EXPLORING SPECIALIZED CARE FOR NON-TUBERCULOUS MYCOBACTERIAL (NTM) PATIENTS IN BRITISH COLUMBIA (BC)

Prepared by:

Audrey Campbell, MD MHSc FRCPC Public Health & Preventive Medicine Physician Clinical Assistant Professor, University of British Columbia Assistant Professor, Northern Ontario School of Medicine Assistant Clinical Professor (Adjunct), McMaster University

Jasmine Pawa MD CCFP MSc FRCPC Public Health & Preventive Medicine Physician Adjunct Lecturer, Dalla Lana School of Public Health, University of Toronto

2018

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	4
FUNDING	4
ABBREVIATIONS AND ACRONYMS	5
EXECUTIVE SUMMARY	6
BACKGROUND	9
BC CONTEXT	9
KNOWLEDGE GAP	10
OBJECTIVES	10
METHODS	10
DATA COLLECTION TOOL	11
PARTICIPANTS	11
COMPENSATION	11
ETHICS	12
DATA ANALYSIS	12
RESULTS	13
RESPONDENT CHARACTERISTICS	13
DEMOGRAPHIC AND OCCUPATIONAL CHARACTERISTICS	13
GEOGRAPHIC REPRESENTATION	13
NTM CARE VOLUME AND TYPE OF NTM	13
REFERRAL	13
GUIDELINES	14
DIAGNOSTIC TOOLS AND TREATMENT	14
BARRIERS TO NTM CARE	16
ENABLING FACTORS FOR NTM CARE	16
MODEL OF NTM CARE IN BC	17
NTM REGISTRY	18
ADDITIONAL INFORMATION	20
DISCUSSION	21
NTM REGISTRY	21
Resource needs	21
MINIMUM DATASET	22
Reporting form	22
MODELS OF NTM CARE	23
DEDICATED NTM CLINICS IN OTTAWA, TORONTO, AND CALGARY	23
OTHER JURISDICTIONS (BC, US)	24
REASONS FOR CLINIC ESTABLISHMENT	24
CONSIDERATIONS FOR CLINIC MODELS	24
STRENGTHS AND LIMITATIONS	25

SUMMARY	25
APPENDIX A – ADDITIONAL TABLES AND FIGURES	27
APPENDIX B - NTM SURVEY	29
APPENDIX C - NTM REPORTING FORM	30

ACKNOWLEDGEMENTS

The authors with to thank Provincial TB Services, Clinical Leadership for their feedback in developing the survey, and those individuals who shared information regarding NTM care in other jurisdictions, including Dr. Ted Marras, Dr. Gonzalo Alvarez, and Ms. Judith Lang.

FUNDING

Funding for this project was provided by the Shared Care and Specialists Services Committee Redesign Funding for Physician Engagement

ABBREVIATIONS AND ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome ATS: American Thoracic Society BC: British Columbia BCCDC: BC Centre for Disease Control CD: Communicable disease CF: Cystic fibrosis FNHA: First Nations Health Authority GP: General practitioner HIV: Human Immunodeficiency Virus HSDA: Health Service Delivery Area IDSA: Infectious Diseases Society of America MAC: *Mycobacterium avium* complex MDS: Minimum dataset MHO: Medical Health Officer MOH: Ministry of Health MSP: Medical Services Plan NTM: Non-tuberculous mycobacteria PHN: Public health nurse PHO: Provincial Health Officer PHSA: Provincial Health Services Authority PNTM disease: Pulmonary non-tuberculous mycobacterial disease RHA: Regional Health Authority TB: Tuberculosis **US: United States**

EXECUTIVE SUMMARY

Non-tuberculous mycobacteria (NTM) are mycobacterial species other than those of the *Mycobacterium tuberculosis* (*M. tuberculosis*) complex and *Mycobacterium leprae* (*M. leprae*). NTM infections can occur throughout the body, however pulmonary infections, lymphadenitis, and skin and soft tissue infections are the most common in humans.¹ Pulmonary non-tuberculous mycobacterial (PNTM) disease is increasingly identified in Canada;⁵ this is likely attributable to a true increase in incidence, increased or more sensitive testing, and greater patient and clinician awareness. Thus, practitioners in the province are increasingly asked to manage NTM patients. Risk groups for NTM include those with immunosuppression and structural lung disease, as well as older adults. Thus, as an aging population includes more susceptible hosts, it is important that the health system is prepared to meet NTM care needs in the future.

Yet, NTM presents diagnostic and management challenges. NTM are ubiquitous in the environment, thus it is necessary to distinguish whether a positive clinical sample represents infection, sample contamination with environmental sources, or colonization. Treatment decisions are also complex as not all positive NTM cultures require or benefit from treatment, and patients are often elderly with multiple comorbidities. Where treatment is administered, multiple antibiotics are often required for long durations, medications can have adverse effects, treatment success rates have been estimated at 56% and 75% when the medication is tolerated, and disease recurs in more than 30% thus many experience a chronic course.

The BC Centre for Disease Control (BCCDC) has historically focused on communicable diseases, however there is an increasing emphasis on non-communicable (chronic) diseases. Thus, the care of NTM patients in the province fits within a chronic disease mandate.

In BC, Provincial Tuberculosis (TB) Services based at the BCCDC, has been providing direct patient care and supporting clinicians across the province in caring for patients with NTM for years, despite an unclear mandate and a lack of dedicated personnel and financial resources. An increased understanding of clinician experiences and needs related to NTM would help Provincial TB Services best understand how to support practitioners and (if required) advocate for additional resources.

Objectives

In order to increase the capacity for consistent, patient-centred, evidence-based NTM care across the province that will improve the health outcomes of British Columbians, this project aimed to:

- 1. Understand the current practice of NTM care across BC
- 2. Identify opportunities to better support health care providers in the care of NTM patients
- 3. Explore the need for and, if applicable, establish the role and scope of a provincial NTM program
- 4. Explore the need for and, if applicable, establish the role and scope of a specialized NTM clinic at the BCCDC
- 5. Determine the feasibility of and requirements for an NTM dataset/registry to better understand health outcomes

Methods

An environmental scan and needs assessment was conducted through a self-administered online survey distributed to a convenience sample of diverse practitioners across the province who were actively involved with caring for patients with NTM, advising on patient care, or otherwise making decisions that affect patient care. Specifically, participants must have been involved with NTM care in the past 12 months. Physicians, Nurses, laboratory practitioners, Pharmacists, and other health care providers were

sent recruitment emails. Thirty-six individuals completed the majority of mandatory questions, and 34 completed all mandatory questions. Ethics approval was received from the University of British Columbia (UBC) Behavioural Research Ethics Board (BREB).

Results

There was diverse age and geographic representation, and years of practice experience, among respondents. About half of the respondents were Respirologists, however various other occupational groups were represented as well, including Infectious Disease Physicians, Public Health & Preventive Medicine Physicians, Medical Microbiologists, Public Health Nurses (PHN), Pharmacists, and a TB Case Manager. Respondents cared for a median of 10 NTM patients annually, although this number varied widely (range 0-120 patients). Respondents worked in diverse practice settings, including hospitals, clinics, public health agencies, and laboratories; close to one-third worked for Provincial TB Services. Two-thirds (67%) usually treated MAC disease. Almost 90% of NTM patients treated had PNTM.

Expert consultation and supporting resources

The majority (81%) of respondents referred to other practitioners with expertise in NTM for care of their NTM patients, with the majority identifying BCCDC TB Control alone or in combination with other specialists. The most common guidelines used for care of NTM patients were the Canadian TB standards, and the American Thoracic Society (ATS) guidelines or jointly released statement by the ATS/Infectious Diseases Society of America (IDSA). Two respondents indicated that they used the BCCDC TB clinic and followed their advice, and didn't list further guidelines.

