



# The state of tuberculosis surveillance in Canada

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## Abstract

Tuberculosis incidence in Canada has remained essentially unchanged over the past decade. A strategic plan to reduce the burden of disease, underpinned by high-quality surveillance data, is sorely needed. However, tuberculosis surveillance data are lacking in Canada for multiple reasons. There is no single entity responsible for coordinating a tuberculosis response, including strategies for surveillance, thus inhibiting effective solutions. This in turn affects the timeliness and comprehensiveness of national tuberculosis surveillance reporting: between 2000 and 2020, there was an average 25-month delay to publication of annual surveillance data and the comprehensiveness of reports has precipitously fallen over time. Compounding these issues are case report forms for tuberculosis surveillance data which have not been updated since 2011, failing to keep up with the changing tuberculosis epidemiology and to provide information required for strategic planning. Common-sense steps can be taken to vastly improve the utility of collected tuberculosis surveillance data, and the development of a strategic plan for tuberculosis elimination. These include initiating a country-wide consultation on surveillance needs; allocating resources for data collection and analysis and data sharing; setting precise, measurable goals; and, importantly, establishing an oversight committee with representation from all provincial/territorial tuberculosis program leads who are held to account for performance.

## Résumé

L'incidence de la tuberculose au Canada est demeurée essentiellement inchangée au cours de la dernière décennie. Un plan stratégique visant à réduire le fardeau de la maladie, étayé par des données de surveillance de haute qualité, est grandement nécessaire. Cependant, les données de surveillance de la tuberculose font défaut au Canada pour de multiples raisons. Il n'existe pas d'entité unique chargée de coordonner la réponse à la tuberculose, y compris les stratégies de surveillance, ce qui empêche de trouver des solutions efficaces. Cette situation a une incidence sur la rapidité et l'exhaustivité des rapports nationaux de surveillance de la tuberculose : entre 2000 et 2020, la publication des données annuelles de surveillance a été retardée de 25 mois en moyenne, et l'exhaustivité des rapports a chuté de façon vertigineuse au fil du temps. Ces problèmes sont aggravés par le fait que les formulaires de déclaration des cas pour les données de surveillance de la tuberculose n'ont pas été mis à jour depuis 2011, ce qui entrave leur capacité à suivre l'évolution de l'épidémiologie de la tuberculose et à fournir les informations nécessaires à la planification stratégique. Des mesures de bon sens peuvent être prises pour améliorer considérablement l'utilité des données de surveillance de la tuberculose collectées et le développement d'un plan stratégique pour l'élimination de la tuberculose. Il s'agit notamment de lancer une consultation à l'échelle du pays sur les besoins en matière de surveillance, d'allouer des ressources pour la collecte et l'analyse des données et leur partage, de fixer des objectifs précis

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et mesurables et, surtout, d'établir un comité de surveillance composé de représentants de tous les responsables provinciaux/territoriaux du programme de lutte contre la tuberculose qui sont tenus de rendre compte des performances.

**Keywords** Tuberculosis · Surveillance · Communicable diseases · Public health

**Mots-clés** Tuberculose · surveillance · maladies transmissibles · santé publique

At the first-ever United Nations High-Level Meeting to End Tuberculosis in 2018, representatives from Canada committed to ending tuberculosis as a global health threat (Sahu et al., 2019). The World Health Organization classifies Canada as a low-incidence country with an annual incidence rate of 4.7 per 100,000 persons; however, the rate of disease has remained essentially unchanged for over a decade (Public Health Agency of Canada, 2022b).

Overcoming the persistence of tuberculosis in low-incidence settings is resource intensive and requires thoughtful, evidence-based action. A “Federal Framework for Action” for tuberculosis was released in 2014, but its goal of reducing the incidence of tuberculosis in Canada to 3.6 per 100,000 by 2015 was not achieved (Public Health Agency of Canada, 2014a). The reasons for its failure are multifactorial, with its implementation inhibited by a lack of oversight and limited data. Any future strategic plan will depend on strong leadership, and valid, robust, and timely surveillance data.

Herein, we describe current limitations of tuberculosis elimination efforts in Canada, with a focus on surveillance paired with concrete steps towards their resolution. As demonstrated by the COVID-19 pandemic, surveillance data are critical to inform and monitor public health responses (British Columbia Centre for Disease Control, 2022; Public Health Ontario, 2022).

## What are the key issues with tuberculosis surveillance in Canada?

Adequate tuberculosis surveillance in Canada is hindered by shortcomings in four main areas: leadership and governance, timeliness in reporting, data accessibility, and comprehensiveness of reports.

