

# Tuberculosis in the United Kingdom: **RISING RATES**

March 2026



THE ALL-PARTY PARLIAMENTARY GROUP

Tuberculosis

## About the All-Party Parliamentary Group on Global Tuberculosis

The All-Party Parliamentary Group (APPG) on Global Tuberculosis (TB) was formed in 2005 to accelerate progress towards ending the TB epidemic. It is chaired by Sojan Joseph MP, with Nick Herbert (Lord Herbert of South Downs) as the Group's co-chair. Results UK provides and funds the secretariat.

Further details on the APPG on Global Tuberculosis its membership and its work can be found on our website: <https://appg-tb.org.uk/about/>

For more information on the inquiry process, including evidence submissions and witness sessions, please contact the APPG Secretariat at [info@appg-tb.org.uk](mailto:info@appg-tb.org.uk)

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# 1: CO-CHAIRS' FOREWORD

Many people assume that tuberculosis is a disease of the past – but across the UK, rates are rising, reversing decades of progress and highlighting the urgent need for coordinated action.

Although TB is both entirely preventable and curable, it remains a threat in environments shaped by entrenched inequalities. Overcrowded or insecure housing, poor nutrition, obstacles to timely healthcare and gaps in support all create fertile ground for the disease. These challenges are not confined to one group, and so an effective response must combine social action with strong clinical care.

England's National TB Action Plan (2021–2026)<sup>1</sup> provides an important strategic framework for reducing TB incidence, improving detection, and supporting people through treatment. Yet the recent rise in cases demonstrates that further action is needed. The planned renewal of the Action Plan for 2026–2031<sup>2</sup> offers a critical and timely opportunity to build on successes, address gaps and ensure a coordinated, equitable, and adequately funded response.

While this report examines TB trends across the UK, its evidence and recommendations focus primarily on England, which accounts for most cases. Many of the issues explored – from health system fragmentation to social determinants of health – are relevant across the UK, where each nation faces its own challenges.

Throughout 2025, members of the All-Party Parliamentary Group on Global Tuberculosis and our parliamentary colleagues engaged in events highlighting the importance of TB funding, both in the UK and globally, particularly in the context of the Global Fund's Eighth Replenishment.<sup>3</sup> These discussions also highlighted the need for a coordinated, strategic approach to tackling TB in the UK, which informed the decision to launch this inquiry.

During the course of this inquiry, we heard from clinicians, researchers, public health specialists, TB services and people with lived experience of TB. Their testimonies demonstrate that England already has the expertise, tools, and knowledge to reverse the current trend – if deployed through a cohesive, inclusive strategy that reaches everyone.

On behalf of the APPG, we would like to express our deepest thanks to everyone who contributed evidence to this inquiry – especially those who shared their personal experiences. We recognise how emotionally difficult it can be to revisit periods of illness, uncertainty and disruption, and we are truly grateful to those who chose to do so. Your testimony has given this report its heart as well as its insight. It ensures that our findings reflect not only the data and the policy landscape, but the lived realities of the people and families behind every TB case. Your willingness to speak candidly and generously will help drive improvements in care, awareness and support for others in the future.



**SOJAN JOSEPH**  
MP for Ashford

*Sojan Joseph*



The Rt Hon **LORD HERBERT**  
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*Nick Newbark*

## 2: EXECUTIVE SUMMARY

Tuberculosis (TB) is re-emerging as a significant public health challenge in the UK. TB rates in the UK are now rising, and the country is at risk of losing its World Health Organisation (WHO) low-incidence status – defined as fewer than 10 cases per 100,000 population<sup>4</sup> – with a current notification rate of 9.25 per 100,000.<sup>5</sup> This trend exposes gaps in prevention, early detection, treatment and support, particularly for high-risk groups like migrants, people experiencing deprivation, and those with complex social needs.



As such, the All-Party Parliamentary Group on Global Tuberculosis launched this inquiry to understand the factors driving this increase and to identify actionable solutions. Through written submissions, oral evidence and discussions with clinicians, public health experts and people with lived experience, the inquiry captured a stark picture of domestic TB challenges and the UK's role in the global response.

Throughout the evidence-gathering process, stakeholders consistently highlighted gaps in leadership, coordination and investment. TB services face increasingly complex caseloads without corresponding increases in resources, alongside challenges in delivering screening, supporting people with social risk factors and sustaining specialist expertise. Fragmentation across integrated care boards, local authorities, NHS services and national bodies contributes to inconsistencies in access, treatment pathways, and patient outcomes.

Low awareness of TB – both in the public domain and within parts of the medical community – continues to cause avoidable delays in diagnosis and reinforce stigma. People with lived experience described financial, social and long-term health impacts, as well as barriers to navigating a system that is often difficult to access and not always responsive to those most affected.

The evidence gathered through this inquiry underlines the urgency of coordinated action across leadership, workforce, service provision, prevention, and global engagement to prevent further deterioration of the UK's TB control and to safeguard public health.

# 3: RECOMMENDATIONS TO TACKLE THE RISING RATES OF TB IN THE UK

## Prevention and Early Detection

### RECOMMENDATION 1

Strengthen national TB prevention and early detection programmes across England.

### RECOMMENDATION 2

Address structural and social barriers to accessing screening and treatment.

### RECOMMENDATION 3

Increase clinical and public awareness of TB symptoms and reduce stigma through sustained national communication.

## Workforce and Capacity

### RECOMMENDATION 4

Implement the Getting It Right First Time (GIRFT) recommendations to address workforce shortages inequities.

### RECOMMENDATION 5

Establish a national TB training and professional development programme.

## Leadership and Coordination

### RECOMMENDATION 6

Appoint a national named TB lead within the Department of Health and Social Care.

## Service Provision and Access

### RECOMMENDATION 7

Ensure equitable service provision of the LTBI screening programme across all Integrated Care Boards to achieve full coverage for high-risk populations.

### RECOMMENDATION 8

Implement a national procurement system for TB medications to prevent shortages, improve access to child-friendly formulations and reduce treatment disruption.

## Lived Experience

### RECOMMENDATION 9

Integrate mental health support for all TB patients and caregivers.

### RECOMMENDATION 10

Ensure comprehensive financial and practical support for TB patients and their families across services.

