

Patient's Guide to Standards of Care

for People Living with NTM Disease in the UK

Based on the Standards of Care
developed in July 2024, Version 1





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Introduction



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NTM Patient

Welcome to the Patient's Guide to the Standards of Care for non-tuberculous mycobacteria (NTM).

As the number of people with NTM increased across the UK, the patchy nature of diagnosis and treatment became clear. Many, like us, struggled for years before being diagnosed. It was imperative that action needed to be taken. In July 2024, NTM Network UK published the Standards of Care for NTM: a written guide to the minimum standard of care people with NTM can expect in order to achieve their best possible health outcomes.

The Patient's Guide summarises these standards. With substantial input from our NTM community of patients and healthcare professionals, the Guide puts patients' health and well-being front and centre. It provides information on what you should expect from your care providers, bearing in mind the resources available within the NHS. It also has a section with background information on NTM disease, and signposts where you can gain additional support such as NTM Patient Care UK.

We hope you find the Patient's Guide empowering and of benefit to your long-term well-being.

With very best wishes,

Tanya, Sarah, and the many other NTM patients who contributed



How to use this guide

The Patient's Guide is designed to complement the full Standards of Care document by providing you with clear and accessible information.¹

The Standards of Care, and this guide, are divided into six main sections, each focusing on a different aspect of NTM care and reflecting the healthcare journey taken by many people with NTM disease. These sections cover the presentation, diagnosis, treatment and further management of both NTM pulmonary disease (NTM-PD) and extrapulmonary NTM (EP-NTM) disease. Within each section, 'Quality Statements' define the key aspects of care or service you should expect to receive at every step. The [Standards of Care summary](#) , found below (page 6), provides an overview of the key messages from each section and highlights what you should expect from your care. Clicking on the title of each section will take you to that section. The final section at the end of the Patient's Guide contains further information about NTM disease, which can help you learn more about the condition and how it may impact you.

Throughout this document, key terms are coloured and underlined when first introduced in each section. Clicking the [words](#) with the  icon will take you to the [glossary](#)² (page 37) which contains concise explanations to aid your understanding.

The Standards of Care include metrics to assess the quality of NTM care being provided. These are described for the majority of Quality Statements and are in the full Standards of Care document; your healthcare provider should be aware of them.

To help ensure that you receive the best possible care and support while managing your NTM disease, consider taking the following actions:

- Familiarise yourself with the Standards of Care and the details provided in this guide to understand your condition better
- Bring the guide to your medical appointments to discuss with your healthcare providers
- Do not be afraid to discuss your concerns and expectations with your healthcare team, and make sure they adhere to the Standards of Care
- Keep a record of your symptoms, treatments, and healthcare visits, so you have comprehensive information available for discussions with your healthcare providers
- Do not hesitate to ask your healthcare team for clarification on any aspects of your care that are unclear

¹Please note the current document does not contain any references; a full list of references can be found in the full Standards of Care document if of interest.



How to use this guide (continued)

- Reach out to patient support organisations for additional resources and community support
- If you feel that your care does not meet the Standards of Care, advocate for adjustments by discussing specific guidelines with your healthcare providers
- Keep up-to-date with any changes or updates in NTM care practices and treatments by engaging with support networks and educational resources
- Actively participate in decisions about your treatment and care plans to ensure they align with your personal needs and the outlined standards
- Share your experiences and feedback with healthcare providers and patient organisations to help improve NTM care services

There is a section providing details on [What to do if you are concerned about the care you are receiving](#)[☑] towards the end of the document (page 32) for further guidance.

Abbreviations

Throughout the Patient's Guide, some common terms are abbreviated which are listed below.

COPD: Chronic obstructive pulmonary disease

CT scan: Computed tomography scan

EP-NTM: Extrapulmonary NTM disease

GP: General practitioner

NTM: Non-tuberculous mycobacteria

NTM-PD: NTM pulmonary disease

Standards of Care summary

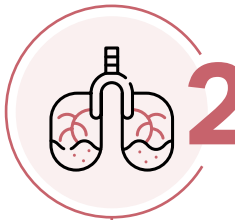


1

Person-centred care

NTM care should be individualised, with you at the centre. You should expect to:

- Know how to voice concerns and be supported in doing so without fear of compromised care
- Have a personalised self-management plan and active involvement in your care decisions
- Be given access to peer support resources and the opportunity to provide feedback on NTM services



2

Presentation and diagnosis of NTM disease

Healthcare providers should be alert to the signs and symptoms of NTM disease to ensure you receive a quick and accurate diagnosis. You should expect to:

- Have prompt investigation, including appropriate imaging and diagnostic tests, if you have persistent and ongoing symptoms that are compatible with NTM disease
- Provide appropriate samples, including sputum



3

Treatment decisions and multidisciplinary support

Treatment decisions should involve input from a team of healthcare professionals and be personalised to fit your specific needs. In addition, they should follow available guidelines. You should expect to:

- Be supported by a knowledgeable multidisciplinary team who understand the complexity of NTM disease
- Discuss treatment goals and risks with your healthcare team, and expect a personalised management plan
- Be informed about, and involved in, monitoring medication interactions and airway clearance practices

Standards of Care summary



4

Monitoring and review

You should have regular monitoring and follow-up to review how your NTM is progressing. You should expect to:

- Have regular follow-up appointments to monitor your response to therapies, whether drug or non-drug therapies
- Monitor any potential reactions to medications and report new symptoms that may occur
- Be involved in decision-making about any necessary changes to your treatment



5

Well-being and prevention of additional infections

A personalised approach, which considers both psychological well-being and physical health, should be taken to maximise your well-being and reduce the risk of re-infection. You should expect to:

- Be supported by your healthcare team to reduce the risk of re-infection
- Receive support for both the physical and psychological aspects of your NTM disease



6

Research and education

Coordinated research efforts and education should be undertaken to enhance the understanding and management of NTM disease. You should expect:

- To be informed about research opportunities, invited to participate, where appropriate, and have a say in setting research priorities
- All professionals involved in NTM care to receive training and engage in ongoing professional development to demonstrate continued expertise
- To have access to information about how well local services meet quality measures

1



Section 1 Person-centred care

Introduction

Person-centred care means that the care you receive is respectful and responsive to your individual needs and values. It looks beyond your healthcare requirements to consider all aspects that are important to you, such as your family and lifestyle choices. This section covers how the treatment and care of NTM disease can take a person-centred approach, ensuring you are both informed and involved in managing NTM disease.



