was left focused on the remaining problem groups: Indigenous people, immigrants, and "the lower socio-economic orders." Approaches to these remaining problems had international roots, and varying reception in Canada.<sup>1</sup>

Canadian health care was changing during this time. The funding debates around the 1966 Medical Care Act forced an assessment of health priorities just as new health scourges, from pollution to traffic accidents, emerged. Increasing costs renewed efforts by the federal government to offload much of its responsibility for Indigenous health care to the provinces. In 1967, the Pearson government reviewed spending and the budget of the Medical Services Branch, which was responsible for Indigenous and northern health, and a budget cut was ordered.<sup>2</sup> Within weeks of details being sent to regional directors in early 1968, the news became public in the territories, and spread quickly from there.<sup>3</sup> National media coverage and letters to the editor were accompanied by volumes of letters to the federal government from a wide range of sources ranging from private citizens to Alberta Premier Ernest Manning.<sup>4</sup> All called for a reinstatement and even increase in health spending for Indigenous people, and most highlighted the needs of "Eskimos" and the North. Just over a month after the news became public, health minister Allan MacEachen reversed the cuts.<sup>5</sup> The reversal, along with the later reversal of the

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<sup>1</sup> The Madras research on the equivalence of home and sanatorium treatment helped in deinstitutionalizing in southern Canada, and there was pressure to do the same for Indigenous people. US studies on preventative drug treatment were noted in Canada but adoption was slow. The Madras finding on the importance of drug-taking supervision had been mostly ignored.

<sup>2</sup> Director General of Medical Services to Regional Directors, Medical Services, 1 February 1968, Library and Archives Canada, RG29 vol 2721 file 810-8-4 pt.1.

<sup>3</sup> Canada, House of Commons Debates, 7 March 1968, (Hon. W.G. Dinsdale (PC)) RG29 vol 2721 file 810-8-4 pt.1. [https://parl.canadiana.ca/view/oop.debates\\_HOC2702\\_07/435](https://parl.canadiana.ca/view/oop.debates_HOC2702_07/435). Dinsdale said it was Northern Region Director Gordon Butler who first made the cuts public in the Northwest Territories, where the news was covered by the CBC, then picked up by the Winnipeg Free Press, spreading from there.

<sup>4</sup> Ernest Manning to Lester Pearson, March 14, 1968, LAC, RG29 vol 2721 file 810-8-4 pt.1.

<sup>5</sup> Record of Cabinet Decision, Privy Council Office, March 19, 1968, LAC, RG29 vol 2721 file 810-8-4 pt.1.

Trudeau government's 1969 White Paper - the last major push for Indigenous assimilation - demonstrated a growing Indigenous power to marshal public support and effect change. This influence was felt in health policy, as observed by senior Medical Services official William Frost: "It must be conceded that the power of Indians is increasing as a result of almost continuous news media coverage."<sup>6</sup>

New attention to Indigenous health revealed new problems. The most fundamental was that no one really knew what was going on. A department official given the task of creating a tuberculosis overview wrote in frustration in 1970:

In summary, attempting to compile national data or even regional data from figures supplied would not only be a waste of time, but the results would be grossly inaccurate and misleading, but I'll try -- AGAIN ... [in a note appended later:] Having tried again and having consulted regional directors (see subsequent memos), DBS [Dominion Bureau of Statistics] and others I have reached the conclusion that no one knows how many registered Indians in Canada have or have had active tuberculosis."<sup>7</sup>

Several research projects, mostly funded by National Health Grants, aimed to fill gaps, often using data from old patient records. One study found that more Inuit than non-Inuit relapsed and developed active disease again, usually four to twelve years after original treatment. It also found that many Inuit had been given what was called 'incomplete' treatment; that is, fewer drugs for less time than was considered enough by late 1960s standards.<sup>8</sup> Other research showed that Inuit tended to metabolize the most common tuberculosis drug, isoniazid (INH), faster than usual.<sup>9</sup>

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<sup>6</sup> Memo on "Interim Report - Policy Review Study," from W.H. Frost to M15 [Assistant Deputy minister of Medical Services], February 22, 1973, LAC, RG29 vol 2659 file 801-1-4 pt.3a.

<sup>7</sup> M.J. Ferrari, Public Health Adviser memo to File [Director General, Medical Services], 10 July 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11. Emphasis in the original.

<sup>8</sup> Stefan Grzybowski to R.D. Thompson, Regional Director, Pacific Region, Medical Services, National Health and Welfare, LAC, George Jasper Wherrett fonds, MG30-B138 vol 5 section 6; S. Grzybowski et al., "Reactivation of inactive tuberculosis in Northern Canada," *American Review of Respiratory Disease* 104, no. 6 (December 1971): 861-5, <https://doi.org/10.1164/arrd.1971.104.6.861>.

<sup>9</sup> C.W. Jeanes, O. Schaefer and L. Eidus, "Inactivation of isoniazid by Canadian Eskimos and Indians," *Canadian Medical Association Journal* 106, no. 4 (February 19, 1972): 331-335, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1940416/pdf/canmedaj01637-0046.pdf/?tool=EBI>.

The results pointed to a large pool of latent tuberculosis disease as a reservoir that fed continuing high incidence of active tuberculosis. By 1969, the theory of disease operative in the North was that it was a 'lifetime' condition, and the roots of sustained high rates was reactivation of old infections. Any new cases arose from reactivations that produced positive smear tests; that is, with people with viable Mtb in their sputum.<sup>10</sup> Such infection often spread to children or young people, who developed 'primary tuberculosis' within weeks. This was rarely noticed, and set the stage for 'incapacitating, communicable' 'adult tuberculosis' in later years. Tuberculosis became classified as a chronic disease requiring sustained health measures.

The new surveillance data confirmed that the worst tuberculosis in Canada in the late 1960s was among eastern Arctic Inuit. Rates were thought to be the highest in the world, and similar to Europe's industrial revolution epidemic at its peak.<sup>11</sup> The difference was antibiotics prevented death, and screening measures found active cases at earlier, less severe stages

The failure to control the tuberculosis epidemic in the region called for a radical change in approach. With the retirement of Percy Moore as director of the Indian and Northern Health Service (INHS), change became possible. Moore was succeeded in 1965 by his assistant Henry Procter. Procter reorganized the INHS, establishing new regions and giving them more latitude to set their own directions. The new Northern Region, based in Edmonton, now spanned both territories. Its services expanded with little obvious budget constraint. New hospital capacity was undertaken, nursing stations and health centres increased, and more nurses and local community

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<sup>10</sup> J.D. Galbraith, Chronic Disease Consultant, Northern Region, "Tuberculosis Statistics-1969: Narrative Report, Medical Services," 20 April 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11 [subsequently cited as Galbraith Statistics Narrative, April 1970, RG29, LAC].

<sup>11</sup> [Stefan Grzybowski, G.J. Wherrett, J.D. Galbraith and Karel Styblo], "A Study of Epidemiology of Tuberculosis in the Native Population of Northern Canada: Supplementary Report," [December 1970], 1-2, attached to letter from G.J. Wherrett to J.H. Wiebe, Director General, Medical Services, January 19, 1971, LAC, RG29 vol 2964 file 851-4-001 pt.12 [subsequently cited as [Grzybowski et al.], Supplementary Report, [December 1970], RG29, LAC].

health workers (CHRs) trained and hired. The region also developed a new approach to tuberculosis as the evacuation program was gradually discontinued.

The new approach was codified in a tuberculosis control document in late 1967.<sup>12</sup> It was a multi-faceted program structured around four goals and associated measures, the top two of which were preventative. People with active tuberculosis were still sent south to hospitals, but were usually sent back to northern hospitals or to their homes after assessments. Another innovation was a computer-based tuberculosis registry that consolidated historic and current case data for the entire North, It may have been one of the first computerized health surveillance registries in Canada.<sup>13</sup> Not only was the control program a new approach for the North, it also included three preventative practices not yet common in Canada: chemoprophylaxis for high risk groups with latent tuberculosis, use of drugs in combination, and supervised drug-taking in the community. This approach was a precursor to the Frobisher Bay project.

## **People**

Throughout the history of tuberculosis among Inuit, specific individuals had outsized influence in shaping events, their actions shaped by their own backgrounds. The Frobisher Bay project was established by four men, physicians who had developed careers around tuberculosis reduction. They had in common long, front-line experience with the disease, credentials in biomedicine and research, and international reputations and networks. They differed in age and areas of experience, including relations with Indigenous people.

The name usually associated with the Frobisher Bay project was Stefan Grzybowski, the most prolific and internationally connected of the men, and most notably gregarious. Grzybowski

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<sup>12</sup> "Northern Region Tuberculosis Control," December 1967, LAC, MG30-B138 vol 5, section 7.

<sup>13</sup> "Tuberculosis Control by Electronic Computer," Text of presentation by D. Harkness, Northern Medical Services, to Canadian Tuberculosis Association Conference 1971, LAC, RG29 vol 2964 file 851-4-001 pt12.

was born in Poland in 1920 but trained and lived in the UK from the start of World War II. In 1954 he was recruited for Ontario's tuberculosis prevention program, where he applied new techniques to problem regions, and advocated for better data. In 1964, he moved to Vancouver as the inaugural Chair in Respiratory Diseases at the University of British Columbia (UBC), where he stayed until his retirement in 1993. Grzybowski's many international credentials ranged from consultant for the World Health Organization (WHO) to honorary member of Argentina's medical association. In Canada, he helped develop national tuberculosis standards, and consulted on epidemiology.<sup>14</sup> Grzybowski was the principal investigator of the Frobisher Bay project, but he got the idea from George Wherrett, who became an advisor to the project.

