The Canadian Bronchiectasis and Nontuberculous Mycobacteria Registry: a study protocol

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This longitudinal study will be used for analysis to form evidence-based clinical practices, and serve as a resource in Canada to inform future studies in NTM and bronchiectasis
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Abstract

Background Bronchiectasis is a complex, chronic disease with geographic and ethnic diversity. While the most substantial cohort studies have been conducted in Europe and the USA, Canada also faces considerable challenges. The comprehensive Canadian Bronchiectasis and Nontuberculous Mycobacterial (NTM) Registry aims to 1) outline the clinical characteristics and natural history of bronchiectasis in Canada, 2) identify risk factors contributing to disease progression within Canadians, 3) integrate comprehensive clinical information to better understand the phenotypes of bronchiectasis and 4) support the development of large-scale, randomised controlled trials in Canada.

Methods The Canadian Bronchiectasis and NTM Registry is an ongoing prospective, longitudinal, multicentre, observational cohort study. It aims to enrol at least 2000 participants to collect data such as medical history, aetiological assessments, lung function tests, microbiological profiles, radiographic evaluations, comorbidities and quality of life (QoL) metrics. Participants will undergo annual follow-ups to gather longitudinal information regarding outcomes, treatments and changes in QoL. The inclusion criteria are a diagnosis of bronchiectasis by clinical history and computed tomography and/or pulmonary NTM infection as defined by American Thoracic Society/Infectious Diseases Society of America guidelines. The study's protocol received ethical approval from the lead site, the University of Calgary, with future additional approval from local ethics committees at all participating centres.

Discussion The outcomes of the registry will be instrumental in uncovering the clinical traits and natural history of bronchiectasis. This longitudinal study will be used for analysis to form evidence-based clinical practices and serve as a resource in Canada to inform future studies in NTM and bronchiectasis.

Background

Noncystic fibrosis bronchiectasis, hereafter referred to as bronchiectasis, is characterised by cycles of inflammation and chronic infection and was once considered the "most neglected disease" in all of respiratory medicine [1]. Over the last decade, the prevalence of bronchiectasis has increased by 40% and is now estimated to be up to 566 per 100 000 people [2], making it the third most common chronic airways disease [3]. Despite higher prevalence than cystic fibrosis (CF), a disease with similar pulmonary clinical sequalae, bronchiectasis remains relatively neglected, undertreated and underserviced in part due to historic low prevalence, diverse clinical presentations and heterogeneity of underlying aetiologies [4]. The burden and mortality of bronchiectasis is high with estimated annual healthcare costs of USD 630 million [5] and hospital admissions ranging from two to six people per 100 000 [6]. Currently, incidence,

prevalence and morbidity are unknown in Canada. This has important implications because, given the heterogeneity of disease, geographical variation likely plays a significant role in aetiology and management of sequalae (*e.g.* local practice patterns around nebulised antibiotics to suppress chronic infections).

The prevalence of pulmonary disease caused by nontuberculous mycobacterium (NTM) is on the rise globally, with a notably high occurrence in individuals suffering from chronic pulmonary conditions, including bronchiectasis [7, 8]. Moreover, NTM colonisation and infection may be a cause or consequence of bronchiectasis and can exacerbate disease progression. Recent guidelines recommend individuals diagnosed with bronchiectasis undergo screening for NTM [9, 10] as this may have downstream implications for management (*i.e.* use of macrolides) [11, 12]. However, epidemiologic data related to this disease is limited in Canada with one study evaluating NTM cultures from 1998 to 2010 identifying annual rates of pulmonary NTM isolation and disease prevalence were 11.4 isolates and 4.65 cases per 100 000 population in 1998 and 22.2 and 9.08 per 100 000 in 2 010, with frequency of pulmonary isolation and disease increasing steadily [13]. A recent meta-analysis reported that while the overall prevalence of NTM in bronchiectasis was 7.7%, there was significant regional variability with the highest in North America at 50% [14]. Limited data is partly attributable to NTM not being a reportable infection and isolation of these organisms not necessarily being indicative of disease [15]. Treatment decisions are complex as not all patients with positive cultures require or benefit from treatment. Where treatment is administered, multiple drugs are required for long durations (several months to years), patients are often frail and disease recurs in more than 30% [16].

