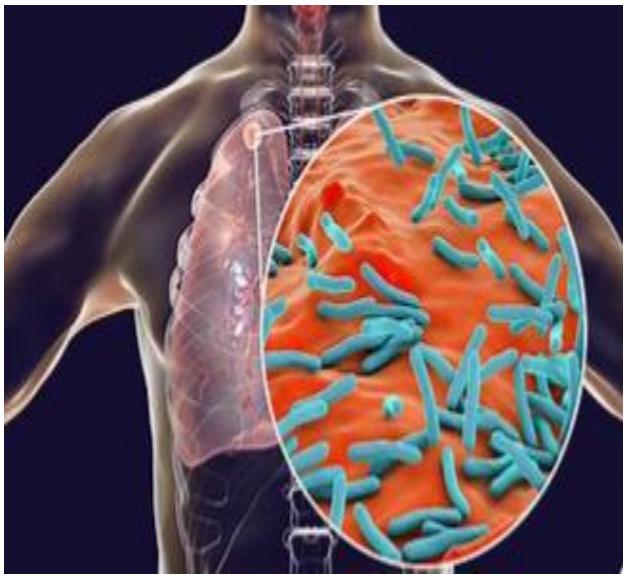
RNOH/GIRFT Review of Tuberculosis

National Report

March 2025

This report has been produced by the Getting It Right First Time Projects Team at the Royal National Orthopaedic Hospital (RNOH/GIRFT). It aims to reduce unwarranted variation to ensure best outcomes for patients and to maximise the use of existing resources and assets.



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Contents

1 Executive Summary

Tuberculosis (TB) continues to be the major infectious disease accounting for loss of life worldwide. While the number of notifications (a diagnosed case of TB to the relevant health authorities) has fallen in the past, TB in England continues to be a major burden and we are unlikely to achieve the WHO (World Health Organisation) eradication target by 2035. Unfortunately, for a variety of reasons, the number of notifications has actually increased significantly over recent years.

TB remains a major public health issue and despite several years of decline in notifications England remains off target for WHO eradication which would see England reducing the number of notifications to 1.05 per 100,000 population. To support this agenda, the Public Health England (PHE) and NHS England (NHSE) TB strategy 2015-2020, and the TB Action Plan for England 2021-2026 were put in place. Regrettably over recent years the decline in notifications has reversed with an 11% rise in 2023 over 2022 according to UK Health Security Agency (UKHSA) data, and the trend continuing in early 2024 data. Large increases occurred in non-UK born notifications, with those who were UK born also increasing, which is a reversal in trend since 2013. As expected, the increases are concentrated in large urban areas in the most deprived postcodes. The rate of notification was especially high amongst the homeless and prisoners, over 28 per 100,000, in contrast to the all England rate at 7.8 per 100,000.

NHSE and PHE (formerly Public Health England and now UKHSA – UK Health Security Agency) have focused on several areas in their ongoing attempts to improve outcomes and reduce notifications. To support these improvements, NHSE commissioned the GIRFT Projects Team at the Royal National Orthopaedic Hospital (RNOH/GIRFT) to deliver this review, with the aim of identifying further improvements to sustain care and highlight good practice.

This report sets out how RNOH/GIRFT delivered against the objectives of the review which used the GIRFT methodology of data driven peer reviews of services. This report includes identified good practice in the key areas of TB care and makes recommendations to improve services. As per the commissioning scope, some areas such as TB diagnostics and children and young people's care were not a major focus but during discussions it was apparent these were important aspects and therefore also feature in the report.

As per the GIRFT methodology, a comprehensive data set was developed based upon Hospital Episode Statistics (HES) and the enhanced surveillance returns from UKHSA. However, information on processes of care were not always available, so to inform our review a comprehensive survey was conducted using Delphi principles.

The response to the survey was excellent which led to a large data set being developed for each service who participated in the survey (**see Annex A** for a list of those who participated). This resulted in the development of a detailed data pack for each participating provider where the provider was anonymously benchmarked against their peers. This data pack then formed the basis of 20 'deep dive' meetings with selected providers lasting between 2 to 4 hours where the TB services were explored in detail. From these visits both good practice and service issues were identified to form the basis of this report. To facilitate service development for each participant, a report was produced after each 'deep dive' which included specific recommendations for that provider.

To make the data pack easier to follow, some 80 'core slides' were developed and these have been shared with the responsible officer within the ICB (Integrated Care Board) for each service, with multiple packs being sent if the ICB had more than one TB service provider. We

asked ICB leads to review the pack and meet with TB service leads and provider commissioners to discuss aspects of the service. Each comprehensive provider data pack sits with each TB service provider and we asked that this should be shared with their ICB if requested.

The aim of this RNOH/GIRFT TB review is to instigate a step change in care, reducing the burden of TB on patients, their carers, providers of TB services and the local and national health systems. Whether we can redress the trajectory of elimination is unknown but completing these recommendations will be a significant and positive step towards that goal.

This report includes recommendations for improvement which will need to be delivered by the NHS, NHS England and other key stakeholders and it is vitally important that the recommendations are properly implemented nationally, so that the needed improvements to TB services are realised for the benefit of patients.

Many of the recommendations are relatively straightforward, in that they require a focus on providers to modify their services with support from ICBs and LAs (Local Authorities) to embed changes. Some recommendations require developments and changes at a regional and/or national level. We have attempted to identify in the recommendations where the focus for these changes is needed, recognising they may be at multiple organisations who need to be involved to deliver some of the improvements.

The GIRFT Team at NHSE and the Prevention Directorate in NHSE have now asked RNOH/GIRFT to develop and deliver a framework to support this implementation which will commence in January 2025 for 12 months. More information about the plans for implementation will follow.

2 Acknowledgements

This report was based upon the close working of a small team and the Clinical Lead, Martin Allen. Martin would like to thank Gill Salter for her organisation and coordination of the project, and Allison Beal from RNOH/GIRFT as Programme Manager for overseeing the delivery of the review.

The detailed analysis of a multiplicity of data items and datapack development was performed by Edge Health with Yammi Yip leading this, supported by Kieran Dale and overseen by Jon Bruce.

Developing the key lines of enquiry and the questions for the survey was hugely supported by clinical colleagues from the British Thoracic Society and specialist TB nurses over the course of several meetings.

With thanks to colleagues within NHS England, Jeff Featherstone, Stephen Hindle. From UKHSA; Esther Robinson, Surinder Tamne and Tracey Langham, for their support with this review, and to Sharon Cox for the provision of the National Tuberculosis Surveillance System (NTBS) data. Finally, special thanks must go to Adele Mackin who has been the liaison between NHSE, and special thanks to Lynn Altass of NHSE who initiated the review and worked tirelessly to make it happen.

Martin Allen,

December 2024

3 Structure of this Report

This report has been structured into five sections: Our Background and Approach; Policy and Payment; Clinical Care; Prevention; and Workforce.

There are many documents and information referred to in this report; some of these are attached as Annexes, as per the list below, and the remaining larger documents are stored centrally for access in NHS Futures.

The link to the documents is HERE. You may need to request access to the secure folder to access these documents but, once granted, you will be able to access all documents relating to the review.

The Annex documents include:

A: TB service survey participants
B: Martin Allen Biography
C: Futures link to all additional documentation
D: A list of deep dive TB services
E: The answers to the specific survey questions
F: Glossary of the common abbreviations used
G: Useful links.

4 Background and Approach

Getting It Right First Time (GIRFT) is a national programme in England developed by the GIRFT national team under the chairmanship of Professor Tim Briggs. GIRFT has been designed to improve patient care, by reducing unwarranted variations in clinical practice. GIRFT helps identify clinical outliers and best practice amongst providers, highlights changes that will improve patient care and outcomes and delivers efficiencies (such as the reduction of unnecessary procedures) and cost savings.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience.

GIRFT Projects at the Royal National Orthopaedic Hospital (RNOH/GIRFT), like GIRFT in NHSE, is under the chairmanship of Professor Tim Briggs. RNOH/GIRFT was commissioned by the NHS England prevention team to support the implementation of the National TB Action Plan for England 2021-2026 by conducting a GIRFT review of TB services in England.

The review was clinically led by **Martin Allen**. Martin is the GIRFT Respiratory Clinical Lead, Consultant physician for respiratory services at University Hospitals of North Midlands NHS Trust, and NHS National Specialty Adviser for physiological measurements (See biography in **Annex B**).

4.1 Objectives of the Review

The objectives of this review were to:

- identify how different services are providing TB care, including prevention, detection

and control, and reflect this back to each provider
- identify good practice for TB
- help to reduce diagnostic and patient delays
- gain a better understanding of TB workforce models
- improve TB services through appropriate rationalisation and service transformation that future proofs TB services
- assess the restoration of services post Covid 19 and how they have changed

The review supports the delivery of the National Latent TB Testing and Treatment programme and the TB Action Plan for England 2021-2026.

4.2 Methodology

Our approach was based on the methodology developed by GIRFT which uses data to identify the impactful and high priority opportunities for transformation. This includes opportunities to generate re-investment savings, improve service quality and address unwarranted variation in practice and / or spending.

The scope of the review was to look at TB service providers whether they were based in secondary care or in a community setting, and to look at the engagement within TB systems of ICBs.

4.3 Phase 1 of the Review

The first phase of the review was the identification of data sources that were available and how to gain access to them in the key areas we wished to review. For many areas there were gaps in knowledge and information, especially around the process of care and workforce numbers in relation to levels of service activity.

To fill this information gap, a series of draft questions were developed, focused upon the key deliverables of the TB action plan, for example, recovery from Covid and reasons for treatment delays. Using Delphi methodology, the questions were shared with clinical colleagues, discussed in meetings and in offline reviews, modified and then discussed again, with several consultant colleagues taking responsibility to develop areas. The process was then repeated several times until the questions were refined and no further modifications were necessary. The questions were structured into the following themes:

- Staffing/workforce
- Bacillus Calmette–Guérin Vaccine (BCG)
- Preventative Treatment
- Organisational Support and Infrastructure
- Screening Services
- Diagnostics
- Contact Tracing
- Inclusion Health
- Management of TB

We also reviewed the already developed links and pathways into and out of secondary care and the effectiveness and usage of these.

There were 170 questions in the survey, with an additional separate section to be completed by nursing and support staff workforce. These questions were shared with the following key stakeholders to gain agreement:

- Representatives of the Specialty Advisory Group (SAG) of the British Thoracic Society (BTS)
- The National TB Nurse Network of the BTS
- NHS England
- UKHSA TB Surveillance Team
- Several TB providers
- TB specialist nursing leads

Once the survey questions were confirmed they were developed into a 'webform' which was shared with the main contacts within each TB service. To provide more information and to encourage participation, we held a webinar to launch the TB Review on 29th June 2023. We also set up a dedicated mailbox to ensure effective communication and engagement during the review.

4.4 Results of the Returns

The duration of the work was from January 2023 through to September 2024. The review used the full dataset for 2022 for TB data returns, with the survey responses aligned to this period. Over this period there were 4000 TB notifications in England.

We issued surveys to the 120 TB services in June 2023 for completion by 31st August 2023, with an extension of an additional 2 weeks due to the summer holidays. We were delighted to receive a high volume of returns of 117 in total.

4.5 Data pack production

Over a course of several meetings the information from the survey, the NTBS and HES data were assimilated into a data pack. This included information on basic epidemiology for the provider and further data collated into themes. For ease of use, histograms were used to express where the provider stood against their peers and the "mean" and charts were developed where data was available from NTBS. A bespoke datapack for each participating TB provider was produced so they could benchmark their service against the other providers on the various different metrics and dimensions. To facilitate interpretation of the 200 page data pack, a 'core' data set was pulled from the data and placed at the start of the pack.

We held a second national webinar on 15th February 2024 timed with the issue of the datapacks to provide a 'tutorial' on how to interpret them.

We also developed datapacks at ICB level to inform them about the current service provision within their region. The ICB datapacks were issued to each ICB and to each provider within that ICB.

The table in **Annex D** shows the services providers who participated in the survey.

4.6 Phase 2: Clinical Lead 'Virtual Deep Dive' Visits

In order to validate and explore the data, the RNOH/GIRFT clinical lead undertook 20 virtual 'deep dive' reviews with TB providers. These were selected based on the details in the datapacks, including the geography of the provider (rural vs urban) and the number of TB notifications. We asked for a broad attendance at the virtual deep dive reviews from all staff

delivering TB services including: the service lead consultant, the lead TB nurse, Infectious Disease (ID) leads, CYP (Children and Young People) consultants, microbiology staff, pharmacy staff, administrative staff, UKHSA colleagues, and ICB and acute provider managers and service leads.

The virtual deep dive reviews lasted between 2 and 4 hours and engagement was excellent. There was a set process for the reviews in which the service leads were invited to present 'what worked well' and' what their issues were' before exploring the datapack in detail with Martin Allen and focusing on any unwarranted variation, as well as identifying and recognising areas of good practice. The schedule of visits and the link to the Key Lines of Enquiry (KLOE) we used are in **Annex C**.

4.7 Communication and Engagement

We delivered a series of communication and engagement activities throughout the lifecycle of the review including:

- An information leaflet to all stakeholders providing information about the review
- A fortnightly Project Team Meeting which included colleagues from RNOH/GIRFT, NHSE and UKHSA
- A national webinar on 29th June 2023 to launch the survey
- Regular TB Review Updates which provided progress on the review at each key stage
- A second national webinar to explain and aid understanding of the datapack on 15th February 2024
- A stakeholder workshop to develop and agree the content for this report
- A final webinar on 26th September 2024 to outline the key findings from the review

5 Summary of Recommendations

Please note that all the recommendations in this report are listed in this section for your reference. We have identified who we think should have responsibility for implementation of each recommendation using the key below.

Table 1: Key

P	Provider (TB Service)
ICB	Integrated Care Board / system
LA	Local Authority
R	NHSE regional team
N	National

Table 2: All Recommendations by Section

Recommendations in relation to NHSE, Region and ICB Policies

Recommendations	Resp.
1. All providers to have a policy that meets national recommendations for delivering a TB service and must include a section on preventative treatment.	P, ICB
2. There should be (at least) a bi-annual meeting with TB service leads, their managers and the ICB/LA to address and resolve issues. While not	P, ICB, LA

comprehensive and covering all aspects, it should include a. provision of a workforce sufficient to deliver a service, as outlined in the TB Action Plan b. assurance that all individuals eligible for latent TB screening are assessed and managed c. agreement re capturing and coding activity that should be reimbursed as per the national payment system d. plans for managing drug shortages within the ICB and region.	
3. ICBs and LAs should have a nominated lead clinician and a lead commissioner for TB, including NTM.	ICB, LA
4. When outbreaks occur supporting staff and / or resources need to be made available from acute providers, commissioners and LA / Public Health to support services, to ensure the routine care and operation of the TB service is not compromised. This can include additional funding, administrative support and other areas such as press liaison.	P, ICB, LA
5. Regions and ICBs should work together to facilitate ICBs commissioning and supporting development of large services that are providing regional or supra regional activity through a pan ICB commissioning model, e.g. through the relevant ICBs agreeing a lead ICB for the development of TB services. The benefits of this cannot be underestimated in providing high quality but local care, especially in the low prevalence areas where skill sets to deal with TB may be limited, especially in NTM, MDR/XDR and complex care, be it due to social risk factors or medication related problems. Where skill sets are limited, e.g. in low prevalence areas, development of TB networks should be established across ICBs and supported or organised by regions depending upon the local circumstances.	R

Recommendations in relation to Underserved Populations

Recommendations	Resp.
6. Each ICB and local authority should have clear 'standard operating procedures' for supporting the many facets of TB care, as identified above. This should be by a named individual who has responsibility for liaison within the ICB /LA for these aspects and should not depend on TB nurses continuing to seek action, specifically around substance misuse, benefits and housing.	ICB, LA
7. Work should take place nationally with the Health and Justice Department to consider commissioning arrangements to improve the assessment and management of individuals to determine their risk of tuberculosis.	P, ICB, R, N
8. Closer working between the prison health service and TB teams would help all parties by ensuring: 1) better information about when patients are being moved and to where 2) appropriate anti-tuberculosis drugs are used and potential interactions managed 3) bi-lateral education between TB teams and prison staff will improve	P,R

knowledge and understanding 4) Access to prisons by TB staff can minimise the need for patients to be escorted in acute providers for review	

Recommendations in relation to Diagnosis of TB and Delays in TB Management

Recommendations	Resp.
9. All TB services need to review the reasons for delayed diagnosis and undertake remedial action where there are systematic failings. This should be a feature of regular cohort reviews, taking note of the common reasons in **Table 4** and should be discussed with ICBs / service commissioners to address any shortcomings.	P, ICB, LA
10. Consideration needs to be given for the improved availability of smears in higher prevalence areas. All services should strive to culture samples for the reasons stated above, recognizing the laboratory standards that should be met	P
11. Although not part of the review, the infrastructure to support microbiology in both staff and equipment should be reviewed by providers and ICBs. This could include access to rapid PCR testing, and the Xpert program.	P, ICB
12. There should be an SOP for undertaking bronchoscopy for diagnosis, ideally in a negative pressure facility with appropriate precautions to minimise risks to staff.	P
13. Provision of negative pressure facilities for induced sputum should be available together with the trained staff, for all age groups	P, ICB
14. Turnaround times for IGRA testing should be appropriate for service delivery.	P, ICB
15. An SOP should be in place to ensure TB services are informed of potential TB infection from radiology, microbiology and pathology (histology) services.	P

Recommendations in relation to the NTBS and Data Flow

Recommendations	Resp.
16. NTBS should be updated to clarify definitions, including symptom onset, recognising that resources are needed for this and including clinical service users.	N
17. NTBS should separate VOT and DOT into two categories.	N
18. NHSE should support the development of a clinical platform, possibly commercially, that is a unified data management system for TB that interacts and uploads information between hospital systems and NTBS while adding communication, differentiating that NTBS is a surveillance platform and very different from a clinical management system.	N

Recommendations in relation to Coding and Payment Mechanisms

Recommendation	Resp.
19. A new treatment function code for 'Tuberculosis service' should be established with a tariff to be determined but similar to that of respiratory medicine for new and follow up activity.	N
20. All services need to meet with the provider management and coding departments to ensure nursing activity is captured using the correct OPCS that map to the HRG Dz41z. If this cannot be captured electronically then	P

paper templates that are uploaded by clinic administrative or coding staff should be used.	
21. Activity around contact tracing, DOT and VOT should be captured mapping to the Dz42z with a mandatory tariff.	P, ICB
22. ICBs need to recognise this activity and ensure payment as per the national tariff payment mechanisms. If new payment systems are developed, TB activity should be paid at tariff. Any new OPCS codes for preventative treatment which are being considered would need to be included in this payment system in the future. Acute providers need to recognise the income and ensure it is hypothecated into TB services.	P, ICB
23. MDTs and cohort reviews are a key aspect of delivering and improving care. The attendance should be formally recorded and mechanisms developed to capture the activity for reimbursement	P, N, ICB

Recommendations in relation to Education and Training

Recommendation	Resp.
24. SPA time for providing education and training from medical students through to qualified health care professionals needs to be recognised and embedded in medial job planning. A similar recognition should occur for nursing and pharmacy staff.	P
25. A regular series of lectures and seminars need to be provided to appropriate staff. We recommend at least an annual presentation to primary care as part of their CPD and a biannual presentation to acute medicine and emergency departments that should occur not long after the new staff intake, with at least an annual to biannual 'grand round'. These should especially be in place in low prevalence areas of TB to maintain the high index of suspicion. Less formal lectures and education to the wider ICB and LA is helpful in promoting their understanding of the issues.	P, ICB, LA
26. There are numerous education and training opportunities during service delivery, e.g. internal, regional (where they exist) MDTs and cohort reviews. These should have an educational as well as service function and therefore attendance is required by both established staff and those in training across all professions, with recognition in job plans / scheduled time.	P
27. National Societies, Royal Colleges together with regional groups need to ensure there is adequate courses available for medical, nursing staff and other relevant staff groups to attend. These should include formal lectures / symposia but also small group working to enable discussion of the very practical aspects of TB care.	P, N
28. There needs to be access to appropriate budgets with time allowed to attend courses specifically for nursing staff. This activity should formally document their CPD as a requirement for revalidation.	P, ICB
29. For nursing staff who've recently been appointed formal training programmes which have a combination of lectures and practical exposure need to be enhanced and of an appropriate level and cost to allow attendance.	P, ICB, N
30. We noted numerous examples of excellent information from both national and locally developed sources, often in multiple languages. NHSE should take responsibility for acting as a repository for this information which should be freely available to all parties with no cost.	N
31. Education in TB needs to be established in the undergraduate curricula of all medical schools and in the postgraduate curricula of doctors in training,	N

with a particular emphasis in specialties that have a role in managing tuberculosis in its widest sense. For those individuals undertaking Higher Speciality Training in respiratory and infectious diseases it should remain a core element of training.	

Recommendations in relation to Research & Academia

Recommendations	Resp.
32. In light of the burden TB produces across the world national and local grant giving bodies should ensure TB applications are available and publicised. The research should not only be international and original but evaluation of services and clinical care, including new diagnostic and treatment interventions. Support from equipment manufacturers and pharmaceutical companies should be welcomed to work collaboratively with clinical services, ideally multiple ones as part of a TB research networks.	N
33. Service evaluation / clinical research should have a higher profile and should form part of all departments modus operandi. Such research should be recognised for the importance it has of improving care and should receive funding from grant giving bodies. Coordination of this clinical evaluation should take place possibly supported by specialist societies and charitable organisations to ensure clinical 'buy in'. Supporting staff in training, both medical, nursing and others e.g. pharmacy to participate in academic activity should be recognised and supported, as noted above with dedicated nurse time.	P, R, N
34. TB services should aim to be more collegiate in how they work across ICBs, regions and nationally ideally via funded clinical research networks to support clinical service evaluation. It is important to recognise the support and funding that can take place with commercial companies and supporting this work in the TB service is essential for evaluation of new interventions.	P, ICB, LA, R, N
35. Qualitative research is an important aspect of improving TB services. An example that should be followed is the patients and carers views of the TB service they receive. This should include all individuals who have exposure to the TB service, i.e. those with active disease, contacts thereof and the wider population being evaluated for and receiving preventative treatment. Depending upon the size of the service such a review should take place annually or biannually to help inform clinical, managerial and commissioning decisions within the TB services. Such a practice was described during one of the visits and the impact on improving the patient journey and satisfaction was clear.	P, ICB, LA

Recommendations in relation to Inpatient Management

Recommendation	Resp.
36. For cases where code Dz51z is used ICB commissioners may wish to validate its correct use.	ICB
37. All providers should have SOPs / IPC policies for dealing with potentially infectious TB.	P, ICB
38. If patients are to be admitted with potentially smear positive disease providers should ideally have negative pressure facilities on site. If MDR/XDR is suspected / confirmed patients should be transferred to a facility with negative pressure rooms and appropriate expertise in clinical	P, ICB

management.	
39. All patients admitted with tuberculosis should be reviewed by the TB nurse to ensure appropriate contacts are recognised and support information and education is provided, together with ensuring the correct medication is being taken. Patients should not be discharged until this review has occurred.	P, ICB
40. When patients with known tuberculosis are admitted under another specialty the TB team should be informed and review considered. Any planned follow up appointments with the TB service should not be cancelled.	P
41. Patients discharged from the wards on TB medication should have their treatment reviewed by the lead TB pharmacist or their deputy to ensure medication has been both written up and dispensed appropriately.	P
42. For patients who are having a biopsy / surgical procedure where TB is a possibility should have samples sent in the appropriate medium to allow potential identification and culture.	P
43. As noted in the education section 6.10 the lead tuberculosis clinician should be providing education to acute providers acute provider clinicians to maintain a high index of suspicion.	P

Recommendation in relation to Outpatient Management

Recommendation	Resp.
44. Consideration needs to be given to the estate from where TB services operate, and should include sufficient clinic (nursing and medical) and administrative space, easy access on bus routes, free car parking and located by high prevalence areas when appropriate with imaging and phlebotomy collocated. Space must be sufficient for undertaking visual assessments, there should be strict IPC procedures in place which include air exchanges per hour for clinics. Language interpretation facilities need to be established and these should be available for both routine and ad hoc clinics.	P, ICB
45. Beyond the clinic there should be sufficient space for the nursing and admins staff to have a formal base, where there should be sufficient phones, computers etc. Additionally, nurses should be able to access ad hoc clinics, ideally close to their working base.	P
46. Nurses should be mentored and encouraged to become prescribers and to go through appropriate training to be able to request chest radiographs.	P

