NTM-PD Healthcare Professional Toolkit

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

This toolkit has been developed and funded by Insmed Ltd., with expert advice and input from a group of experts in the field of diagnosing and treating NTM-PD. Medical writing support, funded by Insmed Ltd., was provided by Remedica Communications Ltd.

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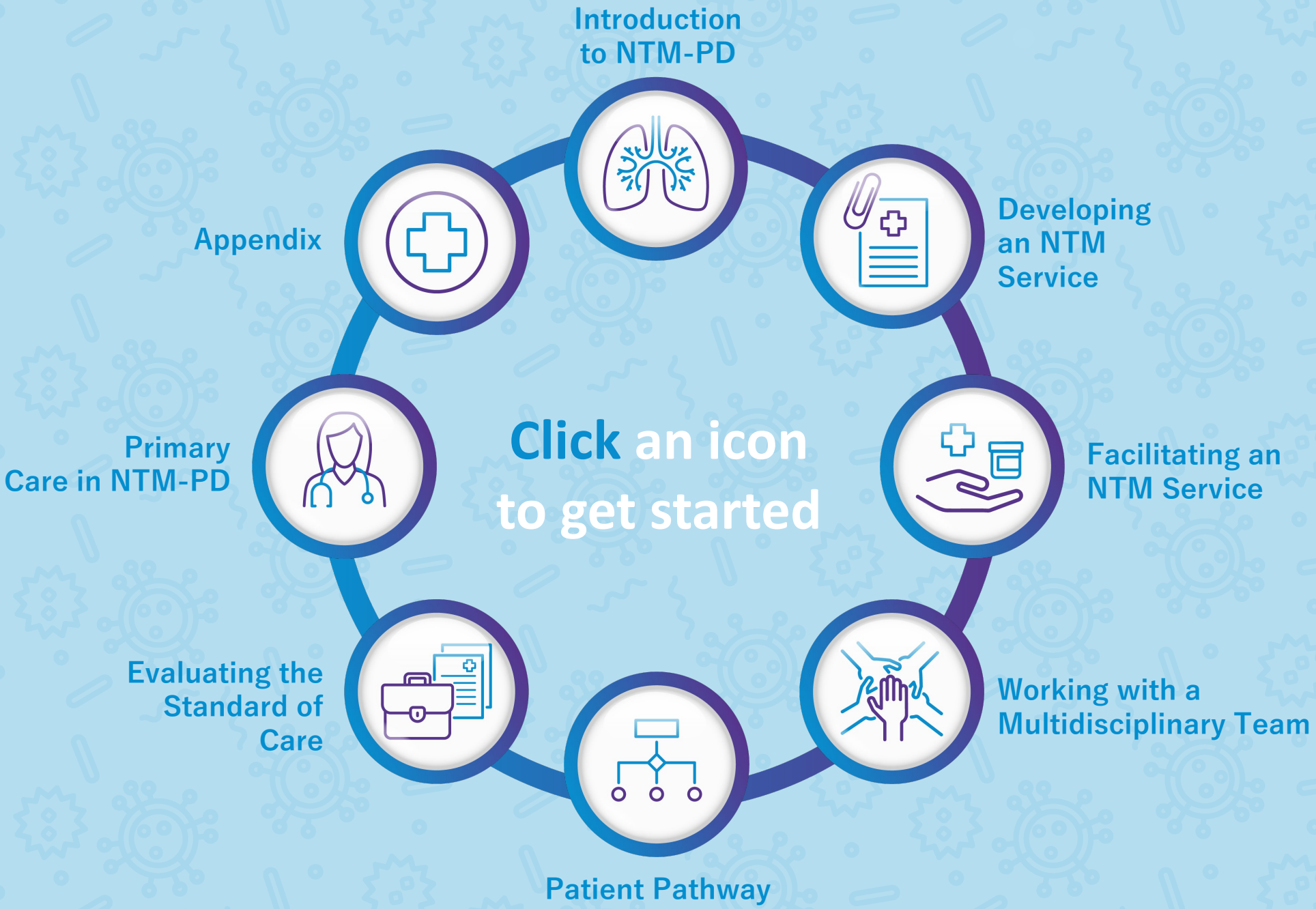
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Executive Summary

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.[1] NTM pulmonary disease (PD) is the most common clinical manifestation of NTM infection and is a growing health concern.[2] NTM infection is a challenging condition to diagnose and treat, due to lack of awareness, and the high percentage of asymptomatic individuals.[1]

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

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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.[3]

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).[4]

Between 2008 and 2012, respiratory diseases were responsible for 20% of annual deaths in the UK.[5]

Lung diseases cost the UK £11 billion each year, in costs to the NHS and in lost productivity.[6]

Despite the fact that there are nearly 700,000 hospital admissions for respiratory conditions each year in the UK, [4] 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.[7]

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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.[8]

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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.[8]

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.[9]

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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.[8]

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.[10]

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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.[8]

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.[11]

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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.[8]

Public Health England has developed principles on respiratory disease for those working in healthcare.[12]

Note: The Public Health England team leading this policy transitioned into the Office for Health Improvement and Disparities on 1 October 2021.

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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.[8]

The Quality Statement for Respiratory Disease 2022 for Wales focuses on the proper diagnosis, management, and treatment of respiratory disease in both adults and children.[13]

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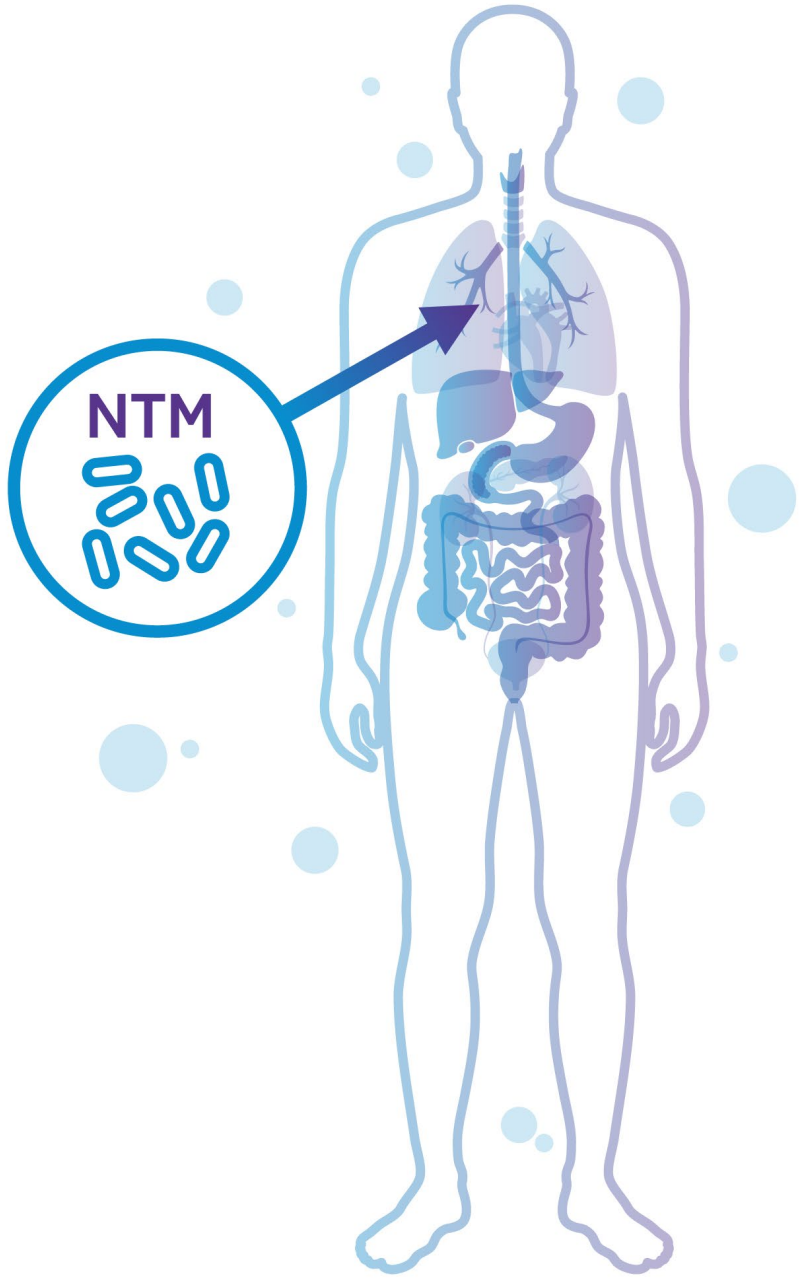
Disease Overview

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.[1]

NTM species isolated from sputum samples vary in virulence,[14] and *Mycobacterium avium* complex (MAC) often correlates with disease.[15]

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.[1]



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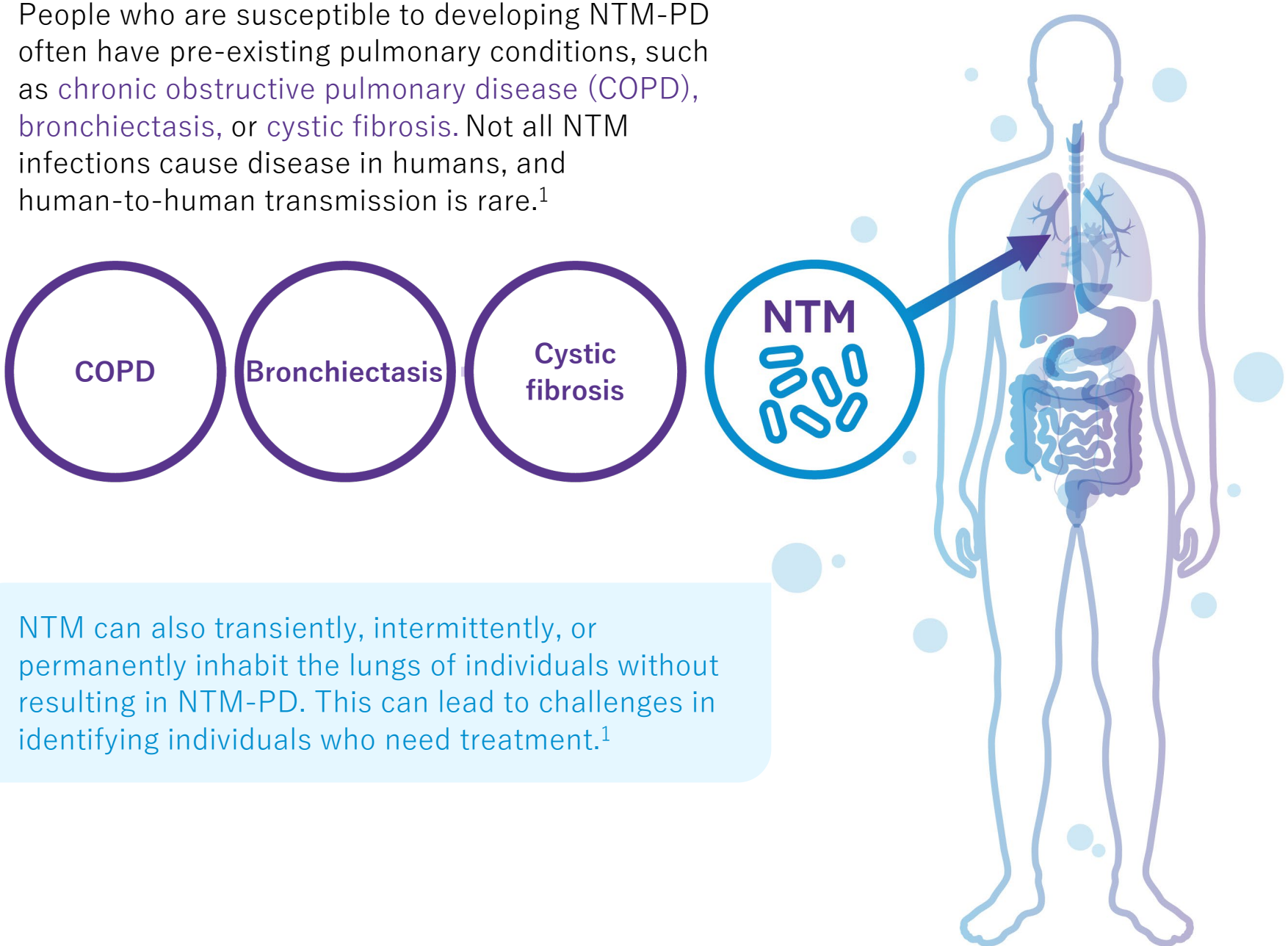
Disease Overview

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.[1]



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.[1]

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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.[1,16] Across the UK, there are differences in how NTM-PD patients are identified using microbiological tests for mycobacterial species.[16]

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.[17]

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.[15]

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.[18,19]

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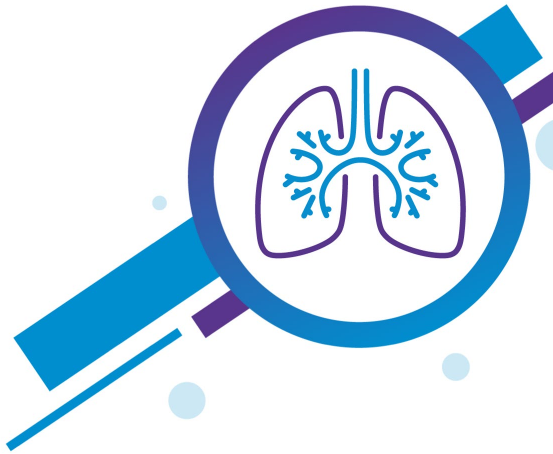
Introduction

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.[20,21]

Appropriate and timely intervention has the potential to reduce the associated economic burden of NTM-PD.[21]

Since mortality is highest within the first 3 months after diagnosis, rapid initiation of therapy must be offered.[21]



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Unmet Needs

Awareness of NTM-PD is low among HCPs,[22] and the low number of NTM-specific treatment centres in the UK negatively impacts patients' access to care and support.[16]

This unmet need could be addressed by establishing NTM treatment centres that facilitate screening of susceptible individuals,[16] regular assessment of their physical and emotional health, and management of symptoms that can severely affect patients' quality of life.

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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.[16]

Lack of support for patients diagnosed with NTM-PD in the UK led to the establishment of NTM Patient Care UK in 2018,[16,23] which provides educational resources and information to increase understanding of NTM for patients and clinicians.[23-25]

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.

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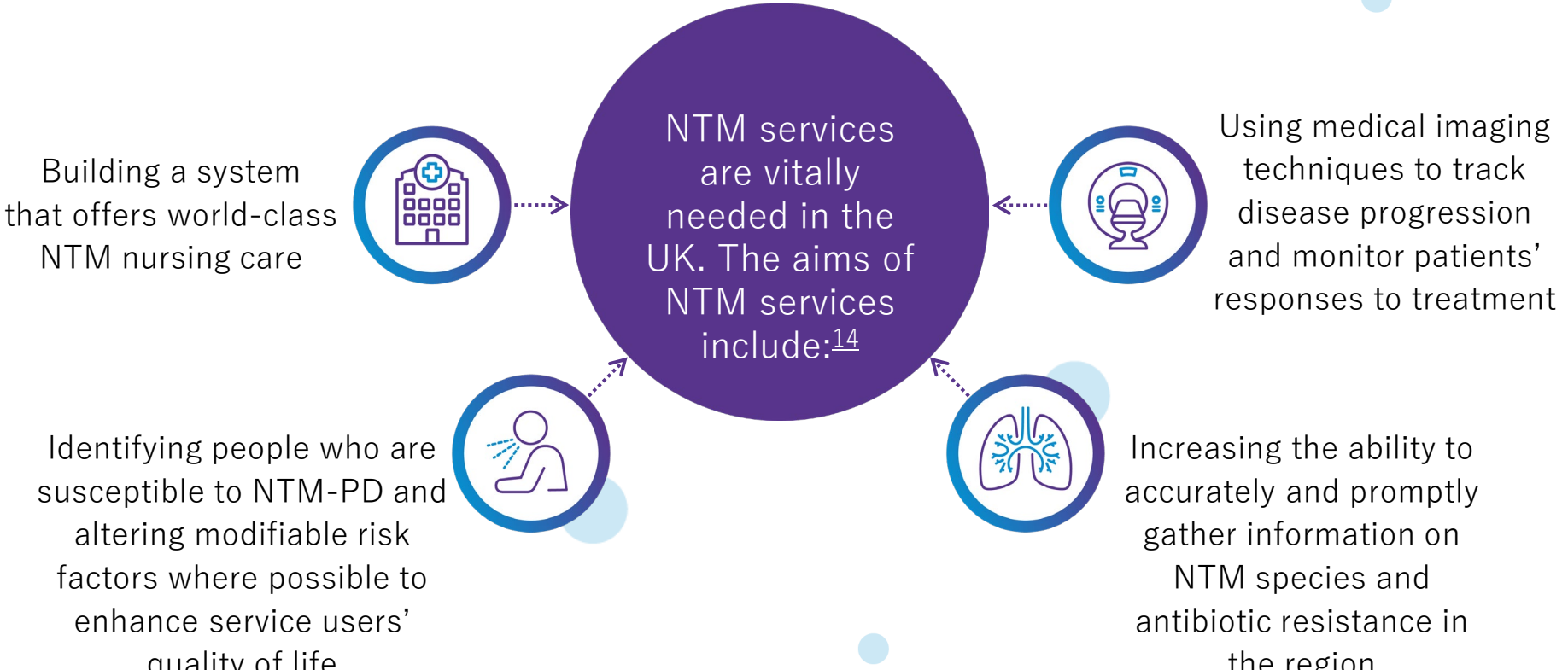
Integrated Care Models

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.[16]

NTM services are vitally needed in the UK. The aims of NTM services include:[16]



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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:[16]

- 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.[16]

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.[16]

Hub-and-spoke Illustration

“Satellite” small clinics that use resources from the main ‘hub’

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Aims of NTM Services

NTM services:

Should include clear referral and disease management pathways.[16]

Enhance 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.[16]

Flexibly support 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.