Wherrett belonged to an early generation of tuberculosis control leaders in Canada, and was by far the most prominent for more than forty years. He was born in rural Manitoba in 1896, trained as a physician in Winnipeg and the UK, and started as a tuberculosis specialist in Saskatchewan and New Brunswick. From 1933 until his retirement in 1962, he was executive secretary of the Canadian Tuberculosis Association (CTA). Through the 1960s and 1970s, he was a consultant on Indigenous tuberculosis and respiratory issues, mainly for the federal government.<sup>15</sup> Wherrett's large impact on tuberculosis public health in Canada was based on his involvement in organizing initiatives across the country and on his lobbying for funding and political support. He also published several important works: the 1945 western Arctic health review that launched federal northern health care; a 1964 monograph for the Hall Commission on tuberculosis; a 1969 eastern Arctic tuberculosis review; and a 1977 history of tuberculosis in

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<sup>14</sup> E.A. Allen, "Professor Stefan Grzybowski [Dedication]," *International Journal of Tuberculosis and Lung Disease* 2, suppl.1 (September 1998): S1-2,  
<https://www.ingentaconnect.com/contentone/iuatld/ijtld/1998/00000002/a00109s1/art00001>.

<sup>15</sup> LGB. "G.J. Wherrett: Obituary," *British Medical Journal* 282, no.6276 (16 May 1981): 1632,  
<https://www.bmj.com/content/282/6276/1632>.

Canada.<sup>16</sup> He was president for a term of the International Union Against Tuberculosis (IUAT). Wherrett was often prescient, predicting many of the forces that shape current public health attitudes and funding.

The project depended on the cooperation of two federal health officials, the most involved being John Douglas Galbraith. Galbraith was born in rural Ontario in 1908, and trained as a physician so he could be a missionary overseas. Instead, on graduating in 1936, the United Church posted him to remote coastal BC, from where he wrote his 1940 letter to the prime minister to protest lack of tuberculosis treatment for Indigenous people. From 1940 to 1966, Galbraith ran Indian hospitals in BC. In 1966 he joined the federal Northern Region as its Chronic Diseases Consultant, and stayed there until he retired in 1973.<sup>17</sup> Galbraith's international roles were not as extensive as those of the other men, but he was attuned to new research, and was frequently lent by the Region to projects in southern Canada. Galbraith worked directly with Grzybowski, was often consulted by Wherrett, and became closely associated with the eastern Arctic studies and the Frobisher Bay project.

Galbraith's superior, Northern Region director Gordon Butler, sponsored the project within the health department and allowed it to use regional health resources. Butler was appointed head of the Region at its creation in 1966. He remained there until 1971, shortly after the Frobisher Bay project was approved. Butler's background was colonial. He was born in 1919 in Northern Ireland, joined the British colonial service, and was stationed in Nigeria from 1945

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<sup>16</sup> G.J. Wherrett, "Survey of health conditions and medical and hospital services in the Northwest Territories," in H.A. Innis, G.J. Wherrett and Andrew Moore, "Arctic Survey," *Canadian Journal of Economics and Political Science* 11, no. 1 (Feb., 1945): 48-82, <http://www.jstor.org/stable/137379>; *Tuberculosis in Canada* (Ottawa: Royal Commission on Health Services, 1965); "A Study of Tuberculosis in the Eastern Arctic," *Canadian Journal of Public Health* 60, no.1 (January 1969): 7-14, <http://www.jstor.org.ezproxy.library.uvic.ca/stable/41984288>; G.J. Wherrett, *The Miracle of the Empty Beds: A History of Tuberculosis in Canada* (Toronto: University of Toronto Press, 1977).

<sup>17</sup> J. Galbraith and W. David Galbraith, *From Slate to Computer: A Memoir of Dr. J. Douglas Galbraith* (Victoria: Trafford Publishing, n.d. [2003?]).

to 1960. He then was hired by the Canadian government to be a physician based in Churchill, covering the central Arctic. As a medical officer Butler had sat on an Eskimo health committee chaired by Percy Moore, at which he had proposed alternatives to mass evacuations. The proposals were not acted on under Moore, but later became part of the Northern Region's tuberculosis control program. As regional director, Butler was known for expanding nursing stations and health centres, and supporting northern nurses. After 1971, he was promoted out of the region, and died in 1982. A bursary was established in his name for Indigenous people in health-care studies at UBC.<sup>18</sup>

Other department officials and external medical professionals also had roles in the project. The most notable was Karel Styblo, the first head of an international body called the Tuberculosis Surveillance Research Unit (TSRU), an entity of the WHO and IUAT. Styblo's unit collaborated on projects around the world that demonstrated best practices with wide potential. He contributed planning and data analysis. Styblo later became internationally renowned for his contributions to tuberculosis epidemiology, most famously for what became known as DOTS, (directly observed therapy - short course), a protocol for supervised drug-taking of which the Frobisher Bay project was a precursor. Canada was one of the TSRU's first collaborating countries, with Grzybowski involved in the projects. The Frobisher Bay project was one of the first projects, and was cited as a notable collaboration in a thirty-year retrospective of the unit.<sup>19</sup>

Nurses and Inuit field workers were part of the project, but few details of their roles are recorded. Elaine Dorken a UBC research nurse was a co-author on papers, took part in planning,

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<sup>18</sup> "Public Health People: Dr. Gordon C. Butler," *Canadian Journal of Public Health* 64, no. 2 (March/April 1973): 219-220, <https://www.jstor.org/stable/4198718>; Private correspondence with Gordon Trueblood, former colleague of Gordon Butler, April 2020.

<sup>19</sup> Annik Rouillon, "The International Tuberculosis Surveillance Research Unit (TSRU): The first thirty years," *International Journal of Tuberculosis and Lung Disease* 2, no.1 (January 1998): 6, [https://www.kncvtbc.org/uploaded/2015/10/TSRU\\_the-first-30-years\\_article-by-Annik-Rouillon.pdf](https://www.kncvtbc.org/uploaded/2015/10/TSRU_the-first-30-years_article-by-Annik-Rouillon.pdf).

decision making, coordination and training Inuit workers.<sup>20</sup> Marie Denis, a federal nurse, was hired to oversee the fieldwork, and was later sought out to participate in similar research in the North.<sup>21</sup> Of the Inuit workers, only one was identified by name, Elisapee Egeseiak, Denis' assistant.<sup>22</sup> The Inuit women were the ones managing the project participants. The only other information recorded about them was that they were midwives.<sup>23</sup>

## Treatment

It was the new research conducted by the Frobisher Bay project proponents in the late 1960s, that suggested the best next step for reducing tuberculosis incidence in the North. Grzybowski, Galbraith, and Wherrett, analyzing data with Styblo, recognized the high Inuit reactivation rate and incomplete treatment that pointed to latent tuberculosis as a major source of the problem. At the same time, Galbraith had conducted his own studies in the Northern Region, and Wherrett's eastern Arctic survey had produced a central registry of Inuit case files from old and new treatment records that helped prepare for the project. The chosen approach combined mass chemoprophylaxis with supervised drug use and a novel combination of drugs.

Chemoprophylaxis had been only slowly adopted in North America. Two of the earliest uses were in Greenland and Alaska, where tuberculosis rates were similar to those among Inuit in

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<sup>20</sup> "Programme of Chemoprophylaxis in Eskimos with Ethambutol and Isoniazid: Report of a Visit to Frobisher Bay, October 16th to November 15th, 1971, in G.J. Wherrett to Stefan Grzybowski, November 14, 1971, LAC, RG29 vol 2964 file 851-4-001 pt.11 [subsequently cited as Wherrett Frobisher Bay visit report, November 1971, RG29, LAC]; Northern Regional Director, Medical Services to Lorette Morel, Health Education Nursing Consultant, Canadian Tuberculosis and Respiratory Diseases Association, December 12, 1972. LAC, RG29 vol 2964 file 851-4-001 pt.12 [subsequently cited as Northern Regional Director to Morel, December 1972, RG29, LAC]; Malcolm E. Schonell to J.D. Galbraith, February 11, 1971, LAC, RG29 vol 2964 file 851-4-001 pt.12 [subsequently cited as Schonell to Galbraith, February 1971, RG29, LAC].

<sup>21</sup> Wherrett Frobisher Bay visit report, November, RG29, LAC; Director General, Program Management, Medical Services to Ontario Regional Director, June 14, 1974, LAC, RG29 vol 2965 file 851-4-001 pt.13.

<sup>22</sup> S. Grzybowski, J.D. Galbraith and E. Dorken, "Chemoprophylaxis trial in Canadian Eskimos," *Tubercle* 57, no.4 (December 1976): 268, [https://doi.org/10.1016/S0041-3879\(76\)80004-9](https://doi.org/10.1016/S0041-3879(76)80004-9).

<sup>23</sup> Northern Regional Director to Morel, December 1972, RG29, LAC.