Recommendations in relation to Medicines Management

Recommendations	Resp.
47. A senior pharmacist of bands 7 or greater should be attached to and support the TB service. The amount of time required should be on a pro rata basis for the potential workload based upon both notifications and the preventative therapy population. Recognition of their role in XDR/MDR and NTM should be included together with time in job plans to attend internal MDTs and cohort reviews. The role of pharmacy support for regional MDTs needs to be included in the future development and funding of such services.	P, ICB
48. The senior pharmacist should also provide support and education for ward-based pharmacists when tuberculosis expertise is not available, support the dispensing pharmacists, TB nurses as they gain their skills and	P

qualifications in nurse prescribing and medical staff.	
49. The pharmacist should work with local, regional and national teams to provide advice and support, including to the system, when there are shortages of anti TB medications.	P, ICB, R
50. The pharmacist should work with dispensing teams and the TB service to ensure that information given to patients is appropriate in both language and content, recognising that some individuals on active or preventative treatment may not be able to read. The use of pictograms and other information should be routine option.	P
51. Drug shortages are a major issue for the TB service and need to be recognised nationally. There should be a national infrastructure to minimise future drug shortages, ensure there is a clear cascade of information centrally from NHSE via pharmacists if there are potential shortages. Plans should be in place across regions and nationally for shared support and to minimise stockpiling.	R, N

Recommendations in relation to Directly Observed Therapy and Video Observed Therapy (DOT & VOT)

Recommendations	Resp.
52. There be sufficient administrative staff to ensure that if DOT or VOT is given this is captured on both NTBS and provider activity.	P, ICB
53. There should be sufficient work force to deliver DOT or VOT when clinicians deem it is needed. For DOT activity HCSW have a major role in supporting this intervention.	P, ICB
54. In wide geographical areas VOT should be considered or alternative methods of delivering DOT e.g. by use of local pharmacies need to be explored and supported potentially financially by ICBs.	P, ICB
55. If VOT is used by commercial companies / independent providers / external services the ICB should support the financial aspects.	ICB
56. Ideally infrastructure should be in place to deliver local VOT. This requires the appropriate staff, sufficient phones and resolution of IG issues.	P, ICB

Recommendations in relation to Non Tuberculous Mycobacteria (NTM)

Recommendations	Resp.
57. The NTM recommendations from the NTM Network UK Standards of Care should be adapted to local services and implemented within an appropriate time line.	P, ICB
58. Services should review their provision and infrastructure for NTM and develop formal business plans, in conjunction with their host provider and the ICB, to deliver an NTM service.	P, ICB
59. Discussions should take place with NHSE, BTS and regions on the development of regional and or national advice to help support the management of NTM, given the difficulties of treatment outlined and potential for use of high cost drugs.	R, N

Recommendations in relation to MDR/XDR Multi drug resistant mycobacteria (MDR) / Extensively drug-resistant tuberculosis (XDR)

Recommendations	Resp.
60. The BTS clinical advisory service for MDR/ XDR service is of great benefit	N

to clinicians and needs to be continued, appreciating the need for external funding.	
61. Consideration needs to be given between NHSE and BTS whether the service should continue to provide advice on the management of non MDR/XDR patients, recognising from this data there is a clear need. A view should be taken if the service moves to become a clinical advice service that includes 'difficult problems' as well as MDR /XDR if this should include NTM, given that similar complex drug regimens and interactions occur, recognizing that such developments would need to be supported financially nationally	N

Recommendations in relation to Children and Young Person Services (CYP)

Recommendation	Resp.
62. While there is no set figure, we would suggest that where there greater than 10 CYP notifications, with the commensurate contact tracing, a paediatrician with knowledge and interest in the management of tuberculosis should be part of the TB team. With fewer cases access to an infrastructure at regional level need to be available for advice and support.	P,ICB, R
63. Ideally one of the TB nurses dealing with CYP should be trained in child health.	P
64. Resources to support the management including the diagnosis of CYP should be in place, this includes both infrastructure and time in job plans for SPA and DCC time to support MDT attendance.	P, ICB
65. A regional network to support colleagues where there are relatively few notifications, contacts or latent TB should be established on at least a regional basis. This should also provide advice for MDR/ XDR and difficult cases. To facilitate there needs to be time in medical job plans, nursing and A&C time to support a regular MDT, the frequency of which would be dictated by activity and local competencies at managing CYP TB.	P, ICB, R

Recommendations to Bacillus Calmette-Guerin (BCG)

Recommendations	Resp.
66. Ensure appropriate recording of BCG vaccination when it is administered by the TB team to ensure the activity is both captured and feeds into the HRG for potential payment, as per section 6.9.	P
67. Any repatriation of the BCG from maternity to the TB service needs to come with appropriate resources.	P, ICB

Recommendations in relation to Contact Tracing

Recommendations	Resp.
68. The ambition of the TB Action Plan to have five or more contacts per infectious case needs further support within organisations and staffing to deliver the shortfall. This probably needs active management as seen from the data.	P, ICB, N
69. There needs to be information for contacts and carers in an appropriate format and language that explains the rationale of contact tracing to support attendance and adherence.	P, ICB, LA
70. Services should consider the optimal way, for their population, the best method of delivering services for adults and CYP, be this family clinics,	P, ICB

evening clinics, remote follow up etc.	

Recommendations in relation to Latent TB and Preventative Therapy

Recommendations	Resp.
71. Any service needs to be developed in conjunction with the acute provider and ICB. Irrespective of the model there needs to be sufficient capacity to deliver the latent service without impacting on the basic care of notified patients and the contacts.	P, ICB
72. Appropriate codes need to be authored in OPCS to capture latent TB activity and used for reimbursement to ensure any services is financially sustainable.	P, N
73. Migrants, including asylum seekers, need to be identified and have access to an appropriate LTBI program. In some services there needs to be improved coordination with all parties re arrival / dispersal and to where, with better data flows.	P, ICB, R, N

Recommendations in relation to Workforce Issues in the Management of Tuberculosis

Recommendations	Resp.
74. All staff should participate in the internal MDT and cohort reviews which need to be recognised as DCC in medical job plans and timetabled in nursing and administration staff.	P, ICB
75. Ideally when there is no paediatrician involved in the service, which occurs in over one third of services a paediatric trained nurse should be part of the TB team.	P, ICB
76. In light of the increasing workload all services should undertake a review of their nursing infrastructure to ensure it is fit for purpose based on these recommendations.	P, ICB
77. A key aspect of these recommendations is the recruitment of HCAs to support qualified nursing staff to function at top of license.	P, ICB
78. Consideration needs to be given to specific support and education of HCAs in delivering TB care with appropriate training, ideally on line, and with a formal qualification.	P, ICB, N
79. Administrative staff play a key role and these should be embedded in the TB service and be of significant seniority to be able to support nursing and medical staff, including the update of NTBS, e.g. treatment completion.	P, ICB
80. For latent / preventative services TB teams should have the infrastructure in place, pro rata, to deliver the service. This staffing model is applicable for dealing with positive IGRA tests, details are in section 8.3. Where services are involved in reviewing patients in primary care, doing the IGRA then acting on the results then additional resources are required.	P, ICB
81. All services should review their staffing infrastructure against table 8 and the footnote, identify gaps and produce a remedial plan to address shortfall within 4 months.	P, ICB

6 Policy and Payment

This section covers what policies exist in managing TB, and explores important aspects of underserved populations and why there may be delays in management. Included in this section are our findings around data flows and how such data influences payment mechanisms for services.

6.1 Overview of clinical services and policy

There are several existing policies and guidelines for management of TB published by specialist societies such as the BTS, Royal College of Nursing (RCN), The National Institute for Health & Care Excellence (NICE) and also from NHSE and UKHSA. The latter includes plans for managing latent TB and importantly the TB Action Plan 2021 to 2026. This key document has 5 priority areas, namely:

1. Recovery from COVID
2. Prevent TB
3. Detect TB
4. Control TB
5. Workforce.

Against these five priority areas are several actions with outcomes and, which key stakeholders and partners should be involved in delivery.

This is an important document that provides the vehicle for change and aspects of this have been reviewed both within the development of our survey and throughout this report.

6.2 Data and Information about Policies and Funding

Data from the survey shows that 59.4% of TB services are hosted by acute providers, 8.5% are community based and 31.1% are a combination of acute provider and community.

In 70.1% of the returns the services had a policy or Service Operating Policy (SOP) that had been agreed between the service provider and the ICB, although that left 25.2% where there was no agreed SOP and 4.7% not knowing if they have a SOP.

The majority of the SOP's had been developed by the acute provider (24.8%) or jointly in 27.6% of those asked, 7.6% being developed by the ICB in isolation and 8.6% developed by the local authority (LA) & public health (**See slide 25 in the National Dataset - a link to this can be found in Annex C).**

When asked about a policy for screening international health workers, there was a more varied response, being present in 47% of services surveyed, though in the deep dives it was clear that often the absence of a policy was because that was delivered by occupational health or another provider, with the TB service reviewing patients when needed. However, policies and SOPs for managing preventative treatment were more variable and present in only 59% of services.

From a funding perspective there was concern (as shown in **Figure 1**) that the funding did not match the service need, with 52.6% saying there were insufficient funds to deliver the TB Action Plan. These concerns did not seem to relate to the size of the service and may reflect the rapidly increasing demand at the time we collected the data. Demand had increased as a result of higher notifications and subsequent contact tracing, TB issues with the asylum and migrant population, an increase in those patients who are being screened as a consequence

of a rapid expansion of biological therapies (with the demand falling on TB services) together with the additional work required to both screen, and manage the outcomes of this screening, of the larger numbers of staff being recruited internationally across the health service.

Fortunately, outbreaks over the last 3 years in schools, prisons, asylum seeker hostels and health care workers are uncommon. With respect to outbreaks in asylum seeker hostels, we noted that two showed high proportions of 66.7% and 40%, but on closer review, the data was shown to be spurious, as the first hostel, a community trust had 2 notifications, of which 2 were asylum seekers and the second also had 2 asylum seeker notifications out of a total of 5. Outbreaks are important as these put further pressure on services that are already under resourced. We noted that just under half of the providers have no additional support to help manage outbreaks and there was no additional funding from commissioners in 40% of outbreaks.

6.3 Regional Issues

An important and neglected aspect is when the TB service also has a regional role. The acute provider is reluctant to fund additional clinical time for seeing patients 'out of provider' and the ICB is often unaware of patients attending these regional or sub-regional clinics or being discussed at MDTs (Multi-Disciplinary Teams). Furthermore, the administrative staff required to organise meetings and subsequent communication to run a regional infrastructure is often absent or unfunded.

Whilst we heard about some examples of good engagement with the ICB, and LA / public health, with one public health consultant working across all areas, we also heard of many examples where the ICB / LA were not engaged and did not attend any meetings with the TB teams and their service managers. This led to problems and lack of understanding when the expansion of or a change to TB services needed to be discussed. In one example we were told that as funding had not been transferred into the acute provider, this had resulted in the closure of the centrally funded Latent Tuberculosis Infection (LTBI) programme, with a second service considering cessation. Such a breakdown in communication is unhelpful when attempting to provide holistic care and regular meetings should occur.

We saw numerous examples where oversight by experienced teams is required for complex patients who need a high level of enhanced case management (ECM). This may include advice for multi drug resistant mycobacteria (MDR) and extensively drug resistance of mycobacteria (XDR), where we found the specialised commissioning service recognise the activity and pay for drugs as a 'pass through' cost but do not support the additional time required for managing such patients. The example above of MDR/XDR is illustrative of similar issues found of non-tuberculous mycobacteria (NTM) and CYP services.

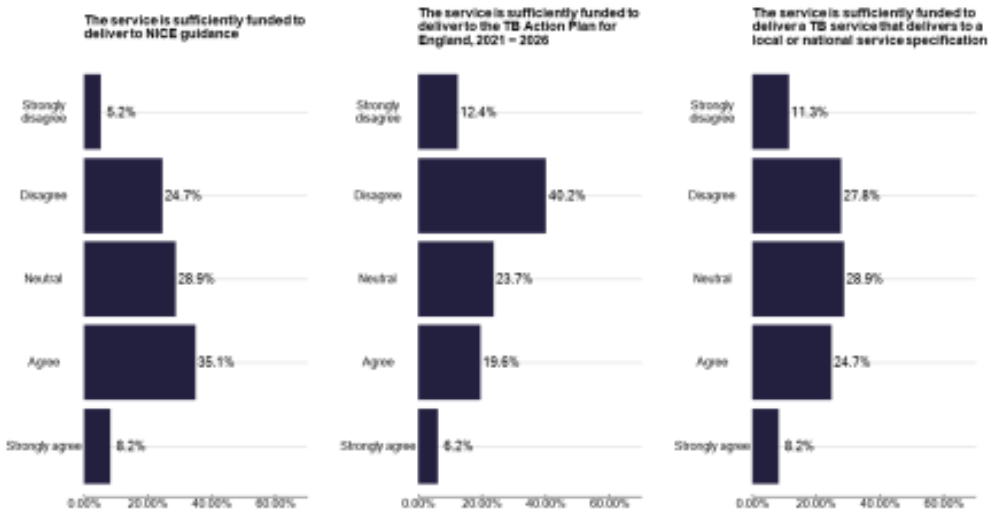
We found one service delivering excellent TB care via CYP, ID (Infectious diseases) and respiratory TB services in two large acute hospitals under one ICB with a population of around 900k. They provide ad-hoc phone advice, clinical support to colleagues (including seeing patients), and a regular regional MDT, with excellent communication covering a population of 2.5 million. For this supra ICB regional service, however, they receive no extra funding.

This regional responsibility existed in all the large services visited and needs to be recognised, supported and developed to prevent the collapse of these essential services. Whether this is developed by the region or a lead ICB with cross ICB financial support would need to be agreed for each network.

This 'regional oversight' is especially important when there are new consultant appointments with little experience of managing TB and / or in low prevalence areas where staff have little experience of managing TB. We noted that one large service, although unfunded, was attempting to support services along the lines of a managed clinical network, a concept that needs further development together with appropriate funding. If, for a variety of reasons, a TB service standard cannot be delivered, services should work with adjacent providers, ICBs and regions to support the service. Examples may include: additional staff, staff from other providers doing sessions in that provider, a more formal network being established etc. Funding for this should be discussed between providers, ICBs and the NHSE Region.

Figure 1 – Funding

The opinions of providers surveyed about the income that was sufficient for their service to deliver against specific policies.



Recommendations in relation to NHSE, Regional and ICB Policies

Recommendations	Resp.
1. All providers to have a policy that meets national recommendations for delivering a TB service and must include a section on preventative treatment.	P, ICB
2. There should be (at least) a bi-annual meeting with TB service leads, their managers and the ICB/LA to address and resolve issues. While not comprehensive and covering all aspects, it should include a. provision of a workforce sufficient to deliver a service, as outlined in the TB Action Plan b. assurance that all individuals eligible for latent TB screening are assessed and managed c. agreement re capturing and coding activity that should be reimbursed as per the national payment system d. plans for managing drug shortages within the ICB and region.	P, ICB, LA
3. ICBs and LAs should have a nominated lead clinician and a lead commissioner for TB, including NTM.	ICB, LA

4. When outbreaks occur, supporting staff and / or resources need to be made available from acute providers, commissioners and LA/Public Health to support services and to ensure the routine care and operation of the TB service is not compromised. This can include additional funding, administrative support and other areas such as press liaison.	P, ICB, LA
5. Regions and ICBs should work together to facilitate ICBs commissioning and supporting development of large services that are providing regional or supra regional activity through a pan ICB commissioning model, e.g. through the relevant ICBs agreeing a lead ICB for the development of TB services. The benefits of this cannot be underestimated in providing high quality but local care, especially in the low prevalence areas where skill sets to deal with TB may be limited, especially in NTM, MDR/XDR and complex care, be it due to social risk factors or medication related problems. Where skill sets are limited, e.g. in low prevalence areas, development of TB networks should be established across ICBs and supported or organised by regions depending upon the local circumstances.	R

6.4 Underserved Populations

While not a specific focus of the review, we noted variation in care delivered to the underserved populations, which are those populations with additional needs e.g. substance misuse, prison populations, homeless etc.

We found some excellent examples of holistic care in some TB services, while for other services we found that the lead TB nursing staff were spending hours attempting to identify the appropriate support for patients within an ICB/LA. Whilst not all services had a prison within their catchment area, we did note that prisons, which are part of the health and justice department arrangements, seemed an issue for some TB services (see section 6.5).

6.5 Enhanced Case Management (ECM)

There were many comments during our review about managing patients, contacts and others needing preventative therapy with complex needs, usually defined using the RCN (Royal college of Nursing) criteria. The volumes of these are shown in **Figure 2 and 3,** with the extent of ECM not directly relating to the size of the service **Figure 4**.

Information from NTBS showed that the number of notifications where mental health issues, alcohol or substance misuse was a major problem were relatively few although data quality issues may play a role if NTBS were notified about this information at a later date.

To support patients from a social perspective an infrastructure is needed, which the TB service will have a point of contact for relevant social services e.g. drugs and alcohol, homelessness etc. but we were told that these were frequently lacking from the ICB and LA perspective and absent in 66% of services. There is the excellent examples of a hostel in London for patients but variability in provision within ICBs/LAs, with a large teaching hospital having poor provision of holistic care while an adjacent acute provider within the same ICB provided comprehensive support.

Figure 2 – Percentage of patients requiring ECM

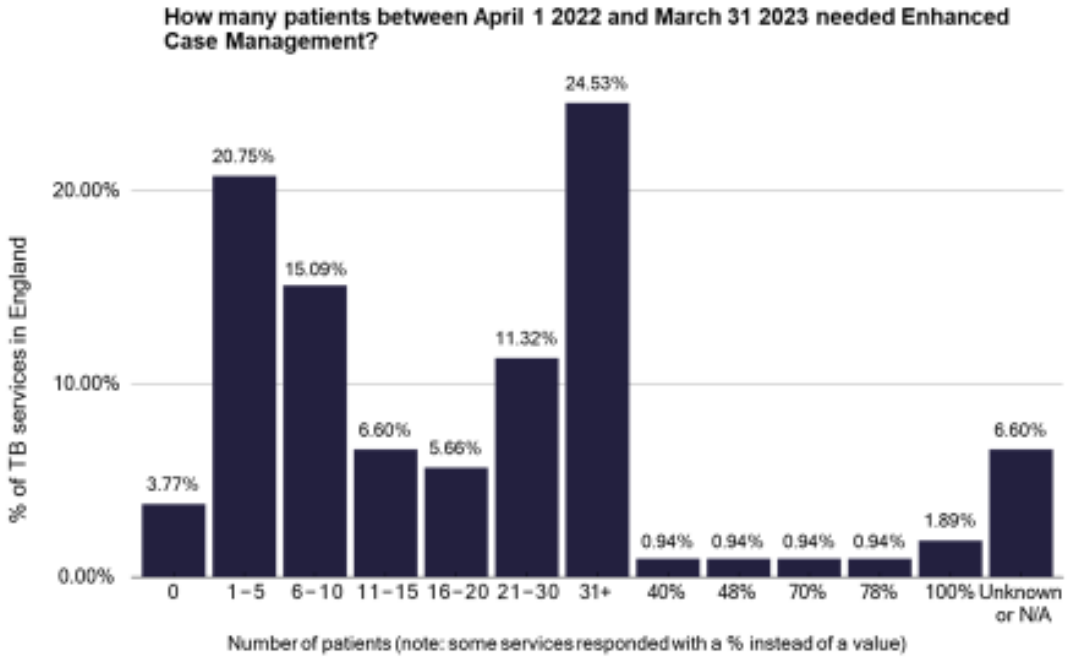


Figure 3 – Percentage of patients on LTBI treatment requiring ECM

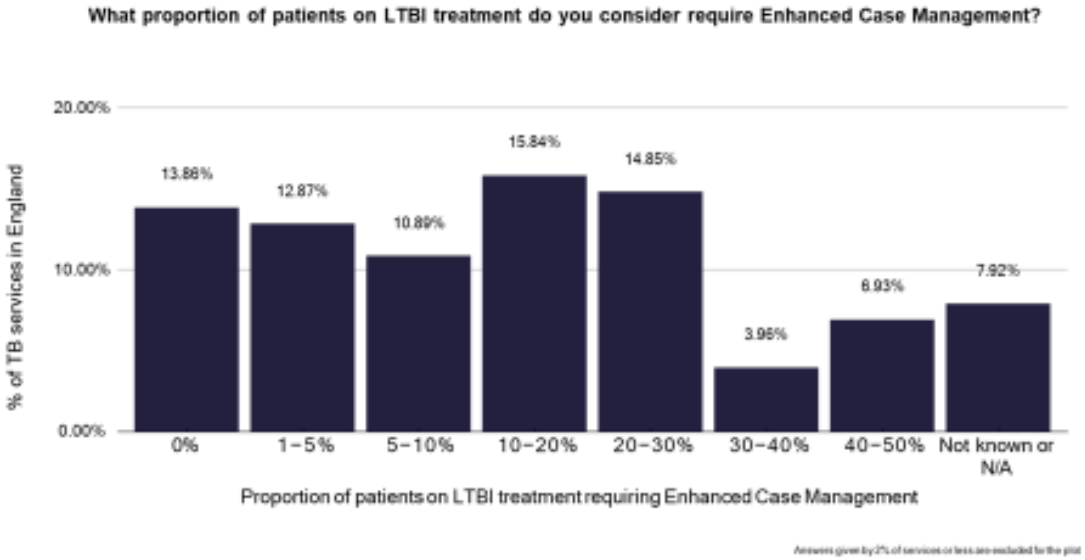
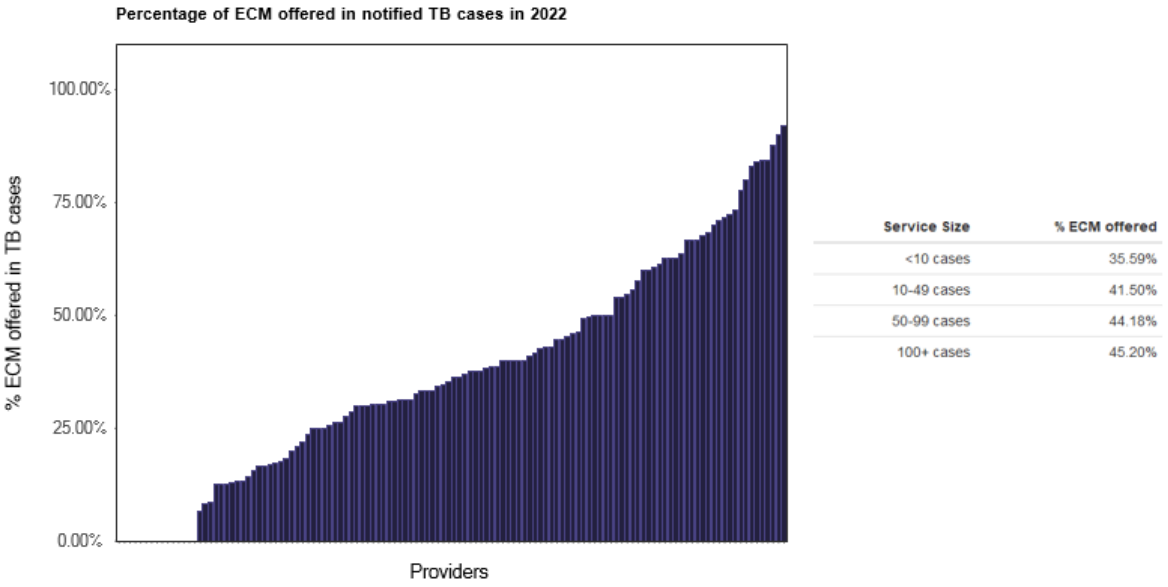


Figure 4 – Percentage of ECM offered in notified TB cases



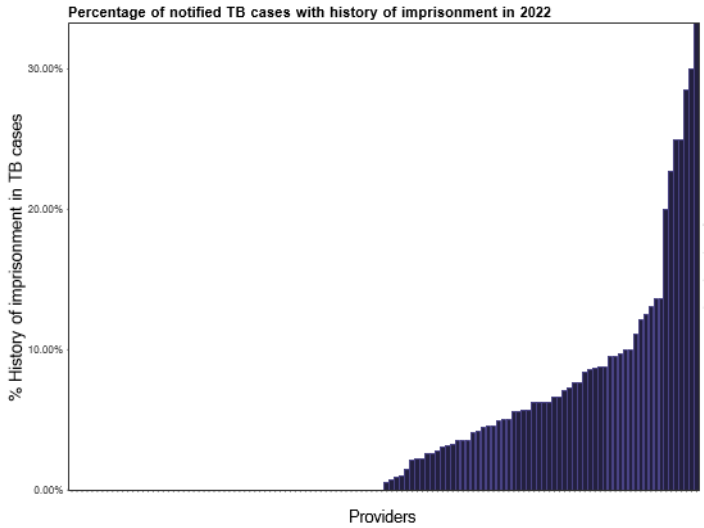
Service Size	% ECM offered
<10 cases	35.59%
10-49 cases	41.50%
50-99 cases	44.18%
100+ cases	45.20%

6.6 Prison Related TB Issues

An area that caused some concern was the prison population as in **Figure 5**. We were told that when there are TB patients moving between prisons this can lead to poor continuity of care, but more importantly, the overall initial assessment for potential TB was not as robust, and a sharp contrast from the HIV infrastructure that exists. This was commented on by an ID physician who supports both a HIV and a TB service. We also noted the difficulty TB nurses sometimes have in gaining access into prisons to support TB patients.