Several themes were observed in the responses from respondents about accessing medications for NTM patients. First, the BCCDC was frequently mentioned as being important for supporting medication access, either alone or in combination with other practitioners or programs. Second, where challenges were noted, these appeared to particularly related to medications that require special access and in particular the medication clofazimine. In one case, the affordability of macrolides for patients was highlighted. Challenges with the delivery of intravenous aminoglycosides was also noted.

There were various reasons for referral to NTM experts, with some requiring only medication support and other seeking broad support for all aspects of patient care. It is also noteworthy that about one-fifth were not comfortable with using all NTM medications and one-fifth were neutral; given the critical role that medications play in NTM treatment during an often chronic and relapsing course, this highlights a key area for support.

With respect to other resources and events that could be used to support the care of NTM patients, live learning events for health care providers were rated favourably (including rounds about complex NTM cases). A library of resources and reports related to NTM were also assessed as potentially helpful. Written resources and online resources were rated more favourably for patients.

Barriers and enabling factors

The most common barrier to providing NTM care was medication access, followed by time. Interestingly, financial barriers (e.g., lack of a billing code) was identified as a barrier by less than onefifth of participants. The two most important enabling factors for NTM care were to access NTM medications, and to be able to refer to a specialized NTM centre. A majority also endorsed the importance of being able to consult a specialist in NTM care, to access provincial guidelines and tools, and to access NTM outcome data.

Model of NTM care

Close to two-thirds of respondents felt that the system of health care services for patients with NTM in BC needs to change, however there was not one clear preferred model of care. The most popular models were decentralized NTM clinics involving a network of sites across the province where patients would receive evaluation and treatment once referred by the diagnosing clinician; a centralized NTM clinic for initial care and specific consults located in Vancouver, where in-person care would be provided for the initial consult following referral from the diagnosing physician, followed by the provision of subsequent care by the diagnosing clinician; and virtual visits (telehealth, via video or teleconference) from NTM specialists based in Vancouver, with patients and clinicians . The lowest support was for total care by the diagnosing clinician (supported by only two respondents). Other lower-rated options were exclusive virtual care involving mobile applications (apps) and other electronic devices to support patients in managing their condition at home.

NTM Registry

One of the most striking findings from the survey was the overwhelming support for a NTM registry in the province, as all but one of 34 respondents indicated that a NTM registry should be created in BC. The purpose indicated as most important by the highest proportion of people was determining the clinical- and cost-effectiveness of health care; followed by tracking recommended treatment and preventive care for patients; and describing the natural history of NTM. The majority felt that a NTM registry should be housed with BCCDC Provincial TB Services. Active case ascertainment (i.e., registry staff locating patients and gathering data) was favoured over passive or sentinel case ascertainment approaches; however, it should be noted that this survey did not determine respondents' understanding of what this would involve logistically in terms of financial resources and personnel, nor what role practitioners would have to play in submitting data. This would require separate and dedicated consideration. In the interim, a NTM case reporting form that might be used to collect data for registry is proposed.

Role of BCCDC Provincial TB Services

There is appreciation for the consultative and referral relationship with Provincial TB Services in managing NTM patients. Several notes of thanks were spontaneously written to the BCCDC within the comments sections throughout the survey.

Summary

The responses from a convenience sample of 36 diverse practitioners reveal a desire to receive support, and to collaborate, in the care of NTM patients. The majority of practitioners do not want to manage NTM cases entirely on their own. Respondents also felt that the model of NTM care in the province needs to change, and while no one model emerged as clearly preferred by the majority of respondents, what is clear is a mix of centralized and decentralized services are rated more favourably and the extremes of care (completely centralized or completely independent practitioner care) were less supported. There is an appetite for additional practitioner NTM supports with live learning events highlighted as particularly appealing. There is overwhelming support for a NTM registry, that is housed with BCCDC Provincial TB Services. However, a dedicated exploration of practitioners' willingness to participate in data collection, and resource availability for a registry, is recommended.

BACKGROUND

Non-tuberculous mycobacteria (NTM) are mycobacterial species other than those of the *Mycobacterium tuberculosis* (*M. tuberculosis*) complex and *Mycobacterium leprae* (*M. leprae*), which cause tuberculosis (TB) and leprosy respectively.^{2 3} Although NTM infections can occur throughout the body, pulmonary infections, lymphadenitis, and skin and soft tissue infections are the most common in humans.⁴ Pulmonary *Mycobacterium avium* complex (MAC) disease comprises the majority of NTM disease.⁵ Other etiologic agents include *Mycobacterium kansasii* (*M. kansasii*) and *Mycobacterium abscessus* (*M. abscessus*), although more than 150 different species of NTM have been identified.⁴

NTM presents diagnostic and management challenges for clinicians. As NTM are ubiquitous in the environment, particularly in soil and water, it is necessary to distinguish whether a positive clinical sample represents infection, sample contamination with water sources, or colonization.⁴ For example, Winthrop et al. (2010) found that only half of individuals with positive NTM respiratory cultures met the clinical criteria for active infection.⁶ Since not all positive NTM cultures represent active infection, clinical, radiologic, and microbiologic evidence is required for diagnosis, in conjunction with excluding other possible etiologies. Treatment decisions are also complex as not all positive NTM cultures require or benefit from treatment and often the patients being considered for therapy are elderly with multiple comorbidities. If the decision is made to treat, there are several complicating factors. Multiple antibiotics are required for long durations (i.e. more than one year); there are challenges with adverse effects of medications including drug-drug interactions; treatment success rates have been estimated at 56%⁷ or 75% when tolerated;⁵ and disease recurs in >30% of patients thus many experience a chronic course.⁸

Pulmonary non-tuberculous mycobacterial (PNTM) disease is increasingly identified in Canada;⁵ this is likely attributable to a true increase in incidence, increased or more sensitive testing, and greater patient and clinician awareness. Since NTM is generally not spread by person-to-person transmission and is not considered a notifiable disease in British Columbia (BC) (i.e. reporting to public health is not required as it is for *M. tuberculosis*) it is difficult to fully understand disease epidemiology, but there is sufficient evidence of increased occurrence. In BC during the period 1990 - 2006, the median incidence of all NTMs from pulmonary specimens was 6.7/100,000 (range 3.4 to 9.1/100 000). MAC was the most common NTM species (77%).⁹ In BC, the prevalence of pulmonary NTM isolates significantly increased from 10.47 per 100,000 to 11.92 per 100,00, from 2006 to 2013, respectively (p = 0.001).¹⁰ In Ontario, there was a significant increase in the four most common NTM species from pulmonary specimens (9.1/100 000 in 1997 to 14.1/100 000 in 2003 [p < 0.0001]), with a mean annual increase of 8.4%.¹¹ In Ontario, five-year PNTM disease prevalence significantly increased from 29.3 cases/100,000 persons in 1998–2002 to 41.3/100,000 in 2006–2010.¹² Risk groups include those with immunosuppression and structural lung disease, as well as older adults. Thus, as an aging population includes more susceptible hosts, it is important that the health system is prepared to meet NTM care needs.

In a 2015 study from the United States (US), nationally the average cost per medical encounter for a patient with PNTM was 9,451.¹³ Nationally, 86,244 cases totalled 815 million per year; and the median number of 1,208 cases per state cost 11.5 million. Medical encounters among individuals ≥ 65 years of age were twice as high as those < 65 years of age (562 million vs. 253 million, respectively).

