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PHE London's response to the London Assembly Health Committee investigation into Tuberculosis in London 2015

Please find below a response from PHE London to the key questions posed by the London Assembly Health Committee to support their investigation into Tuberculosis in London.

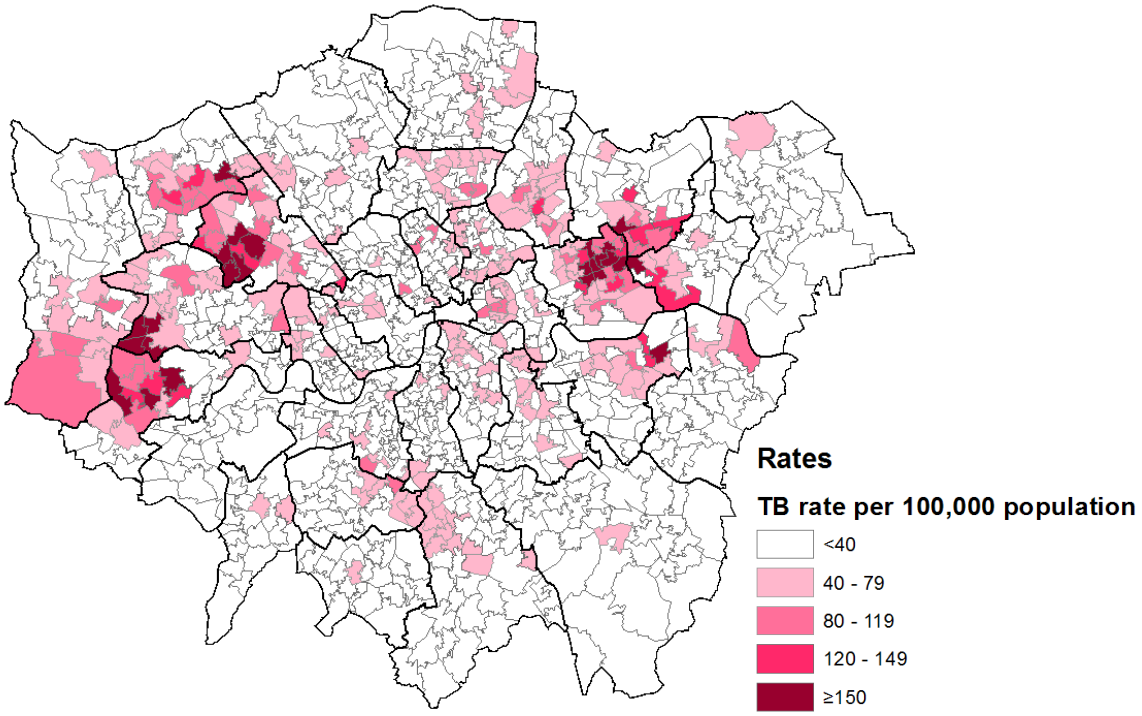
Why is it important to focus on TB in London now?

London has been called the TB capital of Western Europe; the number of TB cases has risen by nearly 50% over the last fifteen years and as a result, London has the highest number of TB cases of any major city in Western Europe. In the last few years TB rates have stabilised and begun to decline, but despite the best efforts of health and social care professionals, the disease remains an urgent public health problem, particularly for migrants and socially deprived and vulnerable groups. This is why Public Health England (PHE) London has made TB one of its priorities.

In 2013, 2985 tuberculosis (TB) cases were reported among London residents, a rate of 36 per 100,000 population. While this was a decrease of more than 10% compared to 2012, London accounts for 38% of the UK TB burden and its numbers and rates remain high compared to the rest of the UK and comparable western European cities.

Rates remain highest in the London boroughs of Newham (335 cases, 107 per 100,000 residents) and Brent (279cases, 89 per 100,000 residents) Rates at local authority level can, however, mask 'hotspots' of very high activity in smaller areas within London (Figure 1).

Figure 1: TB rates by MSOA of residence, London 2013



In 2013, TB rates were highest among males, and also young adults aged 20-39 years old. The majority (83%) were born abroad and rates in this group were approximately 10 times greater than those in the UK born. While the number and rate among non-UK born patients has decreased in recent years, the number of cases among UK born residents has remained stable, at around 500 per year – and more than twice the rate across the rest of the country (10 per 100,000, vs. 4 per 100,000). There were 141 cases in children aged less than 16 years, and 29 aged under 5 years (all of whom apart from one were born in the UK).

The number of cases among individuals who had recently entered the UK (less than two years prior to diagnosis) has decreased, and only accounted for 9% of all TB cases in 2013. Little or no change in case numbers has been seen among other non-UK born populations in London. Many cases have been resident in London for long periods of time prior to their TB diagnosis. Of note, it is estimated that only a third of TB cases in London are due to recent transmission.

The most common country of birth for non-UK born cases was India, although numbers born there fell 17% compared to 2012.

