



**NTM** Network UK  
Non-tuberculous mycobacteria

# STANDARDS OF CARE

For people living with non-tuberculous mycobacterial (NTM) disease in the UK

## LAUNCH MEETING eBOOKLET

Tuesday 9<sup>th</sup> July 2024, 13:00–17:00

University College London Institute of Child Health  
30 Guildford Street, London, WC1N 1EH

### CHAIR

Prof Marc Lipman  
Royal Free Hospital, London  
University College London

### VICE CHAIR

Dr Ronan Breen  
NHS Forth Valley



# WELCOME

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Dear Colleagues and Friends,

On behalf of NTM Network UK, we are delighted to welcome you to the launch of our Standards of Care for people living with non-tuberculous mycobacterial (NTM) disease in the UK. This event marks a significant milestone in our ongoing efforts to improve the quality and consistency of care for individuals affected by this challenging condition.

Our journey to develop these Standards of Care began with a recognition of the significant variations in care for people in the UK with NTM disease. Through research and collaboration with experts across the multidisciplinary team, we identified an unmet need for a standardised approach that ensures all patients receive high-quality, patient-centred care, regardless of where they are treated. The resulting document is the first of its kind globally, and we are proud to share it with you today.

We are pleased to welcome a dynamic and diverse group of healthcare professionals from across the UK and beyond. Our attendees include consultants, dietitians, pharmacists, physiotherapists, research scientists and many other specialists, all united by a shared commitment to enhancing NTM care. The multidisciplinary nature of this meeting underscores the collaborative approach essential to addressing the complex needs of people with NTM.

During this meeting, you will hear directly from the dedicated healthcare professionals and people living with NTM who contributed to the creation of the Standards. Their insights and expertise have been invaluable in shaping a comprehensive guide that addresses the diverse needs of people with NTM. We will provide an overview of the Standards' key themes and discuss the multidisciplinary approach that underpins their development, ensuring that all aspects of care, from medical treatments to psychological support, are considered.

This meeting is not only an opportunity to introduce the Standards of Care, but also a forum to discuss the next steps in implementing these guidelines across the NHS. Your participation and input are crucial as we move forward with this initiative, and we look forward to engaging in productive discussions about how we can collectively achieve the best possible health outcomes for people with NTM.

Thank you for joining us at this pivotal moment. Together, we can make a meaningful difference to the lives of people with NTM throughout the UK.

