



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## **Trustees' Annual Report for the period**

**From 02/11/2021 Period start date**  
**To 01/11/2022 Period end date**

**Charity name: NTM PATIENT CARE UK**

**Charity registration number: 181372**

### **Objectives and Activities**

	SORP referenc e	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	<p>The purpose of NTM Patient Care UK is to provide information and support to NTM patients. We also work with Healthcare Professional (HCP) teams to improve understanding of patient needs, co-ordinating and facilitating the transfer of information in both directions between the two.</p> <p>This purpose is set out in the Constitution as the following objectives;</p> <p>Working to improve the lives of people with non-tuberculous mycobacterial (NTM) infection in the UK, in particular but not exclusively by;</p> <p>a) the provision of education and information to increase understanding of NTM in both the clinical and patient communities.</p> <p>b) the development and implementation of a support network for NTM patient communities.</p>
Summary of the main activities in relation to those purposes for the public benefit, in particular, the	Para 1.17 and 1.19	<p><i>Main activities for this reporting period include to the following;</i></p> <p>a) NTM Patient Care UK has worked with national healthcare organisations including</p>

<p>activities, projects or services identified in the accounts.</p>		<p>NHS England and NHS Improvement (NHSEI), the Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (AWMSG) to provide patient advocacy and representation for NTM patients in relation to relevant treatment decisions.</p> <p>b) NTM Patient Care UK has held regular Zoom Meetings for NTM patients and HCPs with an interest in NTM. These meetings have included talks &amp; presentations on areas with specific relevance to NTM patients such as physio, pharmacy, microbiology and dietetics, as well as general Q &amp; A sessions. These meetings also provide both support and a forum for NTM patients to share and discuss their experiences of NTM and associated issues.</p> <p>c) Continued development and improvement of a NTM Patient Care UK website to allow the patient association to provide information and support to NTM patients.</p> <p>d) NTM Patient Care UK has developed both posters and leaflets for dissemination in respiratory clinics and other relevant locations. This has significantly increased engagement with NTM patients and HCPs to develop support in the further development of the patient association.</p> <p>e) NTM Patient Care UK has continued to raise awareness of this disease within the medical community and actively engaged with a number of NTM patients and their wider support community.</p> <p>f) Organisation of an NTM Patient Care UK Management Group and instigation of regular Meetings to develop strategies for the patient association to help meet its intended goals.</p>
<p>Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit</p>	<p>Para 1.18</p>	<p>The trustees have had regard to the Charity Commission's guidance on public benefit.</p>

**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	N/A
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	<p>Main activities for this reporting period have included the following;</p> <p>a) Provision of improved support and information specific to NTM patients.</p> <p>b) NTM Patient Care UK has worked with national healthcare organisations including NHS England and NHS Improvement (NHSEI), the Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (AWMSG) to provide patient advocacy and representation for NTM patients in relation to relevant treatment decisions.</p> <p>c) Development and implementation of a website that provides NTM patients with a source of information and advice specific to their situation. This includes patient stories, frequently asked questions, news stories, research info, links to other information sources as well as information on physio, mental health and other useful info.</p> <p>d) Provision of regular Zoom meetings to provide relevant information and support specific to NTM patients. This has improved support available to these patients as well as providing an excellent opportunity for informal interaction between NTM patients and</p>

		<p>HCPs. This interaction has provided an improved understanding of NTM and the patient experience within both groups.</p> <p>e) NTM Patient Care UK has had a key role in the approval of Arikayce, a drug that is necessary when the usual combination antibiotics fail to resolve mycobacterial infections such as NTM.</p> <p>.</p>
--	--	---

### 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	NTM Patient Care UK funds are in a reasonably healthy state.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	NTM Patient Care UK has no policy for holding reserves and a policy is not considered necessary as the charity has had limited spending during this reporting period and a single grant received. This will be considered in future reporting years if necessary.
Amount of reserves held	Para 1.22	Significant funds were carried over from the previous reporting period and as the charity has had limited spending reserves are not considered necessary.
Reasons for holding zero reserves	Para 1.22	The charity has had limited spending over the reporting period, so reserves are not considered necessary.
Details of fund	Para	N/A

materially in deficit	1.24	
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	NTM Patient Care received a grant from a pharmaceutical company (£4,000.00) in January 2022.
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
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, NTM patients and HCPs to ensure the best representation of the needs of NTM patients. More details of Trustee selection are provided in the Constitution.