In 2013, 9% of London TB patients had at least one social risk factor (of homelessness, drug or alcohol misuse, imprisonment or mental health issues), and a third of these had multiple risk factors. Social risk factors were more common among TB patients who were UK born, male, white or of black Caribbean ethnicity. Patients with social risk factors had poorer treatment outcomes. TB rates were highest in the most deprived areas of London: 30% of TB patients were resident in the most deprived quintile compared to 6% in the least deprived.

Levels of drug resistance remain high in London, with 9% of TB cases resistant to one or more first line drugs and 2.1% multi-drug resistant. Drug resistance is more common among those with a social risk factor and also those with infectious forms of TB.

In London, 86% of patients with drug sensitive disease not involving the central nervous system completed treatment within 12 months. The most common reason for not completing treatment was being still on treatment. Four per cent were lost to follow up, and while the proportion dying was small (3%), TB caused, or contributed to, almost half of these deaths. Treatment completion was lower among those with disease involving the central nervous system, with 49% completing at 12 months and 37% still on treatment. Outcomes were much worse among those with drug resistant disease (including rifampicin, multi-drug resistant and extensively drug-resistant (XDR) cases): 53% had completed within two years, with one in four still on treatment and 18% lost to follow up.

Despite TB rates decreasing slightly in 2013, TB remains a serious public health problem in London, where rates are substantially higher than New York, other US cities and most European capitals. The decline is likely to be due in part to changes in migration patterns, as it was concentrated in young adults born abroad, who had recently entered the UK predominantly from the Indian sub-continent. The absence of a decline in other groups, particularly the UK born, suggests that further work is needed to address the burden of TB in risk groups in London. In addition, increasing numbers of drug resistant cases present a further challenge.

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The London Annual TB Review (using 2013 data) released in Oct. 2014, updated the latest epidemiology of TB in London, describing the areas and populations at increased risk and in addition provides a two page **TB Profile** for each London borough (see links below for further information).

The London report makes recommendations on how to improve TB control in London these include the following:

- Continue excellent case management, including universal HIV testing, adhering to the national Royal College of Nursing guidance on TB case management as best practice.
- Ensure TB is being tackled among hard-to-reach groups with complex social needs:
- Commission and support highly-targeted case finding and prevention activities which focus on high-risk groups
- Implement recommendations from NICE guidance in these groups.
- Continue to tackle TB among other high risk groups, including implementation of NICE recommendations around screening for latent TB.
- Continue and expand cohort review as the tool to improve local TB control, including monitoring of outcomes for patients on longer treatment plans.

What are the main challenges for improving prevention, diagnosis and treatment of TB in London?

There are many challenges to improving the prevention, diagnosis and treatment of TB in London. These include:

1. Improving access to services and ensuring earlier diagnosis
2. Raising awareness of TB among patients and health care professionals
3. Providing universal access to high quality diagnostics
4. Improving treatment and care services
5. Ensuring comprehensive contact tracing
6. Improving BCG vaccination uptake
7. Reducing drug-resistant TB
8. Tackling TB in under-served populations, by improving access to and completion of treatment.
9. Supporting those TB patients who are homeless into accommodation; this has been shown to increase treatment completion and so reduce the chance of developing a drug-resistant form of TB
10. Systematically implementing new entrant latent TB testing and treatment
11. Ensuring fully staffed TB teams and an appropriate workforce to deliver TB control
12. Improving links to third sector organisations particularly those that engage with individuals at risk of TB

13. Social factors have a major role to play in TB infection, transmission and effective therapy. TB may infect and cause disease in people of any race or socioeconomic group. However, a number of factors work together to make certain groups and populations more vulnerable to acquiring TB, becoming unwell and transmitting the infection. All of these factors exist in parts of our capital city and therefore an approach to deal with TB that only focuses on the medical aspects of the illness is unlikely to be successful. Some of these key factors include:
    - Homelessness – increases the likelihood of exposure to TB but also makes managing the care and treatment of patients very difficult. The ‘Find and Treat’

service based at University College Hospital has particular expertise in managing this patient group but cannot reach all patients in London. The problems presented by homeless patients with TB are a strain on the resources of all TB treatment centres across London. A co-ordinated approach between health and social care will really help to address this issue

- Overcrowding/poor housing – is often linked to problems of poverty and homelessness. This is a real issue in some of our boroughs and increases the transmission of infection from active cases of pulmonary TB.
- Poor access to healthcare – some of our most vulnerable and marginalised patient groups are at an increased risk of developing TB but also have historically found it difficult to access consistent health and social care services. This increases the chances of late presentation and diagnosis, harm to the patient and transmission to others. It also increases the risk of treatment failure and/or the development of drug resistance.
- Drug and/or alcohol dependency – drug and alcohol use increases the risks of developing and also of dying from TB. This group requires specific support.
- Poverty – TB disproportionately affects people living in poverty throughout all countries and London is no exception. The impact that TB has on a family can make this significantly worse if the wage earner is unable to work.

