

## **London Assembly Health Committee – Tuberculosis in London**

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## **London Assembly TB investigation - additional information request**

28 August 2015

### **1. A breakdown of which London boroughs are currently offering universal neonatal BCG vaccination**

A report for the London Immunisation Board noted that 24 out of 32 CCGs across London commission the offer of universal BCG. The CCGs which do not yet commission the offer of universal BCG all have TB rates well below 40/100,000 population.

Currently the BCG vaccine remains unavailable to order, due to delays in supply from the manufacturer. Public Health England (PHE) is in dialogue with the manufacturer with a view to restoring deliveries to the UK as soon as possible. PHE are providing regular updates to services who administer BCG and other stakeholders.

### **2. A breakdown of which London boroughs are currently offering latent TB screening through GP practices, or will/are planned to commence doing so within the next year**

Newham CCG has been offering primary care based LTBI testing and treatment since mid 2014.

NHSE is funding primary care based LTBI testing and treatment to commence in 2015/16. The majority of London's CCGs have prepared or are preparing plans to implement this programme in 2015/16. Nine CCGs submitted plans in August with at least another 13 submitting plans in September. The outstanding four CCGs will receive support to ensure their plans are submitted to take advantage of the NHSE funding support.

The work to support CCGs plan and implement LTBI testing and treatment is being focussed on CCGs with TB rates  $\geq 20/100,000$  or TB cases  $\geq 0.5\%$  England's total TB numbers. In London this work is focused on 26 of London's 32 CCGs.

### **3. Figures for expenditure on TB control and management in London in each year from 2012/13 to 2014/15**

Estimates of the expenditure on TB control and management in London are difficult to define for several reasons. These are:

- PHE staff usually have several areas of responsibility and it can be difficult to break their time down to direct costs.
- TB is one of many areas of responsibility for NHSE staff, the exception being the specialist TB nurse teams.
- TB is coded and can be costed for inpatient stays but falls under either Respiratory Medicine or Infectious Diseases for Outpatient visits. Estimates of expenditure have been made for the Impact Assessment which was drafted to review the financial impact of the National TB Strategy on the NHS. This excluded costs to PHE and any other stakeholders.

- Estimates have been made of small, well defined cohorts of patients for research purposes which are not translatable to the pan London TB population.
- The London TB network manager has successfully worked with a number of local CCGs and TB services to ensure that local TB population needs are met.

**4. Government funding levels (both confirmed and expected) for the delivery of the national TB strategy in each year from 2015/16 to 2020/21. Please show how the funds will be allocated in each year between: a) TB Boards, b) latent TB testing, c) latent TB treatment, and d) other activity. Please also indicate, for each element, the amount that will be allocated specifically to London**

Please note that this work is all estimated.

It is assumed that the amount allocated to London is proportional to London's proportion of the national TB number of notifications. London's TB cases usually account for about 40% of TB cases across England.

The Impact Assessment carried out by NHSE stated that its purpose was to outline and detail the estimated resource implications to NHS England of implementing the proposals outlined in the collaborative TB strategy for England, 2015 to 2020. Its scope considered the impact of the strategy on NHS resources and the extent to which the strategy will improve health outcomes in England of people affected by TB. It did not look at the impact the strategy might have on other organisations or stakeholders.

Nationally, following the recommendations of the Impact Assessment, NHSE allocated £10 million to support implementation of the national TB strategy specifically LTBI testing and treatment. £1.15 million has been set aside to support national procurement of the analysis of the LTBI test. This national procurement will ensure standards are maintained across England and that there is equity and cost effectiveness for LTBI testing and test analysis. £500,000 has been earmarked to support IT development to ensure that the outcomes of the LTBI test are accurately collected and reported and £8.35 million is for GP incentives and treatment of LTBI.

PHE is supporting the set up and running of the TB Control Boards. PHE agreed to support and set up the TB Control Boards including the appointment a TB Programme Manager for each TB Control Board and other key appointments.

**5. Newham's LTBI programme**

This programme is being evaluated and an evaluation is likely to be available in 2016.

Lynn Altass  
National TB Strategy Programme Manager

## **LTBEx meeting 29 July 2015**

### **Background to project**

The LTBEx (London TB Extended Contact Tracing) pilot programme was first proposed in 2012. It is currently (until September 2015) funded by Public Health England (London). The aim of the programme is to provide an investigation service in response to TB incidents/outbreaks where there is likelihood of onward transmission beyond household contacts e.g. schools, colleges, workplaces.

Contact tracing is particularly important in London, where the mobility of the population means that people may live, study, work, and socialise across borough/CCG boundaries.

### **How it works**

Prior to LTBEx, diagnosed cases were notified to the relevant London Health protection team, who carried out a risk assessment to determine if screening was needed. Due to the number of TB clinics (30) and health protection teams (4) there was variation in how the risk assessments were conducted, based on resources and experience, and the outcomes were therefore also variable. Most clinics were unable to do on-site screening, so different contacts got differing levels of service.

On some occasions there was also considerable delay, as clinics were overwhelmed by increased numbers of people to screen. Additionally, it was very difficult to trace results of the screening, as so many clinics were involved.

LTBEx is a small, multi-disciplinary team (includes predominantly nurses and led by a Health Protection Consultant and a Health Protection Specialist) which can undertake on-site screening and provide a centralised, pan-London service. They also maintain the only contact tracing database in London, and the team are currently developing the first standardised model for TB contact risk assessment. The service provides an interface between public health and clinical services.

### **The process**

An incident is usually referred to LTBEx by the relevant regional HPT. LTBEx carries out a risk assessment, including an environmental assessment of e.g. a workplace, to determine scale of contact, based on proximity and length of time of contact.

If screening is deemed necessary, the team will provide on-site screening for latent TB infection for the relevant contacts. Either Mantoux or blood testing will be used, depending on the availability at the local TB clinic. The team also carries out a medical questionnaire to try and rule out active TB cases

The on-site screening allows for greater convenience for potential patients (who do not have to attend a clinic) and for the clinics (who do not have to process large numbers of

additional cases). The screening with a skin test takes place over 2-3 days (testing + results) so provides a much faster diagnosis than clinical referral, for larger numbers of contacts (>20)

### **Additional benefits**

- The team provides awareness raising/Q&A sessions for people being screened and anyone concerned e.g. parents, providing an opportunity for reinforcing public health messages which is embedded in a real-time health concern.
- There is significantly (c. 25 %) greater uptake of screening offered by providing it on-site
- Nursing staff working on the project can develop and enhance their public health knowledge, skills and awareness
- Can also contribute to other positive outcomes, for example by encouraging GP registration
- Reduction of resource burden on clinical services
- Can provide insight into issues including stigmatisation and reasons for low uptake of screening. The team is currently doing some work on this with UEL
- Even if people don't take up the offer of LTBI treatment (and some don't), the act of screening in its own right can raise awareness so that if TB symptoms develop later people may be more likely to acknowledge and act upon them.

### **Future of the service**

Current funding agreement runs out in September 2015. This potentially means the loss of resources, knowledge and experience gained by the team. In the absence of continued funding, the requirements for contact tracing in London would revert back to HPTs and TB clinics, placing a significant resource burden on these services and risking a return to variable levels of service provision.

Ideally, the team could be funded and commissioned as a stand-alone team with PHE, independent of TB clinics, allowing for a unified service offering, a reduction of resource burden on TB clinics, and the potential to expand the team's work into wider TB prevention activity in line with the aims of the collaborative national TB strategy. There would also be scope to develop workforce training through nursing secondments to the team, strengthening the public health and clinical interface, an approach that would bring significant benefits to TB in London.

## **Views on the role of the Mayor/GLA**

The team's observation is that there is significant stigma within the communities and misperceptions around TB prevalence, including among healthcare professionals. They suggest that this can be combatted by a combination of high level political focus and an acknowledgement of the scale of the issue in London (by the Mayor or similar high profile figure) and by educating people who can act as community advocates at a grassroots and culturally relevant level.

They also suggest the Mayor could pioneer and support projects and teams such as LTBEx which offer innovative and effective approaches to TB control and improve the quality and accessibility of services and thus reducing inequalities.

## **London Assembly Health Committee investigation into tuberculosis in London**

### **Stakeholder response – LTBE (PHE London TB Extended Contact Tracing Team)**

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

London has had a relatively large and highly experienced TB workforce for many years. Despite this, the numbers and rates of cases have remained consistently high in the last two decades, and London has the dubious honour of being the “TB capital” of Western Europe.

With the launch of the PHE and NHS England *Collaborative Tuberculosis Strategy for England*, and given that TB is one of the priority areas for PHE, this is a golden opportunity to re-focus efforts on TB prevention and control in London now.

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

Traditionally, there has been no pan-London coordination and commissioning for, or delivery of TB services in London, and there has been no central accountability for TB prevention and control. Political commitment to the prevention and control of TB has also been previously lacking in London, unlike in New York, where the Mayor, through the New York City Department of Health and Mental Hygiene Bureau of Tuberculosis Control, is accountable for coordinating and delivering TB control activities cross the city – see <http://www.nyc.gov/html/doh/downloads/pdf/tb/tb2003.pdf> for more information.

There are over 30 TB clinics in London. Despite the development of a pan-London TB service specification in 2014-15 (which is currently being updated), services are commissioned and delivered very differently across the capital. This means that there is considerable variation in the range of services that are available in different parts of London, which could result in a “postcode lottery”. For example, there is marked variability in access to diagnostic tests, and in the ability of TB services to make home visits for patients and their families while on treatment.

Although there is (variable) provision of TB diagnostic and treatment services across London, access to services for patients and their contacts remains challenging. TB teams are commissioned to deliver services from 9am-5pm, Monday to Friday, typically in a hospital setting (even though many TB services are commissioned as community TB teams). Many of the TB services in London are not sufficiently resourced to offer a flexible service, such as contact screening in the community (see also *Examples of Good Practice* below).

Many clinics also rely on referrals from primary care, so if patients are not registered with a GP, or if the GP does not suspect TB when they see the patient, this leads to delays in referral and diagnosis, which will have a negative impact on patients, their contacts, and in many cases the wider public health. Furthermore, there is limited capacity to provide TB services in prison and detention settings in London (despite a prison history being an independent risk factor of getting TB), or for TB services to develop links with drug and alcohol services to support vulnerable groups in a more holistic way.

Despite the fact that there is a dedicated TB workforce in London, training opportunities for TB nurses, support workers and outreach staff are scarce, and there are currently no competency frameworks available for TB workforce development (see also *Examples of Good Practice* below).

Although TB can affect anyone, it is still predominantly a disease affecting those in areas with the highest deprivation. For example, the London Annual TB report for 2014 (2013 data) highlighted that one third of all TB patients in London lived in areas with the highest indices of multiple deprivation, compared with only 6% of patients who lived in areas with the lowest indices (see: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/385823/2014\\_10\\_30\\_TB\\_London\\_2013\\_data\\_1.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385823/2014_10_30_TB_London_2013_data_1.pdf) for more information).