There is a review of the prison TB services underway which we hope will stress the importance of assessing for TB in a similar way to that for the prison HIV service. Supporting prison health staff in understanding TB management is important and we heard examples where TB staff were visiting prisons to provide education. There are opportunities to minimise travel by exploring options for remote education between service providers and the justice department, covering prisons, detention etc. and for remotely reviewing patients.

Figure 5 – Percentage of notified TB with history of imprisonment



Service Size	% with imprisonment history
<10 cases	3.95%
10-49 cases	4.80%
50-99 cases	2.93%
100+ cases	3.04%

Recommendations in relation to Underserved Populations

Recommendations	Resp.
6. Each ICB and local authority should have clear 'standard operating procedures' for supporting the many facets of TB care. This should be by a named individual who has responsibility for liaison within the ICB /LA for these aspects and should not depend on TB nurses continuing to seek action, specifically around substance misuse, benefits and housing.	ICB, LA
7. Work should take place nationally with the Health and Justice Department to consider commissioning arrangements to improve the assessment and management of individuals to determine their risk of tuberculosis.	P, ICB, R, N
8. Closer working between the prison health service and TB teams would help all parties by ensuring: 1) better information about when patients are being moved and to where 2) appropriate anti-tuberculosis drugs are used and potential interactions managed 3) bi-lateral education between TB teams and prison staff will improve knowledge and understanding 4) Access to prisons by TB staff can minimise the need for patients to be escorted to acute providers for review	P,R

6.7 Diagnosis of TB and Delays in TB Management

Improving the diagnosis culture positivity and reducing delays in diagnosis and starting treatment are key aspects of the TB Action Plan.

Based on NTBS returns, the delays from symptom onset to treatment are shown in **Figures 6 and 7** for pulmonary and non-pulmonary disease respectively. However, this data may be open to misinterpretation because when asked about this during visits, colleagues were uncertain what defined symptom onset (though it does show a flatter relationship across providers for pulmonary over non pulmonary).

In two of the deep dives, where there was a delay in diagnosis for non-pulmonary we were told that these both related to ophthalmic TB. Identifying delays in diagnosis is important and 93% of those surveyed confirmed that they look for reasons for delay including in cohort reviews. We asked in the survey for a free text response on why delays occurred, and these are shown in **Table 3.**

Figure 6 Average days from symptom onset to treatment for notified pulmonary TB cases

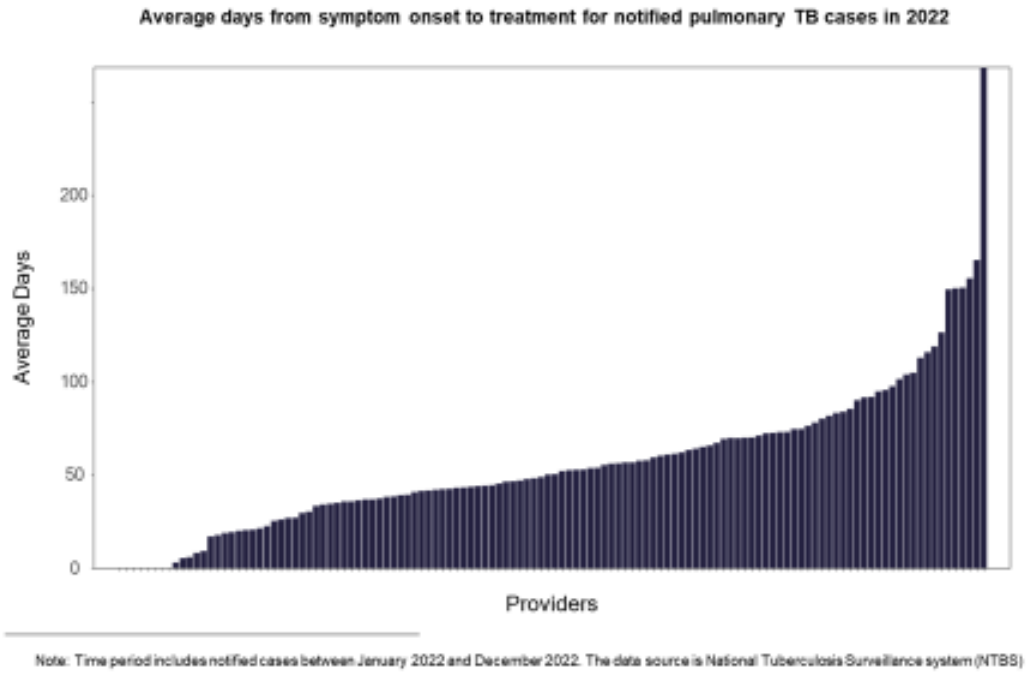


Figure 7 Average days from symptom onset to treatment for notified non-pulmonary TB cases

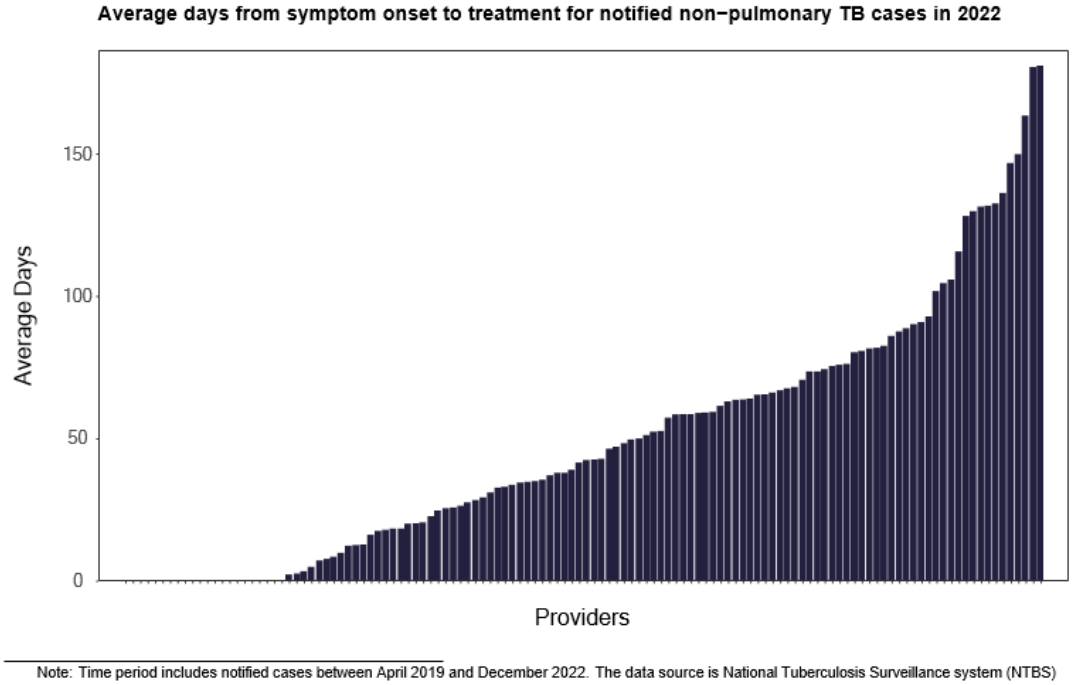


Table 3 Reasons for delay in diagnosis

No.	Reasons for delay in diagnosis
1	Delayed diagnosis and referral
2	Including patient related factors
3	Health care system and provider factors
4	Resources and infrastructure limitations
5	Diagnostic and clinical management challenges

Many of these reasons given are potential areas for consideration to reduce delays, some of which are referenced throughout the report. When delays in diagnosis or treatment occur, these should be a focus of the cohort reviews, but a lack of 'joined up data' from primary and secondary care often makes it difficult to track patients through. A more joined up data approach would have benefits by allowing the tracking of "failing to attend" patients with positive Interferon gamma release assay (IGRA) as part of a screening program.

The impact on service size and the percentage of patients who wait more than two weeks to start treatment was of interest. In those services having less than 10 notifications per annum, 11.8% of patients waited over two weeks, while in those with greater than 100 notifications per annum only 4.9% waited over two weeks. This highlights the TB infrastructure issues in those services with lower TB numbers.

Although specific aspects of the diagnosis of TB were not part of the review scope, we did ask some basic questions around diagnosis. The diagnosis of TB is a clinical one, supported by identification of mycobacteria, ideally with culture, to both confirm it is not an atypical mycobacterium and to determine sensitivities. We found that only 40% of services were able to provide smears daily for identifying TB, with the remaining services showing that smears would be available only within the working week. We heard from large services that there were delays in some samples being sent to adjacent hospitals with a turnaround time of over 48 hours. We found that the reasons for this were variable and often related to a lack of infrastructure for laboratory staff to both perform and interpret the smear. Additionally, consultant microbiologists were often limited in their time to support the TB service, including time to attend regular MDTs and cohort reviews.

During our deep dive visits we asked how colleagues would attempt to get samples if smears were unavailable, with the commonest response being a fibre-optic bronchoscopy with appropriate washings. Most participating providers had a SOP for this and the bronchoscopies were done in a unit that normally had negative pressure ventilation and that routine practice was always to put the patient with suspected TB at the end of the list. An alternative method of trying to obtain a sputum sample is by induced sputum, recognising that this is an aerosol generating procedure. Therefore, induced sputum should be undertaken by trained staff, who are adequately protected in a negative pressure facility. Unfortunately, not all TB services could provide negative pressure facilities, with rooms being repurposed for other uses.

For children and young people, laryngeal swabs or gastric washings were sometimes performed, with bronchoscopy and induced sputum being an option for older children, though we heard of significant difficulties in accessing negative pressure units and appropriate staff.

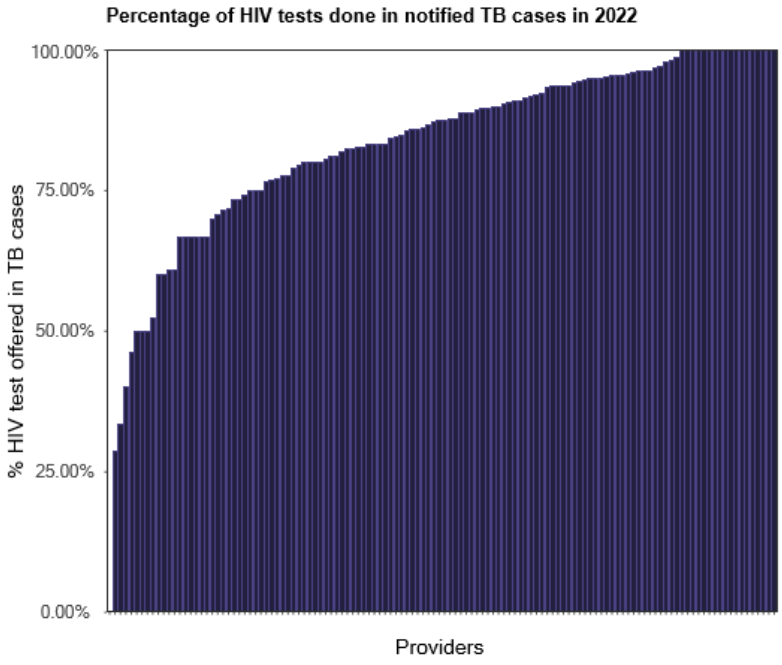
A clear aim of the TB Action Plan is to increase the number of patients who have culture confirmed diagnosis to allow appropriate treatment guided by sensitivity testing. We saw in NTBS data that only 63% of services did so at the time of the survey, with considerable variation. Another way to promote an early diagnosis was by raising the awareness of all clinicians, as recommended in the education section 6.10.

When potential TB is identified from other sources, e.g. Biopsies, informing the TB service is important to allow consideration of prompt treatment. This happened in 97% of microbiological services, while 15% of radiology services and 44% of pathology services had no system in place. This is disappointing, as many radiology services have systems for flagging lung cancer which could be adapted. For pathology (histology), we heard that several TB providers had approached their pathology service and had not been able to secure an alert system for when acid alcohol fast bacteria (AAFB) or suggestive granulomata were seen.

A clear advance over recent years and supplanting TB skin tests has been immunological (IGRA) testing. Given its use in detecting latent TB, a relatively prompt turnaround is needed, but in 22% of services this was over one week. The infrastructure to support the results, especially as part of the latent TB programme, had led to some services where the consultant was the main link in interpreting and taking action on the results, which is an unacceptable burden. The utility of such tests do need to be assessed and we heard examples where audits of the IGRA results and outcomes from them were analysed to continue to confirm their utility. Clearly such immunological testing does not identify active disease, hence the importance of obtaining samples for culture and hence sensitivity / resistance patterns if actual TB disease is considered. Processes need to be in place, depending on where the IGRA is requested, to follow up positive results, especially if a patient fails to attend clinic or a review.

Finally, HIV testing is a key recommendation. **Figure 8** shows that testing was generally undertaken by service providers, but HIV testing is performed slightly less often in lower volume services, whilst recognising that missing a test when there are less than 10 cases has a large impact on the relative proportion. In 88.3% of cases the HIV test was offered and done; it was not offered in only 2.1% of cases and the HIV status already known in 5%. Apparently refused a HIV test from the NTBS return.

Figure 8 – Percentage of HIV tests done in notified TB cases



Service Size	HIV Test %
<10 cases	77.97%
10-49 cases	85.54%
50-99 cases	90.80%
100+ cases	90.51%

Note: Time period includes notified cases between January 2022 and December 2022. The data source is National Tuberculosis Surveillance system (NTBS)

Recommendations in relation to Diagnosis of TB and Delays in Management

Recommendations	Resp.
9. All TB services need to review the reasons for delayed diagnosis and undertake remedial action where there are systematic failings. This should be a feature of regular cohort reviews, taking note of the common reasons in **Table 4** and should be discussed with ICBs and service commissioners to address any shortcomings.	P, ICB, LA
10. Consideration needs to be given for the improved availability of smears in	P

higher prevalence areas. All services should strive to culture samples for the reasons stated, recognizing the laboratory standards that should be met	
11. Although not part of the review, the infrastructure to support microbiology in both staff and equipment should be reviewed by providers and ICBs. This could include access to rapid PCR testing, and the Xpert program.	P, ICB
12. There should be an SOP for undertaking bronchoscopy for diagnosis, ideally in a negative pressure facility with appropriate precautions to minimise risks to staff.	P
13. Provision of negative pressure facilities for induced sputum should be available together with the trained staff, for all age groups	P, ICB
14. Turnaround times for IGRA testing should be appropriate for service delivery.	P, ICB
15. An SOP should be in place to ensure TB services are informed of potential TB infection from radiology, microbiology and pathology (histology) services.	P

6.8 The National Tuberculosis Surveillance System (NTBS) and Data Flow

TB notification is a legal requirement but to support additional information the enhanced surveillance programme for TB NTBS was developed. While this is a very comprehensive dataset providing annual reports, it is a surveillance system and not a clinical management tool. Feedback from the deep dives suggests that NTBS needs further refinement. The expanding use of Video Observed Therapy (VOT) was not being captured and 'what constitutes symptom onset' for both pulmonary and especially extra pulmonary disease, is leading to wide variation in the reported time of symptom onset to treatment. Funding to further develop and evolve NTBS in light of changing epidemiology is required. A particular issue for this review was the access to NTBS data for Yorkshire. While individual sites can see their own data, we were unable to access site level data NTBS returns with just a regional return. We understand this was a request from Yorkshire to see the data this way.

Perhaps more important than the actual fields were their timely completion. We questioned staff on why they appeared to have a good HIV testing responses as shown in **Figure 8,** but the activity recorded on both the start and completion of preventative therapies**,** as shown in **Figure 9 and 10,** were lower in the returns than colleagues thought they had achieved during the deep dives. Further discussion highlighted that staff do not always have the capacity to revisit NTBS to update with further information after the initial notification. This confirms the need for additional administrative staff to both input into and maintain NTBS if it is to a valid source of information.

Whilst NTBS is an excellent data set, it is not a clinical management system, with no availability for real time communication to individuals within the local service. Based upon a significant outbreak several years ago, one provider has developed an excellent in-house system for communicating between nurses, medical staff and other parties to support the ongoing management of TB. Further work on such a database is required, recognising that the data fields already exist.

A more comprehensive data system, like those in other services, should be developed to include the above but also allow communication between all parties including primary care and patients and carers using standardised but adaptable template letters. Such a database should pull information from already available hospital systems, including microbiology and pathology, while being able to uplift information into NTBS to minimise duplication of work.

This would fulfil the requirement for maintaining NTBS while having a clinical use as an information tool for managing patients and facilitating rapid communication with all parties. While such a tool does not exist at present, similar platforms, including commercial ones, are being developed for other disease areas and NHS England should consider investing in such a platform that is available for all services.

Figure 9 – Percentage of adult contacts started preventative treatment for latent TB

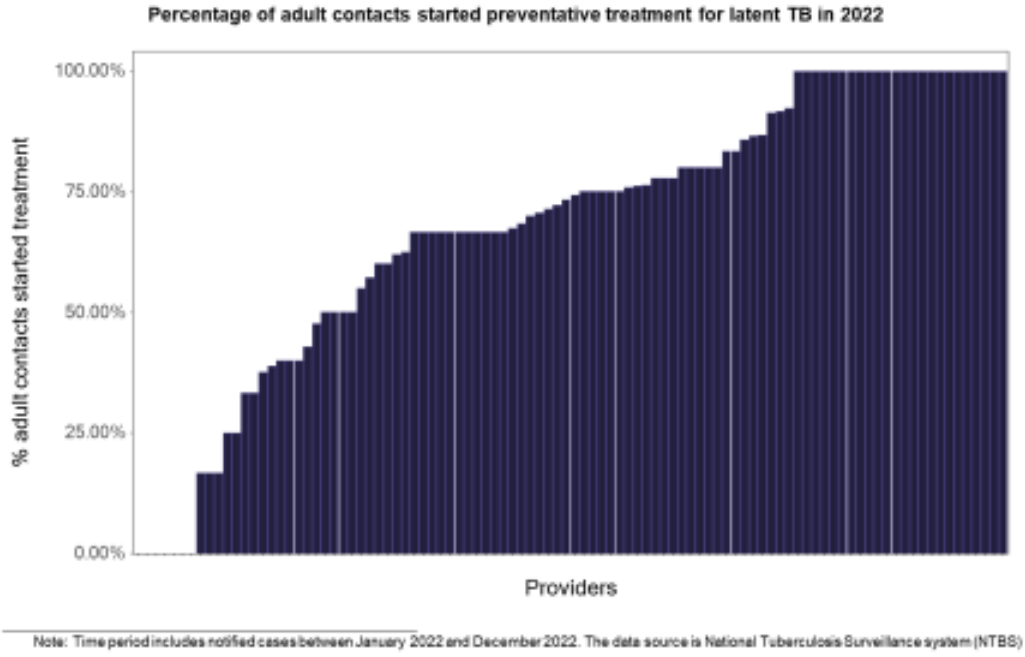
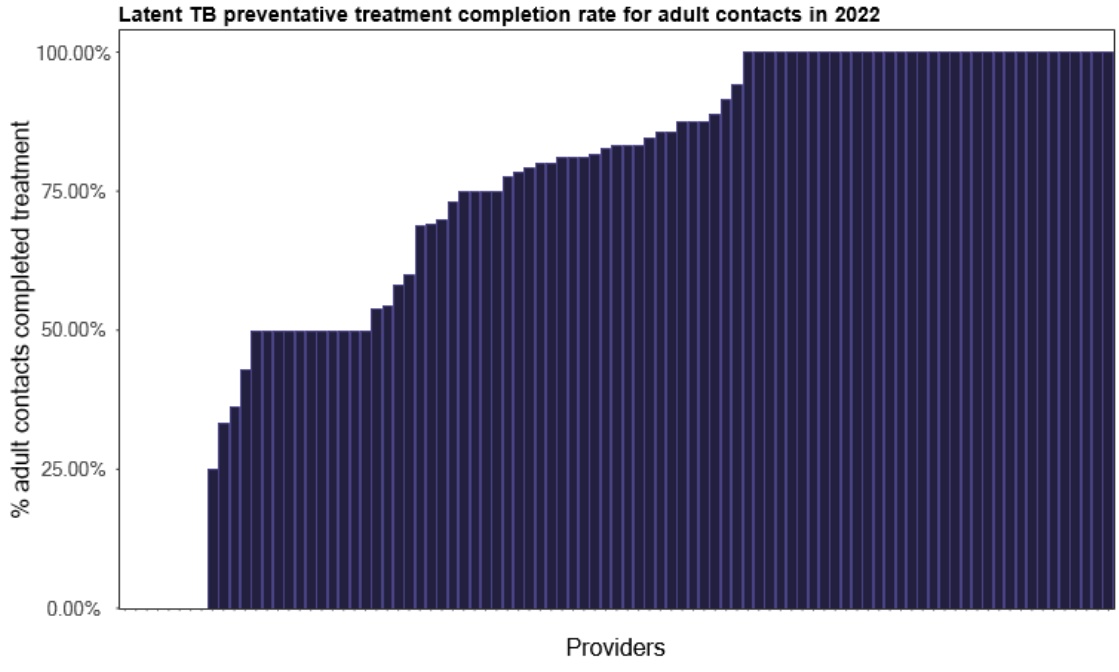


Figure 10 – Latent TB preventative treatment completion rate for adult contacts



Recommendations in relation to NTBS and Data Flow

Recommendations	Resp.
16. NTBS should be updated to clarify definitions, including symptom onset, recognising that resources are needed for this and including clinical service users.	N
17. NTBS should separate VOT and DOT into two categories.	N
18. NHSE should support the development of a clinical platform, possibly commercially, that is a unified data management system for TB that interacts and uploads information between hospital systems and NTBS while adding communication, differentiating that NTBS is a surveillance platform and very different from a clinical management system.	N

6.9 Coding and Payment Mechanisms

Coding is the process whereby activity by a provider is formally recorded using a recognised system. In England, primary care uses the Systematized Nomenclature of Medicine Clinical Terms (SNOMED) coding system, while community activity is less well captured. In secondary care / hospital providers there is a well-established system based upon the World Health Organisational Clinical Disease Codes, code ICD10, which capture diseases and symptoms. To these, where relevant, a procedure code may be added (e.g. Code OPCS 4.10).

The combination of both disease and procedure codes gives thousands of combinations, so to aggregate these, Health Resource Groups (HRGs) are used to describe patterns of work that have a similar resource use. Under the national tariff payment system HRGs form the basis of income for most acute providers. For TB we can determine the inpatient activity from the ICD 10 codes and have used these to look at overall inpatient activity, irrespective of the speciality, i.e. if infectious diseases (ID), or respiratory. Additionally, for complex TB patients with a prolonged (28 day) length of stay there is a specific HRG that attracts a different tariff, as per the inpatient section 7.1.

However, the bulk of TB work occurs in an outpatient setting where there is minimal coding of activity, and it is attributed to a particular speciality by a Treatment Function Code (TFC). For example, a respiratory physician may see patients with TB, asthma, Chronic Obstructive Pulmonary Disease (COPD) and lung scarring in the same clinic, but it is not possible to know how much of what disease is seen, only that the patient was seen as a new or follow up patient.

Furthermore, different specialities may see TB patients e.g. ID, and so the overall number of patients seen in medical clinics in England is unknown. This activity is paid for purely by the patient being a new or follow up patient. The sensible way of being able to differentiate this activity nationally, irrespective of which speciality sees the patient, is to have a ‘Tuberculosis Service’ treatment function code with an appropriate tariff for the new and follow up activity, which recognises activity at provider level.

The situation for TB nursing is better, as there are specific procedures that map to a specific code HRG Dz42z, which has a mandatory tariff attached of approximately £189.00. The procedures that map to this HRG of ‘TB nurse education’ include skin testing, administration of BCG (code E95.2), DOT (E95.3) and contact tracing (E95.4).

