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To: Professor Jonathan Benger
Chief Medical Officer and Interim Director of the Centre for Guidelines
National Institute for Health and Care Excellence (NICE)
10 Spring Gardens
London SW1A 2BU

Dear Professor Benger,

Re: the need to update the current NICE TB clinical and public health guidelines (NG33)

I am writing in my capacity as Chair of the TB Action Group, the only network in the UK led by and for people affected by tuberculosis (TB). I would like to express my full support for the letter dated 20th December from senior clinicians regarding the need to update the current NICE TB guidelines, which are now outdated.

The TB Action Group works directly with individuals affected by TB, and we consistently hear about the gaps in timely diagnosis, appropriate treatment, and ongoing care. Consequently, ensuring that healthcare professionals have clear, evidence-based, up to date NHS guidelines, tailored to current advances, is critical to improving both clinical outcomes and the overall patient experience. For those of us who have lived through TB or supported loved ones through it, the need for up-to-date, robust clinical guidance is not an abstract issue – it is about protecting vulnerable communities, ensuring gold-standard care for TB patients and survivors, and preventing unnecessary trauma and suffering.

The latest TB annual incidence report from the UK Health Security Agency (UKHSA) confirms what many of us have experienced first hand: long delays in diagnosis averaging more than four months, rising cases of multidrug-resistant TB (MDR-TB), and more complex forms of the disease. These delays can lead to more advanced disease at presentation, resulting in

longer and more complex treatment, a higher risk of community transmission, and worse health outcomes, including long-term complications and disability such as post-TB disease.

People affected by TB need a timely diagnosis using the latest technologies, such as GeneXpert, and access to the safest and most effective treatment options available. The introduction of shorter, all-oral regimens for MDR-TB and simpler regimens for drug-sensitive TB in other countries has improved outcomes and reduced the emotional and physical toll on patients. Yet, here in the UK, many patients are still being treated with older, more toxic regimens that require months, if not years, of treatment, significantly impacting quality of life.

Many TB patients and survivors, particularly those from marginalised and vulnerable communities, continue to face significant barriers to accessing NHS care. These challenges are compounded by dwindling resources in primary care, increasing pressures on TB services, and broader societal factors affecting health outcomes, such as poor-quality housing, racism, discrimination, and poverty. Updated guidelines are essential not only for improving clinical outcomes but also for addressing inequalities in TB care. People from minoritised ethnic groups and members of health inclusion groups – such as individuals experiencing homelessness or those born outside the UK, particularly migrants from high-incidence countries, asylum seekers, and those with refugee status – face a much higher risk of contracting TB and experiencing poor outcomes. To address these disparities, these communities need clear, evidence-based guidance to ensure consistent, high-quality care across the NHS.

Finally, as a network representing people with lived experience of TB, we believe it is crucial that the voices of those affected are considered when shaping future guidelines. We would be happy to contribute to this process in any way that would be helpful to NICE.

Thank you for your time and consideration. We hope you will recognise the importance of these issues and prioritise updating the NICE TB guidance to ensure that the standard of NHS care in the UK reflects recent developments and advances, offering the best possible outcomes for those affected by TB.

Yours sincerely,

A handwritten signature in black ink that reads "Amy". The script is cursive and elegant, with a large initial 'A' and a long, sweeping tail on the 'y'.

Amy McConville
Chair, TB Action Group