



# NTM-PD Healthcare Professional Toolkit

A medical education toolkit for HCPs interested in  
improving the provision of care for NTM-PD patients

Development of this non-promotional medical education toolkit was funded by Insmmed Ltd and has been devised in consultation with a steering committee of NTM-PD experts.

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# Introduction



# Introduction

## Executive Summary

**Non-tuberculous mycobacteria (NTM)** are mycobacterial species that are commonly found in the environment. They vary in pathogenicity, and can cause lung, sinus, lymph node, joint, central nervous system and catheter-related and disseminated infections in susceptible individuals. NTM pulmonary disease (PD) is the most common clinical manifestation of NTM infection and is a growing health concern. NTM infection is a challenging condition to diagnose and treat, due to lack of awareness, and the high percentage of asymptomatic individuals.<sup>1</sup>

Developed in collaboration with healthcare professionals (HCPs) with experience of managing patients with NTM infections, this toolkit is designed to help HCPs improve the provision of care for people with lung infections caused by NTM (NTM-PD). The toolkit provides insights and guidance on the set up or enhancement of treatment centres for this underserved patient group, covering:

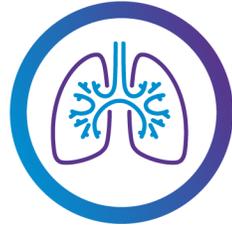
- Developing a business case
- Facilitating an NTM service
- Devising management plans for NTM patients
- Setting up a multidisciplinary team (MDT)
- Auditing NTM services

The healthcare professionals who contributed to the production of this toolkit are listed in the appendix.



# Introduction

## The Burden of Respiratory Disease



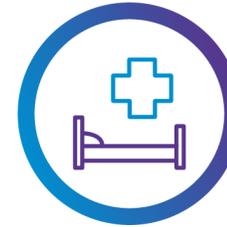
Respiratory conditions typically affect the lungs or other parts of the respiratory system, and place a large burden on healthcare providers around the world.



Lung diseases cost the UK £11 billion each year, in costs to the NHS and in lost productivity.<sup>4</sup>



Respiratory diseases represent one of the UK's top three killers, and people who are from socioeconomically disadvantaged backgrounds are susceptible to conditions like asthma and chronic obstructive pulmonary disease (COPD).<sup>2</sup>



Despite the fact that there are nearly 700,000 hospital admissions for respiratory conditions each year in the UK, funding for research into these diseases is low, compared to the disease burden and cost to society in terms of missed work days and rehabilitation.<sup>2,5</sup>



Between 2008 and 2012, respiratory diseases were responsible for 20% of annual deaths in the UK.<sup>3</sup>



# Introduction

The NHS Long Term Plan sets out the priorities for care quality and outcomes improvement for the decade ahead, which include a focus on provision of better care for major health conditions including respiratory diseases. There is also an increasing focus on supporting patients to be actively involved in their own care.<sup>6</sup>



# Introduction

## The Burden of Respiratory Disease

The NHS Long Term Plan sets out the priorities for care quality and outcomes improvement for the decade ahead, which include a focus on provision of better care for major health conditions including respiratory diseases. There is also an increasing focus on supporting patients to be actively involved in their own care.<sup>6</sup>

The [Service Framework for Respiratory Health and Wellbeing](#) applies to Northern Ireland, and includes professional standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation, and palliative care of people who currently have, or are at greater risk of developing, respiratory disease.<sup>7</sup>

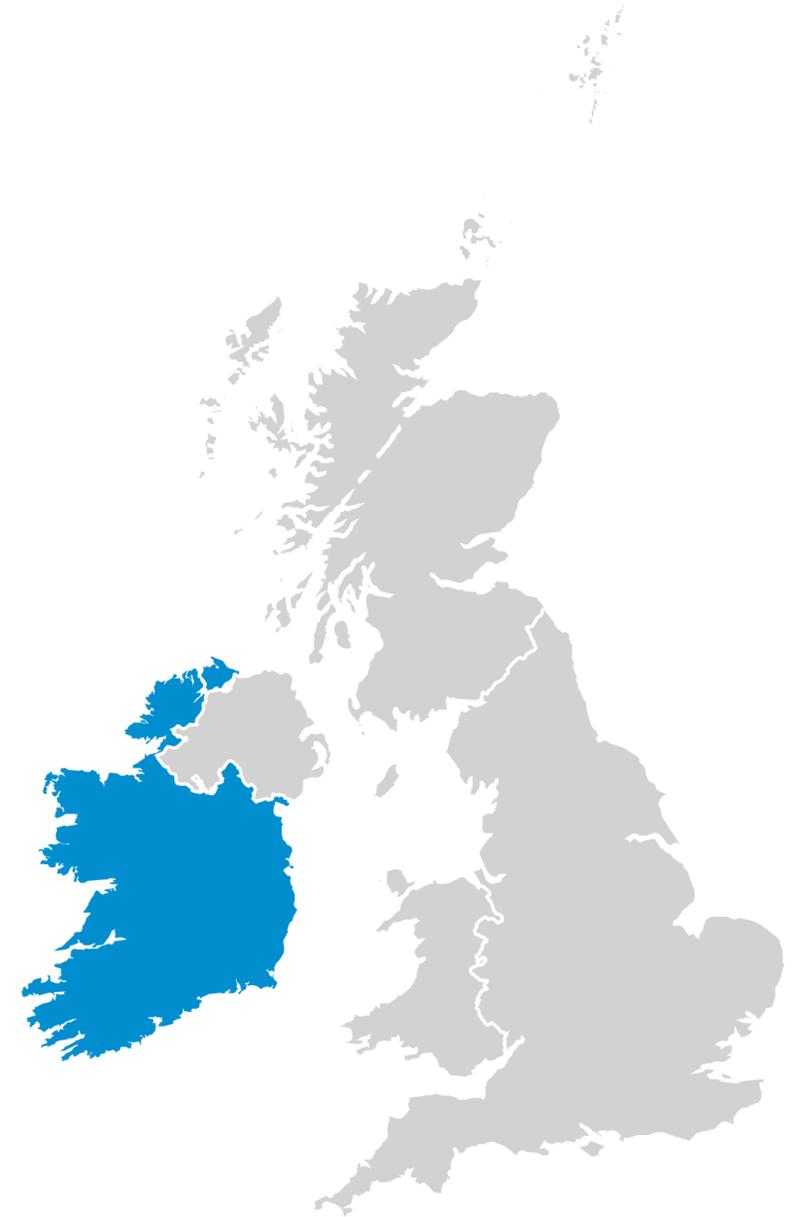


# Introduction

## The Burden of Respiratory Disease

The NHS Long Term Plan sets out the priorities for care quality and outcomes improvement for the decade ahead, which include a focus on provision of better care for major health conditions including respiratory diseases. There is also an increasing focus on supporting patients to be actively involved in their own care.<sup>6</sup>

The Irish Thoracic Society (ITS) promotes research into respiratory diseases and releases publications that educate the public about the causes and prevalence of conditions like asthma, sleep apnoea, and lung cancer.<sup>8</sup>



# Introduction

## The Burden of Respiratory Disease

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The [Respiratory Care Action Plan 2021-2026](#) for Scotland identifies ways to improve outcomes for people living with respiratory conditions. The plan encourages new and innovative approaches with the aim of sharing best practice.<sup>9</sup>



# Introduction

## The Burden of Respiratory Disease

The NHS Long Term Plan sets out the priorities for care quality and outcomes improvement for the decade ahead, which include a focus on provision of better care for major health conditions including respiratory diseases. There is also an increasing focus on supporting patients to be actively involved in their own care.<sup>6</sup>

Public Health England has developed principles on respiratory disease for those working in healthcare.<sup>10</sup>



# Introduction

## The Burden of Respiratory Disease

The NHS Long Term Plan sets out the priorities for care quality and outcomes improvement for the decade ahead, which include a focus on provision of better care for major health conditions including respiratory diseases. There is also an increasing focus on supporting patients to be actively involved in their own care.<sup>6</sup>

The [Health Delivery Plan 2018-2020](#) for Wales has the aspirational goal of Wales becoming a world leader in delivery of care to respiratory patients.<sup>11</sup>