### Absence of leadership and a coordinated national response to tuberculosis

There is no single entity responsible for coordinating a response to tuberculosis in Canada. Since the Canadian Tuberculosis Committee (CTC)—and all its subcommittees—was disbanded in 2011, a leadership vacuum has emerged. At the national level, tuberculosis and its surveillance fall broadly under the responsibility of the Public Health Agency of Canada (PHAC), with tuberculosis-related

activities dispersed through multiple divisions, while technical guidance and recommendations to support surveillance are the responsibility of the Communicable Infectious Disease Steering Committee of the Pan-Canadian Public Health Network (Pan-Canadian Public Health Network, 2012). Other national-level organizations exist, such as the National Collaborating Centre for Infectious Diseases, but have no authority or mandate to lead or direct tuberculosis surveillance efforts. In the absence of national leadership, an ad hoc network of clinicians, researchers, and advocates—the Canadian Tuberculosis Elimination Network—was formed, but participation is voluntary, and as a result, their authority to implement change is limited.

### Delayed reporting of tuberculosis surveillance data

Until March 2022, the most recent tuberculosis data published by PHAC were for the reporting year 2017 (LaFreniere et al., 2019). In March 2022, PHAC released a full report on tuberculosis for the year 2018 and a high-level infographic for 2020 (Public Health Agency of Canada, 2022a, 2022c); a full report covering 2019 and 2020 was released in July 2022 (Public Health Agency of Canada, 2022b). For tuberculosis data published for reporting years covering 2000 to 2020, the average delay in publication was 25 months, with minimum delays over a year. Without timely analysis and reporting, “annual” reports do not reflect contemporary contexts and have minimal application to developing strategies for prevention. As a practical example, the national impact of the COVID-19 pandemic on tuberculosis in Canada could only be evaluated more than 2 years after it began.

### Lack of accessibility and relevance of tuberculosis surveillance data

Tuberculosis surveillance data are managed by PHAC within the Canadian Tuberculosis Reporting System (CTBRS) (Public Health Agency of Canada, 2014b). Data submitted to the CTBRS come from two non-nominal case report forms containing 37 items related to baseline, treatment, and outcome characteristics of each person diagnosed with tuberculosis disease. However, these forms have not been updated since January 2011. To compile case-reporting information required by PHAC each year, provinces and territories navigate a myriad of sources—digital and paper—that are rarely

designed or adapted for infectious disease reporting nor for integration with each other. In parallel, the Canadian Tuberculosis Laboratory Surveillance System monitors emerging trends in drug resistance (Public Health Agency of Canada, 2014b); however, it is not integrated within the CTBRS, leading to barriers in analyzing drug resistance beyond simple demographic (age, sex, and location) data.

Despite the effort required of provinces and territories to submit data to the CTBRS, access to the data contained within it is limited. The Canadian Notifiable Disease Surveillance System makes available only case counts and rates by year, with stratification by age and sex in more recent years (Government of Canada, 2021). No formal mechanisms exist to request more detailed data by provinces and territories or by researchers, with limited analyses performed by PHAC and annual reports scattered across different repositories.

### **Paucity of surveillance data released in tuberculosis reports**

The granularity of tuberculosis surveillance reports in Canada has substantially fallen over time. Reports from 2000 to 2012 provided detailed presentations of data—often stratified by year to understand temporal trends and by province/territory to understand regional trends. Reports in this period included nearly 60 tables and figures of surveillance data. However, between 2013 and 2017, reports contained about 14 tables and figures of surveillance data, providing little more than a snapshot of disease incidence, origin of cases, and treatment outcomes. Though the 2018 report rose to nearly 70 tables and figures, the report covering 2019 and 2020 had only 24.

### **What is the way forward?**

Even though there are several issues plaguing the utility of tuberculosis surveillance data in Canada, concrete steps to address each issue are possible. We draw on how tuberculosis surveillance is conducted in the United States—another low-incidence country, but one that has seen its tuberculosis incidence fall 25% in the last decade to 2.4 per 100,000 persons (Filardo et al., 2022)—for potential solutions.

### **Establish a Canadian Tuberculosis Elimination Advisory Committee**

A major signal from the federal government that it is committed to achieving tuberculosis elimination would be to re-establish a Canadian Tuberculosis Elimination Advisory Committee, with representation from all provincial/territorial tuberculosis program leads and impacted populations (e.g.,

