



Writing to improve uptake of latent TB testing and treatment

The success of any latent TB testing and treatment service will ultimately depend on effective communications that encourage individuals to come through the door. This is no easy task, given the diverse nature of the audience and the poor understanding that shapes many people's attitudes and behaviour in relation to TB.

This guide provides some language to use around TB, for anyone developing awareness resources. This language has been tried and tested – across TB Alert's own materials – to give people the understanding and motivation they need to take up the offer of a latent TB test.

The following information should be read alongside Section 3 of [Access, Testing and Treatment: A toolkit for new entrant latent TB programmes](#). This section examines how service providers can engage communities in testing and treatment by using patient information and health literacy best practice, and social marketing techniques.

Understanding new entrant communities

People who have recently arrived in England from Africa and Asia tend to have some knowledge of TB, though with many misconceptions about the illness. However, few new entrants know that TB is a risk to them in England and the majority know nothing at all about latent TB and how it increases that risk.

Overcoming barriers

Providing good quality information about TB, delivered through trusted channels, is the single most effective means we have to overcome people's barriers to latent TB testing and treatment. Yet too often, we read language used to describe TB that is frightening, stigmatising or confusing. Here then, are some key messages and terminology that writers should consider using when developing information materials.

Key messages

These messages are designed to explain TB, address known barriers to latent TB testing and treatment, and inspire action:

- latent TB does not show symptoms
- treatment reduces risk to your health and wellbeing
- treatment protects family, friends and the wider community

Barriers to taking up latent TB testing and treatment

- fear of diagnosis: health implications and social stigma
- belief that BCG vaccination provides full protection
- belief that pre-entry screening implies they are free from TB
- low rates of GP registration
- not understanding rights to healthcare
- mistrust of authority
- need for interpreters and confidentiality concerns
- fear that testing relates to immigration status or race
- understanding reduced by language and literacy needs
- poor quality sources of health information
- acceptability of blood tests
- feeling well and/or health is not currently of a high priority

Key messages continued

- you should be tested even if:
 - you had a BCG vaccination, because its protection reduces over time
 - you have had a chest x-ray for your UK visa, as these cannot see latent TB
- NHS services are confidential
- testing and treatment is free
- anyone can be affected, but living in a country where TB is more common increases risk
- you can request translation and interpretation
- register with a GP
- book your test now

Terminology

Describing latent and active TB

The single most important aspect of raising awareness about latent TB is to clearly describe latent and active TB and the relationship between the two conditions.

Consistently use the terms ‘active TB’ and ‘latent TB’, using the idea of being asleep or awake to describe how they work. This approach is readily understood by our audiences. Alternatives such as ‘TB disease’, ‘LTBI’ or ‘latent TB infection’ are stigmatising or confusing. ‘Sleeping TB’ is also problematic, as patients will hear clinicians use ‘latent TB’ throughout the pathway and may be confused or alarmed if they do not know they are one and the same thing.

“When people talk about tuberculosis (TB), they usually mean ‘active TB’. If you have active TB, the bacteria are making you ill and you might be passing TB on to other people.

If you have latent TB, the TB bacteria in your body are ‘asleep’. You are not ill and you cannot pass TB on to others. However, the bacteria might ‘wake up’ in the future, making you ill with active TB.”

Who should be informed about latent TB testing and treatment?

Latent TB testing and treatment is only offered to the people who will benefit from it, which is why your CCG testing and treatment programme is using criteria set out in either the NICE Guidelines, the Collaborative TB Strategy or both.

NICE Guidelines	Collaborative TB Strategy
<ul style="list-style-type: none">• Children and adults aged up to 65 in contact with infectious TB• Under-served populations: homeless, substance misuse, prison history and vulnerable migrants• Immunocompromised• Healthcare workers• New entrants (time unspecified) from countries with TB incidence >40 per 100K	<ul style="list-style-type: none">• Aged 16-35• Settled in England within the last five years• From countries with TB incidence >150 per 100K and any country in sub-Saharan Africa

Excluding people who would not benefit from latent TB testing and treatment

The majority of people living in England would not receive any benefit from a latent TB test, as they are unlikely to have ever been exposed to TB bacteria. There is also no benefit in testing for people who have been treated for latent or active TB before. This is why it is a good idea to target awareness messages and activities carefully, to avoid services receiving inappropriate requests for testing. However, care needs to be taken to ensure that messaging is both easy to understand and avoids stigmatising specific communities.

We have seen a lot of materials that encourage people to be tested if they 'have not been tested or treated for TB before'. This is wrong, as almost everyone who would benefit from latent TB testing will have been given a TB chest x-ray during their visa application process.

This table explains some of the wording and messaging to use or avoid and why

Use	Avoid	Explanation
you do not need to be tested if you have been treated for latent or active TB before...	you do not need to be tested if you have been tested or treated for TB before...	previous TB <i>testing</i> does not exclude anyone from a latent TB test, however previous <i>treatment</i> does
testing and treatment	screening	<i>screening</i> is considered stigmatising and potentially exclusionary – particularly as it is related in people's minds to pre-entry screening that takes place as part of the visa application process
illness	disease	stigmatising
affected by TB	carrier, victim, sufferer	stigmatising
complete treatment	adhere, comply	stigmatising and fear of compulsion
active TB, latent TB	TB disease, LTBI, latent TB infection	the words <i>disease</i> and <i>infection</i> are stigmatising and can cause fear
asleep/wake-up	dormant, inactive/activates, reactivates	our research has shown that the idea of TB being either <i>asleep</i> or <i>awake</i> is clearly understood by our audiences
you may benefit from a latent TB test...	eligible, target, at risk of latent TB	<i>eligible</i> suggests services are only free to some, <i>target</i> is stigmatising and/or potentially threatening <i>benefit</i> avoids problematic terms whilst also providing emotional leverage you are not really <i>at risk</i> of latent TB...
newly settled, new entrant, recently arrived	migrant, immigrant	<i>migrant</i> and <i>immigrant</i> are often used in a stigmatising way
latent TB, the sleeping form of the illness	sleeping TB	clinicians will inevitably refer to latent TB throughout the patient pathway, possibly alarming and confusing patients who have only heard of sleeping TB