# 4: BACKGROUND AND CONTEXT

Tuberculosis (TB) is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*.<sup>6</sup> It most commonly affects the lungs (pulmonary TB), but can also affect other parts of the body, like the brain, kidneys, and spine. TB occurs in two forms: latent TB, where a person carries the bacteria without symptoms or risk of transmission, and active TB, where the infection becomes symptomatic and contagious. About 5-10% of people with latent TB will develop active disease in their lifetime, particularly if their immune system becomes weakened.<sup>7</sup>

## 4.1 GLOBAL CONTEXT

Although TB is often perceived in the UK as a disease of the past, it remains the leading cause of death from infectious disease globally. According to the World Health Organisation (WHO) Global Tuberculosis Report 2025, more than 10 million people develop TB every year, and over one million die as a result. The WHO also estimates that a quarter of the world's population carries *Mycobacterium Tuberculosis*, leaving millions at risk of developing active TB.<sup>8</sup>

**10+**  
**MILLION**  
people develop  
TB each year

**1+**  
**MILLION**  
deaths annually

**1 in 4**  
**PEOPLE**  
globally carry TB  
bacteria\*  
\*can develop into active TB

While global efforts since 2000 have saved an estimated 83 million lives, incidence is declining far more slowly than needed to meet international targets.<sup>9</sup> Conflict, displacement, under-financing, stigma, inequitable access to healthcare and the growing threat of antimicrobial resistance all hinder progress. TB is also a leading cause of death for people living with HIV.<sup>10</sup>

The UK has traditionally played a significant role in international TB control – through official development assistance (ODA), scientific and operational research and significant support for multilateral mechanisms such as the Global Fund. Sustaining this commitment remains essential. Yet TB remains a pressing domestic public health issue, highlighting the need for domestic commitments to match those made internationally.

## 4.2 TB IN THE UK TODAY: WHAT IT IS AND WHY IT STILL MATTERS

Prior to the COVID-19 pandemic, England had been making meaningful progress in reducing TB incidence under the *Collaborative TB Strategy for England: 2015 to 2020*.<sup>11</sup> This approach brought greater coordination across the system, enabled targeted investment in prevention and outreach, and strengthened clinical pathways for diagnosis, treatment and follow-up. These measures were associated with sustained declines in TB incidence and improvements in treatment outcomes.

However, this progress has not been maintained and TB remains a persistent and serious public health challenge in the United Kingdom today. The combined impact of the pandemic, disruption to routine services, and limited funding has weakened TB prevention, detection and follow-up.

In 2024, 5,490 people were diagnosed with TB in England, marking a 13.6% increase on the previous year.<sup>12</sup> The disease disproportionately affects urban centres, with London accounting for 20.6% of notifications, followed by the West Midlands, North West and the East of England.<sup>13</sup>

TB in the UK continues to mirror patterns of inequality and exclusion. The disease is more common in communities facing poverty, overcrowded housing and barriers to healthcare access.<sup>14</sup> People in insecure living or working conditions often face additional challenges in seeking timely diagnosis and completing treatment. Structural inequalities like housing insecurity, social stigma and uneven access to preventative services contribute to ongoing transmission. TB is both a medical and a social issue, requiring a coordinated cross-government response.



## 1 IN 5 PEOPLE WITH TB BORN IN THE UK HAVE AT LEAST ONE SOCIAL RISK FACTOR

Despite the availability of effective treatment, the UK's TB response faces significant systemic challenges. Evidence submitted to this inquiry pointed to underfunding, workforce shortages, and the need to strengthen leadership at the national level.

Specialist TB nurses, clinical teams and administrative support are stretched, limiting the capacity for early detection and comprehensive care. Participants also noted low levels of public and clinical awareness, contributing to delays in diagnosis and reinforcing stigma.

TB is far from a relic of the past and remains a marker of persistent health inequality in the UK. Evidence to this inquiry indicates that the current challenge is not a re-emergence of TB as a new threat, but a loss of momentum in the systems that previously enabled effective control. This context is necessary in understanding why renewed investment, strategic leadership, and practical improvements to existing pathways are urgently required across services.

### 4.3 RATIONALE FOR THIS INQUIRY

The APPG on Global Tuberculosis initiated this inquiry in response to growing concerns about the trajectory of TB in the UK and the pressures facing the system responsible for its prevention, diagnosis and treatment. Recent increases in TB notifications, combined with repeated drug shortages and operational strain across services in the UK, indicate that existing arrangements are no longer sufficient to protect public health or support people affected by this disease. At the time of writing this report, the UK Health Security Agency (UKHSA) has indicated that the UK is very likely to fall below the low-incidence threshold by the end of the 2025<sup>15</sup>, marking a significant warning sign about the resilience of national health systems and the sufficiency of current policy and investment.

This inquiry also builds on previous national efforts to control TB in England, including the joint Public Health England and NHS England *Collaborative TB Strategy for England: 2015 to 2020*<sup>16</sup>, which was associated with sustained reductions in TB incidence prior to the COVID-19 pandemic and demonstrated the impact of clear national direction, coordinated delivery and relatively modest, targeted investment. The APPG on Global TB and its earlier reports<sup>17</sup> were influential

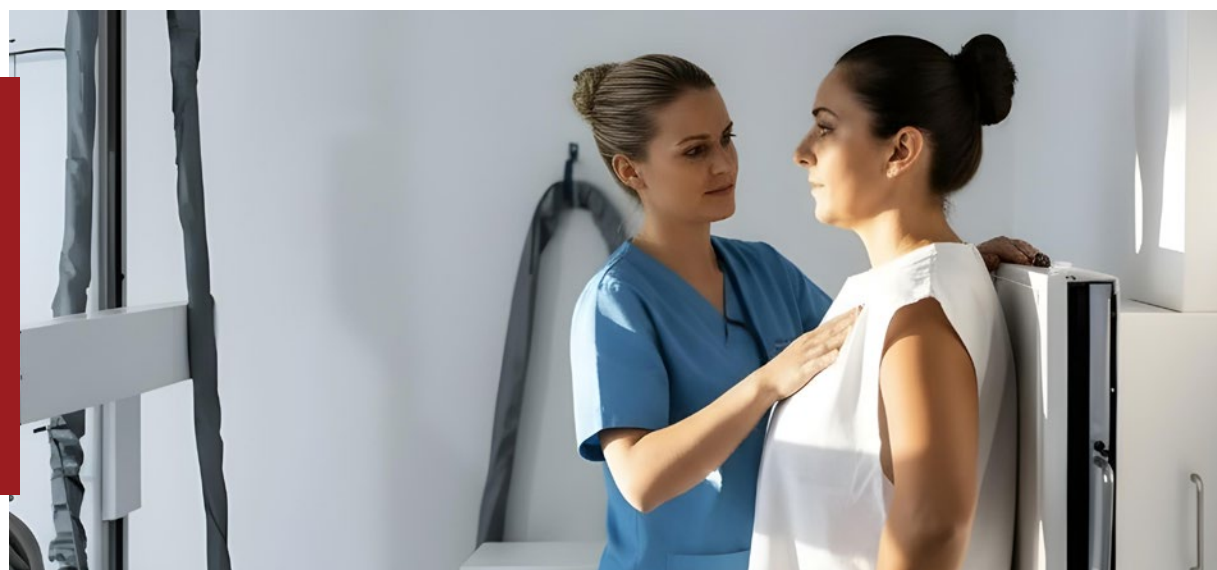
in the development of this strategy and hosted the official launch in 2015. In 2019, the APPG published a report<sup>18</sup> which assessed progress towards the end of the strategy and highlighted what was achieved through a funding commitment of £11.5 million<sup>19</sup>, alongside strong clinical and public health leadership. The disruption caused by COVID-19 and the conclusion of this strategy interrupted that progress, rather than indicating a failure of the approach itself.