Looking at the activity over the three years from 2021 to 2023 inclusive, there were 44,480 uses of the BCG code as an outpatient in England, reflecting over half of the specific HRG activity. For contact tracing over these three years, there were only 7000 contacts coded, accounting for only 8% of the HRG activity, while for DOT (directly observed therapy) there were 3723 episodes coded in this period, only 5% of the overall HRG activity. Thus there is

marked variation in what the actual activity is versus that captured in OPCS and therefore eligible for payment under the HRG tariff. The issues of DOT and VOT are discussed in section 7.4, but with 9000 or so contacts screened, of which over 2000 received treatment (having several visits each of which should have been coded), there is gross under recording and potential loss of income amounting to several millions of pounds for services.

Currently, in both NTBS and OPCS there is no mechanism to capture VOT activity. This has been discussed with the Clinical Classifications Service and although OPCS-4 is not mandated in outpatients and remote activity is not within the current scope of OPCS-4, as there is no coding standard, there is nothing to prohibit the recording of OPCS-4 codes in the different settings.

In essence by using the DOT code, E95.3 but using the setting listed below in **Table 4**, actual DOT can be captured as the code in setting 1 or 2 as it is face to face, while VOT is the same code of E95.3 but in the setting of a remote consultation, be it a new appointment for the first VOT episode or a follow up telemedicine for subsequent VOT. Both of these will map to the HRG of Dz41z and be eligible for payment.

Table 4 - Clinic types

Code	Description
1	First attendance face to face
2	Follow-up attendance face to face
3	First telephone or **Telemedicine** consultation
4	Follow-up telephone or **Telemedicine** consultation.

The funding of services was a common discussion point during visits, where staff expansion was limited by financial flows into the service. However, as noted previously, many services are not capturing the activity as shown in **Figure 11** below.

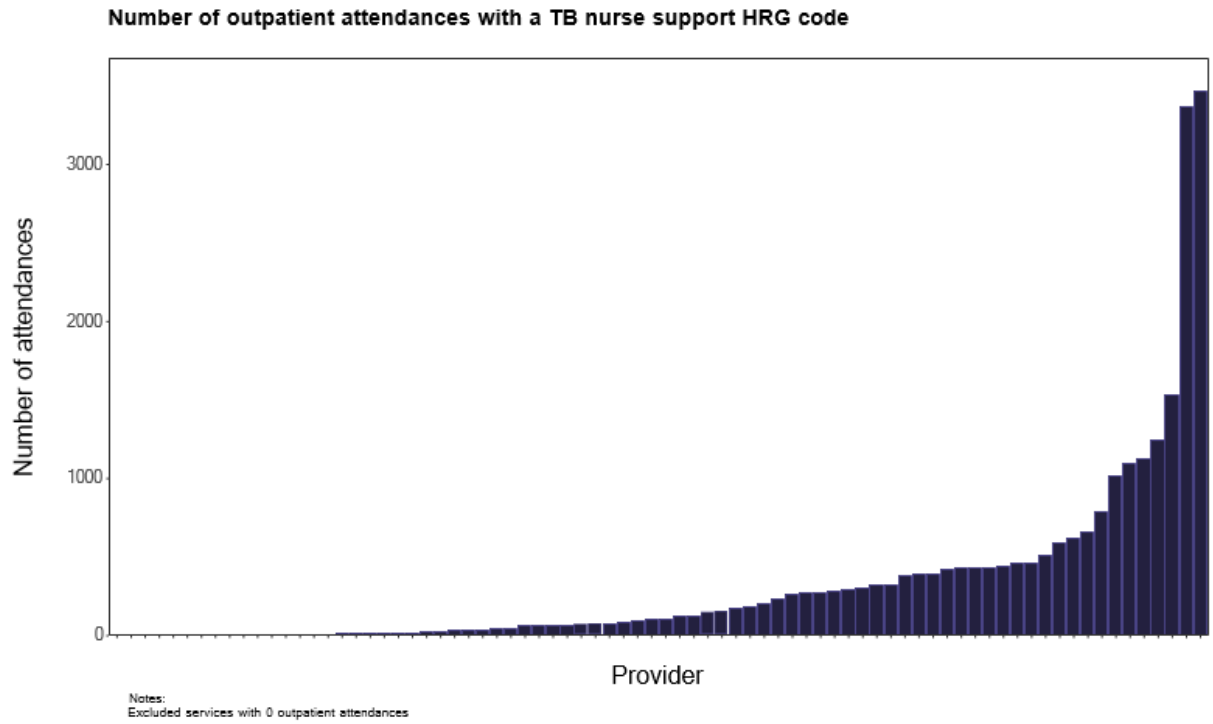
The relationship between size of service and activity recorded was weak, with only one large (over 100 notifications) service recording over 3400 attendances, giving a potential income to the service of £624,000. It is therefore essential that services record their nurse led activity, then discuss it with the hospital management and coding department to ensure robust mechanisms are in place, and then discuss with the ICB about appropriate reimbursement.

There is an expanding workload in identifying latent TB and then administering preventative therapies to such groups as: individuals with a positive IGRA from occupational health screening; individuals identified as a consequence of biological treatments; new migrants; and asylum seekers. Thus, a request has been made to OPCS to cover ‘assessment for latent TB’ and ‘management of latent TB’, which if agreed will map the HRG Dz42z and attract payment for the activity.

We appreciate that national payment systems are in a state of flux. After a period of development where the payment by results system achieved its aims of incentivising and delivering activity, there was a move to a more refined system such as the aligned payment incentive, where there was opportunity for local negotiation. Unfortunately, this has not been fully implemented due to Covid, where activity was put on a block contract to maintain provider stability. Unfortunately, many commissioners in ICBs have retained a block contract, with some modification to use the national payment scheme to support elective recovery. Given the importance of TB services, these should be considered as part of the elective recovery

agenda for both outpatient services and for procedures noted in the HRG Dz42z, thus ensuring appropriate payment for activity.

Figure 11 – Number of outpatient attendances with TB nurse support HRG codes



Recommendations in relation to Coding and Payment Mechanisms

	Recommendation	Resp.
19.	A new treatment function code for 'Tuberculosis service' should be established with a tariff to be determined but should be similar to that of respiratory medicine for new and follow up activity.	N
20.	All services need to meet with the provider management and coding departments to ensure nursing activity is captured using the correct OPCS code that maps to the HRG Dz41z. If this cannot be captured electronically then paper templates that are uploaded by clinic administrative or coding staff should be used.	P
21.	Activity around contact tracing, DOT and VOT should be captured mapping to the Dz42z with a mandatory tariff.	P, ICB
22.	. ICBs need to recognise this activity and ensure payment as per the national tariff payment mechanisms. If new payment systems are developed, TB activity should be paid at tariff. Any new OPCS codes for preventative treatment which are being considered would need to be included in this payment system in the future. Acute providers need to recognise the income and ensure it is hypothecated into TB services.	P, ICB
23.	MDTs and cohort reviews are a key aspect of delivering and improving care. The attendance should be formally recorded and mechanisms developed to capture the activity for reimbursement	P, N, ICB

6.10 Education and Training

Early and accurate diagnosis of tuberculosis and improved adherence to treatment are the key aspects of improving care and outcomes. Access to diagnostics tests can help, but the issues remain around a high index of suspicion of TB and then supporting patients in their journey from starting to completion of treatment. Key to this is an educated and trained workforce with a patient or carer who understands the issues around TB management. There are many opportunities to improve this and we heard excellent examples during our visits which are included in **Annex C.**

From a medical perspective, it is the responsibility of the clinician to remain updated on current practice by formal Continuing Professional Development (CPD) which should be reflected in their annual appraisal. There is a need to attend appropriate educational courses that are often provided by specialist societies, with good examples of the British Thoracic Society (BTS) providing lectures and symposia within their meetings that are also applicable to non-medical clinicians. For doctors in training, specifically Supporting Professional Activities (SPAs), formal education needs to occur as part of the national training program that is assessed annually, as they are the future clinicians delivering TB services. We heard excellent examples during the deep dive visits where TB services provided regional education for medical registrars.

Of course, training in TB should occur throughout the whole career of medical staff and there should be adequate provision of training in undergraduate medical schools, with a combination of lectures and case-based working to cover the variety of aspects of TB care.

While education of staff delivering TB care is crucial, so is education of other staff who may be involved in managing TB. We found excellent examples where the clinical lead for the TB service was involved in providing education within primary care for both doctors and nursing staff. We heard similar examples in acute providers, usually delivered as part of formal 'grand rounds' together with more targeted clinical education in emergency departments and acute medicine areas (admission units, short stay wards and same day emergency care). This initiative was a consequence of a patient admitted with features of TB that had not been recognised, triggering issues of infection prevention.

For this excellent education practice to occur in all the groups and settings described above, there should be sufficient SPA time in the clinical leads' and other colleagues' job plan to deliver this education and acute commissioners / ICBs need to recognise the benefits of this. Of course, less formal exchanges of information take place in MDTs and cohort reviews, with attendance of those medical staff in training and nursing staff having it included as part of their formal work plan. It needs to be recognised that other parties such as ICB commissioners and local authority leads may benefit from education and support. During the visits we had several ICB staff who commented that they found the information from the deep dives helpful in understanding the issues and complexities in TB care. We would suggest that such 'support' of ICB/LA staff knowledge is essential in developing and promoting TB services.

It is important to state that it is not only medical staff who can and should be delivering the education and training to medical students through to consultants. We heard excellent examples where nursing staff were providing education to prison staff. It is also extremely important that there is sufficient time for unqualified, qualified and senior TB nursing staff to attain appropriate CPD. We were pleased that 69% of respondents said that they had a formal training budget but 2% of these recognised that that funding was external, though regrettably

just under 20% had no formal training budget; this needs to be addressed. Exposing student nurses (and medical staff) to delivering TB care is an important aspect of training, though 46% of services did not provide any nursing placements, presumably due to a shortage of supervisors. This is something for providers to consider.

A major concern around nurse training and education was the lack of suitable courses for staff who may have recently been appointed into a TB nurse role. We heard that courses that did exist were too expensive and/or too advanced. Often training was based upon an apprentice type model in the provider, with, when allowed, spending limited time in adjacent services on an ad hoc basis. Given the complexities of TB management, a more established process needs to be developed that includes formal lectures and the practical aspects of care, including addressing those individuals with complex needs, as seen in the large numbers who need enhanced case management.

Whilst knowledge of TB in health care professionals is important, it is equally so for patients and their carers so they can understand their disease and the treatment plans. This is especially difficult where there are language and cultural barriers, but we heard excellent examples where these issues were being overcome, working with the local population to address the issues. Information for patients and carers needs to be given throughout their journey, and we noted the multi-professional opportunities for this via nursing and pharmacy staff when prescriptions were being dispensed. This information needs to be provided in a format that is accessible for patients and carers, recognising that English is often not their first language, with a pictorial option in a series of different formats, ideally held in some form of national repository. Good examples can be found in our library of documents (**see Annex C**). Engaging with services users, as recommended in the research section 6.11, is an excellent way of identifying gaps in information.

Recommendations in relation to Education and Training

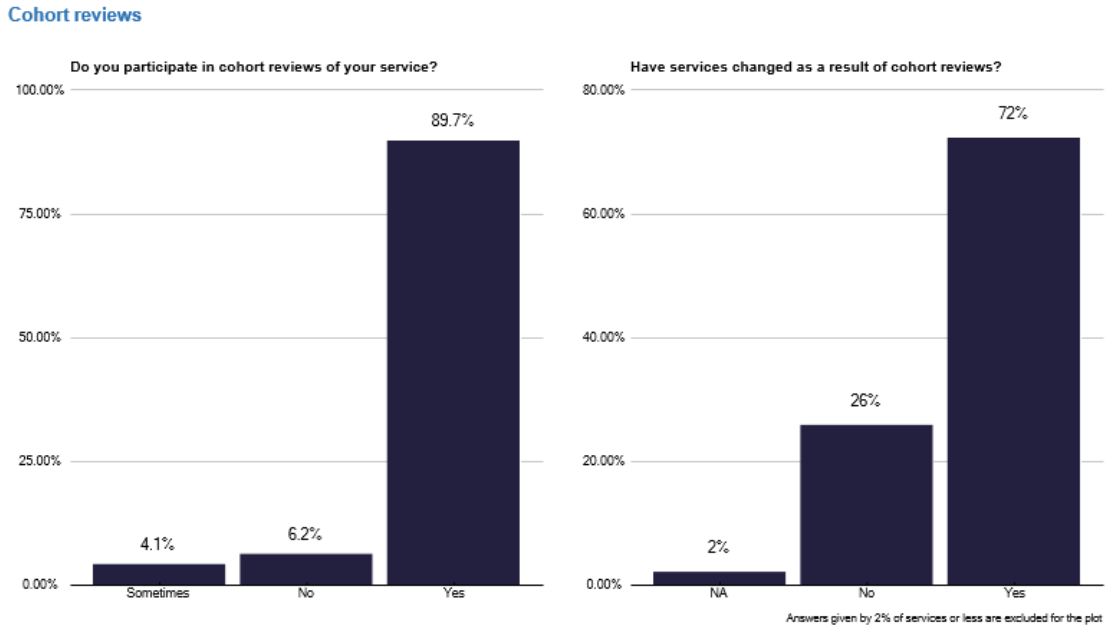
	Recommendation	Resp.
24.	SPA time for providing education and training for medical students through qualified health care professionals needs to be recognised and embedded in medical job planning. A similar recognition should occur for nursing and pharmacy staff.	P
25.	A regular series of lectures and seminars needs to be provided to appropriate staff. We recommend at least an annual presentation to primary care as part of their CPD and a biannual presentation to acute medicine and emergency departments that should occur not long after the new staff intake, with at least an annual to biannual 'grand round'. These should especially be in place in low prevalence areas of TB to maintain the high index of suspicion. Less formal lectures and education to the wider ICB and LA is helpful in promoting their understanding of the issues.	P, ICB, LA
26.	There are numerous education and training opportunities during service delivery, e.g. internal, regional (where they exist) MDTs and cohort reviews. These should have an educational as well as service function and therefore attendance is required by both established staff and those in training across all professions, with recognition in job plans and scheduled time.	P
27.	National Societies and Royal Colleges, together with regional groups, need to ensure there are adequate courses available for medical, nursing staff and other relevant staff groups to attend. These should include formal lectures and symposia but also small group working to enable discussion of the very practical aspects of TB care.	P, N

28.	There needs to be access to appropriate budgets with time allowed specifically for nursing staff to attend courses. This activity should formally document their CPD as a requirement for revalidation.	P, ICB
29.	For nursing staff who've recently been appointed, formal training programmes which have a combination of lectures and practical exposure need to be enhanced and of an appropriate level and cost to allow attendance.	P, ICB, N
30.	We noted numerous examples of excellent information from both national and locally developed sources, often in multiple languages. NHSE should take responsibility for acting as a repository for this information which should be freely available to all parties with no cost.	N
31.	Education in TB needs to be established in the undergraduate curricula of all medical schools and in the postgraduate curricula of doctors in training, with a particular emphasis in specialties that have a role in managing tuberculosis in its widest sense. For those individuals undertaking Higher Specialty Training in respiratory and infectious diseases, it should remain a core element of training.	N

6.11 Research and Academia

Research of both an original nature and service evaluation is essential to improve cost effective outcomes for tuberculosis. We found several services, usually in larger departments, who had dedicated academic sessions, working with colleagues overseas in high prevalence areas, but we found little, large scale service evaluation type research. Cohort reviews have had a significant impact in improving care as shown in **Figure 12** but a more systematic approach to improving service delivery did not seem to occur. Moreover, there seemed little support for this clinical research from charities, professional societies and grant giving bodies, though we note one service had ensured there was some academic time for a nurse to undertake research.

Figure 12 - Cohort Reviews



Recommendations in relation to Research and Academia

	Recommendations	Resp.
32.	Considering the burden TB produces across the world, national and local grant giving bodies should ensure TB applications are available and publicised. The research should not only be international and original but should also include evaluation of services and clinical care, including new diagnostic and treatment interventions. Support from equipment manufacturers and pharmaceutical companies should be welcomed to work collaboratively with clinical services, ideally multiple ones, as part of a TB research networks.	N
33.	Service evaluation / clinical research should have a higher profile and should form part of all departments' modus operandi. Such research should be recognised for the importance it has in improving care and should receive funding from grant-giving bodies. Coordination of this clinical evaluation should take place with support from specialist societies and charitable organisations to ensure clinical 'buy in'. Support of staff in training, both medical, nursing and others e.g. pharmacy to participate in academic activity, should be recognised and supported with dedicated nurse time.	P, R, N
34.	TB services should aim to be more collegiate in how they work across ICBs, regions and nationally, ideally via funded clinical research networks, to support clinical service evaluation. It is important to recognise the support and funding that can take place with commercial companies and supporting this work in the TB service is essential for evaluation of new interventions.	P, ICB, LA, R, N
35.	Qualitative research is an important aspect of improving TB services. An example that should be followed is the patients and carers views of the TB service they receive. This should include all individuals who have exposure to the TB service, i.e. those with active disease, contacts thereof and the wider population being evaluated for and receiving preventative treatment. Depending upon the size of the service, such a review should take place annually or biannually to help inform clinical, managerial and commissioning decisions within the TB services. Such a practice was described during one of the visits and the impact on improving the patient journey and satisfaction was clear.	P, ICB, LA

7 Clinical care

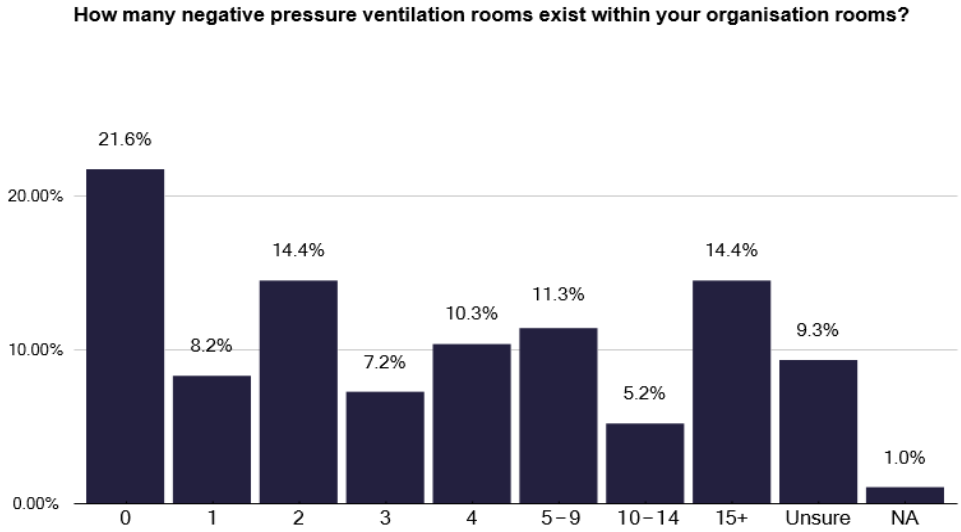
7.1 Inpatient Management

Inpatient management of TB is a relatively small proportion of the 4380 notifications, with 116 children (3%) admitted and only 61 (1%) having tuberculous meningitis. Some 196 patients, (4% of all notifications) had a prolonged length of stay of 28 days or greater as identified by the HRG Dx51z. These patients are often associated with homelessness, substance misuse, social issues and complex drug regimens and as such attract a higher tariff of approximately £22.000-£23,000, depending on whether they are an elective or acute admission. We did note that three providers had 100% use of this code and on review for one provider this was the only admission, while a second was from a community trust. Given the high tariff for this HRG it is important that commissioners scrutinise and validate the activity.

For patients admitted through acute pathways, we were told that TB was not always considered, leading to a delay in both taking the appropriate samples and isolating the patient. While this may be an issue in low prevalence areas, we did not find any evidence of this. However, education of clinicians is essential to maintain the high index of suspicion, as noted in education and training section 6.10. Ensuring that there are appropriate policies in place to manage potentially infectious TB is important and should be in the standard provider SOPs / IPC policies. Isolating patients in side rooms to minimise transmission of infection is important and ideally this should be in a negative pressure room, especially until there is information that the individual does not have MDR/XDR. We asked about provision of such facilities, and they were absent in 21.6% of services, as shown in **Figure 13**. During our deep dive visits this was recognised as a problem for both adults and children, especially when undertaking induced sputum.

Admission is an ideal time for the TB nurses to identify contacts and to explain the nature of TB; however, this may not always occur, with patients often being discharged without any TB nurse input. We also heard of patients being discharged on the wrong medication, which was then identified by the TB nurses in their 2-4 week follow up clinic. The TB pharmacist has an important role here to check that patients are receiving the right medication at discharge. We also heard that sometimes the lead clinician and TB nurses were not told when newly diagnosed patients or those admitted for other reasons with known TB. It is important that the TB team are made aware of such admissions, especially to ensure there are no errors or changes in medication.

Figure 13 Number of negative pressure ventilation rooms that exist within your organisation rooms



Recommendations in relation to Inpatient Management

	Recommendation	Resp.
36.	For cases where code Dz51z is used, ICB commissioners may wish to validate its correct use.	ICB
37.	All providers should have SOPs / IPC policies for dealing with potentially infectious TB.	P, ICB
38.	If patients are to be admitted with potentially smear positive disease, providers should ideally have negative pressure facilities on site. If MDR/XDR is suspected or confirmed, patients should be transferred to a facility with negative pressure rooms and appropriate expertise in clinical management.	P, ICB
39.	All patients admitted with tuberculosis should be reviewed by the TB nurse to ensure appropriate contacts are recognized, support information and education are provided, and the correct medication is being taken. Patients should not be discharged until this review has occurred.	P, ICB
40.	When patients with known tuberculosis are admitted under another specialty, the TB team should be informed and a review considered. Any planned follow up appointments with the TB service should not be cancelled.	P
41.	Patients discharged from the wards on TB medication should have their treatment reviewed by the lead TB pharmacist or their deputy to ensure medication has been both written up and dispensed appropriately.	P
42.	For patients who are having a biopsy or surgical procedure where TB is a possibility, should have samples sent in the appropriate medium to allow potential identification and culture.	P
43.	As noted in the education and training section 6.10, the lead tuberculosis clinician should be providing education to acute providers and acute provider clinicians to maintain a high index of suspicion.	P

7.2 Outpatient Management

From initial referral to discharge, the bulk of care for individuals with TB, and their contacts, is undertaken as an outpatient for both adults and paediatrics. Beyond workforce (see section 9), the key aspect is the clinic infrastructure. There was considerable variability. One service had a TB clinic based in a high prevalence area away from the main hospital building with easy access to bus routes and plentiful free car parking. The facility was part of a new build GP premises that had co-located X-ray and phlebotomy, with a large, ventilated waiting area that was not used for any other patients when TB clinics were running, together with an embedded pharmacy. However, this was an exception. Many TB clinics shared waiting rooms with other respiratory patients, often with poor ventilation and often not adjacent to imaging or phlebotomy facilities, with 30% of bloods taken by TB nursing staff. This puts an unnecessary demand on qualified staff when there are no health care support workers (see workforce section 9). Most services checked liver function tests and visual acuity appropriately**.** Clinic ventilation, an important consideration for staff and patients' alike post Covid, was rarely achieved, with ventilation only known about in 28% of services and only considered adequate in 5.2% of services.

A major issue is the availability of rooms (both as a base and especially for performing their own frequent clinics) for nurses and admin staff. This can be especially difficult for clinics running at the same time as medical TB clinics but is essential to support patients and carers. To facilitate efficient service delivery, we were pleased to note that 83% of nurses could request radiographs. However, 65% of respondents said they did not have dedicated space to access at any time and this seemed a particular problem for some community TB teams. This is a potential problem, as individuals on anti-tuberculosis medication could not always be reviewed promptly if needed, say for an abnormal liver function test or other such reason. We were concerned that access to clinic space may be a factor in the delay in some patients starting treatment after notification but were assured that this was not the case with services finding a venue to commence treatment. This was especially so where infectious disease services were involved in managing TB, as they would often bring patients up to the ward for a discussion and initiation of therapy, with respiratory services accessing dedicated day case areas if needed. With pressures on clinic space in mind, we asked if there were extended working days or weekend working to make it easier for those patients who work or have children to attend, but these only existed in 2.1% and 7.3% of services respectively.

Another factor which is essential in managing throughput is administrative time. It appeared that where there was input from dedicated TB admin and health care support workers, this improved the efficiency of TB services. One of the issues which did impact on clinic throughput was translation services, with all services having access to language line and 71% also having onsite or visiting interpreters. However, sometimes, appropriate interpreters from language line were not always available and it adds considerable time to the consultation which needs to be factored into the clinic booking (as in workforce section 9).