With best regards,

**Prof Marc Lipman**

Chair, NTM Network UK

**Dr Ronan Breen**

Vice Chair, NTM Network UK

# AGENDA

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## TIME SESSION

**13:00 LUNCH & NETWORKING**

**14:00 WELCOME & INTRODUCTIONS**

Prof Marc Lipman

Chair, NTM Network UK

Consultant Physician, Royal Free Hospital, London

Professor, Division of Medicine, University College London

Dr Ronan Breen

Vice Chair, NTM Network UK

Consultant Physician, NHS Forth Valley

**14:05 SESSION 1: WHY HAVE WE DEVELOPED NTM STANDARDS OF CARE?**

**Session chair: Prof Marc Lipman**

### **Patient experience of NTM in the UK**

Mrs Shirley Harwood

Trustee & Patient Advocate, NTM Patient Care UK

Ms Sarah Minty

Management Group member & Patient Advocate, NTM Patient Care UK

### **NTM Network UK survey results**

#### **How are we managing NTM-PD? The first UK-wide survey of clinical practice**

Dr Akanksha Mimi Malhotra

ST5 Respiratory and General Medicine, Barts Health NHS Trust, London

Academic Clinical Fellow in Respiratory Medicine, University College London

#### **Survey of physiotherapy practice in the management of NTM pulmonary disease**

Mrs Lisa Morrison

Principal Physiotherapist, West of Scotland Adult CF Unit, Glasgow

#### **Survey of nutrition and dietetics in people living with NTM disease**

Mrs Fiona Moore

Specialist Cystic Fibrosis Dietitian, West of Scotland Adult CF Unit, Glasgow

### **What the Standards do and do not aim to do**

Prof Marc Lipman

Chair, NTM Network UK

Consultant Physician, Royal Free Hospital, London

Professor, Division of Medicine, University College London

# AGENDA

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## TIME

14:45

## SESSION

### **SESSION 2: WHAT ARE THE NTM STANDARDS OF CARE?**

Session chair: Dr Ronan Breen

#### **Overview of patient journey covered by the Standards**

Dr Ronan Breen

Vice Chair, NTM Network UK

Consultant Physician, NHS Forth Valley

#### **Overview of one Quality Standard from each section**

##### **Section 1: Person-centred care**

Ms Christabelle Chen

Lead Respiratory Pharmacist, Barts Health NHS Trust, London

##### **Section 2: Presentation and diagnosis of NTM disease**

Dr Martin Dedicoat

Consultant Physician, University Hospitals Birmingham NHS Foundation Trust

##### **Section 3: Treatment decisions and multidisciplinary support**

Dr Anne Dunleavy

Consultant Physician, St George's Hospital, London

##### **Section 4: Monitoring and review**

Dr Toby Capstick

Consultant Respiratory Pharmacist, Leeds Teaching Hospitals NHS Trust

##### **Section 5: Well-being and prevention of secondary infection**

Dr Alison Pearce

Lead Consultant Clinical Psychologist for Adult Psychology, University Hospital Southampton NHS Foundation Trust

##### **Section 6: Research and education**

Dr Stephen Aston

Consultant Physician, Liverpool University Hospitals NHS Foundation Trust

Senior Clinical Lecturer in Infectious Diseases, University of Liverpool

# AGENDA

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## TIME

15:20

## SESSION

### SESSION 3: WHAT HAPPENS NEXT?

Session chair: Prof Marc Lipman

#### Overview of next steps

Prof Marc Lipman

Chair, NTM Network UK

Consultant Physician, Royal Free Hospital, London

Professor, Division of Medicine, University College London

#### Panel discussion: How the Standards can be practically implemented

Dr Stephen Aston

Consultant Physician, Liverpool University Hospitals NHS Foundation Trust

Senior Clinical Lecturer in Infectious Diseases, University of Liverpool

Dr Robin Brittain-Long

Consultant Physician, Aberdeen Royal Infirmary

Dr Toby Capstick

Consultant Respiratory Pharmacist, Leeds Teaching Hospitals NHS Trust

Ms Christabelle Chen

Lead Respiratory Pharmacist, Barts Health NHS Trust, London

Dr Martin Dedicoat

Consultant Physician, University Hospitals Birmingham NHS Foundation Trust

Dr Alison Pearce

Lead Consultant Clinical Psychologist for Adult Psychology, University Hospital Southampton NHS Foundation Trust

16:00

### AFTERNOON TEA & NETWORKING

17:00

### MEETING CLOSE

# About the Standards of Care for people living with NTM disease in the UK

Our Standards of Care document is the first of its kind in the world. It has been developed in response to our previous work, which identified significant variations in care for people in the UK with NTM disease. This included a lack of standardised healthcare pathways and limited patient-centred approaches to management.

People with NTM disease are vulnerable, and often have underlying lung conditions, such as bronchiectasis and chronic obstructive pulmonary disease, that already impact on their quality of life and ability to tolerate medication and therapies. With NTM disease, they can experience worsening, debilitating symptoms such as persistent intense cough with sputum, bringing up blood, shortness of breath, chest pain, fatigue, and weight loss. This can result in low mood and poor nutritional status - all of which make their NTM difficult to treat.

Our new Standards of Care provide a written guide to the minimum level of care that people with NTM disease should expect to receive from the NHS, and will support them and their healthcare providers in achieving the best possible health outcomes.

In developing our Standards of Care, we have used a multidisciplinary approach, with expert input from healthcare professionals, people with NTM disease, and professional associations. This has allowed us to take a holistic view of NTM care, ensuring that, as well as drug therapies, we value and recognise important but sometimes overlooked aspects of treatment, such as nursing, nutrition, physiotherapy and psychological input.