During the lifetime of the strategy, the APPG provided an ongoing parliamentary forum for engagement with Public Health England, NHS England, clinicians and civil society organisations, helping to sustain political visibility of TB and scrutiny of delivery. Evidence sessions and published outputs from this period reinforced the importance of national coordination, workforce investment and consistent commissioning – lessons that remain directly relevant as TB incidence rises again. This inquiry therefore draws not only on current evidence, but on over a decade of accumulated policy experience in TB control, including recommendations developed through the APPG's 2019<sup>20</sup> and 2022<sup>21</sup> reports.

In this context, the APPG on Global Tuberculosis launched this inquiry to:

- assess the current approach to TB prevention and care;
- identify gaps in coordination, funding, and delivery across national and local systems;
- understand how social determinants are driving TB incidence in specific communities in the UK;
- gather evidence and insight from experts, frontline health workers, public health officials, and people affected by TB;
- provide clear, actionable recommendations for government and key public health bodies to take on board.

This APPG inquiry complements the *Getting It Right First Time (GIRFT)* national review of TB services<sup>22</sup> – a review commissioned by NHS England (NHSE) and UKHSA, in response to rising TB rates. The review aimed to identify service improvements, highlight good practice, and inform recommendations for reducing the TB burden. The GIRFT review recommends a coordinated approach across local, regional, and national levels. Locally, TB providers are encouraged to adapt care delivery with support from Integrated Care Boards (ICBs) and Local Authorities (LAs). Regional and national recommendations focus on system-level improvements involving NHS England and other stakeholders. However, the implementation of the GIRFT recommendations is not funded, so national adoption is reliant on individual capacities at the ICB level.



# 5: METHODOLOGY

To understand the current state of TB prevention, diagnosis, treatment and system leadership in the UK, the APPG on Global Tuberculosis undertook a structured evidence-gathering process combining oral testimony and written submissions. The methodology was designed to capture detailed insight from professionals working across the TB pathway, organisations involved in public health and service delivery, academic specialists and people with lived experience of the disease. Combined, these sources provided qualitative evidence on operational pressures, gaps in policy and practice and the wider structural and social factors shaping TB outcomes across the UK.

## 5.1 EVIDENCE COLLECTION

The inquiry was open for nine weeks, from 18 July to 19 September 2025, during which the APPG on Global Tuberculosis invited written submissions. Fourteen responses were received from organisations, researchers, clinicians, frontline staff and individuals with lived experience. These contributions highlighted key areas of concern, identified alarming gaps in national and local service provision and set out initial recommendations for strengthening the UK's TB response.

Building on the themes emerging from this written evidence, the APPG on Global Tuberculosis convened a single oral evidence session on 27 October 2025. Selected witnesses were invited to expand on, clarify or challenge the issues raised in the written submissions. Contributors included consultants from Regional TB Services, representatives from leading TB research and clinical institutions and people with lived experience whose insights and testimony were critical in grounding the inquiry in real-world impact.

Taken together, the written and oral evidence collected provide a detailed picture of the pressures facing TB services and the systemic issues affecting prevention and care.

## 5.2 LIMITATIONS

The inquiry exposed significant gaps in the UK's TB evidence base, which the APPG considers important to explicitly acknowledge.

First, national data remains uneven and incomplete, as TB services across the country collect and report information on risk factors, service capacity and treatment outcomes in different ways. This variation makes it difficult to compare performance across regions and understand where services are working well, as well as to identify where support is most urgently needed.

Second, the inquiry faced challenges in engaging some of the populations most affected by TB, including people experiencing homelessness, recent migrants, and individuals involved with the criminal justice system. These groups often have limited access to consultation processes, for example due to restricted internet access or unfamiliarity with political engagement. While the APPG worked closely with clinicians and specialist services supporting these communities to understand the challenges that they face, direct engagement with these groups was limited. This mirrors the broader difficulties in delivering TB prevention, diagnosis, and care to some of the most at-risk communities.

Third, the input from devolved nations was also limited. The APPG could not fully explore differences in policy, service organisation or outcomes across Scotland, Wales and Northern Ireland. This constrains understanding of regional variations, including whether certain approaches or innovations in service delivery might be transferable nationally.

Fourth, all submissions received by the APPG were from health-sector stakeholders and no evidence was received by the key government departments that hold responsibility for TB in the UK, particularly the Department of Health and Social Care and UKHSA. This limits insight into the policy decisions, cross-departmental coordination and funding priorities that influence service delivery and capacity.

Despite these limitations, the evidence collected was coherent and consistent across clinical, research, public health and lived experience contributions. The APPG considers it to be a concrete foundation on which to begin identifying some of the most urgent challenges facing TB services and to inform the recommendations set out in this report.



# Themes From **THE EVIDENCE**



7: Prevention and  
**EARLY DETECTION**

8: Workforce and  
**CAPACITY**

9: Leadership and  
**COORDINATION**

10: Service Provision  
**AND ACCESS**

11: Lived  
**EXPERIENCE**

7

Prevention and  
**EARLY DETECTION**



# 7: PREVENTION AND EARLY DETECTION

The NHS has the expertise and infrastructure to deliver effective TB prevention and early detection nationwide. Strengthening service coordination, screening pathways, and clinical follow-up is key to reducing TB incidence and hospitalisations across England. Evidence submitted to the inquiry made clear that England's, and thus the UK's, current approach is not reaching people at risk early or consistently enough to interrupt transmission or prevent progression from latent to active disease. Stakeholders described a system in which effective and strong TB practices exist, but access and outcomes vary significantly depending on geography, capacity and how local services are designed and organised.

Stakeholders emphasised that without a coordinated national approach and clear pathways, supported by dedicated and sustained resources, services will continue to struggle to reach people promptly, which can delay diagnosis and treatment. This inquiry heard that strengthening early detection, therefore, requires both investment in community-facing pathways and the removal of practical and administrative barriers that currently delay diagnosis.