Quality Statement 1.1

People with NTM disease should have access to fair and equal care across all healthcare settings

Lack of awareness around NTM disease can lead to common misunderstandings and confusion. For example, NTM disease is NOT [tuberculosis^q](#), despite the similarity of its name. The symptoms of NTM disease, such as coughing with [sputum^q](#), [fatigue^q](#), and breathlessness, can result in social isolation and a sense of shame. Many people with NTM disease have other health issues, so all healthcare providers need to consider these and any other barriers to accessing care.

What it means for you

- You should know **how to voice concerns** if you feel not listened to, [discriminated^q](#) against, or [stigmatised^q](#)
- You should be **supported in speaking up** and **reassured** that your care and access to services will not be compromised if you do so

Quality Statement 1.2

People with NTM disease should be empowered to effectively self-manage their disease

Self-management involves activities you carry out to look after your own health when living with a condition like NTM disease. Examples include:

- Learning about NTM disease
- Managing your care by:
 - » Keeping track of your symptoms and recognising changes that may need medical attention
 - » Taking your medicines correctly and on time, if you are on treatment
 - » Coordinating your healthcare such as attending regular medical appointments, recommended tests and procedures
- Maintaining overall health and well-being by:
 - » Adjusting your diet and exercise regimen as necessary
 - » Managing stress and maintaining mental health

You are best placed to understand your needs. By taking control of your health and well-being, self-management can build your confidence and skills in meeting these needs. This approach also allows healthcare resources to be used more efficiently, focusing on areas where help is most needed.

What it means for you

- You should be provided with a **personalised self-management plan**. This plan should include contact details for local services and provide direction to reliable information through trusted NTM disease websites



Quality Statement 1.3

The care people with NTM disease receive should be personalised through shared decision-making, and consider their overall health and well-being

You should be actively involved in decisions about your care, including working with healthcare providers to make informed choices about your treatment. These decisions should consider all aspects of your health and well-being, including [quality of life](#)⁹, physical health, mental health, and life expectancy. You should expect to:

- Be heard and have your views respected
- Engage in discussions about your care
- Have access to the information you need to make decisions about your care
- Have the opportunity and support to make choices for yourself
- Be respected for the decisions you make, including the choice to stop or refuse treatment
- Be provided with the resources and support you need to build confidence and knowledge so that you can effectively engage in joint decision-making

What it means for you

- During each healthcare visit, you should feel **actively involved and empowered** to take part in deciding your treatment and care

Quality Statement 1.4

People with NTM disease should be signposted to peer support groups to promote well-being

Peer support involves individuals seeing each other as equals, and focusing on learning and growing together. Access to structured peer support through verified patient forums allows you to share your experience, find services, and access trustworthy information. By making the most of community resources and expertise in a safe, shared space, this support can also help you manage your condition. Although there are few support networks and limited information available for people with NTM disease, NTM Patient Care UK offers access to trusted information and support to help you manage your condition.

What it means for you

- You should be **guided towards** and **given access to resources** like the [NTM Patient Care UK](#)  website where you can join relevant patient forums and support networks



Quality Statement 1.5

People with NTM disease should actively participate in the design, planning, delivery and review of NTM services

By involving you in the development and evaluation of services, healthcare providers can better understand and meet your needs. This involvement can therefore lead to improved outcomes for you and other people with NTM disease. With patient input, all healthcare professionals involved in NTM care can better coordinate services to meet your specific needs, such as “one stop shop” clinics, video consultations, and [outpatient^q](#) treatment.

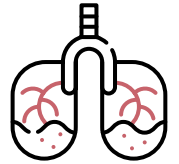
What it means for you

- You should have the **opportunity to give feedback**, openly or anonymously, on everything from consultations to service design and performance at local, regional, and national levels
- Your input should help **shape relevant national healthcare guidelines**

2

Section 2

Presentation and diagnosis of NTM disease

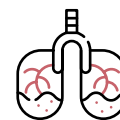


Introduction

Although NTM pulmonary disease^Q (NTM-PD) guidelines provide clear criteria for diagnosing the condition, this can be associated with an unacceptably long delay. This is, in part, because the disease features are not specific to NTM-PD. Also, clinicians might not consider NTM as a potential cause of symptoms, leading to delays in ordering the appropriate diagnostic tests.

For extrapulmonary NTM disease^Q (EP-NTM), diagnostic delays can occur because healthcare professionals may not recognise NTM as a cause of symptoms until other treatments fail, such as repeatedly giving antibiotics that do not work against NTM. Also, like NTM-PD, the symptoms people with EP-NTM experience may not be specific to the condition.

Possible NTM disease requires a thorough evaluation, including assessments for underlying conditions to enable early diagnosis and prevent worsened health outcomes in the long term. This section emphasises the importance of healthcare providers being alert to the symptoms and signs of NTM, and understanding when NTM might arise, to ensure that you receive a prompt and accurate diagnosis.



Quality Statement 2.1

Persistent and ongoing symptoms that could be linked to NTM should be investigated quickly

Healthcare professionals should be aware of diagnostic criteria for NTM-PD, which are defined in clinical practice guidelines.

NTM disease is relatively rare, so general practitioners (GPs) may not see many people with it in their practices. However, they can recognise symptoms that may need investigating. In primary care, if you have persistent symptoms that suggest possible NTM disease, such as those detailed in the [Additional Information](#) [↗] section (page 32), your GP should consider specific investigations for this.

For example, if there is a concern about NTM-PD, your GP may order [mycobacterial](#)^o [sputum cultures](#)^o and chest X-rays or [computed tomography](#)^o (CT) scans, and you may be referred to [secondary care](#)^o.

In secondary care, if you have long-term symptoms that could be due NTM, you should have a prompt evaluation that includes relevant tests to diagnose NTM disease.

What it means for you

- If you have **symptoms** that might be due to NTM you should be investigated **promptly** and **appropriately**

Quality Statement 2.2

Possible NTM cases should be evaluated quickly. This should include relevant microbiological investigations and a review by a healthcare provider with experience of NTM

There are [microbiological](#)^o criteria for diagnosing NTM disease that healthcare professionals should be aware of. To evaluate whether you meet these criteria for NTM-PD, you may be asked to:

- Provide sputum samples
- Have procedures that help obtain sputum or samples from the lung

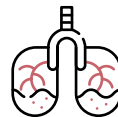
To evaluate whether you meet these criteria for EP-NTM, samples for mycobacterial culture should be taken from the site of possible disease such as blood, soft tissue, skin or bone. Further information on collecting samples to diagnose NTM-PD can be found in the [Additional Information](#) [↗] section (page 32) at the end of the document, including what to do if you have difficulty coughing up sputum.

