

Tackling TB in London

October 2015



Health Committee Members

Dr Onkar Sahota (Chair)	Labour
Andrew Boff (Deputy Chair)	Conservative
Kit Malthouse MP	Conservative
Murad Qureshi	Labour
Valerie Shawcross CBE	Labour

Role of the Health Committee

The Health Committee is tasked with reviewing health and wellbeing across London, including progress against the Mayor's Health Inequalities Strategy, and work to tackle public health issues such as obesity and alcohol misuse. The Committee will consider the Mayor's role as Chair of the new pan-London Health Board and the impact that recent health reforms are having on the capital, notably NHS reconfiguration and the decision to devolve public health responsibilities to local authorities.

The following terms of reference were agreed by the Committee:

- To examine how the new national TB Strategy will be implemented in London
- To consider how the Mayor and the GLA could further support the reduction of TB in London

Contact

Lisa Lam, External Relations Officer

Lisa.Lam@london.gov.uk

020 7983 4067

Lucy Brant, Scrutiny Manager

scrutiny@london.gov.uk

020 7983 4000

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Chair's Foreword

Many Londoners will be surprised to hear that tuberculosis (TB) still exists in the capital. Many more will be shocked to learn that London has been described as the TB capital of Western Europe. It is not a disease of a bygone era. In London, around seven people develop symptoms of TB every day.



The causes are complex and far from simply medical. TB affects those who most need our help: migrants, the elderly, prisoners, homeless people and those who are marginalised from society. TB has a relationship with deprivation as well as clinical causes.

Prevention is poor and awareness low, even among the medical profession itself, complicated by the difficult nature of reaching those who are most likely to be affected. This creates the conditions for new strains of drug-resistant TB to emerge. The treatment is expensive, complicated and terribly gruelling. The quality of care for TB sufferers also varies across the capital resulting in duplication and gaps in coverage.

We have set out recommendations which will go a long way to tackling TB. They are broad and require the Mayor to work with partners in a focused and determined way. As a Committee, we call on the Mayor to take political responsibility and bring TB to the forefront of consciousness for all Londoners.

We see TB as a barometer of health inequalities. If the Mayor is to reduce health inequalities in London he must combat TB and its underlying social factors. Ultimately, if we are to address the problem, we need to understand it and prevent individuals from falling to the margins of society.

I would like to thank colleagues on the Health Committee for their hard work and commitment, and the GLA officers who helped produce the report. I would also like to extend my thanks to all the guests who gave their time to attend our meetings, and to the staff and patients of the Whittington Hospital TB unit for sharing their experiences with us.

A handwritten signature in black ink, appearing to read 'Onkar Sahota', written in a cursive style.

Dr Onkar Sahota AM MBA FRCGP, Chair of the Health Committee

Executive summary

Tuberculosis (TB) is a significant public health challenge in London. The city accounts for almost 40 per cent of all cases of TB in England, and one third of London boroughs are classed as high incidence by the World Health Organisation. This means that some parts of London have TB rates comparable with countries such as Algeria and Iraq. For over a decade, London has had the dubious title of ‘TB capital of Western Europe’.

A barometer for health inequalities

TB disproportionately affects particular groups within London’s population. These include marginalised groups such as prisoners, homeless people, people with substance abuse issues, refugees and migrants. London also has significant numbers of people with existing medical conditions, such as HIV and diabetes, which increase the risk of developing TB. The disease is strongly linked with deprivation, and efforts to tackle TB in London must focus on addressing both the social and clinical causes of TB.

We have found that many Londoners – including some doctors – lack basic information about what TB is, its symptoms, and how it is spread. This makes preventing and diagnosing TB more challenging. TB is also heavily stigmatised, placing an additional burden of fear and isolation on people who have the disease. We call on the Mayor to use his profile to raise awareness and to challenge the stigma that prevents people from talking openly about TB. Greater efforts to manage and control TB are critical in the light of the rise of drug resistance. Drug-resistant TB is considerably more difficult and vastly more expensive to treat. It will place a growing burden on health services if more is not done to ensure prompt diagnosis and treatment adherence.

Variation in services

London has some of the best clinical TB services in the country, but the system is fragmented, and access to high quality care is not universally available to all Londoners. This approach leads to duplication, inefficiency and extra costs to services. Health services should explore ways in which TB control and management can be better standardised across London to address variation in the quality of care. Not all services are available in every borough, even where guidelines state that they should be; for example, universal vaccination for new-born babies has not been achieved.

We found there is a lack of information about both the benefits and the limitations of screening and vaccination. This presents a challenge for public

health workers, but also an opportunity to educate the public more widely about TB. The Mayor should work with Public Health England and voluntary organisations to enable this.

The need for outreach

Community-based services, tailored to the individual needs of people who have TB, are effective and should be better supported. In particular, outreach services which work with vulnerable groups should be prioritised. London has developed innovative services which are widely recognised as good practice for TB control. But the funding for these types of interventions is not secure. The Mayor must lobby for more resources and investment to protect and expand these services, to help London to play its part in reducing the national burden of TB.

The role of the Mayor

It is vital to the success of TB control strategies that local government recognises both the moral and the economic incentive for action. We call on the Mayor to take political accountability for TB control and to lead the pan-London response to TB. He should use his influence with local government leaders to drive forward measures for the prevention, as well as the treatment, of TB.

The Mayor is uniquely placed to lead the drive to reduce TB in London. He can make direct policy interventions in areas such as housing, transport and community relations. He can also lobby the NHS and local and national government to promote the cause of TB and ensure it receives the attention and funding it requires. Inaction now increases the risk of TB to Londoners, and will make it harder – and more expensive – to tackle TB in the years to come.

Reducing the TB burden will be a real sign that London is on the path to becoming a healthier and fairer city. But only by addressing the wider social factors behind ill health will TB in London be reduced – relying just on clinical services will not be enough. Measures to improve housing and reduce poverty will be vital as part of a “health in all policies” approach. TB is very much a barometer for health inequality in London, and should be viewed as a key indicator for the success or failure of the Mayor’s Health Inequalities Strategy. Unless these underlying social issues are tackled, it is unlikely that the national TB strategy will be effective in London.

Introduction

What is tuberculosis?

Tuberculosis (TB) is an infectious disease caused by the bacterium *Mycobacterium Tuberculosis*. TB bacteria are released into the air when someone with infectious TB coughs or sneezes. The majority of people exposed to TB will either fight the bacteria off, or will carry it within their bodies without getting sick and without becoming infectious. This is known as **latent TB infection**. Most people who get TB have had a prolonged exposure to an infectious person – usually someone in the same household. TB cannot be caught through everyday travel on the bus or Tube, or through spitting.

Between ten and thirty per cent of those infected with latent TB will go on to develop 'active' TB disease at some point in their lives, usually when their immune system has been weakened by other factors. Once reactivated, the TB bacteria can cause disease in any part of the body, but it most commonly affects the lungs. This is known as **pulmonary TB**. Pulmonary (infectious) TB is the only form of TB which can be passed on to other people. TB that affects other parts of the body is known as **non-pulmonary TB**. A person with non-pulmonary TB disease will be unwell themselves, but will not be able to pass the disease on to other people.

The most common symptoms of infectious TB disease are:

- Persistent coughing (more than three weeks), sometimes with blood
- Weight loss
- Tiredness
- Night sweats
- Fever
- Loss of appetite

A typical case of TB is usually treated with a six-month course of antibiotics. Drug-resistant cases can involve lengthier and more complex treatment with antibiotics and injectable drugs, and can often require in-patient care in hospital. If treated correctly, TB can be completely cured with no long-term effects. Left untreated, TB can cause permanent damage to organs and tissues and can be fatal.

The purpose of this investigation

The London Assembly Health Committee last investigated TB in 2003. That investigation warned that more needed to be done to combat the growing threat of TB in the capital and called for a London-wide TB plan. Twelve years later, we have found that many of the issues highlighted in that investigation remain a challenge for London's TB services. Public Health England continues to view TB as a significant public health challenge, and has listed it as one of its key strategic priorities. In January 2015, it launched a collaborative national TB strategy alongside the NHS. The strategy calls for a co-ordinated, multi-agency response to TB control and management across England.

Our investigation has focused on the role of the Mayor in tackling TB in London. In the first part of this report, we look at the scale and nature of London's TB problem. The second part looks at the pressures facing London's existing TB services. The final part of the report discusses how the Mayor can support the delivery of the national TB strategy in London through a 'health in all policies' approach.