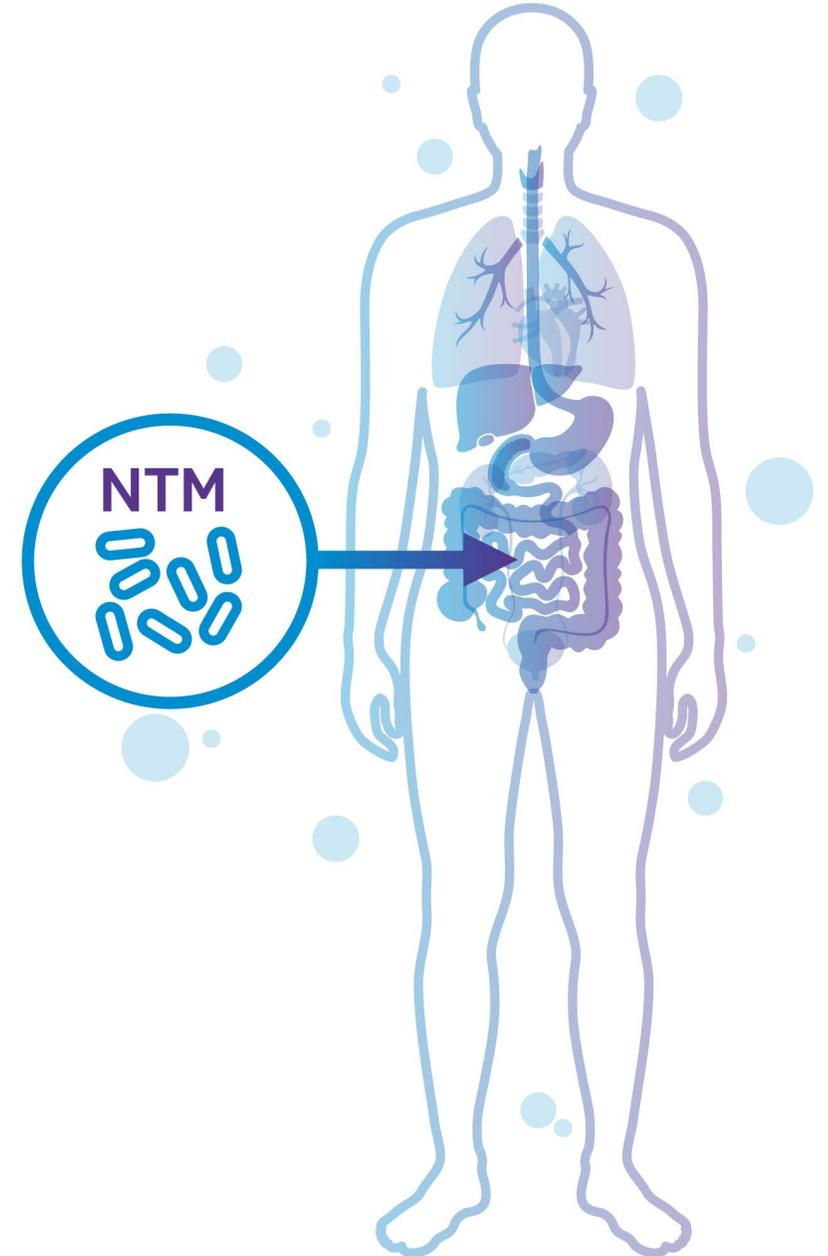
# Introduction

## Disease Overview

Non-tuberculous mycobacteria (NTM) refer to mycobacterial species other than the *Mycobacterium tuberculosis* complex and those that cause leprosy. NTM are commonly found in the environment and can cause lung, sinus, lymph node, joint, central nervous system, and catheter-related infections.<sup>12</sup>

NTM species isolated from sputum samples vary in virulence, and *Mycobacterium avium complex* (MAC) often correlates with disease.<sup>13</sup>

For the majority of patients, the lungs are the primary site of infection. Progressive inflammatory lung damage or ‘NTM pulmonary disease’ is known as NTM-PD.<sup>12</sup>

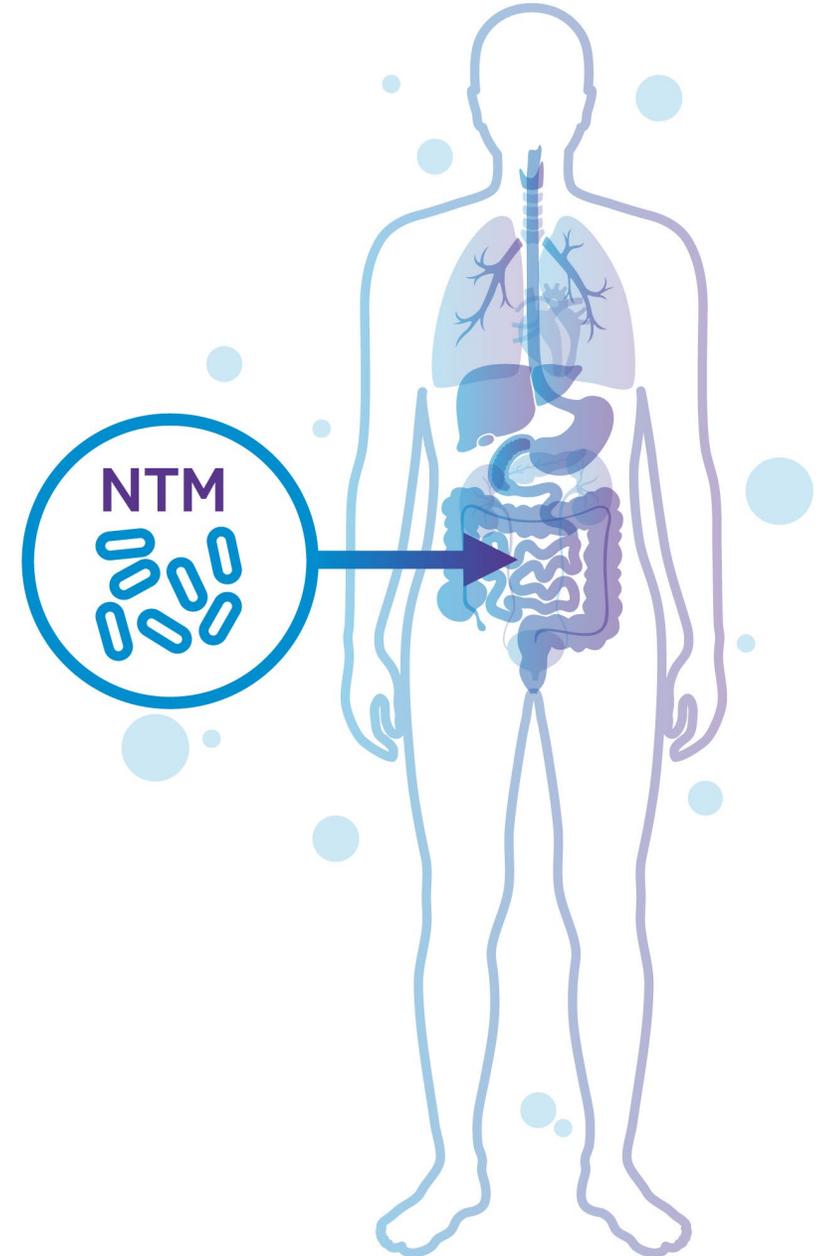


# Introduction

## Disease Overview

People who are susceptible to developing NTM-PD often have pre-existing pulmonary conditions, such as chronic obstructive pulmonary disease (COPD), bronchiectasis, or cystic fibrosis. Not all NTM infections cause disease in humans, and human-to-human transmission is rare.<sup>12</sup>

NTM can also transiently, intermittently, or permanently inhabit the lungs of individuals without resulting in NTM-PD. This can lead to challenges in identifying individuals who need treatment.<sup>12</sup>



# Introduction

## Epidemiology of NTM-PD

There is a need for improved identification of patients who are at risk of developing NTM-PD, because the disease can be fatal and severely affect patients' quality of life. Across the UK, there are differences in how NTM-PD patients are identified using microbiological tests for mycobacterial species.<sup>14</sup>

Data published in 2016, based on data collected between 2007 and 2012, found that the incidence of pulmonary NTM-positive cultures (not in itself an indication of the rate of NTM-PD infection) increased from 4.0 per 100,000 to 6.1 per 100,000 based on reports to Public Health England laboratories serving England, Wales, and Northern Ireland.<sup>15</sup>

Although more recent data are not available, this upward trend of incidence has continued and appears to be reflected worldwide. Studies from North America, Europe, and Asia have all shown increasing NTM disease incidence over the last 20 years.<sup>16</sup>

Advancements in molecular biology techniques, such as the use of whole genome sequencing (WGS) and mycobacterial growth indicator tubes, have improved the accuracy of methods used to detect and isolate NTMs.<sup>17,18</sup>



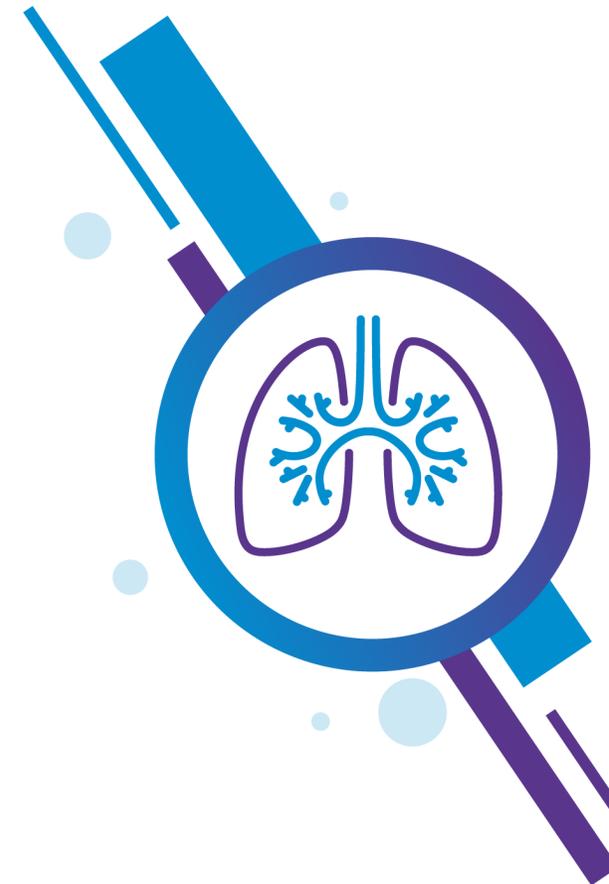
# Introduction

## Epidemiology of NTM-PD

NTM-PD is a chronic condition that often requires years of treatment for patients, with individuals at risk of reinfection or relapse.<sup>19</sup>

Where treatment is indicated, rapid initiation of therapy is associated with increased survival.<sup>20</sup>

Appropriate and timely intervention has the potential to reduce the associated economic burden of NTM-PD.<sup>20</sup>



# Introduction

## Unmet Needs

Awareness of NTM-PD is low among members of the public, and the low number of NTM-specific treatment centres in the UK and negatively impacts patients' access to care and support.<sup>14</sup>

This unmet need could be addressed by establishing NTM treatment centres that facilitate screening of susceptible individuals, regular assessment of their physical and emotional health, and management of symptoms that can severely affect patients' quality of life.<sup>14</sup>



# Introduction

## Unmet Needs

The success of the network of multidrug-resistant tuberculosis (TB) treatment centres suggests that people living with comparable conditions like NTM-PD may benefit from a similarly focused approach.<sup>14</sup>

Lack of support for patients diagnosed with NTM-PD in the UK led to the establishment of NTM Patient Care UK in 2018, which provides educational resources and information to increase understanding of NTM for patients and clinicians.<sup>21</sup>

Many patients with NTM-PD have a comorbidity such as cystic fibrosis (CF) or bronchiectasis, providing an opportunity for clinicians who manage other respiratory diseases to gain experience or become involved with the running of NTM services in a particular region.



