



## Non-Tuberculous Mycobacterial (NTM) lung infections

### Introduction

**Non-Tuberculous Mycobacteria (NTM) are a group of bacteria commonly found in the environment around us (soil and water). There are many types of NTM and some, but not all, can cause lung disease and a condition called Non-Tuberculous Mycobacteria pulmonary disease (NTM-PD). Some people are at a higher risk of developing NTM-PD, such as people with cystic fibrosis or bronchiectasis.**

**The diagnosis and decision to treat NTM-PD are often challenging and require multiple assessments, which may include many sputum (mucus) samples and sometimes bronchoscopies. It may also take a long time until a decision to treat is made. The treatment is also lengthy and the drugs used may come with side effects.**

**We are asking the following people to complete this survey:**

- **People diagnosed with bronchiectasis, both with and without NTM-PD**
- **People with NTM-PD infection (current or past) with or without a diagnosis of bronchiectasis.**

**We want to learn about the challenges that you have encountered during the evaluation and treatment of NTM-PD, to help healthcare professionals improve how they deal with this condition.**

**This survey will take up to 15 minutes to complete, and is anonymous. You may want to ask other people – relatives, your nurse or doctor - to help you with answers in cases where you are not sure, but it is up to you.**



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### About you

**These questions are about the person with the condition. If you are filling in the survey on behalf of a patient please answer these questions on their behalf:**

\* 1. Are you...?

- A person with bronchiectasis **and** NTM-PD (current or past infection)
- A person with bronchiectasis **without** NTM-PD
- A person with NTM-PD **without** bronchiectasis (current or past infection)
- Other (please specify)

\* 2. In what country do you live?

\* 3. What is your age?

- 0-17 years
- 18-30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61-70 years
- 71-80 years
- 80+ years

\* 4. Are you...?

- Male
- Female

\* 5. Were you aware of the existence of NTM prior to this survey?

- Yes
- No
- Not sure

\* 6. Have you ever been tested for NTM by a special sputum sample or bronchoscopy?

- Yes
- No
- Not sure

\* 7. Have you ever been told that an NTM was found in your sputum/phlegm?

- Yes
- No
- Not sure



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### Your experiences of NTM

8. How long ago was the first time an NTM was found in your lungs?

- Under 1 month
- Between 2 - 6 months
- Between 7 - 12 months
- Over a year

9. Do you know which species of NTM were grown in your sputum/phlegm?

- Mycobacterium avium or Mycobacterium intracellulare (also known as MAC or MAI)
- Mycobacterium Kansasii
- Mycobacterium abscessus
- Do not know
- Other (please specify if you know)

10. Were you offered treatment for NTM-PD?

- Yes
- No
- Do not know / Do not remember



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You answered 'No' or 'Not sure' to an NTM being found in your sputum/phlegm

11. What was the reason your doctor told you he/she did not offer treatment? Please tick all options that apply

- The species was not causing harm to the lungs (not pathogenic)
- The species was not likely to respond to available medications (resistant)
- The medications may cause harm (side effects)
- The medications are too expensive
- The medications are not available in my country
- No reason was given
- Do not know / do not remember

12. Are you still being tested for NTM-PD?

- Yes
- No
- Not sure



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About your treatment for NTM-PD

13. How long did you receive treatment for NTM-PD for?

- 1 month or less
- Between 1 month and 1 year
- Between 1 and 2 years
- More than 2 years
- I am still taking treatment for NTM-PD

14. How were the drugs to treat NTM-PD used by you? Please tick all that apply

- By pills (oral)
- By infusion (intravenous)
- By injection (intramuscular)
- By inhalation

15. If you received treatment for NTM-PD in the past, what was the reason for stopping treatment?

- Treatment was completed successfully
- Treatment was not helping
- I had severe side effects from the drugs
- Do not know / Do not remember
- I am still taking treatment for NTM-PD
- Other (please specify)



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Challenging issues

16. If you were ever diagnosed with NTM-PD, which of the following issues were most challenging? Please rate each aspect

|  | Not an issue          | Not very difficult    | Difficult             | Very difficult        | N/A                   |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Sputum (mucus) production  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Blood in sputum (mucus)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cough  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Shortness of breath  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Poor appetite  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Pain   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling tired  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Fever  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Exacerbations (episodes of increased sputum (mucus) or change in its colour; new or increased shortness of breath and/or fever that led you to go to the doctor) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Emergency hospital admission   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Depression or anxiety  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other very difficult issues (please specify)

17. In your opinion, what issues need more attention to improve the management of NTM-PD?

|  | Unimportant           | Not very important    | Important             | Very important        | N/A                   |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Finding drugs that are more effective in treating NTM-PD | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding drugs for NTM-PD that have fewer side effects    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Reducing the cost of drugs                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Improving the availability of drugs                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding tests that diagnose NTM-PD more rapidly          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding tests that may allow to shorten treatment        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding tests to say which patients need treatment       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding methods to prevent NTM infection                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (please specify)

18. Please rate how your daily activities below are limited by NTM-PD:

|   | Not limited at all    | Limited a little      | Much limited          | Very much limited     | N/A                   |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Maintaining relationships with family and friends | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Driving   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Having sexual relations                           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Maintaining an independent lifestyle              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Working outside home                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Attending social activities                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Household chores                                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Exercising  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Sleeping  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (please specify)

19. To what extent has quality of life of your spouse/carer been limited by you having NTM-PD?

| Not limited at all    | Limited a little      | Much limited          | Very much limited     | N/A                   |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Tell us more



20. Which aspects concerning management of NTM-PD posed a challenge for you?

|   | Not difficult         | Not very difficult    | Difficult             | Very difficult        | N/A                   |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Time to get (correct) diagnosis of NTM-PD                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to NTM specialist  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access to information about NTM-PD                                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Worries over diagnosis and treatment of NTM-PD                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Worries that I might be "contagious" and put my family at risk          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Difficulty getting access to drugs                                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Cost of drugs   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Long duration of treatment  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Side-effects of drugs   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not achieving eradication of the NTM infection despite taking treatment | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not achieving improvement of clinical symptoms despite taking treatment | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other (please specify)



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Impact of NTM-PD on work productivity

21. What is your employment status?

- Full employment
- Part employment
- Retired
- Not employed

22. In the past six months, how many days in total have you lost from work because of symptoms related to NTM-PD? Please give a number between 0 and 180

23. In the past six months, how many days in total has your carer/spouse lost from work because of symptoms related to your NTM-PD? Please give a number between 0 and 180



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Final question

24. Please add any other comments about NTM-PD that you feel are important



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## Get involved

25. If you are interested in sharing more of your experiences of living with different aspects of bronchiectasis or NTM as part of our patient advisory group, then please follow this link: [Get Involved](#) to enter your email address and we will send you further details of what is involved.