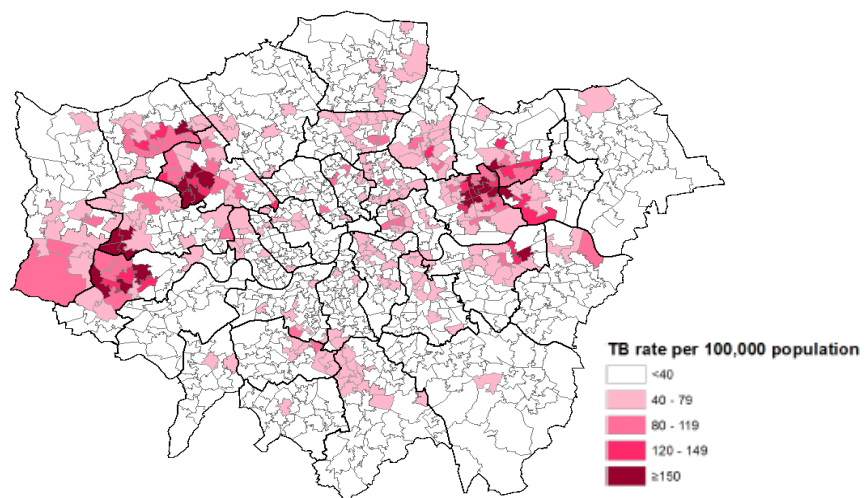
1. The situation in London

Despite being viewed as a disease of the past, TB remains a significant public health challenge for London. A combination of clinical, social and environmental factors make some Londoners particularly susceptible to TB. However, many people lack even basic information on how TB is spread, and its symptoms. This makes preventing and diagnosing TB more challenging.

TB is not evenly distributed across London. While some boroughs report only a handful of cases a year, others are facing high levels of TB similar to parts of the developing world. TB affects some of London's most vulnerable and marginalised people and communities, and is strongly associated with deprivation and health inequality. It is also a heavily stigmatised disease. Fear and misinformation continue to hamper efforts at prevention and treatment.

- 1.1 There were over 2,500 new cases of TB in London in 2014, making up approximately 40 per cent of all cases in the UK. One third of London's boroughs exceed the World Health Organisation "high incidence" threshold of 40 cases per 100,000 population. And some boroughs have incidence levels as high as 113 per 100,000 people – significantly higher than countries such as Rwanda, Algeria, Iraq and Guatemala.¹

TB rates vary across London boroughs and wards



Source: Written submission from Public Health England to London Assembly July 2015

Who gets TB in London?

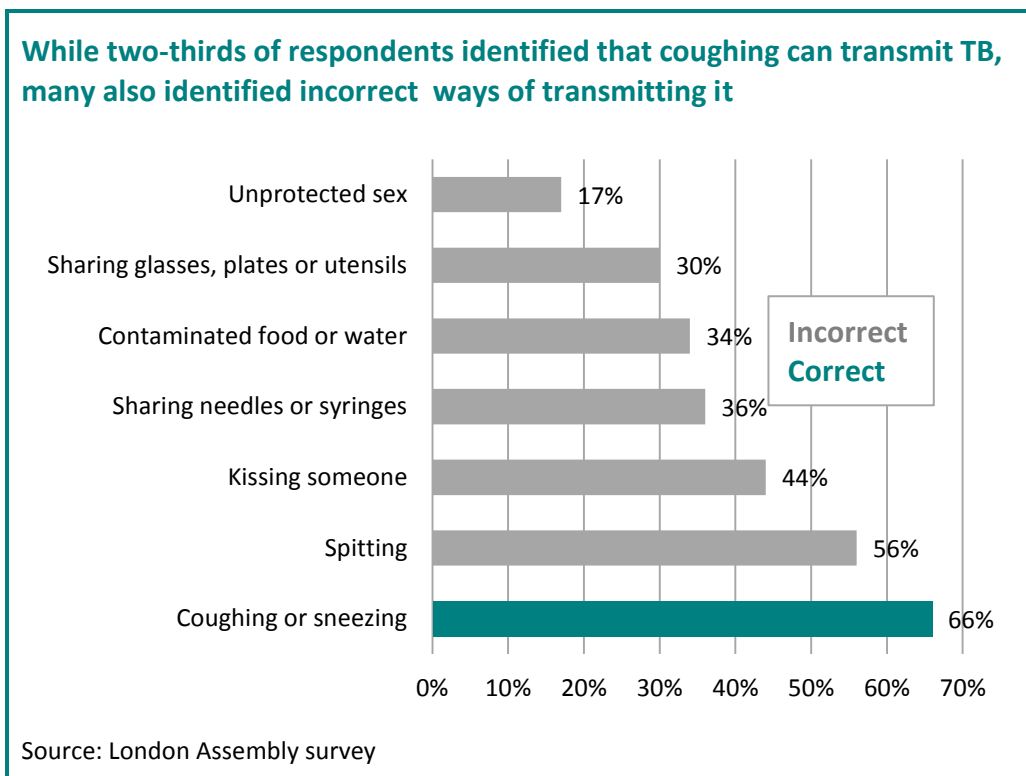
- 1.2 Anyone can get TB. However, there are certain groups within the London population who are at higher risk. For some, this will be because they live in an area where there are already high levels of TB, or because they have been exposed to TB in another country with a high incidence of the disease. This makes them more likely to have been infected with TB in the past. Worldwide, around one in three people – two billion people – are thought to have latent TB infection.² In London, the most common countries of origin for non-UK born cases are India, Pakistan and Somalia.³
- 1.3 The people who are most at risk of developing active TB disease are people whose immune systems have been weakened. This makes it difficult for the body to fight off the infection or keep the bacteria in a latent state. People with chronic poor health due to lifestyle factors are more likely to suffer from weakened immune systems. These factors include smoking, poor nutrition, stress, and drug or alcohol abuse. Many people in high-risk groups, such as rough sleepers, have a number of co-existing health problems which make them particularly susceptible to TB. TB is strongly linked with deprivation. Overcrowded and poorly ventilated living conditions make it easier for TB to spread in the air. This can affect people who live in crowded or sub-standard accommodation, as well as prison populations and people who sleep rough or in hostels.
- 1.4 Specific health complaints, including diabetes and HIV, also weaken the immune system. London has high rates of both of these diseases. Treatments for other conditions, such as drugs used to treat cancer and to facilitate organ transplant, can also weaken the immune system. Babies and children, and older people, also have naturally weaker immune systems than healthy adults.
- 1.5 There is a clear link between TB and migration, but it is a complex story that is easy to misinterpret. While more than 80 per cent of London TB cases occur in people who were born abroad, it is unlikely they brought active (infectious) TB into the country: people from high incidence countries must be free of active TB to get a visa to enter the UK. We do not know, however, how many people are coming to London with latent TB. It is not feasible or cost-effective to screen everybody at the border for this, and those with latent TB do not present an immediate public health risk.
- 1.6 A number of the factors that trigger latent TB into active TB – poor housing, chronic ill health, poor nutrition – are more likely to affect certain groups and

communities in London, many of whom were not born in the UK. But they can affect UK-born Londoners too: we met a patient at a TB clinic who had caught TB over 50 years ago from a close relative, but their latent TB had only recently turned into active TB as a result of an illness that weakened their immune system. And while the number and rate of TB cases in non-UK born Londoners has decreased in recent years, the number of cases among UK-born residents has not.⁴ The most effective strategy in the fight against TB is therefore to reduce levels of poverty and deprivation for **all** Londoners.

- 1.7 One consequence of globalisation is that infectious diseases like TB cannot be addressed in isolation by one city or one country. A global disease requires a global response. But in the absence of a sustained global effort, there are still measures that can be taken at a national, regional and city level. The national TB strategy is an important step for England, but London’s unique characteristics mean that more needs to be done here if TB is to be kept under control.

Raising public awareness

- 1.8 Our survey found that many Londoners are in the dark about TB and how it spreads. Almost one in five Londoners we asked said they could not name a single symptom of infectious TB.



1.9 Myths around TB, how it is spread and what it means, stigmatise the people who are unfortunate enough to catch the disease. This makes it harder for them to seek treatment and receive support. Stigmatisation of TB means that many people are fearful of seeking a diagnosis even when they become very unwell. This in turn increases the chances of wider onward transmission within the community. Public Health England told us:

“In its most extreme manifestation the social stigma of TB has led to individuals being excluded from friends, their community and sometimes even their families.”⁵

1.10 Our survey found that almost half of all adults in London believe that people with TB should stay away from other people while they are being treated: in reality this is both unnecessary and impractical. More than two in five say that they would be worried to tell their employer they had TB, and a quarter say they would be scared to tell their friends and family. These figures suggest that TB remains a difficult illness for people to discuss and that fears of social ostracism may be well-founded.

1.11 Patients and clinicians told us that TB in some communities is seen as more than just a disease. It can embody and reinforce social divisions and discrimination. We heard that in some communities, admitting to a diagnosis of TB could result in being excluded from work or from public gatherings, and could damage a person’s chances of getting married. In some cultures it is associated with witchcraft, or viewed as a curse. Certain risk factors for TB can in themselves create stigma, such as HIV infection, a prison history, homelessness, or refugee status.⁶

1.12 TB is an infectious disease, not a moral judgement. It is absolutely vital to the success of TB control strategies that the widespread lack of awareness around TB is challenged and addressed. Misinformation and stigmatisation do not only make life more difficult for people who are already suffering a serious and unpleasant illness. It can make people needlessly frightened about their own health. It can also make people dangerously complacent, believing that TB can only infect certain ‘types’ of people.

1.13 Global TB campaigners have referred to the ‘triple burden’ of TB and have called on health programmes to holistically address *“the devastating health impact of the disease itself, the harsh burden of treatment, and the isolation of social exclusion driven by stigma.”⁷* We agree: it is time for a serious, grown-up conversation about TB in London which is based on evidence and medicine, not blame and fear.