There is an urgent need to invest more in services for TB diagnosis, treatment, and prevention, targeted at high-risk and hard-to-reach patients, alongside setting up new entrant latent TB testing and treatment programmes.

How do stigma and lack of awareness affect TB control in London?

Although TB is an infection that can affect absolutely anyone it still provokes a very negative response in many individuals, cultural groups and society in general. 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. This leads to some people having great difficulty with treatment compliance.

Tackling stigma and raising TB awareness will improve TB control in London in the long term; as these can lead to a delay in diagnosis, which can lead to a patient remaining infectious for longer, and therefore they have the potential to transmit their disease to others, for a greater length of time. Lack of awareness can be both from a patient's point of view and that of the health professional. Both need tackling in London if we are to bring TB under control.

Which agencies and organisations need to be involved in tackling TB in London?

- PHE London
- NHS England and CCGs
- The NHS
- The London Find and Treat Service
- Local Authorities
- TB Alert
- The Mayor and the GLA
- Migrant and refugee communities and community groups
- Schools and educational establishments

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How can the Mayor and the GLA support the delivery of the national TB strategy in London?

The Mayor and the GLA could usefully support the delivery of the national TB strategy in London by:

- raising the profile of TB by speaking out about TB and those that it affects, and by so doing reducing the stigma associated with this disease
- through a targeted information campaign so that patients are more aware of the symptoms of TB and seek early testing and treatment. The Mayor could usefully use his TB Ambassador Emma Thompson to front a TB awareness raising campaign
- raising awareness of TB among patients should involve the local authority and community groups as well a direct TB campaign in higher incident boroughs
- ensuring a joined-up approach of active case finding, and testing and treatment for LTBI, by encouraging full involvement of statutory agencies and council departments, such as social care, housing, education and benefits
- encouraging and empowering the voice of people affected by TB. These individuals and groups are an important source of support and role models for others.
- review how third sector organisations could help improve access to services and patient support
- facilitate appropriate access to information and services for under-served populations, such as the homeless. Questions should be raised to determine whether screening, immunisation and treatment services reach out to diverse populations in London and are accessible to deprived or marginalised sections of the population
- supporting the work of the London TB Control Board, a multi-stakeholder group that coordinates a focused, city-wide, multi-agency approach to tackling TB. The London TB Control Board provides strategic oversight and direction to the control, commissioning, quality assurance and performance management of TB services across London

What examples of good practice are there in London (and further afield) in TB control?

Examples of good practice in London and the UK, that support improved TB control, include:

- The London Find and Treat Service – is a specialist outreach team that work 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 London TB Extended contact tracing team (LTBeX) is a multidisciplinary team assisting PHE London and NHS TB teams with the public health management of TB incidents and outbreaks
- Olallo TB Project - housing and supporting homeless Eastern Europeans with TB in London
- Regular TB Cohort Review
- Homerton Hospital TB team working in partnership with the London Borough of Hackney housing department have developed a service level agreement to house homeless people with no recourse to public funds

- Newham CCG working with local clinicians and GPs have developed a programmes of primary care based latent TB infection screening
- Screening for latent TB infection in students attending English for Speakers of Other Languages (ESOL) courses in Birmingham
- Citizens advice work with homeless TB cases in the West Midlands
- Refugee Council Screening in the West Midlands
- British Thoracic Society Multi-drug resistant (MDR) TB advisory service – supporting clinicians via a network of experienced clinicians who have treated MDR TB

Examples of good practice from the Netherlands:

- X-Ray van based TB screening which we now have as well in F&T, but we learned a lot from their approach
- Surveillance and systematic treatment of latent TB infection
- Specialist MDR/XDR TB sanatorium compatible with long-term inpatient treatment if required (months to years)
  - State of the art infection control
  - Access to activities of daily living, including kitchen, gym, social & outdoor areas
  - Comprehensive medical, social and psychological support
  - Facilities for enforced detention within the facility if required

Examples of good practice from New York:

- New York City TB Control Board led clear responsibility and accountability for TB control in New York City
- Quarterly Cohort Review for all patients, with findings fed directly back to those with responsibility for programme
- Large workforce of trained lay TB support workers: matched to patients by gender and ethnic group, provide on-going support with treatment completion
- Comprehensive contact tracing, including at least one home visit for every patient to build relationship and improve identification of contacts

Prepared by:
Dr Sarah R Anderson - PHE London TB Lead
Dr Helen Maguire and Charlotte Anderson - PHE Field Epidemiology Service (Victoria)
Professor Yvonne Doyle - Regional Director, Public Health England London

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Reference documents

Tuberculosis in London: Annual Review (2013 data)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385823/2014_10_30_TB_London_2013_data__1_.pdf
London borough TB profiles (2013 data)
http://www.lho.org.uk/LHO_Topics/Data/LondonBriefings.aspx