We propose that the diverse Canadian population and healthcare system structure will reveal distinct aetiologies, prevalence, presentation and quality of life (QoL) characteristics amongst Canadian bronchiectasis and NTM patients. The aims of the Canadian Bronchiectasis and NTM Registry include 1) determining national bronchiectasis and NTM prevalence rates, 2) defining bronchiectasis aetiologies and identifying specific phenotypes amongst Canadian patients, 3) recording impacts on QoL of patients, and 4) collecting follow-up data to determine longitudinal effects. The registry will be the sole extensive, prospective, multicentre, longitudinal cohort study dedicated to adult bronchiectasis and NTM patients within Canada. The registry aims to enrol eligible participants with bronchiectasis and/or NTM and systematically gather clinical information and QoL measures, providing longitudinal follow-up for forthcoming studies and audit areas for improvement in patient outcomes. Taken together, we describe the study protocol of the proposed registry design and development.

Methods and analyses

Study objectives

The objective of this study is to develop the Canadian Bronchiectasis and NTM Registry with baseline and annual follow-up data. This would serve to support collaborative research, assist in multi-centre clinical trials for the treatment of NTM and bronchiectasis, and aid in the development and implementation of a national registry to ultimately optimise the care of patients. Key areas of need include determining clinical- and cost-effectiveness of health care, tracking compliance with guideline-recommended treatment, measurement and monitoring safety of therapy, measuring quality of care, standardising preventative care for patients (*e.g.* appropriate follow-up, testing and recommended medical regimens), and describing the evolution of pulmonary NTM disease in Canada (including but not limited to evaluation of the burden and patterns of disease within populations and communities). Long-term objectives from this pilot study include:

1) Understanding the current practice of bronchiectasis and NTM care across Canada.
2) Identifying opportunities to provide improved support to healthcare providers in the care of bronchiectasis and NTM patients across Canada.
3) Facilitating research into the different types of bronchiectasis and NTM infection, as well as pathophysiology, microbial and immunoinflammatory factors driving the natural history of these diseases.
4) Determining the feasibility of and requirements for a national bronchiectasis and NTM dataset and registry to better understand health outcomes.
5) Leveraging the database to engage development and clinical trials of therapeutics in unique patient populations in Canada.

Registry design

The Canadian NTM and Bronchiectasis Registry is a multicentre, prospective, noninterventional, observational cohort study enrolling consecutive adult patients with bronchiectasis and/or pulmonary NTM in Canada. The structure for the registry protocol and case-report forms was adapted from the US Bronchiectasis and NTM Registry protocol [17], with the consent of leadership. Consequently, the data collected in the Canadian registry closely mirrors that of the US Bronchiectasis and NTM Registry, albeit

with certain adjustments to cater to specifics of the Canadian context regarding bronchiectasis. Due to the observational nature of the study, the management of bronchiectasis has been under the purview of the attending physicians at each participating local hospital. Hence, researchers involved were advised to adhere to the latest guidelines for managing adult bronchiectasis and NTM disease in their routine clinical practice [9, 10, 18], to ensure consistency and standardisation of care processes before the study commenced. The study received necessary approval from the University of Calgary, Calgary, Alberta Canada ethics board (REB21-1131).