BC context

In BC, Provincial Tuberculosis (TB) Services are based at the BC Centre for Disease Control (BCCDC). In addition to their work with TB, this team has been providing direct patient care and supporting clinicians across the province in caring for patients with NTM for years. This has gradually evolved over time as there is clear diagnostic and treatment overlap with TB and a dedicated core group of practitioners

and support staff with interest and expertise in providing care for this challenging infection. This work has been accomplished despite an unclear mandate and a lack of dedicated personnel and financial resources. These constraints challenge day-to-day operations and hinder planning for the future, even as there is evidence of increased NTM disease, identification of new species of NTM, and ongoing diagnostic and treatment complexities. An increased understanding of clinician experiences and needs related to NTM would help Provincial TB Services best understand how to support practitioners and (if required) advocate for additional resources.

The BCCDC has historically had a focus on communicable diseases. However, there is an increasing emphasis on non-communicable (chronic) diseases. NTM, which usually has a chronic course, is therefore a relevant consideration under a chronic disease mandate.

Knowledge gap

A rapid literature review has identified surveys of practitioners regarding practices in NTM management (e.g., medication regimens utilized and their adequacy),¹¹ and NTM-related knowledge; ⁵ however, a needs assessment has not been identified. A 2014 study that found some differences between practitioners in their beliefs and practices related to NTM diagnosis and management, also suggested that an important, unanswered question is what prompts referral to NTM experts. ⁵

This project aims to devise recommendations to approach systematic NTM care in BC by addressing:

- the experiences, practices, and attitudes of health care practitioners across BC related to NTM
- perceived barriers and enabling factors for providing care
- whether or what additional supports are needed (e.g. personnel, clinical, educational, data, and financial resources)

The aim is to improve patient care in this complex area. The audience for this work includes, but is not limited to, Provincial TB services. The information in this report may also be useful to a broad audience of decision-makers involved with planning NTM services in the province.

Objectives

In order to increase the capacity for consistent, patient-centred, evidence-based NTM care across the province that will improve the health outcomes of British Columbians, this project aims to:

- 1. Understand the current practice of NTM care across BC
- 2. Identify opportunities to better support health care providers in the care of NTM patients
- 3. Explore the need for and, if applicable, establish the role and scope of a provincial NTM program
- 4. Explore the need for and, if applicable, establish the role and scope of a specialized NTM clinic at the BCCDC
- 5. Determine the feasibility of and requirements for an NTM dataset/registry to better understand health outcomes

METHODS

An environmental scan and needs assessment self-administered online survey was distributed to a convenience sample of health care practitioners in BC with experience providing, or involvement with, health care for NTM patients. In addition, a rapid, directed literature review was undertaken to identify

studies and grey literature documents relevant to NTM care. Literature from the past 10 years was of particular interest.

Data collection tool

A survey was developed based on a review of the NTM literature.¹⁴ As NTM practitioner needs assessment surveys were not found, practitioner surveys in other clinical areas were adapted and utilized.^{15 16 17} This survey was reviewed by the provincial physician lead and shared with representatives from TB clinical leadership for input prior to distribution. The survey was revised based on this input and the final survey is presented in Appendix B. The final survey consisted of a mix of closed and open-ended questions in the following areas: demographic characteristics; volume of NTM patients and type(s) of NTM seen; experience providing NTM care including comfort levels, barriers, and enabling factors; NTM models of care; and the need for and details of a NTM registry.

Participants

The online, self-administered survey was distributed to a convenience sample of physicians (Family Physicians and specialists including Respirologists, Infectious Disease Physicians, Medical Microbiologists, Internists, and MHOs), Nurses, laboratory practitioners, and Pharmacists, actively involved with caring for patients with NTM, advising on patient care, or otherwise making decisions that affect patient care. Specifically, participants must have had involvement with NTM care in the past 12 months. The intent was for practitioners to be located across the province of BC. A list of possible participants was provided by the Medical Head of Provincial TB Services, with input from other clinical leadership personnel at the BCCDC. Additionally, snowball sampling was used by requesting participants to identify others that the survey team might approach, helping to increase the chance for a representative sample.

To be eligible for inclusion, health care practitioners had to be competent in English (as the survey was administered in English only). A recruitment email including a survey link was sent to potential participants, and upon opening the survey link, they were able to view a consent letter detailing the purpose of the study and benefits/risks of participation. Practitioners were able to decline participation at the beginning of the survey and cease participation at any point during it. The survey required an estimated 45-minutes to complete.

Compensation

Non-salaried physicians (general practitioners [GPs] and specialists) were offered a sessional rate for 45minutes to complete the survey (\$99.43 and \$117.29, respectively). Salaried physicians (e.g., MOHs, Physician Epidemiologists, etc.), and non-physicians who are salaried health care professionals (such as Nurses, Pharmacists, and Laboratory Technicians), were offered gift cards valued at \$50 or less. The reason for the different methods of compensation was that the project funding source only permitted sessional compensation for non-salaried physicians. Gift cards for salaried health care professionals were paid for through the Operations budget.

In order to be remunerated, respondents needed to provide their personal identification (e.g. name, address, Medical Services Plan [MSP] billing number) to an Operations Manager at the BCCDC. This individual did not see the survey responses, thus respondents' identifying information was not linked to their survey. The provision of this identifying information was voluntary; however, remuneration could not proceed without it.

Ethics

Ethics approval was received from the University of British Columbia (UBC) Behavioural Research Ethics Board (BREB).

Data analysis

Descriptive statistics (counts and percentages, measures of central tendency and variability) were used to summarize respondents' demographic information, experiences, attitudes, barriers and enabling factors, and needs. The data was analyzed using Microsoft Excel®. Quotations in response to open-ended questions were extracted and are presented throughout this report in italics.

RESULTS

Respondent characteristics

Forty-eight individuals started the survey and 42 agreed to continue with the survey; 36 individuals completed all questions but one marked as mandatory, and 34 completed all mandatory questions.

Demographic and occupational characteristics

A higher proportion of survey respondents were male than female (55% vs. 45%) and there was diverse age representation (see Appendix A, Table 1). Respondents had practiced for a median 21.5 years, ranging from new practitioners to 46 years' experience. Although half of respondents were Respirologists (52%), various other occupational groups were represented as well, including Infectious Disease and Public Health & Preventive Medicine Physicians, Medical Microbiologists, Public Health Nurses, Pharmacists, and a TB Case Manager. Some groups were not represented, including Family Physicians (with both general and focused practices), General Internist Physicians, and Nurse Practitioners, and Laboratory Technicians. Respondents worked in diverse practice settings, including hospitals, clinics, public health agencies, and laboratories; close to one-third (29%) worked for Provincial TB Services.

Geographic representation

There was representation from all five Regional Health Authorities (RHAs) and the Provincial Health Services Authority (PHSA), as well as many Health Service Delivery Areas (HSDAs) (see Appendix A, Table 2). Two-thirds worked in urban/suburban areas and 12% worked in a small town. None reported working in rural/geographically isolated/remote areas, although some comments later in the survey reference rural practice and it's uncertain how these participants differentiated between "rural/remote" and "small town." One-fifth did not identify a primary geographic population.

NTM care volume and type of NTM

Respondents cared for a median of 10 NTM patients annually, although this number varied widely (range 0-120 patients). For example, nine respondents cared for 5 patients or less and ten cared for 40 patients or more. Two-thirds (67%) usually treated MAC disease. Other types of NTM treated include *M. abscessus, M. chelonae*, and *M. kansasii*. The majority (almost 90%) of NTM patients treated had PNTM. Those who indicated that patients had non-pulmonary disease reported disseminated disease, as well as skin/soft tissue and bone infections. One respondent described that patients with MAC often have PNTM, but other species have extra-pulmonary presentations. The vast majority of respondents indicated the patients they cared for did not have either cystic fibrosis (CF) or Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) (97%).

