



Public Health  
England



developed in collaboration with and  
with partner funding from **NHS England**

# Access, testing and treatment

## A toolkit for new entrant latent tuberculosis programmes



This toolkit was developed by TB Alert, the national tuberculosis charity, in partnership with NHS England and Public Health England.

*The Truth About TB* is a national programme from TB Alert that raises public and professional awareness of tuberculosis.

#### **About TB Alert**

TB Alert is the only specialist tuberculosis charity in the UK. We work in this country and internationally to fight a disease which claims 1.5 million lives a year. Our work focuses on:

- raising public and professional awareness about TB, addressing barriers to treatment and providing support to patients during their treatment
- bringing together statutory health services, voluntary organisations and people affected by TB to plan and deliver better TB services
- advocating for the policies and resources to improve the care of patients and the prevention and control of TB

Our vision is the control and ultimate elimination of TB. Our mission is to increase access to effective treatment for all.

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#### **About Public Health England**

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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#### **About NHS England**

The mission of NHS England is to deliver high quality care for all, now and for future generations.

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# Foreword

I am very pleased to introduce the latent tuberculosis (TB) toolkit *Access, Testing and Treatment: A Toolkit for New Entrant Latent Tuberculosis Programmes*. Testing and treating latent TB has been recognised as an effective and important tool to support the World Health Organization End-TB strategy and the programmatic approach to latent TB testing and treatment is one of the key intervention areas in the Collaborative Tuberculosis Strategy for England 2015 to 2020.

Whilst there is ample research evidence to demonstrate the effectiveness of latent TB treatment to prevent TB reactivation, and whilst numerous pilots have shown the feasibility of latent TB testing and treatment programmes, the big challenge is to ensure that eligible people enrol in testing and start and finish their treatment.

Experience has shown the complexity involved in identifying and raising awareness among eligible patients, encouraging them to be tested and then supporting those who test positive through their treatment. That is why this toolkit, authored by TB Alert (the national TB charity) was produced in collaboration with NHS England and Public Health England – to provide practical guidance and support to address those issues.

The toolkit looks at each of the three stages which providers need to cover – access, testing and treatment. It identifies specific issues which might arise and strategies which can help address them. It also introduces a range of resources that exist to raise public awareness, improve professional education, promote better communication between providers and patients, and support patients during treatment. Many of these resources have been developed specifically for this programme as part of TB Alert's established programme *The Truth About TB*.

The new latent TB programme has generated enthusiasm among TB clinicians and inspired many stakeholders in clinical commissioning groups (CCGs) all around the country. This toolkit provides the guidance and resources to help ensure that all who are eligible will successfully undergo latent TB testing and, if necessary, treatment. It supports appropriate person-centred interventions to a consistently high standard which are integral to the success of tackling latent TB in England and which may also serve as a blueprint for interventions in other countries.

**Dr Dominik Zenner**

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# Introduction: about latent TB

The Collaborative Tuberculosis Strategy for England<sup>1</sup> recommends latent TB infection testing and treatment for recent entrants to England from countries with the highest rates of TB. The focus on new entrants reflects the fact that people with *latent TB infection* (latent TB) are most likely to develop *active disease* (active TB) within a five-year timeframe after arrival. Pre-entry x-ray screening was piloted in 15 countries from 2005 and then rolled out globally from September 2012. This means that everyone applying for a visa to visit England for over six months, and who was resident in a country with over 40 cases of TB per 100,000 population, now needs to undergo x-ray screening. However, x-rays can only detect active pulmonary TB.

A tuberculin skin test (TST or Mantoux) or blood test (IGRA) will show if someone has latent TB, which may reactivate in the future and turn into active TB. If they do have latent TB, a course of antibiotic treatment will significantly reduce their chances of becoming ill at a later date, thus preventing active TB and potential onward transmission. In countries like England, with well-established and over-arching health services, there is a case for treating latent TB

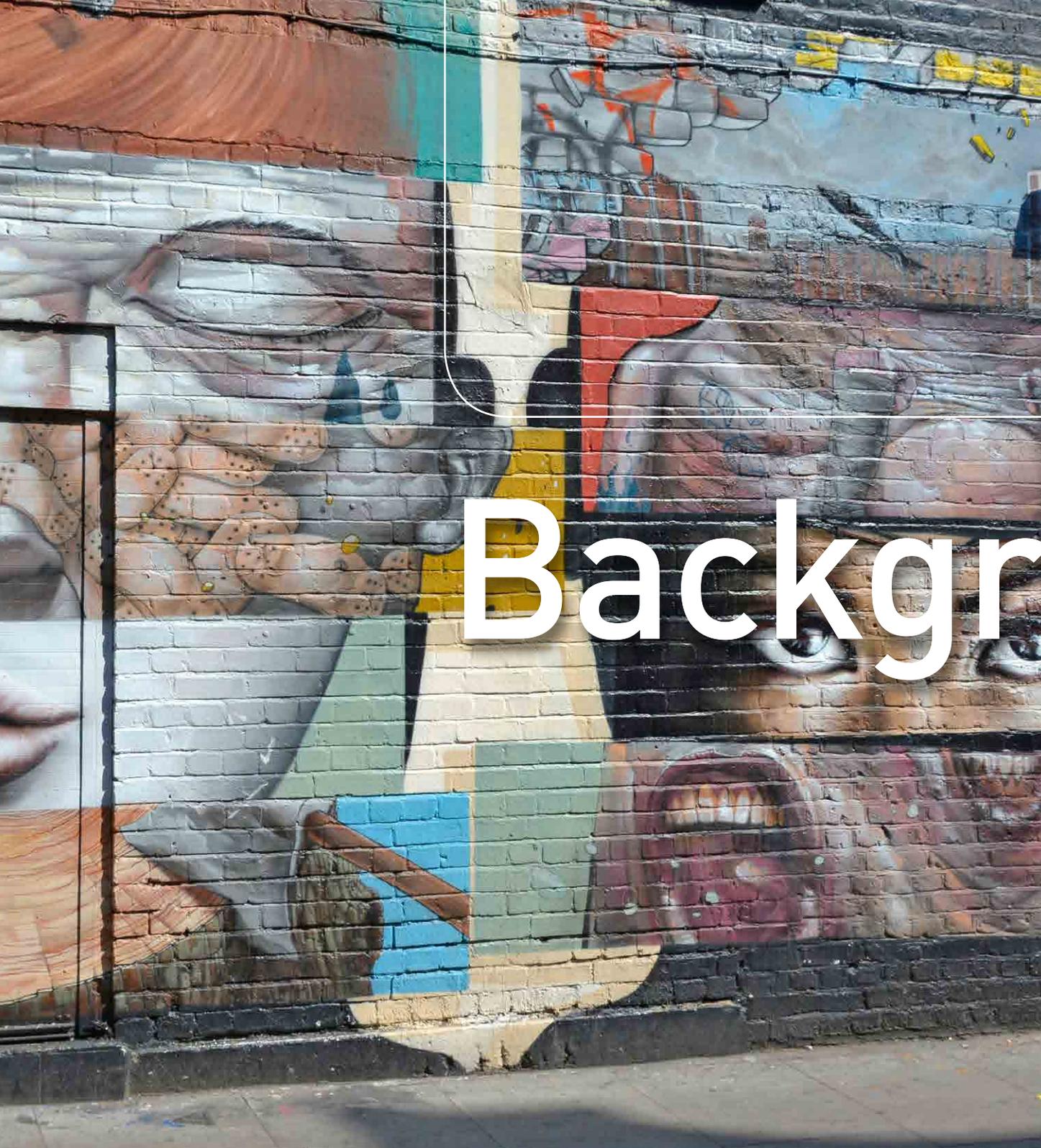
as part of a multi-faceted programme that works towards eliminating TB as a public health problem.

The building blocks of this toolkit are the public health and clinical steps required to successfully implement the testing and treatment programme. It is divided into three sections – background; the testing and treatment pathway; and increasing uptake of testing and treatment – with short best practice examples throughout to demonstrate various challenges that have been addressed effectively in different localities.

The importance of engaging a variety of partners across the health, social care and community sectors cannot be over-estimated – something that can feel like a daunting and complex task. This toolkit facilitates such collaboration at a local level by offering a variety of information, tools and resources.

## Acronyms

|               |   |
|---------------|---|
| <b>CCG</b>    | clinical commissioning group                      |
| <b>GP</b>     | general practitioner                              |
| <b>GPN</b>    | general practice nurse                            |
| <b>HCA</b>    | healthcare assistant                              |
| <b>HIV</b>    | human immunodeficiency virus                      |
| <b>IGRA</b>   | interferon-gamma release assay                    |
| <b>JSNA</b>   | joint strategic needs assessment                  |
| <b>LMC</b>    | local medical council                             |
| <b>LTBI</b>   | latent tuberculosis infection                     |
| <b>MDR-TB</b> | multi-drug resistant tuberculosis                 |
| <b>NHSE</b>   | National Health Service England                   |
| <b>NICE</b>   | National Institute for Health and Care Excellence |
| <b>PHE</b>    | Public Health England                             |
| <b>TB</b>     | tuberculosis                                      |
| <b>TSO</b>    | third sector organisation                         |



Section 1

# Background

# Section 1: Background

## Essential facts about TB

### TB prevalence in England

While TB rates in England are much lower than many parts of the world, they still remain high in relation to comparable western countries. The main focus of TB control, to date, has necessarily been on the prompt diagnosis and successful treatment of active TB cases. Effective identification and early treatment, together with efficient contact tracing, remains the foundation of TB control, as people with active TB are likely to experience serious illness and have the potential to pass it on to others. It is, however, possible to improve TB control further by preventing TB occurring in the first place. This can be achieved by identifying and treating people who have been infected with TB but have not yet developed active disease.

For detailed data about TB in England, visit:  
<http://fingertips.phe.org.uk/profile/tb-monitoring>

### How TB works

Tuberculosis is caused by a germ called a mycobacterium. It can cause TB disease in any part of the body but is only infectious when people have TB in their lungs or their larynx and cough the germs into the air. It can also be spread by sneezing, singing and talking. When someone breathes in these germs they may become infected with TB – this is called latent TB infection (LTBI) or latent TB. A person with latent TB is well, has no symptoms and cannot possibly pass on the disease, but there is a risk that they may develop active TB at some point in their life.

For more information about TB, visit:  
[www.thetruthabouttb.org](http://www.thetruthabouttb.org)

# Why this toolkit is needed

## Expanding partnerships for TB prevention

This national latent TB testing and treatment programme represents a new and expanded way of working in England. Diagnosis and treatment is usually managed by specialist TB services run by secondary or community healthcare providers. However, best practice recommends that migrants from countries with high rates of TB are tested in primary care or alternative community settings linked to primary care services. This, in turn, requires the involvement of primary care, secondary and community care, local authorities and third sector organisations that work with affected communities.

## The value of involving primary care services

With their long-standing experience of carrying out a variety of prevention and screening programmes, GPs are ideally placed to make this initiative a success. This programme can also help to reduce the serious delays in diagnosing active TB which still occur, and which lead people to experience advanced disease, permanent organ damage and prolonged infectious periods.

A pilot project has shown that involving GP practices in TB testing initiatives can improve awareness of TB in primary care overall, improve collaboration between primary care providers and TB services, and lead to TB being diagnosed more promptly.<sup>2</sup> In addition, the most effective way to maintain people's health is through proper use of primary care services, and this initiative has the potential to encourage people who have recently arrived in England to register with a GP.

## Addressing the concerns of a potentially marginalised group

This programme involves approaching people who are essentially well and raising the possibility that they may be infected with a potentially serious and stigmatising condition. This requires a sensitive approach and the establishment of trust, especially as people who are new to England may have concerns about their immigration status and be worried that a positive result may have an impact on their right to remain in the country. This can be achieved through partnerships between health services and statutory or third sector organisations that come into contact with those who are eligible for testing and treatment.