This report also indicates that 41% of TB patients in London were unemployed in 2013, and that 9% has a reported social risk factor (such as a history of homelessness and/or imprisonment, or drug or alcohol abuse). These statistics clearly indicate that TB continues to be intrinsically linked with health inequalities in London.

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

TB is a disease that is hugely stigmatised in many cultures, and patients from some communities may be unwilling/unable to accept their TB diagnosis, or they may want to keep it a secret from their family and friends. Given that contact screening is such an important element of TB control, this stigma can make it incredibly difficult to identify close contacts and ensure that they are offered screening in a timely way. In some cases, contacts will not take up the offer of screening, despite repeated attempts to engage them with TB services, because of the misconceptions and/or stigma associated with TB, or because of a lack of awareness of TB.

Despite a general lack of understanding about TB in the population, there has not been a concerted effort to raise awareness of TB in London as a whole. A coordinated and pan-London programme of information and education would address some of the misconceptions and stigma surrounding TB, and this, coupled with more targeted campaigns for the communities most affected by TB, could potentially have a large and positive impact. For example, with the correct information, people with symptoms may present earlier, be diagnosed earlier and start their treatment quicker, and adhere to their full course of treatment; thereby supporting wider TB prevention and control efforts more effectively. In addition, their contacts would be more likely to understand the importance of screening, and its relevance to them, and would therefore be more likely to attend for screening at the appropriate time.

We suggest that a number of initiatives could be explored, to address the stigma to and lack of awareness of TB in London, including:

- a coordinated TV, radio and print media campaign – eg: in coordination with public service broadcasters, and London Live
- a pan-London schools campaign on TB, its signs and symptoms, diagnosis and treatment. NB: LTBE has recently developed a TB prezi, which we use in school TB screenings throughout London to raise awareness of TB amongst students (see also *Examples of Good Practice* below)
- joint funding for cross organisational awareness raising campaigns (eg: TB and drug and alcohol services) would be useful in addressing issues in vulnerable and often hard-to-engage groups

Central coordination and accountability are key to ensuring that there is a multi-stakeholder approach to tackling TB awareness raising, as in New York – see:

<http://www.nyc.gov/html/doh/downloads/pdf/tb/tb-patient-brochure.pdf>



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

TB prevention and control in London requires a centrally coordinated multi-stakeholder approach, in order to be effective.

Stakeholders involved in this effort should include:

- the Greater London Authority – providing political commitment to, and leadership for TB prevention and control, via the London Health Commission, and work to tackle health inequalities across the capital
- NHS England and London CCGs – to ensure that TB services are appropriately and equitably commissioned
- Multidisciplinary specialist TB services across London – including TB nurse specialists, outreach workers, chest consultants and administrative staff
- NHS providers – including in primary care (GPs) and specialist TB services
- Public Health England (London) - to provide leadership and public health direction to TB prevention and control efforts, through the London TB Control Board and London Assembly Health Commission; to support TB surveillance and reporting via the London TB Register; and support onsite TB screening via initiatives such as LTbEx (see also *Examples of Good Practice* below)
- Local authorities (including Public Health departments, Children’s Services, Adults’ Services, Education departments, Housing departments)
- the Third Sector (including those providing homeless, alcohol and drugs services)
- the public

As mentioned previously, TB services across London currently lack the capacity and resources to undertake all TB prevention and control activities themselves. New pan-London initiatives that support TB services in the community (such as LTbEx), which have been shown to be effective and cost-effective, should also continue to be supported and centrally funded (see also *Examples of Good Practice* below).

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

The three key, and interdependent areas that we believe that the Mayor and the GLA are best placed to support the delivery of the national TB strategy in London, are:

- housing – ie: providing pan-London standards and funding to secure accommodation for TB patients who are homeless, an/or have no recourse to public funds
- tackling inequalities – as mentioned previously, TB in London is still a disease that predominantly affects the most deprived communities, and concerted efforts are needed to address these inequalities and the social risk factors that many TB patients face
- raising awareness of TB - through a centrally funded and coordinated pan-London campaign, including in schools, as outlined above

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

(i) Political commitment and accountability - as noted previously, centrally coordinated (and funded) multidisciplinary approaches to TB, such as that seen in New York, are the most effective in preventing and controlling TB. Political accountability is a key component to such an approach, and should be central to any TB control efforts in London.

(ii) The London TB Extended Contact Tracing (LTbEx) team - LTbEx is a pan-London service, which was launched in January 2013, with funding from the Health Protection Agency, now Public Health

England. This innovative project combines both clinical and public health aspects of tuberculosis (TB) prevention and control, to support and enhance effective TB incident investigations and management across London. As a dedicated contact tracing team, LTbEx works closely with the four HPTs and TB services across London to provide a consistent and integrated approach to TB risk assessment, incident management and screening. This model has been endorsed in the recently published Collaborative Tuberculosis Strategy for England 2015 to 2020.

By focussing primarily on delivering onsite screening for latent TB infection in the under 35s, including during evenings and at weekends, LTbEx provides additional capacity to TB clinics, and enhances partnership working amongst all stakeholders. It overcomes cross-boundary difficulties where an incident involves contacts across several geographical areas, and addresses health inequalities, such as access to health services, and stigma; which has resulted in higher screening uptake in incidents that have been supported or managed by LTbEx.

The LTbEx team have developed an animated Prezi, which we use for contact screening in schools and colleges. This prezi provides information to students about TB, and the TB screening process, and has proved to be a very effective tool in engaging young people in onsite TB screening.

LTbEx has developed and maintained a dedicated database for TB contacts – the first of its kind in the country. Provisional findings using these data indicate that LTbEx improves screening uptake and yield, and is an acceptable approach to TB incident management and screening.

TB clinics have valued the support of LTbEx in large scale screening exercises, which they often would not have had the capacity to respond to themselves, and they see this as an important service which should be routinely funded in the future.

LTbEx is currently developing resource packs for health protection teams and TB clinics for TB risk assessments and incident management, and as a pan-London service, the team is also uniquely placed to develop and implement agreed standards for London, which can be applied elsewhere.

At the time of writing, funding for LTbEx runs out at the end of September 2015.

(iii) the third sector – organisations such as TB Alert (<http://www.tbalert.org/>) have been providing support to health professionals and TB patients for many years, and have developed TB information campaigns and information materials in a number of key translations. As a national charity, it is well placed to support awareness raising initiatives in London, and more widely.

Submitted by the London TB Extended Contact Tracing (LTbEx) team  
22 July 2015

## Health Committee investigation into Tuberculosis in London

Submission by RESULTS UK

RESULTS is an international NGO that uses advocacy and campaigning to bring about the end of extreme poverty. We do that by recruiting, training and inspiring hundreds of volunteers around the world to speak up and call for change. We call on the governments of wealthy nations to spend more money on overseas aid, to spend the money they spend more effectively and efficiently and to ensure that anything they support reaches the poorest and most vulnerable people all the time.

As part of this work we campaign and advocate on tuberculosis (TB) both in the UK and abroad.

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

TB is a threat to global health security. It is the only major airborne, drug-resistant, infection, and experts estimate that the drug-resistant TB could claim an additional 75 million lives over the next 35 years.<sup>1</sup> Whilst a small fraction of these deaths will be in the UK (an estimated 9,400) these are unnecessary deaths that can be avoided through appropriate TB control.<sup>2</sup>

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

There are two principle challenges:

1. A lack of awareness of the disease among the population, particularly those who are at highest risk of developing active TB.
2. The reduced likelihood of high risk groups of engaging with health services increases diagnostic delays with consequential worsening of symptoms and increased chance of onward transmission.

The second challenge is, in our opinion, the greatest obstacle to effective TB control. Nearly all policies relating to TB control rely on effective health interventions. The efficacy of such interventions is dramatically reduced if high-risk populations do not engage with health services.

One example is LTBI screening and treatment of high-risk groups. By definition, those who are accessible and engaged in any LTBI screening process are not those who are most at high-risk.

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

Stigma is, by definition, hard to quantify and therefore a large proportion of evidence relating to its impact will be anecdotal. Nonetheless, stigma must be considered a significant barrier to effective TB control. This is particularly the case in relation to housing. In instances where many individuals are sharing

accommodation, anyone who falls ill with TB may be unwilling to admit their illness, or be seen to be taking medication, on the basis of potentially losing their housing if their illness is discovered.

In this instance we must ask whether the lack of appropriate housing, or the stigma, is the main obstacle to effective care and prevention.

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

The issue is not so which agencies and organisations but how they will work together. TB requires a multi-disciplinary approach. In the case of outreach programmes – which we believe are integral to overcome the reluctance to access healthcare that hinders an effective response to the disease – these programmes should be integrated with other priority health conditions such as HIV and Hepatitis. This requires not only TB services to work together, but also the creation of joint commissioning routes for TB and blood-borne infections. Overcoming this primarily bureaucratic obstacle is critical to reducing transmission of these diseases and making long-term savings.

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

Accountability is key. If a high-profile, preferably elected, individual is shown to have responsibility for controlling the disease, it will help break through the bureaucratic and commissioning obstacles which impede progress. London can provide *the* model for how a city or region might approach delivering the strategy by appointing the Mayor, or a Deputy Mayor, as the individual with the responsibility of reducing rates of TB.

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

Two particular programmes merit examination for national scale-up:

- 1) Homerton's housing SLA and the Olallo Project. Both of these look to provide long-term, secure housing for TB patients of no fixed abode. This prevents bed-blocking (thus saving the NHS large sums of money) but also gives patients the greatest opportunity of breaking the cycle of ill-health and homelessness which increased their risk of initial infection. It should be the norm across the country that dedicated housing is available for people who are admitted to hospital with long-term health conditions like TB.
- 2) Find & Treat is an excellent model and we are pleased to see that it has been recommended for national scale-up. Nonetheless, Find & Treat has several limitations which can be relatively easily overcome:
  - a. It is currently not able to screen for conditions other than TB, largely due to the lack of viable commissioning routes. TB outreach must be

integrated with outreach for other conditions. This will be cost-saving, and help reduce rates of disease but also could destigmatise TB screening by making it part of a range of health conditions that the service addresses.

- b. Find & Treat is very focused on homelessness and marginalised groups. Outside of the capital and other major cities, this approach is not viable. If commissioned to become a comprehensive, health inequalities outreach service, Find & Treat could and should expand its focus beyond homeless groups.