# Introduction

## Integrated Care Models

Optimising treatment for patients with NTM-PD can be achieved through recruitment of a multidisciplinary team (MDT) of clinicians who work together to deliver patient-centred care.<sup>14</sup>

NTM services are vitally needed in the UK. The aims of NTM services include:<sup>14</sup>

- Identifying people who are susceptible to NTM-PD and altering modifiable risk factors where possible to enhance service users' quality of life.

- Increasing the ability to accurately and promptly gather information on NTM species and antibiotic resistance in the region.
- Building a system that offers world-class NTM nursing care.
- Using medical imaging techniques to track disease progression and monitor patients' responses to treatment.



# Introduction

## Integrated Care Models

Developing networks that promote integrated care such as integrated care systems (ICSs) and hub-and-spoke models are important in meeting the needs of patients with diseases like NTM-PD.

### These systems:<sup>14</sup>

- Improve patient access and consistency of care.
- Enable access to expertise and experience from a range of healthcare and social care professionals and services.
- May help to minimise patient commuting distances for clinic visits.

A hub-and-spoke model of care can be implemented by setting up local clinical networks that connect centres of expertise, which manage diseases associated with NTM, such as CF units, tuberculosis clinics, and bronchiectasis teams.<sup>14</sup>

The central ‘hub’ can provide resources to support the ‘spokes’.

The aim of a hub-and-spoke model is to provide opportunities for discussion of complex cases with experts, and regular regional MDT meetings should be included where information can be shared in real time with specialists.<sup>14</sup>

Hub-and-spoke Illustration



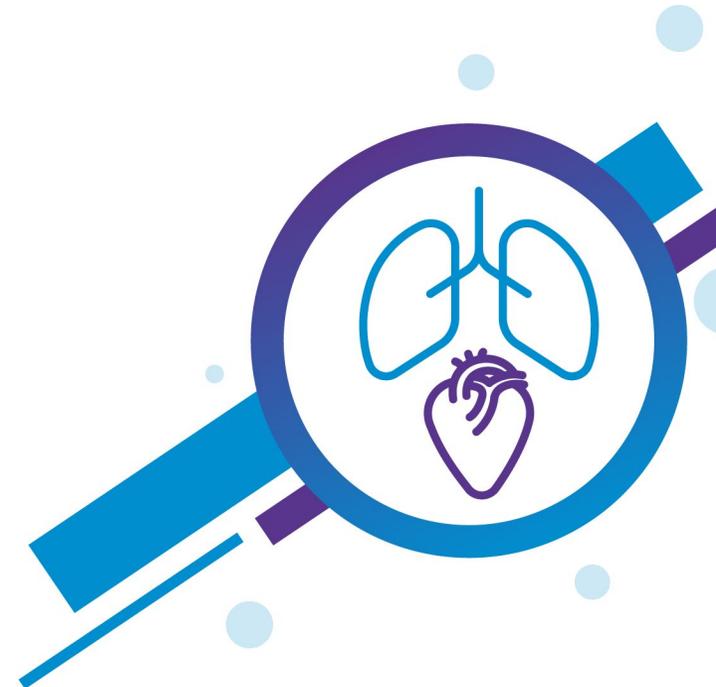
# Introduction

## Aims of NTM Services

NTM services should include:<sup>14</sup>

- Clear referral and disease management pathways.
- Enhancing interactions between NTM-PD patients, pharmaceutical companies, and medical researchers to allow patients to access therapies that are in clinical development through participation in clinical trials.
- Flexibly supporting patients with diverse needs and issues relating to NTM-PD. Enthusiastic members of NTM-PD MDTs are important for providing channels for patients to access care from regional experts. Follow-up appointments, use of telemedicine technologies, and home visits are key parts of establishing a model of care that suits the needs of individual patients.

This toolkit aims to provide support to you and your organisation in setting up an NTM service to help improve care for patients with NTM in your locality. If there are NTM services for patients in your region, this toolkit offers suggestions on how to improve them.



# Introduction

## Purpose of the Toolkit

The guidance in this toolkit is intended to support the implementation and delivery of an NTM-PD service by providing information on:

1. Developing a business case.  
  
A business case is needed to explain why you want to set up an NTM service, or if there is a service already...how you want to improve it. This could involve:
  - Establishing a multidisciplinary team.
  - Collaborating with local and regional respiratory disease treatment centres.
  - Improving referrals, which allows patients to access treatment at the earliest opportunity.
2. Auditing and making adjustments to the service that better meet the needs of patients.
3. Supporting patients in the optimisation of their care.



# Developing an NTM Service



# Developing an NTM Service

## Setting Up a Business Case

Setting up an NTM service will generally require submission of a robust business case to justify the need for such a service.

It is important to ensure that relevant personnel are involved in the planning, setup, and running of a successful NTM service. These individuals can provide their expertise for making the business case and play important roles in setting up the service. Examples of relevant parties include:

- Clinical leads (e.g., respiratory consultants)
- Physicians
- Nurses
- Pharmacists
- AHPs with an interest in NTM
- Project directors/managers
- Patients
- Information governance managers
- Contracts or procurements managers
- Human resources

Examples of additional hospital departments or services that could be involved in developing the business case:

- Infectious diseases
- Physiotherapy
- Microbiology
- Radiology



# Developing an NTM Service

## Setting Up a Business Case

**Note:** This list is not exhaustive and provides only guidance on things to consider for when you are setting up a business case.



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Select from the list below:

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[Strategic context](#)

[Scope and objectives](#)

[Constraints](#)

[Risk analysis](#)

[Impact analysis](#)

[Financial considerations](#)

[Interested parties](#)

[Project management](#)

[Alternative options](#)

## Considerations for a business case

- What are some of the current issues with the management of NTM patients in your locality?

### Think about...

- Number of patients with NTM-PD in your area
- Number of NTM-positive cultures
- Number of prescriptions for macrolides



- How patients are currently managed (e.g., with a combination of pharmacotherapy and physical exercise)?
- How would the proposed service improve the management of NTM-PD?
- Which individuals will play key roles in running the service?



Click [here](#) to download a business case template that can be amended according to your proposal's requirements. More detail on what information should be included in each section of a business case is provided in the [appendix](#).

# Developing an NTM Service

## Setting Up a Business Case

### Background

- It is important to set the stage for the service.
- What are the major unmet needs in this therapy area?
- Why is an NTM service necessary?
- What is the burden of NTM-PD in your area?

### Strategic context

How will the NTM-PD service align with NHS priorities, national and local policies, and the objectives of the organisation?

Examples of national and local policies are the [NHS England Long Term Plan](#) or [Respiratory Care Action Plan for Scotland](#).



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# Developing an NTM Service

## Setting Up a Business Case

### Scope and objectives

- Detail the scope of the service.
- Create specific, measurable, achievable, realistic, and timely objectives for the service.
- How will the service be resourced?
- Will the service offer training or allow people to develop different skills? (e.g., provision of tailored care for patients).
- What are the financial considerations for the service?
- What equipment will be needed to run the service?

### Constraints

Outline the potential constraints of the service, in terms of:

- Organisational concerns
- Clinical considerations
- Potential problems with resources
- Financial matters
- Issues with equipment



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# Developing an NTM Service

## Setting Up a Business Case

### Risk analysis

Think about the risks associated with the service and how they will be managed: e.g., If one of the team is away for a period of time...how will the service be run?

- What kinds of questions would you have in a risk assessment for the service?
- Are the drugs and devices used to treat NTM-PD familiar to the people running the service?
- How will the service address drug resistance and lack of adherence?
- What would be the financial consequences of not having the service in your area? (e.g., would patients be shuttled between different hospitals to achieve a diagnosis? How would this affect initiation of treatment?)

### Impact analysis

Describe the impact of implementing the service in your locality. Are there any case studies that show how patients would benefit from this service?

- Consider if the service can be managed alongside existing services for tuberculosis, CF, bronchiectasis, or COPD.
- Is it possible that an increase in cases could lead to other departments becoming overwhelmed?
- How could the NTM service be run efficiently? (e.g., by sharing skills and services among relevant personnel)



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# Developing an NTM Service

## Setting Up a Business Case

### Financial considerations

Working out MDT staff roles, along with the minimum number of hours that they will be able to dedicate to the running of the service, will be essential. Consider if some roles (e.g., nurse) can be split between the hospital and the community.

#### Think about:

- Paying for staff
- Administrative costs
- Cost of clinical monitoring
- Paying for and cleaning clinic rooms
- Medical equipment
- IT equipment
- Budget for medication



How can people determine costs and check that predicted costs are accurate? It is important to find out how money can be saved at each stage. Ask questions (e.g., is it more expensive to treat patients as outpatients or intensively administer antibiotics in a clinical setting?).



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# Developing an NTM Service

## Setting Up a Business Case

### Financial considerations

#### Describe the estimated costs in detail.

What are the resources that will be needed to set up and maintain the service?

How often should a patient see a respiratory specialist or physiotherapist?

- Consider costs incurred to start the NTM service.
- Consider ongoing costs.
- It may be possible to obtain estimates of costs from previous business cases.

If these are unavailable, consider asking for advice from existing NTM services.

Look at an [example of an NHS business case](#) or ask local or regional services for similar respiratory indications (e.g. TB or CF) for insights on how to calculate costs for respiratory care services.