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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
2. Auditing and making adjustments to the service that better meet the needs of patients
3. Supporting patients in the optimisation of their care

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.

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Abbreviations

CF	cystic fibrosis
COPD	chronic obstructive pulmonary disease
HCP	healthcare professional
ICS	integrated care systems
ITS	Irish Thoracic Society
MAC	*Mycobacterium avium* complex
MDT	multidisciplinary team
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
PD	pulmonary disease
TB	tuberculosis
WGS	whole genome sequencing

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Developing an NTM Service

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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

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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.

Select from the list below:

Considerations for a business case

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

How patients are currently managed (e.g., with a combination of pharmacotherapy and physical exercise)?

Think about...

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

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**.

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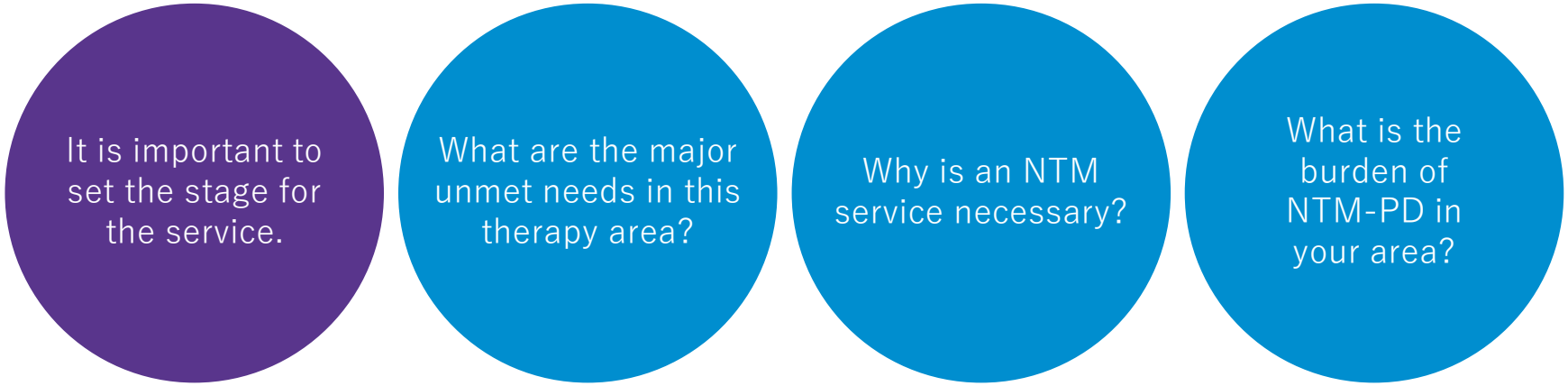

Strategic context

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.

Scope and objectives

NTM services are vitally needed in the UK.

To set up a business case, you will need to:

- Detail the scope of the service.
- Create specific, measurable, achievable, realistic, and timely objectives for the service

Questions to consider:

- 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

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)

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?)

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.

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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Abbreviations

AHP	allied healthcare professional
CF	cystic fibrosis
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease 2019
MDT	multidisciplinary team
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
TB	tuberculosis

Facilitating an NTM Service

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Facilitating an NTM Service

Screening Patients

Annual screening for NTM is recommended by the NICE guideline on the diagnosis and management of cystic fibrosis.[1]

Before macrolide therapy is initiated, COPD and bronchiectasis patients should be screened for NTM according to the BTS.[2] 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 and a stable clinical course should have their sputum tested annually.[3]

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.[3]

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Diagnosing NTM-PD

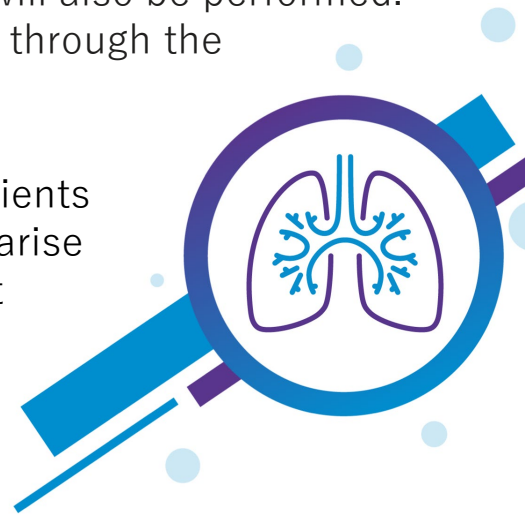
Repeated isolation and identification of NTM taken from sputum, can be a central part of diagnosis, alongside CT scans and X-rays.

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 may access resources to familiarise themselves with the diagnosis, burden, and management of NTM-PD.[4]



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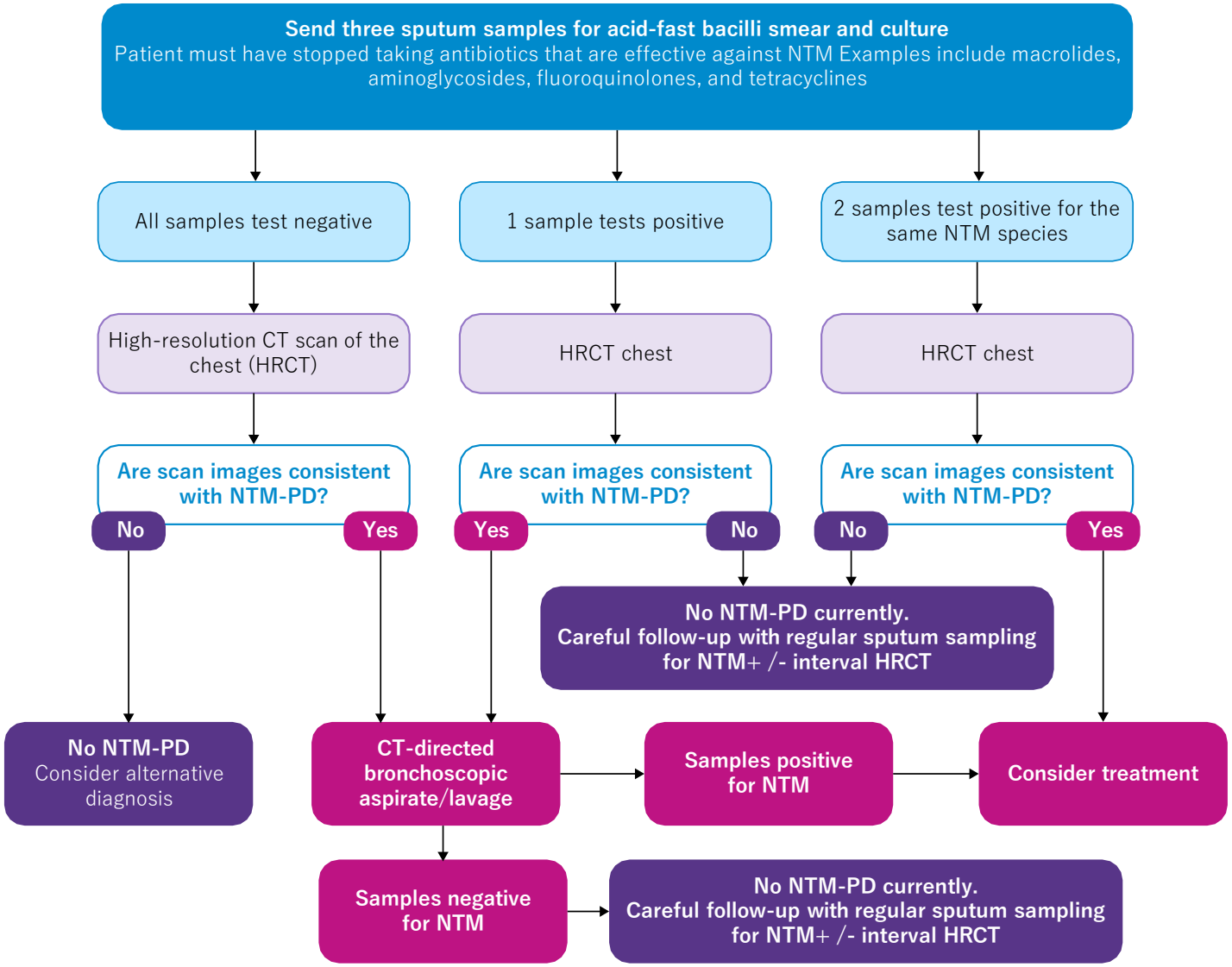
Clinical suspicion of NTM-PD[5]



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:[5,6]

- 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.

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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.

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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, Asthma + Lung UK has information on treating depression in patients with respiratory conditions.[7]

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

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Facilitating an NTM Service

Supporting Patients with NTM-PD

Contents

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:

ASTHMA+ LUNG UK

NTM 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.[8]

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.

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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**
- **Empower patients in decision-making**
- **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.

Asthma + Lung UK has a COPD passport that may also be useful for NTM patients.[9]

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

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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.

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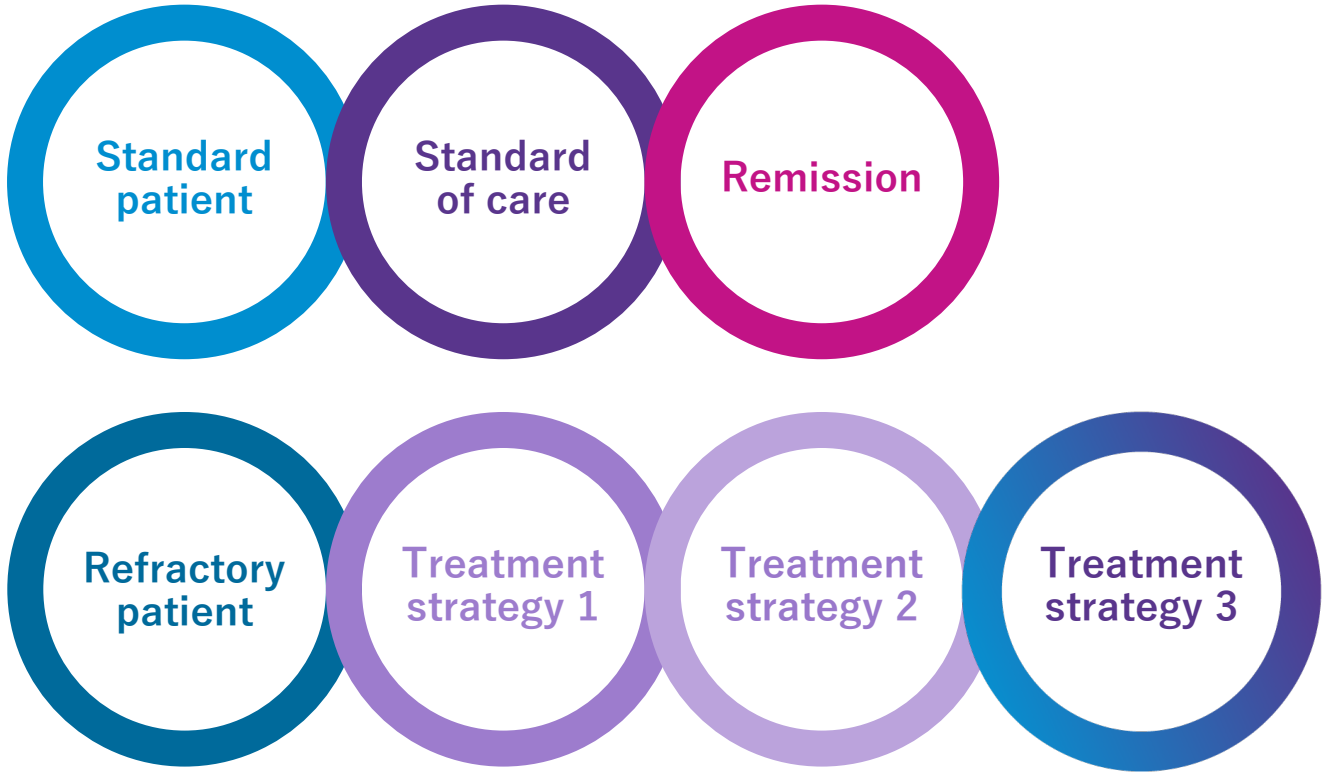
Facilitating an NTM Service

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.

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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 has launched the Standards of Care for people living with NTM disease, which aim to provide a guide on the minimum level of care that patients should expect.[10]

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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.

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To:
Evaluating standard of care

Facilitating an NTM Service

Abbreviations

ACT	acceptance and commitment therapy
AFB	acid-fast bacillus
ATS	American Thoracic Society
BTS	British Thoracic Society
CBT	cognitive behavioural therapy
CF	cystic fibrosis
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease 2019
HCP	healthcare professional
HRCT	high-resolution computed tomography
MDT	multidisciplinary team
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
TB	tuberculosis
WGS	whole genome sequencing

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Facilitating an NTM Service

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Working with a Multidisciplinary Team

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Working with an MDT

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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.[1] 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.

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?

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Working with an MDT

Setting Up an MDT

Assembling a core team

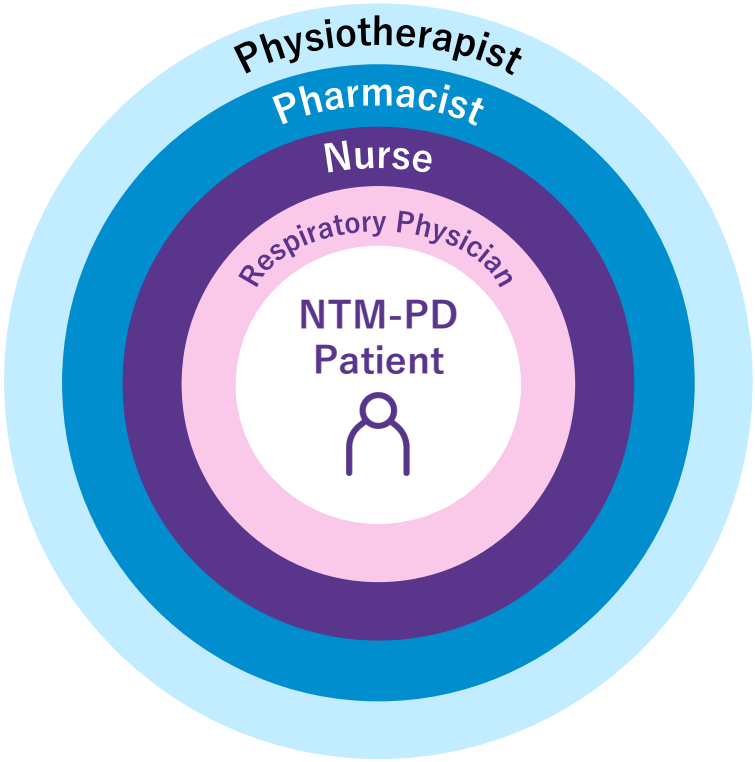
Demonstrating enthusiasm for the service and keeping knowledge of managing patients up-to-date are essential characteristics for initiating or leading the MDT.