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<sup>1</sup> “Antimicrobial Resistance: Tackling a crisis for the health and wealth of nations”. The independent Review of Antimicrobial Resistance, December 2014. [http://amr-review.org/sites/default/files/AMR%20Review%20Paper%20-%20Tackling%20a%20crisis%20for%20the%20health%20and%20wealth%20of%20nations\\_1.pdf](http://amr-review.org/sites/default/files/AMR%20Review%20Paper%20-%20Tackling%20a%20crisis%20for%20the%20health%20and%20wealth%20of%20nations_1.pdf)

<sup>2</sup> “The global economic impact of anti-microbial resistance” KPMG LLP, December 2014. <http://www.kpmg.com/UK/en/IssuesAndInsights/ArticlesPublications/Documents/PDF/Issues%20and%20Insights/amr-report-final.pdf>



## Submission by TB Alert to the London Assembly Review into Tuberculosis (TB) in London

The London Assembly's investigation into tuberculosis provides a valuable opportunity to respond to the fact that while TB has become recognised as a priority issue at national level, that focus is frequently not reflected on local and regional footprints.

The national dimension is evidenced by Public Health England (PHE) having named TB one of its seven priority issues, alongside conventionally high profile issues such as alcohol, obesity, smoking and dementia<sup>i</sup>. Of PHE's seven priorities, the incidence of tuberculosis more than any other has a bias towards being higher in London, with some 40% of the national caseload occurring in the capital. Additionally, in the context of the Mayor's responsibility to address health inequalities, 70% of TB in England occurs among people who live in the two most deprived quintiles<sup>ii</sup>.

The local dimension was highlighted by Public Health Minister Jane Ellison MP at a summit in March 2015 for boroughs with high incidence of TB and/or Hep C, when she said "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' and begin to think innovatively about introducing alternative interventions to JSNA processes."<sup>iii</sup>

Tuberculosis is therefore an issue on which London as a city and the Mayor as its elected strategic leader should take especial note and recognise a clear responsibility to act to improve health outcomes. We submit that a critical early step is for TB to be adopted as one of the Mayor's health focus issues<sup>iv</sup>. The London Health Board could regularly review progress made against this priority.

This investigation recognises that local government has an increasingly important role to play in TB control. That role takes three forms:

- Local leadership and coordination, with Health and Wellbeing Boards as the forum where key leaders from the health and care system work together to improve the health and wellbeing of their local population and reduce health inequalities.
- Public health and the prevention of illness, with the leadership of the Director of Public Health playing a key role in tackling the threat to the local population from infectious diseases.
- As providers of social care, with local authorities working with NHS colleagues to ensure integrated care packages for individual patients.

Under the Collaborative TB Strategy for England, regional TB Control Boards will have responsibility "to plan, oversee, support and monitor all aspects of local TB control, including clinical and public health services and workforce planning"<sup>v</sup>. Control Boards will not hold budget; this will remain with local commissioners or, for some aspects of TB, in specialised commissioning. It seems that Control Boards only direct financial authority will be to approve applications made to PHE and NHSE to release nationally held funding for testing and treating new entrants to the country for latent TB infection.

Since power and budgets sit, ultimately, at local levels, and regional and national influence can generally be exerted only through advocacy and wider policy levers, the authority of the Mayor in the context of TB has similarities to that of the London TB Control Board. Progress will most effectively be made, therefore, if the Mayoralty and the Control Board work in close collaboration to exert their combined influences. Tuberculosis is not an issue where there are multiple opportunities and entry points to exert influence; this kind of joint working is therefore necessary to leverage pan-London influence in tackling TB-related health inequalities and improving health outcomes. It can be seen, for



example, that by bringing policy levers such as the London City Charter to the work of tackling TB, valuable synergies can be achieved. We therefore recommend that a senior health official or adviser of the Mayor, is a member of the London TB Control Board with the authority to speak for and make commitments on behalf of the Mayor. This Mayoral representative on the London TB Control Board would have a secondary function of monitoring the effectiveness of the Board in fulfilling its responsibilities.

We would highlight the important role of third sector organisations in tackling TB. Such organisations often have detailed understanding of, trust of, and access to communities affected by TB, and can help reach them to raise awareness, tackle stigma, improve uptake of testing and treatment for latent TB, provide support to especially vulnerable patients during the minimum six month course of treatment, and support public health teams in undertaking contact tracing. Such roles, in order to efficiently and effectively result in improved health outcomes, need to be on a commissioned basis. We therefore recommend that the Mayor and the Assembly, within its strategic and operational plans for building the role of the third sector, reflect this need to engage the third sector as commissioned providers of TB services.

### Summary of recommendations

- 1 Tuberculosis to be adopted as one of the Mayor's health focus issues.
- 2 A senior health official or adviser of the Mayor to be a member of the London TB Control Board.
- 3 The development of the third sector in London to recognise its role as a commissioned provider of TB services.

### About TB Alert

TB Alert is the only TB-specific charity tackling tuberculosis in the UK. It is recognised by government as the national TB charity<sup>vi</sup> and is the only voluntary sector organisation on the TB Oversight Group which has overseen the publication of the Collaborative TB Strategy for England.

Please address correspondence to Mike Mandelbaum, Chief Executive, TB Alert, [mike.mandelbaum@tbalert.org](mailto:mike.mandelbaum@tbalert.org), 01273 234865.

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<sup>i</sup> From evidence into action: opportunities to protect and improve the nation's health. London: Public Health England, 2014. Accessed on 28 July 2015 from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/366852/PHE\\_Priorities.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366852/PHE_Priorities.pdf)

<sup>ii</sup> Collaborative Tuberculosis Strategy for England 2015 to 2020. London: Public Health England, 2015, p5

<sup>iii</sup> Accessed on 28 July 2015 from <https://www.gov.uk/government/speeches/helping-local-authorities-to-reduce-tb-and-hepatitis-c>

<sup>iv</sup> Focus issues on health in London. Accessed 28 July 2015 from <http://www.london.gov.uk/priorities/health/focus-issues>

<sup>v</sup> Collaborative Tuberculosis Strategy for England 2015 to 2020. London: Public Health England, 2015, p10

<sup>vi</sup> See, for example, <http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120322/text/120322w0001.htm>, accessed 28 July 2015

30 July 2015

Dr Onkar Sahota AM  
Chair, Health Committee  
The Greater London Authority  
City Hall  
The Queen's Walk  
London  
SE1 2AA

Dear Dr Sahota,

**Re: London Assembly review into Tuberculosis in London**

On behalf of the homelessness charity St Mungo's Broadway, I am writing in response to the call for submissions to the London Assembly review into tuberculosis (TB).

We welcome the launch of the Public Health England (PHE) and NHS England *Collaborative TB Strategy for England 2015-2020*, and its focus on tackling TB in under served populations. We believe that the Mayor and the GLA have an important leadership role in making sure that the national strategy is implemented locally in a way that reflects London's particular challenges and opportunities.

Despite a welcome fall in TB cases nationally and in London since 2011, it is vital to retain a focus on reducing the number of people affected by TB in the capital. Data from PHE shows a particular burden upon those born outside the UK, but also on the most marginalised groups. One in ten 2013 TB cases was associated with one or more of the 'social risk factors' identified by PHE – a history of homelessness, drug or alcohol use and imprisonment.

To effectively protect all Londoners from the public health risk posed by TB, screening and treatment must work for the most vulnerable. This particularly includes people who are homeless in the capital, many of whom are exposed to multiple TB risk factors.

38% of St Mungo's Broadway London residents have been in prison, 47% have a history of problematic alcohol use, and 56% a history of substance use. People with poor diet and physical health, including those with weakened immune systems, are at particular risk. 20% of St Mungo's Broadway residents in London were born outside the UK.



London is home to examples of very good practice in TB detection and treatment, and is better served than many other areas in the UK. However, issues still hinder progress for particular groups of people sleeping rough, or living in hostels or semi independent accommodation.

Active case finding is a crucial first step. The excellent Find & Treat service has significant expertise working with people exposed to social risk factors, including in St Mungo's Broadway hostels. However, the current service cannot reach everyone who has been homeless. Staff report that clients living in semi independent accommodation are not always reached by Find & Treat services.

People experiencing social risk factors are also less likely to complete treatment successfully. In 2012, 7.1% of TB cases with at least one social risk factor were lost to follow up, compared to 3.7% of those without. 6.1% of cases with at least one social risk factor died, compared to 3.7% of those without.

A significant challenge is the complex treatment regime. For patients with multiple needs including homelessness, substance use and mental health, sustaining a rigid and demanding treatment regime can be difficult.

Successful treatment may depend on clinical monitoring of clients to ensure compliance. This approach works best where clinical teams work closely with our project staff so that workers are able to provide support. A supportive hostel or other accommodation environment can help address issues alongside TB that affect risk, compliance and recovery, including mental health, other physical health issues and substance use.

Supporting patients with no recourse to public funds during treatment can be problematic. Some are excluded from the support available in St Mungo's Broadway hostels or hospital discharge services because they lack access to housing benefit. This severely restricts accommodation options: patients may 'bed-block' in hospital during treatment or be lost to follow up while sleeping rough or in insecure accommodation. We note in Hackney an example of good practice that homeless clients who might otherwise not be eligible, can secure accommodation on a temporary basis in order to ensure compliance with treatment.

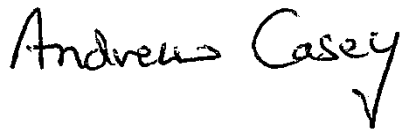
The GLA should ensure that more is done to detect, find and treat TB among those in London who are most at risk as a matter of urgency. As part of work to implement the national strategy in London, we believe the committee should recommend that:

- resources are available to ensure that London's effective screening and treatment services reach people who have experienced homelessness in **all accommodation types**
- good practice in **partnership work** between clinical and hostel staff is highlighted and encouraged across all London's hostels as a way to improve treatment completion rates and place TB in the context of overall recovery from the issues that cause homelessness.

- accommodation available for people with **no recourse to public funds** is consistent across boroughs and minimises risks to individuals and public health

We look forward to hearing the outcome of the review. Please do not hesitate to get in touch if you have any questions or would like further information.

Yours sincerely,

A handwritten signature in black ink that reads "Andrew Casey". The signature is written in a cursive style, with the first name "Andrew" and the last name "Casey" clearly legible. There is a small checkmark-like flourish at the end of the signature.