#### Consider:

How to avoid wasting resources. This may be linked to inappropriate investigations, administrative costs, prescribing of ineffective treatments, or not optimising treatment for any reason, such as COVID-19 restrictions.



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# Developing an NTM Service

## Setting Up a Business Case

### Interested parties

A stakeholder is anyone who has an interest in the NTM service, irrespective of their individual role, responsibility, or contributions.

In your business case you should explain what kinds of stakeholders will support the NTM service.

Have these individuals been contacted?

Provide evidence of support from collaborators.

### Project management

How will the NTM service be managed and how will this affect provision of care?

What is the projected timeline for development of the service?

How will the service be audited?

How will patients be monitored?

### Alternative options

Describe alternative options to your current or proposed service.

What are the similarities and differences between current services and the NTM service being proposed?

Can existing services merge with a new organisation?

**Tip: Consider healthcare law and how the service will comply with legal requirements.**



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# Working with a Multidisciplinary Team



# Working with an MDT

## Setting Up an MDT

### Consider what you already know about NTM services in your area.

- Does a service already exist?
- If there is a service, do you know who is involved with running it?



### Setting up a multidisciplinary team (MDT)

A multidisciplinary team is a group of healthcare workers who have different areas of expertise but work together to provide holistic, person-centred care and support.<sup>22</sup> An MDT utilises knowledge, skills, and professional experience to better meet patients' needs.

A healthcare professional who has a good background understanding of NTM infections and is able to communicate with the patient and/or their carers is a central part of an MDT.

Patient advocacy groups may be able to assist in connecting relevant clinicians with each other. This includes nurses, pharmacists, respiratory or infectious disease physicians, and other personnel such as physiotherapists, dietitians, health psychologists, and occupational therapists.



# Working with an MDT

## Setting Up an MDT

### Assembling a core team

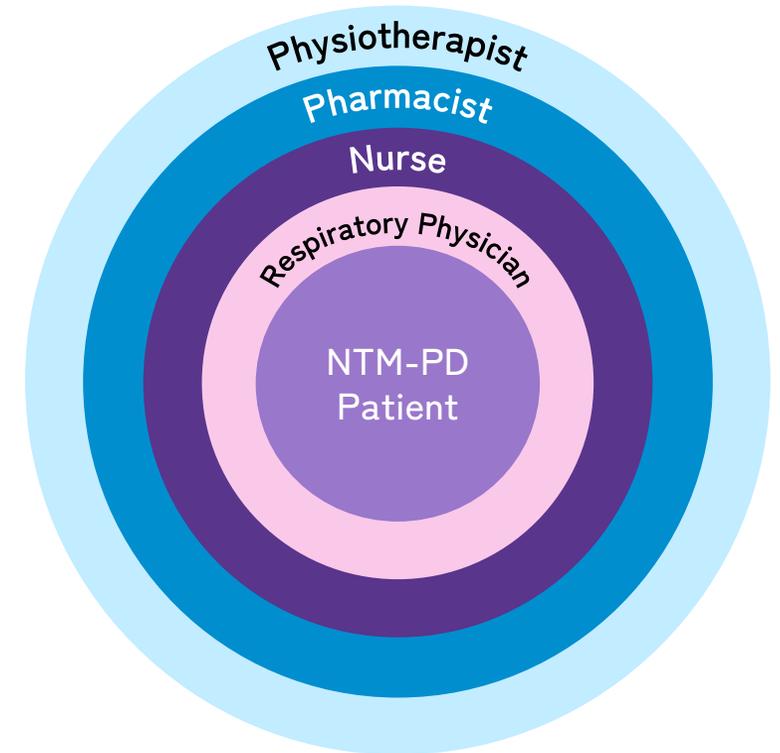
Demonstrating enthusiasm for the service and keeping knowledge of managing patients up-to-date are essential characteristics for initiating or leading the MDT.

A small core team may consist of a nurse, physician, pharmacist, and physiotherapist who have experience of treating patients with respiratory diseases.

This team facilitates the connection between the patients and the wider MDT. The core team has a central role in making patients feel like the NTM service is easy to access.

The core team would benefit from being able to identify contacts at other treatment centres or referral sites, when this would be helpful for a particular patient's needs.

In addition, the core team should be involved in making sure that patients are able to attend follow-up appointments.



Example of a potential core team in an NTM-PD service, adapted from [Auvin et al., 2019](#)



# Working with an MDT

## Setting Up an MDT

### The full MDT

Specialties that are relevant to the management of patients with NTM-PD include microbiology, radiology, occupational therapy, physiotherapy, dietetics, and psychology. At this stage of assembling the MDT, a clear organisational structure, and individual awareness of each person's role in the team is essential.

Auditing processes (which are covered in more detail in the [auditing](#) section of this toolkit) should be used on a regular basis to evaluate whether the service adequately meets the needs of the patient community. It is important to establish who in the team is responsible for collecting feedback.

Consideration may be given for professional training courses for MDT members, for example to enhance communication skills or develop leadership capabilities. This will help create a plan that can accommodate transfers of responsibility where necessary, as the team changes over time.



# Working with an MDT

## Principles of an MDT

According to a 2015 NHS England report, the principles of a successful MDT revolve around:<sup>23</sup>

### Developing a shared purpose

This allows the patients, healthcare providers, and other stakeholders to focus on and agree to an overarching aim for the provision of care for people with NTM-PD. There should be unity in vision and goals of the service.

In developing goals for the service, ensure that they are meaningful to patients, providers, and stakeholders, and are measurable and achievable.

Open communication will facilitate progress by learning from mistakes and introducing problem-solving efforts to find solutions to issues that negatively affect patient care.

### Accountability and governance

It is important that the service is clear on the accountability and governance arrangements, as this will help to improve patients' and stakeholders' confidence in the service.



# Working with an MDT

## Benefits of an MDT

Some of the potential benefits of the MDT in an NTM service include:<sup>23</sup>

- Reduced hospitalisation of patients and associated costs because patients are closely monitored and treated appropriately
- Improved service provision because the MDT members are specialists in this therapy area
- Improved levels of innovation in patient care because MDT members liaise with patients on an individual level
- Enhanced patient satisfaction and increased staff motivation
- Greater continuity of care across different care settings
- Getting patients involved in clinical trials



# Working with an MDT

## Clinical Information Systems

Information about patients and the care they receive is recorded and stored in a clinical information system, so that MDT members can have an overview of patients' status, treatment, and decisions that have been made about their care.

Information about patients' medicine, allergies, illnesses, test results, hospital discharge summaries, appointment letters, and referral letters can be included in a healthcare record.

### A patient record in an NTM service should:

- Be easily accessible and searchable for MDT members.
- Have decision-making processes included alongside patient notes.
- Have up-to-date and historic records, which are important for clinical governance and audits.
- Have all edits to the document, including who made the changes and when they made them, visible.

**Note:** Only members of the MDT should be able to edit the patient's healthcare record.



# Working with an MDT

## Structure of an MDT

### Examples of personnel involved in an NTM MDT:

- [Respiratory Physician or Infectious Disease Specialist](#)
- [Pharmacist](#)
- [Nurse](#)
- [Physiotherapist](#)
- [Radiologist](#)
- [Microbiologist](#)
- [Occupational Therapist](#)
- [Psychologist](#)
- [Dietitian or Nutritionist](#)
- [Other \(e.g., GPs, Consultants Treating Comorbidities\)](#)

Click on each role on the list to find out more about what they bring to an MDT.



# Working with an MDT

## Respiratory or ID Physician

Respiratory physicians or infectious disease (ID) specialists who have experience of treating patients with NTM-PD are vital members of the MDT and have the clinical role of making treatment decisions, managing patient referrals, and ordering tests and scans which are used to monitor patients' progress.

### Leadership

The respiratory physician/ID specialist usually leads the NTM service. Your role is varied and may involve building and maintaining the infrastructure and processes of the MDT, responsibility for governance, chairing MDT meetings, liaising with primary/secondary care colleagues, receiving feedback on the efficacy of treatment, how patients are coping, and using information provided by MDT members to make decisions on how patients are managed.

### Organisation

Organising imaging and laboratory testing or reviewing existing findings from tests and scans may form a key part of your role.

### Communication

A key part of your role is liaising with patients and their carers, their referrers, and other members of the MDT to provide the highest standard of care for service users.

Recording relevant patient data including clinical decisions, non-pharmacological and drug treatments, and outcomes, into a dedicated NTM-PD database is desirable.



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# Working with an MDT

## Pharmacist

Pharmacological management of NTM-PD often involves use of complex medication regimens in patients who often have comorbidities and are taking other drugs.

The role of a pharmacist is increasingly patient-facing, some are independent prescribers and carry out very broad clinical responsibilities, and NTM MDT pharmacists will offer guidance and outline expectations of NTM treatment.

### Key responsibilities of a pharmacist

- **Drug monitoring**

As a pharmacist, you are likely to be involved with monitoring adverse events and drug interactions. Making sure that the recommended treatments are on formularies and guidelines, and checking that patients know how to take the medication according to their prescription instructions, is also a key part of the pharmacist's role in the MDT.

- **Patient education**

Being knowledgeable about contraindications, drug-drug interactions, adverse events, and the patient's allergies/ lifestyle factors that affect treatment is essential for the pharmacist in an MDT. With this knowledge, you can educate the patient about their medication and what they need to do in order to optimally benefit from treatment. The pharmacist can suggest specific formulations to suit a patient's lifestyle and preference.