# OVERVIEW

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## About NTM Network UK

**NTM Network UK is a multidisciplinary group of healthcare professionals and researchers from across the UK who have an interest in NTM infections and patient care. It was established in response to the need for improved management of the rising number of NTM infections identified in clinical practice in the UK.**

NTM Network UK provides a framework within which NTM infections and disease can be investigated, researched and managed using a systematic approach.

The overall goal of the Network is to improve the quality of care for people with NTM. For more information, or to join the Network, please visit [www.ntmnetwork.com](http://www.ntmnetwork.com).

### FREQUENTLY ASKED QUESTIONS

#### Who can join NTM Network UK?

Membership is open to anybody with a clinical, research or public health interest in NTM.

#### Are you only interested in NTM pulmonary disease?

No, the Network is interested in understanding more about all types of NTM infections, including single isolates, pulmonary disease and extra-pulmonary manifestations.

#### What is the structure of the Network?

The Network has multidisciplinary Steering and Management Groups responsible for strategy and day-to-day activities. Eight Interest Groups, run by the members, focus on specific areas of NTM clinical care and research.

#### How often does the Network meet?

NTM Network UK members' meetings take place virtually, 3-4 times per year. Interest Groups meet as needed depending on their work programmes.

#### How can I support the Network?

There are multiple ways you can support the Network. As a Network member, you can get involved with the development of specific projects, educate and train other members in your specialty area, or assist with fundraising initiatives. We also welcome donations, from both members and non-members alike, through the donations page on our website:

[www.ntmnetworkuk.com/donations](http://www.ntmnetworkuk.com/donations).

## Speaker biographies



### **Dr Stephen Aston**

Consultant Physician  
Liverpool University Hospitals  
NHS Foundation Trust

Senior Clinical Lecturer  
in Infectious Diseases  
University of Liverpool

Stephen completed undergraduate and core medical training in Birmingham. He started specialist registrar training in infectious diseases and general internal medicine in 2010. Following PhD work based in Malawi on the diagnosis and management of community-acquired pneumonia in adults living with HIV in low-resource settings, Stephen returned to Liverpool to complete his clinical training. He now has a joint clinical-academic appointment at the University of Liverpool. Stephen undertakes a portfolio of multidisciplinary and clinically-oriented research, exploring strategies to mitigate the progression of antimicrobial resistance through optimised antibiotic prescribing in a variety of contexts, particularly in the management of suspected sepsis/serious bacterial infection and acute and chronic respiratory infection.



### **Dr Ronan Breen**

Consultant Respiratory Physician  
NHS Forth Valley, Scotland

Ronan is a Consultant Respiratory Physician at Forth Valley Royal Hospital, Larbert. He was previously a consultant at Guy's and St Thomas' NHS Foundation Trust, London, for 16 years, where he ran the TB and NTM service. He obtained a Doctorate of Medicine looking at paradoxical reactions in TB patients with and without HIV co-infection, which included the development of lung-based immunological testing for mycobacterial diagnosis using bronchoalveolar lavage and induced sputum. As an NHS consultant, he has been an active collaborator in research studies in TB, NTM and the use of endobronchial ultrasound.



### **Dr Robin Brittain-Long**

Consultant Physician  
Aberdeen Royal Infirmary

Robin is a Consultant Physician with over 25 years of clinical experience and over 15 years of clinical research experience. He is a specialist in infectious diseases, general medicine and acute medicine, and has led the TB service in Aberdeen for the past 10 years. He set up a dedicated NTM service in his hospital in 2017 and was chair of the Treatment Decisions group of the NTM Network developing the Standards of Care. He is passionate about trying to improve the care provided to patients with NTM disease.



# FACULTY

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## Dr Toby Capstick

Consultant Respiratory Pharmacist  
Leeds Teaching Hospitals NHS Trust

Toby is Consultant Respiratory Pharmacist at the Leeds Teaching Hospitals NHS Trust. He is a member of the British Thoracic Society Multi-Drug Resistant Tuberculosis Clinical Advice Service, British Thoracic Society Pharmacists Specialist Advisory Group, NTM Network UK, the UK Inhaler Group, and the UK Clinical Pharmacy Association Respiratory Group.