1.14 We share Public Health England’s view that raising awareness in a constructive way will take more than plastering messages about TB across the side of London buses.⁸ Effectively communicating with diverse communities in London about TB will be a challenge. However, it is difficult to see how an informed public discussion can take place in London without some attempt to educate the wider population about the basics of the disease.

1.15 The Mayor’s position as a leading spokesperson for London can help promote the debate beyond the clinical arena and ensure that TB doesn’t slip off the radar. Public Health England told us that the profile of the Mayoralty meant that a Mayor is in a position to connect with people in ways that are not available to clinicians. This ties in directly with one of the key aims of the Mayor’s health inequalities:

“Individuals need to be equipped with the knowledge, skills and confidence they need to take control of their own health.”⁹

1.16 The Mayor has said that he accepts ‘his responsibility to lead by example’ in tackling health inequalities.¹⁰ Engaging in a sustained and meaningful discussion about TB is a powerful opportunity to translate these words into action. London will need to lead by example if the national burden of TB is to be reduced.

Recommendation 1

The Mayor, in conjunction with the third sector and Public Health England, should develop and deliver a London-wide programme to educate the general public about the symptoms of TB and how it is spread.

Low awareness among GPs

1.17 In addition to low levels of awareness within the general population, patients told us that doctors were not diagnosing TB quickly enough. Late diagnosis can cause clinical complications, as well as increasing the risk of onward transmission. The latest figures show that less than half of people in London diagnosed with TB begin treatment within two months of symptom onset.¹¹ One patient, who eventually ended up hospitalised for four months, told us that the symptoms had been missed by their GP:

“I had night sweats and fevers, was constantly coughing, had lost my appetite, lost weight and was very lethargic – all the symptoms of TB, but the surgery did not pick up on any of them, even when I was treated for drop foot (I had collapsed on my feet one night – I

was so ill with TB that I could not move) and only given water tablets as treatment and sent away.”¹²

- 1.18 There are a number of possible reasons for late diagnosis. First, the symptoms of TB can be easily confused with a number of other health conditions. This may lead patients themselves to delay seeking advice, and to GPs misdiagnosing on first inspection. Second, ensuring continuity of access to the same GP can be challenging: many people report seeing several different doctors who may not be fully aware of a patient’s medical history and social risk factors for TB. They are also less likely to detect a progressive deterioration in health over time. Third, doctors in low-incidence areas may simply not be ‘thinking TB’ when an ill person is in front of them:

“A GP might encounter one or two cases of TB in ten years, depending on where they work...with someone working in an area where there is lots of TB, we need to educate them better.”¹³

- 1.19 Ideally, raising public awareness will empower patients to challenge their GPs if they think they might have TB. We also welcome the commitment in the national strategy to educating the health workforce about TB. We would also like to see better education for other people who work closely with at-risk groups, including housing officers and youth support workers.

Drug resistance

- 1.20 Drug-resistant TB has been described as ‘the nightmare on the horizon’. Nine per cent of London TB cases are already resistant to one first-line antibiotic, and this figure is set to rise. An inadequate global response has contributed to the growing epidemic of drug-resistant TB, with cases reported in most countries worldwide.¹⁴
- 1.21 Drug resistance arises when people fail to complete the full course of antibiotics needed to completely kill off the TB infection. Taking medicine regularly for six months is an onerous task, particularly for people with chaotic lifestyles (who are at higher risk of catching TB). Once a drug-resistant strain develops, it can be transmitted to other people and begin to circulate in the wider population.
- 1.22 Drug-resistant TB is significantly more complex and expensive to treat than drug-sensitive TB. Treating a drug-sensitive case can cost as little as £1000. The costs of treating a complex drug-resistant case can reach £100,000 or more. Treatment for drug-resistant TB can take two years to complete and can require lengthy periods in hospital.

Treatment for TB is gruelling

Patients with drug-resistant TB take an average of 19 pills a day over the two year course of treatment. This works out at 14,000 tablets – the equivalent of one pill a day for 38 years. Many of the drugs used to treat resistant strains can have severe and potentially life altering side effects, including nerve damage, kidney and liver impairment, and loss of sight or hearing. Patients will often experience less severe – but debilitating – effects such as fatigue and nausea.

- 1.23 London's health services already spend an estimated £30 million a year on treating TB.¹⁵ If drug-resistant strains become more widely prevalent in the community, these costs will soar. More worryingly, resistant strains may continue to mutate to the point that they become untreatable with any drugs at all. There have already been a handful of these types of extremely drug-resistant (XDR) TB cases in the UK. A single case of XDR-TB can cost more than half a million pounds to manage. One TB doctor told us:

*"We have the largest outbreak of drug-resistant TB ever documented in Western Europe in London and plenty of evidence that current efforts to contain transmission, even occurring at household level, are insufficient."*¹⁶

- 1.24 The effects of widespread drug-resistant TB on London and its health services are frightening to contemplate. This is why it is vital that the city acts to get a grip on its TB problem before the situation spirals out of control. This will require efforts to reduce transmission of active TB as well as ensuring people who are undergoing treatment are able to complete the full course of antibiotics correctly.

2. Tackling TB in London

London has some of the best clinical TB services in the country, and pockets of outstanding work exist across the city. However, the system is fragmented and the best quality care is not universally available to all Londoners. London’s clinical services face growing pressures, notably the rise of drug-resistant strains of TB. These pressures will mount if action isn’t taken to ensure that services for the most vulnerable Londoners are protected, and if more isn’t done to support services in areas most affected by TB. The success of the national TB strategy in London will also depend on factors that are beyond the reach of traditional clinical services.

Commissioning clinical services

- 2.1 The commissioning landscape for TB services in London is complex. Each one of London’s 32 Clinical Commissioning Groups (CCGs) is individually responsible for commissioning and delivering its own TB services. This approach leads to duplication, inefficiency and extra costs. It also leads to variation and inconsistency in care across London. While local health commissioning can lead to tailored services that better reflect the specific requirements of a local population, it can also create a “postcode lottery”; for example, regarding access to diagnostic tests. Public health issues by their nature require a more strategic approach to commissioning. The scale of London’s TB problem means that more services are needed; however, this high level of demand also creates a necessarily more fragmented landscape, which contrasts starkly with other European cities:

“Amsterdam, one clinic; Rotterdam, one clinic; Paris, five clinics; Barcelona, one clinic. London, thirty clinics, all providing a very different model of care, all very dependent on local commissioning arrangements, all with very different arrangements. There is a need to rationalise the provision of TB services across London.”¹⁷

- 2.2 Some TB services, such as neo-natal vaccination and the mobile Find & Treat service, are already commissioned and delivered as pan-London services. A 2014 report by the British Thoracic Society into developing a gold standard model of care for TB concluded that *“Where the number of active cases within a CCG is low, commissioning TB services on a collaborative basis is more likely to provide high-quality services.”¹⁸*

- 2.3 We think it is worth exploring whether London should be considered as one unitary authority for the purposes of commissioning TB services. The mobility of London's population, and the nature of TB as a disease, means that it is difficult for each CCG to plan ahead and commission TB services accurately. High annual levels of population churn and movement across different boroughs can make local needs assessments out of date. Taking a London-wide view and commissioning TB services at the city level could improve the quality of those services, make them more consistent across London and save money.
- 2.4 The existence of the NHS pan-London service specification in 2014-15 shows that the need for a consistent approach to TB control across all London CCGs has been recognised. The service specification sets out the main service requirements which all CCGs should ensure when commissioning clinical TB services. But to secure high-quality services, commissioners need to consider their local TB incidence and current and potential population demographics, (for example, new demands as a result of migration). London's population is highly mobile: millions of people study, work, and socialise well beyond the boundaries of the borough in which they live. And high annual levels of churn and movement across different boroughs can rapidly render accurate assessments of local need out of date.
- 2.5 Healthcare providers will need to carefully consider any changes to commissioning models, to ensure that a more unified approach still allows for innovation and is flexible enough to cater to local needs. But there have already been steps towards a more unified approach to key public health issues in London. The London Sexual Health Transformation Programme, a collaboration between twenty two London boroughs, aims to deliver a new collaborative commissioning model for sexual health genito-urinary medicine (GUM) to improve outcomes and efficiency.¹⁹ We think this model should be examined further in the context of TB control.

Commissioning community-based services

- 2.6 Other cities have taken a different attitude to TB control, by successfully focusing on prevention and community-based interventions rather than traditional hospital-based services. The voluntary sector has an invaluable role to play in the delivery of community-based TB services. Unlike statutory service providers, the voluntary sector provides models of provision and support that can work flexibly around the needs of patients. This is particularly true of people with complex lifestyles who may require more personalised interventions that can be co-ordinated with wider medical and social support. This can include providing a safe environment in which to take

medication, assistance with accommodation, mental health support, or help with expenses such as food or transport to clinics. We would welcome a commitment from the Mayor to look at ways in which voluntary organisations could be better supported in their efforts to compete for commissioning contracts to provide TB services.