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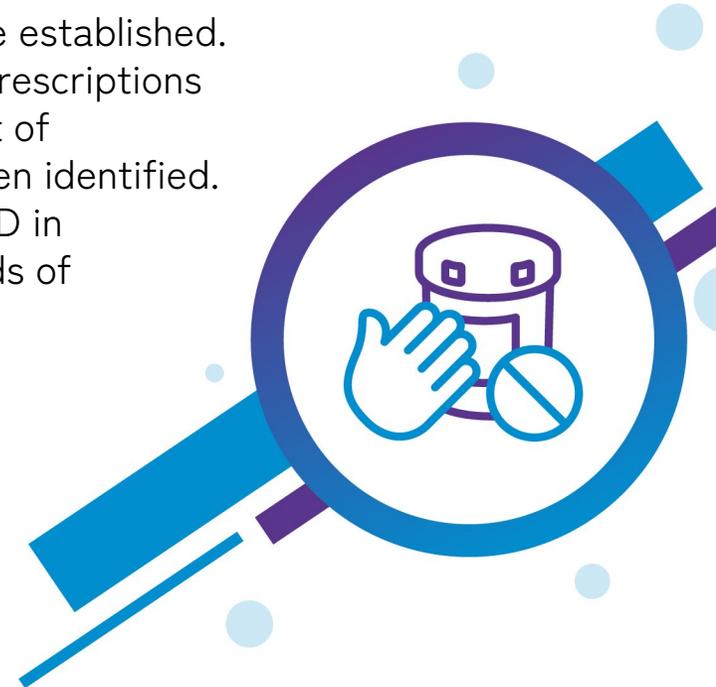
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# Working with an MDT

## Pharmacist

### Responsibilities of the pharmacist:

- **Horizon scanning**  
As a pharmacist, staying up-to-date with drugs in clinical development, their performance in clinical trials, and their potential to treat patients with NTM-PD would be a strong asset. Looking for new therapeutics and adding them to relevant formularies at the earliest opportunity will allow patients to gain appropriate access to diverse treatment options.
- **Setting up the MDT as a core team member**  
You may lead the drive for a local NTM-PD service to be established. Requests for advice from pharmacists on appropriate prescriptions for patients with NTM-PD have led to the establishment of NTM-specific treatment services where this gap has been identified. If you see multiple or rising numbers of cases of NTM-PD in your area, consider setting up an MDT to meet the needs of these patients.



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# Working with an MDT

## Nurse

### As a nurse:

- You will be informed when NTM-PD has been diagnosed and administer the treatments in conjunction with instructions from the prescriber, usually the MDT lead respiratory physician/ID specialist.
- Patient education is a key part of your role. To support the health literacy of your patients you will provide education and advice on their disease and management plan, including secondary symptoms such as breathlessness, anxiety, weight loss, pain, and incontinence. Independent prescribers will have additional expertise to offer on the patients' drug treatments and devices.
- You may collaborate with, and inform clinicians of test results, ensuring that enough biological samples are obtained from the patient, and if necessary, review hospital or GP records, making sure that all information is up to date.
- You may carry out home visits, an opportunity to observe a patient in an environment that is comfortable for them. This can give you insights into how they are managing their medication in the real world. You may also be able to deliver education about drug storage or how to use medical devices that are related to the management of NTM-PD.

Examples of questions to ask patients are included in the [appendix](#).



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# Working with an MDT

## Nurse

Home visits may further be important in assessing the psychological health and wellbeing of the patient, who may be more comfortable discussing their concerns in their own home. The patient's carer may also be present to encourage them to share their experiences in a setting that feels less time pressured than a clinic appointment.

### Examples of things to assess:

- Mobility.
- Sensory abilities.
- Activities of daily living.
- Balance and gait problems.
- Living situation and associated hazards (e.g., Is there any damp or mould that could affect the patient's breathing?).
- Social support.
- Disease management (including prescription drugs and dietary supplements).
- Height, weight, blood pressure, and general physical condition.
- Adherence to the treatment regimen.
- Assessing the feasibility of administering intravenous treatments in the home.
- Making sure the patient can properly use inhalers or nebulisers where necessary.



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# Working with an MDT

## Nurse

The benefits of having a nurse in the MDT include exchange of information about how best to support individual patients with treatment adherence, understanding individual factors that may influence treatment outcomes, and interacting with carers to help them assist the patient with daily activities.

A nurse will ideally have experience of supporting patients with respiratory diseases. In the absence of specialist NTM nurses:

- Bronchiectasis/CF nurses may have increased capacity to support NTM-PD patients, because of emerging CF treatments.
- These nurses may be particularly helpful for NTM patients with comorbid CF.
- TB nurses often have highly adaptable and specific skill sets that would be useful in this area.

Nurses without specialist NTM/TB/respiratory knowledge should be given training on managing patients with respiratory conditions. Coordinating appropriate clinical assessments, checking and monitoring side effects of treatment, and attending follow-up appointments are also part of the nurse's role.



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## Physiotherapist

The MDT would benefit from a physiotherapist with NTM experience, or minimally experience in airway clearance techniques in patients with long-term respiratory conditions.

Key objectives of physiotherapy in patients with NTM-PD include assessing all patients with a chronic productive cough or difficulty clearing sputum, and improving aerobic capacity and exercise tolerance.

Physiotherapists can advise patients with impaired exercise capacity on participation in regular activity, including where appropriate a pulmonary rehabilitation programme. All interventions can be tailored to the patient's symptoms, physical capability, and disease characteristics.

Physiotherapy plays a key role in reducing exacerbation of symptoms such as coughing and breathlessness. This can significantly improve quality of life. As a physiotherapist, your role may include the management of secondary symptoms such as breathlessness and incontinence. You can also perform nebulised drug reaction assessments to examine the patient's reaction to mucus thinners and antibiotics.



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# Working with an MDT

## Physiotherapist

Identifying NTM-PD cases that worsen can help you make a plan of action to optimise patient care.

### You could:

- Collect sputum samples to send to microbiology for testing, which can guide treatment decisions and provide greater detail on the species responsible for the patient's symptoms.
- Play an active role in annual screening by assessing the patient's ability to carry out energetic activities.

The patient-facing physiotherapist role is an important constituent of an MDT. A key part of making sure that patients benefit from the service is facilitating engaging activities.

Examples of activities include exercises that strengthen chest muscles, and brisk walks which are known to reduce inflammation.<sup>24</sup>

Signs that a patient is not responding to treatment include night sweats, weight loss, and breathlessness.

Screening for NTM in patients with associated diseases, such as bronchiectasis, is recommended by the British Thoracic Society (BTS).<sup>25</sup>

As a physiotherapist who sees patients with related conditions such as COPD, if you think a patient may have NTM-PD, you can take the proactive measure of sending sputum samples for testing.



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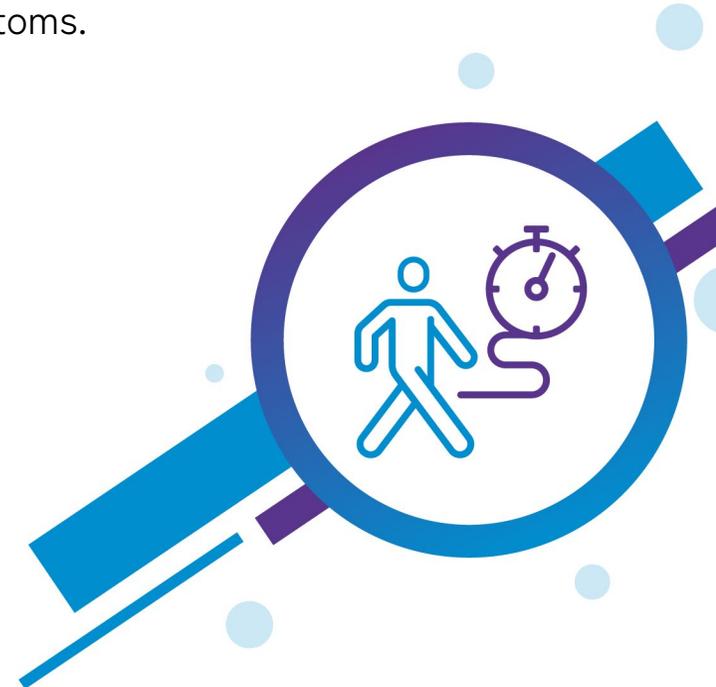
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# Working with an MDT

## Physiotherapist

### The six-minute walk test

- Created by the [American Thoracic Society](#) (ATS) in 2002, the six-minute walk test (6MWT) requires the patient to walk as far as possible in six minutes.<sup>26</sup>
- The patient is permitted to slow down, stop, or rest where necessary. They should resume walking as soon as they are able.
- Cones may be set up at either end of a 30-metre stretch as turning points for patients, and chairs can be placed at 15-metre intervals for rest.
- The patient is instructed to walk back and forth around the cones, pivoting briskly around them and continuing to walk back the other way without hesitation.
- The 6MWT can be used at any time during the patient's treatment journey to assess progress or changes in symptoms.



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## Radiologist

A radiologist with an interest in NTM and associated respiratory disorders is an important part of an MDT.

Lung damage is not always immediately apparent in X-ray images, and the increased sensitivity of computed tomography (CT) scans is a factor in the recommendation of the BTS guidelines for this technique to be performed routinely to track NTM-PD patients' response to treatment.<sup>[12,27](#)</sup>

Although some patients' symptoms can improve or resolve in response to treatment, radiological findings have shown that lung damage can persist in many patients who later test negative for NTM.<sup>[28,29](#)</sup>

The radiologist's contributions to the MDT affect treatment and long-term management of NTM-PD, because understanding and communicating the physiological changes in the patient's lungs, regardless of changes in symptoms, can guide treatment decisions that are made by the respiratory physician or ID specialist.



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## Microbiologist

Lack of timely diagnosis is an unmet need in this therapy area, due to low disease awareness.<sup>1</sup> As a microbiologist, you play a key role in diagnostics as you will be the party with access to patient sputum specimens to determine if they are positive for acid-fast bacilli (AFB).