Referral

The majority (81%) of respondents referred to other practitioners with expertise in NTM for care of their NTM patients, with the majority identifying BCCDC TB Control alone or in combination with other specialists. A small number of respondents mentioned that they specifically consulted with the BCCDC in the context of seeking support for complex cases (e.g., if a patient has been on treatment and relapsed, or seeking "advice on unusual organisms (e.g., *M. abscessus*, etc.)." An Infectious Disease Specialist was

second most commonly identified. A small number mentioned referrals to a Respirologist, MHO, and Medical Microbiologist. Among those who referred, one-fifth (20%) referred all of their NTM patients, while the majority (81%) referred some patients. For the latter, clinical characteristics and the type of NTM were common factors in making the decision to refer. To a lesser extent, medication access was also a factor in the decision to refer.

Guidelines

Among 35 respondents, the most common guidelines used for care of NTM patients were the Canadian TB standards, and the American Thoracic Society (ATS) guidelines. ATS and the Infectious Diseases Society of America (IDSA) have jointly released a statement on the diagnosis, treatment, and prevention of NTM disease; and some respondents referred to the joint ATS/ISDA guideline. Two respondents indicated that they used the BCCDC Communicable Disease Manual. A few respondents indicated that they involved the BCCDC TB clinic and followed their advice, and didn't list further guidelines.

Diagnostic tools and treatment

Thirty-six respondents listed the NTM diagnostic tools that were available at their practice location, and chest x-ray, chest CT, sputum smear and culture were most commonly identified. Bronchoscopy was identified as a tool by some participants. A few individuals mentioned molecular diagnostics (e.g. NAAT, PCR), gene sequencing (e.g. 16S rRNA), and mass spectrometry (MALDI-TOF). Drug susceptibility testing, TST/Mantoux skin testing and IGRA were also listed by a few respondents.

Several themes were observed in the responses from 37 respondents about accessing medications for NTM patients. First, the BCCDC was mentioned by a number of respondents as being important for supporting medication access, either alone or in combination with other practitioners or programs (see Box 1). Second, where challenges were noted, these appeared to particularly related to medications that require special access and in particular the medication clofazimine. In one case, the affordability of macrolides for patients was highlighted (see Box 1). Challenges with the delivery of intravenous aminoglycosides was also noted.

Box 1: Comments related to NTM medication access

BCCDC
Drugs are easily accessed through BCCDC Pharmacy
No concerns in obtaining approval for medication by BCCDC TB Control
Often refer to BCCDC
Usually refer to BCCDC
Through BCCDC for certain medications, SAP applications, regular prescriptions +/- home iv
Prescribed by ID or BCCDC
Ethambutol and rifamycins provided through BCCDC pharmacy free of charge. Prescriptions provide for macrolides at patient's own expense
Usually rely on BCCDC for rifampin and ethambutol access. Occasionally work together with one of

our ID specialists

Challenges

No problem except for clofazimine

It can be very difficult to access medications for patients who are failing conventional therapy. For example, clofazimine testing is done separate to testing for the rest of the susceptibility profile. You need the susceptibility testing to access the drug. Even when patients meet criteria for the drug, at times the Special Access Program will deny coverage. Routine therapy is not difficult to access.

Sometimes can be challenging e.g., clofazimine...otherwise between the BCCDC and local pharmacies in [city name] have been able to access most meds

Standard therapy rifampin, ethambutol accessed through provincial pharmacy other first line available through local pharmacy's. Special access required for others- process is both time consuming for the clinician and pharmacy as well as can be a delay in treatment.

Standard therapy is available. Special access medications - time consuming and delay in treatment

Generally good, cost of macrolides for some patients is a challenge, paperwork for clofazimine is limiting

Note that in another section of the survey, the lack of coverage of macrolides by the BCCDC pharmacy was also identified as a challenge.

Table 3 presents the level of agreement for various statements related to providing NTM care. Several observations are noted. First, referral for care of NTM patients appeared to be important to the majority of respondents, as two-thirds disagreed or strongly disagreed with the statement that they didn't refer to NTM experts. Second, referral to other NTM experts for medications only was indicated by one-third of respondents, while approximately half disagreed or strongly disagreed. Over one-quarter referred to NTM experts to support all aspects of patient care, while over half disagreed/strongly disagreed with this (55.6%). Therefore, there appears to be a combination of reasons for referral, with some requiring only medication support and other seeking broad support for all aspects of patient care. Third, just over half were comfortable using all NTM medications (53.3%); however, as one-fifth were not comfortable and 22% were neutral, and given the critical role that medications play in NTM treatment over an often chronic and relapsing course, this still seems like an important need for support.

Table 3: Agreem	ent with statements	regarding NTM care

Statement	Level of agreement, count (%) Total $n = 36$				
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I am confident providing total NTM care as a result of my formal training	7 (19.4%)	12 (33.3%)	6 (16.7%)	8 (22.2%)	3 (8.3%)
I am confident providing total NTM care as a result of my practice experience	10 (27.8%)	13 (36.1%)	4 (11.1%)	7 (19.4%)	2 (5.6%)
I am comfortable using all NTM medications	9 (25.0%)	12 (33.3%)	8 (22.2%)	5 (13.9%)	2 (5.6%)
I refer to other NTM experts to support all	1 (2.8%)	9 (25.0%)	6 (16.7%)	15 (41.7%)	5 (13.9%)

aspects of care for my NTM patients					
I refer to other NTM experts only for medications for my NTM patients	1 (2.8%)	11 (30.6%)	6 (16.7%)	12 (33.3%)	6 (16.7%)
I don't refer to other NTM experts for care of my NTM patients	2 (5.6%)	5 (13.9%)	5 (13.9%)	12 (33.3%)	12 (33.3%)

Barriers to NTM care

The most common barrier to providing NTM care was medication access (61%) followed by time (58%) (see Table 4). Experience was identified as a barrier by over one-third of respondents (39%). Financial barriers (e.g., lack of a billing code) was identified as a barrier by less than one-fifth of participants.

Barrier	%	п
Medication access	61%	22
Time	58%	21
Experience	39%	14
Presence of specialized centres	33%	12
Knowledge	28%	10
Education / training	25%	9
Presence of specialized consultants	25%	9
Other*	22%	8
Financial (e.g., lack of a billing code, remuneration amount)	17%	6

One respondent describes considerations for remote contexts:

It is much more challenging to take care of patients living remotely with NTM, particularly older women. It is far more difficult to deal with toxicities and side effects without being able to see or easily communicate with the patient.

Another respondent offered an interesting suggestion for knowledge sharing, specifically that there was a need for "*clinical rounds to present challenging cases*."

Enabling Factors for NTM Care

The two most important enabling factors for NTM care were to access NTM medications, and to be able to refer to a specialized NTM centre (68.5% and 65.8%, respectively, agreed or strongly agreed with this statement, see Table 5). A majority also endorsed the importance of being able to consult a specialist in NTM care, to access provincial guidelines and tools, and to access NTM outcome data (60.0% for each). There was an interest in receiving support in caring for NTM patients, as sixty-three percent disagreed or strongly disagreed with a statement about not wanting education, support, or referral services in relation to NTM care. Interestingly, just over one-third of respondents indicated the importance of a complex care billing code in making care easier, while a similar proportion were neutral, and close to 30% disagreed.