In addition, you should undergo a detailed assessment that includes investigating weight changes, nutrition, checking for other illnesses and use of medication that may promote NTM disease such as long-term [steroid](#)^o use.

For both NTM-PD and EP-NTM, timely and proper investigation is essential to manage NTM effectively and prevent progression. Being informed about the diagnostic process helps you engage with healthcare providers and ensures thorough investigation.

What it means for you

- You should expect to have **appropriate diagnostic samples** taken **before or immediately after** your initial assessment by a healthcare professional who is experienced in managing NTM



Quality Statement 2.3

Appropriate imaging for possible NTM-PD should be performed promptly

There are [radiological](#)^Q criteria for imaging NTM-PD that healthcare professionals should be aware of. Imaging should usually include:

- **Chest X-rays**
- **CT scans of the chest**

If NTM-PD is suspected, conducting timely and relevant imaging is important to support NTM management decisions. Initial imaging allows the disease to be monitored over time. It is important to note that changes observed in organs or tissues on imaging tests may not be specific to NTM-PD, so other conditions should also be considered during evaluation.

What it means for you

- You should expect **appropriate imaging** during your initial assessment

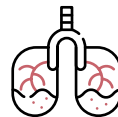
Quality Statement 2.4

Mycobacterial samples from people with NTM should be sent to laboratories that are equipped for identification and testing to find the best antimicrobial treatment

For correct diagnosis and treatment planning, mycobacterial samples should be tested in appropriately equipped laboratories with international accreditation and the necessary expertise. These tests are normally completed at a [national reference laboratory](#)^Q, though some hospitals have their own facilities to do this. The laboratory should aim to identify the specific type of mycobacteria which can help determine [drug sensitivity](#)^Q and guide which [antimicrobial](#)^Q drugs might work best for you.

What it means for you

- Your treatment should be in line with **recognised guidelines** for managing your specific type of mycobacteria



Quality Statement 2.5

A weakened immune system should be investigated as an underlying cause in people with EP-NTM who do not have clear risk factors for the condition

NTM bacteria are not highly infectious and usually cause extrapulmonary disease in people with weakened [immune systems](#)^q, which can be caused by:

- Medical devices
- Operations
- Organ transplants
- Taking medications which weaken the immune system

Those with EP-NTM who do not have an obvious [risk factor](#)^q (such as underlying lung conditions and low body weight) should be referred to [immunology](#)^q services and assessed for potential immune system weaknesses.

What it means for you

- You should expect your healthcare provider to consider **checking** for a **weakened immune system** if you have **no clear risk factors** for developing EP-NTM

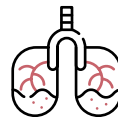
Quality Statement 2.6

Regular sputum sampling should be considered for individuals at increased risk of NTM-PD

There are several factors which can increase a person's risk of NTM-PD, detailed in the [Additional Information](#)^q section (page 32). If you are at higher risk of NTM-PD, sputum samples should be collected to prevent damage due to undiagnosed NTM. This testing is typically repeated once a year based on clinical need.

What it means for you

- You should expect **regular sputum** tests



Quality Statement 2.7

People with underlying lung disease starting long-term macrolide therapy should have sputum samples sent for microscopy and mycobacterial culture

While long-term use of [macrolide antibiotics](#)^q, such as azithromycin or clarithromycin, is common to prevent [flare-ups](#)^q for some other chronic lung conditions, they should not be used in patients with NTM. This is because doing so increases the risk of [antibiotic resistance](#)^q.

Therefore, if you have an underlying lung disease, such as asthma, [bronchiectasis](#)^q or [chronic obstructive pulmonary disease](#)^q (COPD), you should expect to have sputum samples collected before you begin receiving long-term macrolide antibiotics. Further information on collecting samples to diagnose NTM-PD can be found in the [Additional Information](#)^q section (page 32), including what to do if you have difficulty coughing up sputum.

What it means for you

- You should expect **sputum testing for NTM before starting long-term macrolide antibiotic therapy**

3

Section 3



Treatment decisions and multidisciplinary support

Introduction

Exposure to NTM bacteria^Q can result in:

- An infection that the person's immune system^Q can control or clear by itself
- The bacteria being present without causing NTM disease
- Ongoing and progressing NTM disease

If NTM disease has been diagnosed, the next step is to decide whether treatment is required. Treatment for NTM-PD^Q often involves a combination of non-drug approaches, such as airway clearance techniques, and specific bacteria-targeting treatments^Q. This decision requires careful consideration of the specific risks and benefits for the individual, and sometimes the decision made is to monitor rather than treat. For EP-NTM^Q, prompt treatment is usually recommended.

This section highlights the need to work closely with a multidisciplinary team^Q to identify and manage the best treatment plan for you.



Quality Statement 3.1

Management of NTM disease should align with the current guidelines

There are comprehensive guidelines for managing NTM-PD that your healthcare provider should follow, to ensure you receive high-quality care consistent with other people across the UK. In contrast, comprehensive guidelines for EP-NTM are limited, which means care may vary between you and others. When available, specific guidelines should be followed.

What it means for you

- Your **treatment** should align with **recognised guidelines**

Quality Statement 3.2

People with NTM disease should be supported by a multidisciplinary team that have access to professional support networks where required

Your care should be managed by a multidisciplinary team of healthcare professionals with experience in managing NTM disease. This is because management is complex and may require long-term treatment with drugs that can have challenging side effects, including interaction with other drugs you may be taking.

The core members of your multidisciplinary team should ideally include a:

- Doctor/physician, to identify, diagnose and plan the management of your NTM disease, as well as monitor your treatment. This will most likely be a respiratory or infectious disease physician with experience of NTM. When you are first seen, your physician should screen for nutritional and physiotherapy needs. They should continue assessing for these while you are in their care
- Case worker or [clinical nurse specialist](#)^o, to coordinate your care from diagnosis onwards, provide appropriate support and give you the information you need
- Specialist NTM disease pharmacist, to review NTM treatments and consider complex factors such as allergies. They will also advise on aspects such as drugs (including dosage), [drug-drug interactions](#)^o and local prescribing guidelines. Treatments should be reviewed before, during and at regular intervals after your treatment
- Specialist respiratory [physiotherapist](#)^o (if you have NTM-PD), to assess airway clearance and provide guidance on physical activity, helping to improve your health-related [quality of life](#)^o and manage symptoms like cough and [sputum](#)^o production

Regular meetings and strong communication with core members of your multidisciplinary team are crucial for providing you with consistent, high-quality care and improving treatment outcomes.