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.[1] 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.



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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.

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Working with an MDT

Principles of an MDT

According to a 2015 NHS England report, the principles of a successful MDT revolve around:[2]

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.

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Working with an MDT

Benefits of an MDT

Some of the potential benefits of the MDT in an NTM service include:[2,3]

- 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

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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.

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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.

Working with an MDT

Pharmacist

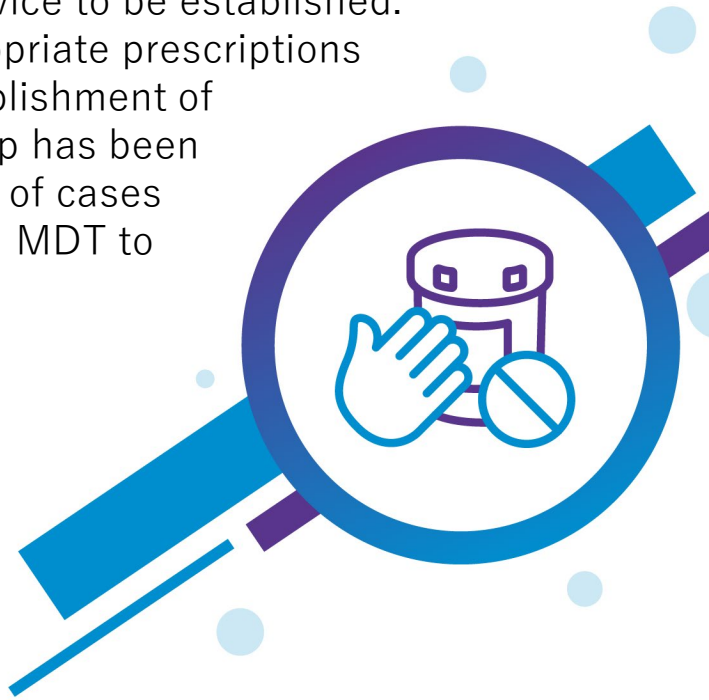
Responsibilities of the pharmacist:

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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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

Click **here** to download a guidance sheet to support patients in establishing a treatment routine

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-PD 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.

Click **here** to download a guidance sheet for helping patients with their medications

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Working with an MDT

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 who have 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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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 shopping, housework, or walking the dog.[4]

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 bronchiectasis, is recommended by the British Thoracic Society (BTS).[5]

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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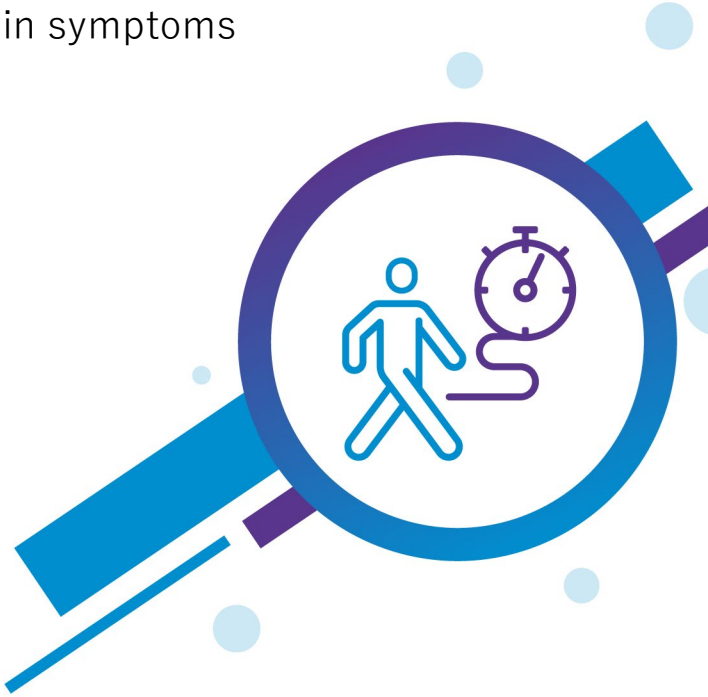
Physiotherapist

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[6]
- 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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Working with an MDT

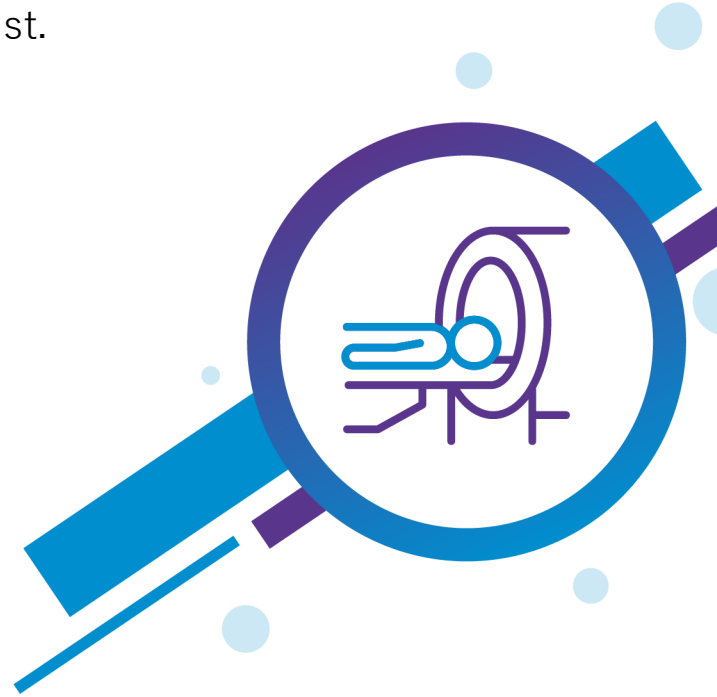
Radiologist

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.[7,8]

Although some patients' symptoms can improve or resolve in response to treatment, radiological imaging may still show signs of lung damage.[9,10]

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.



Working with an MDT

Microbiologist

Lack of timely diagnosis is an unmet need in this therapy area, due to low disease awareness.[11] As a microbiologist, you play a key role in diagnostics as you will be the team member 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.

Working with an MDT

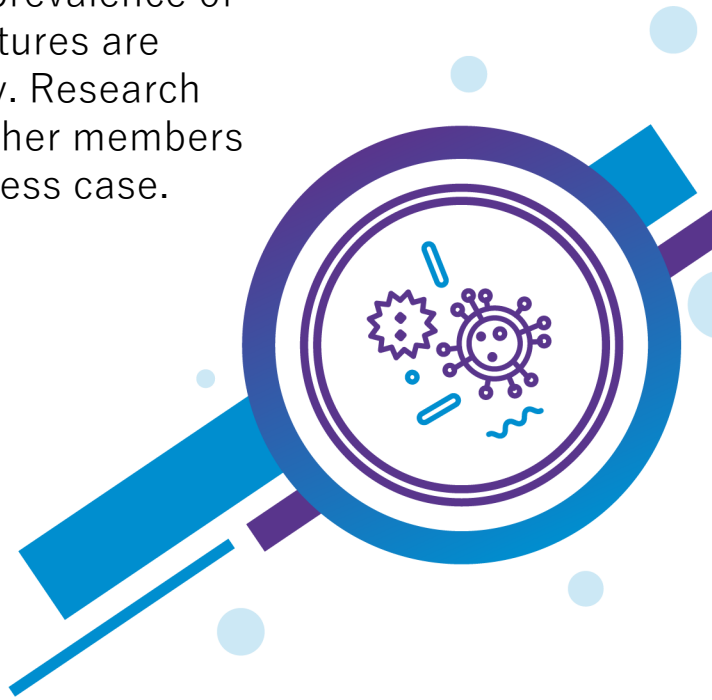
Microbiologist

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.



Working with an MDT

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.

Working with an MDT

Psychologist

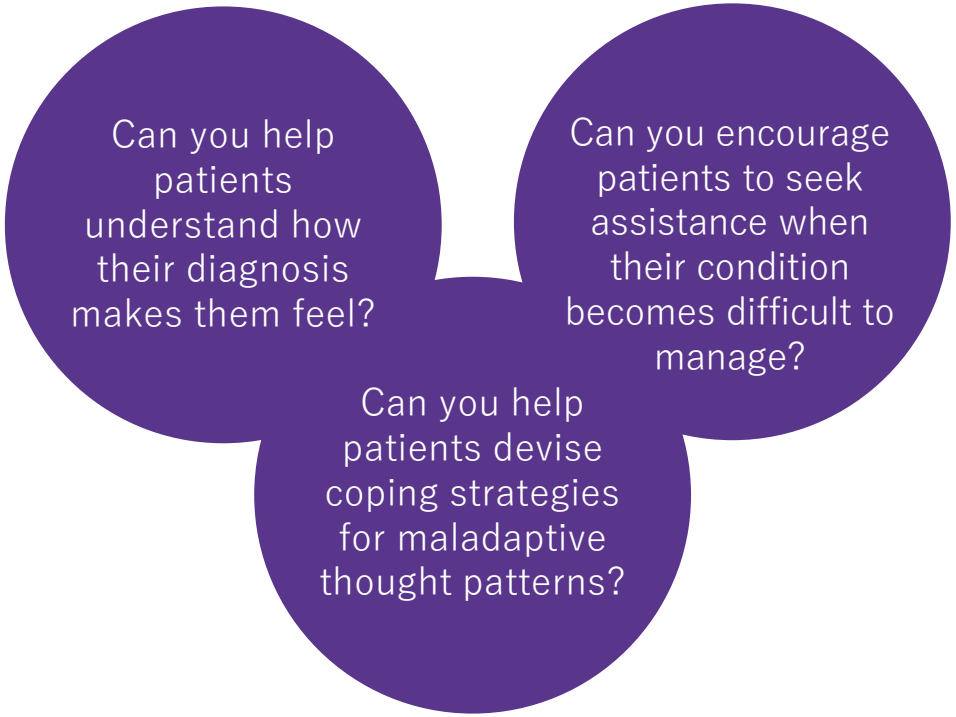
Psychological support may lead to significant mental health benefits for people living with NTM-PD, especially in the context of COVID-19.

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.[12]

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:



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Working with an MDT

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.[13-16]

Failure to stabilise weight is associated with poorer outcomes in NTM infection.[17] 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.[6] As a dietitian, you may find that helping patients devise meal plans that are rich in antioxidants and protein may prove to be beneficial.[18] 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 patients with NTM-PD are:

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

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Working with an MDT

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.[19] 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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Working with an MDT

Goals of the Service and Patient Referrals

Focusing on these principles will help the NTM service achieve its goals:[20]

- 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

Contents

Working with an MDT

Training Courses and Resource materials for MDT Members

The NTM Network UK has online resources for healthcare professionals, such as respiratory physicians, microbiologists, radiologists, and pharmacists.[21]

NTM Network UK provides access to various NTM resources for the clinical management of NTM infections in addition to resources healthcare professionals can use in aiding patients.

NTM Network UK's Standards of Care document, which outlines the diagnostic and treatment process for NTM disease, aims to provide consistent, high-quality care across the UK.

Member resources include recordings of presentations given by expert speakers at NTM Network UK member meetings and recordings of presentations from NTM Network UK educational events.

Guidance on investigating suspected cases of NTM-PD are included in this toolkit.

Contents

Working with an MDT

Abbreviations

6MWT	six-minute walk test
ACT	acceptance and commitment therapy
AFB	acid-fast bacillus
AHP	allied healthcare professional
ATS	American Thoracic Society
BMI	body mass index
BTS	British Thoracic Society
CF	cystic fibrosis
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease 2019
CT	computed tomography
ID	infectious diseases
MDT	multidisciplinary team
MRI	magnetic resonance imaging
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
OT	occupational therapist
TB	tuberculosis

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Working with an MDT

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Patient Pathway

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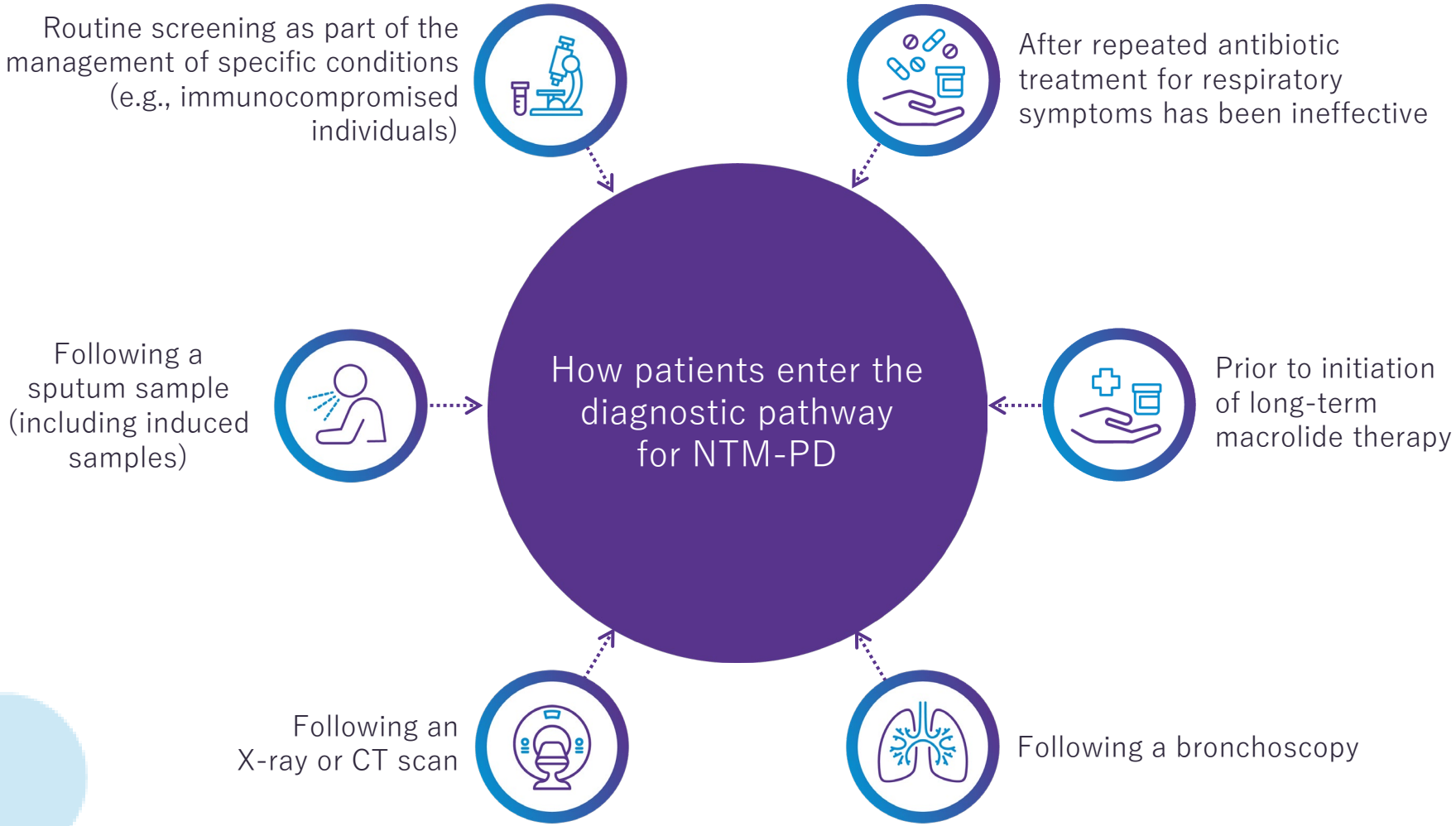
Screening Patients



Patient Pathway

Screening Patients

There is a need to improve screening (and diagnosis) of patients at high risk of developing NTM-PD.

Consider screening for NTM in patients with:

- Bronchiectasis[1]
- CF[1]
- COPD[1]
- HIV[1]
- TB[2]
- Patients being investigated for other lung conditions, such as lung cancer, where NTM may be a possibility[3]
- People with a history of NTM-PD
- People with a history of NTM infection

Patient Pathway

Logistical Considerations

NHS organisations should ensure that there are pathways to inform appropriate clinicians or MDTs about any positive mycobacterial cultures. This may include the NTM MDT, infectious diseases, respiratory and/or cystic fibrosis teams.