Canada, and "the highest rates recorded anywhere in modern times."<sup>24</sup> The 1956 Greenland trial was very large, but only looked at side effects and self-reported compliance.<sup>25</sup> The 1957 Alaska trial, part of the initial US trials, and lasting for years, investigated effectiveness, and found the treatment produced a 68 percent drop in incidence of active disease.<sup>26</sup> Among the early Canadian uses were two projects in the early 1960s, one large, one small, both led by Grzybowski.<sup>27</sup> By 1967, Grzybowski was using chemoprophylaxis in Vancouver, Galbraith was overseeing its use in Eskimo Point (Arviat), and Grzybowski and Wherrett had recommended its use in Saskatchewan.<sup>28</sup> In Manitoba, where Wherrett had conducted a province-wide review in 1964, chemoprophylaxis was adopted in 1969.<sup>29</sup>

Non-institutional drug use was being supervised in India and Hong Kong by the 1960s, but seems not to have been used in North America until Grzybowski adopted it. His early 1960s projects did not use it, but in their conclusions Grzybowski noted that close supervision was necessary because of widespread patient non-compliance. By 1967 Grzybowski was using the technique, which he called the 'Madras routine,' extensively in his Vancouver programs, for

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<sup>24</sup> Stefan Grzybowski, "Natural History of Tuberculosis: Epidemiology," *Bulletin of the International Union Against Tuberculosis* 66, no. 4 (December 1991): 193, <https://pubmed.ncbi.nlm.nih.gov/168751s4/>.

<sup>25</sup> E. Groth-Petersen et al., "Mass chemoprophylaxis," *American Review of Respiratory Diseases* 81, no. 5 (May 1960): 643-652. <https://doi.org/10.1164/arrd.1960.81.5.643>.

<sup>26</sup> G.W. Comstock, "Isoniazid prophylaxis in an undeveloped area," *American Review of Respiratory Diseases* 86, no. 6 (Dec 1962): 818, <https://babel.hathitrust.org/cgi/pt?id=uc1.b3520777&view=1up&seq=835>.

<sup>27</sup> S. Grzybowski et al., "A Trial of Chemoprophylaxis in Inactive Tuberculosis," *Canadian Medical Association Journal* 101, no. 9 (November 1, 1969): 81-86, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1946284/>; S. Grzybowski and M.J. Ashley, "Report of a Crash Tuberculosis Program in a High Incidence Area," *Canadian Journal of Public Health* 56, no. 12 (December 1965): 527-529, <https://www.jstor.org/stable/41983820>.

<sup>28</sup> S. Grzybowski, "Epidemiological Features of Tuberculosis in Saskatchewan and Trends in Therapy," in Seminar for Physicians to discuss the Wherrett-Grzybowski Report on Tuberculosis Control in Saskatchewan, April 14-April 15, 1967, University of Saskatchewan, 25, LAC, MG30-B138 vol 5, Section 6 [subsequently cited as Saskatchewan Seminar 1967, Wherrett fonds, LAC].

<sup>29</sup> "Manitoba Sets These Guidelines for Control of Tuberculosis throughout the Province," *Canadian Medical Association Journal* 101, no. 11 (November 29, 1969): 33, <https://www.ncbi.nlm.nih.gov.ezproxy.library.uvic.ca/pmc/articles/PMC1946361/pdf/canmedaj01332-0019.pdf>.

"uncooperative patients."<sup>30</sup> The Northern Region implemented supervised drug use from the start of the chemoprophylaxis in its 1967 tuberculosis protocol.

The earliest chemoprophylaxis trials used only one drug, INH. Yet, as in treatments for active disease, combinations of drugs were more effective in chemoprophylaxis, especially among Inuit who quickly metabolized INH. The Vancouver program had added streptomycin (SM) to INH. The Northern Region program used INH with either SM, which required an injection, or preferably, para-amino salicylic acid (PAS) which did not. These were the only drugs available until the 1970s.

Grzybowski's downtown Vancouver project was likely the first use in Canada of all three practices together. The second was likely the project in Eskimo Point, a community of about 350 people in the central Arctic, which had had serious tuberculosis outbreaks in 1963 and 1967. The Eskimo Point project, supervised by Galbraith, started with outreach: public meetings, leaflets in syllabics, and home nurse visits to every prospective patient to explain the program.<sup>31</sup> Treatment itself lasted 18 months, and required an extra nurse and CHR to provide the supervision. The nurse went to participants' homes every day to administer their drugs. Schoolchildren were given drugs by their teachers every weekday. All participants had a monthly check at the nursing station, and nurse visit at least once a month. An official noted that, "with a few exceptions the co-operation received from the community has been very good."<sup>32</sup> The Eskimo Point project was still in progress as Frobisher Bay was being planned. The much larger project aimed to refine and amplify the Eskimo Point protocol to become a mass program for a much larger community.

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<sup>30</sup> Grzybowski in Saskatchewan Seminar 1967, 25, Wherrett fonds, LAC.

<sup>31</sup> L. Black, "Morbidity, Mortality and Medical Care in the Keewatin Area of the Central Arctic - 1967," *Canadian Medical Association Journal* 101, No.10 (November 15, 1969): 37-8, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1946535>.

<sup>32</sup> Black, "Morbidity," 39.

## **Frobisher Bay**

The idea for the Frobisher Bay project arose around 1966 during a collaboration between Wherrett and Grzybowski on a review of Saskatchewan's tuberculosis needs. Wherrett proposed to Grzybowski a project to address high tuberculosis rates in the eastern Arctic. Wherrett used funding from the CTA to collect and analyze patients' records, and Grzybowski used a National Health Grant for an eastern Arctic epidemiology study beginning in October 1969.<sup>33</sup> Grzybowski's work started with two data studies, one a survey of three representative communities, and another of Inuit reactivations since 1965.<sup>34</sup> This was completed in 1970 with the help of Styblo and Galbraith, and gave solid numbers on incidence of disease. The rate among Inuit at Frobisher Bay was a staggering 2500 cases per 100,000 people.<sup>35</sup> Young people were disproportionately affected, and young women had by far the highest rates, an even more staggering 3716 per 100,000 people.<sup>36</sup> About one third of the cases were reactivations of old disease. These facts led to its labelling as an uncontrolled epidemic. In the first project milestone report in October 1970, Grzybowski recommended a new approach:

As such programs as mass BCG vaccination, adequate treatment and early diagnosis of active cases of tuberculosis over the past 10-15 years did not lead to a more dramatic decrease in rates it can be confidently predicted that tuberculosis will still be a major problem in the next few decades unless mass prophylaxis is successfully implemented.<sup>37</sup>

A suggested treatment protocol had already been developed.<sup>38</sup> It resembled the Eskimo Point

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<sup>33</sup> Brian Brett, Acting Regional Director, Northern Region to Acting Zone Director, Baffin Zone, "Protocol to Give Antituberculosis drugs to Eskimos - Frobisher Bay," 23 July 1971, LAC, RG29 vol 2964 file 851-4-001 pt.12 [subsequently cited as Brett to zone directors July 1971, RG29, LAC].

<sup>34</sup> Galbraith Statistics Narrative, April 1970, RG29, LAC.

<sup>35</sup> Stefan Grzybowski, "Tuberculosis Among the Canadian Eskimos," [October 1970], LAC, RG29 vol 2964 file 851-4-001 pt.11 [subsequently cited as Grzybowski, Tuberculosis report, [October 1970], RG29, LAC].

<sup>36</sup> [Grzybowski et al.], Supplementary Report, [December 1970], Fig.2, RG29, LAC.

<sup>37</sup> [Grzybowski et al.], Supplementary Report, [December 1970], 3, RG29, LAC.

<sup>38</sup> Chemoprophylaxis Programme in Eskimos: Summary of Protocol, December 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11 [subsequently cited as Frobisher Bay protocol, December 1970, RG29, LAC]. This is a revision of a protocol originally developed in August 1970.

project in using supervised multidrug chemoprophylaxis. It differed in using mass measures for screening and treatment, and in the plan to hire Inuit workers to treat the participants, along with a nurse and clerk to support them. This was consistent with calls through the 1960s from Wherrett and others to use Indigenous people where possible to deliver health services.<sup>39</sup>

The plan was to survey everyone in Frobisher Bay to find all Inuit meeting a set of criteria suggestive of latent tuberculosis at risk of reactivation. Out of a community of just over 1300 people, most of them Inuit, it was estimated that 300 to 400 people would meet the project criteria. About 80 percent would be given drugs, the rest would be control subjects. All would get a health exam at the start and at regular intervals, and those with serious problems would be excluded.<sup>40</sup> The project proposed to use a new drug, EMB, alongside INH. The choice was based on Grzybowski's assessment of previous trials using INH alone, the Inuit tendency to metabolize INH quickly, and the superiority of EMB to existing drugs, even though it was still undergoing federal approval.<sup>41</sup> As EMB was known to cause vision problems, vision tests would be part of initial and ongoing health checks. For the treatment, Inuit workers would bring pills to each participant and observe the pills being swallowed. They would do this three times a week for a year and a half. The choices of drug and long duration were to forestall 'what if' questions that might arise if less intensive, less potent measures were used and results not as good as hoped.<sup>42</sup>

After the October 1970 proposal, Grzybowski, Wherrett, Butler and Galbraith discussed it with regional staff.<sup>43</sup> Butler would proceed if Frobisher Bay staff were supportive, and if supervision details could be worked out. Butler wrote to Ottawa in December about his decision,

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<sup>39</sup> George Wherrett, "Tuberculosis in Native Races," Text of presentation to 4th Annual National Tuberculosis Conference, October 20-22, 1969 LAC, RG29 vol 2964 file 851-4-001 pt.11; Martens, "Culture," 496. [subsequently cited as Wherrett national conference presentation, 1969, RG29, LAC].

<sup>40</sup> Wherrett, Frobisher Bay visit report, November 1971, RG29, LAC.

<sup>41</sup> Frobisher Bay protocol, December 1970, Appendix A, RG29, LAC.

<sup>42</sup> Grzybowski, Galbraith and Dorken, "Chemoprophylaxis," 264.