**Andrew Casey**

Director of Health  
St Mungo's Broadway



## 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.

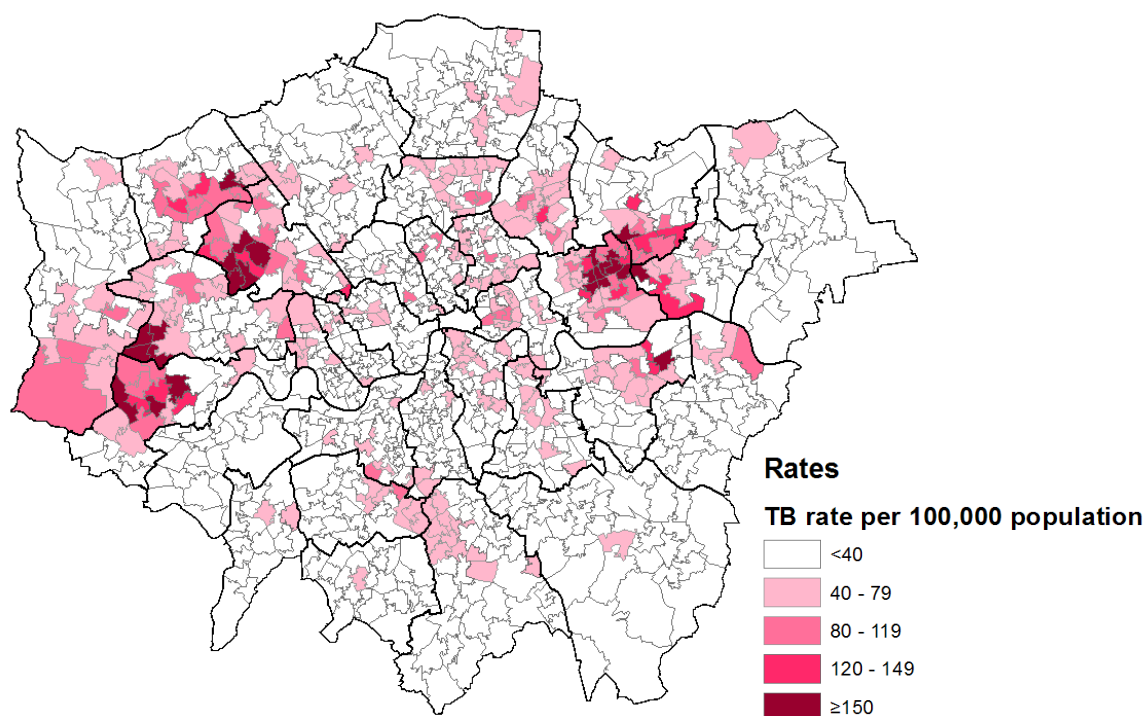
### Why is it important to focus on TB in London now?

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 (279 cases, 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.



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



## **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

July 2015

### **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](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](http://www.lho.org.uk/LHO_Topics/Data/LondonBriefings.aspx)



# **London Assembly-Health Committee investigation into Tuberculosis in London**

## **London Borough of Newham**

### **Newham Clinical Commissioning Group**

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

Newham has the highest incidence of TB in London and the UK with 336 new TB cases in 2013 with a rate of 107 per 100,000 compared to 13.5/ 100,000 in the UK and 36/100,000 in London.

The highest risk of disease is among people with complex social care needs including drug and/or alcohol misuse, homelessness, imprisonment and mental health issues due to lifestyle and poor immunity. They present to health services late with worse disease and treatment outcomes including higher rate of acute service use and drug resistant TB making it more difficult and costly to treat. Their contacts are more difficult to trace and screen for possible acquired infection. One in 10 patients with TB in Newham belong to this group.

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

Active TB can be indolent subsequently patients may present late. Other delays in accessing treatment include low levels of awareness of TB in the general population, and even in many high-risk groups. Patients may not engage with healthcare services for a variety of reasons including cultural and religious beliefs, language barriers, homelessness, poverty, substance misuse and high levels of population mobility

Low levels of patient and public engagement result in a poor awareness of the disease among underserved groups. Their eligibility to receive support from locally delivered universal services and any other support during treatment are also likely to reduce access to services.

Lack of organised education and training programmes on TB for nonclinical staff in GP practices and among local authority staff including environmental Health, housing, drug and alcohol misuse, social care, outreach and benefit teams.

Lack of targeted and culturally appropriate behaviour change programmes available locally to address the burden of TB in Newham

A recent TB stakeholder group in Newham identified a lack of a locally based multidisciplinary strategic committee/group involving key stakeholders to provide clear strategic leadership and oversee local TB service development in order to improve outcomes and reduce inequalities. A stakeholder group has subsequently been established.

Non-availability of a dedicated budget to commission targeted, evidence based and more effective TB prevention strategies particularly aimed at underserved groups

Gaps in addressing wider determinants particularly housing for patients with TB (including children) with overcrowding, inappropriate housing and homelessness as stability of tenure is pivotal to treatment completion (6-12 months).

## Gaps in integration in the TB care pathway across settings

Lack of BCG vaccination for children who are not vaccinated against TB, arriving in Newham from areas who have had no BCG for high risk groups.

Lack of financial support to assist patients with TB from underserved groups who are financially challenged to improve treatment completion rates and include basic needs such as travel to clinics as well as providing accommodation during treatment.

Lack of information in multiple languages.

Lack of BCG programme for teenagers to cover those children who have moved into the Borough without being vaccinated for BCG.

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

Stigma and lack of awareness prevent a clear understanding of the disease, the adoption of preventative measures, the recognition of signs and symptoms and subsequently timely access to services.

Cultural barriers include language issues, poor awareness and lack of knowledge about TB and existing TB services amongst the general public and underserved groups.

Feedback at a recent Newham health watch event suggested that young Asian women may not present to services with symptoms for the fear of jeopardising their opportunity to marry.

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

TB services need to be commissioned collaboratively between NHSE, local authorities, CCG's and delivered by multi disciplinary universal services. In addition to traditional NHS and Local authorities providers should include:

- Schools
- Faith groups
- Homeless shelters
- Community centres
- Sports clubs

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

There is a strong economic case for effective management of TB. As well as the public health imperative, the lack of an effective strategy and poor management of TB can be very costly in the long term<sup>1</sup>. Supporting the delivery, in London, of the Collaborative TB Strategy for England 2015-2020 by championing TB in the next funding round.

Supporting a clear accountability structure for the development of appropriate multi agency commissioning frameworks to address the gaps in service

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<sup>1</sup> 'Stopping Tuberculosis in England; An Action Plan from the Chief Medical Officer(2004)

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

Newham CCG, working with all GP practices and local health services, developed a pioneering approach in the implementation of primary care based latent TB screening in 2014 to identify and treat people with latent TB infection. This approach aims to reduce the number of people developing active TB disease and decrease the spread of TB.

When a resident from a country where TB is common registers with a Newham GP they are offered a blood test to check for latent TB infection. If latent TB is detected they are offered a chest X-ray and a three-month course of treatment. The majority of treatment for latent TB infection is provided through local pharmacies that are easy for patients to access. Patients and staff are optimistic about the programme and to date (July 2014 – January 2015) over 2,300 tests have been carried out with nearly 600 (25%) people being diagnosed with latent TB.

Meradin Peachey  
Director of Public Health  
London Borough of Newham

**Subject:** RE: London Assembly review into Tuberculosis (TB) in London

**Dear CCG and Clinical Colleagues**

**I am copying you in on my DRAFT response to the London Assembly review on TB in London.**

**Please add in your comments below by next Friday 4 Sept.**

**OR feel free to respond separately direct to GLA scrutiny using the link in the original e-mail. CCG is lead on local implementation of TB strategy. Frontline Clinical staff add important perspective.**

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

London is the Tb capital of Western Europe. London is one of the few global cities in the world. It has a diverse international population and extensive global travel opportunities for Londoners and people from outside London. There are opportunities with the launch of the national TB strategy and its 10 key steps to make a difference and mitigate the impact of TB in London.

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

Introduce LTBI screening in new migrant populations who have “latent” infection and can have a shorter course of treatment to be cleared of the infection at an early stage.

Detecting and treating Tb in isolated unregistered populations with social factors e.g. homeless, no recourse to public funds, alcohol/drug misuse issues,

Improve Tb treatment completion rates

Ensure Tb contact tracing to reduce transmission in households

Improve prevention & management of drug resistant TB

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

There is still a lot of fear and stigma within communities and in the media about TB both as a killer and spread from affected persons. Messages about symptom awareness, early detection, key risk to household contacts, effective (albeit prolonged) treatment and that people do recover from Tb need to be promoted through multimedia routes including radio & personal contact by outreach workers & non-health settings including libraries, schools, leisure facilities, faith and community groups.

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

In line with national strategy but particularly all health organisations, public sector organisations and community and voluntary organisations in contact with high risk populations.

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

Not sure. Supported affordable housing/pathways for homeless/no recourse to public funds whilst on treatment and engagement with key embassies on pathways back to home countries (these are currently taking far too long for the few who try to take up this latter option).

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

Latent Tb infection screening underway in Newham.

Ealing had a latent Tb screening pilot over 2 years ago which demonstrated a high detection of screen positive latent TB cases; currently applying for funding from London TB control board. Hounslow and Brent also applying, so between us we would cover the high incidence NWL tb area.

We have had good support locally from faith groups (gurudwaras, churches, mandirs, mosques), homeless charities (St Mungos) and have a good network with clinical services, outreach worker and excellent NWL Tb clinical network and Find and Treat.

I suppose the only other thing I could add as an example of good practice is the NWL TB network – works across commissioners, clinicians and clinics in NWL to share issues, examples of new developments and good practice.

Kind regards,

Bal

Dr Bal Kaur  
PH Consultant  
LB Ealing  
T – 07508 277638

## **London Assembly review into TB in London: London Borough of Hackney response**

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

- London has stubbornly high rates of TB, amongst the highest of comparable European countries
- Recent publication of national strategy, and associated funding for new structures and programmes (including TB control boards and latent TB infection screening of vulnerable migrants), offers an opportunity to coordinate action across the capital
- Public sector budget pressures are driving significant changes in health and social care services which pose a real risk to established local partnerships which have supported successful identification and treatment in the past

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

- See above for financial pressures
- Case finding of refugees/unregistered migrants who do not engage with public services
- Continued stigma around TB acts as a barrier to presentation and treatment
- Chaotic and mobile lifestyles of high risk groups (including vulnerable new migrants, homeless, people with substance/alcohol misuse problems, (ex) prisoners, etc.) are barriers to identification and treatment completion

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

- As above.... Reluctance to present for diagnosis and treatment
- Can be difficult to maintain patients in housing (required for treatment completion) if it becomes known they have TB
- Affects vulnerable, marginalised groups in particular and thus contributes to widening health inequalities

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

- NHS England - lead on delivery of the new strategy, hold commissioning budget
- PHE - strategic leadership, building and using the evidence base, holding NHSE to account
- NICE – development of evidence-based, practical guidance for national and local use
- Local authorities - housing provision (prevent/reduce homelessness and support treatment completion), support (but not lead) coordination between different local agencies including faith and community groups
- NHS (including CCGs) - delivery of high quality, effective services (identification, screening, treatment); awareness raising in A&E and primary care
- Faith and community groups - awareness raising and addressing stigma in communities, potential role in co-production of targeted find & treat services

- GLA, LGA, PHE (London), NHSE (London) - pan London campaigns and other relevant activity to raise awareness of TB and reduce stigma

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

- As above – contribute to pan-London campaigns to raise awareness and reduce stigma
- Ensure availability of high quality and affordable housing, to support prevention and treatment completion

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

- Homerton hospital in Hackney delivers a highly effective TB treatment service - it has one of the highest nurse-to-patient ratios in the country (in line with strategy recommendations), 100% treatment completion rates and excellent follow-up/contact tracing
- London Find & Treat service (multi-disciplinary outreach team) is very effective in case finding and screening high risk under-served groups (including homeless, alcohol and substance misuse, vulnerable/unregistered migrants, ex-prisoners) and supporting them into treatment - <https://www.uclh.nhs.uk/OurServices/ServiceAZ/HTD/Pages/MXU.aspx>
- Latent TB infection screening of new migrants from high prevalence countries and other high risk patients as recommended by NICE (e.g. immunocompromised) – need to supplement primary care led service with innovative approaches to reach those not registered with a GP
- Hackney Council currently funds housing for high risk TB DOTS patients during their treatment regime to improve treatment completion rates - however, the future of this service is uncertain within the new commissioning structures and current financial climate (this is not strictly a local authority commissioning responsibility, but lies with NHSE)
- UCL Video/virtual Observed Therapy (VOT) study shows promise in delivering a highly cost-effective intervention for some high risk patients (still in early stages however).