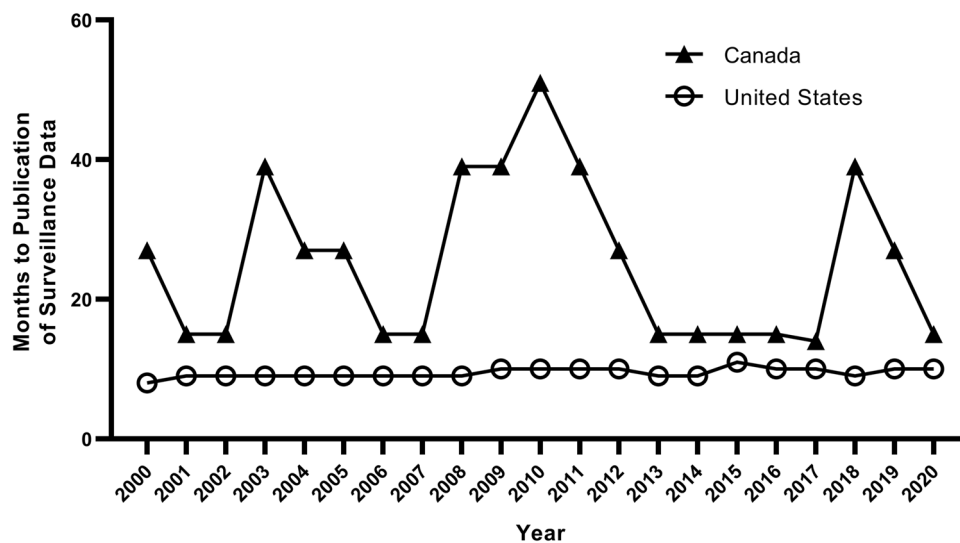
Indigenous and immigrant communities) to ensure accountability. Such a committee could be modelled after the Division for Tuberculosis Elimination within the National Center for HIV, Viral Hepatitis, STD, and TB Prevention of the Centers for Disease Control and Prevention in the USA, with the authority and capacity to provide much-needed coordination and leadership on collaborative national and subnational tuberculosis responses while holding federal, provincial, and territorial entities accountable.

### **Initiate a country-wide consultation on tuberculosis surveillance needs**

The current case report forms submitted to the CTBRS are over a decade old, and so too was the last major consultation of stakeholders on needs for program monitoring. In contrast, case report forms in the USA were updated as recently as 2020. A country-wide consultation on tuberculosis surveillance—bringing together federal, provincial, and territorial ministries of health, civil society, representatives of tuberculosis-affected communities, clinicians, and academics—would help identify priorities moving forward. Such a consultation could allow for refinement of the data elements collected by the CTBRS; annual indicators reported by PHAC and provincial/territorial TB programs; agreement and accountability structures for high-quality, timely reporting of surveillance data; and establishment of surveillance standards for challenges to elimination (e.g., immigration, transmission, drug resistance, and tuberculosis infection).

### **Allocate funding and prioritize tuberculosis surveillance**

Accurate, timely, publicly accessible surveillance data are only possible with adequate funding, organizational structures, and tailored digital health data systems. The resources available to provinces, territories, and PHAC to collect, validate, and share tuberculosis surveillance data vary. Many provincial health data systems were not designed for infectious disease data collection, and many must triangulate data from multiple sources with limited resources to fulfil reporting obligations to the federal government. Despite alarms being raised for decades, only Ontario has a formalized agreement to share epidemiologic data with PHAC. These are all major barriers to accurate and timely data sharing. Comparatively, in the USA, though each state manages its own surveillance data system, all states use CDC-developed systems or follow the HL7 format (United States Centers for Disease Control and Prevention, 2022) for surveillance data and surveillance data thus are reported in a much more timely manner (Fig. 1). The Pan-Canadian Health Data Strategy (Public Health Agency of Canada, 2021) attempts to address



**Fig. 1** Time to publication of surveillance reports from 2000 to 2020 in Canada and the USA. We calculated the time to publication of surveillance reports from January 1 of the subsequent year (i.e., for the 2020 surveillance report, we counted the first day as January 1, 2021). In the USA, an exact month was unknown for the year 2002, and so it was assumed to follow the pattern from the preceding

and subsequent year. In Canada, exact months of publication were unknown for all reports not published in *Canada Communicable Disease Report*; it was assumed all publications where month was unknown were published in March, following recent and historical norms

these fundamental roadblocks, prioritizing the interoperability of data-sharing systems and modernizing health data collection and access, and data governance structures; however it must be successfully executed and resourced to mitigate these issues.

### Set precise, monitorable goals for tuberculosis elimination

A critical function of tuberculosis surveillance is its use for program monitoring and evaluation, including at national and subnational levels. Developing or adapting an action framework to achieve tuberculosis elimination targets, with precise interim goals, is an important step to ensure transparency and accountability. This framework would motivate relevant, timely reporting of surveillance data, while providing benchmarks to guide evidence-based decisions regarding approaches to tuberculosis elimination at provincial and territorial levels as well as nationally. Such a framework has been provided in the most recent edition of the Canadian Tuberculosis Standards (Heffernan et al., 2022), and its use should be encouraged as a first step.

### Conclusion

Common-sense steps can be taken in Canada to vastly improve the utility of the tuberculosis surveillance data collected. The contrast between Canadian responses to tuberculosis and

COVID-19 in terms of surveillance efforts, data accessibility, and transparency is indicative of a lack of commitment to addressing long-standing health inequities in Canada. Ultimately, improving surveillance for tuberculosis is but one of several essential steps to mitigate its impact and make progress towards elimination. However, the absence of high-quality surveillance data for tuberculosis makes it impossible to track progress, obscures key disparities, and—at its core—is a failure to prioritize the health of all Canadians equally.

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### Declarations

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