## Who the toolkit is for

The toolkit is designed to be used locally to assist programme implementation by local stakeholders as well as individual providers who may be involved in any part of the process. These include, but are not limited, to the following:

- TB control boards
- health and wellbeing boards
- local medical councils
- primary care practitioners: GPs, practice nurses, practice managers
- commissioners: CCGs, local authorities
- local Public Health England teams
- TB services: community or acute care
- local authority departments such as public health, housing, environmental health
- third sector organisations working with eligible groups

## How this toolkit can be used

### Practical guidance for local implementation

This toolkit complements the guidance for commissioners and practitioners provided by Public Health England and NHS England in 2015.<sup>3</sup> While it is clear that a standard series of steps is required to adopt the programme across different localities, the make-up of local health services and how TB is managed in different areas requires flexibility in the way it is implemented. This toolkit aims to provide practical guidance to support this local adaptation and implementation. Developed in collaboration with a variety of stakeholders who are directly involved with implementing the strategy, it focuses on the needs of the client at each stage of the latent TB testing and treatment pathway.

### Guidance on increasing uptake of latent TB testing and treatment

Good information and a variety of delivery channels are essential to ensure people being invited for testing and treatment can – and will – access the service on offer at each step of the pathway. Guidance is provided on:

- raising awareness of TB and latent TB to create a responsive environment for local testing and treatment programmes
- overcoming barriers to testing and treatment, and maximising the uptake of the programme
- providing information and support to patients to enable them to complete their patient journey especially, where necessary, through to successful completion of treatment

As well as offering practical guidance and tools, the toolkit provides information about other resources that are available and may assist patients and providers at different steps along the pathway – these include resources that have been developed specifically to accompany the toolkit.

Resources are described in more detail in Appendix 3 and identified in the toolkit under the following categories:

-  **Public awareness and health promotion**
-  **Professional awareness and education**
-  **Tools and templates for patient-provider communication**
-  **Support resources for patients during treatment**

A dedicated latent TB section within TB Alert's existing TB information website [www.thetruthabouttb.org](http://www.thetruthabouttb.org) provides information, advice and support for new entrants throughout the pathway. All the materials referenced in this toolkit will either be hosted on or linked from the site. Please add the link to your bookmarks now: [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)

## Local advocacy for TB services

Tuberculosis is one of Public Health England's seven priority issues, while the related area of anti-microbial resistance is a second. However, the level of interest in TB varies around the country, with some CCGs, GPs and local authorities seeing TB as more of a priority than others. In part this reflects the fact that TB is not evenly distributed across the country or even across cities, which leads to a wide disparity of provision.

Funding is being provided by NHS England for this latent TB programme in high incidence areas but it is time limited. Indeed, it is prudent to expect CCGs to have to contribute towards local programme costs during (rather than only after) the lifetime of the 2015–2020 Collaborative TB Strategy. It is therefore a good idea to use the rare opportunity of this fully funded period – when commissioners, GPs and others have TB in their line of sight – to build consensus among stakeholders that well-planned and resourced services to prevent, treat and control *all* aspects of TB are an important part of local health provision.

Key among these stakeholders are the CCGs that make commissioning decisions based on local priorities. Health and wellbeing boards are the forum where key leaders from the health and care system agree priorities and make recommendations to commissioners, largely based on issues highlighted in the local joint strategic needs assessment (JSNA). The National Institute for Health and Care Excellence (NICE) recommends that directors of public health should work with health protection teams to ensure that TB is in the JSNA.<sup>4</sup>

It is also very helpful for elected councillors to champion the cause of TB. Where this happens, the public and political profile of the issue is often raised and the likelihood of well-resourced TB services increases. It should not be under-estimated how effective political backing can be, and the link between TB and health inequalities can often increase political interest in the illness.

# Best practice examples

NHS England is providing initial funding to 59 CCGs with rates of  $\geq 20/100,000$  or  $\geq 0.5\%$  of the national caseload of active TB, to implement latent TB testing and treatment programmes. A number of these programmes are already underway. Best practice examples drawn from different parts of the country are given throughout the toolkit.

The best practice examples described are:

## **Improving awareness and uptake**

- Linking in with existing community-based public health initiatives (Wolverhampton)
- Building new links with local third sector organisations (Birmingham, Doncaster and Manchester)

## **Maintaining strong local engagement and leadership**

- A dedicated local lead and a committed steering group (Newham and Birmingham)

## **Improving test uptake in primary care**

- Integrating testing with pre-registration assessment (Sheffield)

## **Improving overall TB management**

- Training offered by TB nurses (Manchester and Newham)

## **Improving treatment uptake**

- Concurrent TB nurse and consultant clinics (Leeds and Sheffield)
- Nurse-led clinics (Manchester and Coventry)

## **Improving completion rates**

- Case management for people on treatment for latent TB (Birmingham, Leeds and central London)



● ● ● Section 2

# Latent TB testing and treatment

## pathway

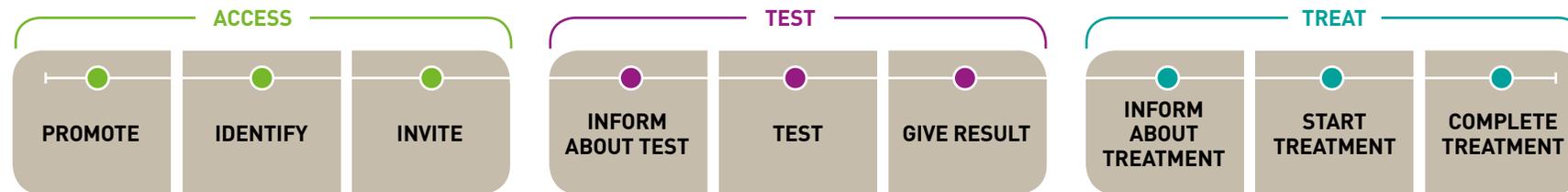
issues,  
strategies and  
resources



## Section 2: Latent TB testing and treatment pathway: issues, strategies and resources

No matter how latent TB testing and treatment is organised locally to reflect local provision and services, there will be a standard series of steps that are necessary to implement the programme. These steps are identified in Figure 1.

**Figure 1: Steps along the patient pathway**



**Table 1: Overview of requirements at each step in the patient pathway**

The requirements for each step of the pathway – logistics, the identity and information needs of implementers, and the needs of patients – are outlined in Table 1. This overview should be interpreted to take

account of local variations and arrangements such as which implementing organisations are involved at each stage and whether other tests (such as blood-borne viruses, HIV) are being carried out.

|  | ACCESS  |  |  |
|--|---|--|--|
|  | PROMOTE   | IDENTIFY   | INVITE   |
| <b>Logistics: what activities are required?</b>      | <ul style="list-style-type: none"> <li>Information and outreach through GP surgeries and local health promotion programmes, in the community, and via mainstream and social media; promote GP registration among new entrants; increase awareness among health and social care staff in primary care and local authorities</li> </ul> | <ul style="list-style-type: none"> <li>Assess new GP registrants; retrospective search through GP register; identify and reach new entrants not yet registered</li> </ul>      | <ul style="list-style-type: none"> <li>Invite eligible person</li> </ul>         |
| <b>Implementers: who is involved?</b>                | <ul style="list-style-type: none"> <li>Health promotion and public health teams; GP practice staff; local third sector organisations</li> </ul>   | <ul style="list-style-type: none"> <li>GP practice staff; health promotion and public health teams; local third sector organisations</li> </ul>                                | <ul style="list-style-type: none"> <li>GP practice staff; TB services</li> </ul> |
| <b>Knowledge: what do implementers need to know?</b> | <ul style="list-style-type: none"> <li>Eligible groups, and key strategies and channels to reach them; understanding of TB-related beliefs and stigma; local latent TB programme structure</li> </ul>   | <ul style="list-style-type: none"> <li>Eligibility criteria and rationale; understanding of TB-related beliefs and stigma</li> </ul>   |  |
| <b>Knowledge: what do patients need to know?</b>     | <ul style="list-style-type: none"> <li>Latent TB and the difference from active TB; latent TB testing and treatment; eligibility and rights to healthcare</li> </ul>  | <ul style="list-style-type: none"> <li>Latent TB and the difference from active TB; testing and treatment and relevance of pre-entry screening and BCG; eligibility</li> </ul> |  |

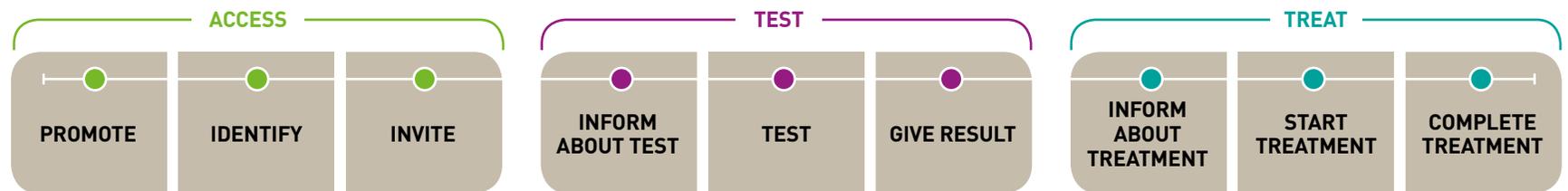
**TEST**

| INFORM ABOUT TEST  | TEST  | GIVE RESULT  |
|--|---|--|
| <ul style="list-style-type: none"> <li>Explain the test and its rationale</li> </ul>   | <ul style="list-style-type: none"> <li>Take blood; arrange collection of sample</li> </ul>  | <ul style="list-style-type: none"> <li>Results sent to GP; patient informed; positive results sent to TB service; patient advised of positive outcome and next steps, or negative outcome and future prevention</li> </ul> |
| <ul style="list-style-type: none"> <li>GP administrative and clinical practice staff; phlebotomist; TB service</li> </ul>  |   | <ul style="list-style-type: none"> <li>Laboratory; GP practice staff; TB service</li> </ul>  |
| <ul style="list-style-type: none"> <li>Rationale behind the test; TB basics (the differences between active and latent TB); local testing arrangements</li> </ul>              | <ul style="list-style-type: none"> <li>Rationale behind the test; TB basics (the differences between active and latent TB); tubes and equipment required; sample collection procedure; reporting results; next steps</li> </ul> | <ul style="list-style-type: none"> <li>Next step if positive or negative; contact details of local TB service; TB basics including treatment process</li> </ul>  |
| <ul style="list-style-type: none"> <li>Latent TB and the difference from active TB; testing and treatment and relevance of pre-entry screening and BCG; eligibility</li> </ul> | <ul style="list-style-type: none"> <li>Information on test; when and how results are given (including information about tests carried out simultaneously, such as blood-borne viruses, HIV)</li> </ul>                          | <ul style="list-style-type: none"> <li>Meaning of positive or negative result; next steps for either result</li> </ul>   |

**TREAT**

| INFORM ABOUT TREATMENT   | START TREATMENT   | COMPLETE TREATMENT  |
|--|---|---|
| <ul style="list-style-type: none"> <li>Assess for active TB; inform about treatment</li> </ul>   | <ul style="list-style-type: none"> <li>Assess patient and start treatment; inform GP</li> </ul> | <ul style="list-style-type: none"> <li>Monitor and support; inform GP of treatment outcome</li> </ul>     |
| <ul style="list-style-type: none"> <li>TB service</li> </ul>   | <ul style="list-style-type: none"> <li>TB service, with partners as needed</li> </ul>           |   |
| <ul style="list-style-type: none"> <li>Latent TB in detail; treatment and side effects; holistic assessment and sources of local support</li> </ul>                                  |   | <ul style="list-style-type: none"> <li>Case management; adherence support</li> </ul>                      |
| <ul style="list-style-type: none"> <li>Meaning of positive result once active TB is excluded; about treatment: risks, benefits, side effects, adherence support available</li> </ul> |   | <ul style="list-style-type: none"> <li>Importance of completing treatment; future risk from TB</li> </ul> |

## Stages in the pathway for testing and treating latent TB infection



The nine steps of the patient pathway can be summarised under three key stages:

- access
- testing
- treatment

### Maximising uptake

The aim at all stages is to ensure that the maximum number of eligible people access the programme and are enabled to continue along the pathway until they have either received a negative result, or have completed any required treatment. Care is needed to ensure that progress from one step to the next is as seamless as possible for the patient, especially when they have to see or communicate with someone new. This requires effective collaboration between providers and effective communication with patients. The more organisations, people and venues a person has to engage with, the more risk there is that they will get lost along the way. This can have significant public health and cost implications, especially if someone has had a positive blood test and does not start preventive treatment, or if they start treatment but do not complete it.