Additionally, referral pathways should be in place for you to meet with the following individuals, if needed:

- A [dietitian](#)^o, to support people who may be at risk of malnutrition due to the illness or treatment side effects, by using tools to assess nutritional status and providing dietary management as needed
- A [psychologist](#)^o, to provide support to people who may be dealing with the emotional and psychological impact of living with a chronic condition like NTM disease, enhancing overall well-being and quality of life
- A [radiologist](#)^o, to diagnose NTM-PD in collaboration with physicians through imaging, and assist in differentiating it from other conditions
- A [microbiologist](#)^o, to ensure you receive proper testing and treatment advice, and to facilitate accurate diagnosis and management of your NTM disease within the healthcare team
- An [immunologist](#)^o, to provide insights into possible immune-related causes and potential treatments for your NTM disease, supporting your multidisciplinary team with specialised expertise



Although not every clinic you attend may have all these professionals on site, all clinics should have access to them through established networks. However, all services should have early and ongoing access to support, provided by these healthcare professionals outside of clinic appointments.

What it means for you

- You should have a **group of healthcare professionals** who **understand the complexity** of NTM disease to manage your care, and expect to:
 - » Have a named **caseworker** or **clinical nurse specialist** who you can easily contact about your care
 - » Receive advice on your medicines from a **knowledgeable professional** and get **personalised support** to help you take them correctly
 - » Be assessed for your **nutritional status** and, if needed, supported by a dietitian
 - » Receive education on **airway clearance techniques** if you have **NTM-PD**, along with access to **pulmonary rehabilitation** if needed, and guidance on the importance of **exercise**

Quality Statement 3.3

Treatment goals and potential risk of the disease coming back should be discussed and agreed upon with people with NTM disease before starting treatment

Before starting treatment for NTM disease, it is important to have a thorough discussion with your NTM healthcare team about what you aim to achieve with treatment and the possible risks of the disease coming back. Treatment often involves regularly taking several antibiotics for a long period, which can last from 12 to 24 months for NTM-PD and 3 to 12 months for EP-NTM. These medications can have significant side effects and affect other drugs you may be taking, by reducing their effectiveness and increasing side effects.

The success of your treatment is evaluated by looking at:

- How well the infection clears
- How much your symptoms improve
- For NTM-PD, your [CT^a](#) scan results

The success rates of treatment vary depending on:

- Your overall health
- Where the infection is
- The type of bacteria and how resistant it is to [antibiotics^a](#)

The success rate of treatment is rarely 100%, and there is a risk of the disease returning even after treatment ends. Therefore, it is important for you to discuss this risk and your goals with your healthcare team. Goals of treatment can include curing the infection, slowing it down, or reducing symptoms without necessarily aiming for a cure.

What it means for you

- You should have an **open discussion** with your NTM healthcare team to set clear **treatment goals** and understand the **risk of the disease coming back**



Quality Statement 3.4

People with NTM disease should be considered for antimycobacterial treatment in line with current guidelines and best available evidence

For NTM disease, specific [antimycobacterial](#)[®] drugs can be crucial in managing the condition. However, treating NTM disease is complex and involves taking these medications for a long time, usually months to years. It requires careful planning, including:

- Deciding when to start treatment
- Which drugs to use
- How to take these drugs (by swallowing, inhaling or [intravenous](#)[®] drip)
- Duration of treatment
- How to monitor its effects

It is therefore important that long-term treatment is tailored to your specific type of NTM disease and personal needs. Following guideline-based therapy generally leads to better outcomes, and it is recommended that all treatment decisions be made in line with national guidelines and available evidence.

What it means for you

- You should expect to be offered **antimycobacterial treatment** that is **appropriate** for your situation and in line with **national guidelines** and the best available evidence

Quality Statement 3.5

People with NTM disease should have an individualised, written management plan

It is important for you to have a personalised, written management plan. This plan helps coordinate care among different healthcare professionals you may see, and ensures continuous monitoring of your condition. It should include details about your diagnosis, treatment plans, and any necessary tests, and must be shared with you and all involved healthcare teams. The format of the plan may be a stand-alone document, or it could be included in clinical letters. The plan should be accessible, using language and formats you understand, and should support shared decision-making to keep you involved in your care.

What it means for you

- You should expect to receive an **individualised treatment plan** that helps you understand your condition, treatment options, and any possible side effects
- You should be **actively involved in your care** to ensure consistent monitoring and effective management of your disease



Quality Statement 3.6

People receiving antimycobacterial treatment for NTM disease should have a detailed and accurate medication history review and be assessed for how medicines may affect each other

People receiving treatment for NTM often have other conditions which they take medication for. Certain medications, like rifampicin, are known to interact with other drugs, which can affect how well your treatment works and/or increase the side effects you experience. Therefore, when receiving treatment for NTM disease, it is crucial to have a complete and accurate record of your medications to check for potential drug–drug interactions. Managing these interactions might involve changing your antibiotics or other medications.

You should be made aware of any possible drug–drug interactions, including with over-the-counter and herbal products, and report any new medications to your healthcare team. Your treatment(s) should be included in your written management plan and be accessible to all your healthcare providers to allow for assessment of drug–drug interactions with newly prescribed medication.

What it means for you

- You should be involved in **monitoring** for **drug–drug interactions** and encouraged to report any newly prescribed and over the counter medication to your care team

Quality Statement 3.7

People with NTM-PD should be given support to practice airway clearance techniques and exercise, where appropriate

If you have NTM-PD, practising airway clearance techniques is important for clearing excess sputum from the lungs. This can help to improve symptoms of sputum and cough, as well as prevent [inflammation](#)^o, and further lung damage. Airway clearance techniques are a key part of managing chronic lung diseases like NTM-PD, and should be learned from a specialist respiratory physiotherapist who can also advise on additional therapies.