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Dear Ms Wells

Thank you for your invitation to respond to the London Assembly Health Committee review into Tuberculosis (TB). You have posed six questions which I consider in turn:

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

TB is a significant cause of preventable disease and ill health. The incidence in England has increased steadily from the 1980's until now. The incidence of the disease in London is amongst the highest in Western European cities. London carries a significant share of the national burden of the disease with 37.8 % of cases occurring here. London has 36 cases of TB per 100,000. The incidence of TB in Brent is the second highest among London boroughs with 89 cases per 100,000.

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

Brent has a high proportion of people born abroad including in countries with high rates of TB. Over 90% of those people diagnosed with TB in Brent were born abroad with 20% having entered the country in the last 2 years. This suggests the majority of disease seen in Brent was reactivation of infection acquired in high prevalence countries which highlights the need to focus on diagnosis, including the identification of latent TB, and on improved treatment.

In Brent, despite the high burden of disease, the performance of local TB services is in line with, or better than the London average. Locally the length of time between symptoms occurring and TB being diagnosed is on average 54 days, which compares favourably to 70 days in London as a whole. A marker of the effectiveness of treatment is the percentage of people who complete treatment within 12 months. In Brent this is 87% for those with uncomplicated TB and 57% for complicated TB. For London as a whole the figures are 86% and 49%.

TB is more common amongst those with social risk factors such as homelessness, imprisonment, alcohol and drug use. In Brent seven per cent of all TB cases were associated with these social risk factors. Social risk factors, in particular homelessness, may also be associated with highly infectious or drug resistant strains of the disease and a lower likelihood of completion of treatment. Detection and treatment services need to be tailored to the particular needs of these high risk groups. The Find and Treat service is an excellent example of how this can be achieved. A particular issue is the long duration of TB treatment, the mobility and chaotic lifestyles of some high risk individuals can limit their ability to adhere to this long term treatment.

The prevention and control of TB has been hampered by the lack of an effective vaccine to prevent all aspects of the disease. The current vaccine BCG is mainly effective against severe forms of the disease in those under one year. Given the high levels of TB in London, there is a strong argument for all babies born in London to be given BCG. However the offer of neonatal BCG across the capital was patchy even before the recent supply problems, which have meant the vaccine is currently not available.



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

Stigma and a lack of awareness (of symptoms, of infectivity and of the effectiveness of treatment) may deter people from seeking medical help. Stigma may also hinder contact tracing as people may not wish their TB status to become known to their contacts.

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

Tackling TB in London cannot be left to the NHS due to the multi-factorial nature of the disease. Voluntary sector and faith organisations concerned with housing, welfare, social support, homeless, drug and alcohol misuse amongst others should be involved. From the statutory sector the Department of Health, local government, Public Health England, NHS England, Clinical Commissioning Groups, the criminal justice system and schools need to be involved alongside clinical NHS services.

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

The Mayor and the GLA could support the delivery of the national TB strategy by identifying TB as a priority within existing initiatives such as action on homelessness and through support for the work of the London TB Control Board.

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

Earlier this year, in an event co-ordinated by the GLA's diversity and social policy team, I joined colleagues from Health Protection England and the local TB service (from London North West Healthcare Trust) in order to raise awareness of TB. We aimed to address stigma through challenging common misunderstandings, including exaggerated perceptions in local communities as to how infectious TB is and overly negative views of treatment. It was undoubtedly helpful to have a local Council presence alongside the expertise from PHE and from the local treatment services. Increasing the visibility of TB services and providing consistent and proportionate messages on risk requires such a partnership approach.

In Brent we have a strong tradition of supporting the delivery of TB screening at our Drug and Alcohol Recovery and Addiction Centre, Cobold Road. The partnership between Addaction and the Find and Treat service creates a positive atmosphere where people are keen to take up the offer of screening. Recently 54 people were screened in a single session. A multi-disciplinary approach was used and additional services and support provided during the session. This illustrates the importance of statutory agencies and independent sector groups who have existing links with vulnerable groups as a way of delivering services to those most at need.

While there has been a slight decline in recent years in the number of cases of TB in London in general and in Brent in particular, TB remains a concern for London which will require co-ordinated effort to address the underlying causes, improve treatment outcomes and to reduce the burden of TB in our city. For this reason the attention of the London Assembly Health Committee is welcome.

Yours sincerely



**Dr Melanie Smith**  
Director of Public Health

Just to avoid misunderstanding- as I said in my response this is my personal view having worked on the JSNA. If you require a response from the local authority or PH for the triborough I wouldn't be the best person to comment,  
Thanks

---

**From:**

**Sent:** 21/09/2015 08:29

**Subject:** RE: London Assembly review into Tuberculosis (TB) in London

**Hi Georgina,**

**Sorry for the late response, I only just got this. I was involved in the TB JSNA for H&F, RBKC and Westminster (copy attached) and have put my views on the questions down resulting from the work on the JSNA. I have copied in Ike Anya, who is PH consultant and TB is part of his portfolio – just in case he has anything to add/ comment on?**

### **London Assembly review into Tuberculosis (TB) in London**

The London Assembly Health Committee is conducting an investigation into tuberculosis in London. London has amongst the highest incidence of TB disease in any western capital city, and almost 40 per cent of all UK cases occur in London. There are significant variations in the number of cases in different areas of London and within different groups in the population. Public Health England has identified TB as a priority area for action and has recently launched a national collaborative strategy to tackle TB.

The Mayor of London has a duty to have regard to health inequalities in London when developing his policies. The Committee will be particularly looking at how the Mayor and other local government agencies can support the control and management of TB in the capital. As part of our investigation, we are seeking written submissions from stakeholders.

We would welcome your views on the following key questions to help inform our work.

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

Particularly as the Inner North West London boroughs we have hard to reach populations such as the homeless, which are at high risk of TB.

We have a large influx of people from countries with high TB prevalence including multi-drug resistant TB, we have pockets of deprivation with overcrowding as a risk factor for TB transmission.

TB is treatable and preventable, but because of its relatively low prevalence and the practical difficulties in bringing together multiple agencies it tends to get overlooked.

Although prevalence is relatively low compared to some other conditions, costs could potentially spiral.

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

Co-ordination of services is a particular challenge for TB and TB in London in particular.

Many people at high risk of TB have no recourse to public funds and successful TB prevention needs to ensure that funds are available and co-ordinated between services.

Latent TB currently does not get systematically picked up in primary care in London. The majority of active TB cases will come from LTBI infections in people who have immigrated from high risk countries within the last 5 years. Screening new registrations from such countries or even pro-active screening of GP populations and working with voluntary peer organisations to reach those not registered is needed to systematically prevent future TB cases.

Tertiary services need to be streamlined to offer economy of scale and outreach work needs to be funded better and scaled up (e.g. contract tracing, directly observed therapy).

BCG vaccinations for children at high risk of TB is not done consistently in all boroughs. Whilst the neonatal universal offer has improved, children who are born outside of hospitals or in other countries are being missed.

Prisons in INWL used to be screened for TB by the mobile xray van but since getting their own xray machines this service is no longer in place. It was unclear a year ago whether there was any systematic screening for TB going on in prisons, where TB prevalence is very high and easily transmitted.

Funding issues surrounding outbreak management – PHE has an advisory capacity but in the case of a potential outbreak (INWL has a lot of universities, colleges, schools where large scale contact tracing may become necessary) but funds are assumed to be covered by the hospital trusts. A kind of outbreak slush fund needs to be made available explicitly either by the CCGs or the local authorities or PHE to enable a coordinated well resourced response to a potential outbreak.

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

TB is often not a priority for councils or CCGs and due to low overall prevalence numbers it is not seen as an issue. The further fragmentation of services following the disbanding of PCTs has not helped and the local TB Action group, which was traditionally led by the Director of Public Health at the PCT and brought together all stakeholders, has not been replaced at a local level.

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

In NYC or Amsterdam where a city-wide co-ordination of services has been introduced, TB rates have been drastically reduced. A London wide TB action task force, which has both authority and funds to act, would be best to co-ordinate the many players needed to succeed with TB prevention. The current fragmentation of responsibilities and funds is the biggest challenge London needs to overcome to prevent TB.

TB needs to be tackled by primary care through LTBI screening, tertiary services through streamlined services using economy of scales, PHE and the CCGs by providing funds and other resources in the event of outbreaks, the PH function at the local authorities through local leadership and involving

other relevant council services such as housing for example. Voluntary organisations and mobile xray units are also key.

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

Orchestrating a London wide task force with authority and funds would be the best way to support TB prevention in my view, or at least to co-ordinate at a London level and make funding flows and responsibilities explicit

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

Best person to ask about that would be Lynne Altass from NHS England – in North London they have brought TB rates down by streamlining tertiary services

NYC and Amsterdam approach is the most impressive in changing the course of TB in large cities with high TB prevalence.

Thanks

connie

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# **Tuberculosis (TB): an epidemiological analysis and review of service provision in Hammersmith and Fulham, Kensington and Chelsea, and Westminster**

Tri-Borough Joint Strategic Needs Assessment (JSNA) Report 2014

March 2014

## This Report

This TB needs assessment supports the development of a tri-borough strategy and Clinical Commissioning Group (CCG) commissioning intentions.

It specifically aims to describe:

- the prevalence, trends and characteristics of TB in the tri-borough,
- the current service provision with regards to prevention, screening and management of TB, and
- whether existing services are meeting the needs of residents in the tri-borough and identify gaps in services and areas of unmet need

Data was collected from a number of sources including the London TB Register, the 2011 census from the Office for National Statistics, and local data provided by stakeholders and providers. Interviews were conducted with key stakeholders and providers.

## Report authors and contributors

This report was written by Dr Connie Junghans with the help of Dr Ike Anya, Colin Brodie, and Dr Sarah Carter.