### 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		N/A

	Para 1.51	
Relationship with any related parties	Para 1.51	N/A
Other		N/A

### Reference and Administrative details

Charity name	<b>NTM Patient Care UK</b>
Other name the charity uses	<b>N/A</b>
Registered charity number	<b>1181372</b>
Charity's principal address	<b>Royal Free London NHS Foundation Trust, Pond St, Hampstead, London NW3 2QG</b>

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

		<b>Trustee name</b>	<b>Office (if any)</b>	<b>Dates acted if not for whole year</b>	<b>Name of person (or body) entitled to appoint trustee (if any)</b>
	1	Prof Marc Lipman	Trustee		
	2	Dr Heather Milburn	Trustee		
	3	Shirley Harwood	Trustee		
	4				
	6				
	7				
	8				
	9				
	10				

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

<b>Director name</b>		
<b>N/A</b>		

Name of trustees holding title to property belonging to the charity

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

### **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)**

<b>Type of adviser</b>	<b>Name</b>	<b>Address</b>
Technical & Medical Communications advisor	John Hockley	Axiom Health Ltd,(Registered Office; 21 Birch Drive, Billingshurst, West Sussex RH14 9RH, UK).

#### **Name of chief executive or names of senior staff members (Optional information)**

<b>N/A</b>
------------

### **Exemptions from disclosure**

Reason for non-disclosure of key personnel details

<b>N/A</b>
------------

### **Other optional information**

<b>N/ A</b>
-----------------

**Declarations**

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

**Signed on behalf of the charity's trustees**

	<b>Signature(s)</b>	
	<b>Full name(s)</b>	Prof Marc Lipman
	<b>Position (eg Secretary, Chair, etc)</b>	Chair
	<b>Date</b>	





CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
NTM Patient Care UK

No (if any)

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
11/2/2021

To

Period end date  
11/1/2022

### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Starting Balance	25,123	-	-	25,123	
19/01/2022 Insmed grant	4,000	-	-	4,000	
21/10/2022 HMRC Charities	119	-	-	119	-
		-	-	-	-
		-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>29,242</b>	<b>-</b>	<b>-</b>	<b>29,242</b>	<b>-</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>29,242</b>	<b>-</b>	<b>-</b>	<b>29,242</b>	<b>-</b>
<b>A3 Payments</b>					
08/11/2021 Ionos	1	-	-	1	-
11/11/2021 Ionos	2	-	-	2	-
13/12/2021 Ionos	2	-	-	2	-
30/12/2021 Ionos	1	-	-	1	-
31/01/2022 Axion Health Ltd	1	-	-	1	-
31/01/2022 Axiom	2,098	-	-	2,098	-
31/01/2022 Axiom	6,480	-	-	6,480	-
10/06/2022 Axiom	3,436	-	-	3,436	-
03/08/2022 NRS Printing	57			57	
04/08/2022 Stefanie Carter Admin	632			632	
05/09/2022 NRS	33			33	
06/09/2022 Admin	312			312	
31/10/2022 NRS	23			23	
				-	
				-	
				-	
				-	
				-	
				-	
<b>Sub total</b>	<b>13,078</b>	<b>-</b>	<b>-</b>	<b>13,078</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	
	-	-	-	-	
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>13,078</b>	<b>-</b>	<b>-</b>	<b>13,078</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>16,164</b>	<b>-</b>	<b>-</b>	<b>16,164</b>	<b>-</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>16,164</b>	<b>-</b>	<b>-</b>	<b>16,164</b>	<b>-</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	-	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK	OK
<b>B2 Other monetary assets</b>	Details	to nearest £	to nearest £	to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	