## 7.1 SERVICE MODELS AND LOCAL PATHWAYS

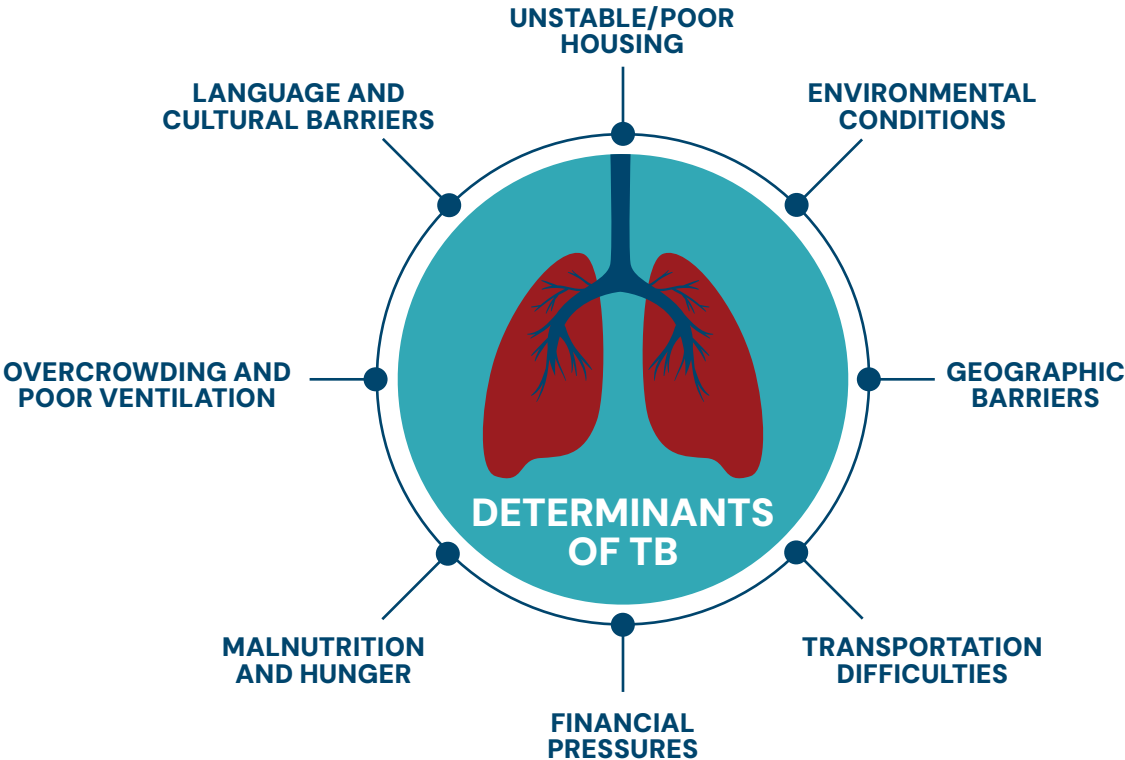
In low-incidence rural areas, like Cornwall, dedicated, standalone TB services were reported to deliver strong, patient-centred care. Operating independently from broader respiratory services allows staff to maintain year-round focus on TB, provide community-based support, and respond rapidly to suspected cases. Specialist teams improve continuity of care and help patients remain engaged with treatment and follow-up, whereas TB embedded in broader services may face competing pressures that dilute focus.

In Newham, a high-incidence urban area in London, witnesses described a structured latent TB infection (LTBI) screening and treatment programme launched in 2014 that integrated primary care with a network of accredited community pharmacies. Stakeholders noted that this model was one of the first of its kind and subsequently informed the design of the national LTBI testing and treatment programme that is now delivered across England.<sup>23</sup> Under this approach, eligible adults were offered LTBI testing through GPs, and preventative treatment was initiated through local pharmacies, which monitored adherence and reported progress back to GPs over a three- or six-month treatment period.

Stakeholders reported that they believed this programme contributed to a substantial reduction in local TB incidence over its first three years, with rates falling from 78 per 100,000 population in 2014 to 48.1 per 100,000 in 2017<sup>24</sup>. Treating a person with LTBI in primary care is at least 3.6 times less expensive than hospital-based care<sup>25</sup>, highlighting the programme's efficiency and economic value of early, community-centred intervention. This screening and treatment programme demonstrates the value of simple and accessible pathways, alongside the importance of embedding TB prevention within local services.

## 7.2 BARRIERS AND SOCIAL DISADVANTAGE

Across all settings, stakeholders raised that barriers to early detection and prevention persist. TB services reported that timely access to screening and treatment can be affected by practical or logistical challenges, like housing instability, insecure income, or transportation. Even well-designed clinical pathways may not reach all those at risk without additional support. Investing in social support alongside clinical pathways is therefore critical to enable timely access to care and reduce the likelihood of late diagnosis.



Some populations face extra challenges. While this inquiry did not receive evidence directly from people experiencing homelessness or from frontline homelessness organisations, TB Services described that these factors can increase the likelihood of late presentation and undermine otherwise effective clinical pathways.

People new to the NHS may encounter additional administrative, structural and cultural barriers to TB prevention and care. Evidence from UKHSA shows that people born outside of the UK continue to account for the majority of TB notifications in England (81.6%)<sup>26</sup>, reflecting patterns of global TB prevalence, international health systems, and the movement of people, rather than the characteristics of any particular group.

Stakeholders explained that global TB incidence has risen in recent years, driven by pandemic disruption, reduced international investment in TB programmes and interruptions to routine prevention and treatment abroad. These global patterns are reflected in the epidemiology observed in England, where TB rates are higher among people born in countries with a greater burden of disease. Social risk factors and higher levels of inequalities in deprived areas of England are also associated with higher levels of TB.<sup>27</sup> Several witnesses cautioned that misinterpreting this relationship risks stigmatising communities and undermines public health efforts.

Effective TB prevention for these communities depends on non-stigmatising, culturally competent pathways that are embedded in trusted and everyday healthcare settings such as GPs and community pharmacies. Stakeholders emphasised that ensuring these pathways are adequately supported and resourced is essential so that people at risk can access screening and begin preventive treatment promptly.

Finally, stakeholders underlined that strengthening domestic TB prevention must go hand in hand with sustained UK engagement in global TB control efforts, which this report discusses in an earlier section. Supporting international programmes, research and surveillance is viewed as integral to reducing long-term risks – both by lowering the global burden of TB and by helping to prevent the emergence and spread of drug-resistant strains.

Alongside the structural and access barriers faced by socially disadvantaged and newly arrived populations, stakeholders highlighted that prison settings in the UK<sup>28</sup> represent another high-risk environment for TB transmission. Factors such as overcrowding, poor ventilation, and frequent population turnover create conditions in which TB can spread more easily.<sup>29</sup> Stakeholders reported anecdotal evidence of rising TB cases in prisons and noted that screening and preventative measures are inconsistently applied, with some facilities lacking systematic entry testing or follow-up.

Stakeholders involved with the inquiry emphasised that early detection in prisons is both clinically and economically effective. Targeted screening for people who may be at higher risk – including those with social or medical risk factors or coming from higher incidence regions – can prevent outbreaks within facilities and reduce the likelihood of onward transmission after release.

Medical professionals that this inquiry heard from highlighted the importance of coordinated pathways that extend beyond prison walls, ensuring continuity of care when individuals are released. This includes timely communication between custodial healthcare, local TB teams and primary care services to maintain treatment adherence and monitoring. Stakeholders stress that dedicated TB pathways in prisons, rather than ad hoc or reactive approaches, are essential for protecting both populations in prisons and the wider staff and community.

### **7.3 PUBLIC AWARENESS**

This inquiry also heard, from multiple sources, that low public awareness of TB remains a significant barrier to early detection and prevention. Many people are unfamiliar with the signs and symptoms of TB, which can be non-specific and can resemble other common illnesses, like respiratory infections including COVID-19, leading people to underestimate the seriousness of their symptoms or delay seeking care, increasing the risk of late diagnosis and onward transmission.