Recommendation in relation to Outpatient Management

	Recommendation	Resp.
44.	Consideration needs to be given to the estate from where TB services operate. This should include sufficient clinic (nursing and medical) and administrative space, easy access to bus routes, free car parking and be in high prevalence areas when appropriate with imaging and phlebotomy collocated. Space must be sufficient for the undertaking of visual assessments and there should be strict IPC procedures in place, including hourly air exchanges for clinics. Language interpretation	P, ICB

	facilities need to be established, and these should be available for both routine and ad hoc clinics.	
45.	Beyond the clinic there should be sufficient space for the nursing and admin staff to have a formal base, including sufficient phones, computers etc. Additionally, nurses should be able to access ad hoc clinics, ideally close to their work base.	P
46.	Nurses should be mentored and encouraged to become prescribers and to go through appropriate training to be able to request chest radiographs.	P

7.3 Medicine Management

Pharmacy plays a key role in tuberculosis services in a variety of ways. While drug interactions are common e.g. with hepatitis and age-related issues for those on multiple therapies, recognising some medications may alter the efficacy of anti-TB treatment. More recently senior pharmacists have had to negotiate the difficult issue of anti-TB drug shortages. Within the acute setting, pharmacists play a role in the oversight of inpatient treatment and have a key role in the dispensing of treatment, both at discharge and in the outpatient setting.

Whilst we found good attendance by pharmacists at the deep dives, it was disappointing that the role of pharmacy in TB services was poorly recognised, being absent in 43% of services. Even when supported, there were difficulties attending key meetings, noting however, that pharmacy support for ID services seemed generally better.

Anti-TB drug shortages have been a significant problem with 97% of services experiencing drug shortages. There is a significant impact on patient care and on clinical teams' workload, as exemplified by a higher tablet burden for patients, potentially affecting drug adherence and increasing the risk of drug errors. Overall, 66% of the survey respondents stated that there had been issues with drug shortages affecting standard treatment, but prioritisation limited the impact on patients with MDR/XDR where only 21% of patients had their regimens modified.

We found excellent examples of dispensing pharmacists providing support and education for patients and carers to improve adherence to therapy, e.g. using dosette boxes and supportive information in a patients' native language. The close liaison between the TB nurses and pharmacists and dispensing services were especially helpful when potential adherence issues were identified by dispensers.

We did note that co-location of the pharmacy within the TB service, either based in the community or adjacent to the TB clinic, was important with regards to patients collecting prescriptions. However, relations between commercial pharmacists and the TB services they support are variable. For one service, there was a dedicated TB clinic with its own entrance, imaging, car parking and an embedded commercial pharmacy; this was an excellent service. This co-location between clinic and pharmacy, in any setting, is important to ensure patients can collect prescriptions easily and to increase familiarity with the drugs dispensed which minimises errors.

Recommendations in relation to Medicine Management

	Recommendations	Resp.
47.	A senior pharmacist of band 7 or greater should be attached to and support the TB service. The amount of time required should be on a pro rata basis for the potential workload, based upon both notifications and the preventative therapy population. Recognition of their role in XDR/MDR and NTM should be included together with time in job plans to attend internal MDTs and cohort reviews. The role of pharmacy support for regional MDTs needs to be included in the future development and funding of such services.	P, ICB
48.	The senior pharmacist should provide support and education for ward-based pharmacists, when tuberculosis expertise is not available, support the dispensing pharmacists and TB nurses as they gain their skills and qualifications in nurse prescribing, and medical staff.	P
49.	The pharmacist should work with local, regional and national teams to provide advice and support, including to the system, when there are shortages of anti TB medications.	P, ICB, R
50.	The pharmacist should work with dispensing teams and the TB service to ensure that information given to patients is appropriate in both language and content, recognising that some individuals on active or preventative treatment may not be able to read. The use of pictograms and other information should be a routine option.	P
51.	Drug shortages are a major issue for the TB service and need to be recognised nationally. There should be a national infrastructure to minimise future drug shortages, and there should be a clear cascade of information centrally from NHSE via pharmacists if there are potential shortages. Plans should be in place across regions and nationally for shared support and to minimise stockpiling.	R, N

7.4 Directly Observed Therapy and Video Observed Therapy (DOT & VOT)

Ensuring adherence to anti-tuberculosis medication is essential to achieve the desired outcomes. Whilst many individuals will take treatment following a clear explanation, some individuals, as highlighted in the enhanced case management returns for notifications and latent treatments, require a more supportive intervention to encourage adherence. This may be by observing patients taking treatment via a video, Video Observe Therapy (VOT), or by directly observing the patient taking the treatment, DOT. Given the latter is usually used five days per week and, after an appropriate risk assessment two nurses may need to attend to administer the DOT, there is a considerable impact on staffing resources.

Unfortunately, VOT is not captured in NTBS at present, so we are unsure how much VOT is being used and if VOT is captured using the same NTBS return as DOT we are unsure how much actual DOT is occurring, highlighting the need to count these independently.

A similar issue probably occurs in the OPCS data capture as there is no formal code for VOT. Assuming the code is used interchangeably, the OPCS recorded activity for the three years from 2020 through to 2023 was 3723 instances, only 5% of the overall HRG Dz41z activity. This probably underestimates the amount of DOT and VOT used, due to under recording of activity with commensurate loss of income.

Figure 14 is based on NTBS data and shows a wide variation in use of observed therapy, with just under half of services apparently not using it, while three services used it for over 40% of

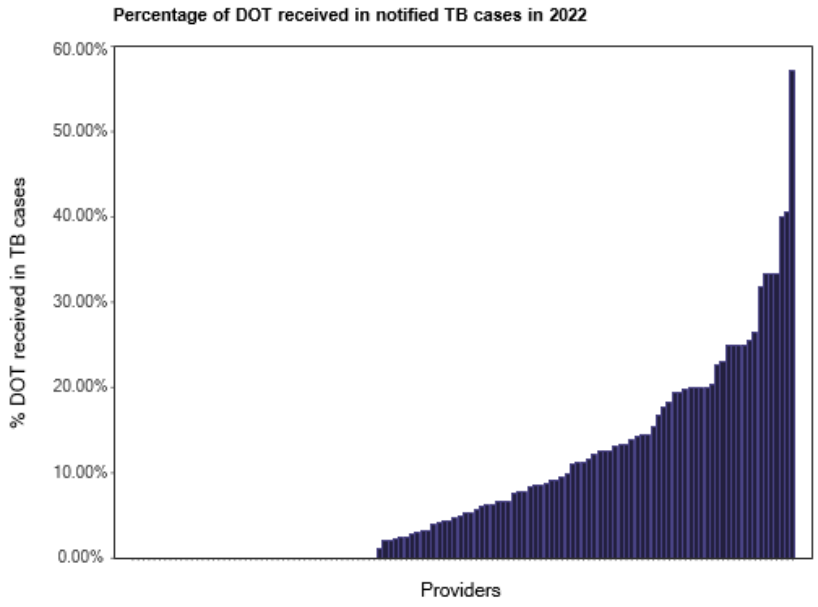
their notifications. These 3 services had 21, 32 and 5 notifications and used DOT in 12 (57%), 13 (40%) and 2 (40%) respectively. Of interest is the finding that in providers with more than 10 cases there was a very consistent use of around 10%, but in those with less than 10 cases observed therapy was used on average in 5.5% of occasions Whether this reflects lack of resources, whether there is no need for observed therapy or uncertainty when to use it, we cannot comment.

Of interest, the uptake of DOT (and possibly VOT, given the coding issue) was limited, with 740 cases offering DOT but only being used in 451 cases. From the deep dives, concerns were raised that more observed therapy was being used than recorded in the NTBS returns and it appears that the information on these patients was not uploaded onto NTBS due to lack of administrative staff, thereby questioning the validity of the data. Furthermore, we heard of occasions when DOT or VOT should have been used, but teams did not have the staff to deliver them.

For VOT there seem to be additional problems. In 53% of respondents there were not enough mobile phones to support a VOT service, and there were reported difficulties with Information Governance (IG) preventing use of VOT. Commercial systems like the London 'Find and Treat' service had been considered but acute providers were reluctant to pay for an outside service and we also heard of examples where ICBs had refused to pay, hence limiting the utility of VOT. However, we found an example where the IG issues had been resolved and VOT was being delivered.

Overall, DOT and VOT are important tools to aid treatment completion, but given the limitations in both NTBS and OPCS on how VOT activity is captured, it seems that there is an underreporting of its use in both OPCS and NTBS due to insufficient administrative support. Other issues limiting its use, which must be addressed, are when it should be delivered, the infrastructure of staff and equipment and IG issues.

Figure 14 - Directly Observed Therapy



Service Size	% DOT received
<10 cases	5.65%
10-49 cases	10.81%
50-99 cases	9.92%
100+ cases	10.61%

Recommendations in relation to Directly Observed Therapy and Video Observed Therapy (DOT & VOT)

	Recommendations	Resp.
52.	There should be sufficient administrative staff to ensure that if DOT or VOT is give, it is captured on both NTBS and provider activity.	P, ICB
53.	There should be sufficient work force to deliver DOT or VOT when clinicians deem it is needed. For DOT activity, HCSW have a major role in supporting this intervention.	P, ICB
54.	In wide geographical areas, VOT should be considered or alternative methods of delivering DOT e.g. by use of local pharmacies, need to be explored and supported potentially financially by ICBs.	P, ICB
55.	If VOT is used by commercial companies, independent providers, or external services, the ICB should support the financial aspects.	ICB
56.	Ideally infrastructure should be in place to deliver local VOT. This requires the availability of appropriate staff, sufficient phones and the resolution of IG issues.	P, ICB

7.5 Non Tuberculous Mycobacteria (NTM)

Non tuberculosis mycobacteria are a group of mycobacteria that are ubiquitous, often residing in soil and that under certain circumstances, often when an individual's host defences are compromised and in the elderly population, can lead to clinical disease. There is considerable morbidity and mortality associated with NTM infection. The actual numbers of NTM isolates, and those that cause actual disease requiring treatment, are difficult to determine as they are not formally notified.

Such patients who require treatment often do so for a protracted period with a variety of anti-tuberculosis drug regimens that are often different from standard treatment and usually taken for a longer period. The management is complicated by standard sensitivity testing being less useful in predicting a response. To complicate matters further such patients with NTM often have a variety of underlying medical conditions, frequently pulmonary, with concurrent treatment, adding to the complexity of drug interactions and drug related problems

Patients with NTM requiring treatment seem increasingly common and our survey showed that 68% of TB services provide some or all of NTM care, reflecting a significant burden on already stretched services. From the deep dives we heard that there was insufficient capacity and resources to manage NTM patients, impacting on delivery of usual TB care. Furthermore, we note that the BTS MDR service is used in an advisory capacity for patients who do not have MDR or XDR, a proportion of which will be NTM.

With the recognition of the burden of NTM, a working party was convened and guidelines and recommendations published on the Management of NTM, from the data and deep dives, this report supports fully the ambitions of improved management of NTM, frequently making recommendations to the majority of sites to initiate discussions with ICBs and provider commissioners about development of NTM services. Where services exist for those patients with bronchiectasis and / or cystic fibrosis they may be expanded, but from the deep dive visits it was apparent that most clinicians thought the NTM service should sit separately from these established services.

On a pro-rata basis, a workforce can be calculated (from the number of current and anticipated NTM cases), to include medical time (be that respiratory and/or infectious disease) and clinical nurse time (often from the TB team), although infectious disease and/or respiratory nurses

can support the service. Services will also require support from pharmacy, respiratory physiotherapy and access to dietetics advice.

Recommendations in relation to Non-Tuberculous Mycobacteria (NTM)

	Recommendations	Resp.
57.	The NTM recommendations from the NTM Network UK Standards of Care should be adapted to local services and implemented within an appropriate time line.	P, ICB
58.	Services should review their provision and infrastructure for NTM and develop formal business plans, in conjunction with their host provider and the ICB, to deliver an NTM service.	P, ICB
59.	Discussions should take place with NHSE, BTS and regions on the development of regional and or national advice to help support the management of NTM, given the difficulties of treatment outlined and potential for use of high cost drugs.	R, N

7.6 MDR/XDR (Multi drug resistant mycobacteria/ Extensively drug-resistant tuberculosis)

Cases of MDR XDR are fortunately fairly low in England with a total of 90 cases, in the time period of the review (2% of all notifications) with approximately a quarter of providers having one or more cases. To help manage this difficult population of patients, who often require complex drug regimens, the BTS MDR service was established. The annual report (Management of NTM) highlights the activity The use of this service was shown to be well appreciated during deep dives, with all colleagues positive about the benefits of access to expert opinion.

As shown in **Figure 15** half of all the services discussed one or more cases and **Figure 16** shows that half of services (but in a different proportion) used the service for non XDR/MDR patients, but with a much smaller distribution. As seen in **Figure 17** the majority of those that used the service were for drug related issues, with 13.4% of discussions being for complex and/or social issues.

Figure 15 – What number of MDR−TB/XDR−TB cases have you discussed with the BTS MDR−TB Clinical Advice Service?

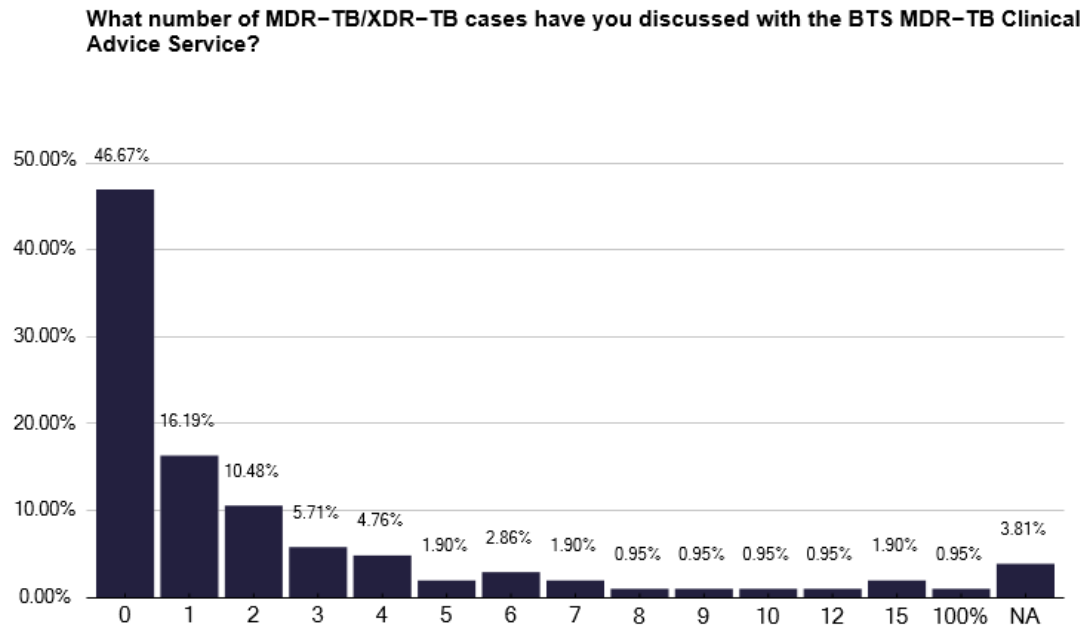


Figure 16 – How many non−MDR−TB/XDR−TB cases have you discussed with the BTS MDR−TB Clinical Advice Service?

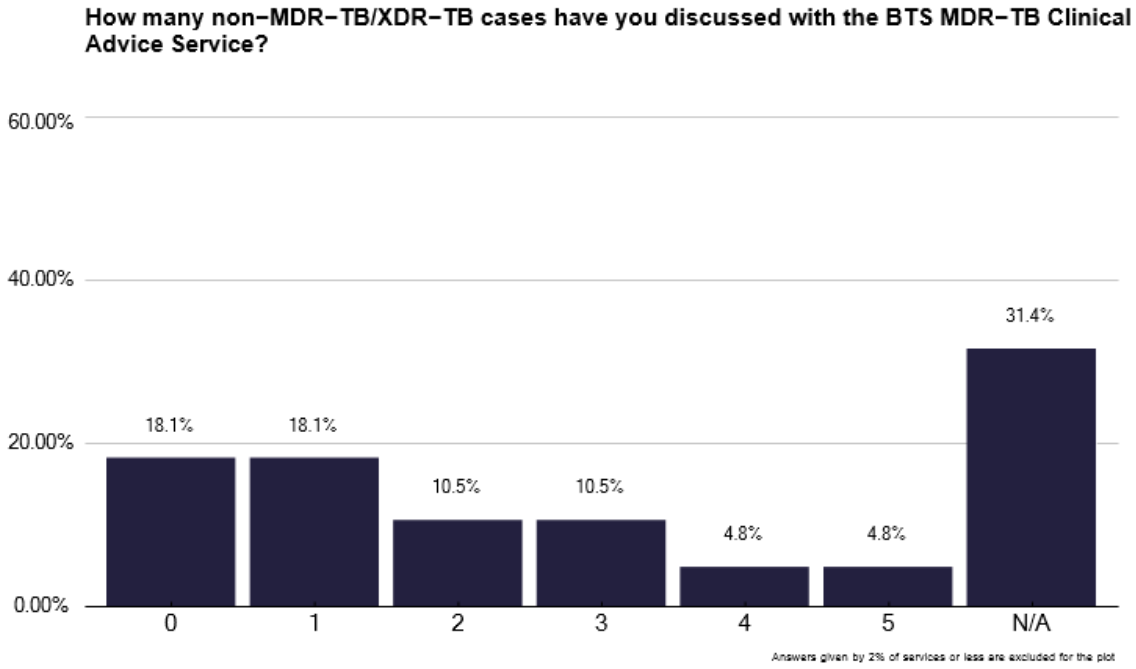
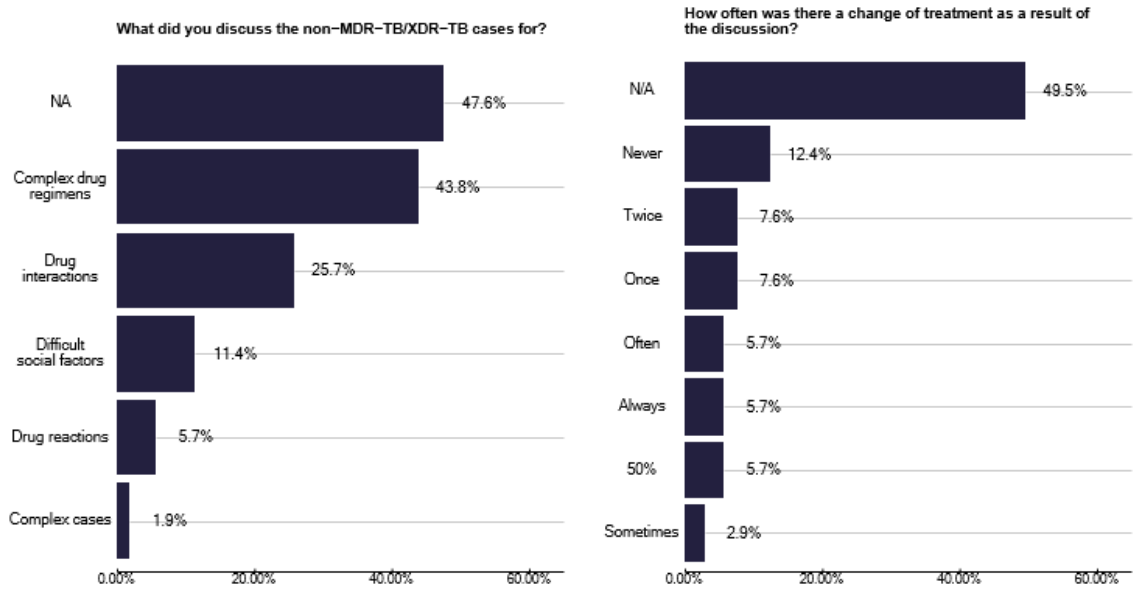


Figure 17 - Management of MDR-TB and XDR-TB



Recommendations in relation to MDR/XDR

	Recommendations	Resp.
60.	The BTS clinical advisory service for the MDR/ XDR service is of great benefit to clinicians and needs to be continued, whilst the need for external funding is recognised.	N
61.	Consideration needs to be given between NHSE and BTS whether the service should continue to provide advice on the management of non MDR/XDR patients, recognising from this data there is a clear need. A view should be taken, if the service moves to become a clinical advice service that includes 'difficult problems' as well as MDR /XDR, on whether this should include NTM, given that similar complex drug regimens and interactions occur. It needs to be recognised that such developments would need to be supported financially nationally	N

7.7 Children and Young Person Services (CYP)

While CYP services were not part of the commissioned review process, we did ask questions in the survey and obtained data NTBS data relating to CYP. Comments are based on this information and the strong representation from CYP colleagues during the deep dive visits.

We note from the epidemiology that tuberculosis notifications in those under 5 years and under one year old are fortunately uncommon i.e. 134 and 39 notifications respectively. However, the workload around contacts is significant for the 3373 children identified, of which 451 were screened and 332 commenced on preventative treatment, with good adherence. We found over half of providers reporting 100% completion, but with some variability.

Whether this is a correct reflection of completion is difficult to determine. Just as for the adult completion rates we heard that failure to complete NTBS for CYP produced apparently lower rates than expected during our deep dive discussions. Management of contacts who declined preventative treatment were different from adults, with CYP arranging some other form of

contact in 50% of returns and less use of advice and inform at 26%, compared to the adult population of contacts with figures of 34% and 47% respectively. Although we did not analyse this data in relation to infrastructure, we note the time in paediatricians' job plans was limited and in 38% of services there was no specific paediatrician involved in managing CYP TB. Where there was paediatrician input, this was by general paediatrics in half of providers. This low medical input may be one explanation why only 25% of services delivered family clinics.

Diagnostics should be equitably available for both adults and CYP, but we heard on more than one deep dive the difficulties of accessing negative pressure rooms or facilities, should induced sputum be used in the older children. With the low volumes of CYP cases and little or no paediatric experience, being able to discuss care with a regional service is essential. Sadly, there was very poor infrastructure for this, with few structured networks, and those networks that did exist were based on good will, with no time in paediatricians' job plans and a lack of an administrative infrastructure to run a formal CYP MDT. This led to frequent and disruptive calls to unsupported centres.

Recommendations in relation to Children and Young Person Services (CYP)

Recommendation	Resp.
62. While there is no set figure, we would suggest that where there are greater than 10 CYP notifications, with the commensurate contact tracing, a paediatrician with knowledge and interest in the management of tuberculosis should be part of the TB team. With fewer cases, access to infrastructure at regional level needs to be available for advice and support.	P, ICB, R
63. Ideally, one of the TB nurses dealing with CYP should be trained in child health.	P
64. Resources to support the management, including the diagnosis of CYP, should be in place; this includes both infrastructure and time in job plans for SPA and DCC time to support MDT attendance.	P, ICB
65. A regional network to support colleagues where there are relatively few notifications, contacts or latent TB, should be established on at least a regional basis. This should also provide advice for MDR/ XDR and difficult cases. To facilitate this there needs to be time in medical job plans, and nursing and A&C time to support a regular MDT, the frequency of which would be dictated by activity and local competencies at managing CYP TB.	P, ICB, R

8 Prevention

Prevention of TB is the ultimate goal to minimise the number of cases that develop the active disease and the risk of passing the disease onto other individuals. Primary prevention is by BCG (Bacillus Calmette-Guerin**)** vaccination for those at risk, which may include the neo-natal Programme, individuals identified as part of the contact tracing program who do not have active or latent disease and individuals travelling for long periods to high risk areas.

Identifying individuals who have been exposed to someone with potentially active TB and so are at risk of developing TB at a later date is the principle behind contact tracing. For those individuals who come to England from countries where there is a high prevalence of TB, a similar principle of assessing if they have evidence of TB exposure and actively managing that risk of subsequent disease forms the basis of preventative therapy. This process is seen in the occupational health screening of NHS workers and in the latent TB program.

8.1 Bacillus Calmette-Guerin (BCG) vaccination

The BCG aspects of the TB service have changed over time with the withdrawal of the routine schools' programme and more targeted use in the neonatal and adolescent population. BCG has a specific procedure code, E952, and between years 2020 and 2023 there were approximately 44,480 outpatient administrations of BCG recorded which represents over half of the TB nurse support Health Resource Group (HRG) activity. While it reflects a significant volume of work, there is more activity in the TB service which is not coded, leading to an apparently high proportion of activity for BCG (see section 6.9 on Coding and Payment Mechanisms).