The best uptake is likely to be achieved with fewer referrals across different organisations and locations, and when language services are provided at every stage. Information materials, using consistent branding, can help to enable familiarity and trust across different venues; these materials need to be provided according to people's preferences, with English always being an option. This toolkit signposts the various resources that are available for service providers to make available to patients at various stages of the pathway.

## Issues, strategies and resources

This toolkit was informed through field visits to localities setting up local programmes, and to places where new entrant testing and treatment has been in place for a while. This fieldwork identified issues that have arisen at various stages in the pathway, and strategies that have been devised to address them. Building on this fieldwork, each step has been expanded on to reflect potential issues, along with strategies that have been shown to help address these issues should they arise, and to identify resources that may be drawn on to support the strategies described.

Details of resources referred to in this toolkit are available in Appendix 3.

## Resources throughout the patient pathway



The latent TB section of *The Truth About TB* website provides information, advice and support for new entrants and access to professional training and resources across the full patient pathway: [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)

People invited for testing and treatment should be provided with local sources of advice and support, including support for translation and interpreting, at each stage of the pathway.



## Stage 1 – Access: promote – identify – invite

To be effective, a programme to test and treat people for latent TB needs to ensure that as many eligible people as possible are identified and invited for testing. Due to the nature of the communities in question, and the fact that this programme focuses on people who are essentially well, there are a number of things to consider to achieve the aim of encouraging and enabling people to access the service on offer. It needs to be promoted positively among the relevant communities, ensuring that the message reaches eligible people so that when they are invited they are confident and feel motivated to take up the service.

People invited to use the service, as well as those providing it, need to understand clearly why it is on offer, who is involved, and the benefits of testing and treatment. This will mean engaging a variety of communities and partners, which can be complex and take a lot of time and effort. There is no doubt that having an identified lead to co-ordinate the promotion elements is helpful. There are usually existing resources and relationships that can be built on locally and it makes sense to scope these out before embarking on something new.

The recommendations on developing a social marketing campaign and working in partnership with the third sector, which are set out in Section 3 (starting on page 42), may help inform this process.

The remainder of this section highlights a number of access issues that providers have already experienced in various parts of the country, and provides some strategies and resources that can be used to address them.

**BEST PRACTICE****Improving awareness and uptake**

**Linking in with existing community-based public health initiatives** can be an excellent way to reach affected communities. The Refugee and Migrant Centre in Wolverhampton is involved in a number of health-related initiatives supported by the local authority public health department. The target groups for the Wolverhampton initiatives are similar to the target groups of people who are eligible to be tested and treated for latent TB. The staff are already trusted by affected communities and, by working with the local public health and TB teams, they have developed a community-based model to offer latent TB testing. The staff at the centre promote the latent TB programme, assist with identifying eligible individuals, invite them for testing at the centre and ensure that all those tested are registered with a GP. The TB team come to the centre and carry out the test and if anyone is found to have a positive IGRA result they are then invited to a special latent TB clinic run by the same TB team that did the test at the centre. In this way people are gaining access to primary care as well as to latent TB testing and treatment.

**Building new links with local third sector organisations** that have regular contact with affected communities is a great help when establishing and embedding a strong local latent TB programme. There are a number of examples around the country where valuable links have been forged between local TB services, new entrant testing and treatment programmes and public health departments. These include Freshwinds, a healthcare charity in Birmingham, involved with latent TB testing of students at colleges that teach English for speakers of other languages; the Conversation Club in Doncaster, where migrants meet regularly and where the local TB nurse ran a mobile testing clinic in a health bus parked outside; and the Black Health Agency in Manchester, which will be supporting the latent TB testing and treatment programme in Manchester by having staff members on site to answer questions from people attending a clinic for latent TB testing.

## Promote

**Promote the latent TB testing and treatment programme to eligible communities and also to service providers.**

### Overview

Ensuring that timely and appropriate information and awareness raising activities take place in communities eligible for latent TB testing and treatment is an important part of the programme.<sup>3</sup> Distributing information through GP surgeries is a good place to start, but, for a number of reasons, many new entrants will not be registered with a GP.<sup>5</sup> Organisations that provide services to new entrants are key partners for community engagement. They include third sector and community groups as well as local authority departments such as housing, welfare, environmental health and public health. It is important that commissioners commit investment to promotion as well as testing and treatment, especially as this area requires close collaboration and innovative partnership working.

### ISSUE

#### People who are eligible for testing and treatment are from diverse groups

New entrants come from many different countries and cultures and have different reasons for entering the UK. Their language skills, attitudes and understanding of TB will vary as will their expectations of health services. These factors will affect how likely each person is to engage with the latent TB testing and treatment programme and whether they remain engaged throughout the process.

### STRATEGY

Ideally, a local lead should be identified to drive the promotion of the programme. Collaboration with third sector organisations that work with and hold the trust of affected communities is essential to promote the benefits of latent TB testing and treatment and familiarise people with the process. When they are invited for testing they, or people in their social and family circles, are then more likely to have an understanding of the programme.

Different levels of information need to be delivered through a variety of media to address different language and literacy requirements, reflecting different information and support needs and varying levels of health literacy (see Section 3, page 44).

### ISSUE

#### Stigma and misconceptions about TB

In some communities, TB is a stigmatising disease and can affect prospects for marriage, work and social inclusion. Much of this stigma is based on misconceptions about TB such as:

- TB runs in families
- it only affects the very poor
- it means you also have HIV

Some people may think there is no need to worry as they believe:

- TB is not an issue in England
- pre-entry screening showed no TB
- BCG protects fully

### STRATEGY

Quality information and use of behaviour change techniques (see Section 3, page 42) are needed that counter specific stigma and misconceptions, using techniques that have been tested with the target audiences to ensure they work. Careful, clear messaging is essential as is close collaboration with third sector organisations that work with and hold the trust of affected communities. If trusted organisations, community leaders and influencers deliver the information, and can talk simply and clearly about the disease, it is more likely that people will respond positively to an invitation for testing.

**ISSUE****Perceived racism, fear of immigration status, and fear of authorities**

Campaigns that focus on particular communities or people who come from particular countries run the risk of appearing racist and/or discriminatory.

**STRATEGY**

It is essential to make clear in all promotional materials and when collaborating with different organisations that this is an offer of a health service based on an identified health risk and that it has no impact on a person's immigration status.

The strategies for tackling stigma and misconceptions also apply here: quality information developed using behaviour change techniques can be used to overcome fears about confidentiality and why individuals have been invited for testing. These strategies and techniques should ideally be tested to see what works and be delivered through trusted sources such as community and faith groups.

**RESOURCES**

-  Promotion budget: localities should ensure that budget is allocated for health promotion aspects of the programme.
-  *The Truth About TB* posters, information leaflets and other resources for use in primary care settings and for targeted health promotion and community outreach; includes links to [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)
-  *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages.
-  Guidance on adapting or developing health promotion information for specific demographics: page 44 and Appendix 2.
-  Information and guidance on working with local third sector partners: pages 45–46.

**ISSUE****Lack of knowledge about TB among frontline primary care staff**

This may lead to inconsistent messaging and a reluctance to participate in the programme.

Knowledge and understanding of TB among primary care staff, many of whom will be working on TB for the first time, is often not much higher than that of the general public. Misconceptions can be just as common in providers, who have differing attitudes and understanding of TB.

**STRATEGY**

The healthcare staff involved in promoting the latent TB testing and treatment programme and assessing people's eligibility for latent TB testing need to be informed about who is eligible, why the testing and treatment is being offered to these groups, and be provided with basic knowledge about active and latent TB. Collaboration with local TB nurses is useful for training and advice. Improved links between TB services and primary care has been shown to reduce diagnostic delays overall.<sup>2</sup>

**RESOURCES**

-  *Tuberculosis in General Practice*: RCGP online training.
-  *Tuberculosis: Management, Control and Prevention*: PowerPoint slides and teaching notes for use in primary care.
-  Training materials for clinical and reception staff in primary care.
-  *Latent TB Testing and Treatment for Migrants: A Practical Guide for Commissioners and Practitioners* and *Latent TB Testing and Treatment: A Short Introduction*: Public Health England.

## Identify

### Identify the people who fit the eligibility criteria.

#### Overview

People may be identified as eligible for latent TB testing prospectively, as they register to join a GP practice, or retrospectively, by looking through GP registers to find those who might meet the criteria. Providers are recommended to start with prospective testing as this can be done more easily when people register with a GP practice.

The eligibility criteria for testing are based on someone's risk of infection *and* their subsequent risk of developing active tuberculosis. The eligibility criteria are:

- people who have lived or spent longer than six months in countries with an incidence rate of over 150 per 100,000 population or all countries in sub-Saharan Africa (a list of these countries can be found in Appendix 1 (page 48) and in the PHE guidance: *Latent TB Testing and Treatment: A Short Introduction*)
- people who have arrived in the UK in the last five years
- those who have not been tested previously
- those aged between 16 and 35

- 📄 A poster is available for use in GP waiting rooms to encourage eligible individuals to self-identify and book an appointment: see Appendix 3.

Frontline primary care staff who are most involved in registering new patients will need to be fully aware of the programme and eligibility criteria. They should routinely ask every new person registering whether they have come from or lived in one of the relevant countries for over six months in the last five years. If they have, and have not had a latent TB test since arriving in the UK, they need to be given information and invited for a test. If the test is not being carried out in the GP practice, they have to be referred to the appropriate service, be it another practice, community health setting or TB clinic. A list of all those identified as eligible for testing should be passed to the service that is carrying out tests.

**Note:** of the people arriving in England from the relevant countries, the highest levels of TB are found in the 16–35 age group which is the focus of this national latent TB testing and treatment programme. However, the latest guidelines from the National Institute for Health and Care Excellence<sup>4</sup> recommend testing and treating new entrants in the 0–65 age range from high incidence countries, so people outside the 16–35 age band should be part of locally organised systematic testing and treatment initiatives.

### ISSUE

#### Low levels of GP registration among eligible population

Identifying people as they register with a practice will arguably lead to the most well-organised and settled people being invited for latent TB testing and treatment. It is likely to be those with the highest health needs who do not register with a GP. Among most communities, women are more likely to register than men.<sup>5</sup>

### STRATEGY

Collaboration with third sector organisations that are in regular contact with target populations has been shown to assist in identifying eligible people for testing and encouraging GP registration. Well designed and delivered promotional activities can have the dual outcome of supporting GP registration and leading to the uptake of latent TB testing and treatment.

### RESOURCES

- 📄 To help new entrants find and register with their local GP, share the link to the NHS Choices local service finder: [www.nhs.uk](http://www.nhs.uk)

**ISSUE****Complexities of identifying eligible people retrospectively**

Identifying people retrospectively is complicated by a possible lack of available detail to tease out eligibility. It will be possible to find all 16–35 year olds who registered in the last five years, but that will not identify who has been in a country of high incidence for six months nor who has recently arrived from a high incidence country.