You should be supported to increase your physical activity, through pulmonary rehabilitation if needed, which can improve your overall quality of life and lung function. Additionally, you should receive a tailored exercise programme that considers physical ability.

What it means for you

- You should be taught **airway clearance techniques** and receive support to practise it regularly
- You should be encouraged and supported to **engage in regular physical activity**



Quality Statement 3.8

NTM services should allow people with NTM disease to receive antibiotic therapy at home or in the community instead of in the hospital

Treatments for NTM disease may include intravenous injections. For people with NTM disease, [outpatient^a](#) or community-based [parenteral antibiotic therapy services^a](#) allow you to receive these sorts of treatment outside of the hospital, offering a convenient and safe treatment option. These services should be designed to meet your needs and provide treatment in a way that is appropriate for you.

What it means for you

- You should expect to receive **intravenous therapy in the community** through outpatient or community-based parenteral antibiotic therapy services, if hospitalisation is not needed

Quality Statement 3.9

People with complex NTM disease should be managed in collaboration with an NTM disease specialist centre

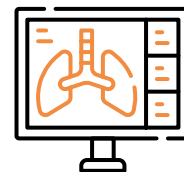
If you have complex NTM disease, your healthcare provider should collaborate with an NTM disease specialist centre, a service that has considerable NTM management experience and can offer a wide range of treatments, to ensure effective management. These centres bring together a team of experts to provide comprehensive care, including:

- NTM disease caseworkers/clinical nurse specialists
- Nutritionists/dietitians
- Microbiologists
- Pharmacists
- Physiotherapists
- Radiologists
- Respiratory and infectious disease physicians

Examples of complex NTM disease can be found in the [Additional Information](#) [↗] section (page 32) of the guide.

What it means for you

- You should expect your complex NTM disease to be **managed in collaboration** with a regional **NTM disease specialist centre**



4

Section 4

Monitoring and review

Introduction

The lack of standardised management for NTM after diagnosis can result in differences in care. Additionally, to provide high-quality care, it is important for your healthcare team to consider your wishes and concerns, and how treatments affect you.

Monitoring and review of NTM involves two main aspects:

- 1. Checking how the condition is progressing or responding**
- 2. Evaluating the effects of medications and other treatments**

A multidisciplinary team of healthcare professionals usually manage NTM disease, and good communication between members of the team is necessary to ensure all are aware of monitoring protocols. Additionally, during development of the full Standards of Care, patient representatives emphasised the importance of considering patient views in disease management.

While many people with NTM disease are monitored without receiving treatment, it is important that they still receive regular check-ups to detect any changes in how their NTM is progressing.



Quality Statement 4.1

People diagnosed with NTM disease, who are not currently on antimycobacterial treatment, should be offered regular follow-up in an appropriate specialist clinic

You and your healthcare provider may choose to delay or postpone treatment if you are experiencing no or mild symptoms, or if you prefer not to start treatment due to concerns about taking too many tablets or potential side effects. If this is the case, your healthcare provider may choose to regularly check for changes in your condition to track your disease.

It is important that you still have regular follow-ups to monitor any changes in your condition to see if it is appropriate for treatment to start. For example, if your NTM disease has advanced or worsened to a point where starting treatment is necessary or beneficial.

If you have [NTM-PD](#), regular [sputum](#) samples should be taken, and imaging such as chest X-rays and [CT](#) scans performed. Additionally, [quality of life](#) should be measured. Monitoring can occur at a specialist NTM clinic or a more general clinic. If you have [EP-NTM](#), monitoring may occur at another appropriate medical specialist clinic. The priority is ensuring that you are being monitored in a standardised manner.

What it means for you

- You should expect to have **ongoing follow-up appointments** whether or not you are on specific treatment

Quality Statement 4.2

People who have started treatment for NTM disease should have their response monitored based on clinical need, including symptoms and quality of life assessments, sputum cultures (for NTM-PD) or other tissue cultures (for EP-NTM), and radiology

Changes in symptoms should be recorded at each clinical visit. This includes weight changes, nutritional status, [inflamed sinuses](#), acid reflux/heartburn, and brittle bones.

If, after six months to one year of treatment for NTM-PD, people still test positive for having the bacteria, they are more likely to have poorer health outcomes. In this situation, please refer to the [What to do if you are concerned about the care you are receiving](#) section. To monitor your progress, sputum samples should be collected from you every 4 to 12 weeks during treatment. Once no bacteria are detected, samples can be collected every 12 weeks, and continue to be collected for one year after treatment ends. Further information on collecting sputum samples can be found in the [Additional Information](#) section (page 32). In NTM-PD, regular chest scans can be helpful to monitor progress.

There is limited [microbiological](#) information on treatment response in people with EP-NTM, so data collection should be tailored by doctors based on how you are doing.

What it means for you

- You should be involved in making sure you have **regular follow-up appointments** and that your **response** to treatment is monitored
- You should be involved in **discussions** about any necessary **changes to your treatment**



Quality Statement 4.3

People with NTM disease should be asked about negative reactions to medications at each medical appointment, and regularly monitored for these according to current guidelines and NTM drug information sheets

People being treated for NTM disease often take multiple [antibiotics](#)^Q, which increases the chance of experiencing negative reactions to the medication. Additionally, they may receive medications for other conditions that can affect the NTM treatment and cause [drug-drug interactions](#)^Q.

Some important steps to consider include:

- Asking your healthcare provider about possible drug-drug interactions with any new medications, at every appointment. This conversation should happen before you take the new prescribed or over-the-counter medication
- Sharing any side effects you have experienced at each medical appointment to increase the chance of detecting any problems. Your healthcare professional should be familiar with common and severe side effects to antibiotics used in the treatment of NTM
- Monitoring and reporting any new symptoms or reactions you experience. You should also be signposted to patient support resources, such as the NTM Patient Care UK website, which can provide information on possible symptoms to look out for

More details on the monitoring of drug reactions are detailed in the [Additional Information](#) ^Q section at the end of the Patient's Guide.

What it means for you

- You should be involved in **monitoring potential reactions** to medications and **reporting new symptoms** that may occur

Quality Statement 4.4

People undergoing treatment for NTM disease should be asked about how well they are managing to follow their treatment plan during regular appointments, and be actively engaged and supported to stick to it

People with NTM disease may have trouble with complex treatment plans or experience side effects, which can lead to them not following their care routine. This includes both [antimycobacterial](#)^Q drugs and non-drug treatments, such as physiotherapy and nutrition plans. Therefore, a physiotherapy management plan and a dietitian-led nutritional care plan should be considered.