A major shift in administering BCG occurred as a result of the UK National Screening Committee's recommendation to screen new born babies for severe combined immunodeficiency (SCID), as BCG makes subsequent treatment difficult, screening needs to occur before BCG administration for those 'at risk' babies. While evaluation of the SCID program began in March 2024, most services have moved to delivering neonatal BCG. From the data, 86% of providers had an SOP for BCG, with administration being by maternity and hospital services in 46.7%, returns with health visitors and primary care providing 17% of vaccination, and remaining within the TB service in 19% of respondents. During visits we discussed BCG delivery and noted the shift into maternity services, though for one service the inability to deliver BCG in a timely fashion led to the service being taken back into the formal TB service, though the resources to deliver it were limited.

Recommendations in relation to Bacillus Calmette-Guerin (BCG)

Recommendations	Resp.
66. Ensure appropriate recording of BCG vaccinations when they are administered by the TB team to ensure the activity is both captured and feeds into the HRG for potential payment, as per section 11.5	P
67. Any repatriation of the BCG from maternity to the TB service needs to come with appropriate resources.	P, ICB

8.2 Contact Tracing

Contact tracing is the process where individuals who may have been exposed to a patient with active TB are identified and reviewed to see if as a consequence of that exposure they have developed either latent or less commonly active TB. This allows treatment, when indicated, to

prevent subsequent disease and occasionally to identify the true index case who may be infectious but has not sought medical advice. As contact tracing is a way of controlling and preventing future disease it forms a key part of the NHSE UKHSA TB Action Plan. Consequently, we have explored this area in detail, looking at the process of who is contact traced, the relationship between OPCS code use, the number of contacts per case, specifically the numbers of 5 and 10 contacts, for both pulmonary and infectious cases. Additionally, we also looked at the number where active disease was identified as part of the screening and clinic process for follow up.

The number of contacts generated per case will depend upon local practice, as noted below, and whether the patient was thought to be infectious. **Figure 18** shows that the majority of TB services screen both household and non-household social contacts for infectious cases, while for extra-pulmonary there is more variation, with 22% reporting as not screening and 78% doing household contacts. In the one deep dive where no screening of extra-pulmonary was reported, there were selective reviews on a case-by-case basis. Those services where there were less than 10 notifications per annum tended to have a higher proportion of patients screened as shown in various pages in the data packs. There was no explanation from the low prevalence sites we visited but this may reflect a more cautious approach, with wider screening undertaken.

The amount of work generated is outlined in **Figure 19** and reflects the number of contacts identified, screened, starting and completing treatment for both adults and CYP. Given that there are multiple visits for those contacts starting treatment, as well as all the number of contacts screened initially, there is a considerable shortfall in the activity recorded in OPCS (as noted in Section 6.9 on Coding and Payment Mechanisms). This highlights the need for better recording of this activity, especially with the potential loss of funding.

Table 5: Number of contacts identified, screened, starting and completing for both adults and CYP

Contacts Category	Total	Adults	Children	Percentage Remarks
Total number of contacts identified	12,521	9,148	3,373	
Total number of contacts screened	6,643	2,622	451	**53.1%** of total contacts screened out of those identified
Total number of contacts started treatment	1,115	736	419	**16.8%** of total contacts started treatment out of those screened
Total number of contacts completed treatment	905	573	332	**81.2%** of total contacts completed treatment out of those started

The number of contacts per case is an important metric to improve detection and management of latent TB, as highlighted in the TB Action Plan. We explored this via the NTBS and survey returns, looking at 5 or more and 10 or more contacts per case based upon if the index case was pulmonary or extra pulmonary and also reviewed the information on contacts per infectious case.

Figure 19 shows the average contacts per notified case with **Figure 20** reflecting the figure more accurately with the removal of an outlier from a case involving a factory. We note from NTBS that the proportion of services seeing over 5 contacts per case varied widely, with 27% of services from the survey saying they achieved this on two or less occasions. Perhaps the

important aspect is ensuring that patients who are infectious have 5 or more contacts reviewed, as per the Action Plan. This is seen in **Figure 21** and more clearly in where only 29 providers achieved the 5 or more contacts per notification of infectious notifications, defined as pulmonary disease, with 94 failing to do so. While the numbers are less, at 961 notifications, we also looked at the number of contacts per case for those with actual proven smear positive disease. This is shown in **Figure 23** with 50 services achieving 5 contacts per truly infectious notification, Assuming the NTBS returns are correct, and the survey would support this, there is considerably more work needed to deliver the action plan target.

Achieving 10 contacts per case occurred less often and was not reported in NTBS in half of services from NTBS and was two or less on 59.6% of occasions from the survey. With the variation in clinical practice noted above, the number of contacts associated with extra-pulmonary disease showed greater variation.

One of the key outcomes of screening is to identify patients who may also have active TB and potentially be the source of the infection. Fortunately, this is uncommon, where around two thirds of providers did not find any active TB and in those that did, it was usually less than 10%. Three services had a high proportion of active cases in those screened which merited further review.

One service with 25% of active TB in those screened was a moderately sized service with 48 notifications, of which 32 were pulmonary. However, they reported only 10 contacts from all these cases, 4 of whom were screened and 1 found to have active TB. The second service with 25% of active TB in their contacts had 10 notifications, 5 of whom were pulmonary, but only 6 contacts were identified, with 4 being screened and one active case. The final service that had 22% of active cases from contact tracing had 50 notifications, of which only 36 were screened with active disease identified in 8 of these.

This is of concern, as the number of contacts identified seems very low and those screened even more so, especially given a number had pulmonary disease. The reason for this low activity is unclear as they were not services visited.

Given the low number of services which are not achieving 5 contacts per infectious case, as in **Figure 20**, and the failure to contact trace those notifications with active disease, perhaps this issue needs to be addressed with national policy.

Within this there is a ‘sweet spot’ that minimises the number of individuals who are screened but maximises the pickup rate, especially for latent TB. Too many contacts screened generates considerable work but a low percentage of those who need treatment, while too few screens mean patients may be missed. Judging this well is a difficult skill that requires the expertise of the TB nursing staff. For admitted patients, most nurses will visit the ward to have an initial discussion on contacts, while home visits are conducted at the start of treatment to glean more information in 72% of pulmonary TB, occurring less if extra-pulmonary.

Most services believe that most patients attend, with 64% thinking they have an 80% or greater attendance for screening if eligible. For those adults who fail to attend, 70.7% of services offer one further appointment and 58.6% further appointments thereafter, with a similar figure occurring for children. If contacts refuse treatment, **Figure 22** shows a difference in practice between adults where 47% are offered “inform and advise” with 34% informing others but in children over 50% the GP is contacted.

For those who attend screening, completion of treatment is noted from NTBS to be around 81% but **slides 64 and 65 in the National Dataset in Annex C** show the variation in number starting and completing treatment. Many TB services thought the figure was higher than seen

in the NTBS return. An explanation given during one deep dive was a tendency for some individuals to go back to the Indian subcontinent for treatment and so there are no records in NTBS about the patient either starting or completion of treatment. However, a more concerning comment, was the failure to update NTBS, with information for all patients about the start and completion of treatment due to a lack of capacity, specifically administrative staff. This potentially invalidates much of the contact tracing data and needs to be addressed, as discussed in the workforce **Section 9.4**.

Contacts of individual or family notifications generate considerable work but can in part be scheduled into clinical time (noting that services are understaffed). However, outbreaks where there is an infectious patient with numerous contacts cause considerable stress within the system. Fortunately, these occur infrequently and are discussed in more detail in the NHSE ICB **Section 8.2**.

Figure 18 – Screening and Treating Contacts

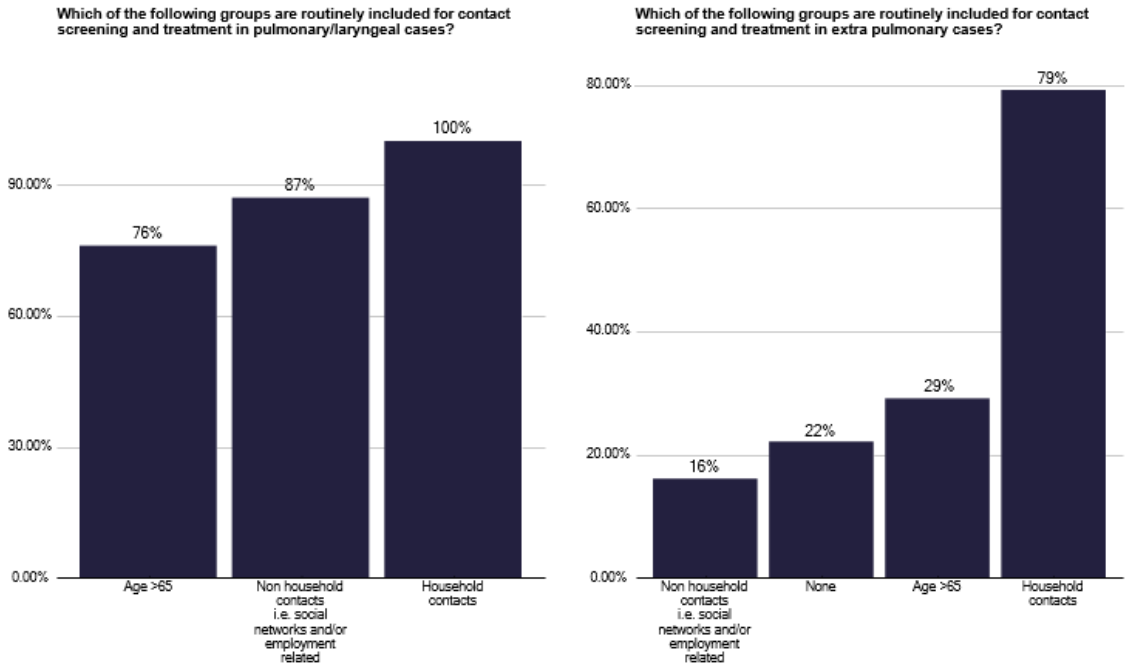
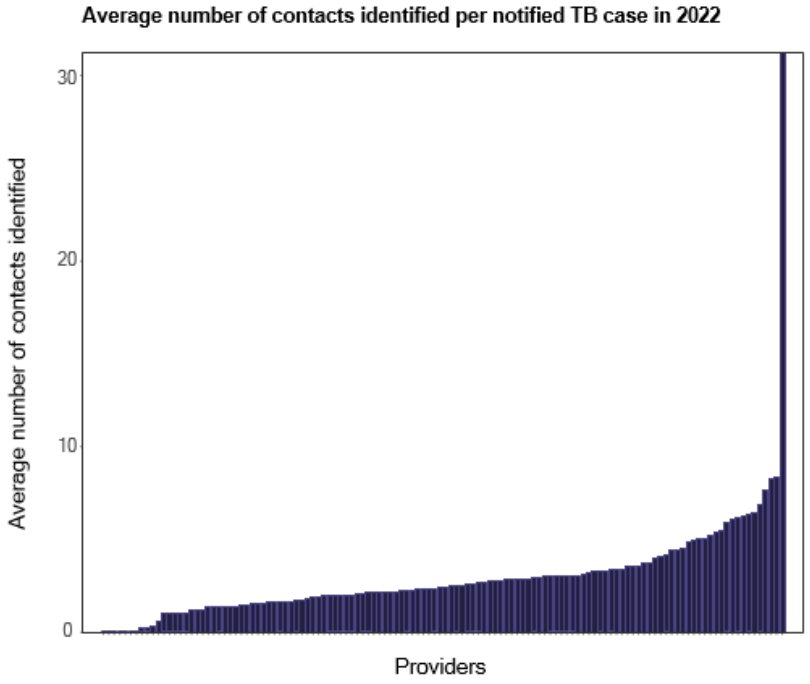


Figure 19 - Average number of contacts identified per notified TB case



Service Size	Average number of contacts
<10 cases	4.0
10-49 cases	2.9
50-99 cases	2.6
100+ cases	2.8

Figure 20 – Average number of contact identified per notified TB case

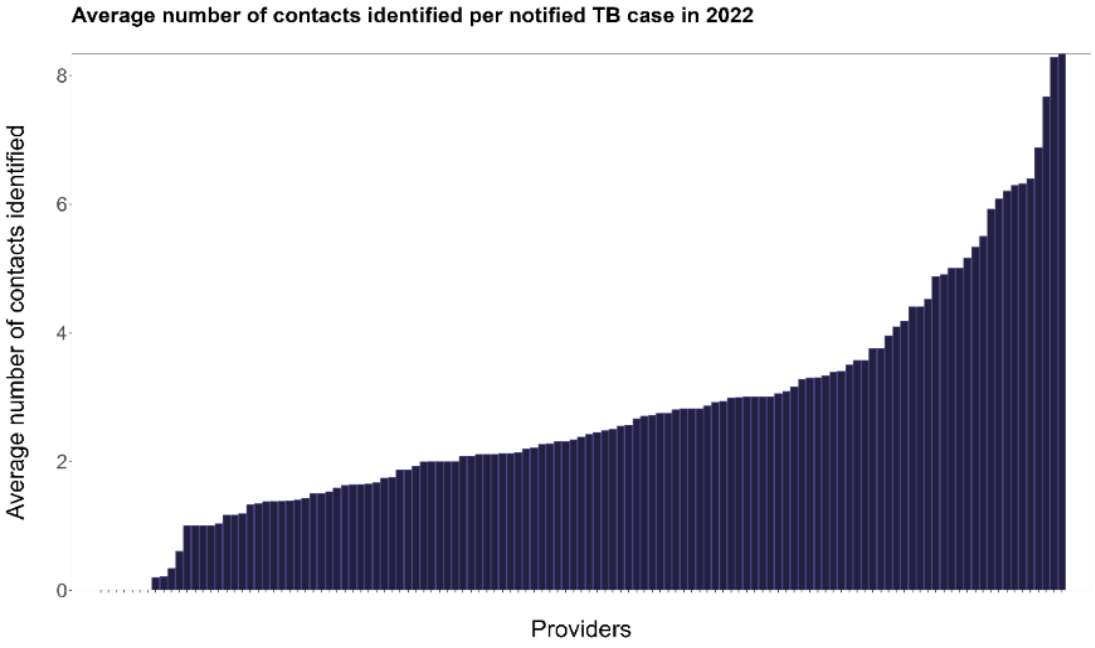


Figure 21 – Average number of contact identified per notified pulmonary TB case

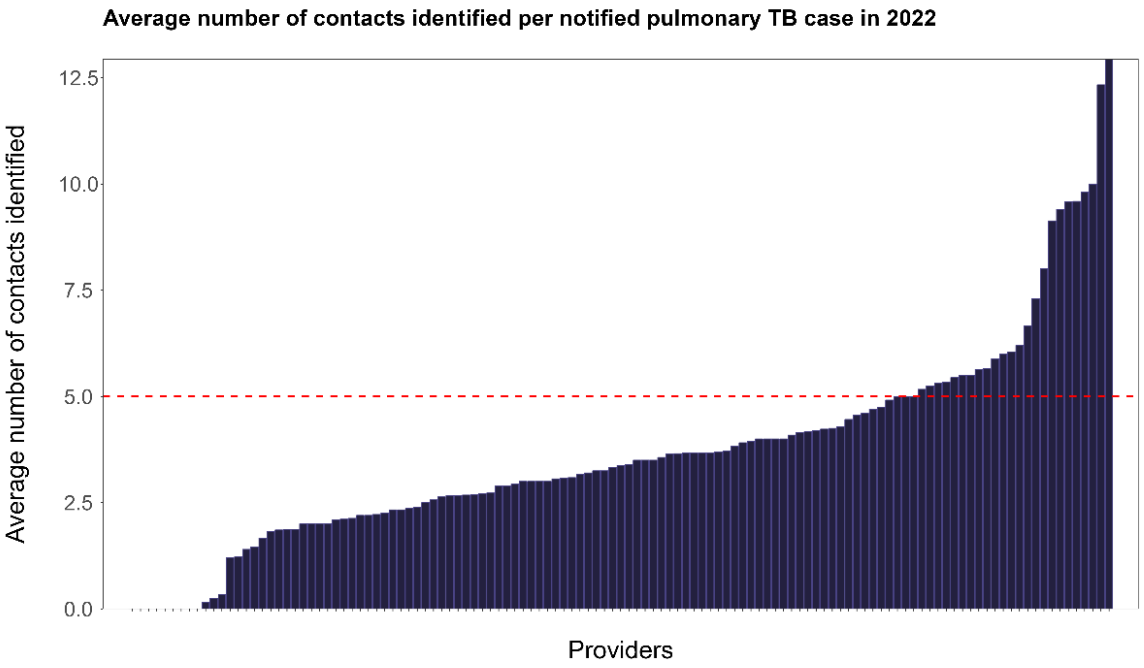


Figure 22 - Screening and Treating Contacts

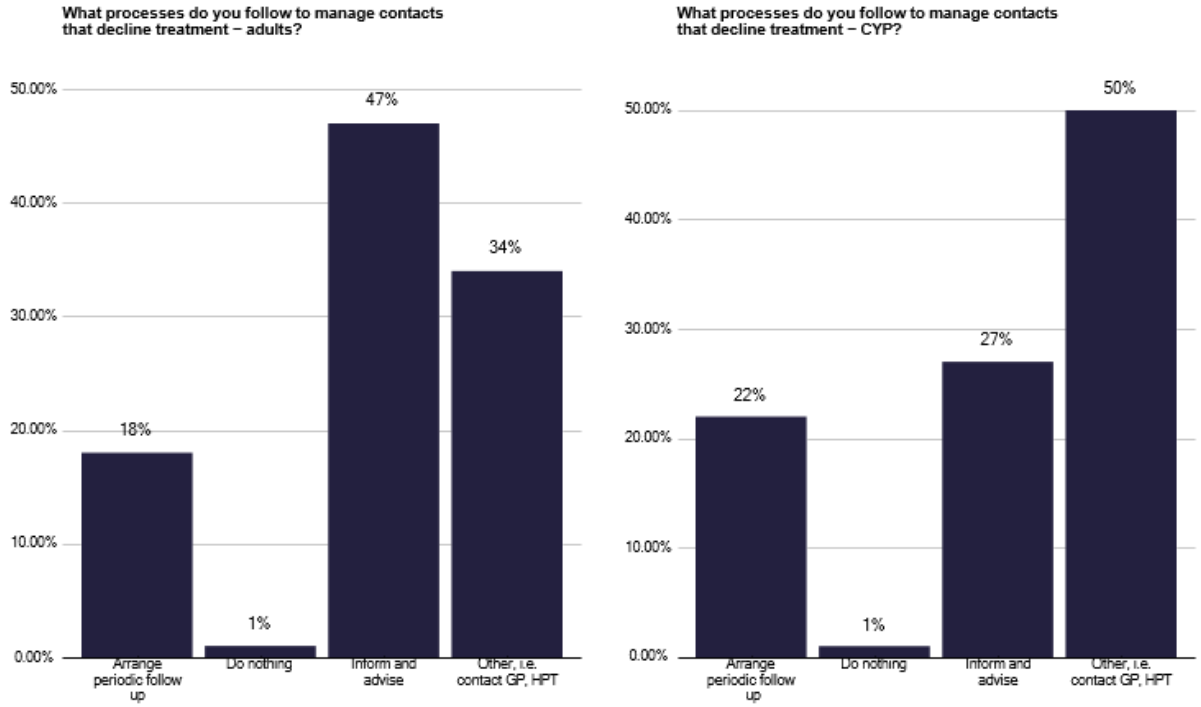
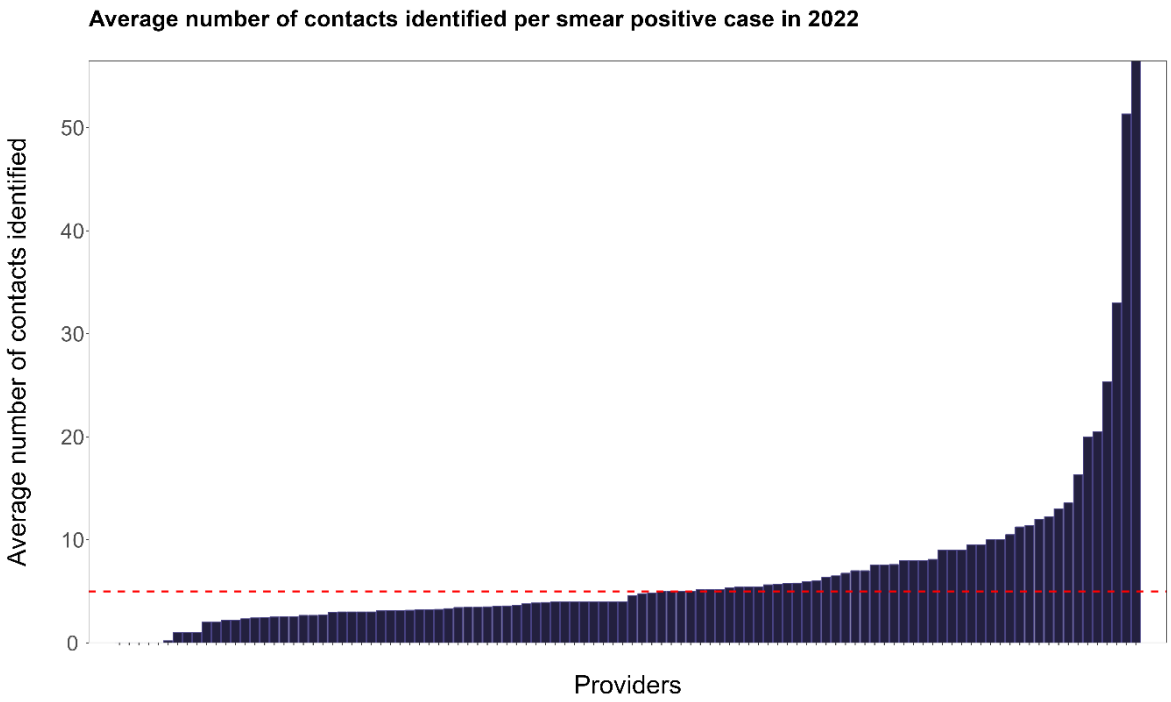


Figure 23 Average number of contacts identified per smear positive cases



Recommendations in relation to Contact Tracing

	Recommendations	Resp.
68.	The ambition of the TB Action Plan to have five or more contacts per infectious case needs further support within organisations, and staffing to deliver the shortfall. This probably needs active management as seen from the data.	P, ICB, N
69.	There needs to be information for contacts and carers in an appropriate format and language that explains the rationale of contact tracing to support attendance and adherence.	P, ICB, LA
70.	Services should consider the optimal way, for their population, the best method of delivering services for adults and CYP, be this family clinics, evening clinics, remote follow up etc.	P, ICB

8.3 Latent TB and Preventative Therapy

Preventative therapy is a term that is used to describe the use of anti-tuberculosis drugs to prevent the onset of disease in individuals who have been exposed to TB and in whom the disease is latent. This is based upon the finding that they are at significant risk of developing tuberculosis with the potential risk of spreading TB to other individuals. The concept of identifying those individuals who have got latent TB and treating them to prevent disease is the same principle of contact tracing, applied to individuals who have been exposed to TB in their previous environment. These can be considered as: Occupational screening of health workers; individuals who are to receive biological therapies or immunosuppression; refugees and migrants coming to live with family members and asylum seekers.

If we consider the occupational screening of healthcare workers, we can see that some 47% of providers had a Standard Operating Procedure (SOP); however, we were told in the deep

dive visits that the SOP often sat with the occupational health service, with the TB team dealing with individuals referred on, usually based on a positive IGRA as used in 91% of services. We also heard of pressures in services to prioritise these so they could start work. In one service this was leading to a 3-month delay in other patients being seen, reflecting the overall lack of capacity to deal with 'routine' care and preventive therapy demand.

A further area creating pressure is the increasing use of biological therapies for many chronic diseases, with many specialist societies producing guidelines prior to starting treatment to assess for previous TB with IGRA testing. Most of the work was done by the specialist service with onward referral to TB services for those with a positive IGRA. However, in over 10% of respondents it was the TB service themselves that were undertaking the initial assessment, which represents a significant workload to make treatment decisions. Occasionally we found that the specialist service was initiating treatment, but we heard in one deep dive that this was based in a renal transplant service, with preventative treatment given by a trained nurse under supervision of the TB service.

Migrant health screening is often embraced as part of the asylum process and is focused on individuals who are coming to work or, more commonly, joining other family members who are already resident in England. Screening sometimes takes place prior to leaving the country of origin.