Inclusion and exclusion criteria

The criteria for inclusion in this registry are as follows. 1) Individuals aged 18 years or older, with or without respiratory symptoms such as cough, chronic sputum production and/or recurrent respiratory infections, who have chest computed tomography (CT) scans showing evidence of bronchiectasis in one or more lobes. 2) Chest imaging findings suggestive of NTM and one or more of the following: sputum specimens, bronchoscopy sample or lung tissue sample testing culture positive for NTM as per current guidelines by the American Thoracic Society (ATS), the European Respiratory Society (ERS), the European Society of Clinical Microbiology and Infectious Diseases, and the Infectious Diseases Society of America (IDSA) [18]. 3) Receipt of a bronchiectasis diagnosis by a pulmonologist using compatible radiographic and clinical findings (figure 1). The exclusion criteria for participants include 1) bronchiectasis secondary to CF, 2) traction bronchiectasis associated with interstitial lung disease, 3) age <18 years, 4) growth of NTM from an extrapulmonary site, 5) suspected NTM based on radiographic findings but lacking supportive microbiological findings and 6) lack of patient consent.

Identification and recruitment

Patients eligible for this study can be identified and enlisted from various healthcare settings, including outpatient clinics, specialised hospital departments or subspeciality care facilities. The study is designed to encompass patients from all these environments, aiming to capture a comprehensive overview of how bronchiectasis is managed and its epidemiology across Canada. The primary site of enrolment will be the University of Calgary, which encompasses two subspeciality clinics (bronchiectasis and NTM). Thereafter, expansion of the registry will be performed across provinces and territories in Canada. Patients will be followed-up at least once a year; however, during the year, the frequency of outpatient clinic visits will be determined as per the protocol of the attending physician and enrolment site.