## Acknowledgements

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## Executive summary

Tuberculosis (TB) is an airborne disease that is treatable, but if left untreated leads to important health deficits and may be fatal. It can be latent in people exposed to TB and emerge as an active disease later in life. The prevalence of TB across the Tri-borough area is twice as high as the national average and, although stable at present, the tri-borough faces unique challenges in preventing TB. TB is a notifiable infectious disease with new cases being reported to Public Health England (PHE). Previously this was the remit of the Health Protection Agency (HPA) which is now part of PHE.

This JSNA reports on the prevalence and characteristics of TB across the tri-borough, describes current service provision and makes recommendations to ensure services meet the needs of the local population.

## Main findings

### *Overall TB strategy and management*

The main concern with regards to TB strategy and management is the lack of clarity surrounding the strategic planning of services. The TB Action group which used to bring together commissioners and service providers is no longer in existence and there is no obvious successor. The commissioning of TB services across Tri-borough now falls to the Clinical Commissioning Groups (CCGs) with input from the Health and Wellbeing Boards. This new arrangement provides opportunities for Adult Social Care, CCGs and Public Health to join up thinking and provide a TB service which addresses current issues around provision of housing for TB patients without recourse to public funds and operate across boundaries. However, currently there is no clear arrangement with regards to the TB strategy. A London TB Control Board (LTBCB) has been set up by Public Health England London and NHS England (London Region) in order to provide strategic oversight and direction and a whole systems approach. Initially the LTBCB will meet quarterly.

### *Services for management of active TB*

Currently there are four centres at which TB services are provided with a large input of specialists for a small service, which are shaped the way they are largely due to historic reasons. Having four smaller services is problematic in terms of funding and providing appropriate staffing levels. Whilst staffing is largely adequate, the trusts struggle to recruit qualified staff in times of maternity or sick leave for example. Economies of scale are needed for the provision of specialist clinics and adequate staffing levels to respond flexibly to increased demands, e.g. while managing a potential TB outbreak or providing for more complex TB cases in the community. Specialist services have to be provided with a minimum frequency but are not working to full capacity and there is a duplication of services. The nursing service at Imperial is provided by two different providers – Imperial nursing service and the CLCH community nursing service. This arrangement, originally designed to ensure



more community input, does not work as well as hoped and creates unnecessary tensions and gaps in service provision. In terms of collaboration between the services the teams at St Mary's Hospital and Chelsea and Westminster have close working relationships. These are less well developed between the Hammersmith and Fulham (H&F) service with the other sites, likely as a result of the split nursing services and split clinic sites.

Whilst remuneration for the service is based on borough residents the services see large numbers of patients across boroughs. Whilst this is not an issue for the teams at St Marys Hospital (SMH) and Chelsea and Westminster Hospital (ChelWest), it does put pressure on the Hammersmith & Fulham TB nursing team who are unable to cross charge for people out of borough. Overall the TB services work well but there are more tensions at Hammersmith & Fulham due to the fact that the service is spread across two hospital sites and jointly provided by the acute trust alongside community nurses.

TB services at the hospitals are currently funded through the community respiratory contract as well as the acute contract but services fall short of service provision in the community. In addition, potential outbreaks are not limited to borough boundaries and frequently there is no coordination of resources across borough boundaries to respond efficiently.

The mobile x-ray unit and Find and Treat team fulfil a unique role in working with the acute trusts and third sector as well as the local authorities to find patients lost to follow up and screen hard to reach populations. They are a highly efficient and important service particularly in Inner North West London where vulnerable groups are particularly prevalent. Previously screening prisoners was part of their remit but has now been taken out, as prisons have their own X-ray equipment. However, this equipment is currently not operational, leaving a vulnerable group with high TB prevalence unscreened at present.

The management of latent TB is crucial in preventing active TB, however at present identification and referral of people at risk of latent TB is patchy. GPs have been identified as the most effective means of identifying and treating latent TB, however no pathways and no clear funding is currently identified and latent TB screening happens ad-hoc. Adequately diagnosing, treating and/or monitoring latent TB is arguably the most important step in controlling TB in London going forward. Peer education through third sector groups, for example for the Somali or Ethiopian community, is not joint up with services at present and the third sector is underused in the diagnosis and management of TB.

Vaccinations are offered at time of birth universally across Tri-borough and uptake is good. However, vaccinations for high risk children are less well coordinated and could be improved.

## Recommendations

### *Recommendation 1: Pooling staff, clinics and resources where appropriate*

#### **Combine specialist services**

In order to tackle some of the issues described earlier and make efficient use of resources, providers need to identify opportunities to pool staff, clinics and resources across provider sites to provide economies of scale. Local services need to be maintained but specialist input for example in paediatric HIV, multidrug resistant TB (MDR TB) for example may best be provided at one site running larger clinics rather than smaller ones at several sites. At present there are trusts close together providing similar expertise for a relatively small workload which is unlikely to be cost efficient.

#### **Reduce clinic sites**

The flux in workload associated with the management of an incident or outbreak argues for a larger single team or a formal co-operation between all the teams and pooling of resources or access to a dedicated resource in order to provide this service. A single service model has been shown to work in North Central London. A coordinated service for the Tri-borough would allow clear clinical leadership, standardize practice, ensure equal access to all patients referred to the acute teams, and allow for fluctuations in workload given the intensity of incident management. This will also improve TB Clinical Nurse Specialist (CNS) career progression and training.

It would be useful to map capacity across the four sites in terms of accessibility and decrease the service to two hubs with additional provision of community services.

### *Recommendation 2: Considering how hospital and community services can be provided more effectively and efficiently*

#### **Strengthen the community aspect of TB management**

One solution to improve effectiveness of the TB service could be to separate out community and hospital nursing. For the maintenance of patient continuity the acute trust needs to remain carrying out work on index case and latent TB infection (LTBI) case management including home visits in the community. However, the community service is well placed to carry out new entrant screening and active case finding (but not contact tracing connected to an index case managed by the acute trust) and provide support for hospital as well as primary care services. NICE guidance suggests that the TB service is best provided by specialists. Hence the community service could either be provided by CLCH who have access to several community clinics as well as GP clinics or by specialist TB services developed through primary care. By removing the new entry screening element from the hospital teams this would free up time for case management for the hospital teams. The community New Entrant

B7 resource at SMH (which is currently vacant) should be reviewed and utilized. Community nurses are also well placed to respond to outbreaks and large screening exercises in coordination with hospital services.

***Recommendation 4: Establishing a local pathway and programme for the management of latent and active TB***

**Establish a latent TB screening programme**

At present timely and thorough Latent TB screening is the biggest factor in preventing further TB. Paradoxically the community aspect of TB is the part of the service that's the least well covered both by the TB services as well as primary care. According to the most recent London TB report <sup>1</sup> even optimal prevention of TB transmission in the UK would only prevent a minority of reactivated TB cases in those born outside the UK. To prevent TB transmission, efforts should be concentrated on new migrants to the UK in the last 5 years. Primary care and community services play a crucial role in this regard.

**Establish a clear pathway for the management of acute and latent TB in the community involving all stakeholders**

There needs to be a clear TB pathway and dedicated funding for GP practices to identify latent and active TB cases and improve interaction and communication with GPs and hospital services with clear responsibilities and referral criteria.

A joint pathway with local authorities for the management of patients with no recourse to public funds would go a long way in preventing an increase in TB cases particularly with regards to drug resistant TB. Identifying funds for a dedicated social worker for TB would contribute to making the service more effective and efficient by establishing good links between the housing department in the council, third sector contacts and the TB teams.

Third sector services, for example voluntary organizations working within high risk immigrant communities, should be utilized by TB services in a coordinated way and included in funding streams. A latent TB screening programme could benefit from joint work with the third sector (e.g. Ethiopian Women's Group, Midaye Somali Development Network).

***Recommendation 3: Reviewing current commissioning arrangements and establishing specific service specification and service level agreements for TB***

**Unbundle the components of TB service costs and establish clear service specifications and service level agreements**

Financing of the services plays a major part in its delivery. The CCGs are crucial in funding both community and hospital TB services adequately going forward.

Currently TB payments are bundled into the acute respiratory block contract or respiratory services for TB nursing by CLCH. The Payments By Result (PBR) method does not allow for flexible allocation of the funds across all the various elements of TB care such as screening activities, data entry, cohort review, contact tracing and incident management. Essential TB work is not just the treatment of a patient with TB but largely preventing cases of TB, hence screening activities need to be funded as part of the overall package of TB care. Unbundling the TB costs and assigning average costs for the different elements of the service may help in providing for all aspects of TB care. Bundling TB into the bigger services risks essential funds being diverted from TB. Additionally, no service specifications exist, making assignment of responsibilities difficult.

Since TB services are part of the acute block contract it is important to know how TB cases are coded for tariff payment – infectious disease cases attract nearly twice the tariff of a respiratory medicine tariff. This would also provide a solution for The TB service at Imperial would benefit from It would also allow for cost efficiencies.

### **Unify services under one provider**

Clear service level agreements specifically for the TB service are needed. The Imperial College Health NHS Trust (ICHNT) allied clinic TB nursing service comprising nurses from ICHNT and Central London Community Healthcare NHS Trust. Whilst the CLCH nurses currently work well with Imperial Colleagues there are a long standing history of issues and concerns, mainly derived from having to work across two organizations with different funding arrangements in place. There are tensions within the H&F service with regards to funding that do not arise in the other centres at which staff, consumables and other resources are paid out of one budget.

Unifying the service for all of the Imperial services under one contract would go one step further in improving the service in terms of management structure, ability to cross cover, optimize clinic access, utilize directly observed therapy (DOT) more effectively and allow uniform practice and clinical accountability. Currently commissioning TB nursing separately across the Imperial sites is neither clinically desirable nor cost effective. In addition, CLCH nurses do not benefit from training in HIV or paediatrics and have limited career progression by not being part of the hospital team under one employer.

### **Consider joint TB funding across regions**

The knock for knock arrangement between boroughs for larger services does not work well with smaller specialized services such as TB. Therefore not operating a strict borough boundary but instead joint funding via the various commissioners might work better. This is a more pressing problem for H&F where two different contractual arrangements are in place for CLCH. A separate pooled resource for providing additional resource at short notice such as external security for sectioned TB admissions at hospital or to fund additional workload around potential outbreaks

would be desirable. Alternatively, resources for outbreak management could be clearly earmarked but this may be resolved by unifying some of the services.

Resources for pharmacy DOT need to be identified in order to meet the need for patients requiring access out of hours and weekends. Providers need to establish between them what pooled resources are required and available to meet demand for the service. This would need to include all provision for incident management and active screening. Employment of non-clinical staff to deliver some of the outreach work including contract tracing may achieve some cost savings.

The work of the mobile X-ray unit and the Find and Treat team who fulfill a unique and crucial role in TB prevention and treatment London wide has to be adequately funded and future proofed. The prisons are currently not screened at all despite high rates of TB among the prison population. This needs to be addressed urgently.