The MDT can review X-ray/CT results if available and examine the patient's lifestyle, symptoms, or comorbidities to determine if NTM is suspected and if further sputum samples are needed.

Obtaining a positive sputum sample should be followed by radiological evaluation of the patient and microbiological analysis to detect the presence of NTM-PD-causing bacteria

MDT meetings should be held weekly wherever possible, and could include a discussion on new positive results within the last 7 days

Review process for investigation of suspected cases of NTM

- Contacting relevant clinical personnel
- Obtaining a repeat sputum sample
- Organising an X-ray/CT scan
- Arranging for the patient to come into the clinic for assessments
- Monitoring each stage and following up as necessary
- Informing the MDT, requesting clinician, and the infectious diseases department

Tip: The MDT may find it useful to develop a *Mycobacterium* "watch list", which details the stage of the diagnostic pathway for each patient with suspected NTM-PD (e.g., one sputum sample sent).

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To: Patient Pathway Summary Diagram

Factors to Consider When Choosing Therapy

Factors that may affect the decision to offer treatment and choice of intervention:

Patient-related factors

- Patient choice
- Disease severity
- Rate of progression of symptoms and radiological change
- Underlying lung disease
- Presence of comorbidities
- Concomitant medicines
- Existing and potential treatment needs
  - Frequency of proposed treatment (e.g., three times weekly vs. daily)
  - Potential need for in-patient modes of care (e.g., presence of *Mycobacterium abscessus*)

Mycobacterial factors

- Pathogenicity of the bacterial species
- Bacterial load
- Drug sensitivity/susceptibility
- History of NTM infection

Tip: Consider if surgical intervention is appropriate (e.g., where there is focal disease in a patient with adequate cardiopulmonary reserve to withstand partial or complete lung resection)[4]

Patient Pathway

Initiation of Treatment

Principles of treatment initiation

Discuss treatment options, including pharmacotherapy, with the patient at an appointment with the responsible respiratory or infectious diseases clinician

Depending on the treatment prescribed, there may be an immediate start (e.g., oral treatment for uncomplicated cases), or a delay between the prescription and administration of treatment

A delay in initiating treatment may be needed to assess individual patient characteristics and the causative agent of a specific case of NTM-PD

Patients may also need time to consider treatment options before coming to a final decision

- Leaflets or websites that provide an overview of treatment options for NTM-PD may be used as sources of information for patients to help them make informed decisions

For patients with serious or prolonged disease, consultation with the MDT may be needed to discuss the initiation of treatment

Ask the respiratory or infectious diseases clinician in the MDT meeting about patients in whom the decision to treat is not mutually agreed. Discuss the initiation of treatment with the MDT within a 1–2-week timeframe.

Organise a follow-up appointment a week after treatment has begun, to assess how the patient is coping with treatment

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To: Patient Pathway Summary Diagram

Pharmacotherapy for NTM-PD

Pharmacological management of NTM-PD

NTM-PD pharmacotherapy often involves a multi-drug treatment regimen. The choice of pharmacotherapy for NTM-PD depends on the causative agent, severity, and other factors such as suboptimal efficacy, drug resistance, disease recurrence, allergies and drug intolerances

In the case of drug resistance or intolerance, consult with an experienced clinician who is part of a regional or national MDT

Macrolide-resistant disease is linked to poor treatment outcomes. However, the mainstay of pharmacotherapy for most NTM-PD is a three-drug combination, usually a macrolide, ethambutol, and rifampicin[5]

The need for novel therapies to combat MAC infection is high because of drug resistance, disease recurrence, and suboptimal efficacy[6]

Key anti-infective drugs and their effects on bacteria that cause NTM-PD[7–11]

Drug Class	Mechanism of Action
Aminoglycosides, macrolides, tetracyclines	Inhibits protein synthesis
Rifamycins	Inhibits RNA synthesis
Quinolones	Affects the structure and function of DNA

Other drugs such as ethambutol, and trimethoprim affect cell wall synthesis, membrane stability, and folate biosynthesis, respectively.

Patient Pathway

Side Effects of Drugs for NTM-PD

Potential side effects of NTM-PD therapies:

Azithromycin[4,12]
Diarrhoea
Hearing impairment
Tinnitus
Hepatitis
Palpitations
QT prolongation

Aminoglycosides[4]
Hearing loss
Dizziness
Vertigo
Ataxia
Tinnitus
Renal toxicity

Clarithromycin[4,13]
Altered sense of taste
Nausea
Vomiting
Headache

Ethambutol[14]
Optic neuritis[4]*
Loss of visual acuity[4]
Loss of red/green colour discrimination[4]

Rifamycins[4,15]
Discolouration of urine, sweat, teeth, and tears
Hepatotoxicity†
Fever
Bone marrow toxicity[16]

Rifamycins are potent inducers of CYP450 enzymes and transporters. These therapeutics have high drug-drug interaction potential[17,18]

*Ask the patient about any visual disturbances, i.e. loss of visual acuity and/or colour blindness they may be experiencing. If they are experiencing disturbances, discontinue ethambutol immediately and arrange an urgent review with an ophthalmologist. † Ask the patient about any sickness/vomiting, rash/itching, lethargy, jaundice they may be experiencing.

Patient Pathway

Administration of Drugs for NTM-PD

Route of Administration	Oral	Inhalation	Intravenous
Overview	• Many of the drugs used to treat NTM-PD are pills or capsules that are taken orally	• Some antibiotics such as tobramycin and amikacin may be inhaled[4,23]	• Amikacin can be administered intravenously[4,29]
Advantages	• Non-invasive[19] • Cost-effective[19] • Self-administrable[20]	• Avoids first-pass metabolism[24] • Reduced risk of systemic adverse events compared to oral and intravenous routes of administration[25] • Helpful for dysphagic patients[26]	• High bioavailability[30]
Disadvantages	• High tablet burden[21] • Variable bioavailability[22] • Gastric irritation[19]	• Few medicines for NTM-PD are available for administration in an inhalational formulation • May require the need to learn how to use specific devices for administration[27] • Cost of purchasing equipment for administration[28]	• Phlebitis, risk of infection at injection site[30] • Must be administered by a trained healthcare professional[30]

Patient Pathway

Drugs for NTM-PD

Amikacin is an aminoglycoside that can be administered intravenously[29]

A nebulised formulation can also be delivered.

IV amikacin may be used within the first 2-3 months of therapy for:[4]

Extensive NTM-PD

Fibrocavitary disease

Patients who have failed prior drug therapy

- Test whether rapidly-growing mycobacterial isolates are resistant to amikacin before initiating treatment
- The dose of amikacin used in MAC therapy depends on the patient's age, weight, and renal function[4]
- Ototoxicity and vestibular toxicity caused by aminoglycosides are usually irreversible. Patients who are treated with amikacin should receive baseline (prior to treatment) and periodic auditory and vestibular testing.[4] Genetic testing can be used to detect the presence of polymorphisms that increase the risk of aminoglycoside-induced adverse events[31]
- Informing patients of symptoms like unsteady gait, tinnitus, and diminished hearing will allow them to report treatment-related concerns at the earliest opportunity. The cause of these symptoms may then be investigated by clinicians in the MDT

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Go to: Patient Pathway Summary Diagram

Patient Pathway

Assessing Patients' Response to Treatment

Questions to think about when reviewing patients' response to treatment

- Is guideline-based therapy (GBT) effective and generally well tolerated?
- Is GBT effective but not well tolerated?
- Is there good patient adherence?
- If adherence is poor, what can be done to improve it?
- Are there any patient-related or drug-related factors that can be modified?

Is the disease considered refractory?
Refractory disease refers to patients whose sputum samples test positive for NTM-PD-causing bacteria, despite having received GBT for at least 6 months.

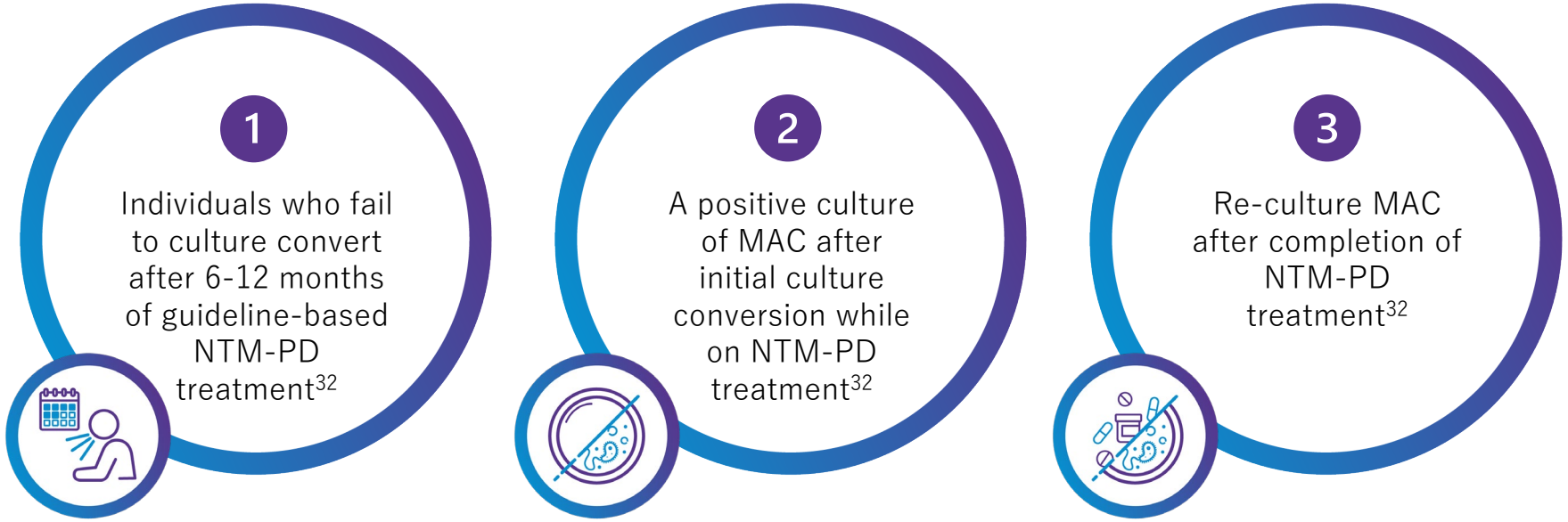
- Refer to NHS standards on physical activity for adults to monitor changes in patients' ability to exercise over the course of receiving guideline-based treatment for NTM-PD
- The NTM Patient Care UK website provides information on exercise for people with lung conditions. Consider speaking to your local pulmonary rehabilitation service or a specialist physiotherapist to find ways to help NTM-PD patients with physical activity

If a patient is refractory, assess patient factors and drug-related factors that may be causing difficulties with treatment.

Patient Pathway

Assessing Patients' Response to Treatment

Refractory MAC NTM-PD patients fit into one or more of the following three categories:



If a patient is refractory, assess patient factors and drug-related factors that may be causing difficulties with treatment.

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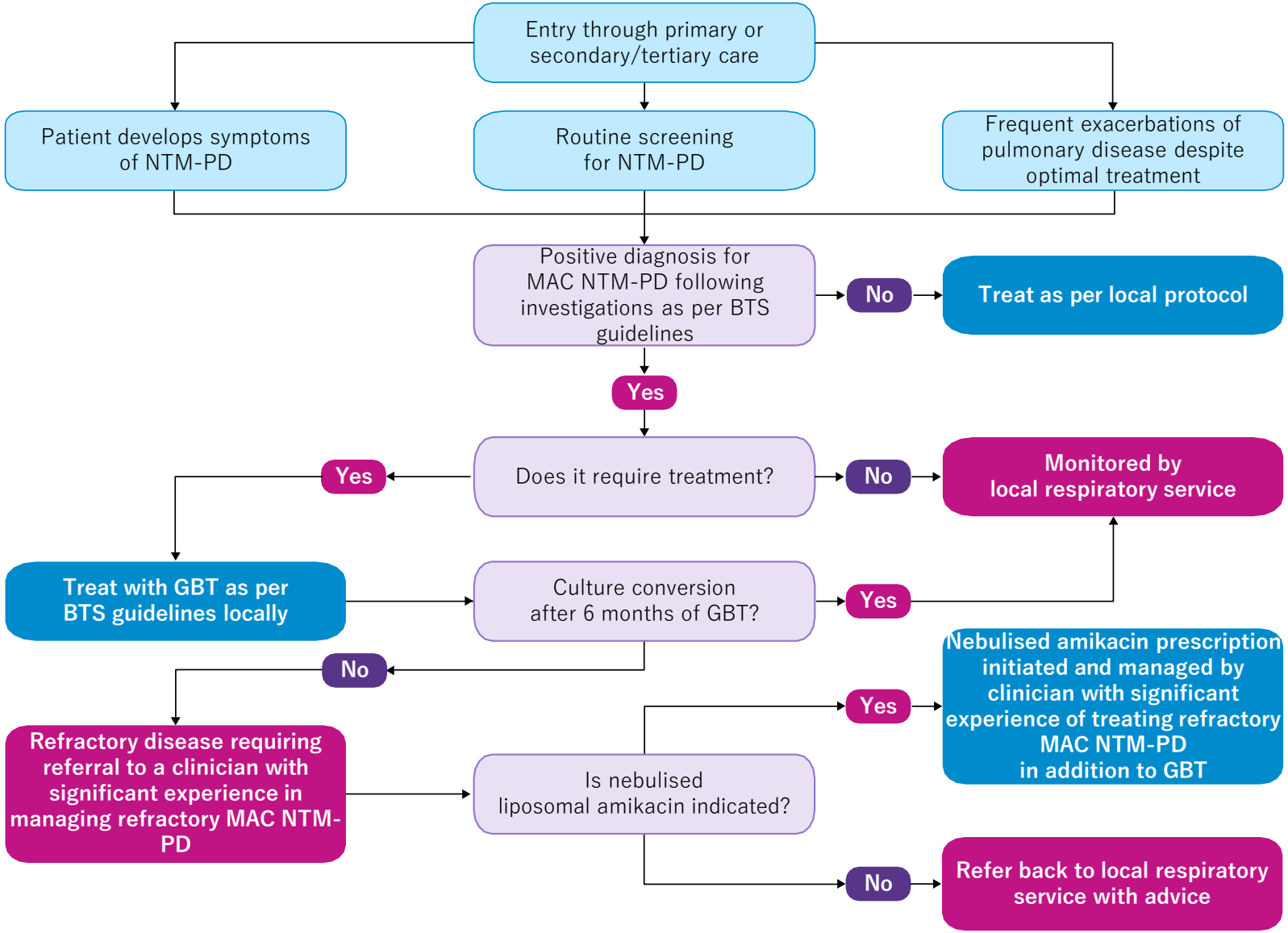
Patient Pathway

Managing Patients with Refractory NTM-PD[33]



Patient Pathway

Watchful Waiting

In some cases of NTM infection, a “watchful waiting” approach is necessary.[34] In this scenario, patients are not administered pharmacological therapy, but instead are monitored for evidence of disease progression.

Patients for whom pharmacological treatment has not been initiated can often benefit from advice on:*

- Weight management
- Diet
- Activity
- Airway clearance

Assistance from HCPs on these aspects can improve patients’ quality of life.

Primary care should have a “trigger” in place to allow patients to be monitored.

Sputum specimens should be obtained for culturing every 1-2 months in order to document when sputum cultures become negative.[34]

Prior to receiving pharmacotherapy, psychosocial factors and health literacy can be addressed with counselling, patient education on living well with NTM, peer support, and networking opportunities, such as those provided by NTM Patient Care UK.

It is important to appreciate that watchful waiting is an active NTM management decision and not a passive period where the patient has no support

*These non-pharmacological measures are also beneficial to those receiving pharmacotherapy.

Monitoring is important to assess response and to detect adverse events

Monitoring of the treatment response may vary depending on patient and disease factors. Generally:[32]

- Sputum sample collected every 4-12 weeks during treatment and for 12 months after completing treatment
- CT scan at 6 months, and at 12 months

Guideline-based Therapy

- Lowers the hospitalisation risk of patients with NTM-PD
- Is associated with lower total healthcare expenditure compared with non-GBT

A multi-drug regimen is typically used for the treatment of NTM-PD. Treatment strategies can differ based on the species of NTM present and the severity of disease[32]

Drug-associated tests to look at potential adverse events are an important part of monitoring patients' response to treatment.[4] Examples include:[4]

- Audiology tests for patients on aminoglycosides
- Visual tests for patients on ethambutol

The first assessment of complex or refractory disease should take place after 6 months of adherence to treatment. Results may not be obtained until month 8 of treatment because of the time taken to grow cultures from serial sputum samples. Another assessment should take place at 12 months.