- 2.7 Moving TB services from hospitals into community settings is only part of the solution. Community health providers also told us that there were more opportunities for a person-centred approach to healthcare through outreach services. This would make it easier to treat multiple health issues simultaneously, rather than expecting a patient to access different services for different conditions. The London Health Commission report looked at this in the context of homeless people. It concluded that there was a need to identify ways to ensure this more holistic approach. We would like to see this approach adopted, and extended to other at-risk groups. As one TB researcher told us:

“Tackling stigma and ensuring people understand what TB is and are aware of the symptoms and feel capable of seeking help for that, will need to be community-based and culturally relevant.”²⁰

- 2.8 London’s diverse charity sector has a deep understanding of the people they work with. They have the knowledge and experience to work in culturally sensitive ways to deliver health messages. The insight that frontline workers can provide into all aspects of TB control and care should be harnessed. The Mayor should encourage commissioners to work more closely with these organisations to develop the evidence for effective community-based services.

The need for outreach

- 2.9 We heard from TB doctors that, in the 21st century, the community work around TB can be more important than hospital-based work, as *“it does not matter how good the drug is if you are not making sure it is delivered to people and that people understand why they are taking it.”²¹*
- 2.10 One of the objectives of the Mayor’s health inequalities strategy is to ensure that all Londoners have the same opportunity to receive good quality healthcare. However, many Londoners are unable to access clinical services as easily as the majority of the population. People with ‘chaotic’ lifestyles due to homelessness, time spent in prison, mental health problems or substance abuse issues can find it all but impossible to access routine GP care. Even people without these complicating social factors can struggle, for example if they cannot take time off work to go to the doctor, or are carers for family

members. We heard from an experienced TB outreach worker in Hackney, who told us:

“Outreach work as a community initiative will only work if you go to people at the right place and critically, at the right time.”²²

- 2.11 To be truly effective, health services need to complement the ways that people actually live, not how we wish they would live. This is particularly true for infectious diseases like TB, where failure to ensure prompt diagnosis and manage a gruelling treatment schedule can allow the disease to spread more widely within communities.
- 2.12 Outreach services can also reduce the burden on hospital-based services and GPs. However, outreach is not universally available in all parts of London. We heard that Newham, which has the highest TB rates in the country, does not currently have an outreach team. In contrast, neighbouring Hackney has successfully reduced its TB caseload and improved treatment outcomes significantly through enlightened partnership working between its hospital services and outreach teams. Other boroughs have struggled to meet demand for outreach services due to a lack of resources.

Improving treatment outcomes through Directly Observed Therapy

Directly observed therapy (DOT) is a programme where a trained support worker visits a TB patient in a community setting and observes them taking their medication. This has been shown to be highly effective in ensuring that people take the full course of treatment effectively. DOT is recommended for patients who have complicating social factors that increase their risk of failing to complete a treatment programme. However, a shortage of resources has led to DOT not being available to patients in some areas. This increases the risk of treatment not being completed correctly, in turn increasing the risk of drug-resistant varieties of TB developing.

- 2.13 Effective outreach can have health benefits that extend far beyond TB control. Positive engagement with at-risk individuals provides a golden opportunity to address other social and medical factors which contribute to poor health. The very fact that TB treatment is a lengthy and involved process offers many opportunities to deal with issues such as substance abuse, homelessness and mental health problems. There is also the potential for mobile services to screen for, and provide advice on, other health conditions including diabetes, HIV and Hepatitis C. During our investigation we have looked at two pioneering services – Find & Treat and the London TB Extended

Contact Tracing team – which have the potential to significantly improve London’s TB situation.

Find & Treat

- 2.14 Find & Treat is a specialist outreach team that works alongside over 200 NHS and third sector front-line services to tackle TB among homeless people, drug or alcohol users, vulnerable migrants and people who have been in prison. The multidisciplinary team includes former TB patients who work as peer advocates. The Find & Treat mobile X-ray unit takes TB control to community settings, such as day centres, hostels and soup kitchens; finds cases of active TB early; and supports patients through treatment.
- 2.15 The service screens almost 10,000 high-risk people every year, covering every London borough. TB clinics and frontline third sector partners across London and nationally refer around 300 complex and socially vulnerable patients a year to the outreach team.
- 2.16 Both the National Institute for Health and Clinical Excellence and the Health Protection Agency independently evaluated the service and demonstrated Find & Treat to be highly cost effective. The service costs around £0.9million a year in London – less than it costs to treat 20 drug-resistant cases.
- 2.17 The national strategy has acknowledged the success of the Find & Treat model and has included expansion of the service nationally as an area of new investment. However, it is not yet clear how much funding has been set aside to develop the service in London. Increasing the capacity of the Find & Treat service could potentially allow the service to expand its work with other vulnerable groups, such as prisoners.

TB in prisons

Prisoners are at increased risk of TB. Many prisoners in London have one or more social risk factors for TB, and the close confines of the prison environment can make transmission of active TB easier. Although most London prisons have digital X-ray machines, we have heard concerns about how effectively prison authorities are using them. We also heard that some of these facilities were not currently operational, and that staffing and resources were thinly stretched. Public Health England has identified a number of challenges for prison services:

- Identification of cases
- Diagnosis
- Isolation of confirmed and suspected cases
- Under-reporting of cases
- Limited in-house TB expertise and awareness
- Constraints of prison regime
- Loss to follow up on release
- Fear and stigma
- Poor access to information²³

Prisons represent a wasted opportunity not only to identify and treat TB cases, but to educate people about the disease before they go back into the community. We strongly urge prison authorities in London to review their approach to TB. We would also like to see further research on the health of prisoners in London as part of Mayoral efforts to reduce health inequalities.

Contact tracing

- 2.18 Once someone is diagnosed with TB, it is important to screen their close contacts to ensure that the disease has not been passed on to them. Close contacts are most often family members, but could also include work colleagues or fellow students. For people who live in difficult circumstances, such as rough sleepers, sex workers, or undocumented migrants, it can be very difficult to trace contacts. Contact tracing is further complicated by the stigmatisation of people with the disease:

“People do not know who they have infected. If they did they would not want to tell me. If they did tell me, I cannot find them. If I find them, they tell me where to go.”²⁴

- 2.19 The award-winning London TB Extended Contact Tracing team's (LTBEx) contact tracing service carries out mass screenings in response to local outbreaks of TB, where there is a risk of onward transmission beyond household contacts. The service is effective because it takes screening directly into community settings, such as schools and workplaces. This enables the LTBEx team to screen large numbers of contacts quickly, reducing pressure on TB clinics and speeding up diagnosis. The service also provides a valuable opportunity to raise awareness and challenge misconceptions about TB. LTBEx is able to screen hundreds of people in a single day – a task that would take local TB clinics several weeks to cope with demand on this scale. The service also ensures uniformity of service. Prior to LTBEx, contact tracing was carried out by individual clinics and health protection teams, with varying service standards. They also maintain the only contact tracing database in London, and the team is currently developing the first standardised model for TB contact risk assessment. The service provides an important interface between public health and clinical services.
- 2.20 LTBEx is a highly innovative and successful service, but faces an uncertain future. Although it has been acknowledged as an effective intervention by the World Health Organisation, and contact tracing is specifically included as a component of the national TB strategy, its funding is not secure. LTBEx costs £0.25million a year to run – less than one per cent of the annual spend on TB in London. But without a firm commitment to funding the programme in the future, the requirements for contact tracing in London would revert back to Health Protection Teams and TB clinics. This would place a significant resource burden on these services. It would also risk a return to more variable levels of service provision. An established and valuable resource which provides education and workforce development alongside effective mass screening is on the brink of being lost. We would like to see this service retained and its funding secured, particularly in light of the service's role in reducing the burden on TB clinics.

Vaccination

- 2.21 BCG vaccination against TB is currently recommended for all babies born in London. However, although this universal policy exists, we heard that only 24 out of 32 London CCGs are offering the vaccination.²⁵ This potentially risks the health of children who are born in low incidence boroughs but subsequently move to higher incidence areas. Selective immunisation policies can also contribute to further stigmatisation of the disease. TB nurses told us that the universal policy is 'definitely the way forward'.²⁶ TB vaccination for new-borns

is included in the maternity funding tariff, and could therefore be offered to babies at no additional cost to CCGs.²⁷

- 2.22 It is unacceptable that children are put at risk of developing a potentially life threatening illness on the basis of which borough they are born in. NHS London needs to act swiftly to identify the barriers that are preventing implementation of the universal policy.

Limitations of the vaccine

- 2.23 Our survey found that over half of Londoners thought that a vaccine exists that is 100 per cent effective against infectious TB. Unfortunately, there is no such vaccine. The BCG vaccine, which was developed over eighty years ago, provides good protection against the most severe forms of childhood TB, such as TB meningitis, but is much less effective in adults and offers much lower protection against pulmonary (infectious) TB. Crucially, it also does not prevent the reactivation of latent TB.
- 2.24 The results of our survey also showed that people were more likely to take up the offer of TB screening if they had not previously been vaccinated against TB. This is a potential headache for the health services: improving vaccination is a vital component of the national strategy, but this finding suggests that it may also create the false belief that vaccinated people are immune to TB. This could, in turn, encourage at-risk individuals to turn down the offer of a TB screening. Public health authorities will need to find a way to improve people's understanding of both the benefits and the limitations of childhood vaccination.