## 1. Key facts about TB: why is it an important issue?

Tuberculosis (TB) is an airborne disease caused by a bacterium which usually affects the lungs but can develop in any part of the body. Pulmonary TB (affecting the lungs) can spread the disease to others. TB is curable in almost every case if the full treatment is taken (usually 6 months involving up to 4 drugs), otherwise the disease can return in a drug-resistant form (which can take up to 2 years to treat and is associated with a higher mortality). Therefore directly observed therapy (DOT) should be considered for every person with adverse risk factors for adherence<sup>2,3</sup>.

The sequelae of untreated TB include pneumonia, spinal/ bone lesions, meningitis and kidney injury and leads to premature morbidity and mortality. TB is still fatal in about 3% of cases. After the initial inhalation of infectious TB, some individuals infected with TB do not immediately progress to active TB but have latent TB. These people do not have active TB disease and are not infectious. However, 10 per cent of these patients (5% in the first two years after infection and 0.1% per year thereafter, but at a higher risk if they are immune suppressed) will go on to develop active TB at a later stage of their life and may be infectious.

The identification and treatment of people with latent TB is therefore an important part of TB control as preventative treatment may stop progression to active disease. TB is notifiable and an important part of prevention is contact tracing (identifying exposed individuals who may have latent infection or active disease) to prevent further transmission or outbreaks. Children, the elderly and immune suppressed people are the most vulnerable to developing active TB. A comprehensive vaccination programme is crucial in protecting children from the most severe forms of TB disease.

Even though TB is relatively uncommon the consequences of poorly controlled and/or untreated TB is of major significance to public health and the NHS for the following reasons: Whilst drug-sensitive TB is relatively cheap to treat (between £1000 and £5000 per case), drug-resistant TB (or at its worst extensively-drug resistant TB) can cost at least 10 times as much. Globally around 4% of all newly diagnosed TB cases are now drug resistant. However, in those who have been non-adherent to their TB treatment multi-drug resistant TB develops in about 20%. A recent report by the all-party parliamentary group about drug resistant TB highlighted the fact that whilst only 2% of South African TB cases were drug resistant, over a third of the entire TB budget was spent on drug resistant TB<sup>4</sup>.

The risk of TB and particularly drug resistant TB is increased in individuals who have one or more social risk factors such as homelessness, drug use, alcohol misuse, imprisonment associated with a high risk of non-adherence. Often a number of risk factors co-exist.

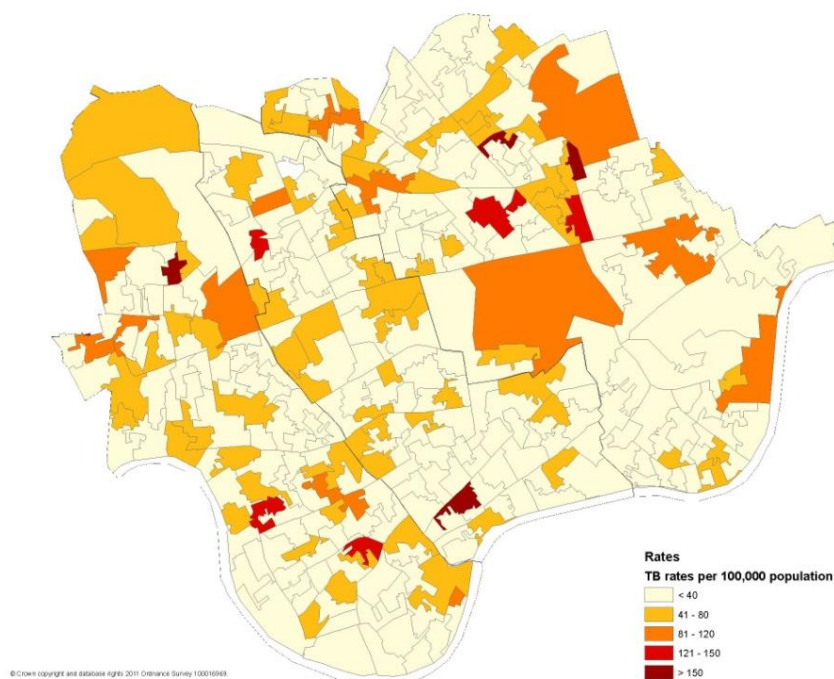
TB presents a particular challenge for the tri-borough area because of its central London location with high levels of homelessness, high density of schools, colleges, universities, work places and neighbouring boroughs with very high TB prevalence, making TB prevention particularly resource intensive for the tri borough due to large scale and complex contact tracing exercises.

## 2. Epidemiology

### 2.1 Prevalence

The prevalence of TB in London (41 per 100,000 in 2012) is significantly higher than the national prevalence (13.9 per 100,000 in 2012). Compared to outer North West London (NWL) boroughs the Tri-borough has low TB rates, with Hammersmith and Fulham at 26, Royal Borough of Kensington and Chelsea at 21, and Westminster at 23 per 100,000. By contrast, Brent has the highest rate of TB cases in NWL at 100 per 100,000, followed by Harrow at 76, Hounslow at 75, Ealing at 74 and Hillingdon at 49. The incidence rate Borough level masks marked variation at local level as seen in the map below which shows TB rates at a middle layer super output area level for the tri-borough (figure 1). 48.5% of all TB notifications were reported pulmonary TB which is very similar to the overall pulmonary percentage from London (48%).

**Figure 1: TB rates in the tri-borough**



### 2.2 Place of birth

The majority of TB cases (89%) in North West London are born outside the UK. A similar trend is also seen in tri-borough. Nationally in 2010, only 23% of cases were diagnosed within two years of entering the UK.

### 2.3 Ethnicity

In the tri-borough most cases are Black African (37%) or white (20%). This contrasts with the rest of North West London where most TB cases are of Indian ethnicity (46%) followed by individuals from Black African ethnicity (19%).



## 2.4 Social risk factors

Homelessness, drug use, alcohol misuse, mental illness and prison are all associated with a higher risk of TB. In addition, treatment completion rates in people with any of these risk factors are often poorer. A total of 9% of notified TB cases had one or more risk factors in 2012. Nationally, among cases with known information, 2.7% had a history of problem drug use, 4.3% of alcohol misuse/abuse, 2.7% of homelessness and 2.5% had a history of imprisonment. Across tri-borough these figures are considerably higher (table 1).

**Table 1: Social risk factors among TB cases by Borough of residence**

⚠: Some of these cases had multiple risk factors and should be treated with caution

2012	Total population	All TB cases	Drug use		Homeless		Prison		Alcohol		Mental		% non- British born
H&F	184,000	68	1	1	3	4	3	4	4	6	4	6%	41%
				%		%		%		%			
RBKC	158,700	48	2	4	3	6	2	4	0	0	8	17	46.3
				%		%		%		%		%	%
Westminst er	219,400	65	5	8	5	8	3	5	2	3	6	9%	52.2
				%		%		%		%			%

\*sources: LTBR, ONS

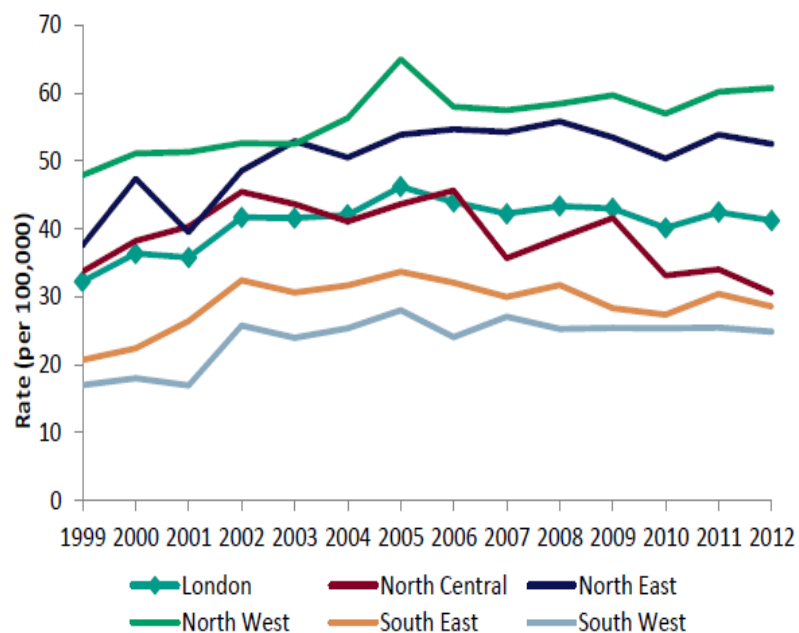
When homelessness is defined as either current, recent, or any time in the past (majority are likely to be currently or recently homeless) then the figures for homeless people affected by TB in 2012 is as follows (table 1): Overall 11% of people with TB were homeless (15/132) in 2012, up from 6% (11/180) and 7% (11/152) in the years previously in the tri-borough. Hammersmith and Fulham reported 46 individuals with TB in 2012, of which 4 (9%) were homeless. Corresponding figures for 2011 and 2010 were 3(4% of 68) and 1(2% of 54). In RBKC 2 individuals were homeless with TB (6% of 33 TB notifications) in 2012 (2011: 3(6% of 47), 2010: 4(11% of 36)). In Westminster 9 people were homeless with TB in 2012 (17% of 53), compared with 8% (5/65) in 2011 and 10% (6/62) in 2010.

In summary the proportion of homeless individuals with TB is increasing in the tri-borough, particularly driven by Westminster and Hammersmith and Fulham (H&F) whereas the Royal Borough of Kensington and Chelsea (RBKC) has remained steady after an initial decrease. The numbers are likely to be a minimum estimate as this information is unreliably recorded on the London TB Register according to them.

## 2.5 Time trends

TB rates in London have risen by 50% between 1999 and 2009. Within London, the North West London (NWL) sector has the highest number of TB cases compared with the other sectors (figure 2). In the last six years TB notifications per year in NWL have remained over 1000 with the highest numbers reported in 2011. Whilst trends have either increased or remained static in the London sectors, the only sector which has shown a marked reduction of TB notifications is North Central, where the TB service and contractual arrangements were changed in 2007, highlighting that TB control may be supported by coordinated service provision and additional multi disciplinary staff that meets TB patient needs.

**Figure 2: Tuberculosis case rates by London Health Protection Team, 1999 – 2012**



London TB rate per 100,000 population by sector of residence reported to the London TB Register (based on Tuberculosis in London: annual review 2012 data)

### In a nutshell

TB presents a significant challenge for the tri-borough primary and secondary care services. High risk groups are particularly prevalent in the inner London boroughs. There is high population churn and a high immigration rate from TB high risk countries. The prevalence of multi-drug resistant (MDR) TB is currently one of the lowest in the capitals of Western Europe despite the fact that TB rates are highest; however any increase in MDR TB is associated with a potential spiralling of costs. The number of TB cases is staying the same or increasing, indicating that TB control across the tri borough is not adequately managed at present. The tri-borough teams also have a high density of large scale contact screening incidents given the number of schools and colleges in the area. The recent NHS re-organisation presents an opportunity to improve TB services but also a danger of disintegrating services.