**STRATEGY**

Data clerks may need to take a certain number of records per quarter and attempt to gather the relevant information to identify people eligible for testing. A financial incentive can be offered to GP surgeries to devote some time to retrospective identification. When patients visit the surgery for other reasons, practice staff could ask them if they moved to England during the previous five years and if so from which country.

**RESOURCES**

- 📖 Training materials for GP receptionists and administrative staff.

**ISSUE****Language issues when needing to contact large numbers of patients to check eligibility**

Large numbers of people of eligible age are registered with GPs with no data available about other criteria. Some practices may rely on contacting the patient by text or letter to:

- inform them that the test is on offer
- encourage them to answer a few questions on eligibility
- make an appointment

This process will be difficult if English is not the patient's first language.

**STRATEGY**

Existing communication methods used by GPs – postal mail, email, phone call or text – are likely to be familiar and trusted, and therefore receive a positive response. However, it is important to have a facility for patients (in potentially large numbers) to call and ask questions, and language barriers will need to be addressed. It is helpful to include relevant patient information about the test or direct them to such information.

**RESOURCES**

- ⚙️ Consider involvement of local translation and interpreting services.
- ⚙️ *Invitation letter* template.

**ISSUE****Some providers are already offering latent TB testing and treatment to people under the NICE guidance,<sup>4</sup> which has wider eligibility criteria than the centrally funded programme**

The eligibility criteria set out by NHSE for additional funding is an effort targeted at a specific group where the yield is likely to be highest and the activity most cost-effective.

**STRATEGY**

It is important that providers understand the distinction between the different testing and treatment programmes and why one is funded as a strategic investment in a targeted push to accelerate a reduction in TB cases.

**RESOURCES**

- 📖 *Latent TB Testing and Treatment for Migrants: A Practical Guide for Commissioners and Practitioners* and *Latent TB Testing and Treatment: A Short Introduction*: Public Health England.

## Invite

### Invite eligible people for a blood test.

#### Overview

Once someone is identified as eligible for testing, they will need to be invited for a test according to how local services are organised. The test may be taken by a healthcare assistant, phlebotomist or practice nurse in the GP surgery where the patient is registered, or by a phlebotomist at another surgery or community clinic. In some places it may be carried out within a TB service in a hospital or community setting. Whichever testing route is used, the information given to the patient about where and when the test will be done must be clear, ideally with a double-check to ensure that the patient has understood the process clearly.

#### ISSUE

##### Ensuring people understand the invitation

Sufficient information needs to be provided for people to understand what the test is for and why it is being offered to them. Particular care is required if the blood test is to be taken in another surgery or community health clinic to make sure the person understands where they need to go, when, and how to get there.

#### STRATEGY

Keep a record of all invitations sent out to match against uptake, ideally with a system to contact people who have not responded to the invitation.

Letters and leaflets given to patients need to include general information about the test as well as information about the local process and appointments – and they may need to be translated into a number of languages or backed up with contact details for interpreting services.

#### ISSUE

##### Language barriers

Information needs to be supplied in an appropriate language with an opportunity provided to ask questions. Language skills will vary as will the preferred language of communication. People who are not fluent in English may even prefer to receive information in English, as they can ask a friend to translate it for them (this may help them disassociate themselves from being concerned about TB in communities with stigma about the illness; it may also be easier to ask someone to translate the English rather than to help read their own language).

#### STRATEGY

Ask patients their language preferences for interpretation during face-to-face communication as well as how they would like to receive written information.

**ISSUE****Misconceptions about the meaning of pre-entry screening and BCG vaccination**

People who have already had pre-entry x-ray screening may think they have already been tested for latent TB and/or declared free of TB. They may therefore assume that they do not need to attend for latent TB testing.

People who have received the BCG vaccination may also think they are fully protected from TB.

**STRATEGY**

Provide information about the difference between active and latent TB and why latent TB testing is still beneficial even if someone has been screened previously for active TB or received the BCG vaccination. Ensure this is clearly explained in the information sent with the invitation.

**ISSUE****Concerns about immigration status**

People with uncertain immigration status or who associate any type of test or screening for TB with their immigration status, may worry about what a positive result may mean for them and be deterred from attending testing and treatment.

**STRATEGY**

Ensure clear information, addressing concerns about immigration status in relation to any test result, is included in the information sent with the invitation.

**BEST PRACTICE****Maintaining strong local engagement and leadership**

**A dedicated local lead and a committed steering group** which meets regularly can make a significant difference to the success of a local latent TB programme. In Newham, where a latent TB programme has been established over the last two years, a steering group meets monthly and finds it an invaluable opportunity to raise and address concerns as they arise. It has also helped improve communication and collaboration between providers and commissioners. A strong GP champion, who can promote the programme from a primary care perspective, helps to engage GPs who may not see TB as a priority among so many other pressures. A local latent TB testing and treatment project manager is an important resource to co-ordinate the programme and to avoid the burden being placed on other stakeholders. Having a strong GP champion and dedicated project manager has also been beneficial in Birmingham where three CCGs are working together to establish a latent TB testing and treatment programme.

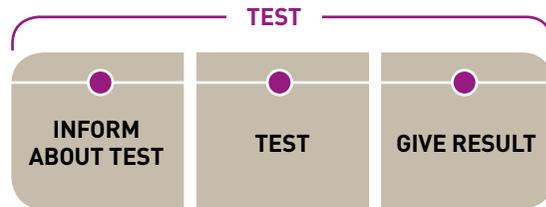
**RESOURCES FOR ALL ISSUES**

 *The Truth About TB* posters, information leaflets and other resources for use in primary care settings and for targeted health promotion and community outreach; includes links to [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)

 *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages,

 *Invitation letter* template with map, directions and contact numbers.

# Test



## Stage 2 – Test: inform about test – test – give result

Once people have been invited for a test, the next step is to enable them to attend their appointment, have the test and receive their result. There are a number of reasons why people may not be able to attend an appointment or pick up their results, while others may choose not to. These factors all need to be taken into account or the efforts made to promote the programme and identify eligible people will be wasted. It is particularly important that people who have taken the test receive their results.

## Inform about the test

**Inform the person about the test and when and how they will receive the result.**

### Overview

Information needs to be provided about the test, what will happen and why, and how the results will be communicated to the patient. People will vary according to their knowledge and understanding of TB and health matters in general, so there needs to be a mechanism in place to provide more detailed information to those who request it.

**ISSUE****Some individuals may want to ask questions before agreeing to the test**

Staff registering people for the test should be able to answer questions or refer the patient to someone who can. Primary care staff may not have the time or knowledge to answer detailed questions and this may lead to people feeling a lack of trust and/or a reluctance to accept the test.

**STRATEGY**

Staff registering people for the test need to be informed about the rationale, risks and benefits, TB basics (active/latent) and the testing and treatment process. As discussed earlier, collaboration with local TB nurses is useful for training and advice. Improved links between TB services and primary care has been shown to reduce diagnostic delays overall.<sup>2</sup>

**RESOURCES**

-  Training materials for primary care clinical and reception staff.
-  *Tuberculosis in General Practice*: RCGP online training.
-  *Tuberculosis: Management, Control and Prevention*: PowerPoint slides and teaching notes for use in primary care.
-  *Latent TB Testing and Treatment for Migrants: A Practical Guide for Commissioners and Practitioners* and *Latent TB Testing and Treatment: A Short Introduction*: Public Health England.

**ISSUE****Fear of a positive result may put people off, especially if they think they are being tested for active TB**

There is also a risk that people may seek information from other people or online which may be misleading and cause concern.

**STRATEGY**

Reiterate information about the difference between active and latent TB. Provide enough information to help people decide whether or not to have the test but not too much to overwhelm people and put them off. It is important to direct people to trusted sources of information that are most likely to be appropriate to them and the questions they have.

**RESOURCES**

-  *The Truth About TB* posters, information leaflets and other resources for use in primary care settings and for targeted health promotion and community outreach; includes links to [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)
-  *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages.
-  *Treatment leaflet*: information on latent TB, medications, side effects and completing treatment.

**ISSUE****The patient does not make an appointment or attend for the test when invited to do so**

In some areas, eligible people will be sent invitations with an appointment to attend for a test; in others they will be invited to make an appointment to suit them. Whichever system is used, there is a possibility that people will not make an appointment or attend due to a variety of reasons.

**STRATEGY**

Localities should ensure that systems are in place to send reminders for people to either book an appointment or attend a test: text messages and email messages are a useful way to do so. Flexibility in appointment times will help to maximise attendance, especially if people are well and working or studying. Ensure that people understand the benefit to themselves and their families. Collaboration with third sector organisations that work with and are trusted by affected communities will help reinforce positive messages and encourage people to attend.

**RESOURCES**

-  *The Truth About TB* posters, information leaflets and other resources for use in primary care settings and for targeted health promotion and community outreach; includes links to [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)
-  *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages.

# TEST

## Test

**Take blood and send it to the laboratory.**

### Overview

The local CCG will have engaged the services of an identified laboratory provider who will be responsible for collecting samples, carrying out the IGRA and sending out results. As this is different to the general laboratory service provider, care is needed to follow the different processes agreed for tubes and connectors used for the test, documentation, collection of specimens and feedback of results. Whoever is doing the test must be fully aware of all these processes, in particular where and when the sample collection will take place.

### ISSUE

**The person taking blood for the IGRA test needs to be aware of the process required for this test which may differ from other tests they do**

They need to use the appropriate tubes, connectors and forms according to the tests being undertaken. In some areas the blood taken will also be used to test for HIV infection and/or a range of blood-borne viruses including hepatitis B and C. Collection of samples will be different from other blood samples as the IGRA test is likely to be carried out by a different laboratory provider. This means that samples may be collected from a different place at a different time and this will need to be taken into account by the person taking the blood.

### STRATEGY

Once the IGRA provider has been confirmed, it is essential to identify where the blood tests will be taken and ensure that all personnel involved understand which tubes, connectors and forms are required, which samples will be taken (IGRA alone, IGRA and HIV, or IGRA and blood-borne viruses) and the arrangements for collecting samples.

### RESOURCES

Information provided by the CCG about local arrangements for ordering supplies and collecting samples.

### ISSUE

**Fear or poor acceptability of blood tests**

Some people simply do not like having their blood taken while others may be reluctant for cultural reasons.

### STRATEGY

The person taking the blood needs to provide reassurance and understanding, and to reiterate the benefits of testing. Encouraging people who have taken the test to share their experiences with others – including on social media – will also help to normalise the test.

### RESOURCES

-  *The Truth About TB* posters, information leaflets and other resources for use in primary care settings and for targeted health promotion and community outreach; includes links to [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)
-  *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages.

## ISSUE

### Providers unfamiliar with TB may be asked questions they are not equipped to answer

In places where a phlebotomist is taking the blood, it is unlikely that they will have been involved in any other stage of the process and may have little or no knowledge about what the test is for and why it is needed. If the person having the test is unsure and asking questions it may lead to a loss of trust in the service if the person taking their blood cannot answer them.

## STRATEGY

If the local programme is organised with phlebotomists taking the blood, then every effort needs to be made to ensure the patient has been fully informed before going for the test. Information should be made available for providers so they are confident to answer basic questions and know where to refer people to appropriate sources of information.

## RESOURCES

Basic information for the phlebotomist about the local programme and arrangements for informing patients of test results.

## BEST PRACTICE

### Improving test uptake in primary care

**Integrating testing with pre-registration assessment** can cover a number of steps in one go, namely identification, invitation, informing about the test and testing. This makes the test more accessible for patients and encourages them to accept the test among a range of others routinely done when registering with a GP practice. This model has been effective in Sheffield.