An important question to ask during the treatment of NTM-PD:

Is the patient responding to treatment?

If the patient is responding to treatment, consider the following:

- Continue treatment
- In case of adverse events, modify treatment
- Stop treatment if the treatment goal is achieved

Investigate why a patient is not responding to treatment by looking at:

- Patient-related factors
  - Can these be addressed?
- Poor adherence
  - Implement measures to support adherence
- Drug-related factors
  - Change the treatment regimen?
- Is the disease considered refractory?
  - Consider looking at patient factors and drug-related factors that may dictate treatment response
  - Look at strategies to resolve the issues

Patient Pathway

Opportunities for Patient Review and Follow-up Appointments

Opportunities for patient touchpoints may include:

Regular (weekly) MDT meeting for the core team to discuss patients who are at a decision point or milestone, as well as patients with complex NTM-PD

Monthly face-to-face reviews with the nurse (or by telephone, according to patient preference and measures employed to prevent the spread of COVID-19

Respiratory consultants or infectious disease specialists may see patients every 2-6 months

Sputum samples may be posted or collected at patients' GP clinics for forwarding to microbiology where samples are tested

It is not mandatory for patients to physically attend the treatment centre for every appointment (remote clinic appointments may be an opportunity for members of the MDT to see the patient on a video call)

A nurse or other point of contact who is available to assist patients with issues through a helpline or email consultation would be helpful

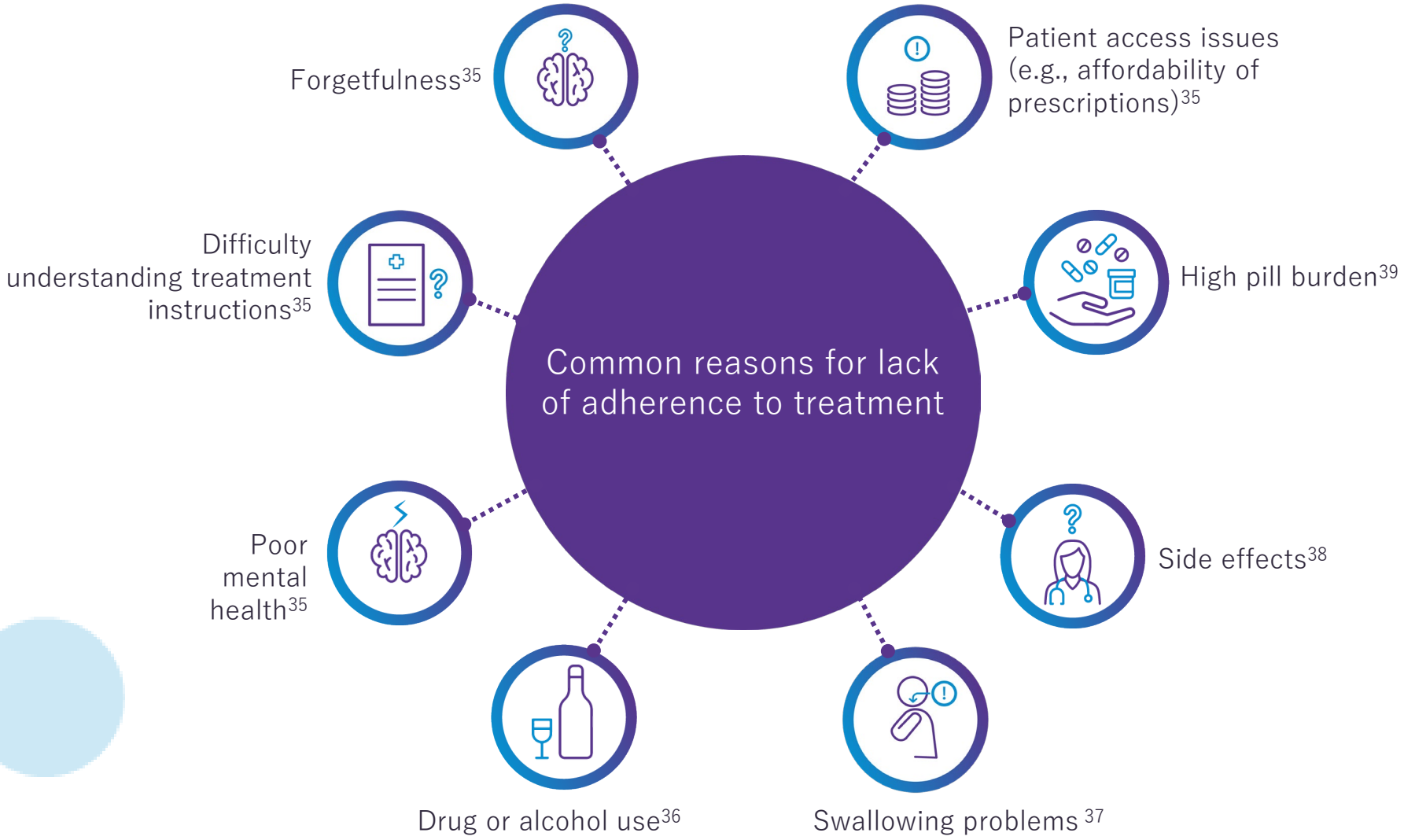
Timings and choice of imaging techniques at follow-up appointments may depend on individual patients' situations, available personnel, and equipment

During active treatment, collect sputum samples every 4-12 weeks. Consider performing a CT scan after 6 and 12 months of treatment

Patient Pathway

Monitoring Treatment Adherence

Potential signs of poor adherence include lack of requests for refill by pharmacy or if the patient appears to be withdrawn or has a negative reaction when discussing treatment, with consistent subtherapeutic concentrations of prescribed medications found in blood tests.



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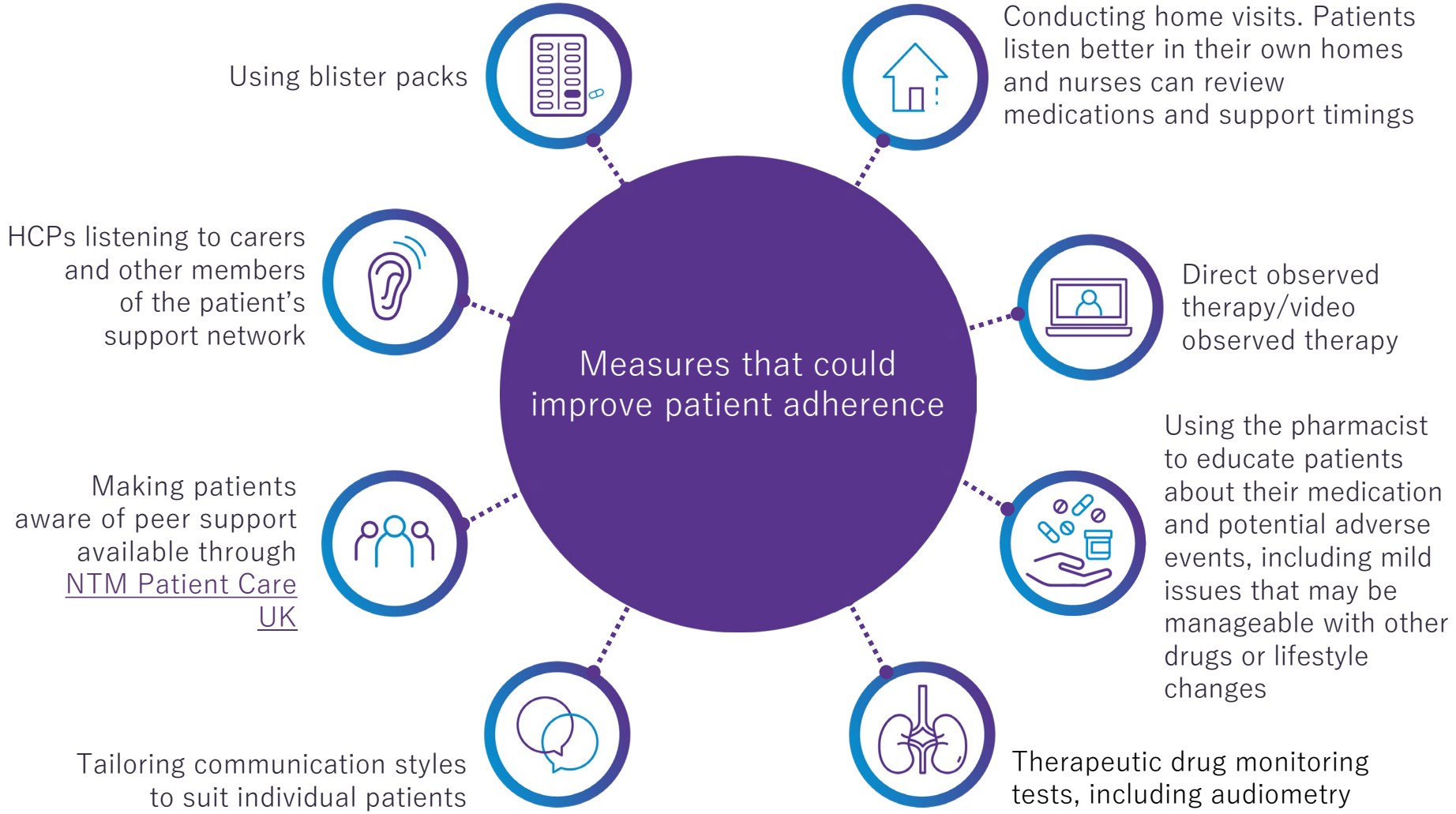
Monitoring Treatment Adherence

Monitoring treatment adherence is an important part of patient care



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To: Patient Pathway Summary Diagram

Patient Pathway

Case Studies

Patient 1

- Male wheelchair user with COPD who received oxygen therapy was admitted to hospital with unexplained type 2 respiratory failure
- Home visits from the nurse did not successfully encourage the patient to take NTM treatment to manage his symptoms
- Another patient who was being treated for NTM-PD talked to the patient, which gave him the motivation to initiate treatment
- After 9 months of adherent treatment, the man was well enough to go on holiday, stopped using a wheelchair, and rarely needed supplemental oxygen

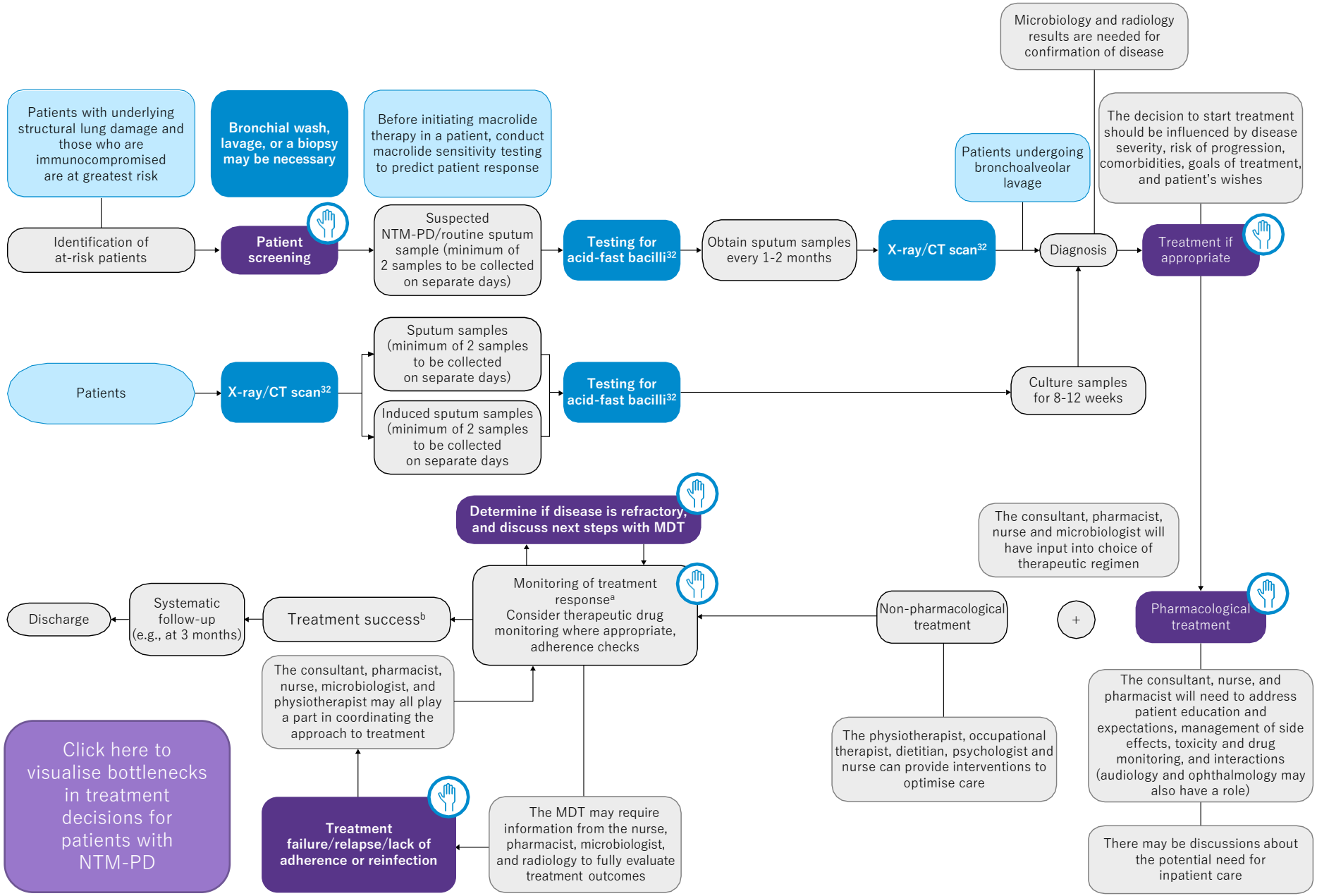
Patient 2

- A patient had severe *M. chimaera* infection and had been treated with ethambutol, rifampicin and azithromycin, before experiencing hearing loss
- During the wait for audiometry test results, the pharmacist and consultant reviewed the prescribed macrolides
- Different members of the MDT came together to discuss the patient, and gather opinions on how to manage the patient's form of complex NTM-PD
- A key consideration of the team was to determine the cause of the hearing loss, because in some cases, treatment-associated hearing loss can be reversed
- These insights were shared by the pharmacist, which helped the consultant to formulate a plan to continue treating the patient's NTM-PD effectively

Patient Pathway

Overview

Decision flow to guide management decisions in the patient with NTM-PD



The GP, consultant, nurses, physiotherapist, and pharmacist or the MDT may request samples if NTM-PD is suspected because of pulmonary symptoms, clinical signs, or as part of routine evaluation
[a]Sputum samples every 4-12 weeks and 12 months after treatment completion); [b]Sputum culture conversion for 3 consecutive samples at different times and days and radiological improvement)