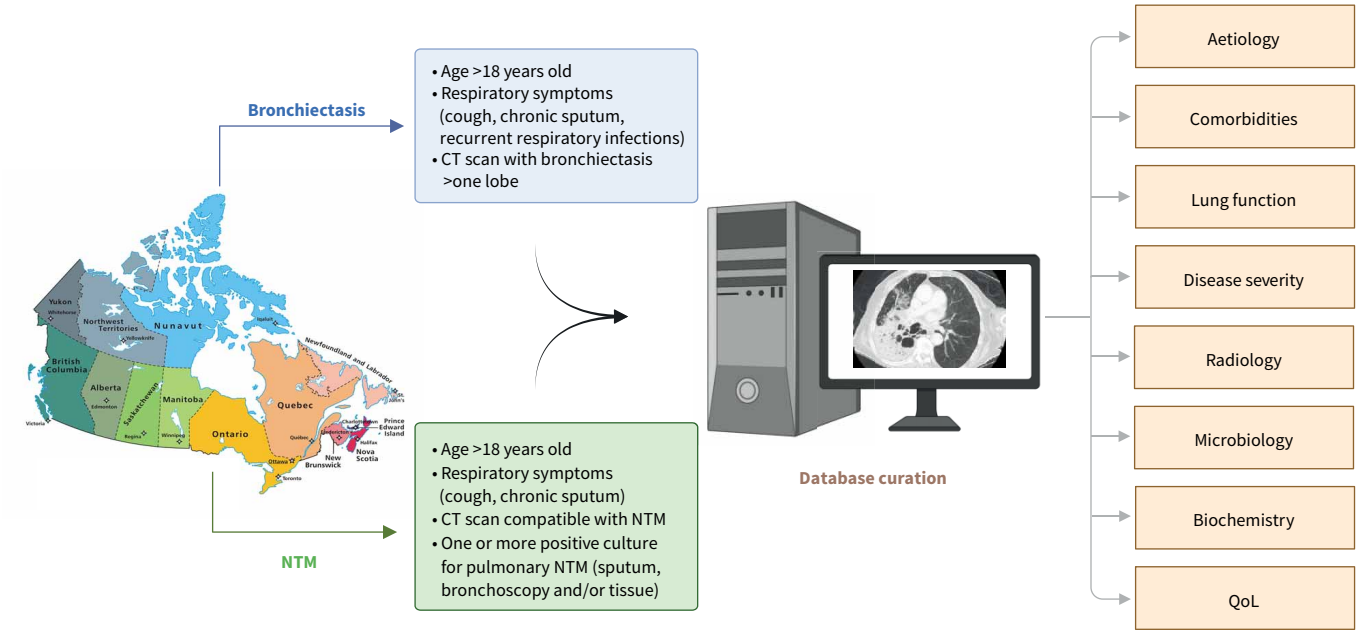

FIGURE 1 Overview of the Canadian bronchiectasis and nontuberculous mycobacteria (NTM) registry. Participants will be identified across Canada and enrolled based on inclusion criteria. Data will be entered into the registry across multiple domains at baseline and on an annual basis. Figure created with BioRender. CT: computed tomography; QoL: quality of life.

Data collection

Data collection will occur across three separate categories, namely 1) entry data at the study's inception, which includes the foundational dataset necessary for patient recruitment; 2) an annual review form, which gathers follow-up information for each year, detailing the frequency of exacerbations, hospital admissions and disease progression, and 3) time of acute exacerbation. Data collection and analysis has been modelled after the US Bronchiectasis and NTM Research Registry, similar to that of other global registries, including the European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) [19]. Harmonisation of data was done purposefully such that future, global analysis across international registries using similar data collected could be completed with the inclusion of this Canadian cohort.

Definition of exacerbation

The registry will have a practical real-world definition for an acute exacerbation, as outlined by EMBARC [19]. In brief, an acute exacerbation will be defined as a sudden worsening of the patient's health with a physician diagnosis of exacerbation and initiation of systemic (oral or intravenous) antibiotics [9]. The database will also document visits to the emergency department for exacerbations that do not culminate in hospital admission. Severe exacerbations will be categorised according to British Thoracic Society guidelines as those necessitating hospitalisation [9].

Follow-up

Patient information is gathered yearly, allowing for a 6-month fluctuation, in accordance with regular clinical visits. This continues unless the patient is formally discharged from care, passes away or chooses to withdraw from the study. Detailed information is described in table 1.

QoL

The Canadian NTM and Bronchiectasis registry will utilise two measures of QoL and patient-reported outcomes to better ascertain disease impact. The registry will employ the QoL–Bronchiectasis (QoL-B) questionnaire, version 3.1 [20] as described by EMBARC [19]. This tool is chosen because it is the sole disease-specific QoL instrument validated for bronchiectasis. The questionnaire encompasses various domains such as physical and role functioning, vitality, emotional and social functioning, the burden of treatment, perceptions of health, and respiratory symptoms. Secondly, the registry will also evaluate the

TABLE 1 Data collection at baseline, annual follow-up and exacerbation events in the Canadian bronchiectasis and nontuberculous mycobacteria (NTM) registry

Baseline	Annual follow-up	Exacerbations
Enrolment date	Age	Microbiology
Age	BMI	Antibiotic regimens
Sex and gender	Comorbidities	Treatment
Ethnicity	Pulmonary function tests	Hospitalisation/emergency room visits
BMI	6-min walking distance	
Comorbidities	mMRC dyspnoea score	
Pulmonary function tests	Smoking history	
6-min walking distance	Exacerbation history in the year prior	
mMRC dyspnoea score	Updated medical history and laboratory tests to determine bronchiectasis aetiology	
Smoking history	Cardiac testing (*i.e.* ECG, echocardiogram)	
Exacerbation history 2 years before study enrolment	Audiometry	
Aetiology of bronchiectasis and associated workup *(i.e.* blood cell counts, immunoglobulins, ABPA testing, *etc.*)	Microbiology	
Cardiac testing (*i.e.* ECG, echocardiogram)	Radiology	
Audiometry	Medications	
Microbiology	Chest physiotherapy regimens	
Radiology	BSI	
Medications	FACED score	
Chest physiotherapy regimens	QoL-B	
BSI		
FACED score		
QoL-B		

ABPA: allergic bronchopulmonary aspergillosis; BMI: body mass index; BSI: bronchiectasis severity index; FACED: forced expiratory volume in 1 s, age, chronic colonisation by *Pseudomonas aeruginosa*, extension, dyspnoea; mMRC: modified Medical Research Council; QoL-B: Quality of Life–Bronchiectasis Questionnaire.

recently validated patient-reported visual analogue outcome measure, the Bronchiectasis Impact Measure, as a patient-reported outcome, which has shown validity and consistency particularly during acute exacerbations as compared to baseline periods [21]. Both measures will be done by integrating an automatic calculation tool within the registry's platform and will be available in both English and French.