He has clinics in the Leeds Interstitial Lung Disease and Tuberculosis services, and works with the Integrated Care Board in Leeds to improve respiratory medicines optimisation across the interface of care.



## Ms Christabelle Chen

Lead Respiratory Pharmacist  
Barts Health NHS Trust, London

Christabelle is the Lead Respiratory Pharmacist for Barts Health NHS Trust and is the North-East London (NEL) Respiratory Network Medicines Optimisation Co-Lead. She is a member of the British Thoracic Society (BTS) and contributes to the BTS Multi-Drug Resistant Tuberculosis Clinical Advisory Service and the BTS Pharmacists Specialist Advisory Group. She also leads as co-chair of the NTM Network UK Pharmacists Subgroup.

Christabelle has been working as a respiratory pharmacist for the last 13 years with subspecialist experience and interest in TB, NTM, cystic fibrosis and asthma. She is an independent non-medical prescriber and passionate about developing innovative pharmacy-led services and clinics within respiratory infections and severe asthma.



## Dr Martin Dedicat

Consultant Physician  
University Hospitals Birmingham  
NHS Foundation Trust

Martin is an Infectious Diseases Consultant in Birmingham. He is the clinical lead for the Birmingham and Solihull TB service. Martin runs an NTM clinic with colleagues.

Martin also works for the TB unit and national mycobacterial reference service at the UK Health Security Agency.

# FACULTY

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## **Dr Anne Dunleavy**

Consultant Physician  
St George's Hospital, London

Anne is a Respiratory Consultant in St George's Hospital in London and is the TB, NTM and bronchiectasis lead within the Trust, leading a service for a large, diverse group of patients. She has research interest in TB, NTM and bronchiectasis. She graduated from University College Dublin and trained in Dublin and then London, including The Royal Brompton, The Royal Free, Northwick Park and St George's. She continues to enjoy the challenges that lung infections present every day.



## **Mrs Shirley Harwood**

Trustee & Patient Advocate  
NTM Patient Care UK

Shirley trained as a nurse, midwife and health visitor and practised for many years before her retirement a few years ago. Shirley was diagnosed with NTM (MAC) in 2008 following a CT scan and bronchoscopy, after having been unwell for several months. She is a trustee for NTM Patient Care UK and an active member of the Management Group. Shirley provides not only her patient perspective to the charity, but also her healthcare background and equally importantly, her drive and enthusiasm, which have helped ensure that NTM Patient Care UK continues to grow and help ever more NTM patients.



## **Prof Marc Lipman**

Consultant Physician  
Royal Free Hospital, London  
  
Professor, Division of Medicine  
University College London

Marc is Director of UCL-tuberculosis (UCL-TB), UCL's cross-disciplinary TB research grouping, and Lead for Mycobacterial Services at the Royal Free Hospital. His research focusses on mycobacterial disease, respiratory infection and HIV, with a particular interest in translational and health services research. He has served on national and international committees, including the UK National Institute for Health and Care Excellence TB Guideline Group and British HIV Association HIV/TB co-infection Working Party. Marc is also the current Chair of NTM Network UK.

# FACULTY

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## Dr Akanksha Mimi Malhotra

ST5 Respiratory and General  
Medicine

Barts Health NHS Trust, London

Academic Clinical Fellow in  
Respiratory Medicine

University College London

Mimi is an Academic Clinical Fellow at University College London and a ST5 Speciality Registrar in Respiratory and General Medicine in the North Central and East Thames deanery. Her research interests relate to mycobacterial disease, health inequities and integrated health policy.

She has co-authored publications as part of the NTM Network, including the first survey of clinical practice in the UK, and a review on extrapulmonary NTM.

Mimi has recently been awarded a Wellcome-funded Clinical PhD that builds on work she is doing as part of her MSc in Public Health at the London School of Hygiene and Tropical Medicine.

Prior to starting specialty training, Mimi worked at The Health Foundation as an NHS England National Medical Director's Clinical Fellow.



