National Audit of Clinical Practice for Adults with Non-Tuberculous Mycobacteria Pulmonary Disease

Background and Rationale

Nontuberculous mycobacteria (NTM) are environmental organisms primarily found in soil and water [1], [2]. By definition they are not *Mycobacterium tuberculosis* (the cause of tuberculosis) or *M. leprae* (the cause of leprosy), and the majority of NTM do not cause disease in humans. When they do this is most often as a chronic lung infection in people often with longstanding underlying lung problems such as chronic obstructive pulmonary disease (COPD), bronchiectasis, and cystic fibrosis [3], [5]. The prevalence of NTM pulmonary disease is increasing [6, 7], and its management can be complex requiring prolonged treatment with multiple drugs in people who are often frail [8]. Guidelines are available to help but evidence from surveys of NHS services suggest that there is considerable variability in their implementation. In response to this, the NTM Network UK has used the guidelines to develop Standards of Care for NTM that can help healthcare practitioners provide high-quality care and indicate to people with NTM what their care should look like [9]. The Standards were launched in 2024 and this audit aims to document how adults with NTM-PD in the UK were managed before their introduction.

Primary objective:	To document what treatments and services are provided to adults with NTM-PD managed in secondary care in the UK.
Secondary objectives:	To explore whether there are national variations in clinical practice and healthcare services. To explore potential reasons for any identified variation.
Inclusion criteria:	Adults diagnosed with new, confirmed NTM-PD from 1 January 2022 Age 18 years and older Confirmed NTM-PD following British Thoracic Society (BTS) guidelines [10].
Exclusion criteria:	Adults with prevalent (ongoing) NTM-PD first diagnosed before 1 January 2022. Age 17 years or less.
Sample size:	We aim to recruit 40 - 50 sites registered with NTM Network UK with each site providing data on 3 consecutive cases, giving an estimated number of cases of 120-150.

Methods

- The audit has been designed to collect anonymised, retrospective clinical data on adults diagnosed with NTM-PD. No identifiable patient information will be requested.
- Information from each site will be collected on the first 3 consecutive adults diagnosed with NTM-PD from 1 January 2022 onwards.
- Healthcare practitioners at each site will need to obtain local information governance approval from the Caldicott Guardian or equivalent to participate.
- Once local approval has been obtained, the audit REDCap link will be sent to the participants along with extra information and instructions regarding the study.
- Healthcare practitioners at participating NTM sites will extract data from patients' records, with no direct patient recruitment or contact required, and submit it through the online audit interface.
- Data will be collected via the REDCap online platform and stored in a secure database at University College London with encrypted digital password protection (Data Safe Haven).
- Data analysis will be performed by a member of the study team.

Data fields required:

Date of diagnosis, categorical age range (years) at diagnosis, gender, ethnic group, respiratory co-morbidities at diagnosis, Charlson Co-morbidity Index at diagnosis, chest CT scan radiographic pattern closest to diagnosis, NTM-PD species identified, multidisciplinary team involvement, available supporting information provided to patient, respiratory physiotherapist, dietitian, specialist nurse, and hearing tests before antibiotic treatments, any airway clearance intervention and/or pulmonary rehabilitation used, specific antimycobacterial therapy used, follow-up provided, date of last evaluation, current care status and state of health.

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British Thoracic Society (BTS) guidelines: a patient must have characteristic symptoms, compatible radiology, and two or more positive sputum samples of the same NTM species or one positive bronchial wash/lavage or compatible histopathological findings with one positive culture [10]. (https://www.brit-thoracic.org.uk/quality-improvement/guidelines/ntm/)

References

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