Aetiology and definition of NTM disease

The cause of bronchiectasis is established by the attending physician of the participant. Comprehensive information on the tests conducted to evaluate for potential aetiology is gathered, adhering to the testing protocols recommended by consensus guidelines. As a result, the foundational data supporting a diagnosis are collected and can be verified as done previously [19]. NTM pulmonary disease will be defined as per guideline recommendations [18], which include clinical (*i.e.* pulmonary symptoms), radiologic (*i.e.* nodular or cavitary opacities or a CT scan demonstrating bronchiectasis with multiple small nodules) and microbiologic (*i.e.* positive culture results from at least two expectorated sputum samples or positive culture results from at least one bronchial wash/lavage or transbronchial lung biopsy demonstrating mycobacterial histologic features) diagnostic criteria.

Lung function

Measurements of height, weight and pre-bronchodilator spirometry results, including forced expiratory volume in 1 s (FEV_1) and forced vital capacity, will be documented. Absolute values and percentage of predicted values will be recorded. If available, post-bronchodilator spirometry will be collected. Spirometry testing will be performed at baseline and at yearly follow-up visits according to the standards set by the ATS/ERS [22].

Bronchiectasis disease severity

To evaluate disease severity in those with bronchiectasis, the bronchiectasis severity index (BSI) [23] and FEV_1, age, chronic colonisation by *Pseudomonas aeruginosa*, extension, dyspnoea (FACED) score [24] will be calculated at baseline and yearly follow-up visits. The necessary variables required for calculations (*i.e.* hospitalisations, the modified Medical Research Council dyspnoea score, radiologic measure of disease, *P. aeruginosa* colonisation state, *etc*.) is captured as part of case forms. The database will feature an automated calculator specifically designed for both the BSI and FACED scores and will allow comparisons of both measures longitudinally [25].

Comorbidities

All participants will have comorbidities recorded including pulmonary (*i.e.* presence of concomitant asthma, COPD, nasal polyps and chronic sinusitis) and extrapulmonary comorbidities (*i.e.* cardiovascular diseases, metabolic disorders, chronic liver diseases and osteoporosis), mental health conditions (*i.e.* anxiety and depression), chronic kidney disease and malignancies).

Microbiology

The microbiological composition of both spontaneous sputum samples and lower respiratory tract specimens (which may include induced sputum, bronchoalveolar lavage or nasopharyngeal swabs) will be identified [19]. Cultures of sputum from participants who are clinically stable as well as those experiencing acute disease exacerbations will be evaluated. Given the strong association between *P. aeruginosa* and increased morbidity and mortality in bronchiectasis [26], detailed information on *P. aeruginosa*, including the timing of its detection, type of strain (mucoid or nonmucoid, if available) and administration of oral, intravenous or inhaled antibiotics for eradication, will be collected. NTM species and burden (*i.e.* acid-fast bacilli smear positivity) will be recorded, if/when available.

Radiology

The extent of bronchial dilatation and the number of lobes affected will be assessed to determine the severity of bronchiectasis utilising the modified Reiff score [27], as has been done previously by international registries [19, 28–30]. The physician will classify the radiological severity in each lobe as no, tubular, varicose or cystic bronchiectasis.

