



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 19/03/2024 **Period start date**
To 01/01/2025 **Period end date**

Charity name: NTM NETWORK UK

Charity registration number: 1207531

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	NTM Network UK was established in December 2014 in response to the need for improved management of the rising number of NTM isolates identified in clinical practice. It provides a framework within which NTM infections and disease can be systematically investigated, researched and managed. NTM Network UK aims to: • Consolidate the multi-disciplinary expertise available to develop standardised, cost-effective methods and tools to identify NTM, and to improve NTM infection and disease diagnosis and management. • Standardise clinical practice and data collection, including clinical assessments, microbiology, immunology, radiology, health status/quality of life scores and outcomes. • Develop protocols for data collection, clinical sampling, and sample storage (to include sputum, blood, laboratory and imaging data). • Obtain multi-centre ethical approval to enable data collection and long-term projects to take place. • Develop a harmonised database of NTM patients for clinical use and research analysis. • Evaluate the process and outputs of the research activities. • Support new areas of research, activities and events proposed by members. • Assess and support the development of collaborations and interactions within NTM

		Network UK, and with other research organisations and clinical groupings. • Work to make public health surveillance of NTM more robust. • Assist with resolving strategic level local and regional issues and risks. • Support the UK patient association, NTM Patient Care UK, in achieving its charitable aims. • Support and provide educational activities in the field of NTM.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<i>Main activities for this reporting period include the following:</i> a) NTM Network UK has held regular Quarterly Members Meetings (Summer and Autumn Meetings 2024) to update members on Network activities, share reports from specialist interest groups, and hear presentations from invited guest speakers. These meetings promote collaboration, education, and knowledge sharing among healthcare professionals involved in the care of people with NTM disease. b) NTM Network UK a Management Group Meeting to review progress, oversee ongoing projects, and plan future activities in line with the charity's strategic objectives. These meetings are held on a 6-monthly basis. c) NTM Network UK has finalised and published the NTM Standards of Care, providing a written guide to the minimum level of care that patients with NTM disease should expect to receive within the NHS. A meeting was held both online and at the University College London Institute of Child Health on Tuesday, 9th July 2024, to introduce the document and support its adoption across the UK. d) NTM Network UK has developed educational materials including a slide deck and A4 handout to explain the purpose and relevance of the Standards of Care. These materials were disseminated to relevant professional societies and healthcare teams to promote understanding and implementation. e) NTM Network UK supported NTM research by developing two scientific abstracts: one reporting on real-world use of bedaquiline in NTM treatment (for presentation at the BTS Winter Meeting 2024),

		and another analysing the cost and value of the work undertaken to produce the Standards of Care. f) The Pharmacy Interest Group, on behalf of NTM Network UK, produced a series of NTM Monographs, providing detailed guidance on the practical use of NTM treatments to support clinicians and pharmacists involved in patient care. g) Across these activities, NTM Network UK has aimed to improve outcomes for people with NTM disease in the UK, by strengthening collaboration between healthcare professionals, promoting consistency and quality in clinical care, and supporting education and research.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have had regard to the Charity Commission's guidance on public benefit.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	N/A
Policy on social investment including program related investment	Para 1.38	N/A
Contribution made by volunteers	Para 1.38	All activities undertaken by NTM Network UK during the reporting period were delivered through the work of volunteers. The Network's members, including clinicians, pharmacists, scientists, and other healthcare professionals, contributed their time and expertise for free in order to develop the materials produced by NTM Network UK. In particular, the development of the NTM Standards of Care, the preparation of scientific abstracts, and the production of the NTM Monographs were achieved through the voluntary efforts of members working collaboratively across the UK. The charity's ability to deliver these outputs relies entirely on the ongoing commitment and goodwill of its volunteer members.
Other		N/A

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<i>Main achievements for this reporting period include the following:</i> a) Publication and launch of the NTM Standards of Care, providing the first UK-wide framework outlining the minimum level of care that people with NTM disease should expect to receive within the NHS. b) Development and dissemination of educational materials, including a slide deck and A4 handout, to support healthcare professionals in understanding and implementing the Standards of Care in their clinical practice. c) Organisation of a Standards of Care Launch Meeting, held both online and at University College London Institute of Child Health, to promote engagement and encourage adoption of the Standards among the professional community. d) Development of scientific abstracts to share findings with the wider healthcare community, including analysis of the use of bedaquiline in NTM treatment and a cost-value review of the Standards of Care development process. e) Production of detailed NTM Monographs by the Pharmacy Interest Group, offering practical guidance for clinicians and pharmacists in the effective use of NTM treatments.

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	N/A
Performance of fundraising activities against objectives set	Para 1.41	N/A
Investment performance against objectives	Para 1.41	N/A

Other		N/A

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity is in positive balance. The reporting period represents the first few months of the network being a charity and so we had limited time to raise funds and no need for expenditure. In our next annual report we will expect to show increased income from fundraising and modest expenditure for support with administration and associated expenses, but maintenance of a healthy positive balance
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The Charity has no policy for holding reserves and a policy is not considered necessary as the charity has had very limited spending during this reporting period. The reporting period represents the first few months of the charity and this will be considered in future reporting years if necessary.
Amount of reserves held	Para 1.22	NA
Reasons for holding zero reserves	Para 1.22	The charity has had very limited spending over the reporting period, so reserves are not considered necessary.
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	N/A

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity had a positive balance of £754.08 at the end of this period. Income had been received via fundraising undertaken by members of the NTM Network undertaking sponsored events
Investment policy and objectives including any social investment policy adopted	Para 1.46	N/A
A description of the principal risks facing the charity	Para 1.46	N/A
Other		N/A

Structure, Governance and Management

Description of charity's trusts:		N/A
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Type of governing document (trust deed, royal charter)	Para 1.25	Constitution of the Charitable Incorporated Organisation (CIO)
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	Charitable Incorporated Organisation (CIO)
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Trustees include founding individuals and healthcare professionals, to ensure the best representation of professionals in NTM care.

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	N/A
The charity's organisational structure and any wider network with which the charity works	Para 1.51	N/A
Relationship with any related parties	Para 1.51	N/A
Other		N/A

Reference and Administrative details

Charity name	NTM Network UK
Other name the charity uses	N/A
Registered charity number	1207531
Charity's principal address	Royal Free London NHS Foundation Trust, Pond St, Hampstead, London NW3 2QG

Names of the charity trustees who manage the charity during period of report

Trustee Name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
Marc Lipman	Trustee		
Ronan Breen	Trustee		
Ibrahim Abubakar	Trustee		

Jennie Keane	Trustee		
Lisa Morrison	Trustee		

Corporate trustees – names of the directors at the date the report was approved

Director name		
N/A		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
N/A		

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
N/A		
Name of chief executive or names of senior staff members (Optional information)		
N/A		

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

Other optional information

N/A

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

	Signature(s)	Ronan Breen	
	Full name(s)	Ronan Angus MacCormick Breen	
	Position (eg Secretary, Chair, etc)	Vice-Chair	
	Date	01/11/2025	