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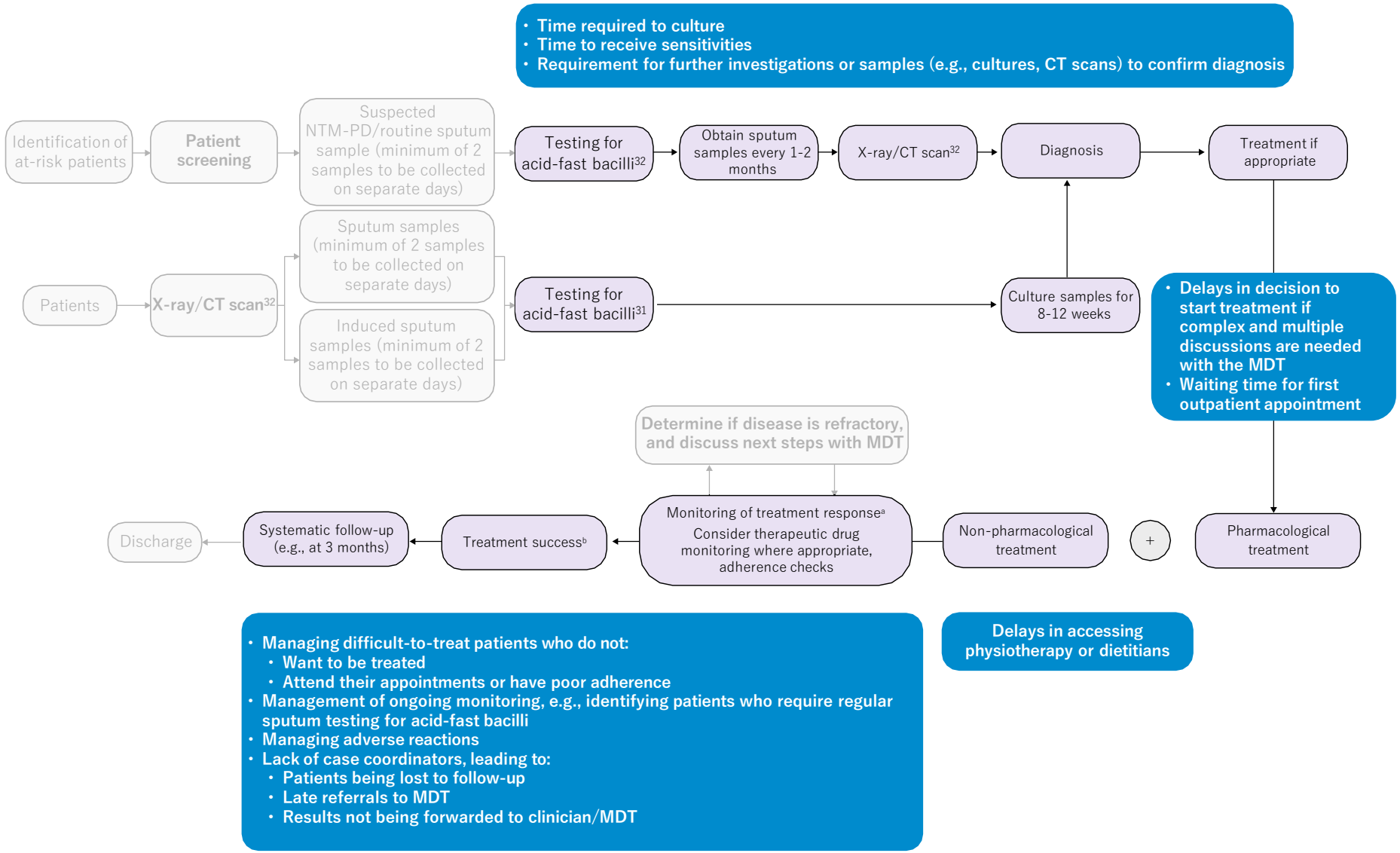
Click on the blue hand icon to navigate to other parts of the patient pathway

Patient Pathway

Management Decisions for Patient With NTM-PD

Bottlenecks in management decisions for patients with NTM-PD



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[a]Sputum samples every 4-12 weeks and 12 months after treatment completion); [b]Sputum culture conversion for 3 consecutive samples at different times and days and radiological improvement)

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Patient Pathway

Abbreviations

BTS	British Thoracic Society
CF	cystic fibrosis
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease 2019
CT	computed tomography
CYP450	cytochrome P450
GBT	guideline-based treatment
HCP	healthcare professional
HIV	human immunodeficiency virus
IV	intravenous
M.	mycobacterium
MAC	*Mycobacterium avium* complex
MDT	multidisciplinary team
NHS	National Health Service
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
TB	tuberculosis

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Primary Care in NTM-PD

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Primary Care Module

Executive Summary

- Although not a common condition, there is a need to raise general awareness of NTM-PD among healthcare professionals
- GPs are in a unique position to support an early diagnosis of NTM-PD
- There are several factors that increase the risk of developing NTM-PD, including structural lung disease (e.g., bronchiectasis, COPD) and a compromised immune system
- Consider the possibility of NTM-PD in patients with new respiratory symptoms that do not resolve over a 6-week period or in those with a general exacerbation or deterioration of respiratory symptoms
- Three sputum samples taken on different days should be sent for analysis in suspected cases of NTM-PD
- Patients are typically treated with a 3-5 drug regimen and on average, are on treatment for 18 months. Medication for NTM-PD can interact with number of other medicines
- If a patient experiences adverse events while they are on NTM-PD medication, contact their specialist pharmacist to discuss alternative treatment options
- Be aware of the potential for recurrence for patients who have previously had NTM-PD
- There is a need to improve communication around NTM-PD between primary and secondary care

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Primary Care Module

Respiratory Diseases and NTM: Background

GPs are uniquely placed to identify individuals infected with NTM and support an early diagnosis

Respiratory conditions place a large burden on patients, healthcare professionals, and healthcare systems around the world.[1]

The UK had a greater mortality rate for respiratory diseases than several European countries from 1985 to 2015.[2] Respiratory diseases were responsible for 20% of annual deaths in the UK between 2008 and 2012.[3]

Socioeconomic deprivation has been linked to morbidity and mortality of asthma and respiratory infections. Causes of increased prevalence of respiratory diseases in deprived areas include higher smoking rates, pollution, and poor-quality housing[4]

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Primary Care Module

Respiratory Diseases and NTM: Background

GPs are uniquely placed to identify individuals infected with NTM and support an early diagnosis

Lung diseases cost the UK £11 billion each year, in costs to the NHS and in lost productivity.[5] Over the five-year period from 2008 to 2012, the proportion of deaths from another leading cause of mortality – cardiovascular disease – declined, whereas the proportion of deaths due to lung disease remained constant.[3,6]

Non-tuberculous mycobacteria (NTM) include all mycobacteria other than *Mycobacterium tuberculosis* complex, which causes tuberculosis (TB), and *M. leprae*, which is the causative agent of leprosy.[7]

A number of NTM species are pathogenic in humans and are responsible for opportunistic infections in patients with underlying respiratory disease or suppressed immune systems.[8]

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NTM are found in a wide range of environmental settings, from soil and surfaces to drinking water.[9]

Infection is frequently acquired by repeated exposure to environments inhabited by NTM.

This may be from:

Inhalation[10]
(e.g., aerosols, showers)

Exposure to NTM-containing soil from gardens[11]

Contaminated water sources[11]
(e.g., showers, taps, hot tubs, and humidifiers)

Mechanism of Infection

Everyone is likely to be exposed to NTM during their daily lives, but most people are not at risk of developing pulmonary disease caused by NTM (NTM-PD).[30]

Factors that increase the risk of NTM-PD[8]

- Alcohol misuse
- Biological agents
- Chronic kidney disease
- Diabetes
- Female sex
- Gastro-oesophageal reflux disease
- Immunocompromise, primary or secondary to disease or drug therapies
- Inhaled corticosteroids
- Low body mass index
- Pneumoconiosis
- Underlying structural disease (e.g., bronchiectasis, COPD)

Primary Care Module

Prevalence

The incidence of people infected with NTM is increasing worldwide; with rates in England, Wales and Northern Ireland reported to have increased almost ten-fold between 1995 and 2012.[12]

A recent study investigating the prevalence of NTM-PD in primary care found that:[13]

- The average annual prevalence of NTM-PD in the general population was 6.38 per 100,000
- The average annual prevalence of NTM-PD in patients with respiratory disease was 27.7 per 100,000
- Approximately 40% of patients with NTM-PD also had a chronic respiratory disease, with COPD being the most common

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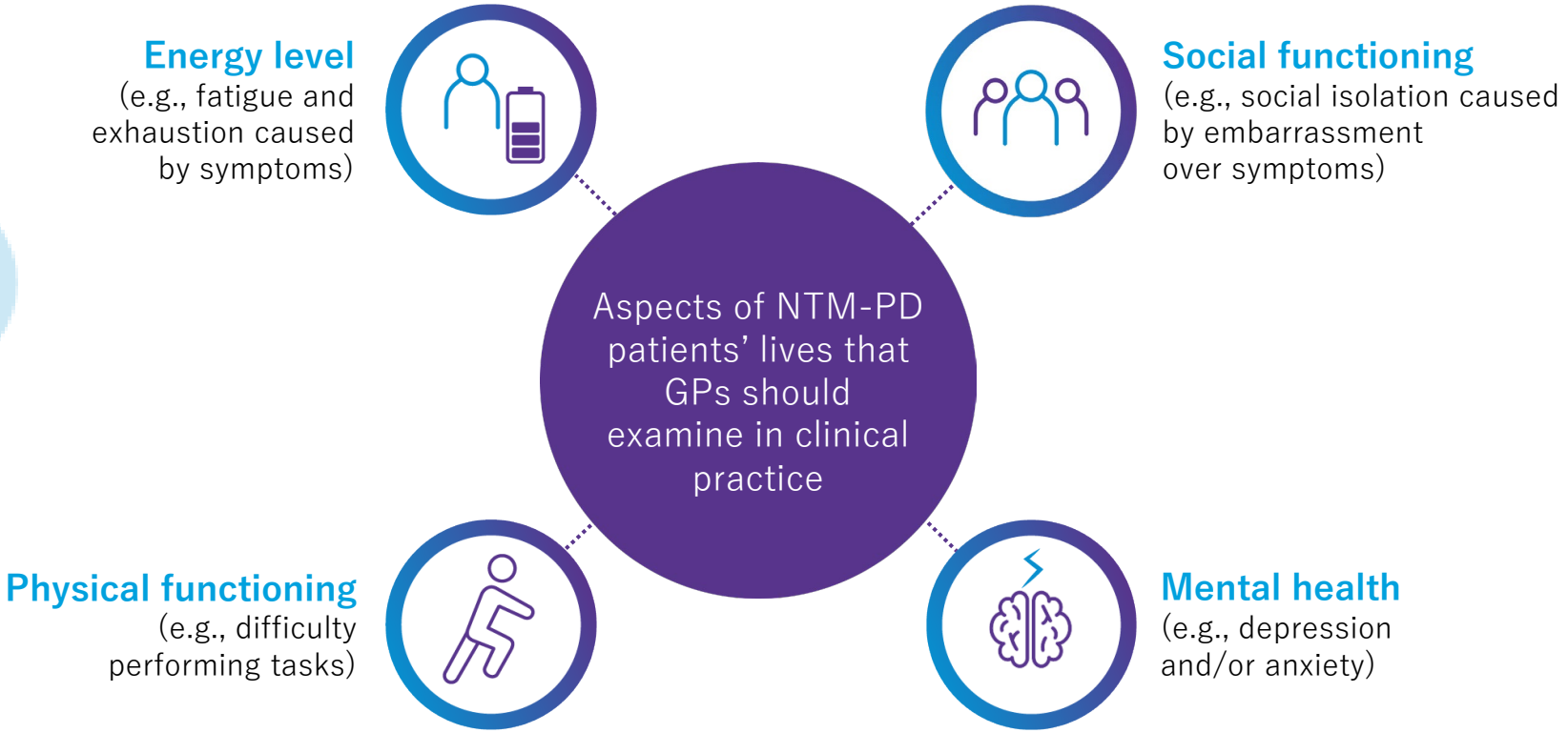
Burden of Disease



> Bothersome symptoms of NTM-PD such as fatigue, productive cough, and dyspnoea can have a detrimental impact on quality of life.[14]
>
> Patient-reported changes in quality of life should be assessed in order to formulate plans that lead to the most desirable outcomes.

A 2021 European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC)[a] patient survey found the following[15]

The top 3 challenges for patients diagnosed with NTM-PD

- Feeling tired
- Coughing
- Exacerbations

86% of patients said their disease had limited their spouse's QoL

The top 3 most difficult aspects of NTM-PD management for patients were:

- The long duration of treatment
- Worries over diagnosis and treatment
- Adverse reactions caused by therapy

81% of patients diagnosed with NTM-PD had been offered treatment. Of these patients:

- 35% successfully completed treatment
- 28% stopped treatment without success

Respondents were not offered treatment for a number of reasons, including:

- The infecting species was not causing pathogenic harm (36%)
- Potential adverse reactions to the medication (36%)
- Likelihood of resistance to available drugs (4%)

[a]The EMBARC survey was developed in collaboration with the European Lung Foundation (ELF) and their bronchiectasis patient advisory group. The aim of the survey was to find out about the challenges encountered during the evaluation and treatment of NTM-PD and to help healthcare professionals improve how they deal with this condition. The survey asked people with bronchiectasis, both with and without NTM-PD; and people with NTM-PD infection (current or past) with or without a diagnosis of bronchiectasis to complete the survey.

Presentation of NTM-PD

Although NTM-PD symptoms can vary, there are some key clinical features to keep in mind:[8,14,16]

- Dry cough or coughing up phlegm or sputum
- Breathlessness
- Exacerbations of existing respiratory disease
- Night sweats
- Lethargy and malaise
- Fever

Consider NTM-PD in the differential diagnosis if you suspect that a patient has any of the following:

- Lung cancer[17]
- Tuberculosis[18]
- Infections caused by *Pseudomonas* aeruginosa[19,20] or the *Aspergillus* fumigatus[21,22]

Contents

When a patient presents with a worsening respiratory symptom, particularly if this forms a pattern of repeated exacerbations or deterioration over time, consider screening for NTM.

Consider screening for NTM in patients who present with:

- New respiratory symptoms that do not resolve over a 6-week period
- A general exacerbation or deterioration of respiratory symptoms

Consider screening for NTM in patients with:

- Bronchiectasis[8]
- CF[8,23]
- COPD[8]
- HIV[8]
- TB[24]
- Patients being investigated for other lung conditions, such as lung cancer, where NTM may be a possibility[25]
- People with a history of NTM-PD
- People with a history of NTM infection
- People who have symptoms and are immunocompromised[8]

Primary Care Module

Relevant Guidelines

BTS Guideline on Bronchiectasis in Adults[26]

Prior to initiating long-term macrolides, ensure that there is no active NTM infection by confirming with at least one negative respiratory NTM culture

NICE Guideline on COPD[27]

Before offering prophylactic antibiotics, ensure that the patient has had sputum culture and sensitivity (including tuberculosis culture), to identify other possible causes of persistent or recurrent infection that may need specific treatment (for example, antibiotic-resistant organisms, atypical mycobacteria, or *Pseudomonas aeruginosa*)

NICE Guideline on Cystic Fibrosis[28]

At each annual review, in relation to pulmonary assessment of people with cystic fibrosis, respiratory secretion samples should be taken for microbiological investigations (including NTM)

The guideline includes recommendations on what to do if a person with cystic fibrosis persistently tests positive for NTM

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Annual screening for NTM is recommended in patients with cystic fibrosis.[29]

Patients who have secondary care follow-up should have this screening carried out as part of their routine care.

Patients who are regularly seeing their secondary care team may have regular NTM screening carried out as part of their routine care.

Patients may enter the diagnostic pathway for NTM in a number of ways, including:

- **Routine screening** as part of the management of specific conditions (e.g., immunocompromised individuals)
- **Following a sputum sample** (including induced samples)
- **Following an X-ray or CT scan**
- **Following a bronchoscopy**
- **Prior to initiation of long-term macrolide therapy**
- **After repeated antibiotic treatment for respiratory symptoms has been ineffective**

There is a need to improve screening (and diagnosis) for patient groups at high risk of developing NTM-PD.

Patient Referrals

NTM-PD symptoms are non-specific and can include chronic or recurring cough, sputum production, fatigue, malaise, shortness of breath, fever, haemoptysis, chest pain, and weight loss.[16]

A diagnosis of NTM-PD is made when three criteria are met:[16]

1. Symptoms consistent with NTM-PD
2. Radiological signs on chest X-ray or CT scan
3. Two positive mycobacterial cultures. Isolation of an NTM-PD-causing agent is essential for diagnosis

Early identification of NTM can have a big impact on the patient's prognosis[18] and allow triage into the appropriate clinic to avoid longer waiting lists

A single positive sputum culture is not considered to be a conclusive result that can be used to establish a diagnosis of NTM-PD. NTM-positive cultures are occasionally detected incidentally without any pathological sequalae.[16]

If NTM-PD is suspected, a referral should be made to a local respiratory service. If a patient has been referred to a respiratory clinic, but is awaiting an assessment, consider sending more sputum samples for testing. This is particularly relevant in cases where only one culture has tested positive for acid-fast bacilli.