<sup>43</sup> Brett to zone directors July 1971, RG29, LAC.

saying the Region would cover the cost of drugs and salaries for new hires, while grant funding would cover the project leaders' costs."<sup>44</sup> James Wiebe, the head of Medical Services, asked for assurances of sufficient local capacity, and tools to measure success.<sup>45</sup> Assurances were given, and an estimate of incidence reduction submitted. The project team expected a greater reduction than Alaska's 60-percent drop with INH alone, and predicted it would be 80 percent.<sup>46</sup>

Wiebe's reason for asking about success measures was to allow for a departmental cost-benefit analysis, with a hope that "the cost-benefit possibilities may well make any increase investment during the program very worthwhile."<sup>47</sup> The first analysis was an anonymous, handwritten calculation in the margin of a memo, possibly in the office of the Programs Medical Officer.<sup>48</sup> It compared the hospitalization costs avoided from fewer cases against the total cost of the project. The cost-benefit ratio favoured the project by one to four. Nonetheless, it was a cursory analysis with limited comparison. The ratio would have been more in favour of the project if such factors as the high cost of transportation had been factored into both sides of the comparison. It likely would have been greater yet if the calculation had considered the compounding benefits of reducing the reservoir of disease. More marginal notations followed, trying to achieve more precise numbers, but none of the comparisons considered anything beyond hospitalization and drugs as the cost of heavy burden of the status quo.

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<sup>44</sup> Gordon Butler, Northern Region Director to J.H. Wiebe, Director General, Medical Services, December 10, 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11 [subsequently cited as Butler notice of project to Wiebe, December 1970, RG29, LAC].

<sup>45</sup> The head of the Medical Services Branch was a director general up to early 1971, when the position was upgraded to assistant deputy minister (ADM).

<sup>46</sup> Schonell to Galbraith, February 1971, 2, RG29, LAC; Comstock's final report showed a reduction of 68 percent, but a report from 1967 shows the 60 percent figure in the Frobisher Bay calculation. (There is a typo in the team letter giving the Comstock report date as 1957.)

<sup>47</sup> J.H. Wiebe, Director General, Medical Services to G.C. Butler, Regional Director, Northern Region, January 19, 1971 2964-851-4-001-pt12.

<sup>48</sup> Northern Region to Assistant Deputy Minister, March 25, 1971; The cost-benefit calculation was handwritten on the memo, but forwarding stamps suggest it was a copy sent to M18, who may have been William Frost, Senior Consultant for Indian and Northern Health.

Past tuberculosis programs had provoked patient resistance, and Wherrett had noted they were based on "compulsion."<sup>49</sup> The project sought to counter that history. Galbraith said, "we are most anxious to do a very good job of public relations on the launching of this program."<sup>50</sup> They sought ethical approval from the CTA, and informed consent from participants, although it is unclear how these terms were understood or implemented, as ethical standards were still fairly new at the time.<sup>51</sup> Starting in early 1971, federal staff were asked to meet with local officials and "key Eskimo groups," and the Region sent north delegations including Galbraith, a communication officer, and others who were able to "talk to many Eskimos regarding this project," particularly Inuit leaders, the local council, and various officials.<sup>52</sup> As Butler explained, "we would want to have full support of the settlement before giving the final go-ahead for this program."<sup>53</sup> The communication strategy was to first emphasize to people the scope of the problem, and leave the project details closer to implementation, an approach described as "educational work." This suggests the campaign was not a two-way consultation.

Even as the groundwork was being laid, a projected April 1971 start date was pushed back. Grzybowski and Styblo had gone to India on a WHO assignment, staffing was taking longer than expected, and EMB had not yet been approved.<sup>54</sup> Federal officials questioned the

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<sup>49</sup> Wherrett national conference presentation, 1969, 2, RG29, LAC; Saskatchewan Seminar 1967, 27, Wherrett fonds, LAC.

<sup>50</sup> J.D. Galbraith to Dr. D. MacIntosh, Chief of Medical Staff, Royal Edward Chest Hospital, 7 December 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11.

<sup>51</sup> J.D. Galbraith to C.W.L. Jeanes, Executive Director, Canadian Tuberculosis Association, 7 December 1970, LAC, RG29 vol 2964 file 851-4-001 pt.11; The Declaration of Helsinki (Ethical Principles for Medical Research Involving Human Subjects) was adopted in 1964 in basic form in response to the Nuremberg trials. It was extensively revised and expanded in 1974. <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects>.

<sup>52</sup> Brett to zone directors July 1971, 2, RG29, LAC.

<sup>53</sup> Gordon Butler to C.K. Bridge, Acting Baffin Zone Director, n.d. [after December 4, 1970], LAC, RG29 vol 2964 file 851-4-001 pt.11.

<sup>54</sup> Grzybowski "Natural History," 193; Gordon Butler to Assistant Deputy Minister, March 25, 1971 LAC, RG29 vol 2964 file 851-4-001 pt.12.

drug's effect on pregnant women and children, but Grzybowski then contributed evidence that no such effects had been discovered in India.

Preparations resumed. In June, Marie Denis was hired to oversee the project, and found people who might be good field workers, eventually hiring an assistant and thirteen others.<sup>55</sup> Beyond a note that they were midwives, nothing is recorded about them, and all that is known of their work was that they were to visit the participants bringing drugs, watch them swallow the drugs, take notes and report regularly to their supervisor. Later, participants were reported saying they had welcomed their supervision. A hint of the potential impact of Inuit workers comes from a non-Indigenous community nurse in southern Canada who had been asked to comment on the work of Indigenous CHRs around her: "If you ask me what the community health worker is doing, I would have to say I don't know, but I do know that my reception in the homes is very different, the women come out to clinics and everyone turns out for immunization."<sup>56</sup>

Preparations continued through the summer of 1971, and the first field work started in September. A total of 1348 Inuit were tested for tuberculosis and x-rayed, and the results were compared to information already on file to identify those who fit the treatment criteria.<sup>57</sup> Starting in October, those identified were interviewed by a physician. Wherrett himself conducted some of the interviews. He reported on the interviews partway through:

The project has been well explained to the people in the community and we did not have a single refusal in the first two hundred. All readily agreed to participate and seemed to appreciate the object of the project, e.g. to eliminate active tuberculosis in the community and avoid the necessity of treatment in hospitals in the south.<sup>58</sup>

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<sup>55</sup> E. Dorken et al., "Ten year evaluation of a trial of chemoprophylaxis against tuberculosis in Frobisher Bay, Canada," *Tubercle* 65, no. 2 (June 1984): 93-99, [https://doi.org/10.1016/0041-3879\(84\)90059-X](https://doi.org/10.1016/0041-3879(84)90059-X).

<sup>56</sup> Martens, "Culture," 502.

<sup>57</sup> Wherrett Frobisher Bay visit report, November 1971, 1, RG29, LAC.

<sup>58</sup> Wherrett Frobisher Bay visit report, November 1971, 1, RG29, LAC.

Wherrett had in the past read x-rays of most participants, and in addition to noting the value of meeting the people, was struck by how important family contacts were.

Of the 1348 people initially screened, 587 became part of the project. Of these, 370 were given chemoprophylaxis treatment, and 217 were untreated control subjects, some being people who met the criteria but could not be supervised, such as hunters.<sup>59</sup> The treatment phase lasted until June 1973. Ninety percent of participants under treatment finished the eighteen-month program. The 44 dropouts participated for an average of ten months, still considered an effective span. About half stopped for medical reasons, and half simply stopped cooperating. Afterward, about three quarters of the participants took part in follow-up observations for several years.

In the three years from the start of the project, none of the people taking drugs developed active tuberculosis, while eight people in the control group did.<sup>60</sup> The result was an incidence reduction "greater than any previously recorded decline in the epidemiology of the disease."<sup>61</sup> After ten years, three people in the treatment group had developed active tuberculosis, compared to 13 in the control group.<sup>62</sup> From this, the success of the project was quantified as an 87-percent reduction of incidence of active disease over what it likely would have been without the treatment. The project had achieved its goals and more: completely preventing new disease in those treated over a three-year span, and reducing it by almost 90 in the decade from its start. This was better than the project team had predicted, and likely would have been even higher if the compounding effect of disrupted transmission were considered.<sup>63</sup> Extrapolating from the

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<sup>59</sup> Grzybowski et al., "Chemoprophylaxis," 264-266.

<sup>60</sup> Grzybowski et al., "Chemoprophylaxis," 267-8; Dorken et al., "Ten year evaluation," 95. Originally nine people were reported as developing disease, but on follow-up, only eight cases were found.

<sup>61</sup> Pamela Orr, "Tuberculosis in Nunavut: looking back, moving forward," *Canadian Medical Association Journal*, 185, no.4 (2013 Mar 5): 287-288.

<sup>62</sup> Dorken et al., "Ten year evaluation," 95.