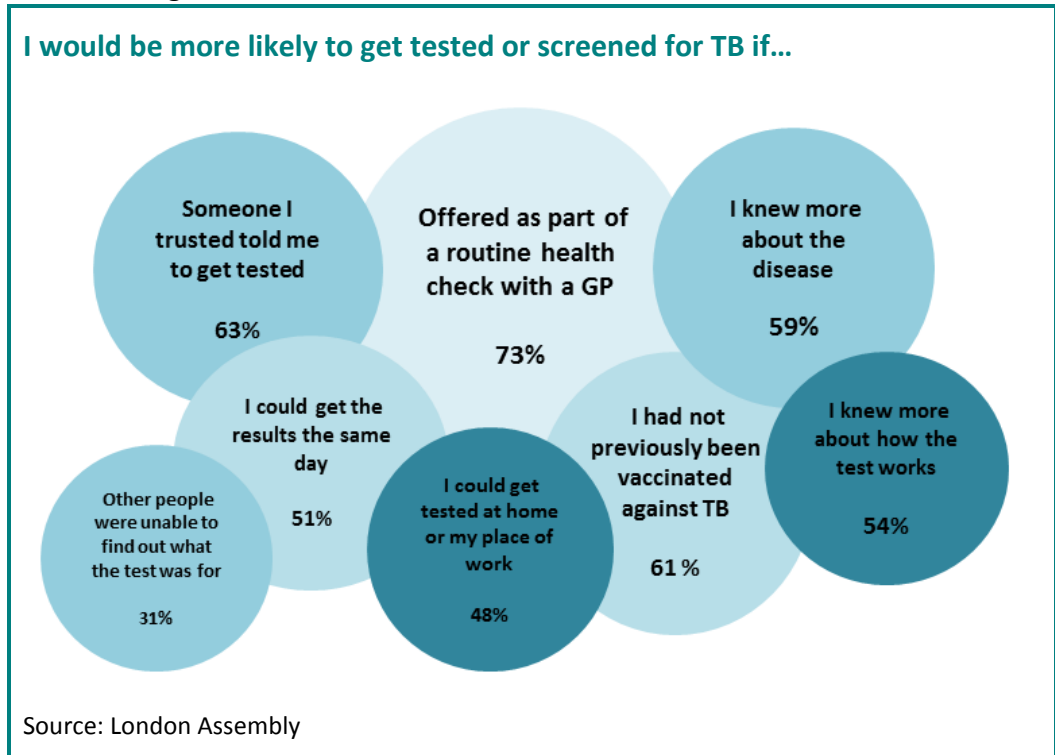
Recommendation 2

NHS London should, in response to this report, set out how it plans to ensure universal BCG coverage across all London boroughs by 2017. Public Health England should consider what steps can be taken to educate the public about the benefits and limitations of the BCG vaccine.

Latent screening

- 2.25 The majority of the new funding (£8.35 million of the £10million national funding) available through the national TB strategy is earmarked for identifying and treating people with latent TB infection before they develop TB disease. The programme will focus on those patients registered with GPs who are identified as high risk.
- 2.26 Broadly, London's population falls behind the national average in the uptake of screening for a range of health conditions. Our survey found that there

were a number of factors which might encourage people to take up the offer of screening.



- 2.27 The messaging around latent TB is challenging. It can be difficult for doctors to persuade people to undergo treatment – and suffer unpleasant side effects – for an infection when they don’t feel unwell, and which may or may not develop into active TB in the future. This is another reason why it is important to develop public understanding of the nature of TB infection and the potentially serious consequences as part of efforts to increase screening uptake in high-risk populations.
- 2.28 There are some concerns that focusing efforts on latent TB screening through GPs will not reach under-served groups, who typically find it more difficult to access GP services. Our recent report into access to GP care highlighted a number of challenges in providing equitable access to GP services in London.²⁸ The challenges are particularly acute for homeless people, recently-arrived migrants, people with mental health problems, and people who live in poverty – groups which we know have the highest TB burden in London.
- 2.29 Some TB doctors have also questioned the focus on latent TB screening, suggesting that this is a continuation of the clinical-based service model that will do little to address the needs of people who are not engaged with health services:

“Let us not allow the current emphasis on [latent TB infection] screening to detract from the two most important things necessary to control TB, and that is finding people with active disease as soon as possible through seamless services, referrals from general practice... and active case finding in risk groups where necessary, and comprehensive investigation of their contacts.”²⁹

- 2.30 We consider the use of targeted latent TB screening as a useful additional weapon in the fight against TB. However, as the national strategy acknowledges, it is just one of a range of tools that will be needed. Investment in services which reduce the need for hospital-based care have the potential to realise considerable savings in the long term. It is vital that funding is secured to ensure that crucial community-based projects can be maintained. The Mayor and local government have a vital role to play in supporting the non-clinical interventions needed to reduce TB across London.

3. What can London's Mayor do?

Only by addressing the wider social factors behind ill health will TB in London be reduced – relying just on clinical services will not be enough. Measures to improve housing and reduce poverty will be vital, as part of a “health in all policies” approach. TB is very much a barometer for health inequality in London, and should be viewed as a key indicator for the success or failure of the Mayor’s Health Inequalities strategy. Unless these underlying social issues are tackled, it is unlikely that the national TB strategy will be effective in London.

The Mayor is uniquely placed to lead the drive to reduce TB in London. He can directly make policy interventions in areas such as housing, transport and community relations. He can also lobby the NHS and local and national government to promote the cause of TB and ensure it receives the attention and funding it requires. Inaction now increases the risk of TB to Londoners, and will make it harder – and more expensive – to tackle TB in the years to come.

- 3.1 The national TB strategy, launched by Public Health England in January 2015, sets out ten objectives needed to tackle TB. It will be harder to achieve these if London’s health inequalities are not also addressed. In 2010, the Mayor published his Health Inequalities Strategy (HIS) setting out a number of strategic objectives and measures to achieve them. As the graphic on the next page shows, the national TB strategy and the HIS are intrinsically linked. Implementing the HIS will be vital for the national TB strategy to be effective in London.

The success of the national TB strategy in London will depend on achieving the aims of the Mayor’s Health Inequalities strategy

The Mayor’s Health Inequalities Strategy

- Empowering communities and individuals
- Equitable access to high-quality health and social care services
- Income inequality and health
- Health, work and wellbeing
- Healthy Places
- Regional vision and leadership
- Build the evidence base and economic case for action
- Develop local leadership to influence and ensure action
- Health in all policies

Objectives of the national TB strategy

- Improve access to services and ensure early diagnosis
- Provide universal access to high quality diagnostics
- Improve treatment and care services
- Ensure comprehensive contact tracing
- Improve BCG Vaccination uptake
- Reduce drug-resistant TB
- Tackle TB in under-served populations
- Systematically implement new entrant latent TB (LTBI) screening
- Strengthen surveillance and monitoring
- Ensure an appropriate workforce to deliver TB control



Funding the strategy

3.2 Implementing the national TB strategy in London is not being helped by the ongoing uncertainty over funding. At the national level, funding has not been confirmed beyond the initial investment of £10 million for 2015/2016.³⁰ Of this, it is not clear how much London will receive: NHS colleagues told us that it is ‘assumed’ that the funds will be allocated proportionally according to case notification, so London should receive approximately £4 million. We are concerned that a lack of financial certainty will make it harder to ensure continuity and that some elements of the strategy may not receive the resources they require.