Not following a treatment plan could be intentional, due to beliefs or concerns, or unintentional, due to forgetfulness or difficulty understanding instructions. It is important to discuss any challenges you are facing openly with healthcare professionals to identify any problems or concerns which can be addressed to improve treatment outcomes.

What it means for you

- You should be **involved in decision-making** processes with your healthcare provider
- You should **follow your treatment plan** and report any issues that may impact your ability to do so



Quality Statement 4.5

People with NTM disease should have the effectiveness of non-drug treatments, such as physiotherapy and nutritional plans, monitored regularly

Poor nutrition and weight loss has been linked with poor treatment outcomes, and may result from NTM disease itself, side effects of NTM treatment, and low mood. As such, physiotherapy and nutritional support are essential for managing NTM disease and promoting well-being.

Chest physiotherapy can help to manage respiratory issues such as reducing breathlessness and improving exercise tolerance. In addition, enhancing airway clearance techniques can improve your ability to follow your treatment plan and manage your care easier.

What it means for you

- You should be involved in making sure **regular follow-up** occurs and that your **response** to non-drug therapies is **regularly monitored**

5

Section 5



Well-being and prevention of additional infections

Introduction

Due to improved disease management, people with NTM are living longer. However, they may face psychological distress or poor quality of life^Q; some of the factors which may contribute to this are listed in the [Additional Information](#)[↗] section (page 32) at the end of the Patient's Guide. Addressing mental well-being is crucial for managing the stresses associated with NTM disease.



Quality Statement 5.1

A personalised approach should be taken when discussing how to minimise the risk of NTM coming back or being re-infected, and this should be based on best available evidence or expert opinion

For people with [NTM-PD^Q](#), preventing NTM re-infection is a key priority, but it is not well-researched. If you receive a diagnosis of a new or additional NTM infection in your lungs, you should discuss with your healthcare provider how to prevent being re-infected and be given guidance on your lifestyle choices, and advice on how to look after your well-being.

While specific evidence is limited, if you have NTM-PD, you should be supported in balancing the risk of re-infection with activities you enjoy and benefit from. For example, wearing a mask and gloves when gardening could help reduce this risk. Precautions you could consider taking are detailed in the [Additional Information](#) ^Q section (page 32).

For people with EP-NTM, there is less information on how to reduce the risk of the disease coming back and being re-infected. However, with medical supervision, reducing medications that weaken your [immune system^Q](#), and which you might take for another condition, could lower this risk.

What it means for you

- You should be supported by your healthcare team to **reduce the risk of re-infection**

Quality Statement 5.2

Psychological well-being must be considered alongside physical health in people with NTM disease

Living with NTM disease can be challenging because you may experience:

- Complex treatment plans
- Long-term medication needs
- The fear of re-infection
- Managing other long-term conditions affecting your lungs and airways

These difficulties may impact your:

- Mental well-being
- Quality of life
- Ability to manage your health effectively
- Engagement with healthcare service

What it means for you

- You should expect to receive **support for both the physical and the psychological aspects** of your NTM disease, to maximise your well-being



6

Section 6

Research and education

Introduction

Improving the understanding and treatment of NTM disease requires ongoing research and education. Every individual with NTM, regardless of where they initially receive care, should have the opportunity to participate in relevant research, and contribute to shaping future research strategies. Given the rarity of NTM, individual centres often lack enough patients to recruit to clinical trials in a timely manner, making larger regional networks essential for coordinating research.

This section emphasises the importance of coordinated research efforts and education to enhance the understanding and management of NTM disease.



Quality Statement 6.1

NTM services should have the means to join relevant research studies and offer these opportunities to patients

NTM disease continues to be rare, despite its increasing frequency in recent decades. This means that most treatment centres see only a small number of people with NTM disease, making it difficult to recruit participants for clinical studies. Nonetheless, you should have the chance to participate in relevant research, no matter where you are initially monitored. Additionally, service providers should support NTM research by offering access to necessary clinical and laboratory facilities, like [sputum](#)^a testing and sample storage.

What it means for you

- You should expect to be **informed about relevant research opportunities**, recognising that they may only be accessible through other providers in your region

Quality Statement 6.2

People with NTM disease should be offered opportunities to participate in relevant research activities

There is a significant lack of high-quality clinical evidence to guide the treatment of NTM disease. This highlights the urgent need for studies to understand how NTM develops and what the [risk factors](#)^a are for disease progression. There is also a need for research studies that identify treatments that work better and are safer than current options.

Given the rarity of NTM disease, effectively recruiting participants for clinical studies within a reasonable time frame requires efficient identification of potential participants. Therefore, embedding opportunities to participate in research into routine clinical care is important, wherever possible.

What it means for you

- You should expect to be told about **relevant research opportunities** that are available and, where appropriate, **invited to participate**



Quality Statement 6.3

People with NTM disease should have the opportunity to help shape research priorities and co-create studies in the field of NTM disease

Historically, people with health conditions have often been excluded from deciding what clinical research should focus on. Improving collaboration among people with NTM, healthcare providers, and researchers is crucial for developing research strategies that address unmet clinical needs that exist in the management of NTM. To facilitate this, support and advocacy groups are key in connecting people with NTM with researchers.

What it means for you

- You should expect to be **invited to have a say in setting research priorities** and in **creating research studies** related to NTM disease

Quality Statement 6.4

Training for all healthcare professionals relevant to the care of people with NTM disease should include information about the condition, and healthcare providers should demonstrate continued expertise through ongoing further professional development activities

People with NTM disease often face delays in diagnosis, partly due to clinicians not being familiar with the condition; in some cases, this arises as a result of healthcare training programmes not always covering NTM disease well. Additionally, since NTM disease is rare, it is crucial for primary care doctors to be particularly alert when examining [at-risk](#)^a individuals.

What it means for you

- You should expect that **all clinicians** working or training in relevant healthcare roles are **knowledgeable about the symptoms and approach to diagnosis** for NTM



Quality Statement 6.5

Services caring for people with NTM disease or conditions that increase risk of NTM should engage in audits, service evaluations and quality improvement activities, and share these results with both those using and hiring the services

[Clinical audits](#)⁹ and service evaluations play an important role in enhancing care quality by assessing if current best practices are being followed and identifying areas for improvement. Developing NTM disease registries would greatly support audits and research efforts by efficiently identifying people with NTM disease.