Reduced visibility of TB in public health campaigns has contributed to this knowledge gap, particularly in areas of lower incidence and witnesses noted that this can increase the risk of late presentation, unnecessary hospital admissions, and ongoing transmission of the disease while perpetuating stigma.

## 7.4 RECOMMENDATIONS

### RECOMMENDATION 1

#### **Strengthen national TB prevention and early detection programmes across England**

The Department of Health and Social Care and NHS England should develop a consistent national framework that ensures equitable access to prevention and early diagnosis regardless of geography. This should include:

- Nationally agreed models for LTBI testing and treatment, building on successful community-embedded approaches such as GP and pharmacy partnerships.
- Sustained funding for dedicated TB teams in both high- and low- incidence areas to maintain consistent focus and continuity of care.
- Clear expectations for rapid assessment, follow up and referral pathways so that people at risk are not lost between services

### RECOMMENDATION 2

#### **Address structural and social barriers to accessing screening and treatment**

The Department of Health and Social Care, NHS England and Integrated Care Board should ensure that TB pathways help people access care promptly and complete screening and treatment. This includes addressing practical barriers such as navigating NHS systems, language differences, and appointment logistics. This should involve:

- Targeted outreach, guidance, and translation support to help people understand and use TB services effectively.
- Accessible entry points for TB screening and treatment, like walk-in chest X-ray services, community-based clinics and pharmacies, to make it easier for people to engage with care.
- Supporting people to navigate appointments and follow-up, ensuring continuity of care across services.
- Implementing consistent, risk-based screening and continuity of care protocols across all UK prisons, with effective information-sharing between custodial healthcare, local TB services and primary care to maintain treatment adherence after release.

### RECOMMENDATION 3

#### **Increase clinical and public awareness of TB symptoms and reduce stigma through sustained national communication**

The Department for Health and Social Care, UK Health Security Agency and NHS England should jointly deliver a targeted and long-term public awareness campaign that raises the profile of TB symptoms and reduces stigma - especially in areas with low incidence where clinical suspicion of TB may not be as frequent. Messaging in this campaign should be accessible in multiple languages and be integrated into broader respiratory health communications.



# Workforce and **CAPACITY**



# 8: WORKFORCE AND CAPACITY

The effective management of TB in the UK is heavily dependent on a knowledgeable, well-supported and adequately resourced workforce. Across the NHS, TB expertise is concentrated in a small number of clinicians, leaving gaps in awareness and treatment capability across primary and secondary care. This, combined with workforce shortages, overstretched staff and systemic pressures, limits the ability of services to diagnose, treat and prevent TB efficiently. Strengthening the workforce and supporting clinicians at all levels is therefore critical to improving patient outcomes and controlling TB nationally.

## 8.1 IMPACT OF MISDIAGNOSIS

Nearly 1.5 million people work for the NHS, making it the largest employer in the UK.<sup>30</sup> These health professionals provide routine and emergency care across healthcare settings and the wider community to all who need it. These professionals are supported by world-leading doctors, clinicians and researchers from some of the best hospitals and research institutions in the world.

Despite this, the NHS has a pronounced shortage of TB expertise across the country. Our inquiry heard, in both written and oral evidence, of multiple examples where NHS staff had failed to correctly diagnose TB infections, which had significant impacts on the individual with TB. Misdiagnoses can have serious consequences: not only for the individual, who may receive incorrect treatment, but also for family, friends, and close contacts due to the transmissible nature of *Mycobacterium tuberculosis*. Accurate diagnosis and timely treatment with the correct course of medication is therefore essential. To support this, the Government and the NHS must ensure that healthcare workers are fully aware about TB and understand that it is not a 'Victorian-era disease', but a very real and active threat to our communities right now. Consequently, healthcare workers must be supported to ensure they are aware of the dangers of TB and are able to accurately and efficiently diagnose and treat it.

## 8.2 PRIMARY CARE STRENGTHENING

Health practitioners are both overstretched and overworked. Many TB cases are diagnosed late, frequently in secondary healthcare settings such as Accident and Emergency (A&E) or hospitals. To reduce this burden, the Government must strengthen primary care interventions – both capacity and resources – to tackle TB early, before it reaches more acute services. Ensuring that primary care teams are supported and trained in TB detection and management is critical to improving patient outcomes and reducing pressure on secondary care.

The GIRFT programme has highlighted serious workforce shortages in TB services, from specialist nurses to case managers, and recommends targeted workforce planning, role clarity and continuing professional development. Implementing these recommendations will help ensure clinicians are equipped to recognise TB, provide appropriate treatment and respond efficiently to patients' complex social and clinical needs. Strengthening primary care capacity, alongside GIRFT-guided workforce improvements, would also reduce unnecessary hospital presentations and improve patient outcomes.

## 8.3 RECOMMENDATIONS

### RECOMMENDATION 4

#### **Implement the Getting It Right First Time (GIRFT) recommendations to address workforce shortages inequities**

Inequities also affect clinical care. Many TB teams, especially nursing staff, are overstretched and under-resourced, leading to low morale and limited capacity to manage complex cases. Low-incidence areas have small, vulnerable services, while high-incidence areas face overwhelming demand. Therefore, NHS providers and integrated Care Boards should implement the recommendations in the Getting It Right First Time Report in order to address workforce shortages.

### RECOMMENDATION 5

#### **Establish a national TB training and professional development programme**

The inquiry highlighted significant gaps in TB knowledge and expertise across NHS staff, from primary care clinicians to specialist nurses. Misdiagnoses, delayed treatment and inconsistent care pathways are often linked to insufficient training and lack of standardised professional development in TB management. A coordinated national programme across NHS England and the Department of Health and Social Care would ensure healthcare professionals have the knowledge, skills and confidence to recognise, diagnose and treat TB effectively, helping to reduce preventable harm and limit onward transmission.

This should involve:

- Developing mandatory TB modules for clinicians in primary care, emergency care, and infectious diseases, including guidance on recognising atypical presentations and understanding risk factors beyond traditional stereotypes.
- Implementing ongoing professional development opportunities, such as workshops, webinars, and case-based learning, to keep staff up to date with WHO-recommended therapies, updated NICE guidelines and emerging evidence.
- Creating a national TB knowledge hub to provide centralised access to clinical guidance, training resources, and case studies for health professionals across the UK.
- Monitoring and evaluating training uptake and effectiveness, ensuring gaps in workforce knowledge are identified and addressed systematically.



# Leadership and **COORDINATION**



# 9: LEADERSHIP AND COORDINATION

Despite the UK's stated commitment to global TB elimination and alignment with the UN Sustainable Development Goals (SDGs), domestic TB control suffers from fragmented leadership and weak coordination. Across NHS England, UKHSA, local authorities, and the Home Office, responsibilities are dispersed, leading to inconsistent planning, limited accountability, and inefficiencies in both prevention and treatment. Multiple clinicians emphasised that no single individual or body currently holds responsibility for TB within the Department of Health and Social Care, creating a leadership void that undermines national strategy. Proposals such as appointing a national, named TB lead reflect the pressing need for clear governance and strategic direction.