<sup>63</sup> Grzybowski, "Chemoprophylaxis," 268; D. Kunimoto et al., "Investigation of tuberculosis transmission in Canadian Arctic Communities using DNA fingerprinting," *International Journal of Tuberculosis and Lung Disease* 5, no.7 (2001): 642, <https://www.ingentaconnect.com/content/iuatld/ijtld/2001/00000005/00000007/art00008>.

earlier Alaska project, the protective effect of chemoprophylaxis was expected to last for close to twenty years from initiation.<sup>64</sup> The project was also considered a success because of the high level of participant cooperation, a 90-percent compliance rate, which was significantly higher than in other chemoprophylaxis projects, or patient-administered drug treatments. The community cooperation was attributed to the advance community relations work, and to the team of field workers. The study report concluded that supervised mass chemoprophylaxis was successful and worthwhile when rates were high "in a country without severe financial constraints."<sup>65</sup>

### **Beginning of the end**

The Frobisher Bay stage of the project was scheduled to end in June 1973, but already by June 1972 it was clearly working and running smoothly. Plans were made to expand to Clyde River (Kanggiqtugaapik) and Cape Dorset (Kinngait).<sup>66</sup> A proposal was prepared for full regional expansion.<sup>67</sup> Mass chemoprophylaxis was considered necessary for high-risk communities, because of the particulars of Inuit circumstances, and was considered urgent because of the likelihood of drug resistance developing. The goal of the expanded project was more than just parity with southern Canada; eradication was now considered possible. By treating 20 percent of all Inuit, the program "could effectively block tuberculosis in the North in a matter of months, drastically altering the expected risk of breakdown and stop the future spread of tuberculosis."<sup>68</sup>

This meant treating 2500 of the most at-risk Inuit across the NWT, and hiring field staff needed

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<sup>64</sup> Dorken et al., "Ten year evaluation," 99.

<sup>65</sup> Grzybowski, "Chemoprophylaxis," 268.

<sup>66</sup> Consulting progress report, G.J. Wherrett to M.L. Webb, Acting Assistant Deputy Minister, July 5, 1972, LAC, RG29 vol 2964 file 851-4-001 pt.12.

<sup>67</sup> Memo on "Extension of tuberculosis protocol to total Eskimo population with appendices from J.D. Galbraith to F.J. Covill, Regional Program Medical Officer, October 20, 1972, LAC, RG29 vol 2964 file 851-4-001 pt.12 [subsequently cited as Protocol extension plan, Galbraith to Coville, October 1972, RG29, LAC].

<sup>68</sup> Protocol extension plan, Galbraith to Coville, October 1972, 2, RG29, LAC.

to complete it by 1975. The estimated total cost over two and a half years was \$490,532. More than half was to pay for EMB, and about a quarter was to pay Inuit staff.<sup>69</sup> Departmental concerns about money were anticipated by noting that costs of the full project had been reduced relative to the Frobisher Bay stage by trimming follow-up observations. The proposal also highlighted the economic and development benefits of hiring and training Inuit.

In October 1972, Galbraith submitted the proposal to the acting regional director. By then Butler had been replaced by Brian Brett, a younger man of different experience and outlook. The proposal was not well received, although direct evidence of this only appeared months later. Indirect evidence appeared in early December, as Grzybowski tried a different route to get the next stage approved. He wrote to an acquaintance, Minister of State for Multiculturalism Stanley Haidasz, saying budget cuts had prevented approval of the project and asked for help:

I wonder if you could help us by securing some government funds specifically for this program - I suppose in the form of additional allowances for the Northern Health Services ... This would be a great service to our Eskimo population and a substantial contribution towards our understanding of yet another approach of control of tuberculosis. I hope you do not mind my asking you to do this but the whole problem is very close to my heart."<sup>70</sup>

The subsequent paper trail ended with a reply to Grzybowski over Haidasz's signature more than two months later. It was a three-sentence note saying the issue did not fall within the purview of his office.<sup>71</sup>

The day after Haidasz's reply, Brett made clear his opposition to the continuation of the Frobisher Bay program in a long list of objections sent to the head of Medical Services<sup>72</sup>. Brett

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<sup>69</sup> As an indication of the enduring popularity of INH, its projected cost for the expansion proposal was just over \$30,000, compared to the project cost for EMB of just over \$288,000.

<sup>70</sup> Letter from Stefan Grzybowski to The Honourable Dr. Haidasz, Minister of State, December 6, 1972, LAC, RG29 vol 2964 file 851-4-001 pt.12.

<sup>71</sup> Letter from Stanley Haidasz to Dr. Stefan Grzybowski, Feb. 21, 1973, LAC, RG29 vol 2964 file 851-4-001 pt.12.

<sup>72</sup> Memo on "Protocol for Chemoprophylaxis of Tuberculosis," from Brian Brett, Regional Director, Northern Region to Assistant Deputy Minister, Medical Services, February 22, 1973, LAC, RG29 vol 2964 file 851-4-001 pt.12.

mischaracterized the expansion as an effort to make the project large enough for statistical validation, a plan he described as "frustrated" equally by "shortage of funds" and "rethinking the project." He wrote that "confusion of thought" and neglect of fundamentals had so far produced only "a number of statistics chasing a hypothesis." He dismissed the drug protocol as having already been validated in literature so that "no great contribution to science has been achieved." He described supervised drug taking as socially detrimental: "A degree of paternalism which supervises drug taking is hardly compatible with developing a responsible attitude to personal health care." Although supervision was being provided by other Inuit, Brett saw this too as a problem, as "it is extremely expensive for what it achieves." He also questioned the effects of x-rays and drugs, and the ethics of designating some people as control subjects. Brett recommended the project end as soon as the Frobisher Bay treatments ended that summer. His rationale was that the project was not necessary, deaths were few and rates were falling, and could fall more with screening. Past screening had not appreciably reduced incidence, but Brett had "higher priorities" than tuberculosis.<sup>73</sup>

The new head of Medical Services, Marian (Bud) Webb, was sympathetic to the project:

It is essential in my mind that we endeavor to control our old enemy, tuberculosis, and to keep it controlled at a level comparable to that which exists in the rest of Canada, before we launch into new programs with ill-defined cost benefit.<sup>74</sup>

Webb asked advice from a senior department official, William Frost. Frost disputed or dismissed many of Brett's objections and endorsed the project's principles and approach. For Frost, though, the significant issue was money, noting the half million-dollar bottom line: "this probably

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<sup>73</sup> Memo from M.L. Webb, Assistant Deputy Minister, Medical Services to M16 [W.H. Frost, Senior Consultant, Indian and Northern Health], 13 March 1973, LAC, RG29 vol 2965 file 851-4-001 pt.13. [subsequently cited as Webb to [Frost], March 1973, RG29, LAC].

<sup>74</sup> Webb to [Frost], March 1973, RG29, LAC.

underlies Dr. Brett's decision."<sup>75</sup> Because "the resources available for tuberculosis control obviously set practical limits on the protocol," Frost recommended a compromise that might satisfy Brett. Frobisher Bay and Eskimo Point could continue to the end, because "if we discontinue the protocol now we may lose what little ground we have gained, and a fairly significant expenditure on drugs will have to be depreciated." For the rest of the region, he proposed limited chemoprophylaxis with only the most at-risk people, and an alternative focus on BCG vaccination, because "it is relatively inexpensive."

Webb took Frost's recommendations as his own recommendations to Brett. Wherrett only learned of it in July and wrote to Webb rebutting more of Brett's points.<sup>76</sup> Wherrett said no study of Indigenous health in Canada had ever been large enough to offer statistical proof of concept, that supervision was used for all ethnicities, and that the objections about x-rays and drugs were "theoretical" and not balanced against the "continuing high burden of disease." Wherrett did not address the project costs. His other arguments had no impact against that.

Frobisher Bay treatments were completed in the summer of 1973, and the northern tuberculosis control protocol was revised in 1974. This new regional protocol required informed consent from participants before treatment, which the Frobisher Bay project had first introduced to the North, but otherwise it followed Frost's reduced measures. Chemoprophylaxis was directed to close contacts of those with active disease. Contact tracing continued, but there were no screening measures. Supervision, which Frost had not addressed, became so loosely defined it appeared to have essentially ended.<sup>77</sup>

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<sup>75</sup> Memo on "Protocol for Chemoprophylaxis of Tuberculosis," from W.H. Frost to M15 [M.L. Webb], March 15, 1973, LAC, RG29 vol 2965 file 851-4-001 pt.13 [subsequently cited as Frost to [Webb], March 1973, RG29, LAC].

<sup>76</sup> Memo from G.J. Wherrett to Assistant Deputy Minister, July 10, 1973, LAC, RG29 vol 2965 file 851-4-001 pt.13.

<sup>77</sup> "Pulmonary Tuberculosis," *Communicable Diseases*, Amended August 1974, 15-16, LAC, RG29 vol 2965 file 851-4-001 pt.13.

## **New directions**

The third period of tuberculosis in the North ended gradually as a new approach took hold. The Frobisher Bay project had occurred at a transition point in Canadian health care, and its new direction then redirected northern tuberculosis control.

By 1970, the nation-wide, jurisdictional debates were colliding with the demands of new health issues, such as cancers, cardiovascular disease, substance abuse and family planning. The new deputy minister of health, Maurice LeClair, sought new tools to guide the department's responses. One tool was the Long Range Health Planning Branch, established in 1971. It quickly became a free-form internal think tank with outsized influence, generating reports offering technocratic solutions shaped by scientific and social theories. Its magnum opus was the Lalonde report, initiated in 1972, released in 1974, and named for Marc Lalonde, who had become health minister part way through its development. The report used the McKeown thesis to deflect responsibility from the federal government onto the individual, and to promote cheaper ways to administer health care. These goals arose early in report planning, as expressed by a senior official: "How can individual citizens be persuaded, and by whom, to accept the major responsibility for their state of health so that dependency on high cost health resources and facilities can be reduced .... How can the federal government persuade other responsible bodies to control and reduce costs."<sup>78</sup> The resulting report presented a broad view of health with an emphasis on individual responsibility, delivered through an integrative approach called health promotion. It prioritized prevention over cure, but completely ignored infectious diseases. Its four priority areas were chosen because of their association with leading causes of death among

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<sup>78</sup> Memo from S.H. Mansbridge, Senior Assistant Deputy Minister, Administration to J.M. LeClair, Deputy Minister of National Health, March 27, 1972, LAC, RG29 vol 2659 file 801-1-4 pt.1.