What it means for you

- You should expect to have access to **information** about how well **local services meet quality measures**



What to do if you are concerned about the care you are receiving

To help ensure that you receive the best possible care and support while managing your NTM disease, consider the following suggestions for addressing concerns about your standard of care.

Talk to your healthcare provider

- Explain your concerns in a respectful and specific manner
- Provide examples, or documentation of the unmet standards
- Ask questions to understand their perspective and seek solutions by working together

Seek a second opinion

- Consult another healthcare professional to verify concerns and explore alternatives

Contact patient advocacy services

- Many hospitals and clinics have patient advocates who can help address concerns you may have and mediate discussions

Reach out to support organisations

- Contact relevant patient support organisations, such as [NTM Patient Care UK](#)  for guidance, resources, and advocacy support
- These can provide information on patient rights and help you navigate the healthcare system

Additional information: symptoms, sampling, and support

This section complements the main Patient's Guide, serving as a resource for further information about your NTM disease.

Background on NTM disease

NTM are [bacteria](#)^o found in the environment, particularly in soil and water. Exposure to NTM bacteria can cause infections, especially in those with weakened immune systems or existing lung conditions. NTM infections are rare and under-researched. The lung is the most common site of infection, where it can cause [NTM-PD](#)^o, though NTM may also affect other parts of the body, where it is known as [EP-NTM](#)^o disease. People with NTM disease in the UK experience significant variations in their care, highlighting the need for standardised guidelines.

Routes of exposure to NTM bacteria and precautions

Likely routes of exposure to NTM bacteria include water droplets, such as showers and hot tubs, and dust generated through potting plants and gardening. You could therefore consider taking the following precautions to limit your exposure to NTM:

- Increasing the temperature of water in your house to at least 55°C
- Using ventilation fans in bathrooms, kitchens and other steamy areas
- Avoiding hot tubs, spas and other recirculating hot water sources indoors
- Wearing high-protection masks while gardening
- Wetting down potting soil to reduce dust

Examples of symptoms associated with NTM-PD and EP-NTM

The symptoms of NTM-PD can differ between people and may change depending on whether they have an underlying lung disease; some examples can be found in the table below. These symptoms are also not specific to NTM disease. However, if you notice your symptoms are happening more often or becoming worse, it could suggest the possibility of having NTM disease, and your healthcare providers should investigate this.

Examples of symptoms associated with NTM-PD

- | | |
|--|--|
| <ul style="list-style-type: none">• Cough• Sputum^o production• Coughing up blood• Shortness of breath• Chest discomfort | <ul style="list-style-type: none">• Weight loss• Fatigue^o• Fever• Night sweats |
|--|--|

Similarly, the symptoms linked to EP-NTM can change and are not always specific, meaning they might not clearly point to you having this condition; some examples can be found in the table below. If you are [at-risk](#)^o and have symptoms that do not improve with regular treatments, and tests do not show common infections, EP-NTM should be considered as a possible diagnosis.

Additional information: symptoms, sampling, and support (continued)

Examples of symptoms associated with EP-NTM	
General	Localised
• Fever • Feeling unwell • Lacking energy • Weight loss	• Skin sores or inflammation^q • Joint inflammation • Lymph node swelling^q • Abdominal pain

Long-term symptoms could include a persistent, debilitating cough or chest infections.

Risk factors for NTM-PD

There are several factors which can increase the risk for NTM-PD, some of which are detailed in the table below.

Risk factor	Examples
Underlying lung conditions	• Bronchiectasis^q • Cystic fibrosis • Severe COPD^q
Medications	• Inhaled steroids^q • Certain biological drugs^q
Other characteristics	• Past infections like tuberculosis^q • Low body weight • Being female

Examples of complex NTM disease

Complex NTM disease can present challenges in diagnosis, treatment and management; as such, cases should be managed in collaboration with an NTM disease specialist centre to ensure effective management. Complex NTM disease include:

- Infections caused by bacteria that do not respond to standard treatment or have clear treatment guidance
- Infections with uncommon NTM bacteria that do not have sufficient evidence for treatment
- Situations where initial treatment is not feasible due to drug interactions or risks
- Cases where the usual treatment has not achieved its goals
- People who may require therapy to adjust their immune system

Additional information: symptoms, sampling, and support (continued)

Sample collection for diagnosing NTM-PD

When collecting samples, your healthcare provider should use less [invasive](#)^o methods whenever possible. However, in complex cases, a different procedure called [bronchoscopy](#)^o may be considered to obtain samples for [culture](#)^o from the lung. When collecting sputum samples, you should ideally be asked to provide three separate samples on consecutive days. If needed, a [physiotherapist](#)^o might assist with sputum collection and support clearing your airways.

What to do if you have difficulty coughing up sputum

Coughing up sputum can be difficult, and some individuals may not be able to produce any at all. If you are struggling to provide sputum samples, please do not worry. If you cannot cough up sputum naturally, you may be asked to inhale a salt-water mist to produce sputum (this is called an induced sputum). Your healthcare team will work with you to find alternative ways to monitor your condition.

Remember, even if you are not coughing up sputum, airway clearance techniques taught to you and reviewed by a physiotherapist can still be beneficial. These techniques help to loosen and move mucus and improve the air flow in your lungs, making it easier to breathe and reducing the risk of infection. If you have any concerns about your ability to produce sputum or the effectiveness of your airway clearance, please do not hesitate to discuss them with your healthcare team. You can also speak with your healthcare team about devices which can help with airway clearance. They can offer guidance and support to help you manage your condition effectively.

Monitoring of drug reactions

The monitoring of drug reactions depends on the specific treatments being used, but may include regular blood tests, hearing tests, eye exams and heart monitoring. Therapeutic drug monitoring may be needed with certain treatments such as [intravenous aminoglycosides](#)^o. This involves checking drug concentrations in the blood at specific times to make sure they stay within a safe and effective range.

Factors which may impact your mental health and quality of life

Due to improved disease management, people with NTM are living longer. However, people may face psychological distress or poor [quality of life](#)^o. Some of the factors which can contribute to this are listed in the table below.