## Ms Sarah Minty

Management Group member  
& Patient Advocate

NTM Patient Care UK

Sarah is a retired Occupational Therapist. She joined the NTM Patient Care UK Group 3 years ago and is currently part of their Management Group. Sarah contracted NTM (MAC) in 2015, shortly after starting medication for rheumatoid arthritis.



## Mrs Fiona Moore

Specialist Cystic Fibrosis Dietitian  
West of Scotland Adult CF Unit,  
Glasgow

Fiona is a Specialist Cystic Fibrosis Dietitian at the West of Scotland Adult CF Unit, where she has worked for over 8 years. Fiona is currently studying for an MSc in Advanced Practice and has completed her supplementary prescribing course. Fiona is Co-Chair of the Nutrition Interest Group for NTM Network UK. She is also part of the British Dietetic Association CF Dietitians Committee as social media officer, and is an ordinary member of the European CF Nutrition Group (ECFNG). Fiona is particularly interested in micronutrients and healthy ageing in CF.

# FACULTY

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## **Mrs Lisa Morrison**

Principal Physiotherapist  
West of Scotland Adult CF Unit,  
Glasgow

Lisa is the Principal Physiotherapist at the West of Scotland Adult CF Unit in Glasgow. She has worked in CF care for 27 years, encompassing both paediatric and adult care. She is responsible for the team of four CF physiotherapists providing holistic care for the 340+ patients attending a Regional Adult CF unit in Glasgow, with direct responsibility for their physiotherapy management from transition through to terminal care. She is the physiotherapy clinical lead for the CF/respiratory unit and manages and supervises the care of the complex respiratory patients. She has developed a research forum within the CF physiotherapy department and participated in successful teaching of junior members of staff.

Lisa has participated in the development of local, national and international guidelines into various aspects of CF care. Lisa is an author, co-author and editor of CF physiotherapy Cochrane reviews. She has been Chair of the NTM Physiotherapy special interest group and has contributed to the NTM Network UK Standards of Care as part of a multidisciplinary team approach. Lisa is currently undertaking a PhD: "Exploring the role of digital health technologies to support the future care of people living with CF".



## **Dr Alison Pearce**

Lead Consultant Clinical  
Psychologist for Adult Psychology  
University Hospital Southampton  
NHS Foundation Trust

Alison is the Lead Consultant Clinical Psychologist for Adult Psychology at the University Hospital Southampton NHS Foundation Trust. She has worked within respiratory services since 2008 with people with cystic fibrosis and asthma, and she previously worked within medical services for people over 65 years old. Alison has a passion for working with people to help them adapt to and live with medical conditions. She is trained in systemic psychotherapy and Eye Movement Desensitisation and Reprocessing therapy. She uses these approaches to help individuals, families and medical teams to think about some of the dilemmas when living with a physical health condition and having to negotiate complex medical systems. As part of her role, she works with the British Psychological Society Clinical Health Psychology Faculty, and it is through this role that she has been involved in shaping the NTM Standards of Care.

# ACKNOWLEDGEMENTS

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## Meeting sponsors



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# ACKNOWLEDGEMENTS

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Find out more at [www.lifearc.org](http://www.lifearc.org).



NTM Patient Care UK is a patient association and registered charity that was founded in December 2018 by two respiratory specialists and two patients. They saw an urgent need to provide both support and information in order to improve the lives of people with non-tuberculous mycobacterial (NTM) infection across the UK.

NTM Patient Care UK plays a crucial role in raising awareness of NTM, in both the clinical and patient communities, and represents and provides a voice for NTM patients, their carers and families via a range of activities.

Find out more at [www.ntmpatientcare.uk](http://www.ntmpatientcare.uk).



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For more information on Shionogi & Co., Ltd., please visit [www.shionogi.co.jp/en/](http://www.shionogi.co.jp/en/).



# NTM Network UK

Non-tuberculous mycobacteria

NTM Network UK is a Registered Charity (CIO);  
1207531 (England & Wales)

Contact us at [admin@ntmnetworkuk.com](mailto:admin@ntmnetworkuk.com)

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