Table 5: Level of agreement regarding factors that make NTM care easier

Statement

Example 2 Level of agreement, count (%) Total n = 35 (34 for the complex billing code statement)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I could consult specialists in NTM care	8 (22.9%)	13 (37.1%)	11 (31.4%)	1 (2.9%)	2 (5.7%)
I could refer to a specialized NTM centre	8 (22.9%)	15 (42.9%)	8 (22.9%)	2 (5.7%)	2 (5.7%)
a complex care billing code existed	4 (11.8%)	8 (23.5%)	12 (35.3%)	7 (20.6%)	3 (8.8%)
I had more education/training about NTM diagnosis	2 (5.7%)	9 (25.7%)	16 (45.7%)	6 (17.1%)	2 (5.7%)
I had more education/training about NTM medications and other aspects of NTM management	2 (5.7%)	15 (42.9%)	11 (31.4%)	6 (17.1%)	1 (2.9%)
I could access provincial guidelines and tools	5 (14.3%)	16 (45.7%)	11 (31.4%)	2 (5.7%)	1 (2.9%)
I could access NTM outcome data	3 (8.6%)	18 (51.4%)	10 (28.6%)	3 (8.6%)	1 (2.9%)
I could access NTM medications	6 (17.1%)	18 (51.4%)	10 (28.6%)	0 (0.0%)	1 (2.9%)
I do not want additional education, support or referral services in caring for patients NTM	2 (5.7%)	1 (2.9%)	10 (28.6%)	17 (48.6%)	5 (14.3%)

Model of NTM Care in BC

Seventy two percent of respondents felt that the system of health care services for patients with NTM in BC needs to change, however there was not one clear model that emerged as preferred by the majority of respondents. (see Table 6). There was an indication that a mix of centralized and decentralized services would be helpful; the more extreme options at either end (completely centralized or completely independent practitioner care) were less supported. The most popular models were decentralized NTM clinics involving a network of sites across the province where patients would receive evaluation and treatment once referred by the diagnosing clinician (50%); a centralized NTM clinic for initial care and specific consults located in Vancouver, where in-person care would be provided for the initial consult following referral from the diagnosing physician, followed by the provision of subsequent care by the diagnosing clinician; and virtual visits (telehealth, via video or teleconference) from NTM specialists based in Vancouver, with patients and clinicians (44%). The lowest support was for total care by the diagnosing clinician (supported by only two respondents). Other lower-rated options were exclusive virtual care involving mobile applications (apps) and other electronic devices to support patients in managing their condition at home. A centralized NTM clinic providing all care in-person in Vancouver following referral by the diagnosing clinician, involving travel for patients outside of the Vancouver-area, was also not as supported (11%). One-third supported virtual consults involving NTM experts in Vancouver replying to letters from diagnosing clinicians. One respondent described the model that s/he would like to see as a "central coordinating clinic with a critical mass of patients and appropriate resources tied into a nodal system of clinics." Finally, one respondent highlighted considerations for rural and remote settings:

I think it is very important to create a systematic way of evaluating and treating NTM patients in BC. I think it should be based in Vancouver but connected with telephone, on-line and telehealth resources to remote and rural areas of BC.

Model of care	Count (%) Total n = 36
Centralized NTM clinic for all care	4 (11%)
Centralized NTM clinic for initial care and specific consults	16 (44%)
Decentralized NTM clinics	18 (50%)

Table 6: Models of care for NTM patients in BC

Virtual Visits (Telehealth)	16 (44%)
Virtual Consults	11 (31%)
Virtual Care	3 (8%)
Independent practitioner care	2 (6%)
Other, please specify	6 (17%)

With respect to other resources and events that could be used to support the care of NTM patients, respondents rated live learning events for health care providers most favourably, which is in line with the previous comment about the preference for rounds on difficult cases (see Table 7). Two-thirds also felt that a library of resources and reports related to NTM would be helpful. Written resources and online resources were rated more favourably for patients, with a lesser proportion of respondents feeling that patient webinars or live learning events would be useful.

Table 7: Resources and events to support NTM care

Response	Count (%) Total responses $n = 35$
For providers - develop a library of resources, archived videos, literature, and reports related to NTM	23 (66%)
For providers – conduct live learning events on a range of NTM-related issues	28 (80%)
For patients – written resources	25 (71%)
For patients – online resources	24 (69%)
For patients – webinar or live learning events	12 (34%)
Other, please specify	0

NTM Registry

The overwhelming support for a NTM registry in the province was striking, as all but one respondent indicated that a NTM registry should be created in BC (33/34, 97%). The purpose indicated as most important by the highest proportion of people was determining the clinical- and cost- effectiveness of health care (56.2%); followed by tracking recommended treatment and preventive care for patients (26.9%); and describing the natural history of NTM (7.4%) (see Table 8). The latter is captured in the following quote:

I think we really need more data on the natural history and clinical course of patients infected/colonised with atypical mycobacteria -(this is where a data base/ disease registry might help) specifically with different types of mycobacteria so that more realistic guidelines could be developed, and that there should be more in the way of educational material for physicians both treating NTM and those referring, and for patients who are particularly challenging a monthly review by physicians most knowledgeable in the treatment of this disease.

Measuring and monitoring safety and harm was the most important purpose for only 6.5% of respondents, but the second most important for 45%. Among four individuals who indicated another purpose, understanding NTM epidemiology was listed by three, as described in Box 2.

Table 8: Purpose of a provincial NTM registry

Registry purpose	Rank* Count (%)							
	Most important (#1)	#2	#3	#4	#5	#6	#7	Total Responses
Determining clinical effectiveness or cost- effectiveness of health care products and services	18 (56.2%)	7 (21.9%)	3 (9.4%)	2 (6.2%)	1 (3.1%)	0 (0.0%)	1 (3.1%)	32
Measuring and monitoring safety and harm	2 (6.5%)	14 (45.2%)	8 (25.8%)	6 (19.4%)	1 (3.2%)	0 (0.0%)	0 (0.0%)	31
Describing the natural history of NTM	2 (7.4%)	4 (14.8%)	5 (18.5%)	1 (3.7%)	6 (22.2%)	9 (33.3%)	0 (0.0%)	27
Tracking recommended treatment and preventive care for patients (e.g., appropriate follow-up, recommended medication regimens, etc.)	7 (26.9%)	3 (11.5%)	4 (15.4%)	6 (23.1%)	5 (19.2%)	1 (3.8%)	0 (0.0%)	26
Measuring quality of care	2 (7.1%)	5 (17.9%)	6 (21.4%)	9 (32.1%)	4 (14.3%)	2 (7.1%)	0 (0.0%)	28
Supporting quality improvement by providing practices with feedback regarding their performance on quality of care metrics over time, benchmarked in comparison with similar practices	0 (0.0%)	0 (0.0%)	7 (25.9%)	2 (7.4%)	8 (29.6%)	9 (33.3%)	1 (3.7%)	27
Other (please describe)	1 (16.7%)	0 (0.0%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	0 (0.0%)	4 (66.7%)	6

* Respondents were asked to indicate what they feel the purpose of an NTM registry in BC should be by ranking 1st ("1") what you believe to be the most important purpose, "2" for second most important (if applicable), and "3" for third most important (if applicable) and so on. Respondents were asked to rank all the items they felt were relevant.

Box 2: Additional purpose of NTM registry: epidemiology

Provincial Epidemiology on NTM cases

Identify patterns of disease within populations, communities, to establish whether endemic/isolated etc. and follow "outbreaks"

Measuring the burden of disease in the province

Twenty-six of the 29 respondents who indicated where they felt a NTM registry should be housed said Provincial TB Services/BCCDC. The other three respondents either didn't indicate a specific organization (e.g., just indicated Vancouver), stated where it should not be used (e.g., not in the US), or just that the registry should be "centralized/provincial to enhance data integrity and access to data/reports" without specifying a site. One respondent specified that the registry should be housed at the BCCDC in Vancouver, and that "all positive cultures for NTM should be included in the registry and then [data should be sought] from the submitting physician. The majority favoured active case ascertainment (see Table 9.

Table 9: Preferred method for case ascertainment

Method for case ascertainment	Count (%)
Active case identification: registry staff locate patients who meet the inclusion criteria and gather data	28 (88%)
Passive case identification: relies on physicians, hospital staff, or other health care workers to report cases to the registry staff	14 (44%)
Sentinel case identification: only certain practices are selected to report data to registry staff based on a predetermined rationale	3 (9%)

It should be noted that this survey did not determine respondents' understanding of what the creation and operation of a registry generally, or active case ascertainment specifically, would involve logistically in terms of financial resources and personnel, nor what role practitioners would have to play in submitting data.