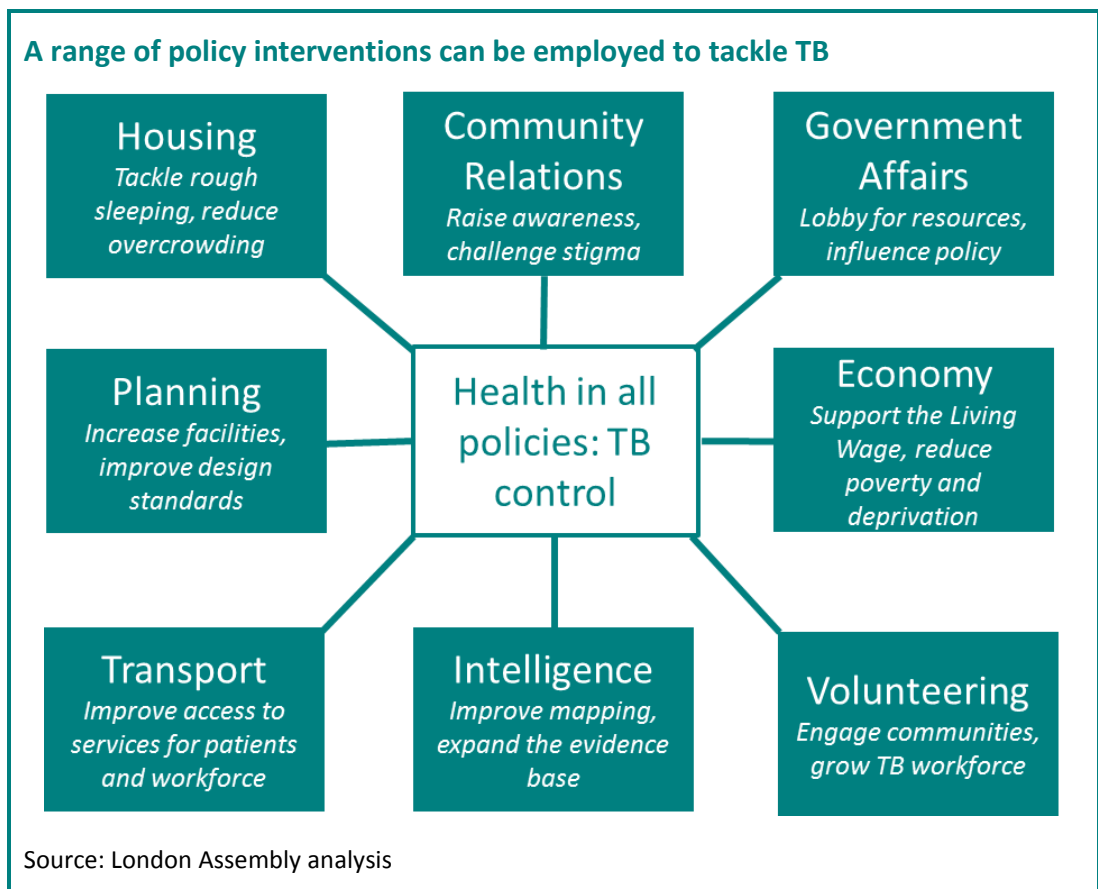
- 3.3 One of the Mayor's commitments in his Health Inequalities Strategy is to *"lobby for a fair share of resources for London's health and social care services and increase investment in public health [and] prevention."* We would like to see this Mayor, and the next, uphold this commitment, by making the case for more funding stability for services that have been proved to be effective in tackling London's TB problem. We heard from Find & Treat and LTBE that there was more that they could do, if funding was secured. This includes extending services to screen for other health conditions, such as Hepatitis C; further resources to help educate and raise awareness; and workforce development, to strengthen the interface between clinical and public health services. The national strategy sets out a five year approach to combatting TB nationally. It would be a retrograde step if services like LTBE and Find & Treat were curtailed or restricted by funding uncertainty.

Recommendation 3

The Mayor should make the business case to Government for funding to maintain and potentially expand the London Find & Treat service and the London TB Extended contact tracing team. Funding should be secured until 2020 as a minimum, in line with the lifetime of the national TB strategy.

Health in all policies

- 3.4 TB cannot be controlled without dealing with the wider social determinants of ill health. In this respect, TB provides a litmus test for the Mayor's Health Inequalities Delivery plan, which is based on the concept of 'health in all policies'. The Mayor has a key role to play, by ensuring that policy in all areas under his direct control reflects a commitment to improving health outcomes and reducing inequality.
- 3.5 There are a broad range of interlocking policy areas that can have a positive impact on TB control and management in London. As Dr Marc Lipman told us, *"the medicine is relatively easy, apart from drug resistance. What is really key is the bigger picture"*.³¹



- 3.6 Enacting a health in all policies approach will have lasting benefits to the wider health of the city as a whole. And, as we set out below, there are some policy areas that could have a particular impact on TB rates in London.

Housing

- 3.7 One in ten TB patients in London is homeless or vulnerably housed. Homeless people are at particular risk from TB. They are more likely to be exposed to TB bacteria in hostel-based accommodation or settings where homeless people gather to sleep. The stresses to the immune system associated with homelessness – such as rough sleeping, poor nutrition, being cold, and, in some cases, mental health issues or substance abuse – then increase the likelihood that someone exposed to TB bacteria will go on to develop the disease.
- 3.8 Homeless people, like any other population group, may not recognise the symptoms of TB. They may also assume the symptoms are simply the impact of their life on their health, and delay seeking help. They may also be less able to access healthcare services because they are not registered with a GP, or

because their circumstances make it difficult to attend appointments. We heard from a variety of TB experts that:

“Homelessness is the greatest impediment to successful completion of treatment.”³²

- 3.9 The outcomes for homeless TB patients who are ineligible for local authority housing are poor. They often drop out of treatment, risking the reactivation of the disease and the development of drug resistance. They are also more likely to infect others – an average of between six and twelve additional cases – which leads to exponential rises in treatment costs.
- 3.10 The Mayor already commissions a number of pan-London rough sleeping services. This offers an excellent opportunity to embed TB control in these programmes and provide integrated healthcare options. However, we have heard that there has been some difficulty in getting these services to engage with outreach organisations like Find & Treat. We would like to see an explicit focus on TB as part of the delivery of these existing services, including TB awareness training for frontline staff who work in assessment hubs for programmes like No Second Night Out.

Recommendation 4

The GLA should explicitly consider provision of TB services as part of its commissioning of pan-London rough sleeping services.

- 3.11 We heard from TB stakeholders that improving access to good quality housing was one of the single most useful things the Mayor could do to contribute to better TB outcomes for London. The benefits extend not only to the health of the individuals concerned, but more widely to the health of the city as a whole, by:
- Making it easier for people to manage and complete a complex treatment regime, therefore reducing the wider risk of drug-resistant strains emerging.
 - Lowering the high costs to the NHS of admitting patients to hospital because they have nowhere else to go.
 - Reducing onward transmission of cases between people who live in overcrowded conditions.
- 3.12 If a patient cannot receive adequate community support and housing, there will be little alternative for TB services other than to admit them to hospital and keep them there for the duration of treatment. This type of ‘bed blocking’

places significant financial strain upon the NHS. There have been cases in which TB patients have remained in hospital unnecessarily for weeks or even months because there was no community support available.

Providing housing to TB patients improves their chances of completing treatment

Since 2009, Homerton Hospital TB team has worked in partnership with the London Borough of Hackney housing department to house homeless people with no recourse to public funds in local temporary accommodation. They have done so by establishing a service level agreement (SLA) which is paid for by City of London and Hackney local authorities. The service has housed 33 patients from 19 different countries, as well as their partners and children when necessary. All patients are on Directly Observed Therapy (DOT), and are given monthly bus passes and food, as well as receiving help with health, psychological and social problems, benefit and asylum applications, and other needs. Since the scheme started, 100 per cent of its patients have completed treatment, and none has been lost to follow up.

- 3.13 A hospital bed in London costs around £500 per day³³. We heard that a week in temporary accommodation could therefore be cheaper than a single day in hospital inpatient care. The NHS London TB service specification acknowledges that providing temporary accommodation *“will save the commissioner funds especially where the alternative is to keep the patient in an acute hospital bed”*.³⁴
- 3.14 The struggle to house ineligible TB patients is common to all TB services in London. Homeless people and rough sleepers are a transitory population, making homelessness a London-wide issue that local authorities cannot tackle individually. It therefore demands a pan-London approach. The success of the Homerton TB SLA reinforces the argument that investing in accommodation resources for homeless TB patients across London would be both humane and cost effective. We would like to see more London boroughs explore this model.

Recommendation 5

In response to this report, the GLA should:

- **Assess the policy – as implemented in Hackney – of housing homeless TB patients for the duration of their treatment, and determine if other boroughs could implement this policy.**
- **Set out how it could encourage other boroughs to adopt a similar approach.**

As we have seen, there are a number of further mayoral policy areas which could directly contribute to better TB control and management in London.

Intelligence

- 3.15 Previous mapping of TB in London has tended to focus on standard indices such as overcrowding, ethnicity and deprivation. However, we heard that there were significant opportunities to use data to develop a more sophisticated picture of the underlying social issues that contribute to TB.
- 3.16 People who work directly with under-served and marginalised groups are likely to be the first people who recognise changes to the TB situation in London. But it can be difficult to corroborate their findings with the evidence that is needed to ensure the most appropriate services are commissioned. Using a wider range of local authority data (see box below) and examining trends in the data over time, should help to create a more detailed picture of the social determinants of ill health. Mapping these factors against TB incidence should also provide more robust information on where and how to target interventions.

Are we exporting TB to the suburbs?

Some frontline TB workers have hypothesised that, as people are priced out of living in inner London, the current geographical hotspots for TB may change. This is an interesting theory, with implications for local clinical services. Mapping data on rental costs, house prices and the movement of populations across borough boundaries against trends in TB incidence may provide insight on this issue.

- 3.17 The GLA holds a vast quantity of relevant data through the London Datastore. We would like to see the GLA reach out to health informatics specialists to explore ways to make this data more widely accessible. Visually mapping data on the social determinants of ill health can help to communicate the need for the ‘health in all policies’ approach that underpins the Mayor’s health inequalities strategy. TB, with its complex social factors, is a perfect case study for this approach. But it is not the only disease or condition that could

benefit from this type of work. Building a greater understanding of the correlations between social factors and specific health conditions will be a valuable tool for all public health work in London.

Recommendation 6

The GLA Intelligence Unit should work in collaboration with TB researchers and epidemiologists to determine how to map new and existing data on the social risk factors for TB in London.