## 9.1 OPERATIONAL CHALLENGES AND SYSTEMIC WEAKNESSES

The lack of coordination is also evident operationally, manifesting in the workforce shortages that were discussed earlier in this report, insufficient infrastructure and an outdated policy environment. Both the GIRFT programme and clinicians highlight serious gaps in staffing across all levels, from specialist nurses to case managers, compounded by burnout following COVID-19. The increasing complexity of patients' clinical and social needs, alongside recurring drug procurement problems, further exposes the system's inability to respond rapidly to urgent events such as large outbreaks. National Institute for Health and Care Excellence (NICE) guidance on TB remains outdated, slowing the adoption of new WHO-recommended therapies and adding to the rigidity of the system. Strengthened national direction, modernised guidelines and renewed funding structures are repeatedly identified as essential prerequisites for a functional and effective TB service.

Regional mechanisms, such as TB Control Boards, have weakened over time and no longer reflect modern health-system structures, such as Integrated Care Boards (ICBs). Clinicians recommend revitalising these boards with updated membership, stronger governance and explicit attention to health inequalities. Improvements to national drug-shortage infrastructure, enhanced communication between suppliers and services and better integrated IT systems - linking primary care, secondary care, and national surveillance - would further strengthen coordination and enable more responsive public-health action.

## 9.2 RECOMMENDATIONS

### RECOMMENDATION 6

#### **Appoint a national named TB lead within the Department of Health and Social Care**

No single individual or body currently holds responsibility for TB within the Department of Health and Social Care, creating a leadership void that undermines national strategy.

- Across NHS England, UK Health Security Agency (UKHSA), local authorities, and the Home Office, responsibilities are dispersed, leading to inconsistent planning, limited accountability, and inefficiencies in both prevention and treatment.
- Proposals, such as appointing a national TB lead, reflect the need for clear governance and strategic direction.
- Operationally, the lack of coordination is felt in workforce shortages, insufficient infrastructure, and an outdated policy environment.
- Regional coordination mechanisms also require reform. TB Control Boards, once key for local oversight, have weakened over time and no longer reflect modern health-system structures such as Integrated Care Boards (ICBs).

# 100

## Service Provision **AND ACCESS**



# 10: SERVICE PROVISION AND ACCESS

Service provision for TB across England is highly uneven, resulting in significant inequities in prevention, diagnosis and treatment. The LTBI programme is a clear example: under the current TB Action Plan, NHS England funds only 27 of the 42 ICBs, leaving large areas without any formal LTBI testing or treatment offer. In 2023, 302,782 individuals were eligible for the LBTI testing programme, a 50% increase from 2022; of these, only 11% (34,680 individuals) were tested.<sup>31</sup> This demonstrates a structural gap between programme design and population needs, particularly affecting new entrants, asylum seekers and displaced communities. Without a restructured, fully funded and inclusive screening model, the programme cannot reach high-risk groups or achieve meaningful prevention.

Inequity also extends to clinical services. Many TB teams remain overstretched and underfunded, especially the nursing workforce, contributing to low morale and limited capacity to manage complex cases. In low-incidence areas, services may be small and vulnerable, while high-incidence areas face overwhelming demand without adequate support. The absence of mandated performance indicators for TB across ICBs means the disease is often deprioritised locally, resulting in variable engagement and inconsistent access to specialist care. The new-entrant screening programme exemplifies these disparities: coverage differs by region and many individuals who require screening simply do not receive it.

***“In large cities, 40% of active TB cases will visit accident and emergency services first...they [patients] will not see their GP. [Who?] Need education and awareness at both primary and secondary care level.”***

– Consultant Respiratory Physician

## 10.1 DRUG SHORTAGES AND FRAGMENTED PROCUREMENT

Persistent drug shortages further exacerbate inequity, forcing clinicians to alter regimens based on supply rather than clinical need. This not only increases treatment burden for patients but also risks non-adherence and the development of drug-resistant TB – an outcome with significant public-health and financial implications.



In July 2025, NHS England and the DHSC issued a level four national patient safety alert<sup>32</sup> in response to drug shortages in the UK due to procurement supply issues. Although there is no global shortage of TB drugs, the way the NHS operates means there is no central procurement system; each trust must procure its own drugs. This supply-chain issue highlights the fragmentation in the prevention and management of TB care across NHS England, DHSC and UKHSA, as no one organisation or department owns the issue. Following the patient safety alert and months of task force meetings, the supply of TB drugs has now improved. However, a longer-term solution is still needed, national-level funding and improved infrastructure, leadership and communication to regions, as highlighted in the Getting It Right First Time TB review.<sup>33</sup>

This inquiry heard from witness accounts how the lack of access to paediatric TB medications means that the NHS is not following the WHO-recommended guidelines on child-friendly formulations that are available globally.

***“We need to improve access to TB medicines in the UK, which can simplify and shorten treatment. Child-friendly fixed-dose combination dispersible formulations have been available internationally for 10 years. Rifapentine tablets were licensed by the US Food and Drug Administration 27 years ago. There is a child-friendly rifapentine dispersible formulation available from two years ago. Yet none of these medicines are available in the UK. These medications benefit both adults and children.”***

– Paediatric Infectious Diseases Consultant and British Association of Paediatric Tuberculosis Representative



Despite this, there are successful examples of coordinated, equitable practice, such as the British Thoracic Society Multidrug Resistant-TB clinical advisory service, which has unified national management of multidrug-resistant TB and supported drug commissioning across many sites. Scaling similar models, alongside reviewing regional service configurations and building stronger local networks with homelessness, substance-use, and social-support services. This type of service model would help address disparities linked to social risk factors and changing epidemiology.

## 10.2 RECOMMENDATIONS

### RECOMMENDATION 7

#### **Ensure equitable service provision of the LTBI screening programme across all Integrated Care Boards to achieve full coverage for high-risk populations.**

TB service provision across England is highly uneven, creating significant inequities in prevention, diagnosis, and treatment.

- The Latent TB Infection (LTBI) programme illustrates this: only 27 of 42 Integrated Care Boards (ICBs) are funded, leaving large areas without formal testing or treatment.
- In 2023, just 11% of the 302,782 eligible individuals were tested, highlighting a major gap between programme design and population needs, particularly affecting new entrants, asylum seekers, and displaced communities.<sup>34</sup>
- Without a fully funded and inclusive screening model, high-risk groups cannot be effectively reached.
- Regional disparities in the new-entrant screening programme further exemplify these gaps, leaving many high-risk individuals unscreened.