NHSE recognised this was a potential issue and so established a programme to incentivise commissioners (first CCGs and now ICBs) to recognise both the public health and health economics benefits of LTBI testing by supporting the IGRA testing in 26 ICBs with the highest numbers of patients. They were individuals newly registering with a GP practice (identified through Type 4 data) who:

- Were born or spent more than 6 months in a high TB incidence country (≥150/100,000 or Sub-Saharan Africa)
- Entered the UK within the last 5 years (including entry via other countries)
- Are aged between 16-35 years
- Have no history of TB or LTBI
- Have not previously been screened for LTBI in the UK.

For those areas where the number of UK arrivals from high TB incidence countries was lower, there was an expectation the ICB would support the testing of these populations. While sensible in principle there have been many issues with the process which, while not comprehensive, include:

1. Issues with information of individuals arriving and then being moved either before assessment could take place, when they had been assessed or after starting treatment.
2. Funding was given to areas where there were high numbers of potential asylum seekers but changing systems led to dispersal of individuals where there was no funding to support testing. This was a major issue in one deep dive meeting where until recently there were 5 hostels holding asylum seekers but they were not part of the national Programme.
3. Failure of either the ICB and/or primary care to accept the need to undertake the testing. In one deep dive there was an excellent process with primary care undertaking the IGRA and referring on, but the practice covered approx. 7000 patients, so for the remaining 450,000 patients' resident within that ICB we were unaware of the number of potential latent TB cases that were not assessed. For two of the deep dives, primary care refused to engage, so to support screening the acute providers reviewed the Flag 4 information that came to the ICB, organising an IGRA for those at potential risk, and then treating the individuals with a positive IGRA. This was a large volume of work

given patients needed to be registered with the acute provider and the IGRA obtained before deciding who needed preventative treatment. In one service, funds were not defrayed to enable this to happen, so the service decided to cease all screening activity in December 2023. At the time of the review there was a backlog of over 3000 Flag 4 individuals, a proportion of whom would have had preventative treatment.

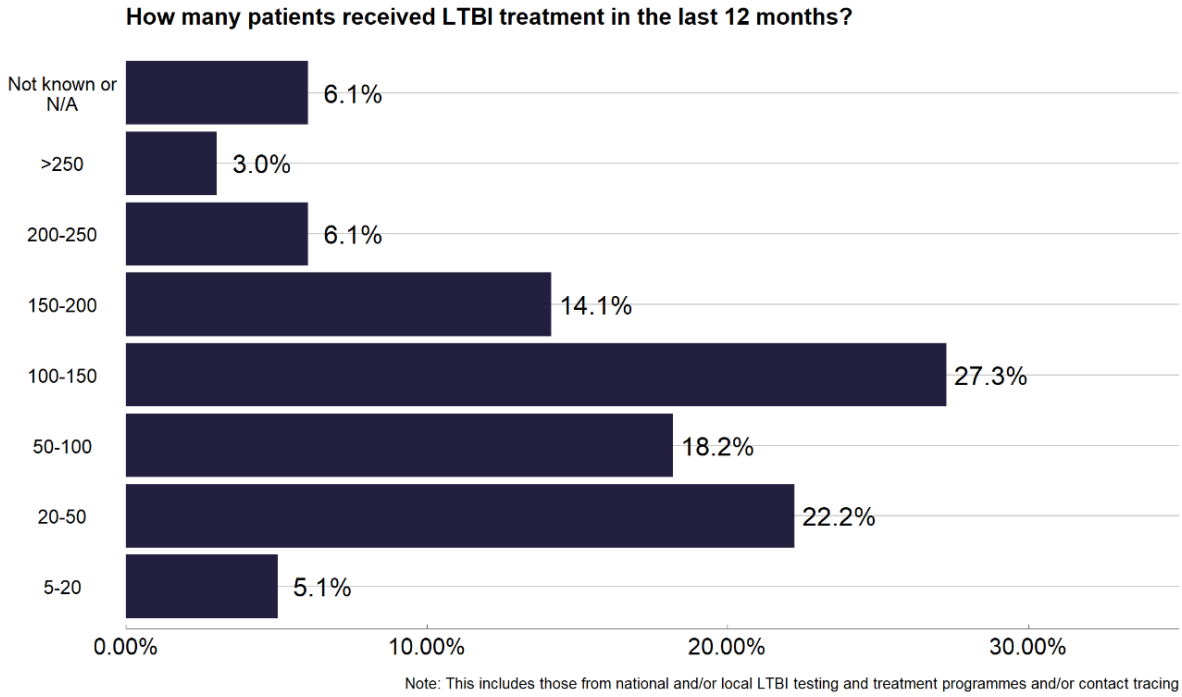
4. In the funded Programme, we heard from visits that there was insufficient income to employ the staff needed to do the IGRA and initial assessments when not delivered by primary care. Some of this may be the ICB not releasing funds in a timely fashion, but the additional workload of registering patients in the acute provider, for example, was an additional cost and workload burden. This added further pressures on staff and the ability of services to manage notified cases of tuberculosis and the contact tracing which follows. This self-reported activity can be seen in **Figure 23** where the estimates of new migrant work in acute providers is massive, especially given the need for ECM and especially language issues.

The nature of the preventive service varied widely, with 41% having no SOP that was compliant with national guidelines. With respect to how patients were managed, a combination of home visits, phone calls, virtual clinics and face to face attendances were used. Some 64% of services had a combination of these, clearly tailoring the delivery to patient need. Half of services gave treatment for the whole period, while others reviewed early at 2-4 weeks and 76% of services seeing at the end of treatment. However, language was an issue in some services and enhanced case management was required for some. Colleagues felt there was good adherence and completion of over 80%, noting 3% did not know about completion rates. Frequently, practice seemed to have been dictated by available resources.

The UK new arrivals service is clearly an important aspect of a long-term reduction of tuberculosis in England by identifying individuals who may develop TB later and potentially infect others. It is notable that most services were stopped during Covid but the one service that continued with the preventative strategy during the pandemic has not seen the increases in TB noted elsewhere.

We did find some innovative models of care. Two excellent examples were:, working closely with a GP practice or teams visiting hostels in a ‘health bus’ where individuals were counselled and had the IGRA performed with onward referral for treatment.. However, with greater dispersal away from hostels and hotels such innovative models may lose their economics of scale. Unfortunately, data on the effectiveness of this programme is limited with respect to the number of potential individuals who are eligible for testing, attend for IGRA testing, and then attend for clinical review, together with numbers starting and completing treatment. If a latent service is to continue then changes need to be considered as set out in our related recommendations.

Figure 24 – How many patients received LTBI treatment in the last 12 months?



Recommendations in relation to Latent TB and Preventative Therapy

Recommendations	Resp.
71. Any service needs to be developed in conjunction with the acute provider and ICB. Irrespective of the model there needs to be sufficient capacity to deliver the latent service without impacting on the basic care of notified patients and the contacts.	P, ICB
72. Appropriate codes need to be authored in OPCS to capture latent TB activity and used for reimbursement to ensure any services are financially sustainable.	P, N
73. Migrants, including asylum seekers, need to be identified and have access to an appropriate LTBI program. In some services there needs to be improved coordination with all parties re arrival and dispersal and to where, with better data flows.	P, ICB, R, N

9 Workforce Issues in the Management of Tuberculosis

9.1 General Workforce Issues

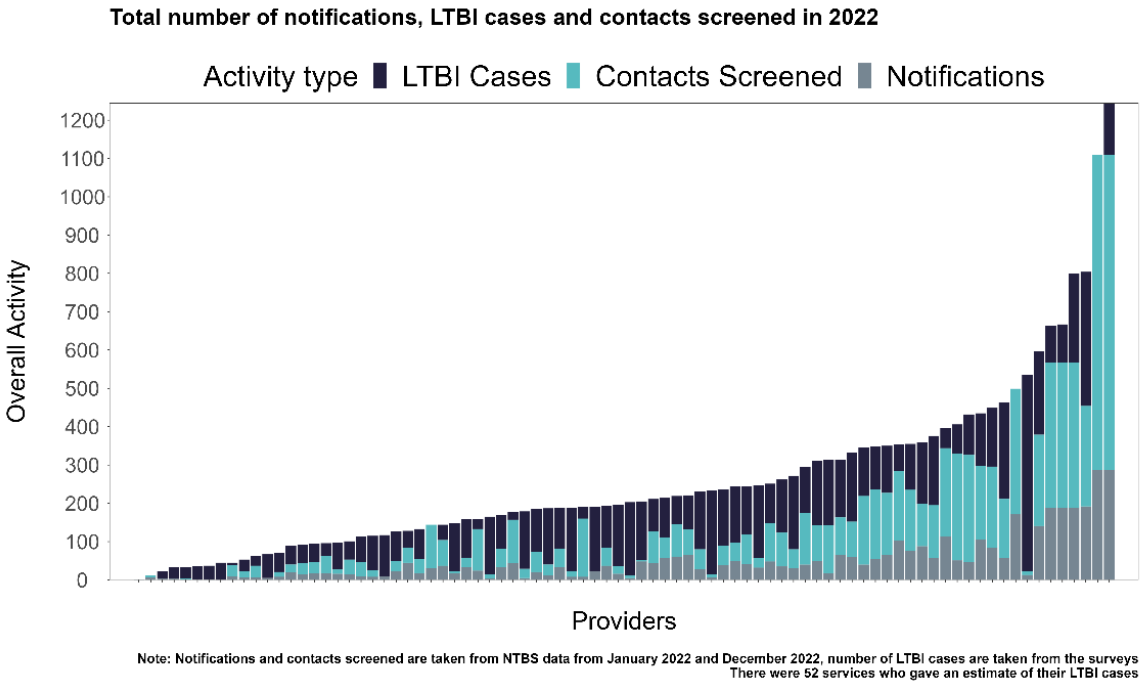
As expected, workforce was the major issue we noted from the survey and during the visits, with staff highlighting that there was insufficient capacity to manage the burden of disease with most sites we spoke to having had no investment for some time. This was especially difficult in some TB services where there was a rapid increase in the number of notifications (and commensurate contact tracing) together with increasing activity in managing individuals with potentially latent TB. We have considered workforce in the staff groups needed to deliver care. To supplement the information on medical staff returned by 104 services, a workforce questionnaire which was used previously to document nursing numbers was completed by 59 services. Both the medical and nursing time were reviewed in depth during the deep dives.

When considering workforce issues it is not only the number of notifications, as used previously by NICE, that is important, but also aspects of contact tracing and preventative therapies. To represent the workforce requirements, we have looked at both the medical and nursing workforce in relation to the number of notifications, as used throughout the report of: <10 notifications, through to 10-49; 50-99 and >100, as shown in **Table 6**

To supplement this, we also developed **Figure 25** where we added in the number of reported contacts screened (not identified) and those receiving preventative therapy. As only 51 services returned information on preventative therapy **Table 7** shows the overall activity against staff numbers. This table and graph do not represent actual workload, as contacts and other latent TB groups, as well as notifications, will have multiple visits, so underrepresents actual treatment activity by a minimum factor of three.

This highlights the huge volume of work that is generally unrecognised and does not factor in the additional work for those individuals requiring ECM and the MDR/ XDR population. All these factors make it complex to state the number and grade of staff for a particular caseload and service. For example, we identified a service with huge workload issues related to language issues that were a major barrier during consultations. An additional poorly recognised workforce issue relates to time allotted to, and the funding for, services that are providing a regional oversight of TB, be that for MDR/XDR, NTM regional MDTs and CYP services. An excellent example from a deep dive was one sub-regional service trying to develop a support network for other adjacent TB services which were being delivered by teams with little experience of managing TB or a low volume service. How this is enabled is a key aspect for the future development.

Figure 25 - Workforce to deliver TB services, including preventative therapies but excluding NTM work



9.2 Medical Workforce

For medical staff, clinical time is structured into sessions, each of 4 hours and can be considered as SPA or direct clinical care (DCC). During deep dives there was some confusion about what was the attribution of SPA and DCC into the TB service. Uniformly, there was insufficient time to deliver what is required. We were clear in the visits that the clinical (medical) lead needs time in their job plan as SPA for: meeting ICB and acute provider managers; co-authoring and overseeing policies and SOPs; developing and medical responsibility for the TB services; constructing business cases; delivering or having oversight of education across the acute provider, primary care and community, as noted in the education section 6.10. The amount of SPA time will vary with the size of the service, but all medical leads need to undertake the interfacing, policy and educational roles and we have put indicative times in **Table 8**.

For all medical members of the team, respiratory, ID and paediatricians, there is a need in their job plan for SPA time for general education, both for themselves and their staff. So specific time needs to be allocated for this and should be evidenced in their continuing professional development and discussed at appraisal, and correctly represented in their job plan. The time needed will depend on the size of the services and will need to be distributed internally depending on who delivers training. We have therefore made a recommendation for medical 'service SPA time' to be distributed by the clinical lead, as in **Table 7.** An example of this was in the northeast, where there was an excellent training programme for registrars; these are essential for the development of future leaders of TB services.

There are several aspects to the concept of DCC work beyond clinics. These include: seeing ward consultations on admitted patients with suspected TB; attending multi-disciplinary team meetings (MDTs), which are attended by 82% of colleagues; attending cohort reviews

which 90% of providers do, (73% stating that their service has improved as a consequence); reviewing GP referrals for suspected TB and arranging rapid diagnostics (an example for one of the visits); reviewing results of bloods and liver function tests; reviewing positive (or as in one visit all) IGRAs to consider the need for intervention; communicating with colleagues in public health, primary care, microbiology and other acute provider colleagues. While difficult to estimate, we have suggested an escalating amount of time for these activities, to be distributed between the respiratory, ID and paediatrician, depending upon the local service. These estimated times are in **Table 8**.

While not part of the scope of the review, time for microbiology support of the service is key and should be addressed as part of an ongoing review. Likewise, imaging input into MDTs needs to be recognised as part of the wider service.

A particular medical workforce issue is the role of the clinician in regional roles, as discussed previously, be it: developing a more formal integrated network to support colleagues; a formal CYP service; MDR/ XDR management oversight; NTM advice etc. It is difficult to quantify the additional time, as often several of the above aspects are delivered, but we estimate that between 4-8 hours of clinical time (distributed as per service), together with a minimum of 4 hours admin time needs to be included and should be funded by regions or multiple ICBs.

A key aspect of care is clinic activity, be it face to face or since Covid, virtually. The clinic template for TB services needs to be determined locally, based upon the population served, recognising the time needed for interpreting or the language line which can significantly slow clinic throughput and should be factored in. A key aspect of service delivery is concurrent nurse led clinics, and time must be allowed for dialogue between medical and nursing staff during the clinic. There is currently work from a variety of sources including the Royal College of Physicians (RCP) on what constitutes a standard clinic template. Although still to be decided, there are proposals to include additional clinic time for complexity of care which includes when translators are required. The standard RCP advice of 30 minutes for new patient and 15 minutes for a follow up should not be applied uniformly to TB clinics.

The number of clinics held will depend upon local prevalence of TB, recognising there are a significant number of referrals into services for suspected TB that proves not to be, so clinic capacity should not be based purely on notifications. There needs to be sufficient capacity to enable patients with active disease to be seen within 2 weeks to start treatment and ideally if infectious within 48 hours, so clinics should have flexibility for additional patients. Patients should not be on ‘waiting lists’ to be seen for either active treatment or contact tracing and with the expanding numbers of individuals needing assessment for and starting preventative therapy, there should be minimal wait times. Adherence to therapy is important so cancellation of clinics, especially at short notice, should be avoided.

9.3 Nursing Workforce

The nursing aspect of the TB service is essential, fulfilling a variety of roles that are often unrecognised by individuals outside of TB, and highlighted throughout this report. While there is no ‘job plan’ for nurses, recognition of their extended role such as in nurse prescribing and ordering radiographs (which 83.3% can do), is essential and needs to be recognised in their banding. Teaching forms a key part of the nurse’s role, beyond that of patients and their carers and includes nurse placements, which occurred in 56% of providers, medical students and other medical staff and the wider team such as in the ICB.

Unfortunately, we heard during all the deep dives that the nursing infrastructure was significantly insufficient to deliver what is required. As with medical staff, nurses often worked

considerably longer than their contracted hours, especially when there were staff absences from short term sickness or annual leave, with 61% of services unable to manage the absence. Determining the ideal staffing numbers is difficult, given the impact that ECM, language and geography have on the service needs. There should be clear leadership within the service by nurses of an appropriate band, which for anything other than small services should be at band 8a and above and have dedicated management time that is separate from their clinical service role as described in **Table 6**. There needs to be sufficient staff to support all the aspects of service delivery contained in the report with also a hierarchy of band 7 to provide leadership during the senior's absence. The number of qualified staff is difficult to determine, as we found that qualified nurses were doing very routine nursing and administrative tasks and recommended in the majority of visits an increase in lower banded staff to enable those qualified to work at top of licence.

Ideally, the nursing staff will do their own clinics and also have clinics running at the same time as the less frequent medical ones, as described in the outpatient section 7.2. The clinic template will depend upon the duties of the nurse e.g. administration of BCG and reviewing contacts, and so needs to be determined locally but does need time built in for discussion with medical colleagues.

For unqualified nursing staff, there were few health care assistants (HCAs) at band 2-4 across most services. It was clear that qualified staff are stretched and undertaking roles below their grade that could be delivered by HCAs including supporting patients and accompanying qualified staff for DOT administration. Given HCAs' potential role at giving more time to qualified staff, early implementation of these recommendation is key. All services should review their nursing structure against the recommendations below with an emphasis initially on ensuring there are the appropriate number of lower banded staff.

9.4 Administrative Workforce

For the efficient running of a service which includes booking appointments, confirming home visits and being a liaison point for the patients and carers, an adequate administration infrastructure is crucial. However, we found from the survey returns and confirmed during deep dives, that very few administrative staff are embedded within the TB service. Whilst consultants' secretaries provided ad hoc support for medical staff, nursing teams were often left doing their own administration.

One consequence we heard repeatedly during our deep dives was that the lack of administrative staff led to nurses having to go back into the NTBS database and update outcomes, something, because of the time pressures they failed to do routinely, prioritising clinical care over administration duties. This is the most likely explanation for why there was an apparently low initiation and completion rate for preventative treatment and other outcomes in some services. A key role of administrative staff is to allow the qualified staff to function at their 'top of licence', especially given the pressures nurses are under while ensuring NTBS is updated and complete. Additionally, they can act as a regular point of contact for patients and carers, either by directly answering calls or responding to emails and phones lines via a 24/ 7 helpline. Again, in **Table 7** we make recommendations on staffing based upon notifications and contacts for providers and ICBs to consider.

9.5 Pharmacy Workforce

Pharmacy time is essential within the TB service but is absent in 43% of services. This needs to be addressed as part of any service expansion and in **Table 8** we recommend an incremental amount of pharmacy time based upon contacts and notifications. The rationale for pharmacy input is explained in the medicines management section 7.3. Where pharmacists are involved at a regional level such as in oversight of specialised commissioned drugs across a network or advising on NTM treatments, the region should consider at least 2 hours per week of senior pharmacy time.

9.6 Latent TB and Preventative Therapies Workforce

The recommendations in **Table 7** are based upon delivering care for those notified patients and the contacts thereof. However, the preventative workload in latent TB is increasing, pressurising services and must be addressed. We know the activity for formal notifications and the recommendations from the national Action Plan to increase the number of contacts reviewed. The staffing in **Table 7** should enable appropriate levels of care.

For the latent work which covers many facets we have less good data, though slide 74 based upon 70 services confirms this is significant. We recommend on a pro rata basis there is one additional WTE band 6 nurse, 0.5 WTE band 4 nurse and 0.5 WTE band 4 administrator per 100 patients eligible for preventative treatment**.** This assumes that the service accepts positive IGRA tests for assessment for treatment and ongoing supervision.

Where services are delivering the actual IGRA testing in occupational health and prior to biological therapies and immunosuppression, as in the latent section 8.3, discussions should take place internally for additional resources or for the occupational health or specialist service to do the IGRA and refer positive results. For the migrant / refugee / asylum work, the initial IGRA testing should be in primary care and organised by the ICB. Where that does not occur, additional resources to ensure a robust and comprehensive ‘capture’ of eligible individuals needs to be in place.

Table 6 Workforce table (by cases)

Workforce	<10 cases	10-49 cases	50-99 cases	100 cases or above
Medical CL SPA time for managing the service	0.26 ± 0.41	0.38 ± 0.56	0.48 ± 0.47	0.91 ± 1.04
SPA time for Respiratory	0.13 ± 0.39	0.06 ± 0.12	0.23 ± 0.45	0.36 ± 0.6
DCC time for Respiratory	0.29 ± 0.32	1.36 ± 1.18	2.12 ± 1.45	2.09 ± 2.76
SPA time for CYP	0.05 ± 0.12	0.15 ± 0.32	0.3 ± 0.29	0.5 ± 0.63
DCC time for CYP	0.05 ± 0.12	0.31 ± 0.42	0.54 ± 0.42	0.79 ± 0.65
SPA time for ID	0.03 ± 0.09	0.03 ± 0.14	0.14 ± 0.23	0.56 ± 0.91
DCC time for ID	0 ± 0	0.25 ± 0.53	1.06 ± 1.74	1.62 ± 1.38
Hours of Nurse Management Time Per Week	13.54 ± 12.55	16.88 ± 19.67	13.8 ± 11.15	23.04 ± 15.4
Number of WTE of Supporting Staffing (Band 3)	0 ± 0	0.13 ± 0.33	0.59 ± 1.26	0.43 ± 1.05
Number of WTE of Supporting Staffing (Band 4)	0 ± 0	0.08 ± 0.25	0.1 ± 0.32	0.68 ± 1.19
Number of WTE of Nursing (Band 5)	0 ± 0	0.11 ± 0.28	0 ± 0	0.5 ± 0.76
Number of WTE of Nursing (Band 6)	0.33 ± 0.67	1.34 ± 1.36	1.75 ± 1.99	2.94 ± 1.74
Number of WTE of Nursing (Band 7)	0.36 ± 0.36	1.12 ± 0.73	1.72 ± 1.24	1.56 ± 1.5
Number of WTE of Nursing (Band 8a)	0.05 ± 0.17	0.26 ± 0.43	0.23 ± 0.42	0.33 ± 0.47
Number of WTE of Nursing (Band 8b)	0 ± 0	0.03 ± 0.19	0.2 ± 0.42	0.05 ± 0.14
Number of WTE of Administration (Band 3)	0 ± 0	0.53 ± 0.75	0.87 ± 1.2	0.7 ± 0.45
Number of WTE of Administration (Band 4)	0.12 ± 0.29	0.35 ± 0.48	0.85 ± 0.7	0.38 ± 0.74

**Values are Mean ± SD.*

Sources: After excluding Yorkshire amalgamated returns, this table included the WTE from Workforce surveys completed by 59 services; SPA, DCC and Nursing Management time from surveys completed by 88 services

Table 7 Workforce Table (by overall activity)

Workforce	<50 activity	50-199 activity	200-499 activity	500-799 activity	800-999 activity	1000-1250 activity
Medical CL SPA time for managing the service	0.15 ± 0.15	0.44 ± 0.63	0.38 ± 0.43	0.93 ± 0.63	1.95 ± 1.57	0.55 ± 0.25
SPA time for Respiratory	0 ± 0	0.08 ± 0.13	0.17 ± 0.43	0 ± 0	0.27 ± 0.38	0 ± 0
DCC time for Respiratory	0.55 ± 0.25	0.9 ± 1.04	2.16 ± 1.24	0.78 ± 0.79	0.78 ± 0.64	0 ± 0
SPA time for CYP	0 ± 0	0.07 ± 0.13	0.14 ± 0.21	0 ± 0	0.27 ± 0.38	1.55 ± 0
DCC time for CYP	0 ± 0	0.26 ± 0.4	0.42 ± 0.3	0 ± 0	0.27 ± 0.38	1.55 ± 0
SPA time for ID	0 ± 0	0.05 ± 0.19	0.13 ± 0.24	0.78 ± 0.79	0.52 ± 0.74	1.5 ± 1.52
DCC time for ID	0 ± 0	0.23 ± 0.51	0.55 ± 0.99	0.78 ± 0.79	1.03 ± 0.74	1.9 ± 1.12
Hours of Nurse Management Time Per Week	21 ± 3.09	20.76 ± 26.11	15.17 ± 12.34	22.5 ± 15.21	18.33 ± 13.85	1 ± 1.01
Number of WTE of Supporting Staffing (Band 3)	0 ± 0	0 ± 0	0.36 ± 0.85	0 ± 0	1 ± 1.73	0 ± 0
Number of WTE of Supporting Staffing (Band 4)	0 ± 0	0 ± 0	0.31 ± 0.74	0 ± 0	0 ± 0	0.5 ± 0.58
Number of WTE of Nursing (Band 5)	0 ± 0	0.03 ± 0.14	0.18 ± 0.48	0 ± 0	0.33 ± 0.58	0 ± 0
Number of WTE of Nursing (Band 6)	0 ± 0	1.29 ± 1.46	1.77 ± 1.66	1.2 ± 0.23	2.8 ± 2.78	2.35 ± 1.55
Number of WTE of Nursing (Band 7)	0.3 ± 0.27	0.94 ± 0.62	1.29 ± 1	0.05 ± 0.06	1.03 ± 1.7	2.7 ± 1.96
Number of WTE of Nursing (Band 8a)	0 ± 0	0.23 ± 0.4	0.28 ± 0.44	0 ± 0	0.33 ± 0.58	0 ± 0
Number of WTE of Nursing (Band 8b)	0 ± 0	0 ± 0	0.06 ± 0.21	0 ± 0	0 ± 0	0 ± 0
Number of WTE of Administration (Band 3)	0 ± 0	0.49 ± 0.87	0.54 ± 0.87	0.5 ± 0.58	0.67 ± 0.58	0.8 ± 0.23
Number of WTE of Administration (Band 4)	0 ± 0	0.37 ± 0.45	0.55 ± 0.71	0 ± 0	0.33 ± 0.58	0 ± 0
Number of services in this category	3	17	24	2	3	2

**Values are Mean ± SD. The activity represents the sum of notifications, LTBI cases and total number of contacts screened*
Sources: 51 services are included in this analysis. The WTE, SPA, DCC, Nursing Management time and LTBI cases are taken from surveys. The number of notifications and contacts screened are taken from NTBS data.