Additional information

Several notes of thanks were spontaneously written in relation to the BCCDC in the comments section, such as "Wishing you all the best - definitely appreciate all the support I get from the BCCDC/TB Services!", and "Thank you."

Two comments (and it is uncertain whether these were made by two separate respondents or the same person) discuss challenges with defining roles in the care of NTM patients, "with resp[iratory] specialist, GP, public health and CDC all playing a role." This is perhaps most relevant to the Models of Care section discussed previously.

Finally, multiple respondents, when asked who else to contact for the survey, suggested getting the input of patients.

DISCUSSION

This report presents the results of a needs assessment and environmental scan collected via an online survey delivered to a purposive sample of diverse practitioners who are involved in the care of NTM patients in BC. The results of this survey are rich and varied, but several key points bear mentioning.

First, that the majority of practitioners do not want to manage NTM cases entirely on their own. There is appreciation for the consultative and referral relationship with Provincial TB Services and BCCDC repeatedly mentioned through the qualitative elements of the survey.

Second, there is an appetite for additional practitioner NTM supports. While a variety of supports were endorsed, live learning events were particularly appealing, with one respondent giving the example of rounds involving complex NTM cases. Interestingly, the need for a complex care billing code was not endorsed by the majority of respondents.

Third, that there is support for a change in the current model of NTM care in the province, although several models were similarly rated favourably by respondents. These models have in common both a centralized element involving NTM experts based in Vancouver, and a distributed element, such that patients aren't required to travel to Vancouver for all of their care but do have a connection to care in Vancouver (that is fulsome, exceeding a consult letter) in some way.

And finally, that there is overwhelming support for a NTM registry, that is based at Provincial TB Services, BCCDC.

NTM Registry

For the purpose of this report, a patient registry is defined as an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individuals with a particular disease, condition, or exposure, containing uniform clinical and demographic data collected for specific and predetermined scientific, clinical, or policy purpose(s).¹⁸ ¹⁹ ²⁰ A registry database is the file(s) derived from the registry.¹⁹

Disease registries are defined by patients having the same or similar diagnoses, such as the clinical conditions associated with non-tuberculous mycobacterial infections (NTM).¹⁹ There is the potential for a patient registry to contribute to improving patient care in a variety of ways as registries can be used to: observe the course of disease; understand variations in treatment and outcomes; examine factors that influence prognosis and quality of life; describe care patterns, including appropriateness of care and disparities in the delivery of care; assess effectiveness; monitor safety and harm; measure quality of care; and promote quality improvement.¹⁹ Where registries capture data elements with specific and consistent data definitions, they can be used to compare clinical data from different centers and countries.²¹ Further, the decision about whether a disease should be notifiable, thus requiring reporting to public health authorities, considers many factors, including: incidence; severity; potential to spread to/among the general population; potential to invoke a crisis; socioeconomic burden (e.g., costs of preventive and therapeutic interventions and long term disability); and preventability (i.e., potential for public health intervention to modify disease incidence).²² Comprehensive registry data may contribute to understanding some of these factors.

Resource needs

The potential value of a registry is clear, yet the creation and maintenance of a registry is a resource intensive way of obtaining health information (compared to, for example, a focused, short-term research study), and it is important to first determine whether a registry is needed. ¹⁹ Registries should only be created when there is a need to collect information over the long-term. Registry-based surveillance is better suited for problem detection and identification; tracking important, new, rare, or rapidly developing health problems; monitoring the delivery of health services; and the documentation of events over time.¹⁸

Respondents in the survey preferred active case ascertainment; given that the vast majority felt that a registry should be housed at the BCCDC, this begs the question of where and how an NTM registry might exist at the BCCDC. The capacity of Provincial TB Services for this endeavour would need to be explored, and is beyond the scope of this report. It would also be important to explore whether/what role the BC Observatory for Population and Public Health (Observatory) might have. The Observatory was established in response to a recommendation of the Population and Public Health Surveillance Plan for BC.²³ The BCCDC is "the hub" and epidemiology resources within the regional health authorities are "the spokes". It is a partnership between the BCCDC, BC Ministry of Health (MOH), BC Provincial Health Officer (PHO), First Nations Health Authority (FNHA), the five BC RHAs, and the Provincial Health Services Authority (PHSA). The Observatory's stated initial focus is to provide collaborative leadership in the development of provincial and regional surveillance capacity with respect to noncommunicable diseases and injuries, risk and protective factors, and environmental health. Over the longer term, the intention is to integrate these activities with the existing communicable disease surveillance system. The Observatory has launched the BC Chronic Disease dashboard,²⁴ which is publicly available on BCCDC website. The dashboard is an interactive tool that provides summary statistics on a variety of non-communicable diseases and conditions in BC. Among the 32 chronic conditions currently listed, NTM is not included.

Minimum dataset

The term Minimum Data Set (MDS) refers to a common set of data items that should be used to collect and report data in a registry.²¹ Generally, a registry data set includes demographic, * diagnostic, management, outcome, administrative, and other information relevant to the health condition of interest. One approach that researchers can use to identify what should be included in a minimum data set is to develop an initial set of data elements, then ask experts to review and score these using a Likert scale based on perceived importance.²¹ Data elements that are scored as important by a certain proportion of experts are recommended for inclusion in the final minimum data set, pending the determination that data collection is feasible. This level of detail was not included in the survey based on key informant feedback during survey development. However, an example of how this might be carried out can be seen in Kalankesh et al. (2015) who used a 4-item Likert scale (1 to 4) ranging from "not important for inclusion in MDS" to "highly important for inclusion in MDS") and elements that were scored 3 ("important") or 4 ("highly important") by more than 50% of survey participants were viewed as having sufficient support for inclusion in a final minimum data set.²¹ 25

Reporting form

A reporting form that might be used to collect NTM data for a registry is presented in Appendix B. This was not based on survey data as selecting MDS items was felt to make the survey too lengthy. Therefore,

^{*} Including basic demographic information in a registry is important as it helps generalize findings from registry data to other populations, facilitates cross-matching and merging with data from other registries/sources, and examine whether demographic variables are related to morbidity and mortality.¹⁶

this form is informed by a literature review and the need to be brief in order to promote practitioner completion.

Models of NTM Care

Dedicated NTM clinics in Ottawa, Toronto, and Calgary

At least three Canadian cities have dedicated NTM clinics: Ottawa, Toronto, and Calgary. Additionally, many jurisdictions have CF and HIV clinics who will see patients co-infected with NTM. No other dedicated NTM clinics were identified as part of this brief scan. Several jurisdictions have TB clinics where NTM patients are also seen. Table 10 summarizes the available information for the Canadian clinics. Box 3 presents relevant resources.

Leading	Goals & Relationship to	Clinic	Stoff"	Funding		
Location	TB Clinic	volume	Staffing	Clinic	Medications	
Ottawa, Ontario (established ~ 5 years ago)	The intended approach is to do an initial consult and support patients to start on treatment; follow up monthly twice; and then refer back to primary care with detailed guidance. At the end of the 18-month treatment the patient can return to the NTM clinic to be assessed or sooner if there are problems, complications, or	- 1-2 clinics per month - usually 10 patients per physician per half-day clinic (2-3 are new consults)	2 physicians, 2 nurses, and a clerk for booking each clinic	Funded through OHIP billing with no other sources of funding	Individuals over 65 typically have publicly- funded coverage but some medications (e.g. linezolid and rifabutin) are harder to obtain coverage	
	questions. The NTM clinic is separate from the TB clinic.					
Toronto, Ontario	Approximately 80% of referrals are from respirologists or	- 2.5 clinic days per week	2 physicians, 1 nurse, 1 fellow, and	Funded through OHIP billing,	Individuals over 65 typically have publicly-	
(Toronto Western Hospital (TWH))	infectious disease physicians and 15% from family physicians. The TB clinic at TWH refers NTM patients they identify to the NTM clinic. They noted that this occurs for 3-4 patients per month and they tend to be older, frail	- approx. 1200 visits per year	administrative support. The nurse position does half-time research and half-clinical (funded by philanthropic support). The fellow position is	research activities, and philanthropic support. Identifying additional funding has been challenging.	funded coverage but some medications (e.g. linezolid and rifabutin) are harder to obtain coverage.	