Treatments

The registry will collect data of regular respiratory treatment for bronchiectasis and NTM participants, which includes the following categories: 1) respiratory medications, such as long-acting muscarinic antagonists (LAMAs), inhaled corticosteroids (ICS), long-acting β_2 agonists (LABAs), combinations of ICS/LABA and LAMA/LABA, intravenous immunoglobulin, itraconazole, leukotriene receptor antagonists, long-term oral steroid use (for 28 days or more), monoclonal antibodies, mucoactive drugs, and nebulised bronchodilators; 2) antibiotic treatments, including inhaled antibiotics, long-term oral antibiotics (defined as >28 days) and

immunomodulatory agents such as macrolides and systemic antibiotics; 3) chest physiotherapy and technique(s) utilised; 4) mucoactive treatments, such as nebulised saline and/or hypertonic saline; and 5) other adjunct therapies, including long-term home oxygen therapy or noninvasive ventilation.

Quality control, data management and monitoring

The registry collects and stores data *via* the electronic data capture application REDCap. Data is secured through REDCap security systems, including user authentication and role-based security. Any data requested by supporters will be de-identified, ensuring the protection of patient privacy. REDCap also employs several quality control measures to ensure data integrity. Firstly, REDCap checks for mandatory field types (*e.g.* a numeric entry for systolic blood pressure) and uses validity functions to check that data ranges fall within specified limits [31]. Secondly, REDCap will alert the end-user whenever data violates quality control measures (*e.g.* double entry and missing values), allowing them to revise the data [31]. Third, research coordinators will be trained according to standard research protocols to ensure the completeness and accuracy of entered data. Every case recorded in the registry undergoes manual verification by a study team member, with any data discrepancies addressed directly with the study site. Cases that have incomplete data or unresolved issues will be excluded to maintain data integrity. Additionally, source data verification and random audits will be performed at study sites to ensure data accuracy and reliability.

Sample size

We chose a pragmatic sample size of 2000 patients, based on the Canadian population size as compared to other global registries and to ensure rare disease aetiologies underpinning bronchiectasis is captured. Given the unique geographic spread across Canada, we aim to capture sites from all provinces and territories. We anticipate that at least 12 centres will be recruited, with expansion beyond this as resources and long-term sustainability permits.

Governance, oversight and data sharing

Bronchiectasis and NTM clinic care providers across Canada will be invited to participate in enrolling patients at their local centres for inclusion in the database as well as deposition of relevant active clinical trials. All patients must provide written informed consent *via* a consent form prior to any collection and storage of data. The registry will be held securely at the home study site, the University of Calgary, through a web-based data management system housed at the Research Clinical Unit with a protected firewall system to ensure physical and technical data security. The study adheres to the principles of good clinical practice, ensuring ethical conduct throughout. Each participating site will secure a favourable ethical review from the relevant research ethics committee or institutional review board, as necessary. Moreover, all additional approvals needed by partner sites will be acquired before the study begins at each location. Local investigators have unrestricted access to their own data. Nonetheless, conducting a comprehensive data analysis necessitates the submission of a research proposal to the primary site, the University of Calgary Scientific Committee. Access to the full dataset is provided once the research proposal receives approval. A clinical trial identifier of NCT06144996 has been assigned to the Canadian Bronchiectasis and NTM Registry, which was formally established in November 2023. The registry study group will adhere to the authorship guidelines recommended by the International Committee of Medical Journal Editors. The findings will be distributed through annual reports, presentations at conferences and publications in peer-reviewed journals.

Participant involvement

We plan to invite participant champions from the bronchiectasis and NTM clinics to participate in further dissemination and translation into national involvement. We will further strive to use this platform as a resource for key stakeholders (both healthcare providers and patients) towards dissemination of reference material and tools to provide support to both groups. Finally, participants who may be interested and eligible for future clinical trials will be identified and enrolled, provided that consent to contact has been obtained.