Reducing the number of clinicians that patients have to see, and places they have to go during the process, enables the patient to follow the pathway more easily. It also helps when setting up and running the programme as it enables targeted education to be delivered to a specific group of healthcare providers – usually healthcare assistants or general practice nurses – giving them the knowledge and skills to ensure people are correctly identified, informed and tested.

# TEST

## Give result

**Inform the person who has been tested of the result – positive or negative.**

### Overview

Everyone who has been tested for latent TB needs to be informed of the result – whether positive or negative – and what will happen next. This will usually be done by the practice that organised the test.

- If negative, general information about TB should be reiterated – in other words, although clear of latent TB, the individual is from a community with high rates of TB and is therefore at increased risk of being newly exposed to TB bacteria in the future.
- If positive, reassurance should be given, as well as clear information about the meaning of the result and what further support and treatment to expect.

In some areas, people with a positive result will be contacted directly by the TB team who will be taking over their care. However it is organised, patients need to be prepared in advance about how to expect their results to avoid unnecessary anxiety and to promote trust. Good communication between primary and secondary care providers is essential so that people are transferred seamlessly from one to the other.

### ISSUE

#### Patient does not attend, call or respond to the result

Ideally, all patients should be informed of their result, whether positive or negative. If positive, they need to be offered treatment. If negative, it is useful to give them advice about what to do if they have concerns about TB in the future.

### STRATEGY

Every effort needs to be made to contact all patients with a positive result so they can be given advice and offered treatment. This may be done via the GP practice, or by the TB team which will be informed of all positive results. If done by the GP practice, it is essential that the TB team is informed as soon as possible of anyone with a positive result who the practice has not been able to reach.

### RESOURCES

- ⚙️ *Positive result letter template.*
- ⚙️ *Negative result letter template.*
- 📢 *Latent TB Testing and Treatment: Information for Patients: Public Health England leaflet in 12 languages.*
- 📢 *TB awareness leaflet: general TB information for people leaving the testing and treatment programme.*

### ISSUE

#### Language barriers may affect someone's ability to understand the result

Confusion about the meaning of the test result may lead to 1) unnecessary concern or 2) no reaction.

### STRATEGY

Information needs to be available in a variety of languages and provided according to the person's language preferences.

### RESOURCES

- ⚙️ Consider involvement of local translation and interpreting services.

## ISSUE

### Fear and anxiety due to a positive result

This may lead to an over-reaction for patients themselves as well as among family and friends. In some cases, assuming they have TB may lead someone to seek help and advice elsewhere, resulting in further confusion.

## STRATEGY

Reassurance needs to be given about the fact that this test is for latent TB *infection* and not active *disease* and that it can be treated free of charge. If the result is being provided in primary care, refer promptly to a TB nurse who will be able to reassure the patient and answer any questions.

## RESOURCES

-  *Positive result letter* template.
-  *Treatment leaflet*: information on medications, side effects and completing treatment.

## ISSUE

### Complacency among those with a negative result

This may lead to people not accessing services if they develop symptoms in the future.

## STRATEGY

Inform about risks of TB and what symptoms to look out for in themselves and others.

## RESOURCES

-  *Negative result letter* template.
-  *TB awareness leaflet*: general TB information for people leaving the testing and treatment programme.

## BEST PRACTICE

### Improving overall TB management

**Training offered by TB nurses** to people involved in identifying, inviting, testing and referring people in GP practices, as well as community settings, not only helps to improve skills and knowledge but also links primary care with local TB teams. This is important when setting up the latent TB programme as well as for TB management overall; this is particularly relevant as delayed diagnosis continues to be a serious challenge. TB nurses in several places, for example Manchester and Newham, have been directly involved in educating GP practice staff and third sector organisations while latent TB testing and treatment programmes are being set up.

# Treat



## Stage 3 – Treat: **inform about treatment – start treatment – complete treatment**

Treating latent TB is key to preventing active TB, so every effort needs to be made to maximise the number of people who complete an adequate course of treatment. Identifying people with latent TB takes time, effort and also incurs significant cost. This is all wasted if people who need it do not receive treatment to prevent future illness and potential transmission. Everyone involved in the referral process and administering treatment for latent TB needs to understand the benefits of such treatment and be able to reassure and

promote trust in those who need it. People found to have latent TB need to understand fully the meaning of a positive test result as well as the risks and benefits of treatment. Being well, it may be confusing and difficult to adhere to treatment, especially if they experience difficulties and/or side effects. So, support is needed throughout treatment in order to complete the full course. If the course is not completed, it will simply not be effective.

## Inform about treatment

**Inform the patient about the treatment for latent TB infection.**

### Overview

Someone with a positive result needs to be referred directly to the service that will provide them with treatment. Even if they have no symptoms, anyone who is found to have latent TB needs to be assessed for active TB and have blood tests and a chest x-ray before being offered treatment.

**The treatment needs to be explained clearly: what it involves, the length of treatment, potential side effects and what support the person can expect. Concerns and questions should be addressed by the healthcare provider who will be supporting the patient through treatment.**

**ISSUE**

**A patient with a positive result does not respond or attend the appointment they have been given to rule out active TB and inform them about the treatment they need**

**STRATEGY**

If the patient has a positive result, it helps to have an identified point of contact between the GP practice and the TB service, enabling good communication and ensuring that those referred have been seen in the TB clinic. It is important to monitor the number of patients who are referred and do not attend and also to agree a process with regard to who will follow up people with positive results who do not attend further appointments.

**ISSUE**

**A number of tests will be required before starting a patient on treatment**

This may both alarm and/or put patients off having treatment.

**STRATEGY**

Clarify the importance of ruling out active TB before starting treatment for latent TB. Give information about other tests and what they are for, especially if additional blood tests are being offered to look for blood-borne viruses such as HIV, hepatitis B and/or hepatitis C.

**RESOURCES**

-  *Treatment leaflet*: information on latent TB, medications, side effects and completing treatment.
-  Information from organisations that work on HIV and other blood-borne viruses.

**ISSUE**

**People are well and do not see the need for treatment**

This is especially relevant when they are told about side effects, the reduced effectiveness of oral contraception and risks associated with alcohol.

**STRATEGY**

Careful explanation about the benefits of treatment and risks of TB to them and their friends and family. Realistic and clear information is required about possible side effects, effects on the reduced effectiveness of oral contraception and advice about alternative family planning methods, and the risks regarding alcohol consumption.

**RESOURCES**

-  *Latent TB Testing and Treatment: Information for Patients*: Public Health England leaflet in 12 languages.
-  *Treatment leaflet*: information on latent TB, medications, side effects and completing treatment.

**ISSUE**

**People refuse treatment**

Even if they are well-informed, people may still refuse treatment.

**STRATEGY**

Find out why someone does not want to take treatment and try and address their concerns individually. Reiterate the benefits of treatment and direct them to the online decision making tool if appropriate. If the patient still refuses, inform them about the risks and what to do if symptoms develop.

**RESOURCES**

-  *TB awareness leaflet*: general TB information for people leaving the testing and treatment programme.
-  *Testing and treatment decision making tool*: online at [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)

# Treat

## Start treatment

**Start the patient on a course of treatment and ensure appropriate support is in place.**

### Overview

Having provided the patient with medication, clear information needs to be given about what happens next, when the next appointment will be and what to do if a problem arises; for example, if they experience side effects, lose their pills, have to go away, cannot make their next appointment. People should be seen at least monthly while on treatment with the opportunity to contact a TB nurse for support in between appointments. As people are well and the treatment can be difficult, each person should be assessed individually and given the advice and support they need to enable them to complete treatment. It is not only in the patient's interest but also in the interest of wider public health.

Full current contact details should be recorded and the patient encouraged to inform the TB team and the GP if these change at any time.

### ISSUE

#### Increased pressures on TB services

This can be a factor due to more people being identified with both active TB and latent TB. This will vary in different areas depending on local demographics and rates of TB but the workload will inevitably increase in patient care, administration and communication.

### STRATEGY

Careful planning and collaboration between commissioners and TB services is essential to ensure that the TB service is fully engaged and can respond to the additional referrals. Estimates of the likely increase in workload are needed and its related cost implications for the service.<sup>3</sup> Where possible, additional support needs to be provided. This is a good opportunity for commissioners and providers in primary, community and/or secondary care to improve local planning for TB management and referral pathways overall.

### ISSUE

#### Arrangements for follow up may be difficult for someone who is well and working or studying

These and other priorities may get in the way of attending appointments or taking a long course of treatment.

### STRATEGY

Careful assessment at the beginning of treatment will help to highlight any potential problems the patient might foresee in adhering to the treatment regimen or attending follow up appointments.

As much flexibility as possible needs to be offered in clinic times and/or treatment options. If it is not possible for a patient ever to attend a clinic, try and arrange follow up elsewhere in primary care, with a pharmacist or other appropriate, acceptable and willing community service.

## ISSUE

### Some people will have concerns about the cost of treatment

This may deter them, especially if they know the treatment is for at least three months.

## STRATEGY

The message that the treatment is free must be clear from the outset and reiterated throughout the pathway.

## ISSUE

### Early side effects may put someone off continuing with treatment

Discolouration of urine and contact lenses can be quite alarming, and feeling sick or itchy is unpleasant and discouraging particularly when taking treatment to prevent an illness that may or may not develop.

## STRATEGY

Clear and realistic information is required regarding side effects with guidance on what to do and who to contact should any occur. Discolouration of urine and contact lenses is inevitable on the three-month regimen which includes rifampicin, and all patients should be told in advance that it is normal and not harmful. While minor side effects can usually be managed with simple over-the-counter remedies, patients should be advised to contact the TB nurse about any side effects they experience.

Although potentially alarming, patients do need to be informed at the outset of serious side effects that may occur in a very few cases.

## BEST PRACTICE

### Improving treatment uptake

**Concurrent TB nurse and consultant clinics** are very helpful in saving patients time and encouraging them to accept treatment. It means that once a patient has seen a consultant physician for a clinical assessment and tests according to local protocols, they can also see a TB nurse and have the opportunity to ask questions and discuss how and when they will take treatment. They can also be assessed for any support they might need or any barriers they might face attending clinic or taking treatment. This has been an effective model in Leeds and Sheffield.

**Nurse-led clinics** in areas where TB nurses are trained nurse prescribers can receive direct referrals of people with positive IGRAs. Nurses follow locally agreed protocols in these clinics to order the necessary tests, rule out active TB and start preventive treatment. Concurrent consultant clinics can still be beneficial, especially if a problem arises that requires the attention of a consultant physician. However, as most people with latent TB are well, a nurse-led model can be more convenient for patients and generally more cost-effective and efficient. Central Manchester and Coventry both follow a nurse-led model.

## RESOURCES



*Treatment leaflet*: information on latent TB, medications, side effects and completing treatment.

# Treat

## Complete treatment

**Continue to support and monitor the patient throughout treatment and record the outcome.**

### Overview

Support and monitoring needs to continue throughout treatment to help the patient complete treatment and address any problems as they arise. Keep a record of all patient contact, including the outcome of treatment, recording whether or not the full course was taken or if it was stopped for any reason and why.

### ISSUE

#### Patient does not attend

Patients may not attend follow up appointments as agreed.

### STRATEGY

The patient should be informed from the start about what they can expect during their treatment, how many clinic appointments they will need to attend, and when. If the patient does not attend they should be contacted by phone and, if not reached, visited at home. An assessment is needed to establish the reason for missing the appointment and steps taken to address any barriers that may prevent someone from attending in the future.

### ISSUE

#### People may move or be moved at short notice

Patients may move or be moved to an area not involved in the programme.