Table 10: NTM clinics in Canada*

	patients. It was also noted that care for these patients is complex with many adverse effects of the medications, long course of treatment, and complex treatments (e.g. the need for PICC lines and drug level testing with some medications).		also supported through philanthropic donations and research activities. Administrative support is funded through OHIP billings of the specialist physicians.	no yo in w co	ave also been oted for ounger idividuals ithout overage irough work.
Calgary,		Wednesday	May include		
Alberta		and Friday	pulmonologists,		
		afternoons	pharmacists, and		
			registered nurses.		

*Where information is not available, this is left blank.

Other jurisdictions (BC, US)

BCCDC Provincial TB Services has two clinics that provide direct patient care – one in Vancouver and one in New Westminster. They do screening, diagnosis, and treatment for TB (active and latent) including immigration surveillance. NTM patients are also seen in these clinics. They tend to be scheduled throughout the clinic day, typically 1-2 NTM patients per day (with approximately 10 patients seen in clinic per half-day). There is a BC Strategic Plan for Tuberculosis Prevention, Treatment, and Control for which there is a 2016 Status Report. There is limited mention of NTM in the strategic plan however.

In the US, it was identified that there is a relevant program at NIH with government support. There is also a program in Denver at the National Jewish Health; it was indicated that patients in this setting tend to have insurance that can be billed for care and that the clinic also receives philanthropic support.

Reasons for clinic establishment

There were several reasons identified for establishing NTM-specific clinics. It was felt that having an independent clinic made sense as it was a great deal of work to add to the existing TB infrastructure. Individuals commented that supporting community providers to diagnose and treat NTM would likely be helpful given the increasing number of cases. It was also identified that it can be challenging to attract clinicians to work in this area given the complexity and time required.

Considerations for clinic models

In terms of models of care, it was suggested an ideal clinic set-up would have a full-time clinician (e.g. a nurse) who could manage a lot of patient queries in addition to physician and administrative support. Support for both a centralized model and guidance for clinicians in the community was recognized however. It was noted it may be challenging for a primary care physician in the community to manage care with only one initial NTM clinic visit and follow up several months later. It was felt to be more possible if a larger amount of support was being provided or the community clinician was a specialist (e.g. Infectious Disease Physician or Respirologist).

Box 3: Relevant resources

Information on NTM clinics and clinicians in Canada

NTM-IR Physician Referral List: https://www.ntminfo.org/patients/physician-referral-list/canada

Ottawa: http://www.ohri.ca/profile/Gonzalo/research-activities

Calgary: https://informalberta.ca/public/service/serviceProfileStyled.do?serviceQueryId=1073903

Other resources

Ontario Agency for Health Protection and Promotion (Public Health Ontario). Best Practices for Pulmonary Nontuberculous Mycobacteria. Toronto, ON: Queen's Printer for Ontario; 2017. Available from: <u>https://www.publichealthontario.ca/en/eRepository/Best_Practices_for_Pulmonary_NTM.pdf</u>.

NTM Info & Research Inc: www.ntminfo.org

Patient education group based in the United States. They also offer pamphlets and booklets that can be ordered.

Strengths and limitations

Although this sample was purposive and not random, there was diverse geographic representation and participation from different occupational groups. This survey was intentionally designed to explore a broad range of topics relevant to NTM care in BC, and to offer the opportunity for respondents to enter both quantitative and qualitative responses.

Close to 30% of respondents worked with Provincial TB Services. This raises the question of whether this group was over-represented in the sample. However, it is likely that this represents the proportion of practitioners involved with NTM care in the province, particularly given that the population of the Greater Vancouver Regional District (within which the BCCDC and Provincial TB Services is located) was 2,463,431, representing more than half of the total population of the province (4,648,055) in 2016.²⁶

One confusing finding from the survey is that the BCCDC CD manual was listed as a resource for NTM care by a small number of respondents. The provincial TB manual mentions NTM but mainly with respect to defining what NTM is. There are also a few other places where NTM is mentioned (e.g., in relation to IGRA, where it states that IGRA results are not influenced by cross-reactivity from BCG vaccination or exposure to most NTM). Otherwise, there is not sufficient information about NTM in the manual to be used as a guide for clinical practice. Those who have NTM-related questions are often referred to the Canadian Tuberculosis Standards, Chapter 11 (which is about NTM). Thus, there is a need for further clarification about how the BCCDC CD manual is used.

SUMMARY

The responses from a convenience sample of 36 diverse practitioners reveal a desire to receive support, and for collaboration, in caring for NTM patients. The majority of practitioners do not want to manage NTM cases entirely on their own. Respondents also felt that the model of NTM care in the province needs

to change, and while no one model emerged as clearly preferred by the majority of respondents, what is clear is a mix of centralized and decentralized services are rated more favourably and the extremes of care (completely centralized or completely independent practitioner care) are less supported. There is an appetite for additional practitioner NTM supports with live learning events highlighted as particularly appealing.

There is overwhelming support for a NTM registry, that is housed with BCCDC Provincial TB Services. However, it is recommended that practitioners' willingness to participate in the ongoing collection and submission of NTM patient data to populate the registry, the availability of human and technological resources for a registry, and possible partnerships for establishing and maintaining a registry should be explored. With respect to the latter, it would be important to explore whether a relationship with the BC Observatory for Population and Public Health might be established for a NTM registry.

APPENDIX A – Additional Tables and Figures

-

Table 1: Respondent age

Table 2: Geographic location for 42 respondents

Geographic location	%	N	
Health Authority			
Northern	5%	2	
Interior	19%	8	
Fraser	14%	6	
Vancouver Coastal	33%	14	
Vancouver Island	10%	4	
First Nations Health Authority	0%	0	
Provincial Health Services Authority	33%	14	
Health Service Delivery A	rea*		
Interior - Easy Kootenay HSDA	7%	3	
Interior - Kootenay Boundary HSDA	7%	3	
Interior - Okanagan HSDA	19%	8	
Interior - Thompson Cariboo Shuswap HSDA	7%	3	
Fraser - Fraser East HSDA	2%	1	
Fraser - Fraser North HSDA	5%	2	
Fraser - Fraser South HSDA	10%	4	
Vancouver Coastal - Richmond HSDA	2%	1	
Vancouver Coastal - Vancouver HSDA	38%	16	
Vancouver Coastal - North Shore/Coast Garibaldi HSDA	0%	0	
Vancouver Island - South Vancouver Island HSDA	5%	2	
Vancouver Island - Central Vancouver Island HSDA	7%	3	
Vancouver Island - North Vancouver Island HSDA	7%	3	
Northern - Northwest HSDA	5%	2	
Northern - Northern Interior HSDA	7%	3	
Northern - Northeast HSDA	5%	2	