### RECOMMENDATION 8

#### **Implement a national procurement system for TB medications to prevent shortages, improve access to child-friendly formulations and reduce treatment disruption.**

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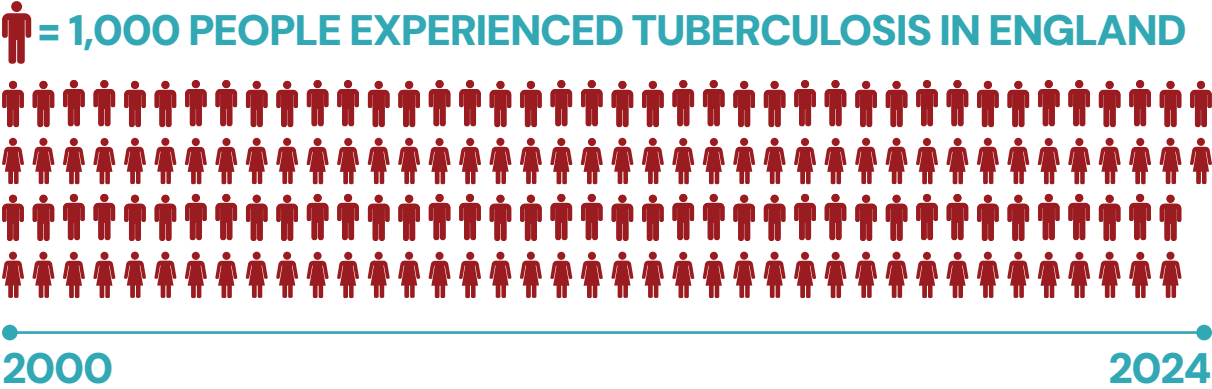
11

Lived  
**EXPERIENCE**



# 11: LIVED EXPERIENCE

Between 2000 and 2024, there have been 158,011 recorded notifications of tuberculosis in England. Behind each of these is a person and their loved ones navigating a disease that is entirely preventable and treatable long before it causes catastrophic harm. These figures represent much more than clinical data: they are over 150,000 individual stories made up of delayed diagnoses, avoidable suffering, disrupted lives, and in some cases, long-term physical and emotional difficulties.



This report emphasises that TB is far from being a disease of the past. It continues to shape the realities of people across 21st-century England. The testimonies that this inquiry heard were deeply impactful - many described experiences that were distressing, traumatic and indicative of systemic shortcomings rather than isolated failings.

Across accounts, several consistent themes emerged:

- Lack of TB awareness in primary and secondary care leading to diagnostic delays, including repeated misdiagnosis as asthma, chest infections or stress-related symptoms.
- Stigma and social isolation, both during illness and after completing treatment.
- Financial, practical and mental health burdens, with some individuals experiencing prolonged hardship due to long diagnostic pathways or extended recovery.

The following sections set out these experiences in more detail, recognising that they reflect the stories we received directly as well as the broader reality faced by many thousands more whose voices are not captured here.

## 11.1 DIAGNOSTIC DELAYS & MISDIAGNOSIS IN PRIMARY AND SECONDARY CARE

Across multiple submissions, people described long, repeated attempts to seek help for their symptoms, which were often dismissed or misattributed to common conditions. A recurring theme was being repeatedly diagnosed with asthma, chest infections or viral illness, even when symptoms persisted over multiple months.

Part of this can be traced to low clinician awareness of TB, as discussed in the workforce and capacity section. Clinicians sometimes only consider TB when patients present with “classic” risk factors – such as being from a high-incidence country, experiencing homelessness, or living with immunosuppression. Yet, TB can affect anyone and delayed recognition in patients without these risk factors can lead to severe consequences.

For example, an individual with an experience of TB recounts:

***“Nothing was working and I became more and more breathless, but the GP again sent me away... I was so ill my husband took me to A&E, where they did an X-ray, gave me more antibiotics, and said I had pneumonia... what they did not spot was that my lungs were full of cavities and the left lung had collapsed... Eventually I saw a different GP who sent me back to the hospital... they asked for a sputum test for TB but assured me I wouldn’t have it... I was sent home ... When they finally discovered I did have TB, they sent me to the TB clinic - but not for another week... I was at home, highly infectious, with nobody having started treatment... Nobody listened to me, and nobody considered that I could have TB...”***

– Lived Experience Contributor

Patients and families reported repeated GP visits over months before referral or diagnosis. One student described a year-long delay that allowed TB to progress to a drug-resistant form, requiring major surgery and leaving long-term respiratory complications. In another case, a young child underwent emergency open-chest surgery after repeated GP visits failed to identify TB. Even after this high-risk procedure, clinicians were unsure of the cause and could only confirm that it was not cancer. It was only several days later, following the suggestion of an infectious disease consultant, that TB was considered. This case highlights the extreme consequences of delayed TB recognition: invasive, high-risk procedures that could have been avoided if TB had been considered earlier.

***“Emergency high-risk, life saving surgery could have been avoided had Finlay been diagnosed and treated for TB much earlier.”***

– Parents of young child who had TB

These lived experiences demonstrate the critical need for improved TB awareness and training among clinicians, better diagnostic pathways and the recognition that TB can occur in anyone. Early identification is essential to prevent avoidable harm, reduce onward transmission and protect families and communities.

## **11.2 STIGMA AND SOCIAL ISOLATION**

As discussed in earlier sections of this report, TB is often misunderstood in the UK, where many still view it as a “Victorian-era disease” – a condition thought to have been eradicated domestically, associated with poverty, poor hygiene, or homelessness and perceived as something that only occurs in countries with weaker health systems. These outdated assumptions fuel stigma, both subtle and overt, even for people who do not fit these stereotypes. Individuals living with TB can experience social policing, where others act as though they are a threat simply because they are ill. This can take many forms: avoidance by friends or colleagues, intrusive questions about living conditions or lifestyle and the feeling of being constantly judged.

The isolation imposed during treatment, particularly when patients are highly infectious, can be deeply distressing. People describe being unable to attend work, school, or social activities,

while visitors are restricted and staff interactions are limited by infection control measures. Even everyday spaces, like hospital waiting rooms or public transport, can become sites of tension and shame.

***“My IV sessions were on the 3rd floor of the hospital and with MDR TB in my lungs, I struggled to walk up three flights of stairs... I was waiting for the lift, when an elderly man told me that I should not be taking the lift, that I was too young and I was holding up space for other people that could potentially need the lift more than I do... But how was I supposed to tell a lift full of 6 other people that the reason I was in the lift was because I have tuberculosis... I stayed quiet because I knew I was going to scare them... I struggled up those stairs, breathless, for weeks. Until my body forced me to start taking the lift again.”***

– Lived Experience Contributor

This account in particular highlights how TB-related stigma can manifest in everyday interactions, creating social barriers and feelings of judgment even within clinical settings. The fear of being perceived as a risk to others often forces patients to remain silent, isolating themselves further and compounding anxiety and stress. Contributors to this inquiry also described ongoing social isolation during and after treatment, as friends, colleagues, and acquaintances sometimes keep their distance out of fear or misunderstanding of transmissibility.

The media also plays a significant role in shaping public perceptions of TB, sometimes perpetuating stigma. Coverage often sensationalises cases or frames TB as a “dangerous” or “exotic” disease, reinforcing fear and misunderstanding. This contributes to the idea that TB is only a threat to certain “at-risk” groups or something to be ashamed of, discouraging open conversation about the disease. Patients may feel compelled to hide their diagnosis, further isolating themselves and limiting opportunities to seek support. Media representations can inadvertently make TB a taboo subject, reinforcing cycles of stigma and social exclusion that persist even after treatment is complete.