At a specialist clinic, additional assessments will be conducted to find out whether there is evidence of active NTM-PD.

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NHS organisations should ensure that there are pathways to inform appropriate clinicians or MDTs about any positive mycobacterial cultures. This may include the NTM MDT, infectious diseases, respiratory and/or cystic fibrosis teams.

The MDT can review X-ray/CT results if available and examine the patient's lifestyle, symptoms, or comorbidities to determine if NTM-PD is suspected and if further sputum samples are needed.

Obtaining a positive sputum sample should be followed by radiological evaluation of the patient and microbiological analysis to detect the presence of NTM.

MDT meetings should be held weekly wherever possible, and could include a discussion on new positive results within the last 7 days.

Review process for investigation of suspected cases of NTM-PD

- Contacting relevant clinical personnel
- Obtaining a repeat sputum sample
- Organising an X-ray/CT scan
- Arranging for the patient to come into the clinic for assessments
- Monitoring each stage and following up as necessary
- Informing the MDT, requesting clinician, and the infectious diseases department

Tip: The MDT may find it useful to develop a *Mycobacterium* "watch list", which details the stage of the diagnostic pathway for each patient with suspected NTM-PD (e.g., one sputum sent).

Medication

In patients with a history of macrolide-resistant disease, medication should be prescribed by a specialist with experience of treating NTM-PD, according to national guidelines[22]

Patients are generally supplied with enough medication for a 3-month period, and adherence is monitored

Duration of treatment can vary; however, on average, patients are on treatment for 18 months.

Breaks in treatment that are not treatment holidays may result in the patient needing to restart therapy completely

When considering which therapy to prescribe, the consultant or specialist pharmacist will review all medication that the patient is currently on. If there is a delay in the patient referral, the list of current medications should be kept up to date.

NTM-PD medication can interact with other therapies.[22]

The consultant will notify you if this is a consideration for your patient and will appropriately prioritise all treatments in discussion with the specialist pharmacist.

If a patient requires treatment for another illness whilst on therapy for NTM-PD, please notify the consultant or specialist nurse to discuss treatment options.

Treatment of NTM-PD should involve an MDT. This will increase resources available to assist patients with practising airway clearance techniques, nutritional support, monitoring their weight,[16] psychological state,[31] and any underlying chronic respiratory diseases. Primary care HCPs may be involved in some aspects of the patient's long-term care plan.

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Managing Adverse Events

Adverse events experienced by patients who are on NTM-PD treatment can be managed in partnership with patients and HCPs.

Nurses form a key part of patient education strategies and may discuss the management of adverse events in order to help patients improve their ability to cope with treatment.

Patient education is important for ensuring that treatment adherence is optimal and that any adverse events are reported at the earliest opportunity.

Pharmacists can play a role in advising HCPs on what can be prescribed to manage adverse events.

There are resources that can be used to look at adverse events associated with particular pharmacologic agents for NTM-PD.

Websites with information on NTM-PD therapies:

- TB Drug Monographs
- BTS Guidelines on Long-term Macrolide Use

If a patient experiences adverse events while they are on NTM-PD medication, please contact their pharmacist to discuss alternative treatment options.

Patient alert cards contain important information for patients about the safety of their medications. In the event of an emergency, patient alert cards help attending HCPs know how to be mindful of potential medication-related AEs or drug-drug interactions that may be relevant to future therapeutic interventions.

It is important that any changes to a patient's NTM-PD treatment regimen are discussed with an NTM-PD treatment specialist. Breaks in treatment that are not an official treatment holiday may result in patients needing to re-initiate therapy for NTM-PD.

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Relapse

Relapse in NTM-PD has been defined as the emergence of at least two cultures that test positive for the same species that caused the initial infection after the end of the patient's treatment.[32]

Recurrence can refer to a relapse caused by the species responsible for the initial infection or a new infection caused by a different species of NTM. Recurrence of NTM-PD is common and may occur after a seemingly successful course of treatment.[33]

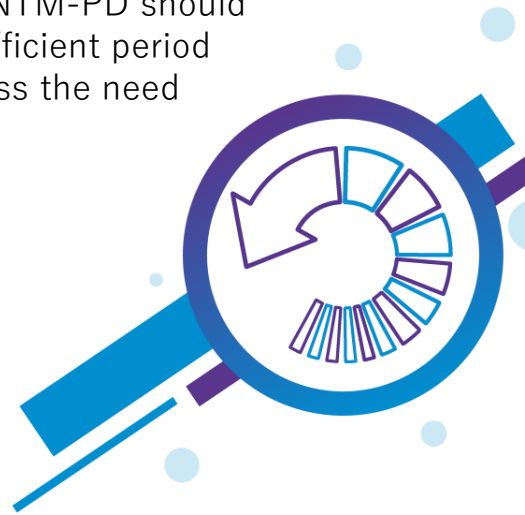
Recurrence is common in patients with NTM-PD.[34] Monitoring patients is key to early diagnosis of relapse. Ensure that the presence of NTM cultures are checked during annual reviews.

If there is any change in symptoms:

- Ensure sputum samples are sent for testing immediately and refer for a chest X-ray
- Consider early referral back to the respiratory service if there are concerns of reinfection

Recurrence rates vary across the population of patients with NTM-PD. This may be due to differences in drug combinations used to treat patients, the doses or durations of antibiotic treatment, as well as the type of disease.[33]

Nodular bronchiectatic disease has been found to have a higher rate of reinfection than fibrocavitary disease. Patients who have been successfully treated for the nodular bronchiectatic form of NTM-PD should be followed up for a sufficient period of time in order to assess the need for further treatment.[33]



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Primary Care Module

Communication Between Primary and Secondary Care

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Interface Between Primary and Secondary Care

It is important for secondary care to raise awareness of NTM-PD in primary care and to provide advice on how primary care should:

- Proceed if NTM-PD is suspected
- Manage comorbidities in patients with confirmed NTM-PD

Although secondary care is primarily responsible for management of NTM-PD, it may be useful for primary care to provide input

MDT meetings are a way of garnering input from the various healthcare professionals (e.g., respiratory consultant, pharmacist, physiotherapist, nurse, dietitian) involved in the care of a patient with NTM-PD

Facilitating Communication Between Primary and Secondary Care

Regular primary and secondary care respiratory MDT meetings can be used to discuss working models

- If there is no local touchpoint between primary and secondary care, meetings and discussions with appropriate consultants may be requested

Educational meetings and training sessions

MDT meetings to discuss complex patient cases

Primary Care Module

Communication Between Primary and Secondary Care

It is important that primary and secondary healthcare providers are in communication with each other to provide optimal assistance to patients with NTM-PD.

The bulk of patient care (e.g., long-term administration of antibiotics such as clarithromycin and rifampicin, as well as radiology or physiotherapy appointments) may take place in secondary healthcare settings. After this, the patient may be managed again at a primary care facility because they may transition to an antibiotic regimen that has a lower risk of adverse events.

Effective communication between primary and secondary care will ensure that patient records are up to date and awareness of treatment strategies for individual cases of NTM-PD are well understood and agreed upon.

There are two major types of communication that can be utilised by primary care providers in the management of patients with NTM-PD. These are **proactive** and **reactive** styles of communication. Examples of how they can be employed in the NTM-PD healthcare setting are provided below.

Proactive

Treatment-emergent concerns can be addressed proactively, such as creating a checklist for HCPs to assess potential adverse reactions and adherence

Making sure that there is a primary contact person to address concerns about patients before they arise would be helpful to address issues at the earliest opportunities

Reactive

Having a system in place (such as implementing home visits or discussions with nurses) for when patients have problems with treatment may help HCPs find solutions to common issues like adverse events, lack of adherence or access to medications

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If there is a positive AFB culture, how do you know whether it is NTM or TB?

In the UK, initial laboratory reports usually use the term 'Mycobacterium culture positive' for acid-fast bacilli-positive sputum samples. This could mean either NTM or TB, and it can take as long as two weeks before full identification reports are issued from reference laboratories. If clinical suspicion for TB is high, then referral to TB services should be made; in-house tests are often available in local hospitals to check whether a diagnosis of TB can be made.

Are patients with NTM infection able to infect other people?

It is highly unlikely that pathogenic NTM infection will spread from one human to another. However, there is evidence to suggest that susceptible individuals, such as patients with chronic respiratory diseases, may become infected if they come into contact with a person infected with NTM.

How should treatment adherence for NTM-PD be managed?

Most patients with NTM-PD are motivated to take their treatment as prescribed. Asking family members to supervise administration of medication can be helpful, as can the use of blister packs. Directly observed therapy and video-observed therapy are also ways of confirming treatment adherence.

How is a patient's response to treatment monitored?

Sputum samples are sent every 4-12 weeks for culturing, with a successful treatment response defined by culture-negative samples. Follow-up X-ray and CT assessments can also show improvements if treatment is successful, which is particularly helpful in patients who are unable to expectorate sputum. At the same time, patients should also experience improvement of symptoms and quality of life.

How should comorbidities be managed?

The specialist pharmacist will be able to advise on the pharmacological management of patients with NTM-PD who have comorbidities that also require medication.

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Primary Care Module

Resources

Resources for HCPs:

- A UK-based resource to support the monitoring and safe use of anti-tuberculosis drugs and second-line treatment of multi-drug resistant tuberculosis
- NICE guideline: Chronic obstructive pulmonary disease in over 16s: diagnosis and management
- British Thoracic Society Guideline for bronchiectasis in adults
- British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD)
- Treatment of nontuberculous mycobacterial pulmonary disease: An official ATS/ERS/ESCMID/IDSA clinical practice guideline
- RESP- Respiratory Education and Scientific Platform
- Non-tuberculous mycobacterial (NTM) infections – and their relevance to general respiratory practice

Resources for Patients:

- NTM Patient Care UK
- Asthma + Lung UK NTM-PD Factsheet

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Primary Care Module

Abbreviations

AE	adverse event
AFB	acid-fast bacillus
ATS	American Thoracic Society
BTS	British Thoracic Society
COPD	chronic obstructive pulmonary disease
CT	computed tomography
EMBARC	European Multicentre Bronchiectasis Audit and Research Collaboration
ERS	European Respiratory Society
ESCMID	European Society of Clinical Microbiology and Infectious Diseases
HCP	healthcare professional
HRCT	high-resolution computed tomography
IDSA	Infectious Diseases Society of America
MDT	multidisciplinary team
NICE	National Institute for Health and Care Excellence
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease
QoL	quality of life
TB	tuberculosis

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Evaluating the Standard of Care

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Evaluating the Standard of Care

Introduction

Several practical and clinical issues have been associated with the diagnosis and management of NTM-PD

There is a need for standards of care to guide HCPs

Conducting an audit can help identify patients with NTM-PD and evaluate management based on the standards of care presented on the following slide

Consistency with recommendations from the BTS and ATS/ERS/ESCMID/IDSA guidelines should be recorded

Guidelines

- Haworth CS, Banks J, Capstick T, et al. British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax*. 2017;72(Suppl 2): ii1-ii64
- Kurz SG, Zha BS, Herman DD, et al. Summary for clinicians: 2020 clinical practice guideline summary for the treatment of nontuberculous mycobacterial pulmonary disease. *Ann Am Thorac Soc*. 2020;17(9):1033-1039

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Evaluating the Standard of Care

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The following standards to guide care and best practice in this area have been devised based on input from a steering committee of experts with experience of treating patients with NTM-PD, scientific literature, and extensive research:

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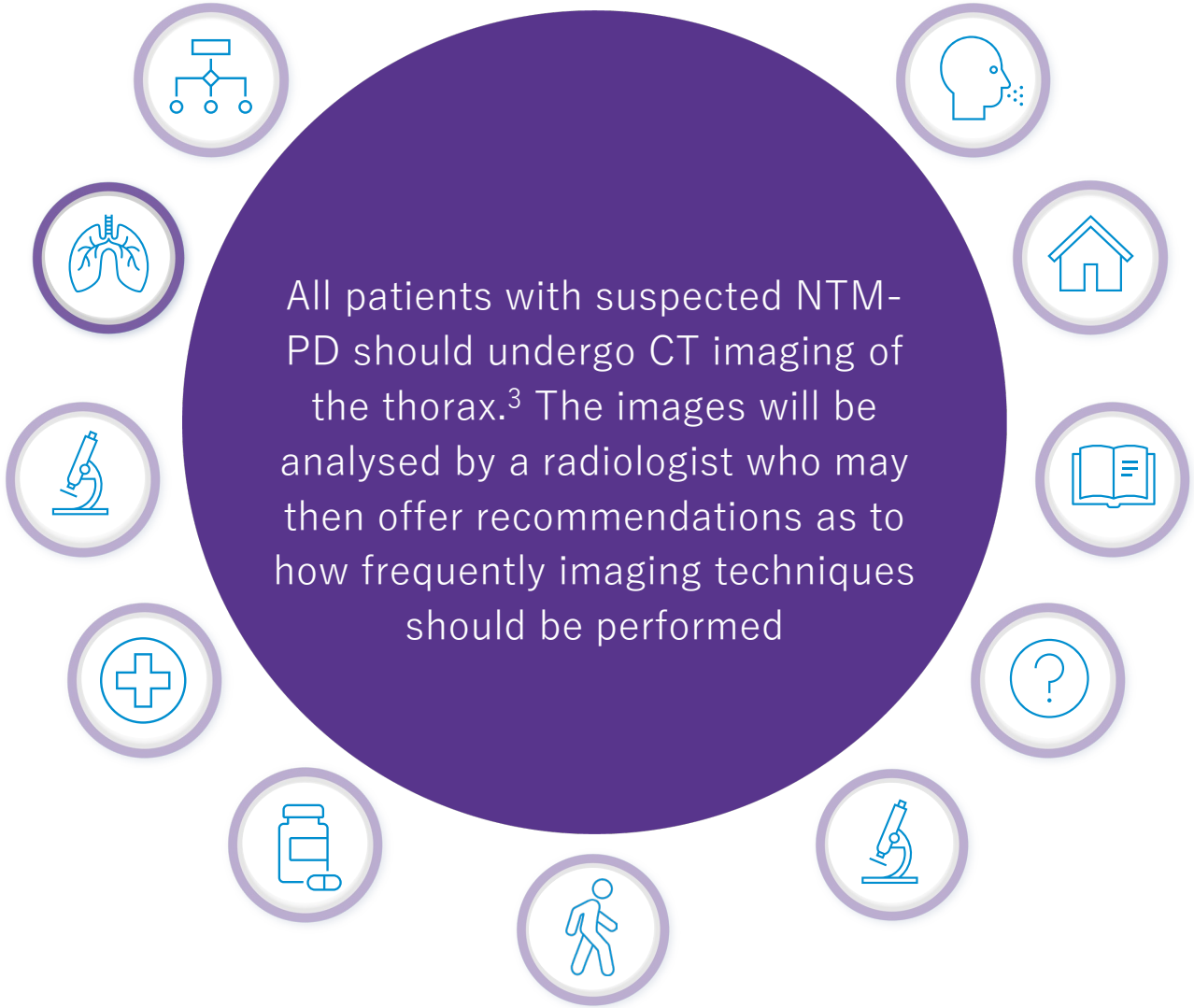