### STRATEGY

Ensure that patients have the right contact details for you, and build trust to ensure they will contact you if they are moved at short notice. Also identify people who are likely to be moved at short notice, such as those in temporary accommodation and/or refugees and asylum seekers, and stress the importance of registering with a GP practice and contacting the local TB service. Liaison with local services, especially housing and migration, can reduce the risk of losing patients.

## ISSUE

### Side effects may persist

Persistent side effects may discourage a patient from continuing treatment.

## STRATEGY

Anyone experiencing prolonged side effects needs to be contacted regularly and given additional support and encouragement. If the patient can no longer tolerate the side effects and wants to stop taking the treatment, advice should be given about the risks of developing active TB and what to do if symptoms occur.

## RESOURCES

-  *TB awareness leaflet*: general TB information for people leaving the testing and treatment programme.

## RESOURCES

-  *Treatment leaflet*: information on latent TB, medications, side effects and completing treatment.

## BEST PRACTICE

### Improving completion rates

**Case management for people on treatment for latent TB** has been shown to produce very good treatment outcomes. In Birmingham, Leeds and central London, where case management has been applied in the same way as for people on treatment for active TB, treatment completion rates have consistently been between 90% and 95%. A study conducted by TB nurses in Birmingham chest clinic showed an increase from 65% to 90% treatment completion after case management was introduced for people on treatment for latent TB. This does inevitably have cost implications, but saves money in the long term by preventing active cases. The effort and investment involved in identifying people with latent TB will only pay dividends if they complete an adequate course of treatment.





# Increasing of latent TB testing and

# uptake treatment

Section 3

# Section 3: Increasing uptake of latent TB testing and treatment

## Community engagement and patient support

Section 2 looked at the practical aspects of delivering a latent TB testing and treatment programme. This section provides more detail on:

- how to engage eligible communities to create a responsive environment for local testing and treatment programmes
- strategies that will help overcome barriers to testing and treatment, and maximise the uptake of the programme
- how to make information and support available to patients to enable them to complete their patient journey, especially through to successful completion of treatment where required

New entrant groups are diverse. They come from many countries and cultures and each individual has their own reasons for travelling to the UK. They may have travelled to work, to study or for family reasons. People identified for testing and treatment will vary in their level of education and skills, and there will be many new entrants who understand little English. Each individual will also have different attitudes to their health, and different understandings of TB and expectations of health services. These factors will combine to influence how likely each person is to engage with the latent TB testing and treatment programme and whether they remain engaged throughout the process.

With such a varied audience, we know that engaging people with the testing and treatment programme will not be straightforward. Few recently arriving migrants realise that TB is a risk to them in England, and many hold stigma and misconceptions about the illness that may deter them from action. There is also the need to convince people who are not actively unwell that it is in their interest to be tested and treated for latent TB.

This toolkit provides strategies and signposts to resources to use, in combination with your local data and existing or new partnerships, to implement a successful latent TB programme. The strategies and resources support the whole pathway from promoting the programme to completion of treatment. They focus as much on encouraging individuals and communities to engage with the programme as they do on providers to make it accessible and on commissioners to support it financially. This information is not exhaustive, but provides guidance based on patient information best practice, social marketing techniques, health literacy and behaviour change theory. Programme providers are urged to map local community health initiatives and organisations that are already working with the relevant communities and that may be invaluable partners in delivering a local latent TB programme. They may be within statutory bodies, the third sector or a mixture of both. A local lead should preferably be identified to take this forward.

# Understanding new entrant communities

When developing a strategy to engage new entrant communities with latent TB testing and treatment, it is important to understand personal, social and structural barriers to engagement and the most effective techniques to overcome them.

## Health seeking behaviour among new entrants

Rates of primary care registration among new entrants are often low. In a study of new entrants from countries with high TB incidence, just 32.5% registered with a GP during a study period ranging from nine to 22 months after arrival.<sup>5</sup> This poses a limit on the impact of primary care-based latent TB testing and treatment programmes, and ultimately their contribution to the Collaborative TB Strategy aim to 'eliminate TB as a public health problem'. Low rates of registration reduce the number of people who can be reached through primary care with information about and invitations for latent TB testing, and also increase the public health risk posed by delayed diagnosis of active TB.

There are many barriers that prevent new entrants from registering with primary care

services, including mistrust of health services, low awareness of rights, language and cultural barriers, and viewing health as a low priority. Some of these same barriers may also prevent new entrants who *are* registered with primary care from accepting an offer of testing and treatment. These barriers are examined further below. It follows that addressing these barriers will not only increase uptake of latent TB testing and treatment but also increase levels of GP registration.

## Attitudes towards TB and latent TB testing and treatment

People who have recently arrived in England from Africa and Asia have good general awareness of TB, but have little understanding that TB is a risk to them in England.<sup>6</sup> It is likely that few new entrants have much understanding of latent TB. Also, their perception of the risks they face from TB will be influenced by pre-entry screening as part of the visa process and the fact that they have probably had a BCG vaccination. What many people do not realise is that pre-entry screening does not identify latent TB whilst the BCG vaccination offers only limited protection. If people simply do not know that they are

at risk of TB, they are unlikely to consider latent TB testing and treatment a priority.

Additionally, many people hold stigma and misconceptions about TB that will make them reluctant to come forward for testing or to accept treatment. Almost all new entrants who are eligible for latent TB testing and treatment will already have been required to be tested for active TB as part of the pre-entry requirements for a visa. This can make them concerned that a further test related to TB will affect their right to remain in England.

Here are some known barriers to engagement with services:

- fear of diagnosis: health implications and social stigma
- belief about BCG protection
- belief that pre-entry screening implies they are free from TB
- fear that testing relates to immigration status

- perceived racism
- mistrust of authority
- understanding reduced by language and literacy needs
- use of poor quality sources of health information
- need for interpreters and confidentiality concerns
- acceptability of blood tests
- fear of potential side effects
- feeling well
- need to stop smoking, stop drinking alcohol when under treatment
- fear of being asked to take TB medication during pregnancy
- concern about reduced effectiveness of oral contraception
- poor continuity of care across providers
- inflexible service types and times

Good quality information, delivered through trusted channels, can overcome barriers to engagement that result from fear or misinformation. To be effective, this information should be developed and delivered using social marketing techniques.

## What is social marketing?

Social marketing uses commercial marketing principles and techniques to improve health and reduce health inequalities. Social marketing uses audience insight and behaviour change theory to understand the health needs of the target audience and to plan beneficial interventions. In particular, social marketing uses behaviour change techniques to address resistant or persistent behaviour that has a negative influence on health.

### Gaining audience insight by mapping local communities

Audience insight supports effective service design, enhances quality of care and supports programme evaluation. Service designers should collaborate with communications and health promotion teams in CCGs, local authority public health departments and relevant third sector organisations to map the local community's:

- demographics
- understanding of TB and latent TB
- barriers to engaging with testing and treatment
- perceptions of health services and attitudes towards prevention and screening programmes in general
- motivations and disincentives to registering with primary care
- preferred media, messaging and delivery routes

### Influencing health behaviour

Behaviour change theory seeks to understand the individual, social, economic and cultural determinants of negative health behaviours, in order to develop mechanisms to overcome them and to achieve positive health outcomes. These determinants include people's perceptions of the risks and severity of negative health outcomes, the benefits of taking advised actions, their barriers to taking action, and their confidence in their ability to change their health-related behaviour.

Behaviour change mechanisms:

- help people to develop accurate knowledge about risks to their health
- explain the benefits of taking particular courses of action
- identify and reduce barriers, through the use of counter-messaging, incentives, reassurance and assistance
- provide people with timely information and tools to enable action
- provide ongoing support and techniques to help people cope with difficult situations

**Communicating with new entrants at transition points**

Information is best received at key transition points in people’s lives, such as starting a new job or moving house, and through trusted and preferred sources. Programme promotion plans should consider the steps that new entrants take as they settle in England and the access points that can therefore be used to reach them.

**Supporting patients at key points in the pathway**

Consider how communications tools and bite-size messages can be used at different stages of the patient pathway to reinforce, remind, motivate and support. In previous sections we have identified specific issues that will come up along the patient pathway and suggested the materials and messaging that will help address them. You can also direct people to the latent TB section of *The Truth About TB* website – [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb) – which contains information about latent TB testing and treatment.

**Table 2: Access points and channels for reaching new entrants**

| Housing   | Employment  | Study  | Support  | Health – access points for non-GP registered  |
|---|---|--|--|---|
| Border Agency: housing for asylum seekers<br><br>Local authority housing departments  | Major employers of people from overseas: <ul style="list-style-type: none"> <li>• NHS</li> <li>• agency staff: cleaning, farming, construction, manufacturing</li> <li>• teachers and academic staff</li> </ul> | Universities, colleges and schools<br><br>ESOL (English for Speakers of Other Languages) providers | Jobcentre Plus<br><br>Food banks<br><br>Advice agencies<br><br>Immigration support services<br><br>Social services | Pharmacies<br><br>Maternity services<br><br>A&E<br><br>Migrant health centres<br><br>Child health services<br><br>Walk-in centres |
| In addition: <ul style="list-style-type: none"> <li>• third sector organisations providing services for specific communities</li> <li>• community leaders and community groups</li> <li>• faith leaders and faith groups</li> <li>• community shops and services, libraries</li> <li>• community and lifestyle media: particularly online and satellite</li> <li>• credible providers of health and social care information: NHS Choices, local authority websites</li> <li>• social peers/role models sharing their experiences – encourage people to share their stories</li> </ul> |   |  |  |   |
| <b>Media preferences:<sup>7</sup></b> <ul style="list-style-type: none"> <li>• high uptake of digital and mobile media: social media, instant messaging, online debates</li> <li>• use internet primarily for entertainment, not education</li> <li>• low engagement with mainstream press</li> <li>• view satellite channels to keep abreast of home country and culture</li> </ul>  |   |  |  |   |

## Meeting specific communication needs

Individuals who are eligible for latent TB testing and treatment will have different information needs depending on their level of education, proficiency in English, and specific attitudes to their health and health services (which may be personal or cultural in origin). These factors are important influencers of 'health literacy', which measures an individual's knowledge, confidence and ability to take action to protect their health.

People with low health literacy are least likely to register with a GP, or if they do, take up latent TB testing and treatment. They are also less likely to ask questions if they do not understand any health information that is provided to them. On the other hand, individuals with good health literacy may question the need for latent TB testing and treatment when they are not unwell, and may request more detail and statistics on risk to support their decision to be tested and treated.

English language proficiency among new entrant groups is highly variable. Language support needs tend to be greatest among South Asian communities, where up to 45% of people may have a language support need, and less acute among new entrants from sub-Saharan Africa. See Appendix 1 (page 48) for more information.

Any communication with eligible communities and individual patients needs to be sensitive to health literacy, language and cultural needs, and use messaging that has a positive impact on health behaviour. This includes using clear and simple language, and avoiding medical jargon or stigmatising words or phrases.

Key messages:

- testing and treatment reduces risk to health, welfare, family and friends – peace of mind
- BCG vaccination and pre-entry test does not mean you are not at risk of TB
- latent TB testing and treatment is not linked to immigration status
- NHS services are confidential
- testing and treatment is free
- anyone can be affected by TB, although people from countries where TB is more common are at increased risk
- translation of information materials is available
- interpretation at consultations is available
- latent TB does not show symptoms
- support is available
- register with a GP
- book your test now

## Language that helps overcome stigma:

| Use  | Avoid   |
|--|---|
| <ul style="list-style-type: none"> <li>• testing and treatment</li> <li>• illness</li> <li>• affected by TB</li> <li>• complete treatment</li> </ul> | <ul style="list-style-type: none"> <li>• screening</li> <li>• disease</li> <li>• carrier, victim, sufferer</li> <li>• adhere, comply</li> </ul> |

### Health promotion for people with social risk factors for TB

People with low health literacy are likely to include many individuals with social risk factors for active TB, as poor literacy and numeracy skills are associated with homelessness, drug and alcohol misuse, and a history of prison. Communications and health promotion should take account of this group; this may be facilitated by connecting with service providers who work with these vulnerable communities. A task and finish group on tackling TB in under-served populations is working to better address the needs of these groups and a report with resources and recommendations is due to be published in autumn 2016.