Making sure that the rest of the MDT are aware of when positive cultures have been identified is an important part of the microbiologist's role in the NTM service. Although not everyone with NTM infection requires treatment, data on prevalence are sparse and disease knowledge limited among members of the general public.

Microbiologists can help advise on the efficacy of different treatments on NTM cultures and ensuring that the wider team has all the information they need, regarding NTM species and drug sensitivities.



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## Microbiologist

### Antibiotic expertise

Providing advice on antibiotic use, and the impact of long-term administration of antibiotics on the treatment of comorbidities to other members of the MDT, is a key part of your role. Using your specialist knowledge, you can help to personalise treatment for patients based on feedback from other members of the MDT.

### Research

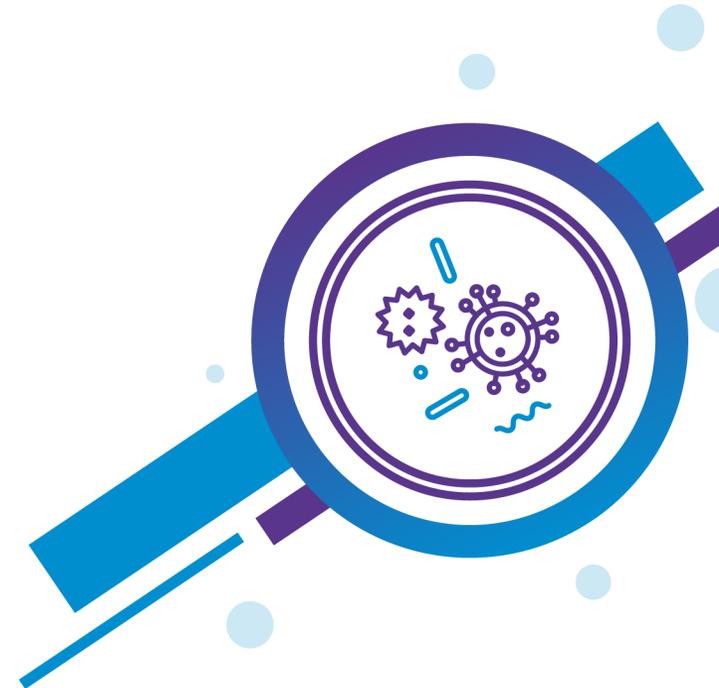
Microbiologists can help epidemiologists understand the prevalence of AFB-positive cultures, and whether or not the positive cultures are associated with symptomatic individuals in the community. Research undertaken by microbiologists can be communicated to other members of the MDT and be used to form the foundation of a business case.



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## Occupational Therapist

As an occupational therapist (OT), you may be asked by the MDT to carry out a home visit to understand and document any practical difficulties that the patient is experiencing.

OTs support patients in carrying out daily activities and may use home visits to conduct risk assessments and evaluate patients' needs. Your role will involve reporting adjustments that need to be made to allow patients to live as comfortably as possible. You can have an important role to play in ensuring that modifications to the patient's home and lifestyle may aid their recovery from illness.

Part of your role may involve assessing the adequacy of the patient's housing and reporting your findings to the relevant party. OTs are most likely to be involved in the care of patients whose disease significantly impacts their ability to function in society. You may find it helpful to make yourself aware of the pivotal role that good housing and living environments can play in the respiratory health of people with NTM-PD.

Examples of questions to ask patients are included in the [appendix](#).



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## Psychologist

Psychological support may lead to significant mental health benefits for people living with NTM-PD, especially in the context of COVID-19.

The patient may be vulnerable to the psychological and social effects of a pandemic, which include isolation, fear of illness, stigma related to their symptoms, and loss of income. These factors can negatively affect adherence to treatment.<sup>30</sup>

Basic psychological clinical assessment at an early stage can allow other members of the MDT, such as the nurse or OT, to refer patients to a psychologist at the first opportunity to address signs of psychiatric or mental health concerns.

As a psychologist, you can find out about the patient's quality of life through a health questionnaire or survey. If a patient doesn't

qualify for the support of a psychologist provided by the service, they could be referred to a local support counsellor or therapist who can work with them, either in a face-to-face setting or through a virtual medium. Acceptance and commitment therapy (ACT) or cognitive behavioural therapy may be helpful to patients.

### Questions to think about as a psychologist in an NTM service:

- Can you help patients understand how their diagnosis makes them feel?
- Can you help patients devise coping strategies for maladaptive thought patterns?
- Can you encourage patients to seek assistance when their condition becomes difficult to manage?



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## Dietitian

Hypermetabolism with increased protein catabolism, loss of lean body mass, and skeletal atrophy are commonly seen in patients with COPD, which is a common comorbidity of NTM-PD.<sup>31</sup>

Low weight for one's age and sex can be linked to poor immune system function, and failure to stabilise weight is associated with poorer outcomes in NTM infection.<sup>32</sup> A patient may be referred to a dietitian by a concerned member of the MDT if they appear to be malnourished.

The [BTS guideline](#) for treating NTM-PD patients explains that the role of the dietitian involves measuring and monitor patients' body mass index (BMI), performing thorough nutritional assessments, and optimising nutritional status with dietary supplementation.<sup>12</sup> As a dietitian, you may find that helping patients devise meal plans that are rich in antioxidants and protein may prove to be beneficial.<sup>33</sup> In addition, appetite-stimulating medications or supplement drinks that contain minerals and vitamins may help boost the immune system of patients who are underweight.

### Examples of foods that are recommended for NTM-PD patients are:

- Meat
- Fish
- Legumes
- Soy
- Dairy products
- Tofu



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## Other Parties Involved with the NTM Service

The move towards virtual MDTs has led to opportunities for increased involvement of parties not described earlier in this chapter. These people will occasionally attend meetings and not necessarily be involved in NTM-specific treatment decisions for individual patients. However, these individuals (such as GPs or specialists such as dermatologists who manage the effects of extrapulmonary NTM disease) may provide patient-specific information at meetings, specialist advice, or attend MDT meetings for educational purposes.

One of the benefits of virtual MDT meetings is that a large number of attendees can be present without social distancing or safety measures being taken to prevent transmission of COVID-19. Additionally, virtual meetings are an inclusive, efficient, and environmentally friendly way to make discussions accessible to people involved in patient care.

Patients can regularly offer feedback to the core team at follow-up appointments or anonymously through forms that are filled out before or after visiting the treatment centre. Anonymised patient feedback provided to core MDT members may be reported in meetings with the wider MDT to improve the service. It is critical that patient confidentiality, which is an ethical and legal duty for healthcare providers, is maintained.<sup>34</sup> Keeping feedback anonymous, regardless of a patient's comfort with sharing their comments and concerns, will promote impartiality and fairness in how they are treated by members of the MDT.



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## Goals of the Service and Patient Referrals

### Focusing on these principles will help the NTM service achieve its goals:<sup>35</sup>

- Communicating effectively with MDT network colleagues and stakeholders.
- Incorporating patient choice into decision-making.
- Incorporating patient views into treatment choices.
- Incorporating patient psychosocial factors into decision-making.
- Incorporating patient comorbidities into decision-making.
- Ensuring equality and inclusiveness in the MDT.
- Managing conflict within teams effectively.
- Rotating chairing duties within and between disciplines.

### Actions that can improve patient referrals:

- Using interdepartmental meetings to raise awareness of the service.
- Highlighting concerns to healthcare professionals.
- Considering ways to improve links between community healthcare professionals and the NTM service.



# Working with an MDT

## Training Courses and Technological Assistance for MDT Members

The NTM Network has an online course with seven modules on the training of healthcare professionals, such as respiratory physicians, microbiologists, radiologists, and pharmacists.<sup>36</sup>

A course developed by an NTM service could outline the circumstances in which a healthcare provider should suspect that a patient has NTM-PD. Identifying patients can be difficult if the clinician relies only on symptoms to establish a diagnosis.

Automated analysis of electronic health records using artificial intelligence can considerably improve screening rates by identifying patients who fit specific criteria to attend provide sputum samples, or attend chest X-rays, MRIs, or CT scans.

Machine learning technologies are increasingly being used to differentiate between NTM-PD and pulmonary tuberculosis.<sup>37</sup> Criteria can include the presence of comorbidities such as COPD or CF, as well as immunocompromised status caused by treatment for other conditions such as rheumatoid arthritis or multiple sclerosis.

[Guidance on investigating suspected cases of NTM-PD are included in this toolkit.](#)



# Facilitating an NTM Service



# Facilitating an NTM Service

## Screening Patients

Annual screening of bronchiectasis patients for NTM is recommended by the BTS guideline for managing bronchiectasis in adults.<sup>25</sup>

Before macrolide therapy is initiated, COPD and bronchiectasis patients should be screened for NTM according to the BTS.<sup>38</sup> Educating these patients about the symptoms of NTM-PD is important.

The US CF Foundation and European CF Society consensus is to advise that CF patients with clinical characteristics of NTM-PD should have their sputum tested annually.<sup>39</sup>

Screening immunocompromised people with a history of respiratory diseases could reveal that more people than previously thought are at risk of developing NTM-PD and may benefit from prophylaxis. While some people may be asymptomatic for long periods of time, it is still important to monitor patients' infections over time and provide medical intervention if it becomes clinically necessary.

The [US Cystic Fibrosis Foundation](#) and [European Cystic Fibrosis Society](#) have developed [Best Practice Guidelines](#) to outline the approach that should be taken to investigate patients with CF who are also suspected to have NTM-PD.<sup>39</sup>



# Facilitating an NTM Service

## Diagnosing NTM-PD

Repeated isolation and identification of NTM taken from sputum, can be a central part of diagnosis, alongside CT scans and X-rays.

NTM-positive samples do not necessarily indicate that a patient has NTM-PD. Further investigations are needed to determine if the patient will benefit from treatment, which can be offered in primary care or in a hospital setting.