Canadians. Infectious diseases were no longer a leading cause of death, and so were invisible in the report, and in new departmental philosophy.

In the North, Brett seemed attuned to the Lalonde philosophy from the start -- he had been asking staff for long term planning in their areas of responsibility since 1973.<sup>79</sup> In Galbraith's area, the Chronic Disease Control Office, Brett said he would prefer to focus on ear problems rather than the "smouldering under-current" of tuberculosis.<sup>80</sup> Brett's own special area of concern was the mental health of young Inuit, and he highlighted teen suicide and infant mortality, which were federal concerns also.<sup>81</sup> These were serious problems that deserved attention, but they diverted resources from tuberculosis, just as the federal government was cutting all departmental resources to meet soaring inflation.

The new departmental direction brought a new structure with overlapping areas of responsibility. A new Health Promotion Branch was established, and its head, a non-physician, was soon offering advice to the head of Medical Services on new tuberculosis treatments, and suggesting to the deputy minister that the department set a national goal of eradicating tuberculosis in five years to demonstrate a commitment Lalonde principles.<sup>82</sup> The comments illustrate the managerial turn in the department, and showed signs of an incomplete understanding of the nature and history of tuberculosis. The cross-branch responsibility created

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<sup>79</sup> Memo on "Long Term Planning - Chronic Disease Control" from J.D. Galbraith to Dr. B. Brett, Director, Medical Services, Northern Region, February 12, 1973, LAC, RG29 vol 2964 file 851-4-001 pt.12.

<sup>80</sup> Memo on "Paper entitled "Tuberculosis in the World Today," from H.B. Brett, Regional Director, Northern Region to Senior Consultant, Indian and Northern Health, Medical Services, August 15, 1973, LAC, RG29 vol 2965 file 851-4-001 pt.13.

<sup>81</sup> Brian Brett, "Mental Health Care for Children of the Western Arctic," *Canadian Journal of Public Health / Revue Canadienne de Santé Publique* 62, no. 5 (1971): 386-94, <http://www.jstor.org/stable/41986993>; Thomas R. Berger, *Report of the Advisory Commission on Indian and Inuit Health Consultation* (Ottawa: Advisory Commission on Indian and Inuit Health, February 28, 1980), 22, [https://publications.gc.ca/collections/collection\\_2018/sc-hc/H34-322-1980-eng.pdf](https://publications.gc.ca/collections/collection_2018/sc-hc/H34-322-1980-eng.pdf).

<sup>82</sup> Memo on "Short Course Treatment of Tuberculosis," from A.B. Morrison, Assistant Deputy Minister, Health Protection to C.E. Caron, Assistant Deputy Minister, Medical Services, March 9, 1976, LAC, RG29 vol 2965 file 851-4-001 pt.14; Memo from A.B. Morrison, Assistant Deputy Minister, Health Protection to Jean Lupien, Deputy Minister, National Health, March 5, 1976, LAC, RG29 vol 2965 file 851-4-001 pt.14.

circumstances Galbraith had warned about earlier: "the tubercle bacillus has its best friend in the multiple agencies that deal with control."<sup>83</sup> In Galbraith's experience, shared responsibility meant fragmented effort.

With devolution of health care to the Northwest Territories in the late 1980s, and creation of Nunavut in the late 1990s, the changes in approach were complicated by the upheavals around jurisdictional change. These diverted attention from tuberculosis protocols. Tuberculosis was integrated into general care, which even in the late 1990s was echoing the Lalonde message of personal responsibility first.<sup>84</sup> Vaccination and case finding continued. Chemoprophylaxis also continued, under different names, but it was not often prescribed and compliance was low.<sup>85</sup> Screening no longer appeared in tuberculosis control protocols, which suggests that even if it was still practiced, it was not a high priority. By the late 1990s, experts concluded that tuberculosis treatment capacity was "impeded by limitations of staff time, training, community support and level of awareness."<sup>86</sup>

Tuberculosis incidence rates continued to drop to the end of the 1970s, but slowly.<sup>87</sup> Through the 1980s, rates first increased gradually then remained steady. The trajectory appeared consistent with conclusions of experienced tuberculosis experts. In Alaska, the leader of the early chemoprophylaxis trials believed its preventative benefits lasted just under twenty years.

Grzybowski, toward the end of his career, had two conclusions based on his work in Frobisher

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<sup>83</sup> Letter from J.D. Galbraith to W.H. Frost, Senior Consultant, Indian and Northern Health, March 24, 1974, LAC, RG29 vol 2965 file 851-4-001 pt.13.

<sup>84</sup> Med-Emerg International Inc., *Northwest Territories Health and Social Services draft strategic plan - a review and recommendations for an integrated health and social services system in the Northwest Territories, Canada* (Yellowknife: Department of Health and Social Services, 1997), 12, <https://pubs.aina.ucalgary.ca/health/66596.pdf>.

<sup>85</sup> Various known as supervised treatment, LTBI treatment, directly observed prophylaxis, DOP or DOT.; Michael Clark and Peter Riben, *Tuberculosis in First Nations Communities, 1999* (Ottawa: Health Canada, [2001]), 21, <https://publications.gc.ca/collections/Collection/H35-4-7-1999E.pdf>; Med-Emerg, *Northwest Territories Health*, 6.

<sup>86</sup> Anne Fanning and Mike Mulherin, *Highlights of the Report on Tuberculosis Control in the NWT* (Yellowknife: Government of the Northwest Territories, February 23, 2001), 1.

<sup>87</sup> Pat Sandiford Grygier, *A Long Way from Home: The Tuberculosis Epidemic among the Inuit* (Montreal: McGill-Queen's University Press, 1994), 141.

Bay and elsewhere. His clinical conclusion was that thorough screening without intensive treatment could amplify active disease, and that both were necessary to disrupt transmission and reduce the reservoir of disease in a community.<sup>88</sup> His over-arching conclusion was that "one does not have to wait for many decades for socioeconomic development, with a higher standard of living. We can control this disease with specific tuberculosis programs."<sup>89</sup> By the late 1980s, it appears some of what had been learned about tuberculosis was being forgotten. Rates began to spike, then climb steadily through the 1990s.<sup>90</sup> In the new philosophical reorientation, with new policies, new staff, and ongoing budget limits, the third period in the history of tuberculosis among Inuit ended. A new period started, with a gradual return to globally high disease incidence rates, and eventually, more deaths.

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<sup>88</sup> Grzybowski, "Natural history," 194.

<sup>89</sup> Grzybowski, "Natural history," 193.

<sup>90</sup> Northwest Territories, Health and Social Services, *Review to Strengthen Tuberculosis Management and Control in the NWT: Assessing the impact of change in response to the 2001 Review (Fanning Report)* (Yellowknife: Government of the Northwest Territories, February 2006), 11, <https://pubs.aina.ucalgary.ca/health/62223e.pdf>; Bob Weber, "Worst TB outbreak in Nunavut's history a national problem: CMAJ," *Toronto Star* (Feb. 14, 2011), [https://www.thestar.com/news/canada/2011/02/14/worst\\_tb\\_outbreak\\_in\\_nunavuts\\_history\\_a\\_national\\_problem\\_cmaj.html](https://www.thestar.com/news/canada/2011/02/14/worst_tb_outbreak_in_nunavuts_history_a_national_problem_cmaj.html).

## Conclusion

The Frobisher Bay project demonstrates that tuberculosis is primarily a political disease. Political factors are more fundamental determinants of its manifestations than the social factors currently considered fundamental, or than biomedical factors, which were previously considered fundamental. The various factors are underlaid by geographic determinants, which exacerbate social upheaval, modify the relevant biomedicine, and make an already expensive disease more expensive yet. These dynamics are apparent in the large history of tuberculosis among Inuit, in which political changes created periods of distinct disease epidemiology and demonstrated that political factors are the "determinants of determinants."<sup>1</sup> The Frobisher Bay projects is an especially good illustration of the dynamics, because the project's origin, timing and outcome offer a clear view of political factors that shaped the disease.

In the large history, during the first period of the long political "absence of mind" in the North, tuberculosis escalated unchecked and became an epidemic. Social determinants triggered the epidemic, as Inuit increasingly gathered near outsiders' settlements, and spent more time in prolonged close quarters. This disease determinant was amplified by government encouragement of fur trading, by new game laws that diminished traditional food supplies, and by political decisions to ignore Inuit health and social needs. The federal "absence of mind" was reversed abruptly when the North came under a political spotlight in the mid-twentieth century. The resulting need to just "do something" about Inuit circumstances brought the second period, during which extreme biomedical measures were introduced and Inuit stopped dying, but they were still very sick.<sup>2</sup> The third period, which included the Frobisher Bay project, had its origins

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<sup>1</sup> Daniel E. Dawes, *The Political Determinants of Health* (Baltimore: Johns Hopkins University Press, 2020), 45.