*5 respondents indicated that their practice was provincial

Table: Occupational characteristics of 42 respondents

Occupational groupFamily Physician with a general practice0%Family Physician with a focused practice (e.g. emergency medicine, etc.)0%Specialist - Respirologist52%Specialist - Infectious Diseases14%Specialist - Medical Microbiologist5%Specialist - General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	N
Family Physician with a focused practice (e.g. emergency medicine, etc.)0%Specialist - Respirologist52%Specialist - Infectious Diseases14%Specialist - Medical Microbiologist5%Specialist - General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Free-standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	
medicine, etc.)Specialist - Respirologist52%Specialist - Infectious Diseases14%Specialist - Medical Microbiologist5%Specialist - General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	0
Specialist - Infectious Diseases14%Specialist - Medical Microbiologist5%Specialist - General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Trivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	0
Specialist - Medical Microbiologist5%Specialist - General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Trivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	22
Specialist – General Internist0%Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	6
Specialist - Public Health & Preventive Medicine Physician and/or Medical Health Officer10%Nurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work setting7%Private office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	2
Medical Health OfficerNurse Practitioner0%Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	0
Public health nurse10%Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	4
Pharmacist2%Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	0
Laboratory technician0%Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	4
Other*7%Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	1
Work settingPrivate office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	0
Private office/clinic (excluding free standing walk-in clinics)31%Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%University2%Laboratory7%	3
Community clinic/Community health centre7%Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	
Free-standing walk-in clinic0%Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	13
Academic health sciences centre (AHSC)/hospital36%Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	3
Non-AHSC teaching hospital12%Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	0
Community hospital17%Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	15
Emergency department (in any type of hospital)0%Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	5
Provincial TB Services29%Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	7
Nursing home/ Long term care facility / Seniors' residence0%Occupational health0%University2%Laboratory7%	0
Occupational health0%University2%Laboratory7%	12
University2%Laboratory7%	0
Laboratory 7%	0
•	1
Pharmacy 0%	3
	0
Other** 10%	4

* TB Case Manager, Medical Health Officer, and Pharmacist Group

**Public health agency, public health program oversight (health authority/office work, not with individual patients), Health Authority, Office of the Chief Medical Health Officer

APPENDIX B - NTM Survey

See attached survey

APPENDIX C - NTM Reporting form

See attached reporting form

REFERENCES

¹ Johnson MM, Odell JA. Nontuberculous mycobacterial pulmonary infections. J Thorac Dis 2014; 6(3): 210-220.

² Satta G, McHugh TD, Mountford J, Abubakar I, Lipman M. Managing pulmonary nontuberculous mycobacterial infection. Time for a patient-centered approach. Ann Am Thorac Soc 2014; 11(1): 117-121.

³ Saleeb P, Olivier KN. Pulmonary nontuberculous mycobacterial disease: new insights into risk factors for susceptibility, epidemiology, and approaches to management in immunocompetent and immunocompromised patients. Current infectious disease reports 2010; 12(3): 198-203.

⁴ Johnson MM, Odell JA. Nontuberculous mycobacterial pulmonary infections. J Thorac Dis 2014; 6(3): 210-220.

⁵ Marras TK, Prevots R, Jamieson FB, Winthrop KL, on behalf of the Pulmonary MAC Outcomes Group. Opinions Differ by Expertise in Mycobacterium avium Complex Disease. Ann Am Thorac Soc 2014; 11(1): 17-22.

⁶ Winthrop KL, Mcnelley E, Kendall B, et al. Pulmonary nontuberculous mycobacterial disease prevalence and clinical features: an emerging public health disease. Am J Respir Crit Care Med 2010; 182: 977-82.

⁷ Field SK, Fisher D, Cowie RL. Mycobacterium avium complex pulmonary disease in patients without HIV infection. Chest 2004; 126: 566-81.

⁸ Kobashi Y, Matsushima T. The microbiological and clinical effects of combined therapy according to follow-up study. Respiration 2007; 74: 394-400.

⁹ Hernández-Garduño E, Rodrigues M, Elwood RK. The incidence of pulmonary non-tuberculous mycobacteria in British Columbia, Canada. Int J Tuberc Lung Dis 2009; 13(9): 1086-93.

¹⁰ Personal Communication, BCCDC Public Health Laboratory, 2017.

¹¹ Marras TK, Chedore P, Ying AM, Jamieson F. Isolation prevalence of pulmonary non-tuberculous mycobacteria in Ontario, 1997-2003. Thorax 2007; 62: 661.

¹² Marras TK, Mendelson D, Marchand-Austin A, May K, Jamieson FB. Pulmonary nontuberculous mycobacterial disease, Ontario, Canada, 1998–2010. Emerging Infectious Diseases 2013; 19(11).

¹³ Strollo SE, Adjemian J, Adjemian MK, Prevots DR. The Burden of Pulmonary Nontuberculous Mycobacterial Disease in the United States. Ann Am Thorac Soc 2015; 12(10): 1458-1464.

¹⁴ Adjemian J, Prevots DR, Gallagher J, Heap K, Gupta R, Griffith D. Lack of adherence to evidencebased treatment guidelines for nontuberculous mycobacterial lung disease. Ann Am Thorac Soc 2014; 11(1): 9-16.

¹⁵ Yaffe MJ, Orzeck P, Barylak L. Family physicians' perspectives on care of dementia patients and family caregivers. Can Fam Physician 2008; 54: 1008-15.

¹⁶ Ziemianski D, Capler R, Tekanoff R, Lacasse A, Luconi F, Ware MA. Cannabis in medicine: a national educational needs assessment among Canadian physicians. BMC Medical Education 2015; 15: 52.

¹⁷ Jennett PA, Laxdal OE. Assessing educational needs in medical practice: guidelines for the CME planning committee member. *Can Fam Physician* 1984; 30: 1917-1922. ¹⁸ Solomon DJ, Henry RC, Hogan JG, Van Amburg GH, Taylor J. Evaluation and implementation of

public health registries. Public Health Reports 1991; 106(2).

¹⁹ Gliklich R, Dreyer N, Leavy M, eds. Registries for Evaluating Patient Outcomes: A User's Guide. Third edition. Two volumes. AHRQ Publication No. 13(14)-EHC111. Rockville, MD: Agency for Healthcare Research and Quality. April 2014. Available from http://www.effectivehealthcare.ahrq.gov/ registries-guide-3.cfm

²⁰ Ibid citing National Committee on Vital and Health Statistics. Frequently Asked Questions About Medical and Public Health Registries.

²¹ Kalankesh LR, Dastgiri S, Rafeey M, Rasouli N, Vahedi L. Minimum Data Set for Cystic Fibrosis Registry: a Case Study in Iran. Acta Inform Med 2015: 23(1): 18-21.

²² For the ACE Subcommittee on Communicable Diseases J-A. Establishing priorities for national communicable disease surveillance. The Canadian Journal of Infectious Diseases 2000; 11(1): 21-24. ²³ BC Observatory for Population & Public Health: Strategic Plan 2016/17 - 2020/21. Available from http://www.bccdc.ca/Our-Services-Site/Documents/FINAL-Obs-Strat-Plan-2016-2022.pdf ²⁴ <u>http://www.bccdc.ca/health-info/disease-system-statistics/chronic-disease-dashboard</u>

²⁵ Heider AR, Maloney N, Satchidanand N, Allen G, Meuller R, Gangloff S, et al. (2014) "Developing a Community-Wide Electronic Health Record Disease Registry in Primary Care Practices: Lessons Learned from the Western New York Beacon Community," eGEMs (Generating Evidence & Methods to improve *patient outcomes*): Vol. 2: Issue 3, Article 7. ²⁶ Statistics Canada (2018). Census Profile, 2016 Census

Greater Vancouver, Regional district [Census division], British Columbia and British Columbia [Province]. Available from http://www12.statcan.gc.ca/census-recensement/2016/dppd/prof/details/page.cfm?Lang=E&Geo1=CD&Code1=5915&Geo2=PR&Code2=59&Data=Count&Sear chText=Greater%20Vancouver&SearchType=Begins&SearchPR=01&B1=All