Community relations

- 3.18 People with TB told us they valued the opportunity to speak to people who had directly experienced the disease themselves. This type of ‘peer advocacy’ can be a valuable outreach and engagement tool, helping to increase awareness and tackle stigma. The views and experiences of people who have recovered from TB are also an important source of information on how to make TB services better:

“It needs narrative, it needs word of mouth...it needs people who can provide a living experience. It needs people who can actually be not only living proof that TB is curable and there is light at the end of the tunnel, ... [but] who have first-hand experience of actually trying to access services and complete treatment.”³⁵

- 3.19 Other cities, including New York, have successfully used volunteers to help people access TB services and support people with TB through the treatment process. We would like to see local authorities work more closely with local Healthwatch groups and volunteers to make use of this resource when considering ways to raise community awareness. The Mayor could also usefully highlight the work of community health champions and volunteers through Team London, the Mayoral volunteering programme. The existing network of volunteers is already embedded within local communities.

Recommendation 7

The Mayor should examine the feasibility of using the existing Team London volunteer network as TB community health champions.

- 3.20 The Mayor appointed the actor Emma Thompson as his TB ‘Ambassador’ in January 2015. This follows similar celebrity appointments to raise awareness of other health issues in London, including HIV/AIDS and breast cancer. The appointment of a high profile ambassador is symbolically important in placing TB on the political agenda. However, the ongoing role of these health

ambassadors in the next mayoralty is not clear. We support the principle of health ambassadors and are grateful to Emma Thompson for her personal commitment to better TB outcomes in London. The interest in her appointment provides a welcome counterpoint to the often negative portrayals of TB in the media. We would now like to see other influential figures take up this type of role. Influential in this context does not necessarily have to mean famous. Before any other health ambassadors are appointed, the Mayor needs to think carefully about which groups need to be engaged and influenced, and who these people would respond to.

- 3.21 City Hall has previously hosted event to raise awareness of health conditions, particularly HIV. For example, City Hall hosted a reception in 2012 to thank London stakeholders for their 30 years of efforts in tackling HIV, and has more recently held public exhibitions of artwork connected to HIV. We think similar awareness raising efforts around TB at City Hall would send a positive message that the Mayor is serious about tackling the disease in London. The Mayor could also look further afield to cities such as New York, which hosts an annual TB walk to raise awareness. Such events will help ensure that TB remains an issue in the public eye. London events could usefully be co-ordinated with wider awareness raising activity linked to World TB Day.

Recommendation 8

The next Mayor should work with the Health team to explore options to continue and expand the role of London TB Ambassadors. City Hall should also host an awareness event to coincide with World TB Day.

Government affairs

- 3.22 If implemented properly, the national TB strategy could have a significant impact in the fight against TB. However, the charity TB Alert has expressed some concern that action at a national level is not necessarily being reflected in regional and local health priorities. The Public Health Minister Jane Ellison highlighted this concern at a summit for high-incidence boroughs in March 2015:

“While your communities are among those with the highest rates of infections and therefore of onward transmission, it appears that some of you do not have TB (or Hepatitis C) on your Joint Strategic Needs Assessments (JSNA). I think we need a stronger focus on prevention.”³⁶

- 3.23 Local authorities, however, are having to deal with cuts to their public health grant from the Government. In June, the Treasury announced that the

2015/16 public health grant to local authorities would be reduced by £200million. The King's Fund has described the reduction in public health spending as 'the falsest of false economies', arguing that it will undermine prevention efforts. Local authorities told us they are increasingly feeling the pressure. The London Borough of Newham, which has the highest TB rates in the country, has called on the Mayor to champion TB in the Government's Spending Review to be announced in November 2015.³⁷

- 3.24 It is vital to the success of the national TB strategy that local government recognises both the moral and economic incentives of investment in TB control and management. Failure to prevent community transmission and tackle drug resistance will result in greater expenditure in later years, with more people requiring more expensive treatment and lengthy stays in hospital.
- 3.25 Beyond this, local government has a critical role in tackling the wider social determinants of TB. We heard that the transfer of public health budgets to local authorities in 2013 had presented "*a wonderful opportunity for much more joined-up working with social services and housing and other services*".³⁸ However, we also heard that there was considerable variation in terms of how London boroughs engaged with TB issues and that results were better in boroughs where local authorities had taken a more integrated approach to TB services.
- 3.26 One example of variation between boroughs is in the use of cohort review – a systematic audit of TB cases and their treatment outcomes. This is an opportunity for everyone involved in TB care to reflect and learn, thereby promoting good practice and identifying gaps in service. Cohort review was pioneered in London and is now a national mandatory requirement for TB services. CCGs and local authorities are invited to attend these meetings, and we heard that this had significant benefits in improving the interface between public health and clinical services, as well as ensuring that local authorities and CCGs were fully aware of the TB needs of their local communities. However, we also heard that attendance by local authorities at cohort review meetings was patchy across London:

*"Some do not ever come despite being invited every time... If we have the CCGs and local authorities in that room when they can hear what is going on about TB in their patch and what the issues are that people face...then the engagement will be better... We cannot, as clinicians, nurses and doctors, address them on our own."*³⁹

- 3.27 Decision makers and commissioners should take the opportunity afforded by cohort review to learn first-hand about the challenges for managing TB in their local areas. This will help ensure that services truly reflect local needs.
- 3.28 A unified, pan-London approach to tackling TB will require unified, pan-London leadership and strategic focus. The Mayor is uniquely placed to head up these efforts. The Mayor's response to the London Health Commission's report acknowledges that the Mayoralty is "uniquely placed to convene and galvanise action."⁴⁰ It is time for this Mayor – and whoever becomes the next Mayor – to use their political influence to ensure that London faces up to its public health challenges head on. The London Health Commission identified the need for a controlling mind to oversee efforts to tackle health inequality: the Mayor, in the role of strategic convenor and influencer, should be active in ensuring that London's local authorities recognise the critical importance of addressing TB on a citywide scale. The Mayor's regular meetings with London local authority leaders through the London Congress provide the ideal opportunity to promote the issue of TB. London's Mayor must work with their political counterparts to ensure that all London boroughs are united in a commitment to deliver the national TB strategy in London.

Recommendation 9

The Mayor, in his capacity of strategic convenor, should use his influence through the London Congress to promote TB control and management across London, ensuring every London borough attends cohort review and includes TB as part of its health and wellbeing strategy.

- 3.29 The London Health Commission's report, *Better Health for Londoners*, recommended that the Mayor should appoint a London Health Commissioner to champion health in the capital. The London Assembly has recently echoed this call in its report on devolution, *A New Agreement for London*.⁴¹ Making such a commissioner accountable for TB in London would help to ensure an ongoing focus on tackling the disease and allow for democratic oversight of the delivery of the national strategy. The Mayor, in his response to the Commission, accepted the need for strategic leadership in public health.⁴² The advocacy group Results UK, which works with the All-Party Parliamentary Group on Global TB, told us:

*"Accountability is key. If a high profile, preferably elected, individual is shown to have responsibility for the disease, it will help to break through bureaucratic and commissioning barriers."*⁴³

- 3.30 We agree that political leadership is key to ensuring ongoing and meaningful engagement on the complex and multi-faceted issues which contribute to London's poor record on TB control. The Mayor, or a direct appointee of the Mayor, would be uniquely well placed to draw together the various agencies that will need to collaborate effectively to deliver the strategy.
- 3.31 As a major world city, London can lead the way in global efforts to tackle TB. We would welcome a clear statement of intent from the Mayor that this city will take up the challenge.

Barcelona Declaration

The Barcelona Declaration is an initiative of the Global TB Caucus, which was formed in 2014. It is a representation of the worldwide political commitment to end the TB epidemic and a challenge to civil society to help educate and engage political colleagues about the disease.

The declaration includes a commitment to "use all the means at our disposal to urge sustained action from our governments, to secure the necessary international and domestic resources to combat TB, and to press for the prioritisation of the disease on political agendas."⁴⁴

A number of UK and London parliamentarians have already signed the declaration, through the efforts of the All Party Parliamentary Group on TB. We would like to see the commitment to the aims and objectives of the Barcelona Declaration reflected across London at all levels of government.

Recommendation 10

London's Mayor should assume political ownership of TB control in the capital. This should include Mayoral/senior political representation on the London TB Control Board.

Monitoring the strategy

- 3.32 As we have seen, there is no silver bullet for TB control and management in London. No single element of the national strategy will tackle the disease on its own. The full range of interventions will need to be applied consistently across London. They will also need to be monitored closely. The London TB Control Board should, in theory, be well placed to do this; however, there has been some suggestion from stakeholders that the progress of the Board should be open to more public scrutiny, to ensure the strategy is delivered in the way that it is intended.

3.33 The London Health Board, chaired by the Mayor, is tasked with driving improvements in London's health, care and health inequalities where political engagement at this level can uniquely make a difference. The Board is a strategic partnership between the Mayor's office, elected leaders and key London health leads. We would like to see the Board be given responsibility for monitoring the delivery of the national TB strategy in London and to report back to the Health Committee so that we can continue to review progress on this important issue. This will be particularly critical in evaluating the success of non-clinical services.

Recommendation 11

Progress on the delivery of each element of the national TB strategy should be reported to the London Health Board annually by the NHS/Public Health England. The GLA should include TB incidence as an indicator in the Mayoral Health Inequalities Strategy.