Discussion

The Canadian Bronchiectasis and NTM Registry represents the first and only prospective multicentre cohort study in Canada aimed at assessing the clinical traits, natural progression and prognosis of bronchiectasis and pulmonary NTM disease. By conducting an exhaustive evaluation of these patients in Canada, the registry will address research inquiries into both NTM and bronchiectasis. It will also provide data to assist physicians in determining the aetiology and managing patients in real-world scenarios. Moreover, the registry will provide the first comprehensive epidemiologic studies from Canada that have unique geographical and diverse population considerations. Given the known geographical differences in the aetiology, epidemiology and microbiology of bronchiectasis [32], as well as species distribution of

NTM [33], data from other regions may not be wholly applicable. Taken together, the Canadian registry will be instrumental in advancing the management of bronchiectasis and NTM, not only at a regional level but also by fostering research collaboration with other global registries.

Data collection has become increasingly common due to the prevalence of electronic systems and can serve to evaluate events within and across healthcare systems and improve quality of care. At present, the lack of approved treatments for bronchiectasis, alongside insufficient clinical trial success, limits the establishment of evidence-based interventions. The development of clinical registries is essential for advancing our understanding of the pathophysiology bronchiectasis, especially considering the geographical variations seen in this disease. EMBARC has significantly contributed to bronchiectasis and NTM research in recent years [34–38] alongside the rise of other registries globally [17, 28–30, 39–42].

Despite the significant morbidity associated with bronchiectasis and NTM infections and the significant healthcare burden they represent, there are limited data regarding the characteristics of patients with these conditions in Canada, as well as varying clinical practice patterns. In 2018, the British Columbia Centre for Disease Control completed a comprehensive survey assessment of bronchiectasis and NTM care providers across British Columbia, including physicians, nurses, laboratory practitioners, pharmacists and other allied health providers that delivered direct care to bronchiectasis and NTM patients over the preceding 12 months [43]. As part of this evaluation, the survey identified overwhelming support for a bronchiectasis and NTM registry by survey participants (33/34; 97.1%) citing unmet needs including determining the clinical- and cost-effectiveness of healthcare, tracking recommended treatment and preventive care for patients, and delineating the natural history of NTM. Active case ascertainment (*i.e.* registry staff locating patients and gathering data) was favoured over passive or sentinel case ascertainment approaches. The report concludes that while a bronchiectasis and NTM registry is an unmet need for Canadian healthcare providers, separate and dedicated consideration is required to ascertain feasibility and logistics in terms of financial resources and personnel.

Several limitations of the registry need to be acknowledged. First, the enrolment of patients from primarily hospitals and/or subspeciality (*i.e.* pulmonary and infectious diseases) clinics may limit capture of the diverse spectrum of bronchiectasis and NTM throughout Canada and may limit generalisability across the population. Once pilot analysis is completed and based on its feasibility, the registry may expand to primary care enrolment and advertisement efforts, allowing for capture of this population. Secondly, as with any registry study, patient withdrawals and incomplete data could introduce bias and there may be confounding factors that are not identified or measured, as has been previously described. To mitigate this, periodic interim data analysis will be completed in an iterative process.

Conclusions

In summary, the Canadian Bronchiectasis and NTM Registry will create an extensive clinical translational database for a large cohort of well-documented individuals with bronchiectasis and NTM in Canada. This registry will offer novel insight into disease epidemiology, progression and healthcare burden among Canadian patients. Moreover, the ability to harmonise data with larger, global registries will provide a broader view of bronchiectasis and NTM and pave the way for future international collaborations.

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This study is registered at www.clinicaltrials.gov with identifier number NCT06144996.

Ethics statement: The study received the necessary approval from the University of Calgary, Calgary, Alberta Canada ethics board (REB21-1131).

Author contributions: C.S. Thornton, N. Boechler and V. Desai drafted the first version of this manuscript. C.S. Thornton and J. Jarand conceived and designed the overall study. C.S. Thornton, R. Somayaji, S. Purighalla, S. Brode, T.K. Marras, R. Cooper, M. Smith and J. Jarand are responsible for study oversight, management and coordination. All authors received the manuscript for intellectual content. All authors read and approved the final manuscript.

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