Additional information: symptoms, sampling, and support (continued)

Possible causes of psychological distress	Possible contributions to poorer quality of life
• Diagnostic delays • Adjusting to diagnosis • Re-infection^q • Managing long-term treatment • Challenges in managing healthcare • Treatment resistance or failure	• Adapting to illness • Stigma^q • Having other health conditions • Ageing • Reliance on healthcare teams managing care

Support for psychological well-being

Psychological distress, such as depression, can present in different ways. Symptoms of depression may include low mood, avoiding social interaction and not engaging in activities. Individuals may also struggle with managing their daily medication and treatments, and expressing concerns to healthcare professionals. In addition, friends and family might also express concerns about psychological well-being. People with NTM may experience feelings like shame, embarrassment or stigma, which can directly impact elements of NTM management, such as attending appointments or following treatment plans.

Healthcare professionals should check in on your well-being with open, supportive questions in a non-judgemental way. This is particularly important during times of change in your life, such as when you receive a diagnosis, if your illness progresses or you have a new treatment plan. To monitor your well-being and health over time, and to identify if you may benefit from additional support, your doctor may use questionnaires when you meet and on an ongoing basis.

Your healthcare team can use a variety of techniques at your appointments to make you feel supported, including [active listening](#)^q, validating and normalising your feelings, joint problem-solving, offering informal support and identifying ways you can help yourself. This may include onward referral, with your consent, to a respiratory psychological professional. If they are not available, your healthcare team should promptly connect you to an appropriate service to ensure you get the support you need e.g. NHS Talking Therapies. All referrals should be monitored to ensure you are getting appropriate help.

Glossary^Q



Active listening: The listener fully concentrates, understands, and responds thoughtfully to what the speaker is saying

Antibiotics: Medicines used to fight bacterial infections

Antibiotic resistance: When bacteria no longer respond to an antibiotic's effects

Antimicrobials: Agents that kill or prevent the growth of germs, including bacteria

Antimycobacterials: Agents that kill or prevent the growth of mycobacteria

At-risk: More likely to develop a particular health condition or event

Bacteria: Tiny living organisms, some of which can cause illness

Bacteria-targeting treatments: Therapies aimed at eliminating or stopping bacteria

Biological drug: A medication made from living things used to treat diseases, like vaccines

Biopsy: A medical procedure that involves taking a small tissue sample for examination

Bronchial wash: A medical procedure to collect samples from the airways for analysis

Bronchoscopy: A procedure to look directly at the airways in the lungs using a thin, lighted tube called a bronchoscope

Chronic obstructive pulmonary disease: A group of lung conditions that cause breathing difficulties

Computed tomography scan: An imaging technique that uses X-rays to create detailed pictures of the inside of the body

Clinical audits: Used to evaluate and improve care and outcomes by comparing current practices to established standards or benchmarks, including any advances in NTM management

Clinical nurse specialist: A nurse with advanced knowledge in a specialised area of healthcare

Culture: Tests to detect and identify bacteria, mycobacteria (such as NTM) or fungi

Dermatology: The branch of medicine dealing with skin issues and diseases

Dietician: A healthcare professional specialising in food and nutrition management

Discriminated: Treated unfairly or unequally because of certain characteristics

Drug-drug interactions: How different medications influence each other's effectiveness or side effects when taken together

Drug sensitivity testing: Tests done to determine which drugs are most effective against germs

Extrapulmonary NTM disease: Symptomatic non-tuberculous mycobacterial infections occurring outside the lungs

Fatigue: A feeling of extreme tiredness and lack of energy

Flare-ups: Episodes when symptoms of a disease become worse or more intense

Glossary

Immune system: The body's defence mechanism against infections and illnesses

Immunology: The study of the immune system and related health issues

Inflammation: The body's response to harm or infection, often causing redness, swelling, and pain

Invasive: Procedures or treatments that enter the body, often through the skin or a body cavity

Intravenous drip: A method of delivering fluids and medications directly into a vein

Lymph node swelling: Enlargement of glands that are part of the immune system

Macrolide antibiotics: A class of antibiotics used to treat bacterial infections

Microbiological: Relating to the study of tiny organisms, like bacteria and viruses

Microbiologist: A scientist specialising in the study of tiny organisms

Multidisciplinary team: A group of healthcare professionals from various fields working together to treat an individual

Mycobacteria: Referring to bacteria which are part of the Mycobacterium genus, including bacteria causing tuberculosis and NTM

National reference laboratory: A specialised facility with the highest standards of expertise and international accreditation, conducting advanced tests to confirm diagnoses and guide treatment, especially for complex or rare conditions

Non-tuberculous mycobacteria: A diverse group of mycobacteria found in the environment, such as in soil and water, which can lead to NTM disease

NTM pulmonary disease: Symptomatic lung infections caused by non-tuberculous mycobacteria

Outpatient: A patient who receives medical treatment or tests without being admitted to a hospital and returns home the same day

Parenteral antibiotic therapy services: Administration of antibiotics through routes other than the mouth, such as injections

Physiotherapist: A healthcare professional who helps patients clear their sputum and maintain good respiratory health

Primary care: Basic or general health care typically provided by doctors specialising in family medicine or internal medicine

Psychologist: A professional specialising in the study of the mind and behaviour

Pulmonary rehabilitation: A programme to help people with lung conditions breathe easier and improve physical function

Quality of life: The general well-being and enjoyment of life, especially concerning health and comfort

Radiological: Relating to the use of X-rays or other techniques in diagnosis or treatment

Radiologist: A doctor specialising in interpreting medical images, like X-rays and CT scans

Glossary^Q

Re-infected: Getting a new infection from NTM bacteria after successfully being treated for and clearing a previous NTM infection

Risk factor: Something that increases a person's chance of developing a disease or injury

Secondary care: Specialised medical care typically provided in hospitals or clinics, usually after referral from primary care

Sinus: A cavity within a bone or tissue, especially those in the face connected with the nasal cavities

Sputum: Mucus and other material coughed up from the lungs

Sputum cultures: Tests to detect and identify bacteria, mycobacteria (such as NTM) or fungi in lung mucus samples

Sterile: Free from living germs or other tiny organisms

Steroids: Medicines that reduce inflammation and affect how the immune system works

Stigmatised: Being socially disapproved or discriminated against based on perceived characteristics

Tuberculosis: A contagious bacterial infection that mainly affects the lungs



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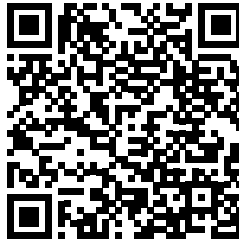
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