Upon clinical suspicion of NTM-PD, a sputum sample will be sent to a microbiologist for an initial AFB test. If the sample is positive for AFB, the sample will be further cultured and a TB and NTM test may be completed in-house or externally, where the sample is sent to a national testing centre.

If NTM is identified, further analysis will involve WGS to determine the NTM species and, for certain species, drug sensitivity testing will also be performed. The results will then be communicated back to clinicians through the microbiology department.

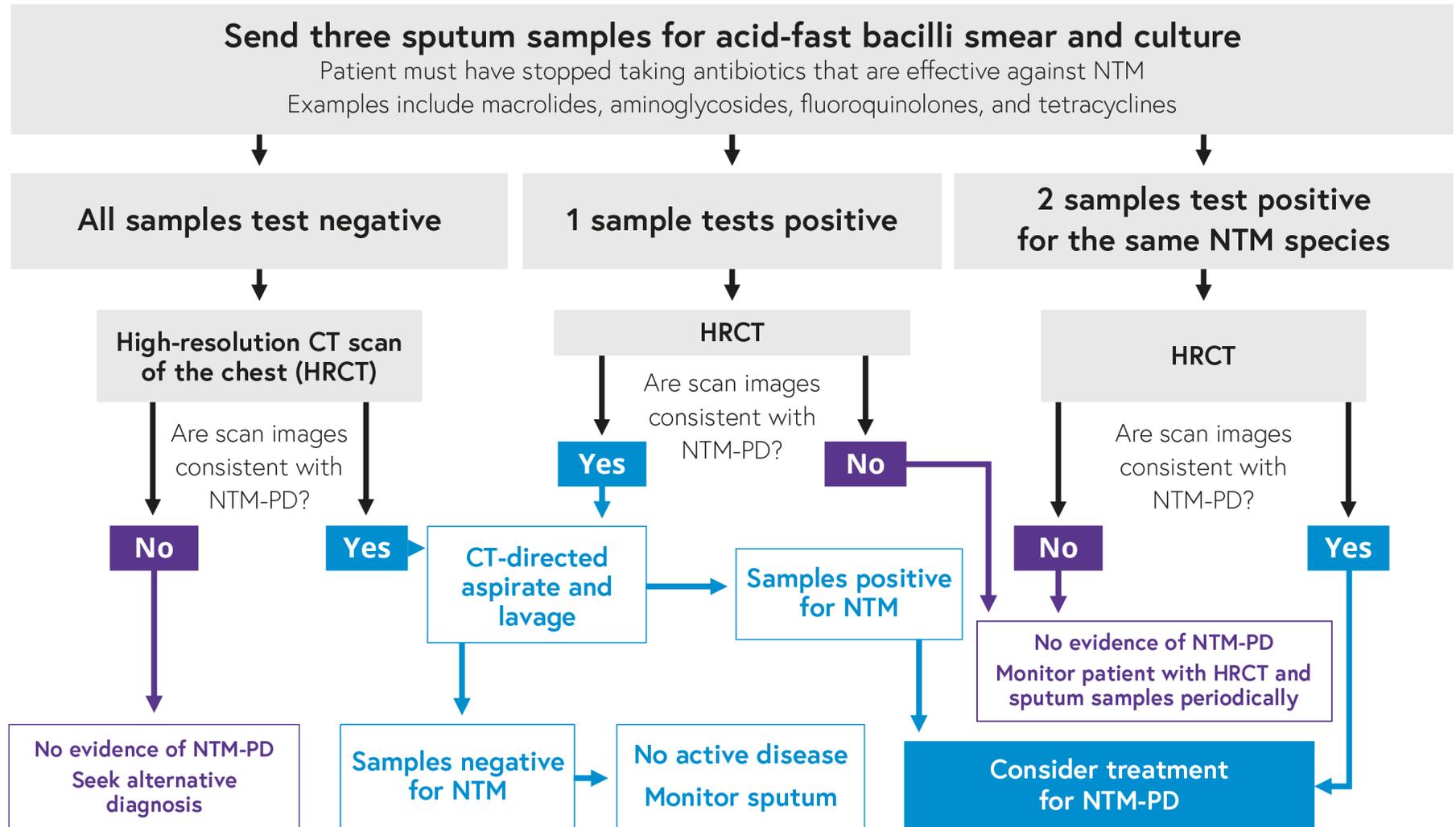
GPs, nurses, or other healthcare personnel who treat patients with respiratory diseases can attend online or in-person courses to familiarise themselves with the diagnosis, burden, and treatment of NTM-PD.<sup>36</sup>



# Facilitating an NTM Service

## Diagnosing NTM-PD

### Clinical suspicion of NTM-PD



Best Practice Guidelines for NTM-PD, modified from  
[Haworth \*et al.\*, 2017](#)



# Facilitating an NTM Service

## Clinical Monitoring of NTM-PD Patients

Note that most medications for NTM-PD are unlicensed and prescribers should refer to international and national guidelines and local trust protocols on treatment of NTM-PD.

An appropriately qualified person in the MDT, such as a nurse, can monitor patients for adverse effects of treatment. [BTS Guidelines](#) and the [ATS](#) recommend patient monitoring assessments include:<sup>12,40</sup>

- Renal function tests
- Auditory and vestibular assessments
- Blood tests
  - Full blood count
  - Urea and electrolytes
  - Liver function tests
- Electrocardiograms
- Visual acuity and colour discrimination testing

MDT members should be prepared to refer patients to other specialists if side effects occur, such as changes in vision, renal function, or cardiac function, which should facilitate referral to an ophthalmologist, nephrologist, or cardiologist, respectively.



# Facilitating an NTM Service

## Clinical Monitoring of NTM-PD Patients

Using non-confrontational questions, a patient-facing member of the MDT (such as the nurse) can ask patients if they have picked up their prescriptions.

**To gather information on adherence, a nurse may ask:**

“How often do you remember to take your medication?”

The patient-facing MDT member may be able to follow up by asking if there are ways to help the patient remember to take their medication.

Questions can be asked in the context of a home visit, in the form of an interview, and the answers can be written on paper or provided to HCPs digitally.

These questions can be used to monitor progress or inform referrals to specialists like psychologists or dietitians.

More detail on questions to ask patients during home visits are provided in [this toolkit](#).



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

Advocating for patients to create support groups, both for patients with respiratory comorbidities and those without similar comorbidities, is useful.

Mental health support can be provided virtually or during face-to-face sessions, where patients may be able to receive cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT), which aim to alter how patients perceive negative thoughts.

There are numerous health questionnaires that patients can complete to report changes in their mental health.

Other useful online resources are available for patients who suffer from poor mental health. For example, the [British Lung Foundation](#) has [information on treating depression](#) in patients with respiratory conditions.<sup>41</sup>

Patients can access mental health support through primary care. Referral to a psychiatrist by the MDT may be appropriate in specific circumstances.



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

### Consider information and support that could be given to patients and their carers:

- How can the condition be monitored in a way that makes the patient feel supported?
- Does the patient need assistance with remembering how to take medicines? (For example: some antimycobacterial agents must be taken before breakfast)
- Are patients aware of common adverse events (such as urine discolouration caused by the use of antimycobacterial agents, fever, and gastrointestinal disturbances)?
- Are there any drug-drug interactions and food/drinks that affect a patient's prescribed treatment regimen's efficacy or safety?
- How should patients manage comorbidities?

Patient support information is available from:  Patient Care UK



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

### Getting the right people involved at the right time is important.

A combination of remote and face-to-face patient assessment can be used to elicit information about current symptoms and adverse events.

The MDT may consider providing a helpline or online portal for patients. This approach was used to manage patients with a number of conditions during the COVID-19 pandemic.<sup>42</sup>

Face-to-face assessments are more likely to provide a holistic picture of the patient's health. For example, the medical assessor can look at the patient's mobility, any changes in weight, and the level of breathlessness.

Home visits offer an invaluable opportunity for patients to be more open about sensitive issues (e.g., continence and social isolation), ask questions of concern, and provide insights into medication storage and device use.



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

It is important to foster positive relationships between patients and their healthcare provider(s). **Patient interactions can be used to:**

- Evaluate control of disease
- Check appropriate use of devices
- Assess continence function
- Investigate the patient's mental health
- Build routines into daily activities
- Provide information on available support networks
- Check patient adherence
- Review medication and side effects

Members of the MDT could use a locally developed guide sheet to help them assess and monitor patients during review sessions.

The British Lung Foundation has a [COPD passport](#) that may also be useful for NTM patients.<sup>43</sup>

The COPD passport outlines questions that the patients need to be asking their doctors.



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

Before each follow-up appointment, the patient could answer a questionnaire with wellbeing and disease management-related questions.

### Examples of questions that could be asked in patient reviews:

- Have you done your sputum samples?
- How are you feeling, physically and emotionally?
- How does your chest feel?
- Do you have pain breathing?
- Have you developed any new symptoms since we last met?
- Have you experienced any side effects from the medication you have been prescribed?
- Do you remember to take your medication?

**Tip:** Focus on making patients feel comfortable about raising issues and experiences relating to their NTM-PD. Ensure that patients know that you can offer practical, physical, and psychological support and that they can ask you for access to a wide range of experts who may be able to help them.

At the end of a review session, a plan of treatment can be discussed. This may be subject to modifications, based on the patient's needs.



# Facilitating an NTM Service

## Supporting Patients with NTM-PD

Stepwise action plans can help the team know what to do in specific situations.



Specialist teams from nearby NTM services may be able to support the needs of difficult-to-treat individuals.



# Facilitating an NTM Service

## Auditing the NTM Service

It is important to consider how performance of the service will be evaluated and how often evaluations will take place.