Conclusion

TB is not yet a disease of the past in London, but it doesn't have to be a disease of the future. It is important to keep infectious diseases like TB under constant surveillance, or, in the words of one TB doctor, "*we find the bugs getting the better of us.*" This means that action needs to start now and continue into the next Mayoralty.

The commitment and dedication shown by frontline workers treating TB must be matched by similar levels of commitment and focus from politicians in preventing TB. The national TB strategy provides a clear blueprint for what needs to be done, but tackling TB in London will take a sustained effort throughout the five years of the strategy's life cycle and beyond. The Mayor, as a leading spokesperson and advocate for London, is uniquely well placed to influence the debate around TB. Mayoral strategies for the growth and development of London must truly reflect the concept of health in all policies. Above all, the Mayor – and future Mayors – must play their part in reducing the health inequalities that persist in London, and ensure that all Londoners have access to high quality services that support their individual needs. Reducing the TB burden will be a real sign that London is on the path to becoming a healthier, fairer city.

Appendix 1 – Recommendations

1. The Mayor, in conjunction with the third sector and Public Health England, should develop and deliver a London-wide programme to educate the general public about how TB is spread, and its symptoms.
2. NHS London should, in response to this report, set out how it plans to ensure universal BCG coverage across all London boroughs by 2017. Public Health England should consider what steps can be taken to educate the public about the benefits and limitations of the BCG vaccine.
3. The Mayor should make the case to Government for funding to maintain and potentially expand the London Find & Treat service and the London TB Extended Contact Tracing team. Funding should be secured until 2020 as a minimum, in line with the lifetime of the national TB strategy.
4. The GLA should explicitly consider provision of TB services as part of its commissioning of pan-London rough sleeping services.
5. In response to this report, the GLA should:
 - Assess the policy – as implemented in Hackney – of housing homeless TB patients for the duration of their treatment, and determine if other boroughs could implement this policy.
 - Set out how it could encourage other boroughs to adopt a similar approach.
6. The GLA Intelligence Unit should work in collaboration with TB researchers and epidemiologists to determine how to map new and existing data on the social risk factors for TB in London.
7. The Mayor should examine the feasibility of using the existing Team London volunteer network as TB community health champions.

8. The next Mayor should work with the Health team to explore options to continue and expand the role of London TB Ambassadors. City Hall should also host an awareness event to coincide with World TB Day.
9. The Mayor, in his capacity of strategic convenor, should use his influence through the London Congress to promote TB control and management across London, ensuring every London borough attends cohort review and includes TB as part of its health and wellbeing strategy.
10. London's Mayor should assume political accountability for TB control in the capital. This should include Mayoral/senior political representation on the London TB Control Board.
11. Progress on the delivery of each element of the national TB strategy should be reported to the London Health Board annually by the NHS/Public Health England. The GLA should include TB incidence as an indicator in the Mayoral Health Inequalities Strategy.

Appendix 2 – How the review was carried out

The Committee conducted a site visit to the Whittington Hospital TB centre on 4 March 2015 and spoke with clinicians and patients about their experiences.

The Committee held two public evidence sessions to collect evidence to inform its investigation.

On 24 June 2015, it heard evidence from:

- Yvonne Doyle, London Regional Director, Public Health England
- Lynn Altass, National TB Strategy Implementation Manager, NHS England
- Dr Marc Lipman, Consultant Physician, Royal Free Hospital
- Jacqui White, Lead Nurse, North Central London TB service

On 8 July 2015, it heard evidence from:

- Dr Sue Collinson, TB Outreach worker, Homerton Hospital
- Dr Alistair Story, Clinical lead, Find & Treat Service
- Dr Jessica Potter, Medical Research Council Fellow, Queen Mary University of London
- Steve Bradley, Patient Advocate, TB Action Group

During the investigation, the Committee received written submissions from the following organisations:

- NHS England
- London TB Extended Contact Tracing team (LTBEx)
- Results UK
- TB Alert
- St Mungo's Broadway
- Public Health England (PHE)
- London Borough of Newham

- London Borough of Ealing
- London Borough of Hackney
- London Borough of Brent
- London Borough of Westminster

The Committee also received written information from former TB patients.

The Committee commissioned ComRes to conduct a survey of 1,006 Londoners on awareness and perceptions of TB. The full results of the report can be found at www.london.gov.uk

Appendix 3 – Endnotes

- ¹ [PHE Worldwide TB Surveillance 2013 Data High and Low Incidence](#)
- ² [WHO factsheet 2015](#)
- ³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/360335/TB_Annual_report__4_0_300914.pdf
- ⁴ Public Health England written submission, July 2015
- ⁵ Public Health England written submission, July 2015
- ⁶ <http://www.tbalert.org/about-tb/global-tb-challenges/stigma-myths/>
- ⁷ [The Barcelona Declaration, Global TB caucus](#)
- ⁸ Yvonne Doyle, London Regional Director, Public Health England, transcript of London Assembly Health Committee meeting, 24 June 2015
- ⁹ [Mayor's Health Inequalities Strategy 2010](#)
- ¹⁰ Ibid, foreword.
- ¹¹ [Public Health England TB monitoring data](#)
- ¹² Written submission from TB patient, July 2015
- ¹³ Dr Jessica Potter, Medical Research Council Research fellow, Queen Mary University of London, transcript of London Assembly Health Committee meeting, 8 July 2015
- ¹⁴ Public Health England written submission, July 2015
- ¹⁵ Lynn Altass, National TB strategy Implementation manager NHS England, transcript of London Assembly Health Committee meeting, 24 June 2015
- ¹⁶ Dr Alistair Story, UCLH, transcript of London Assembly Health Committee meeting, 8 July 2015
- ¹⁷ Ibid. The number of cases of TB compared to other European cities is striking: Amsterdam (143 cases); Rotterdam (128); Paris (525); Barcelona (393); London (3440) [2009 figures provided by NHS England]
- ¹⁸ <https://www.brit-thoracic.org.uk/document-library/clinical-information/tuberculosis/defining-a-model-for-a-gold-standards-for-a-tb-mdt-group-and-associated-networks/>
- ¹⁹ <http://www.londoncouncils.gov.uk/node/27554>
- ²⁰ Dr Jessica Potter, Medical Research Council Research fellow, Queen Mary University of London, transcript of London Assembly Health Committee meeting, 8 July 2015
- ²¹ Dr Marc Lipman, Consultant Physician, Royal Free Hospital, transcript of London Assembly Health Committee meeting, 24 June 2015
- ²² Dr Sue Collinson, Tuberculosis Outreach worker, Homerton hospital, transcript of London Assembly Health Committee meeting, 8 July 2015
- ²³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/328660/TB_guidance_for_HPTs_July_2014.pdf
- ²⁴ Dr Alistair Story, UCLH, transcript of London Assembly Health Committee meeting, 8 July 2015
- ²⁵ NHS England written information, September 2015
- ²⁶ Jacqui White, Lead Nurse, North Central London TB service, transcript of London Assembly Health Committee meeting, 24 June 2015
- ²⁷ Lynn Altass, National TB strategy implementation manager, NHS England, transcript of London Assembly Health Committee meeting, 24 June 2015
- ²⁸ <https://www.london.gov.uk/mayor-assembly/london-assembly/publications/access-to-gp-care>
- ²⁹ Dr Alistair Story, UCLH, transcript of London Assembly Health Committee meeting, 8 July 2015
- ³⁰ NHS England written information, September 2015

- ³¹ Dr Marc Lipman, Consultant Physician, Royal Free Hospital, transcript of London Assembly Health Committee meeting ,24 June 2015
- ³² Dr Sue Collinson, Tuberculosis Outreach worker, Homerton hospital, transcript of London Assembly Health Committee meeting, 8 July 2015
- ³³ [Journal of Public Health April 2015](#)
- ³⁴ London TB service specification v4 (2014) provided by Public Health England, October 2015
- ³⁵ Dr Alistair Story, UCLH, transcript of London Assembly Health Committee meeting, 8 July 2015
- ³⁶ <https://www.gov.uk/government/speeches/helping-local-authorities-to-reduce-tb-and-hepatitis-c>
- ³⁷ London Borough of Newham, written submission, July 2015
- ³⁸ Dr Sue Collinson, Tuberculosis Outreach worker, Homerton hospital, transcript of London Assembly Health Committee meeting, 8 July 2015
- ³⁹ Dr Jessica Potter, Medical Research Council Research fellow, Queen Mary University of London, transcript of London Assembly Health Committee meeting , 8 July 2015
- ⁴⁰ Dr Alistair Story, UCLH, transcript of London Assembly Health Committee meeting, 8 July 2015
- ⁴¹ https://www.london.gov.uk/sites/default/files/A%20New%20Agreement%20for%20London_1.pdf
- ⁴² <https://www.london.gov.uk/sites/default/files/Mayor%27s%20response%20to%20LHC%20Feb%202015.pdf>
- ⁴³ RESULTS UK written submission July 2015
- ⁴⁴ The Barcelona Declaration <http://www.globaltbcaucus.org/#!declaration/c1n8o>

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