<sup>2</sup> Richard Diubaldo, *The Government of Canada and the Inuit, 1900-1967* (Ottawa: Indian and Northern Affairs Canada, 1985), 130, [https://publications.gc.ca/collections/collection\\_2017/aanc-inac/R5-407-1985-eng.pdf](https://publications.gc.ca/collections/collection_2017/aanc-inac/R5-407-1985-eng.pdf).

in a confluence of political factors, and ended with a reconfiguration of those factors, discussed below. The reconfigured political factors led to a fourth period in which disease rebounded, and people once again died of tuberculosis. More recently, the political alarms of 2017 brought renewed control efforts. The outcomes of these efforts are not entirely clear, because the previous censorship around tuberculosis appears to have been renewed as well.<sup>3</sup>

The Frobisher Bay project produced a record drop in tuberculosis incidence among Inuit. It did this by using mass screening and mass chemoprophylaxis to prevent reactivation of latent tuberculosis and in doing so decreased disease transmission in the largest Inuit community. In the 1960s, "it was almost impossible for an Inuit [sic] child to escape being infected [by tuberculosis], but by the mid-1970s, it was difficult to acquire this infection."<sup>4</sup> The benefits did not last. The third period ended as incidence rates rose to a plateau, remained there for a decade, then climbed once more. The pattern is consistent with the span of one-time chemoprophylaxis protection without sustained programs to reduce prevalence.<sup>5</sup> Both the health benefits of this period and their loss were the products of political determinants. They acted directly on disease, and indirectly through action on other determinants. The intersection of different types of determinants, which in South Africa was "pathological," was briefly the opposite in Canada's North. For a time, they interacted positively and lessened the burden of disease on Inuit.

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<sup>3</sup> Kelly Grant, "Inuit group presses Nunavut government for transparency after major tuberculosis outbreak." *Globe and Mail* (July 3, 2022), <https://www.theglobeandmail.com/canada/article-inuit-group-presses-nunavut-government-for-transparency-on>. The federal government is also reducing publically available information on tuberculosis. A previously annual national tuberculosis report that was typically more than 100 pages long has become intermittent, and for 2020, a one-page infographic. Some documents once available online have been taken down: the Bourgeois report on tuberculosis in Nunavut to 2011, and highlights of the 2001 Fanning report. Both were available in 2018. Now, links do not work, and efforts to find the documents have yielded nothing. The full Fanning report is neither available online nor in the public records of the commissioning entity, the Northwest Territories government.

<sup>4</sup> Stefan Grzybowski and E. Dorken, "Tuberculosis in Inuit," *Ecology of Disease* 2, no.2 (1983): 147, <https://www.ncbi.nlm.nih.gov/pubmed/6332010>.

<sup>5</sup> Donald A. Enarson and Stefan Grzybowski, "Incidence of active tuberculosis in the native population of Canada," *Canadian Medical Association Journal* 134, no. 10 (May 15, 1986): 1151, <https://pubmed.ncbi.nlm.nih.gov/3697860/1151>.

Social determinants of health were essentially unchanged around the third period.<sup>6</sup> The two most important social determinants, housing and nutrition, were not addressed until later.<sup>7</sup> Other social determinants remained constant problems; for example, transportation and communication barriers, and health staff shortages.<sup>8</sup> The social factors that did change to some degree were within the project itself. They were health care delivery by Inuit, community social licence, and participants' consent to their treatment. Frobisher Bay project leaders believed these factors were beneficial and contributed to the project's success.<sup>9</sup> The extent to which Inuit workers and participants shared those views is unknown. George Wherrett's report that Inuit preferred the project over evacuation and southern treatment means only that the project was considered better than a difficult and damaging alternative.

Biomedical determinants were likely unchanged during the short term of the project, but did change before and afterward. Regarding biological factors, it is dangerous to make assumptions about a pathogen as distinctively protean as the *Mtb* bacillus, or the human biological responses to it, but known examples of mutability usually occur over spans of time vastly longer than this period. The exception is drug resistance, but in 80 percent of cases examined in this period, the bacteria remained responsive to drugs.<sup>10</sup> Medical factors did change substantially shortly before this period, as federal funding supported research that revealed latent tuberculosis as a significant source of active disease in the region, and new programs validated

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<sup>6</sup> S. Grzybowski, J.D. Galbraith and E. Dorken, "Chemoprophylaxis trial in Canadian Eskimos." *Tubercle* 57, no.4 (December 1976): 268, [https://doi.org/10.1016/S0041-3879\(76\)80004-9](https://doi.org/10.1016/S0041-3879(76)80004-9).

<sup>7</sup> R. Quinn Duffy, *The Road to Nunavut: The Progress of the Eastern Arctic Inuit Since the Second World War* (Kingston and Montreal: McGill-Queen's University Press, 1988), 46, 86. In 1975, Dene MP Wally Firth was still raising concerns about northern housing. Concerns about food supply and nutrition were still being raised in the late 1970s.

<sup>8</sup> Thomas R. Berger, *Report of the Advisory Commission on Indian and Inuit Health Consultation* (Ottawa: Advisory Commission on Indian and Inuit Health, February 28, 1980), 22, [https://publications.gc.ca/collections/collection\\_2018/sc-hc/H34-322-1980-eng.pdf](https://publications.gc.ca/collections/collection_2018/sc-hc/H34-322-1980-eng.pdf). Staffing problems also included language and cultural barriers.

<sup>9</sup> Grzybowski and Dorken, "Tuberculosis in Inuit," 147; Enarson and Grzybowski "Incidence," 1151.

<sup>10</sup> If drug resistance had been a factor, it would have reduced rather than increased project success.

previous trials that could address the problem. The focus on latent disease diminished after the project, as projects to address it were cancelled or scaled back.

Political determinants were the only factors that changed substantially throughout this period, and they did so abruptly between the project start and end. At first, the project was aligned with the political forces, which enabled its implementation. After the abrupt inflection point, the new forces were aligned against it and led to its cancellation. The initial benefit to tuberculosis outcomes was dramatic and immediate. The loss of the benefit was more gradual, but steady. Thus, both before and after the political inflection, tuberculosis epidemiology, a major component of Inuit health, was politically determined. The central role of bureaucrats in the changes is consistent with the historiography of the North, and with Morantz's bureaucratic colonialism, a technocratic form of colonialism that lacked ill will toward its subjects, but also lacked coherence or full consideration of consequences.

The initial picture of Inuit health care in this period was relatively simple with respect to commonly considered political determinants. Structurally, it comprised one entity, the Medical Services Branch of the federal health department. Senior branch officials were the main power centre, with much of the autonomy of earlier federal Indigenous healthcare administrations. Structural simplicity was echoed in its funding. The branch benefitted from the national prosperity of the 1960s, and used it to expand staff, services and facilities. The only financial discussion around the Frobisher Bay project was the cursory cost-benefit analysis completed after project approval, which suggested that cost was not a significant issue. Department decision makers were all physicians, and their worldview was technocratic. They believed in the power of modern medicine and, in ways similar to Velmet's 'technopolitics,' used medical advances to try to make Inuit part of Canadian society. Department leaders still considered tuberculosis an

important issue, which assistant deputy minister Bud Webb referred to as "our old enemy, tuberculosis." This view appears to have been generational, imprinted on those who had had experience of uncontrolled tuberculosis.

The continuing importance of both biomedical knowledge and tuberculosis among department leaders made tuberculosis experts another power centre. George Wherrett and Doug Galbraith were well known and respected for their track records and had great influence with decision makers. Wherrett especially was noted for his decades of national leadership. His reputation allowed him to choose his own priorities and activities in his consulting work for the department. Grzybowski was recognized for his prolific research, international publications and knowledge networks, and was sought out for his expertise. Other evidence of the experts' influence was their freedom to choose their own research. These men, along with Karel Styblo, had ready access to funding for their interests and could leverage it to undertake larger projects.

Neither overt racism nor traditional colonial attitudes were recorded in departmental documents after Moore's retirement. What evidence remained was a paternalism toward the subjects of departmental responsibility, which, it could be argued, was not far different from traditional medical paternalism toward patients generally, and so it is difficult to characterize it as purely racist. Public opinion was aligned with a less damaging view of Indigenous people. By the 1960s, as influential Canadians increasingly criticized federal Inuit administration, Inuit themselves gradually gained a greater voice.<sup>11</sup> Inuit were featured in media coverage of the mass evacuation program, healthcare budget cuts and reaction to them. Resulting public opinion triggered the reversal of health budget cuts, and influenced internal discussions even afterward, as indicated by William Frost's comment about the "power of Indians" rising with continuous media coverage. Inuit had achieved a symbolic resonance in Canadian attitudes, alongside the

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<sup>11</sup> Diubaldo, *Canada and Inuit*, 1.

resonance attached to Canada's North. The tuberculosis experts also showed positive, yet somewhat patronizing attitudes toward Inuit. Patronization seemed to diminish with time, but a sense of Inuit as 'other' remained. Overall, public and political attitudes had created favourable conditions for measures that could be seen as doing the right thing for Inuit.

The processes that determined decisions about Inuit health were as straightforward as the context determinants. The autonomy of northern administration, which had seemed like a personal fiefdom in the past, was now based on medical professional judgement. Once budgets were allocated, the Northern Region, like others within Medical Services, had latitude to spend according to its priorities. The head of Medical Services issued specific directives from time to time; for example, a request for data. Yet even on matters as fundamental to public health as data collection, there was no policy. Consistency across Medical Services depended on shared medical knowledge and norms, and decision making was based on accepted medical judgement.

This set of determinants - relatively autonomous decision makers with a technocratic belief in biomedicine and emphasis on tuberculosis and its experts, alongside ample resources and supportive public opinion - enabled the Frobisher Bay project. The enabling was simply a political decision to spend an estimated \$74,000 to treat 370 people as a first step in eliminating a multi-generational scourge. The outcome, the project result, was indeed the first step. It reduced disease among Inuit and had the potential to reduce it more if political support were to be sustained. It was not.