# Reaching new entrant communities

## Partnerships with existing services

There are likely to be existing health initiatives in areas where many new entrants settle. These are an invaluable source of expertise and can offer practical assistance to implement a local latent TB programme. They may be statutory initiatives or run by third sector organisations – or a combination of both (see best practice examples on page 19). These initiatives may include health promotion campaigns run by communications teams in CCGs or local authorities, which could provide valuable insights into how to reach eligible communities as well as opportunities for collaboration. Third sector organisations and community groups offer a useful conduit for community engagement, including how to find out what work has already been undertaken with eligible groups and whether existing projects can be expanded to include latent TB testing and treatment. Again, ideally, there needs to be a lead person or group to co-ordinate a mapping exercise of existing programmes with eligible communities and to identify and communicate with potential partners.

## Partnership working with the third sector

### The value of the third sector

The Collaborative TB Strategy stresses the need to work with third sector organisations to plan and deliver TB services, and to raise awareness and improve health education about latent TB. This is because the third sector includes a wide range of organisations that have unique capabilities in working with communities eligible for latent TB testing and treatment. These organisations range from registered charities that might already be commissioned partners of local health programmes, through to more informal community groups.

People often talk about the 'voluntary sector' but this toolkit, like the Collaborative TB Strategy, talks about the 'third sector'. This avoids suggesting that the sector is wholly staffed by volunteers or that it can work on an unfunded basis. While smaller organisations may be willing to distribute leaflets or host a talk without payment, the more experienced organisations that have greatest impact on local health outcomes need to be partnered on a commissioned basis.

The third sector's comparative advantages are:

- **knowledge** of health seeking behaviour among migrant communities and of the social and structural barriers they face in accessing healthcare
- **access** to communities in which third sector organisations are embedded
- **trust** that people have for third sector organisations which already assist them on other issues

### Working with the third sector

The third sector can play a wide range of roles in latent TB programmes. As discussed elsewhere in this toolkit, the first stage should be to map those organisations already assisting eligible communities and carry out an assessment of their experience working on TB or comparable health issues. Organisations that might be able to assist this mapping include local authority community engagement and health promotion teams, umbrella bodies such as the local council for voluntary services (CVS) or the local Healthwatch.

NICE produced guidance in March 2016 on *Community Engagement: Improving Health and Wellbeing and Reducing Health Inequalities*,<sup>8</sup> and PHE and NHSE produced a briefing in 2015 entitled *A Guide to Community-centred Approaches for Health and Wellbeing*.<sup>9</sup> These documents are clear and concise, offering excellent guidance which can be applied to any local context.

The NICE guidance explains how local authorities have considerable experience of different ways the third sector can help address health issues. This experience should be drawn on not only in the short term but also with a view to the future. While the initial phase of the latent TB programme is being funded by NHSE through CCGs – and will usually involve CCGs' own health promotion teams – local authorities should be considered a key partner when planning for the long term sustainability of latent TB programmes. The director of public health, based in the local authority, can help establish this liaison.

Third sector organisations with the appropriate experience or training can support latent TB (or other TB) programmes in several ways:

**Programme planning.** The Collaborative TB Strategy stresses the importance of “bringing together all the local agencies, including third sector partners in order for this strategy to succeed.” Third sector organisations can provide valuable insight to help design patient-centred services that are effective, efficient and equitable.

**Creating receptive communities.** While the immediate focus might be on latent TB, people will be more responsive to invitations for testing if there is a stigma-free understanding of TB within their communities. Third sector organisations are well placed not only to build people's understanding of latent TB, but to raise awareness of TB as a curable disease that people catch through no fault of their own.

**Raising awareness about latent TB.** Tuberculosis is a medically complex illness and latent TB is one of its most complex aspects. Not only will most new entrants not understand the nature of latent TB, but they may think their pre-entry x-ray has cleared them of any risk associated with TB. A wide range of awareness resources have been developed by TB Alert (available at [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)) for use in community, educational and primary care settings.

**Pre-testing advice.** The third sector can provide an accessible and trusted source of advice. People invited for testing might have a wide range of questions and concerns about the programme, including needing reassurance that it will not affect their eligibility to remain in the UK, and third sector organisations are well placed to provide this.

**Treatment support.** Experience shows that treatment completion rates for latent TB can easily drop off. Third sector organisations can support the TB team's case management by offering social support which cannot be provided by clinical services.

For all these interventions, it is important to monitor and evaluate the work of third sector partners. Is it possible to attribute their role in increasing the uptake of treatment or completion of treatment? In order to have a meaningful impact on local TB programmes, it is important to build strategic and lasting relationships with third sector partners in the way envisaged by the Collaborative TB Strategy.

*The information in this section is supplemented with information in appendices on the following pages.*



# Appendices

and  
references

# Appendices

## Appendix 1: Eligible new entrants: countries of origin and languages spoken

**Table 3: Top 15 new entrant languages among communities eligible for latent TB testing and treatment – and level of language support needs among speakers (%)**

| Language         | Percentage of speakers with language support need <sup>10</sup> | Main countries of origin of language speakers                                     |
|------------------|---|---|
| Arabic           | 17  | Chad, Comoros, Djibouti, Eritrea, Gambia, Somalia, Sudan (South)                  |
| Bengali          | 30  | Bangladesh, India   |
| Gujarati         | 24  | India   |
| Nepalese         | 14  | Bhutan, Nepal   |
| Pakistani Pahari | 45  | Pakistan  |
| Panjabi          | 32  | India, Pakistan   |
| Pashto           | 25  | Afghanistan, Pakistan   |
| Persian/Farsi    | 21  | Afghanistan   |
| Portuguese       | 19  | Angola, Cape Verde, Guinea Bissau, Mozambique, São Tomé and Príncipe, Timor-Leste |
| Somali           | 24  | Djibouti, Ethiopia, Somalia   |
| Swahili          | 12  | Kenya, Tanzania (United Republic of), Uganda                                      |
| Tamil            | 17  | India   |
| Thai             | 14  | Thailand  |
| Tigrinya         | 22  | Eritrea, Ethiopia   |
| Urdu             | 24  | India, Pakistan   |

**Table 4: Full list of countries identified for latent TB testing and treatment<sup>3</sup> and the main languages spoken by their inhabitants<sup>11</sup>**

| Country                  | Main languages spoken  |
|--------------------------|--|
| Afghanistan              | Persian/Farsi (official) 50%, Pashto (official) 35%, Turkic languages (primarily Uzbek and Turkmen) 11%  |
| Angola                   | Portuguese (official) 71.2%, Umbundu 23%, other 6%   |
| Bangladesh               | Bengali (official) 98.8%   |
| Benin                    | French (official), Fon, Yoruba   |
| Bhutan                   | Nepalese (official) 44.6%, Sharchhopka 28%, Dzongkha (official) 24%, Lhotshamkha 22%   |
| Botswana                 | Setswana 78.2%, Kalanga 7.9%, Sekgalagadi 2.8%, English (official) 2.1%, Sesarwa 1.9%, Sempukushu 1.7%   |
| Burkina Faso             | French (official), Sudanic languages 90%   |
| Burundi                  | Kirundi (official) 29.7%, French (official), Swahili   |
| Cambodia                 | Khmer (official) 96.3%, French, English  |
| Cameroon                 | English (official), French (official)  |
| Cape Verde               | Portuguese (official), Crioulo   |
| Central African Republic | French (official), Sangho  |
| Chad                     | French (official), Arabic (official), Sara (in south)  |
| Comoros                  | Arabic (official), French (official), Shikomoro (official)   |
| Congo (Republic of the)  | French (official), Lingala, Monokutuba, Kikongo  |
| Côte d'Ivoire            | French (official), 60 native dialects  |
| Djibouti                 | French (official), Arabic (official), Somali, Afar   |
| DPR Korea                | Korean   |
| DR Congo                 | French (official), Lingala, Kingwana, Kikongo, Tshiluba  |
| Equatorial Guinea        | Spanish (official) 67.6%, French (official), Fang, Bubi  |
| Eritrea                  | Tigrinya (official), Arabic (official), English (official), Tigre, Kunama, Afar, other Cushitic languages  |
| Ethiopia                 | Oromo (official, Oromiya State) 33.8%, Amharic (official) 29.3%, Somali (official, Sumale State) 6.2%, Tigrinya (official Tigray State) 5.9%, Afar (official, Afar State), Arabic, English |
| Gabon                    | French (official), Fang, Myene, Nzebi, Bapounou/Eschira, Bandjabi  |

| Country                          | Main languages spoken   |
|----------------------------------|---|
| Gambia                           | English (official), Mandinka, Wolof, Fula   |
| Ghana                            | English (official), Asante 16%, Ewe 14%, Fante 11.6%  |
| Greenland                        | Greenlandic (official), Danish (official), English  |
| Guinea                           | French (official), Malinké, Susu, Fulani  |
| Guinea Bissau                    | Crioulo 90.4%, Portuguese (official) 27.1%, French 5.1%, English 2.1%   |
| Haiti                            | French (official), Creole (official)  |
| India                            | Hindi (official) 41%, English (official), Bengali 8.1%, Telugu 7.2%, Marathi 7%, Tamil 5.9%, Urdu 5%, Gujarati 4.5%, Kannada 3.7%, Malayalam 3.2%, Oriya 3.2%, Punjabi 2.8%, Assamese 1.3%, Maithili 1.2%, other 5.9% |
| Indonesia                        | Bahasa Indonesia (official), English, Dutch   |
| Kenya                            | English (official), Kiswahili (official)  |
| Kiribati                         | I-Kiribati, English (official)  |
| Lao People's Democratic Republic | Lao (official), French, English   |
| Lesotho                          | Sesotho (official), English (official), Zulu, Xhosa   |
| Liberia                          | English (official) 20%  |
| Madagascar                       | French (official), Malagasy (official), English   |
| Malawi                           | English (official), Chichewa (common)   |
| Mali                             | French (official), Bambara 46.3%  |
| Marshall Islands                 | Marshallese (official) 98.2%, English   |
| Mauritania                       | Arabic (official and national), Pulaar, Soninke, Wolof (all national), French   |
| Mauritius                        | Creole 86.5%, Bhojpuri 5.3%, French 4.1%, two languages 1.4%  |
| Micronesia (Federated States of) | English (official and common language)  |
| Mongolia                         | Khalkha Mongol (official) 90%, Turkic, Russian  |
| Mozambique                       | Emakhuwa 25.3%, Portuguese (official) 10.7%, Xichangana 10.3%   |
| Myanmar                          | Burmese (official)  |
| Namibia                          | Oshiwambo languages 48.9%, Nama/Damara 11.3%, Afrikaans 10.4%   |
| Nepal                            | Nepali (official) 44.6%, Maithali 11.7%, Bhojpuri 6%  |
| Niger                            | French (official), Hausa, Djerma  |
| Nigeria                          | English (official), Hausa, Yoruba, Igbo (Ibo), Fulani   |

| Country                     | Main languages spoken   |
|-----------------------------|---|
| Pakistan                    | Punjabi 48%, Sindhi 12%, Saraiki (a Punjabi variant) 10%, Pashto (Pashtu) 8%, Urdu (official) 8%, English (official)  |
| Papua New Guinea            | Tok Pisin (official), English (official), Hiri Motu (official)  |
| Philippines                 | Tagalog 28.1%, Cebuano 13.1%, Ilocano 9%, Bisaya/Binisaya 7.6%, Hiligaynon Ilonggo 7.5%   |
| Republic of Moldova         | Moldovan (official) 58.8%, Romanian 16.4%, Russian 16%, Ukrainian 3.8%, Gagauz 3.1%   |
| Rwanda                      | Kinyarwanda only (official) 93.2%, French (official), English (official), Swahili   |
| São Tomé and Príncipe       | Portuguese (official) 98.4%   |
| Senegal                     | French (official), Wolof, Pulaar, Jola, Mandinka  |
| Seychelles                  | Seychellois Creole (official) 89.1%, English (official) 5.1%, French (official)   |
| Sierra Leone                | English (official), Mende, Temne, Krio  |
| Somalia                     | Somali (official), Arabic (official), English   |
| South Africa                | IsiZulu (official) 22.7%, IsiXhosa (official) 16%, Afrikaans (official) 13.5%, English (official) 9.6%, Sepedi (official) 9.1%, Setswana (official) 8%, Sesotho (official) 7.6% |
| Sudan (South)               | English (official), Arabic  |
| Swaziland                   | English (official), siSwati (official)  |
| Thailand                    | Thai (official) 90.7%, Burmese 1.3%, English  |
| Timor-Leste                 | Tetum (official), Portuguese (official), Indonesian, English  |
| Togo                        | French (official), Ewe and Mina, Kabye, Dagomba   |
| Tuvalu                      | Tuvaluan (official), English (official), Samoan, Kiribati   |
| Uganda                      | English (official), Ganda or Luganda, other Niger-Congo languages   |
| United Republic of Tanzania | Kiswahili or Swahili (official), English (official), Arabic   |
| Zambia                      | Bembe 33.4%, Nyanja 14.7%, Tonga 11.4%, English (official) 1.7%   |
| Zimbabwe                    | Shona (official), Ndebele (official), English (official)  |