Stigma related to TB does not end with treatment. Many patients described lingering feelings of shame, fear of disclosure, and social exclusion that affected their relationships, work and community engagement. Even once medically cleared, people reported ongoing anxiety about how others might perceive them, leading to self-imposed isolation or reluctance to seek support.

### **11.3 FINANCIAL, PRACTICAL AND EMOTIONAL BURDENS**

Beyond delayed diagnosis, TB imposes substantial financial, practical and psychological, and emotional challenges. Many patients experience a prolonged period of treatment and recovery, often requiring multiple hospital visits, specialist monitoring, and complex medication regimens. These demands can make maintaining employment difficult, particularly for those who are self-employed or in precarious work, leading to loss of income and financial strain. Loss of income, coupled with additional costs such as travel to hospital appointments, specialised nutrition or equipment for medication administration can place families under severe financial strain.

Practical burdens are also considerable. Children and adults alike may require assistance with daily tasks during treatment, especially when infectious or recovering from surgery. Medication

administration can be time-consuming and complicated, particularly for young children or those needing nasogastric or intravenous treatments. The logistics of attending hospital appointments, managing strict medication schedules, and coordinating with family members or carers can place an additional strain on households.

***“Finlay’s course of TB treatment lasted six months. Six months of mixing up to seven drugs at home each day was a lengthy process: crushing and measuring different tablets to a specific child-sized dose, mixing with sterile water and giving them via syringes down his NG tube. He would sometimes pull his tube out overnight in his sleep, and we would have to call the community nursing team to get it reinserted.”***

– Parents of young child who had TB

Financial pressures extend beyond direct treatment costs. One contributor described the struggle to manage rent, food, and daily expenses while attending hospital three days a week for IV treatment:

***“With rent, food expenses, socialising and just trying to get by, finances were tough... my nurses advised that I apply for Personal Independence Payment (PIP). I filled out a form, which asked me several questions, in detail. They ranked my answers from 0 to 10. I was ranked 0 for every single part of the form... I appealed their response, to which I started to receive the lowest rate of payment a month. It felt like they just wanted me to stop appealing, or challenge them.”***

– Lived Experience Contributor

Another contributor to this inquiry highlighted the impact on their education:

***“As a student from a low-income background who was too ill to work to support myself, I faced treatment and living costs that I could not meet. I had to suspend and later repeat my university studies more than once, which meant I came close to dropping out. I also accumulated significant debt because of treatment costs and loss of earnings, all of which prolonged my recovery and increased stress, with a serious impact on my mental health.”***

– Lived Experience Contributor

The psychological impacts of both isolation and prolonged illness are significant. This inquiry heard from another contributor who recounted months of isolation while unwell, followed by severe mental health challenges, including anxiety and depression linked to both the trauma of illness and the lack of timely psychological support. There have been instances, including one heard by this inquiry, where patients have had to self-refer to alternative services like university counselling. Experiences like these emphasise the importance of integrating psychological support with TB treatment to address the holistic needs of patients, as recommended by the WHO TB guidelines.<sup>36</sup>

The emotional toll is also substantial. Patients report anxiety and depression related to the severity of their illness, treatment side effects, and uncertainty about recovery. Extended isolation, complex treatment routines, and fear of relapse contribute to mental health decline. The APPG heard that some patients sought psychological support independently or through other routes, like university counselling, due to long NHS waiting lists or a lack of specialist services linked to TB care. Early access to targeted mental health support was described as critical in mitigating the psychological consequences of both illness and isolation.

## 11.4 RECOMMENDATIONS

### RECOMMENDATION 9

#### **Integrate mental health support for all TB patients and caregivers.**

People affected by TB often experience significant psychological distress due to prolonged illness, isolation, complex treatment routines and stigma. Delays in diagnosis, high-risk procedures and fear of social exclusion can lead to anxiety, depression and long-term trauma. For children, parents or primary caregivers also face substantial emotional strain while managing treatment and recovery. Consequently, integrated mental health support should be embedded within TB care pathways. This may include:

- Improving the links between TB and mental health services to support people with existing mental health challenges through their diagnostic and treatment journeys
- Extending access to parents or primary caregivers of young children, providing counselling, guidance and emotional support to manage both their child's care and their own wellbeing.
- Establishing TB-specific mental health liaison roles within NHS trusts to coordinate care between infectious disease teams, community nursing and psychological services.
- Ensuring ongoing support during treatment and for at least 12 months post-treatment, to address long-term psychological impacts.

### RECOMMENDATION 10

#### **Ensure comprehensive financial and practical support for TB patients and their families across services.**

TB treatment often requires frequent appointments, complex medication regimens, and, in some cases, surgery or invasive procedures. Many patients are unable to work or study during this period, leading to loss of income and financial hardship. Families may also face additional costs, such as travel to appointments, specialised nutrition, or equipment to administer medication. Without adequate financial and practical support, patients risk accumulating debt, delaying recovery or experiencing increased stress that can exacerbate mental health challenges. To address this, the Department for Work and Pensions, NHS England and local health authorities should:

- Expand access to TB outreach workers who have the necessary skills to support people affected by TB to access financial assistance, benefits and community support schemes.
- Offer subsidised travel for frequent hospital visits and outpatient treatment.
- Ensure proper workforce funding for home medication management.
- Develop guidance for families with children undergoing TB treatment, including support for childcare, schooling, and coordination with community nursing teams.

## 12: CONCLUSION

TB is a live test of the UK's commitment and ability to respond to public health threats. The evidence heard by this APPG inquiry shows that the tools to prevent, detect and treat TB already exist. What is lacking is an adequately resourced plan to deploy them at scale and with consistency.

TB also highlights the limitations of addressing complex health challenges in isolation. An effective response therefore, requires coordinated action across multiple sectors, underpinned by clear leadership, accountability, and sustained investment. Establishing dedicated leadership for TB, fully implementing recommended best practices, and integrating prevention and social support into routine service delivery are essential foundations for meaningful progress.

TB is a preventable and curable disease. With the right plan and sustained resources it can be beaten in the UK. In the 21st Century a high income country with an advanced health system should not be tolerating a disease which has been curable since the advent of antibiotics and which represents a public health threat. It is time for action.

At the same time, TB remains a serious global health challenge. Respiratory diseases move rapidly across borders: TB anywhere is TB everywhere. The COVID-19 pandemic demonstrated this starkly, highlighting the speed with which airborne diseases can spread and disrupt daily life. TB and COVID-19 share several features, including overlapping symptoms and person-to-person transmission, and drug resistance remains a serious threat. The Government must therefore sustain its commitment to combating TB globally. The steps the APPG believes should be taken in this respect are beyond the scope of this report and will be set out separately.

**This inquiry is therefore a call to action. If the UK is serious about reducing health inequalities, strengthening the NHS and restoring its global health leadership, it must start by treating TB with the urgency it demands.**

**ELIMINATION IS ACHIEVABLE.**



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