The political inflection point came while the Frobisher Bay stage of the project was in progress. The disjunction arose from disparate overlapping, factors. The factors were a changing federal bureaucracy, tightening fiscal circumstances, shifting public opinion, and new public

health philosophies rising from the perceived end of infectious disease. Political determinants that had been aligned with the Frobisher Bay project were now aligned against it.

After this inflection, the picture of Inuit health care started to become complex. Structurally, the Medical Services Branch was no longer solely responsible for all aspects of Indigenous health. The branch lost much of its autonomy in departmental structuring. This created overlapping areas of responsibility, a policy-development capacity and new oversight. Centres of power and decision-making shifted. Professional managers began to supplant physicians, and organizational imperatives increasingly influenced medical decisions. The attitudes of department leaders were still technocratic, but new prominence was given to other scientific and social science fields, notably genetics, environmental science, and behavioural science. The Lalonde report, based on causes of mortality of the day, made infectious diseases invisible in federal government priorities. Yet, the burden of infectious illnesses, especially of tuberculosis, remained a significant barrier to health.

The radical change in the health department's attitudinal position was linked to a radical change in its fiscal picture. The fiscal burden of provincial health transfers had increased just as budgets tightened. The core departmental mission was to find ways to reduce health care needs, or to address them more cheaply. For Indigenous people, this was little different from historic federal positions and resource allocations, but now it came with a policy rationale and "objectives oriented management."<sup>12</sup> The resulting budget cuts were especially damaging to tuberculosis control. Not only was tuberculosis especially expensive, but, as eradicationist Fred Soper noted, the most difficult part of disease reduction was the 'final inch,' when overall rates were low, only vulnerable populations remained, and treatment was most difficult and expensive.

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<sup>12</sup> "Minutes of Policy Review Group Meeting," March 20, 1972, 2, LAC, RG29 vol 2659 file 801-1-4 pt.1.

Meanwhile, the structures around Indigenous health care were fracturing, and centres of power shifted as more stakeholders entered the picture. The federal government offloaded Indigenous services delivery to the provinces, while territorial governments sought province-like powers and Inuit sought self-determination.<sup>13</sup> Inuit organized to achieve their goals. Their priority was land and resource rights, but they included health care.<sup>14</sup> The value of organizing for health care was undercut, however, by increased Inuit isolation from other Indigenous people under the new Indigenous healthcare regime; Inuit lost the influence that came with belonging to a larger group with greater capacity to advance shared concerns. More stakeholders meant new factors in the decision making processes related to health, for example, new consultation processes. By 1973, the federal government was required to consult Indigenous people on actions that affected them, even if consultations did not always influence government positions or policy outcomes. As Frost noted, "the government is required to consult, but does not necessarily have to wait for [Indigenous] agreement before taking action."<sup>15</sup>

Power balances in the public space changed also. New disease organizations and environmental groups entered the field. Cancer specialists and environmental scientists gained prominence. New awareness and fundraising campaigns challenged the capacity of the tuberculosis Christmas Seal drive. The venerable Canadian Tuberculosis Association changed its name to the Canadian Tuberculosis and Respiratory Disease Association, then simply to the Canadian Lung Association as it turned attention to smoking and its effects.<sup>16</sup> Wherrett and Grzybowski proposed research into non-tuberculosis lung problems, but not all proposals were

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<sup>13</sup> The Committee for Original People's Entitlement (COPE) was established in 1969, and the Inuit Tapirisat of Canada (ITC) in 1971. The ITC later became the Inuit Tapiriit Kanatami (ITK).

<sup>14</sup> Berger, *Report of Advisory Commission*, 23.

<sup>15</sup> Memo on "Interim Report - Policy Review Study," from W.H. Frost to M15 [Assistant Deputy Minister of Medical Services], February 22, 1973, LAC, RG29 vol 2659 file 801-1-4 pt.3a.

<sup>16</sup> This was also happening globally. For example, The International Union Against Tuberculosis became the International Union Against Tuberculosis and Lung Disease in this period.

funded. By 1974, yet another head of Medical Services, D.B. Dewar, a non-physician, asked internally why he was being asked to renew Wherrett's consulting contract: "I don't really understand this relationship. Can we discuss it?"<sup>17</sup> Wherrett himself was aware of his loss of influence, and regularly expressed gratitude for the opportunity to work on projects. His relationship with the federal department ended in late 1970s. With respect to Indigenous issues, debates and concerns in the public space shifted from the quality of Indigenous life and health to Indigenous self-determination and land rights, amplified by court action and constitutional negotiations.

The immediate result of these new political determinants of health was the cancellation of Frobisher Bay project expansion. Where the department in 1970 had chosen to spend \$74,000 to treat 370 people, in 1973 it chose not to spend \$490,000 to treat 2,500 people, even though it was a slightly lower cost per person, and would bring an immeasurably greater long-term public health benefit. The tuberculosis control protocol remained. It was largely unchanged on paper, but its scope had been restricted, and implementation became less rigorous in an environment of new priorities. These revisions were smoothed by the politics of ambiguity, as the terms referring to treatments became vague, and by the power of symbolism, evoked by new health concepts. For example, the budget cuts were masked by the new language of health promotion, which portrayed integrated health care as an advancement that carried holistic and ecological connotations. Thus, after the brief period when federal officials and health experts aimed to bring Inuit health to the levels experienced by other Canadians, the officials allowed northern health

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<sup>17</sup> Memo slip from D.B. Dewar, Assistant Deputy Minister, Medical Services to PA [unknown recipient likely in Dewar's office], appended to memo requesting approval of contract payment to G.J. Wherrett from W.H. Frost to M19 [unknown recipient likely with Ottawa offices of Medical Services], October 29, 1974. LAC, RG29 vol 2965 file 851-4-001 pt.13.

care to revert to Morantz's "pale imitation" of southern care. The resulting health outcome was the 1980s plateau in disease rates, then the continuous increase.

The loss of the direct benefits of the Frobisher Bay approach was accompanied by the forgetting of the project leaders' lessons of experience, consistent with McMillen's observed lack of historical memory in tuberculosis control. One forgotten lesson was Galbraith's warning about the damage caused by fragmented accountability in tuberculosis control. Wherrett's many lessons included cautions about the dangers of complacency, the need for continuity of knowledge, and most fundamentally, the need to finish the job of controlling tuberculosis. Grzybowski offered two lessons. His clinical conclusion, that both screening and treatment are required to control tuberculosis, is reappearing from under the cover of forgetfulness, and his attention to latent tuberculosis as a source of active disease is receiving renewed attention.<sup>18</sup> His larger lesson, that "one does not have to wait for many decades for socioeconomic development " to control tuberculosis remains mostly forgotten, but it raises current and contentious issues.

The first issue relates to causation: what comes first, good health or good social conditions? The social determinants model assumes good social conditions come first. Grzybowski implies the opposite. Jenness shares Grzybowski's view, saying Inuit need to be in good health and free of tuberculosis before other achievements can be attained.<sup>19</sup> Public health experts came to the same view after the 1990s tuberculosis-HIV outbreaks in New York, observing that biomedical structures and services had more impact on reducing the burden of

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<sup>18</sup> Kianoush Dehghani et al. "Determinants of tuberculosis trends in six Indigenous populations of the USA, Canada, and Greenland from 1960 to 2014: a population-based study." *The Lancet: Public Health* 3 no.3 (March 01, 2018): E133-142, [https://doi.org/10.1016/S2468-2667\(18\)30002-1](https://doi.org/10.1016/S2468-2667(18)30002-1).

<sup>19</sup> Diamond Jenness, *Eskimo Administration: II. Canada. Technical Paper No. 14* (Montreal: Arctic Institute of North America, 1964), 142.

disease than social factors.<sup>20</sup> Elsewhere Grzybowski qualifies his view on the applicability of biomedical measures by saying they are useful in regions "without severe financial constraints." The implication is that the measures are expensive, and that their cost matters. This ties directly to Soper's view that fully treating the 'final inch' is the only way to achieve both health equity and disease control, but it requires the political will to spend the necessary money. This is consistent with Bigg's view that public health is purchasable, given the political choice to buy it.

Political will is a common political reference in the literature on health, even in writing on social determinants where it is stated only in passing. In this history, the primary determinants of political will were centres of power, money, philosophy and public attention. The history also shows that political will was changeable. Monique Bégin, health minister after Marc Lalonde and later a health scholar, observed that in matters of health, Canada is above all "the country of pilot projects."<sup>21</sup> It has a history of funding health projects for a trial period, and when the funding ends so does the project, even if it is very successful.<sup>22</sup> The Frobisher Bay project fits firmly in this tradition. In other words, the Inuit experience of tuberculosis depends on political will and its determinants, which produce responses to disease that last only as long as the political moment.

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<sup>20</sup> A L Fairchild and G M Oppenheimer, "Public health nihilism vs pragmatism: history, politics, and the control of tuberculosis," *American Journal of Public Health* 88, no.7 (July 1998): 1105, <https://doi.org/10.2105/ajph.88.7.1105>

<sup>21</sup> Monique Bégin, "Do I see a demand? ... From 'Medicare' to health for all." Paper delivered at 19th World Conference of the International Union for Health Promotion and Education, Vancouver, June 14, 2007, printed in *Optimum Online* 37, no.3 (October 2007): 15, <http://www.optimumonline.ca/article.phtml?e=4JdoCAfcmUx22&id=284&page=1>.

<sup>22</sup> Bégin, "Do I see a demand?", 16.

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