### Patient outcomes from using the service could be examined, looking at:

- The number of patients who complete a treatment plan organised by the service
- The number of refractory patients who achieve remission with treatment
- The number of patients with intractable NTM-PD that does not resolve with treatment

It would also be helpful to look at patient-reported changes in quality of life before, during, and after accessing care from the NTM facility.

### The operations of the service can be evaluated with questions such as:

- Are the roles of individual members of the MDT well defined in your NTM service?
- Is the structure of the NTM service well understood by MDT members and patients alike?
- Have stakeholders ever been informed of changes to the service?

NTM Network UK is in the process of establishing standards of care for NTM-PD, which will help healthcare professionals to assess provision of care in their locality.



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# Facilitating an NTM Service

## Auditing the NTM Service

Regular meetings with the MDT are an important part of ensuring that operations are running as intended. Allowing staff or patients to submit suggestions anonymously can enable them to feel like their voices are being heard.

Insight from MDT members, patients, and their carers is valuable, and it is important to find ways to evaluate the service that make everybody feel comfortable.

At the core of the service is providing the highest possible standard of care to patients. Developing and implementing ways to evaluate the service is an important part of this.

Setting up patient and carer meetings or allowing service users to fill in a questionnaire about their treatment can help generate new ideas about how facilities can be improved.



# Appendix



# Appendix

## Additional Resources



[American Thoracic Society Guidelines for the Treatment of NTM-PD](#)



[British Lung Foundation website - on NTM Infection](#)



[British Thoracic Society website - British Thoracic Society guidelines for the management of non-tuberculosis mycobacterial pulmonary disease](#)



[NTM action website](#)



[NTM Info & Research](#) (Please note: Not all content on this website is applicable to patients or services the UK)



[NTM-NET](#)



[NTM Patient Care UK website](#)



[NTM Network UK website](#)



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# Appendix

## Writing a Business Case

An in-depth look at the structure of a business case and a description of what can be included in each section.

| Section                                | Description   |
|--|---|
| Proposal Title                         | The name of proposed or current NTM service   |
| Name of Organisations Involved         | The practice(s) where the service(s) will be delivered                                      |
| Accountable Lead Officer/Lead Director | Proposed or current director of the NTM service   |
| Lead Clinician                         | A member of the core team facilitating treatment decisions and managing patients            |
| Responsible Person (Finance)           | A person who is expected to be responsible for the financial aspects of running the service |
| Business Case Author                   | The person writing the business case  |
| Contact Details                        | The telephone number or email addresses of key contacts for the NTM service                 |
| Date                                   | The date that the business case is completed  |

Click [here](#) to download a business case template which can be used or amended according to your proposal's requirements.



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## Writing a Business Case

An in-depth look at the structure of a business case and a description of what can be included in each section.

| Section                           | Description  |
|-----------------------------------|--|
| Executive Summary                 | A brief summary of the entire proposal shows what the proposed NTM service will achieve, and the key benefits for patients. The Executive Summary should not be longer than one page |
| Background                        | Explain the rationale for the service, including an overview of the issue(s) that the NTM service will address   |
| Proposal for Service              | Overview of the proposed service, or how you plan to change an existing service that is not fully addressing the issues mentioned in the 'Background'                                |
| Intended Benefits of the Proposal | List the benefits for the patients and local/regional healthcare systems more generally  |

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## Writing a Business Case

An in-depth look at the structure of a business case and a description of what can be included in each section.

| Section                                 | Description   |
|---|---|
| Current Service Provision               | Discuss the measures (if there are any) that are being taken to address the problem(s) that were outlined in the 'Background' section. What do existing services offer to NTM-PD patients?  |
| Drivers for a New (or Improved) Service | Discuss how your proposed service or the service you are planning to change will meet national or local objectives for the delivery of optimal care for patients with NTM-PD  |
| Activity to Date                        | Include the estimated number of patients that your proposed service is likely to provide for. Explain how resources will be used over time. This section should include a risk assessment   |
| Finance                                 | Include key investment requirements and financial considerations including paying staff, the cost of running tests and clinical monitoring etc. More detail is provided in the ' <a href="#">Developing a Business Case</a> ' section of this toolkit |

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| Section                        | Description  |
|--------------------------------|--|
| Stakeholders Affected          | Provide a list of the stakeholders who have been consulted about the project. Include a description of other potentially interested parties  |
| Service Outcomes               | Explain the impact of the service – the activities and qualities that the service will bring to treatment of NTM-PD. Add how the new service will advantage patients, and how changes to organisational aspects of running a service will improve care |
| Metrics                        | Explain how the service will be evaluated, and the objectives of the new/modified treatment centre   |
| Cost Benefit                   | Explain the financial benefits of the service  |
| Risk and Mitigation Strategies | Write a list of the risks of the service, such as potential delays in recruiting members of the MDT or difficulty achieving targets such as running frequent meetings or follow-up appointments with patients  |

Click [here](#) to download a business case template which can be used or amended according to your proposal's requirements.



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## Writing a Business Case

An in-depth look at the structure of a business case and a description of what can be included in each section.

| Section                    | Description  |
|----------------------------|--|
| Patient and Carer Feedback | <p>Case studies, or patient and carer quotes, which support your proposed service or modifications to any services that are currently offered</p> <p>This section is designed to strengthen your business case and bring your proposal to life</p> <p>Compelling arguments to support the proposal from the patients who will benefit from the service is one of the most persuasive components of a business case</p> |
| References                 | A bibliography featuring the different sources used to inform the research for your business case  |
| Appendices                 | Include any additional material or resources that you may have referred to in the proposal   |

Click [here](#) to download a business case template which can be used or amended according to your proposal's requirements.



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# Appendix

## Questions for Patients



**Examples of questions** that can be asked during patient follow-ups or home visits.<sup>44</sup>

### How has your health been [insert time frame such as the past week/two weeks]?

- Overall, my health is very good
- I have a few health problems, but I am ok most of the time
- My health could improve a little
- My health could improve a lot
- I am not very well but there is nothing that needs to be done for my health

### How is your ability to care for yourself?

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

### How is your ability to perform daily activities? (e.g., work, study, housework, or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities



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## Questions for Patients



**Examples of questions** that can be asked during patient follow-ups or home visits.<sup>44</sup>

**Are you, or have you recently [insert time frame such as two weeks] been in any pain or discomfort?**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**How well are you managing financially?**

- I am living comfortably
- I am doing alright
- I am just about getting by
- I am finding it quite difficult
- I am finding it very difficult

**What do you think of your living situation?**

- I am very happy with my home
- I am satisfied with my home
- I have a few problems with my home, but I manage okay
- My home needs to improve a little
- My home needs to improve a lot



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## Questions for Patients



**Examples of questions** that can be asked during patient follow-ups or home visits.<sup>44</sup>

### How is your mobility?

- I have no problems in walking about
- I have some problems in walking about
- I am confined to my bed

### How have your health condition(s) been managed [insert time frame, e.g., during the past week/two weeks]?

- I am managing my health condition very well by myself
- I am managing my health condition very well with help from other people
- I need a bit more help to manage my health condition
- I need a lot more help to manage my health condition

### How confident are you that you can manage your own health?

- Fairly confident
- Not very confident
- Not at all confident



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## Questions for Patients



**Examples of questions** that can be asked during patient follow-ups or home visits.<sup>44</sup>

**In the last six months, have you had enough support from local services or organisations to help you to manage any long-term health condition(s)? Please think about all assistance you receive, whether from healthcare professionals or other facilities.**

- Yes, definitely
- Yes, to some extent
- No
- I haven't needed such support
- Don't know / can't say

**Have you felt anxiety and/or depression [insert time frame, e.g., in the last two weeks]?**

- I have not felt anxious or depressed [in the last two weeks]
- I have felt slightly anxious or depressed [in the last two weeks]
- I have felt moderately anxious or depressed [in the last two weeks]
- I have felt extremely anxious or depressed [in the last two weeks]
- I don't know/remember



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## Abbreviations

|             |                                       |               |  |
|-------------|---------------------------------------|---------------|--|
| <b>6MWT</b> | six-minute walk test                  | <b>HRCT</b>   | high-resolution computed tomography            |
| <b>ACT</b>  | acceptance and commitment therapy     | <b>ICS</b>    | integrated care systems                        |
| <b>AFB</b>  | acid-fast bacillus                    | <b>ID</b>     | infectious diseases                            |
| <b>AHP</b>  | allied healthcare professional        | <b>ITS</b>    | Irish Thoracic Society                         |
| <b>ATS</b>  | American Thoracic Society             | <b>MDT</b>    | multidisciplinary team                         |
| <b>BMI</b>  | body mass index                       | <b>MRI</b>    | magnetic resonance imaging                     |
| <b>BTS</b>  | British Thoracic Society              | <b>NTM</b>    | non-tuberculous mycobacteria                   |
| <b>CBT</b>  | cognitive behavioural therapy         | <b>NTM-PD</b> | non-tuberculous mycobacteria pulmonary disease |
| <b>CF</b>   | cystic fibrosis                       | <b>OT</b>     | occupational therapist                         |
| <b>COPD</b> | chronic obstructive pulmonary disease | <b>TB</b>     | tuberculosis                                   |
| <b>CT</b>   | computed tomography                   | <b>WGS</b>    | whole genome sequencing                        |
| <b>HCP</b>  | healthcare professional               |               |  |



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# Appendix

## Toolkit Contributors

### **Dr Toby Capstick**

Consultant Pharmacist - Respiratory Medicine  
Leeds Teaching Hospital  
Leeds, UK

### **Dr David Connell**

Consultant Respiratory Physician  
Ninewells Hospital,  
Dundee, UK

### **Rhys Hurst**

Chest Medical Respiratory Physiotherapist  
Royal Papworth Hospital  
Cambridge, UK

### **Jennie Keane**

TB Clinical Nurse Specialist  
Southend University Hospital  
Southend, UK