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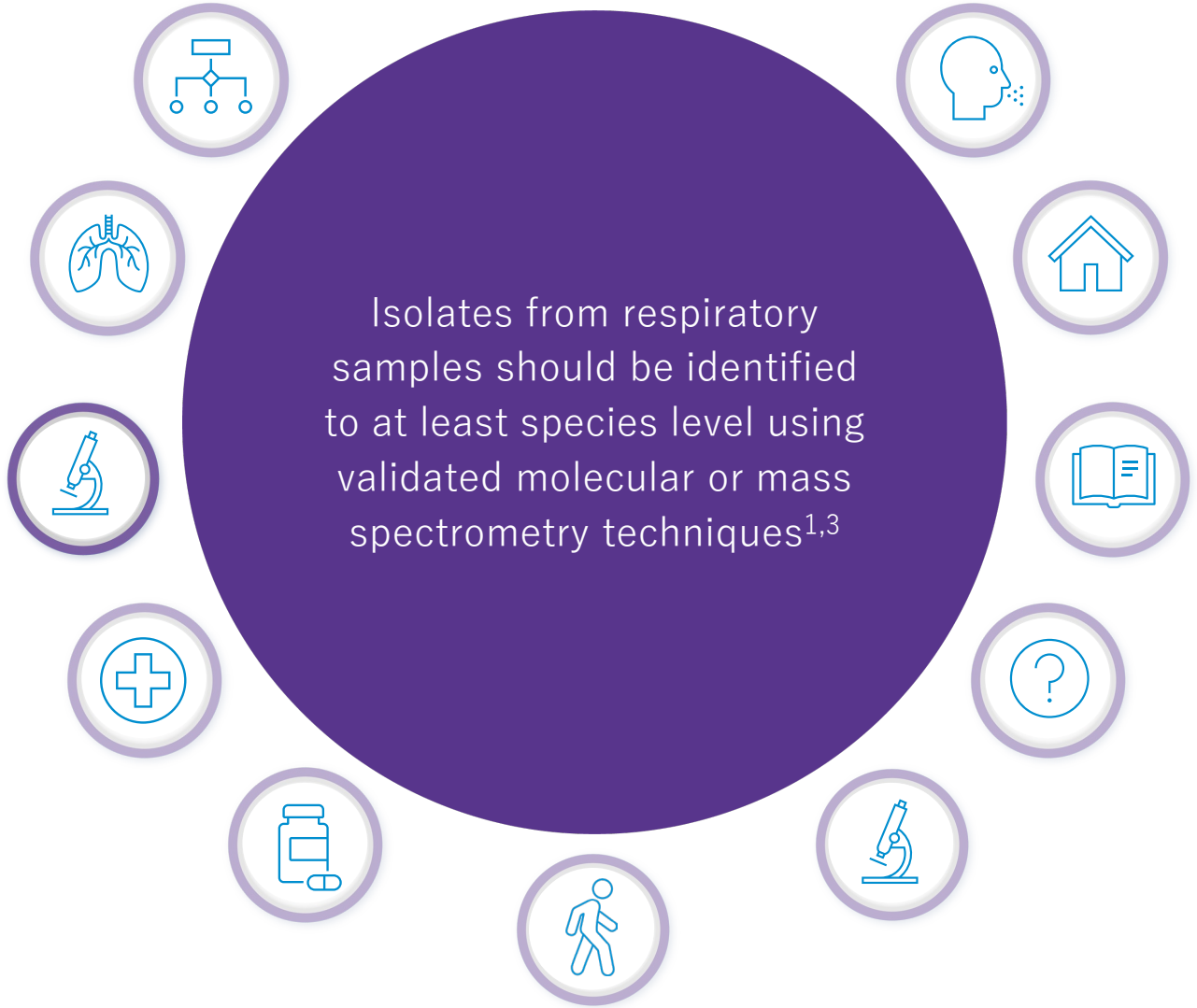

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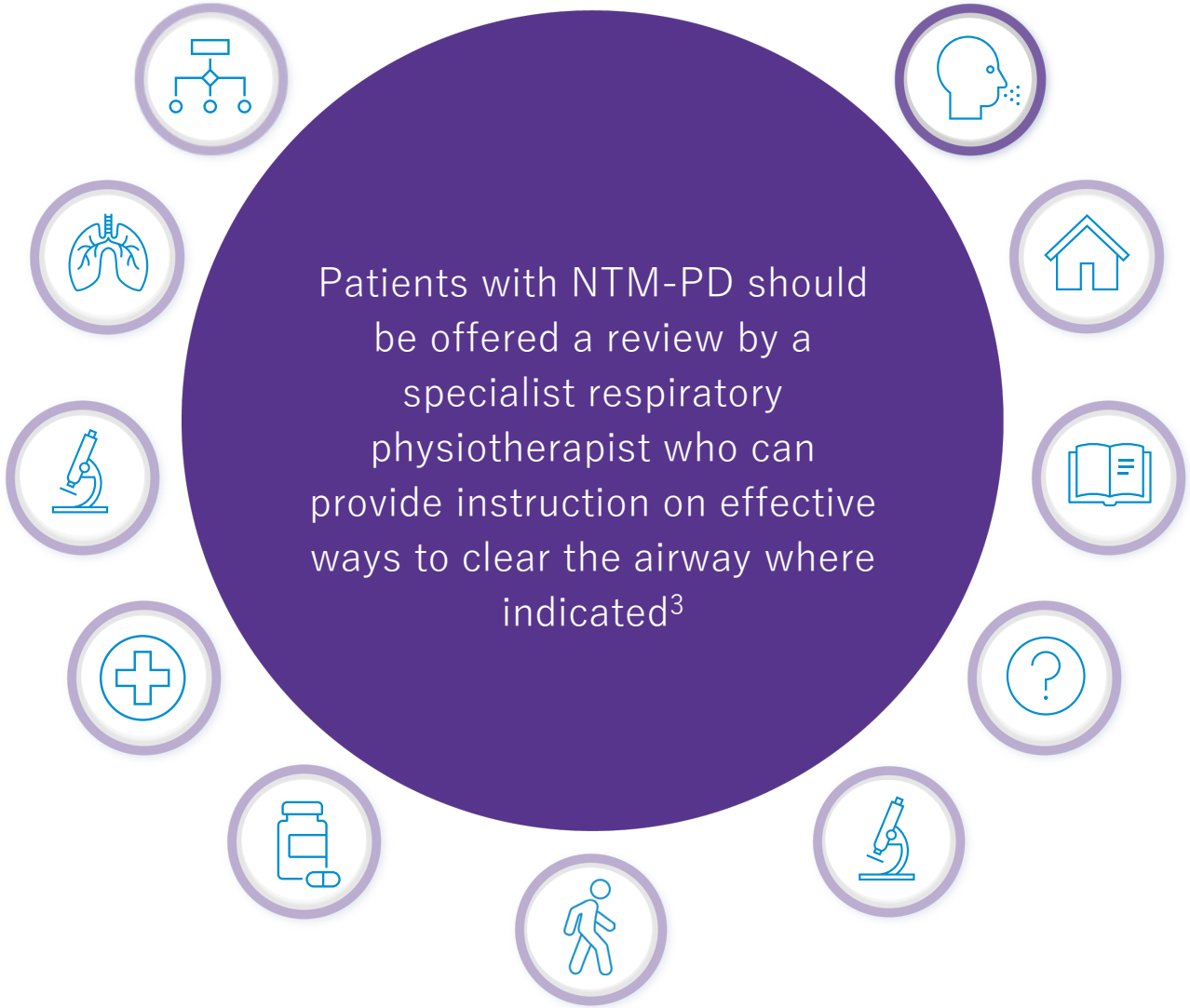

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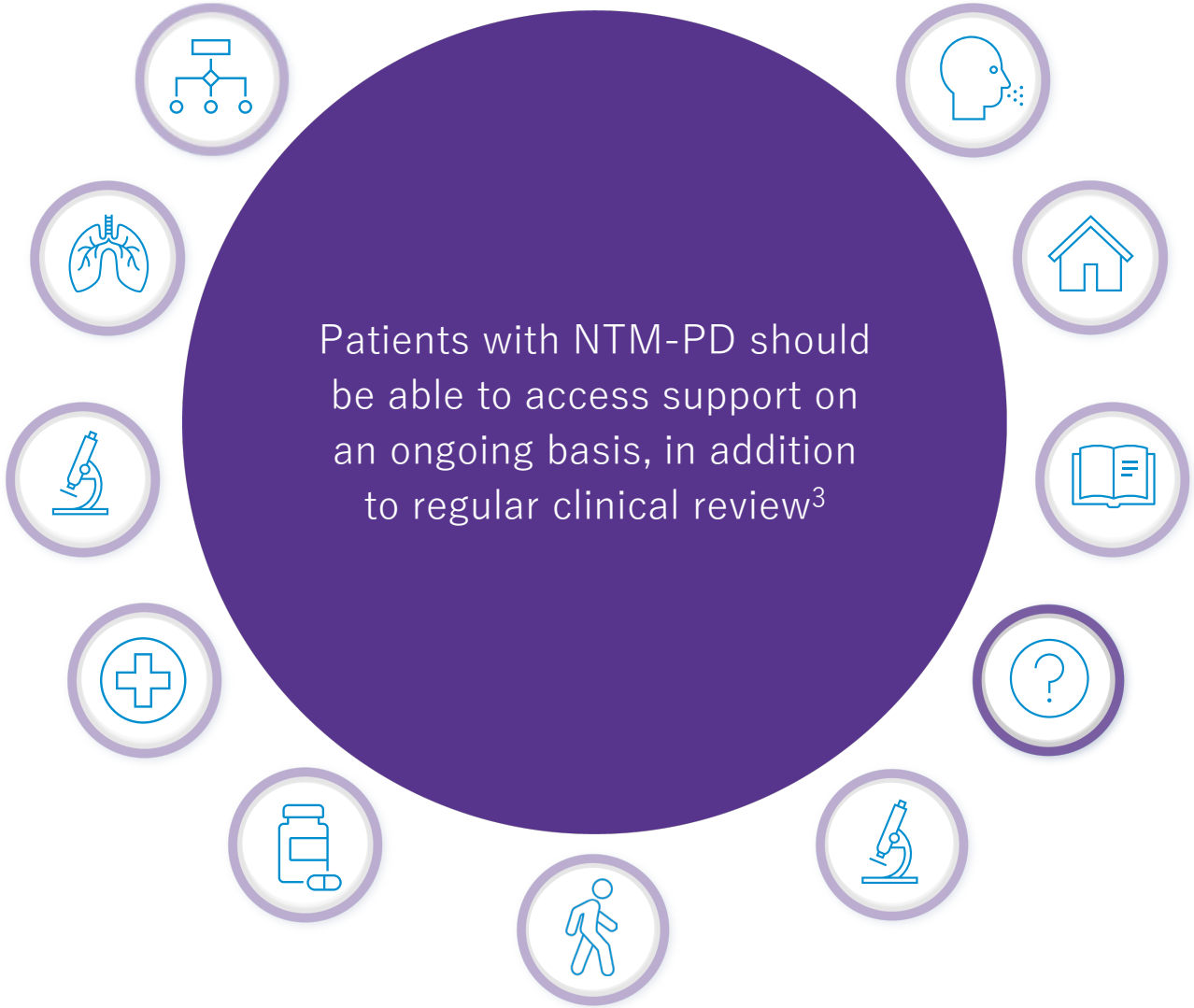

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Evaluating the Standard of Care

Performing an Audit

Performing an audit is a multi-stage process. The following tips can help you get started:

- **Use the guideline recommendations on the diagnosis, treatment, and management of NTM-PD**
- **Define the research period: dates/number of years**
- **Identify your database and data sources**
  - Microbiology results/lab information systems
  - Clinical management and outcomes/patient records
  - Radiology data/personnel to analyse the images
- **Detail exclusion criteria** (e.g., CF, disseminated NTM, positive sputum without other clinical and radiological diagnostic criteria, non-pathogenic species)
- **Define the study population** (e.g., adults with confirmed NTM-PD)
- **Plan data capture** (e.g., demographic categories, priority species, comorbidities, medications [for NTM and other for co-morbid conditions])

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Suggested Fields for Data Collection

Number of patients with at least one culture positive sample (BAL or sputum)
Number of patients excluded and rationale (capture exclusion categories)
Demographics and description of included patients with confirmed NTM-PD • Age (categorical) • Sex • Comorbidities (detailed description of respiratory comorbidities, predefine in your audit planning) • All medication • Immune status (competent, HIV/AIDs, pregnancy, immunosuppressants, etc)
Drug sensitivity testing results (which species, and impact on treatment)
Number and percentage of patients treated by species
Number and percentage of patients with MAC cavitary disease and corresponding treatment
Number and percentage of patients with MAC nodular bronchiectatic and corresponding treatment
Reason for no treatment if known (e.g., refused, palliative care, low pathogenic species)
Probable or confirmed NTM-PD treatment-related AEs
Number of treatment-refractory patients and species type

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Analysis

Record the number and percentage of patients managed per the guidelines for the respective species

Categorise any reported adverse events (e.g., auditory, visual)

Record longer-term data if available

Summarise treatment outcomes (e.g., completed, stopped, ongoing, changed, relapse, lost to follow-up, death)

Record differences in outcomes between patients who are treated in line with guidelines recommendations vs. patients who are not

If guideline recommendations are not followed at your practice, describe your facility's approach and the and rationale

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Evaluating the Standard of Care

Implementing Learnings

Has the audit identified areas of improvement?
Or areas where the team should be applauded?

Develop an action plan with clearly defined processes and responsibilities and share with the team
- Detail how and when these processes should be implemented

Does the audit need to be repeated?
If so, set a timeline

Are there any learnings to be shared across the team/organisation?

Download an example service evaluation template **here**

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Evaluating the Standard of Care

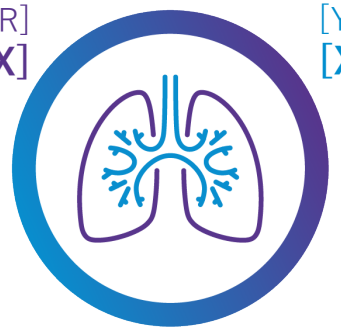
Reporting the Results

Patients

[YEAR] [XXX] [YEAR] [XXX]

Patients screened **for NTM**

[YEAR] [XXX] [YEAR] [XXX]



Patients diagnosed **with NTM**

[YEAR] [XXX] [YEAR] [XXX]

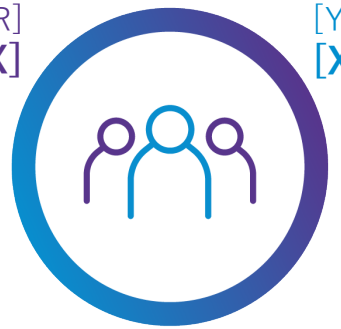
Patients with **positive culture conversion**

Staffing and general organisation of care

[YEAR] [XXX] [YEAR] [XXX]

Number of staff involved **in NTM care**

[YEAR] [XXX] [YEAR] [XXX]



Number of **MDT meetings**

[YEAR] [XXX] [YEAR] [XXX]

Number of patient **home visits for NTM**

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Abbreviations

AE	adverse event
AIDS	acquired immunodeficiency syndrome
ATS	American Thoracic Society
BAL	bronchoalveolar lavage
BTS	British Thoracic Society
CF	cystic fibrosis
CT	computed tomography
ESCMID	European Society of Clinical Microbiology and Infectious Diseases
HCP	healthcare professional
HIV	human immunodeficiency virus
IDSA	Infectious Diseases Society of America
MAC	*Mycobacterium avium* complex
MDT	multidisciplinary team
NTM	non-tuberculous mycobacteria
NTM-PD	non-tuberculous mycobacteria pulmonary disease

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Evaluating the Standard of Care

Bibliography

1. Haworth CS, Banks J, Capstick T, et al. British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax*. 2017;72(Suppl 2): ii1-ii64.
2. Kurz SG, Zha BS, Herman DD, et al. Summary for clinicians: 2020 clinical practice guideline summary for the treatment of nontuberculous mycobacterial pulmonary disease. *Ann Am Thorac Soc*. 2020;17(9):1033-1039.
3. Lipman M, Cleverley J, Fardon T, et al. Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Respir Res*. 2020; 7(1): e000591.
4. NHS – Physical Activity Guidelines for Adults. https://www.nhs.uk/live-well/exercise/exercise-guidelines/physical-activity-guidelines-for-adults-aged-19-to-64/ (Accessed March 2025).
5. NTM Patient Care UK – Exercise. https://www.ntmpatientcare.uk/exercise (Accessed March 2025).

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Appendix

Additional Resources

American Thoracic Society Guidelines for the Treatment of NTM-PD

Asthma + Lung UK - on NTM Infection

British Thoracic Society website - British Thoracic Society guidelines for the management of non-tuberculosis mycobacterial pulmonary disease

RESP.co.uk 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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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
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

Click **here** to download a business case template which can be used or amended according to your proposal's requirements.

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
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 'Developing a Business Case' section of this toolkit

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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
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

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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
Patient and Carer Feedback	Case studies, or patient and carer quotes, which support your proposed service or modifications to any services that are currently offered This section is designed to strengthen your business case and bring your proposal to life 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
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.

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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Appendix

Questions for Patients

Examples of questions that can be asked during patient follow-ups or home visits.

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

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

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

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Appendix

Questions for Patients

Examples of questions that can be asked during patient follow-ups or home visits.

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 is your mobility?

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

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.

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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