## Appendix 2: Developing a social marketing plan and materials to increase uptake of latent TB testing and treatment

You can use this guide alongside the information given within the toolkit to help plan, carry out and evaluate your latent TB social marketing plan.

### Step 1: Understand your audience

1. Identify and segment your audience
  - Appendix 1 contains a list of eligible countries of origin.
  - See toolkit pages 40–43 for information on mapping your local community.
  - The Office for National Statistics provides information on local authority residents by country of origin: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/internationalmigration/articles/populationbycountryofbirthandnationalityreport/previousReleases](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/internationalmigration/articles/populationbycountryofbirthandnationalityreport/previousReleases)
2. Gather information about your audience: people's knowledge, attitudes, and beliefs about TB and health; factors that affect behaviour in relation to latent TB testing and treatment; access to and preferences for information, services and other resources; the influence of variables such as country of origin, age or gender.
  - See toolkit pages 41–42 for TB Alert's experience of these issues.

Use the insights of local health promotion/health and wellbeing and community engagement teams.

### Step 2: Set communications objectives

1. Set targets for **actions** that people can take as a result of receiving programme communications: for example, registering with a GP, booking an appointment for a test – these should relate to the overall objectives of the testing and treatment programme.
2. You can also set targets for **changes in knowledge, attitudes and social norms** that are required to increase uptake and completion of latent TB testing and treatment.

### Step 3: Develop your communications plan

1. Use the materials developed alongside this toolkit, which are available at [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)
2. Consider adapting and/or translating materials for your local demographics.
  - See toolkit pages 44 and 53 for information on messages, use of language and producing information for people with literacy or language support needs.
  - Appendix 1 provides information on new entrant languages and support needs; local level data are available from the 2011 census: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/adhocs/005194ct05582011censusethnicgroupbyproficiencyinenglishbysexbyage2011censusmergedlocalauthoritiesinengland>

### BEST PRACTICE

Involve community members – and people or organisations that represent them – throughout the planning and delivery of a social marketing programme, to better understand communities' needs and how best to reach them. This may be in the form of questionnaires, focus groups, a community advisory panel, or using members of the community to deliver awareness and support activities. Community insight and feedback is invaluable to develop, test and revise materials and activities to ensure they are appropriate and have the desired impact.

3. Identify the channels that you will use to disseminate information: how effective are they, how many people can they reach, can you work through existing programmes and organisations?

→ See toolkit page 43 for information on access points and channels for reaching new entrants.

4. Create a calendar of communications activity: for example, disseminating print materials, community events, one-to-one advice, media releases, web chats.

5. Set a social marketing budget.

→ See toolkit page 45 for the importance of budgeting for promotion and commissioning third sector partners for community outreach.

#### Step 4: Monitor and evaluate

1. Track responses to activities: visits to website, calls for information, attendances at events, appointments booked.
2. Track changes in audience awareness and attitudes and how this influences programme uptake.
3. Make necessary adjustments to the programme.
4. Disseminate results to key stakeholders.

## Developing and translating public and patient information for latent TB testing and treatment

Text should be easy to read and should make use of behaviour change techniques to engage and inspire:

- prioritise information on a need to know, want to know or want to tell basis
- speak directly to the reader using 'you' and 'your'
- be appropriate to culture, gender and age
- use plain English and define any complex terms
- use positive messaging and normalise TB: for example, '8 in 10 people have been tested for latent TB infection, have you?'
- define actions to take: for example, 'call clinic on...' not 'the clinic's number is...'
- relate information on risks and benefits directly to the reader
- sentences should be short, simple and to the point: generally no more than 15 words
- use bulleted lists: limited to 6–8 items in each
- use headings and sub-headings to break up text and guide the reader
- use tables to summarise complex information

Though some translated materials are already available alongside this toolkit, you may wish to translate materials into other languages according to your local needs:

- consider what information needs to be translated: need to know, impact of not translating documents, statutory duty – is it possible to translate a summary of the information?
- identify the specific language requirements of your local population
  - Appendix 1 contains a list of the major languages spoken in England by recently arrived migrants from countries identified for latent TB testing, and the 2011 census contains information on local authority residents by country of origin and language spoken: [www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/languageinenglandandwales/2013-03-04](http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/languageinenglandandwales/2013-03-04)
- are arrangements in place to provide follow-up language support where translated materials may generate enquiries?
- are there alternatives to translation: do other agencies/partners already have or plan similar translated materials; could information be more effectively shared by community organisations/advocates?

## Appendix 3: Directory of resources

### Resource categories

-  Public awareness and health promotion
-  Professional awareness and education
-  Tools and templates for patient-provider communication
-  Support resources for patients during treatment

### The Truth About TB website

-  The Truth About TB website provides information, advice and resources about all aspects of TB: [www.thetruthabouttb.org](http://www.thetruthabouttb.org)
-  A latent TB section within the main website provides content to support latent TB testing and treatment programmes. This can be accessed directly at: [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb) – this section provides information and advice for the public and access to the information described in the four resource categories below.

### Public awareness and health promotion

*Eligibility poster for target communities:* for use in GP waiting rooms to encourage eligible individuals to self-identify and book an appointment.

*Latent TB Testing and Treatment:* Public Health England overview information for patients, available in English, Arabic, Bengali, Farsi (Persian), Gujarati, Hindi, Nepalese, Pashto, Punjabi, Somali, Tamil and Urdu: [www.gov.uk/government/publications/latent-tb-testing-and-treatment-leaflet](http://www.gov.uk/government/publications/latent-tb-testing-and-treatment-leaflet)

*TB awareness leaflet:* general TB awareness raising leaflet to be given to people when they leave the testing and treatment programme (either after a negative test result or completion or non-acceptance of treatment) to ensure that they understand the ongoing risks from TB.

### Professional awareness and education resources

*Training materials for local authority staff, GP receptionists, third sector organisations and health champions:* a range of materials for different audiences, each including an overview of the latent TB programme for staff training purposes, including a PowerPoint presentation and factsheets.

*Tuberculosis in General Practice:* online training for GPs, practice nurses and nurse practitioners contains comprehensive information about the role of primary care in preventing TB, and identifying and treating patients with TB. It has recently been updated to include information about latent TB testing and treatment. The course, which was developed by TB Alert in partnership with Public Health England, NHS England and the Royal College of General Practitioners, can be accessed through the RCGP online training platform at [www.elearning.rcgp.org.uk/tb](http://www.elearning.rcgp.org.uk/tb) – the training can be accessed by non-members of the RCGP.

*Tuberculosis: Management, Control and Prevention:* PowerPoint slides from TB Alert and Public Health England that support TB specialist nurses and other TB stakeholders to raise awareness of TB among primary care professionals: [www.thetruthabouttb.org/latent-tb](http://www.thetruthabouttb.org/latent-tb)

Interactive local and national level TB indicator data from Public Health England's Collaborative TB Strategy indicator monitoring website: <http://fingertips.phe.org.uk/profile/tb-monitoring>

Guidance and resources from Public Health England, accessed through the following link: [www.gov.uk/government/publications/latent-tb-infection-ltbi-testing-and-treatment](http://www.gov.uk/government/publications/latent-tb-infection-ltbi-testing-and-treatment)

- *Latent TB Testing and Treatment for Migrants: A Practical Guide for Commissioners and Practitioners*
- *Latent TB Testing and Treatment: A Short Introduction*
- *Latent TB Testing and Treatment: Implementation Algorithm*
- *Latent TB Infection (LTBI) Testing and Treatment National Data Entry Templates: A User Guide for General Practitioners, Clinical Commissioning Groups and their Clinical Support Centres*

## Tools and templates for patient-provider communication

*Invitation letter template:* template text for GP practices to use to invite people for testing and treatment.

*Positive result letter template:* template letter for GP practices to send to people with a positive result, with information on next steps.

*Negative result letter template:* template letter for GP practices to send to people with a negative result. This can be sent with the TB awareness leaflet described on page 54 to advise about future risk and symptoms of active TB.

## Support resources for patients during treatment

*Treatment leaflet:* guidance for people to use throughout treatment, with information on medications, side effects, completing treatment, sources of support, and space for patients to note appointments, side effects and questions.

## Other useful resources

*NHS Choices,* for information about and contact details for local health services; includes information on GP registration: [www.nhs.uk](http://www.nhs.uk)

*Reaching out to high risk communities:* see Public Health England web pages which contain information about reaching communities with testing and treatment programmes through the national Sickle Cell and Thalassaemia (SCT) Screening Programme: <https://phscreening.blog.gov.uk/2015/08/03/reaching-out-to-high-risk-communities/>

*English language proficiency in England and Wales: main language and general health characteristics:* Office for National Statistics, August 2013: <http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/detailedanalysisenglishlanguageproficiencyinenglandandwales/2013-08-30>

*A Beginner's Guide to Planning and Developing High Quality Health Information,* Patient Information Forum: [www.pifonline.org.uk/pif-resources/pif-guidesreports](http://www.pifonline.org.uk/pif-resources/pif-guidesreports)

*Health Literacy: An Introduction for People who Produce Health Information,* Patient Information Forum: [www.pifonline.org.uk/pif-resources/pif-guidesreports](http://www.pifonline.org.uk/pif-resources/pif-guidesreports)

*Language ID Chart,* Refugee Council: [www.refugeecouncil.org.uk/languages/language\\_id\\_chart](http://www.refugeecouncil.org.uk/languages/language_id_chart)

*Public Health England Marketing Strategy 2014–2017,* Public Health England, 2014: [www.gov.uk/government/publications/public-health-england-marketing-strategy-2014-to-2017](http://www.gov.uk/government/publications/public-health-england-marketing-strategy-2014-to-2017)

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The building blocks of this toolkit are the public health and clinical steps required to successfully implement the latent tuberculosis infection testing and treatment programme. It is divided into three sections – background; the testing and treatment pathway; and increasing uptake of testing and treatment – with short best practice examples throughout.

## TB Alert: the UK's national tuberculosis charity

Our vision is the control and ultimate elimination of TB

Our mission is to increase access to effective treatment for all

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