Table 8 Indicative Workforce Table

Workforce	<10 cases	10-49 cases	50-99 cases	100 cases or above
Medical CL SPA time for managing the service *	2hs	3hs	4hs	4hs
SPA time for Respiratory, ID, CYP per service *	2hs	3hs	4hs	5hs
DCC time for Respiratory, ID, CYP per service *	2hs	4hs	6hs	8hs
Hours of Nurse Management Time Per Week**	10	15	20	25
Number of WTE of Supporting Staff (HCSW) (Band 3 or 4) ***	0.5	1	2	3
Number of WTE of Nursing (Band 6 and 7)****	0.5-1	1	2	3
Number of WTE of Nursing (Band 8a and above)	nil	0.5	1	1
Pharmacy time (hours of B7 or greater)	2	6	8	12
Number of WTE of Admin staff (Band 3 or 4) ***	0.5	1	2	3

KEY

* Hours per week that need converting into sessional time e.g. 0.5 session = 2hs.
** Nursing management time is EXCLUDED from row 8 clinical time.
***HCSW and admin staff should have be at the highest band.
**** For qualified staff there should be a B7 if have B6; for s 5, 6 &10.
For regional work, depending on extent there should be an additional 4-8 hours per week medical, together with 4hs of band 4 admin support. Pharmacy may need to be included.
Preventative treatment for latent TB. Suggest pro rata per 100 initial reviews: x1 WTE B6 nurse (B7 if high ECM), plus 0.5 WTE B4 HCSW, plus 0.5 WTE B4 admin.

Recommendations in relation to Workforce Issues in the Management of Tuberculosis

Recommendations	Resp.
74. All staff should participate in the internal MDT and cohort reviews which need to be recognised as DCC in medical job plans and timetabled in nursing and administration staff.	P, ICB
75. Ideally, when there is no paediatrician involved in the service, which occurs in over one third of services, a paediatric trained nurse should be part of the TB team.	P, ICB
76. In light of the increasing workload, all services should undertake a review of their nursing infrastructure to ensure it is fit for purpose based on these recommendations.	P, ICB
77. A key aspect of these recommendations is the recruitment of HCAs to support qualified nursing staff to function at their “top of license”.	P, ICB

78. Consideration needs to be given to specific support and education of HCAs in delivering TB care with appropriate training, ideally online, and with a formal qualification.	P, ICB, N
79. Administrative staff play a key role, and these should be embedded in the TB service and be of significant seniority to be able to support nursing and medical staff, including the update of NTBS, e.g. treatment completion.	P, ICB
80. For latent and preventative services, TB teams should have the infrastructure in place, pro rata, to deliver the service. This staffing model is applicable for dealing with positive IGRA test (details are in section 8.3). Where services are involved in reviewing patients in primary care, doing the IGRA, then acting on the results, additional resources are required	P, ICB
81. All services should review their staffing infrastructure against table 8 and the footnote, identify gaps and produce a remedial plan to address the shortfall within 4 months.	P, ICB

Annex A: List of TB Service Survey Participants

Airedale General Hospital
Ashford and St Peter's Hospital
Barnsley Hospital (nurse is team leader for Barnsley and Pinderfields)
Barts Health (Mile End)
Barts Health (Newham)
Barts Health (Whipps Cross)
Basingstoke and North Hampshire Hospital
BHRUH Acute Trust
Birmingham and Solihull TB Nursing Service
Buckinghamshire HC NHS Trust (Stoke Mandeville, Amersham and Wycombe Hospitals)
Calderdale and Huddersfield FT (Calderdale)
Calderdale and Huddersfield FT (Kirklees)
Cambridge Community Services (Luton and Dunstable UH)
Cambridge University Hospitals NHS FT (Addenbrookes)
Chelsea and Westminster, West Middlesex
Cheshire and Wirral NHS Community Trust
Cheshire and Wirral Partnership NHS FT
Chesterfield Royal Hospital
Colchester UH (East Suffolk and North Essex NHS FT)
Community TB Nurses in Cornwall covering Royal Cornwall Hospital and Derriford Hospital
Countess of Chester Hospital
Coventry and Warwick TB Communuity Service
Croydon Health
Dartford and Gravesham (East Kent)
Derby and Burton NHS FT, Burton TB service
Derby and Burton NHS FT, Derby TB service
Devon and Exeter
Diana Princess of Wales Hospital (Grimsby)
Doncaster and Bassetlaw Teaching Hospitals NHS FT
Dorset County Hospital FT
East and North Hertfordshire NHS Trust, Lister Hospital
East Kent Hospitals University NHS FT (Buckland Hospital, Kent and Canterbury Hospital, Queen Elizabeth the Queen Mother Hospital, Royal Victoria Hospital [Folkestone], William Harvey Hospital)
East Lancashire NHS Trust
East Sussex Healthcare NHS Trust
Epsom General Hospital
Essex Partnership University NHS FT (Bedfordshire, South East Essex, PAH, Orsett Hospital)
Frimley Health NHS FT, Frimley Park Hospital
Frimley Health NHS FT, Wexham Park Hospital
Gloucester Hospitals NHS FT
Guy's and St Thomas' NHS FT
Hampshire Hospitals FT
Hartlepool and North Tees (University Hospital of North Tees, University Hospital of North Tees)
Homerton Hospital
Hull Royal Infirmary

Imperial Healthcare

James Paget University Hospital NHS FT

Kings College Hospital NHS FT

Kingston Hospital

Lancashire Teaching Hospital and NHS Foundation Trust

Leeds Community Healthcare Trust, Leeds Teaching Hospitals NHS Trust

Lewisham and Greenwich NHS Trust (Queen Elizabeth Hospital, Bromley Hospital, Lewisham)

Lewisham Hospital

Liverpool Children's Hospital

Liverpool Community TB Service and Liverpool University Hospitals NHS Foundation Trust (Royal University Hospital, Broadgreen Hospital, Heart and Chest Hospital, Womens Hospital, Alder Hey, St Helens TH, Halton, Aintree UH, Walton Neurology Centre, Ashworth Hospital, Mersey Care FT)

Locala Community Partnerships CIC (Greater Huddersfield)

Locala Community Partnerships CIC (North Kirklees)

London North West Healthcare (Ealing Hospital, Central Middlesex, Northwick Park)

London North West Healthcare (Northwick Park)

Maidstone and Tunbridge Wells NHS Trust

Manchester FT (Central Manchester)

Medway Maritime Hospital

Mid Essex Broomfield Hospital, EPUT Service

Mid Essex Hospital, Broomfield Hospital, Basildon and Thurrock, Southend

Milton Keynes University Hospital NHS FT

Newcastle, North Tyneside and Northumberland (Freeman Hospital Newcastle, North Tyneside General Hospital, Royal Victoria Infirmary, Wansbeck General Hospital)

NHS Bolton NHS FT, Royal Bolton Hospital

Norfolk and Norwich UH

North Central London (North Middlesex)

North Central London (Royal Free)

North Central London (Whittington Hospital)

North Cumbria Integrated Trust (Cumberland RI and North Cumbria UH)

North Manchester GH

North West Anglia FT (Peterborough Hospital)

Northampton GH, Kettering GH

NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST, North East Lincolnshire

NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST, North Lincolnshire

Nottingham UH

Oxford University Hospitals

Pinderfields General Hospital (Wakefield, nurse covers Barnsley and Pinderfields)

Portsmouth Hospitals NHS Trust

Portsmouth Hospitals NHS Trust

Queen Elizabeth Hospital, Kings Lynn, Norfolk

Rotherham district general hospital

Royal Berkshire Hospital

Royal Bournemouth Hospital (The Royal Bournemouth and Christchurch Hospitals FT)

Royal Devon University Hospital Trust

Royal Manchester Children's hospital

Sandwell and West Birmingham Hospital Trust, TB Nursing Service

Sheffield Teaching Hospitals (Sheffield Children's Hospital, Northern General Hospital, Pilgrim and Royal Hallamshire)

Sherwood Forest Hospitals

SHREWSBURY AND TELFORD HOSPITAL NHS TRUST

Solent NHS Trust

Somerset NHS FT, Yeovil Hospital

South Tyneside and Sunderland NHS Foundation Trust, South Tyneside District Hospital

South Tyneside and Sunderland NHS Foundation Trust, Sunderland Royal Hospital

Southend UH

St George's University Hospitals NHS FT

St Luke's Hospital (Bradford)

Stockport FT

Stoke on Trent TB Nursing Service, University Hospitals of North Midlands NHS Trust

Surrey and Sussex Healthcare NHS Trust

Surrey and Sussex Healthcare NHS Trust

Sussex NHS Foundation Trust, Brighton

The Hillingdon Hospitals NHS FT, Hillingdon Community TB service

Torbay and South Devon NHS FT

UH Bristol and Weston

UH Leicester

University hospitals Dorset

University Hospitals of Morecambe Bay NHS FT, Furness Hospital

University Hospitals of Morecambe Bay NHS FT, Royal Lancaster Infirmary

Walsall Healthcare Trust

Western Sussex Hospitals NHS FT

Wirral University TH

Wolverhampton

Wolverhampton New Cross

Worthing Hospital

WRIGHTINGTON, WIGAN AND LEIGH NHS FOUNDATION Trust

WVT Hereford TB Nursing Service

Wythenshawe Hospital

York district hospital (nurses cover York, Scarborough, Friarage and Harrogate)

Annex B: Biography: Dr Martin Allen, Clinical Lead

Dr Allen GIRFT Respiratory Clinical Lead, Consultant physician at University Hospitals of North Midlands NHS Trust, and NHS National Specialty Adviser for physiological science**.**

Martin is the clinical lead for the NHS England RNOH/GIRFT Tuberculosis review as well as for the Scotland TB review.

Martin trained at Birmingham University and undertook a variety of posts in the midlands before moving to Edinburgh, and then to Yorkshire as a senior registrar. After being appointed as a consultant in Bradford he moved after 3 years to University Hospital of North Midlands where he has developed and led a variety of services in the last 25 years. During this time, he served as clinical director of cardiorespiratory services and head of the medical division. After demitting this management role, he served as the secondary care consultant on a CCG and as honorary secretary for the British thoracic Society.

His main research has been in Chronic Obstructive Pulmonary Disease (COPD) and sleep, but he also has a major interest in respiratory physiology, currently chairing the joint British Thoracic Society (BTS) and Association for Respiratory, Technology and Physiology (ARTP) board.

He chairs the Respiratory Expert Working Group on coding for NHS Digital and sits on the Royal College of Physicians' commissioning group.

In June 2021, he was awarded an MBE in the Queen's Birthday honours list, for services to the NHS, particularly during COVID-19.

Annex C: Link to Folder in Futures

LINK TO FUTURES HERE

All additional Annex documents referenced within this document (which are too large or too many to attach as Annexes) can be found in NHS Futures using the link above.

They include;

- The National dataset (anonymised)
- Full set of survey questions
- Good practice documents
- Martin Allen biography
- Key lines of enquiry

Annex D: List of TB service deep dive visits

Barts Health (Newham)
Birmingham and Solihull TB Nursing Service
Cambridge University Hospitals NHS FT (Addenbrookes)
Coventry and Warwick TB Communuity Service
Doncaster and Bassetlaw Teaching Hospitals NHS FT
Dorset County Hospital FT
East Kent Hospitals University NHS FT (Buckland Hospital, Kent and Canterbury Hospital, Queen Elizabeth the Queen Mother Hospital, Royal Victoria Hospital [Folkestone], William Harvey Hospital)
East Lancashire NHS Trust
Imperial Healthcare
Liverpool Community TB Service and Liverpool University Hospitals NHS Foundation Trust (Royal University Hospital, Broadgreen Hospital, Heart and Chest Hospital, Womens Hospital, Alder Hey, St Helens TH, Halton, Aintree UH, Walton Neurology Centre, Ashworth Hospital, Mersey Care FT)
Newcastle, North Tyneside and Northumberland (Freeman Hospital Newcastle, North Tyneside General Hospital, Royal Victoria Infirmary, Wansbeck General Hospital)
Nottingham UH
Oxford University Hospitals
Solent NHS Trust
Southend UH
Stoke on Trent TB Nursing Service, University Hospitals of North Midlands NHS Trust
UH Bristol and Weston
UH Leicester
Walsall Healthcare Trust
WVT Hereford TB Nursing Service

Annex E: TB Survey questions

Survey Response – reasons for delay between onset to start of treatment

Survey Question – If there is a delay between symptom onset and commencement of treatment what would you think, on average, would be the top 3 reasons for the delay?

Based on the 105 responses provided, the reasons mentioned for the delay in TB treatment commencement can be grouped into the following themes:

1. **Delayed Diagnosis and Referral**:
    - This theme is highly prevalent in the responses, with frequent mentions of delays in recognising TB symptoms by GPs, emergency departments, and other specialties. Misdiagnoses, delayed referrals, and treatment for other conditions before considering TB are common issues highlighted.
2. **Patient-Related Factors**:
    - Many responses point to patient delays in seeking medical attention for various reasons, including socioeconomic conditions, prioritisation of other life issues, fear of authority, or discrimination. Non-attendance at appointments (DNA's) leads to delayed diagnosis and treatment initiation. Several responses point to language barriers, mental health issues, and complex social situations that affect timely access to care.
3. **Healthcare System and Provider Factors**:
    - Low awareness of TB among healthcare providers and the general population, especially in low-incidence areas, leading to TB not being considered in the differential diagnosis. There is also mention of limited access to diagnostic procedures like bronchoscopies and imaging, long waiting times for appointments and results, and inadequate sending of samples for TB culture or PCR.
4. **Resource and Infrastructure Limitations**:
    - Limited clinical capacity, including staffing shortages, lack of clinic spaces, and lack of education in other specialties about TB, are cited as contributing to delays. Additionally, pharmacy and supply issues affecting the availability of medication are noted as reasons for delay to the start of treatment.
5. **Diagnostic and Clinical Management Challenges**:
    - The complexity of TB symptoms, particularly in extra-pulmonary cases which can be non-specific, and the complexity of the diagnostic pathway, including waiting for procedures and the interpretation of scans, are mentioned as factors that can delay diagnosis and treatment.

In summary, while all of these themes are prevalent in the responses, the themes of "**Delayed Diagnosis and Referral**" and "**Patient-Related Factors**" appear to be the most frequently mentioned, followed by **"Healthcare System and Provider Factors", "Resource and Infrastructure Limitations,"** and **"Diagnostic and Clinical Management Challenges."**

a) <u>Survey Response – Have your services changed after COVID?</u>

Based on the responses provided, the top changes mentioned for how services changed after COVID can be grouped into the following themes:

1. **Increased Use of Virtual and Telephone Appointments**:
    - Many responses indicate a significant increase in the use of telephone consultations for follow-ups and reviews, particularly for latent TB patients.
    - Video appointments and virtual clinics have become more common, with platforms like Microsoft Teams and Attend Anywhere being utilized for patient care and multidisciplinary team (MDT) meetings.
2. **Adoption of Remote Monitoring Technologies**:
    - The use of Video Observed Therapy (VOT) over Directly Observed Therapy (DOT) and the introduction of telemedicine for patient monitoring and care have been mentioned as key changes.
    - Online booking systems for appointments and blood tests have been implemented to reduce the need for in-person visits.
3. **Changes in Clinical Practices and Screening**:
    - A shift from Mantoux to Interferon-Gamma Release Assays (IGRA) for TB screening is noted, which can be conducted at home or with less patient contact.
    - There is a move towards nurse-led initiatives, such as autonomous contact screening and nurse-led Latent Tuberculosis Infection (LTBI) clinics.
4. **Operational and Infrastructure Adjustments**:
    - Adjustments to clinic spaces, including increased ventilation and the creation of more side rooms, have been made to accommodate infection control measures.
    - There is mention of increased hybrid working arrangements for staff, allowing for a combination of remote and in-office work.

These themes reflect a shift towards more remote and technologically supported care, changes in clinical and screening practices to reduce face-to-face contact, and operational changes to adapt to the new infection control requirements brought on by the COVID-19 pandemic.

Annex F: Glossary

Abbreviation	Meaning	Definition
A&C	Admin and clerical	
AAFB	Acid alcohol fast bacteria	Mycobacteria have a structure that can be identified by a staining technique using acid and alcohol
BCG	Bacillus Calmette-Guerin	A vaccine primarily used against tuberculosis (TB)
BTS	British Thoracic Society	We improve standards of care for people with respiratory diseases and to support those who provide that care.
BTS MDR	British Thoracic Society MDR Service	The MDR-TB Clinical Advice Service provides advice and support to clinicians across the UK who encounter MDR-TB. The advice is offered by a multidisciplinary panel of Clinical Service Advisers, with expertise in areas such as respiratory medicine, infectious diseases, microbiology, pharmacy and public health. The advice is provided via a secure online case discussion forum and at monthly MDT meetings which are held via Teams.
CPD	Continuing professional development	Continuing Professional Development is a commitment to ongoing lifelong learning.
CYP	Children and Young People	This guidance relates to children and young people from birth until their 18th birthday
DCC	Direct Clinical Care	Sessional system for consultants with one session equating to 4 hours. This reflects direct contact with patients, reviewing their results and communication. It includes MDTs and cohort reviews
DOT	Directly observed therapy	A strategy used to ensure TB patient adherence to and tolerability of the prescribed treatment regimen; a health care worker or another designated person watches the TB patient swallow each dose of the prescribed drugs.
ECM	Enhanced case management	The named case manager co-ordinates ECM and works alongside a specialist multidisciplinary TB team to provide expert clinical and psychosocial care, and where appropriate ensures effective engagement with the client group in the community. The case manager carries out a risk assessment at the beginning of treatment to determine if the patient requires ECM. This assessment should be reviewed throughout the course of treatment.
ENT	Ear, nose and throat	Illnesses, conditions and disorders of the ears, nose and throat.
Gene-Xpert'		A CBNAAT (cartridge based nucleic acid amplification test) is a widely accepted diagnostic test for Tuberculosis. This test is a rapid diagnostic test for Tuberculosis detection as well as Rifampicin resistance in direct smear negative cases.
GMC	General Medical Council	The General Medical Council is a public body that maintains the official register of medical practitioners within the United Kingdom.
Granuloma		A granuloma is an area of tightly clustered immune cells, or inflammation, in your body. They form around an infection or foreign object in your body. They can form almost anywhere, but they're most often found in your lungs. Granulomas can be a symptom of a chronic condition or an infection.
HRG	Healthcare Resource Group	Designed to be standard groupings of clinically similar treatments which use common levels of healthcare resource

ICB	Integrated Care Board	NHS organisations responsible for planning health services for their local population.
ICD 10	International classification of disease, edition 10.	WHO listing of diseases used internationally and form the basis of coding in England, being used to derive the HRG for different conditions
ID	Infectious Disease	Infectious diseases are disorders caused by organisms — such as bacteria, viruses, fungi or parasites.
IGRA	Interferon-gamma release assay	TB blood tests (interferon-gamma release assay or IGRA) are methods of determining whether a person is infected with TB bacteria.
LA	Local Authority	An administrative body in local government.
MDR	Multi drug resistant mycobacteria	Disease is caused by TB bacteria that are resistant to at least isoniazid and rifampin, the most effective first-line TB treatment drugs.
MDT	Multi-disciplinary team	Teams consisting of individuals drawn from different disciplines who come together to achieve a common goal, whether that be a project to introduce a new role, redesign of a patient pathway or providing care in a different way.
NTBS	National Tuberculosis Surveillance system	NTBS is an enhanced surveillance system for public health use completed by colleagues after a notification of tuberculosis. It exists to provide detailed information on each person with TB and the epidemiology of their disease in England, Wales and Northern Ireland
NTM	Non tuberculous mycobacteria	A group of bacteria that cause rare lung infections.
OPCS	Office of Population Censuses and Surveys	Each category contains a specific set of surgical procedures. Procedures eligible for inclusion in the surveillance are defined by Office of Population Censuses and Surveys (OPCS) surgical procedure codes used by clinical coders.
PCR	Polymerase chain reaction	(TB PCR) is a rapid and reliable method for the diagnosis of both pulmonary and extra pulmonary tuberculosis, with an overall sensitivity of 78.3% and a high specificity
PH	Public Health	Prevents, prepares for and responds to infectious diseases, and environmental hazards, to keep all our communities safe, save lives and protect livelihoods. Provide scientific and operational leadership, working with local, national and international partners to protect the public's health and build the nation's health security capability.
RCN	Royal College of Nursing	The RCN is the world's largest nursing union and professional body.
RCP	Royal College of Physicians	The Royal College of Physicians of London, commonly referred to simply as the Royal College of Physicians, is a British professional membership body dedicated to improving the practice of medicine, chiefly through the accreditation of physicians by examination.
SNOMED		SNOMED CT is a structured clinical vocabulary for use in an electronic health record. It is the most comprehensive and precise clinical health terminology product in the world.
SOP	Standard Operating Procedures	A set of step-by-step instructions for performing a routine activity.
SPA	Supporting Professional Activities	As DCC it is a unit of medical time related to professional development, that may be for an individual for self-learning or for providing education and learning for others

SPR	Specialist registrar	doctor in speciality training on-route to becoming a consultant
TFC	Treatment Function Code	A 'basket' of activity in a particular area, e.g. code 340 reflects activity carried out by respiratory teams
UKHSA	UK Health Security Agency	The UK Health Security Agency is a government agency in the United Kingdom, responsible since April 2021 for England-wide public health protection and infectious disease capability and replacing Public Health England. It is an executive agency of the Department of Health and Social Care.
VOT	Video observed therapy	As with DOT but a virtual strategy used to ensure TB patient adherence to and tolerability of the prescribed treatment regimen; a health care worker or another designated person watches the TB patient virtually swallow each dose of the prescribed drugs.
XDR	Extensively drug-resistant tuberculosis	The new definition of pre-XDR-TB is: TB caused by *Mycobacterium tuberculosis (M. tuberculosis)* strains that fulfil the definition of multidrug resistant and rifampicin-resistant TB (MDR/RR-TB) and which are also resistant to any fluoroquinolone. The definition of MDR-TB* remains unchanged. The updated definition of XDR-TB is: TB caused by *Mycobacterium tuberculosis (M. tuberculosis)* strains that fulfil the definition of MDR/RR-TB and which are also resistant to any fluoroquinolone and at least one additional Group A drug (Group A drugs are the most potent group of drugs in the ranking of second-line medicines for the treatment of drug-resistant forms of TB using longer treatment regimens and comprise levofloxacin, moxifloxacin, bedaquiline and linezolid).

Annex G: Other Useful Links

- Getting it Right First Time (GIRFT)
- The British Thoracic Society
- NHS England TB Prevention, Medical Directorate,
- Tuberculosis (TB): action plan for England, 2021 to 2026
- The UK Health Security Agency TB Surveillance Data(UKHSA)Tuberculosis (TB): action plan for England, 2021 to 2026 - GOV.UK (www.gov.uk)
- Tuberculosis (TB) in England: surveillance data - GOV.UK (www.gov.uk)