### 3. TB service provision

#### 3.1 NICE guidance on TB services

##### Elements of a comprehensive TB service

- a) Planning and monitoring
- b) Management of active TB
- c) Improving adherence
- d) New entrant screening
- e) BCG vaccination
- f) Active case finding
- g) Contact tracing and outbreak prevention

The NICE guidance on TB published in 2006<sup>5</sup> and 2011<sup>2</sup> identifies key priorities for implementation. The London Tuberculosis Register which is hosted by Public Health England and completed by TB services in London contains data against which to measure service performance. These came from the London TB Metrics developed by London's TB services.

- a) **Management of active TB** – including adequate treatment regimen, completion and contact screening. Performance measures: (1) A minimum of 1 specialist TB nurse for every 40 TB notifications (annual TB notifications) or 20:1 for cases requiring enhanced case management and admin support of 1 WTE admin worker per TB clinic at AfC Band 3 or above, measured quarterly and annually is required to provide an adequate service. (2) Treatment completion rates: Treatment outcome reported for all TB patients, on a quarterly basis for the 12 month preceding period, to achieve, as a minimum, 85% treatment completion rate (national target) using WHO equation  $\% = (C/T) \times 100$  where C is treatment completions using the 'treatment status at 1 year' field on LTBR (numerator) and T is all TB notifications (denominator) including deaths but now in keeping with international standardization excluding MDR TB cases and denotifications. Prevention of further infection (contacts) (3)
- b) **Improving adherence** – recommends that all patients should have a risk assessment for adherence to treatment, and Directly Observed Therapy (DOT) should be considered for patients who have adverse factors on their

risk assessment, in particular: street- or shelter-dwelling homeless people with active TB, patients with likely poor adherence, in particular those who have a history of non-adherence at risk assessment. Performance measures include (4) Risk assessment and identification of complex needs: Percentage of notified TB patients assessed on a quarterly and annual basis for: drug use, homelessness, past or current prison, alcohol, mental health issues (5) Directly Observed Therapy (DOT): The preferred care support system for patients assessed as requiring DOT is delivery according to the London TB DOT standard where 100% TB patients requiring DOT receive DOT. Lost to follow-up: All lost to follow-ups (LTFU) are identified and referred to the designated support service according to the London protocol for LTFU patients. Performance measure: (6) Services to report number of LTFU cases as a percentage of total TB notifications at 12 months (7) HIV testing - all TB patients to be offered HIV test on an opt-out basis.

- c) **New entrant screening**- recommends that new entrants be identified from Port of Arrival reports; new registrations with primary care; entry to education (including universities); links with statutory and voluntary groups working with new entrants (no performance measures). This is now superseded by point of exit screening and new entrant screening in primary care or the community setting, although arrangements for this are not yet in place.
- d) **BCG vaccination**- recommends that primary care organisations with a high incidence of TB (London is > 40 per 100,000) should consider vaccinating all neonates soon after birth.
- e) **Active case finding** – recommends that active case finding should be carried out among street homeless people (including those using direct access hostels for the homeless by chest X-ray screening on an opportunistic and/or symptomatic basis). This is done mainly by the mobile X-ray unit.

### 3.2 Current service provision in the Tri-borough

The following section gives an overview of services provided for TB in Tri-borough against the elements of a good TB service as recommended by NICE, starting with the planning of services, timely diagnosis of active and latent disease, appropriate treatment, case finding, incident management and vaccination.

Table 2 shows activity data for the different sites. The characteristics of local services, further activity data, and clinic activity are described in Appendices 1-4.

**Table 2: Number and type of notified TB cases by service**

	Episodes (total)	Active cases (of which MDR)	Paediatrics (<16)	HIV	LTBI	Adult	Paediatrics	HIV
<b>St Mary's Hospital (SMH)</b>								
<b>2013 Q1&amp;2</b>	63 (1 denotified)	<b>62 (4 MDR)</b>	5	7	<b>29</b>	24	4	1
<b>2012</b>	116 (13 denotified)	<b>103 (6 MDR)</b>	13	8	<b>98</b>	79	17	2
<b>2011</b>	146 (17 denotified)	<b>129 (not recorded)</b>	10	7	<b>91</b>	53	35	3
<b>Chelsea and Westminster (ChelWest)**</b>								
<b>2013 Q1&amp;2</b>	34 (1 denotified)	<b>30 (0 MDR)</b>	2	6	<b>37</b>	36	0	1
<b>2012</b>	50 (1 denotified)	<b>43 (0 MDR)</b>	3	9	<b>49</b>	47	1	1
<b>2011</b>	84 (5 denotified)	<b>75 (0 MDR)</b>	6	11	<b>51</b>	45	4	1
<b>Hammersmith &amp; Fulham</b>								
<b>2013 Q1&amp;2</b>	59 (5 denotified)	<b>54 (*)</b>	1	*	*	*	*	*
<b>2012</b>	142 (19 denotified)	<b>123 (*)</b>	1	*	*	*	*	*
<b>2011</b>	136 (14 denotified)	<b>122 (*)</b>	5	*	*	*	*	*

\*data not available

\*\* does not include the cases seen at the Royal Brompton and Marsden hospitals

### 3.3 Planning of TB services

Planning of TB services (including needs assessment, service strategy and monitoring) is a crucial part of delivering TB care and is now under the joint remit of Public Health London and NHS England (London region) but was previously done by the TB Action Group, Public Health and the HPA.

Elements of planning include needs assessment by examining prevalence, incidence, service provision and monitoring. It also includes service improvement, service strategy and actions based on the needs assessment and finally the commissioning of TB services.

Commissioning is the responsibility of the CCGs and NHS England. There is potential for fragmentation as various bodies have different responsibilities with regards to assessment, improvement and commissioning.

### 3.4 Diagnosis of active and latent TB (GPs, community and acute services)

GPs and TB services have a crucial role in delivering on this. New entrant identification, screening and advice for patients originating from countries with a

high TB prevalence is important. Previously, patients suspected of TB were referred into hospital services for tuberculin skin testing, IGRA tests and X-rays, whereas GP services may be able take a more active role in aspects of screening and advice by implementing new entrant screening either using an IGRA or tuberculin skin test. GPs are likely to be expected to take a more active role in diagnostic screening and advice with the out of hospital strategy.

Even though the service specification for CLCH TB nursing includes new entrant screening this has been handed over to the GP practices since the end of April 2011. GP practices have been shown to be more cost effective and efficient than Port of Arrival screenings in identifying potential latent TB cases.

However, GP screening has to date been inconsistent and no clear assessment and patient pathway exists for latent TB. H&F ran a pilot into GP screening and there are plans to roll this out in the future. Any latent TB cases suspected by GPs are currently referred into the hospital based TB service for diagnostics and treatment. There is local variation in the early identification of TB cases with GPs in high prevalence areas being faster to recognize and refer TB than other areas.<sup>1</sup> GPs occasionally use choose and book instead of referring into services directly, thus delaying timely diagnostic work up. The identification of latent TB cases is mainly done through screening of patients originating from high prevalence countries. It has recently been agreed by the London Control Board that there is a threshold of 150 per 100,000 by the London Control board, helping provide clear criteria for screening for latent TB for primary care.<sup>2</sup>

There is very little TB support work carried out by the third sector. Some isolated TB projects were run in the past by the Ethiopian Women's Group or Midaye Somali Development Network for example. Joined up work would benefit a latent TB screening programme in the future. There is huge untapped potential for encouraging immigrants from high risk countries to seek help with peer initiatives.

### 3.5 Treatment of TB following diagnosis

There are 3 hospital teams covering St Mary's Hospital (SMH), Charing Cross Hospital, Hammersmith Hospital, and Chelsea and Westminster Hospital. Imperial has three hospital sites – one larger service at SMH and two smaller services in H&F split over 2 hospital sites. TB nurse specialists, TB/ infectious disease or chest consultants, outreach workers and social workers are based in hospital. Social workers are often working in isolation at the hospital sites and there is high staff turnover. There are no social workers specifically dedicated to the TB services. The guidelines

<sup>1</sup> *personal communication Wazi Khan, PHE, March 2013*

<sup>2</sup> *personal communication Dr On Min Kon 20 October 2013*

recommend 1 TB nurse for every 40 TB patients and 1 TB nurse for every 20 complex cases requiring enhanced case management.

H&F is unique in that the TB service is provided via the CLCH community TB nurses based in the two hospitals working together with hospital consultants. Once patients are diagnosed with TB they need to receive the appropriate treatment e.g. with the right medication and making sure that the drug course is completed (6 months usually or may be up to 2 years with drug resistant TB).

The first line drug regimen consists of 4 antibiotics called Isoniazid, Rimpicin, Ethambutol and Pyrazinamide. In the initial phase daily Isoniazid, Rifampicin and Ethambutol is given for 8 weeks. This is then continued either with Isoniazid and Rifampicin for a further 18 weeks.

Adherence to the medication is crucial in preventing drug resistant TB. Directly observed therapy (DOT) is therefore often used in patients at risk of non-adherence. DOT for patients at high risk of non-adherence is an important part of managing acute TB. In the tri-borough DOT happens in around 10% while patients with risk factors are around 20% (this however has to be considered carefully as DOT is often depending on more than just having a risk factor and patients without risk factors may require DOT and vice versa as assessed by the clinicians). There are initiatives by the teams to enable DOT cost effectively such as using Skype or smart phone applications.

Outreach workers provide DOT in hours but there is no dedicated funding or process for out of hours DOT delivery. Every patient has a risk assessment for adherence and loss to follow up, there are clear situations when DOT should be considered, if the case manager does not recommend DOT or DOT is not possible for a patient with risk factors, then there is a formal discussion with the MDT to make the ultimate decision on DOT. At Chelsea and Westminster Hospital the TB nurse specialists deliver DOT in about 10% of patients in collaboration with GPs, hostels and pharmacies relying on the good will of the institutions involved, even though the number of patients with at least one risk factor for non adherence is higher than 10%. Provision of pharmacy DOT needs to be formalized and funded. Funding in the past has been on a case by case basis, which is neither sufficient nor efficient. The team at St Mary's Hospital is the only team with a TB dedicated outreach worker.

TB treatment therefore requires resource-intense case management, multi disciplinary TB clinics, provision of TB beds with negative pressure facilities as well as making sure that contacts are traced and screened to prevent the spread of TB. This treatment is the responsibility of the acute trusts and is currently split between CLCH nursing services and Imperial trust nurses in H&F. TB microbiology services and reference laboratories as well as inpatient infection control services need to be provided. In Westminster and the Royal Borough of Kensington and Chelsea (RBKC)

this element of the TB service is provided through the acute service, in H&F it is split between the acute trust (which pays for the medical staff) and CLCH which provides the nursing element of the TB services in the hospitals. The social element of housing for homeless patients on treatment is provided by the council and voluntary sector or public health in patients without recourse to public funds.

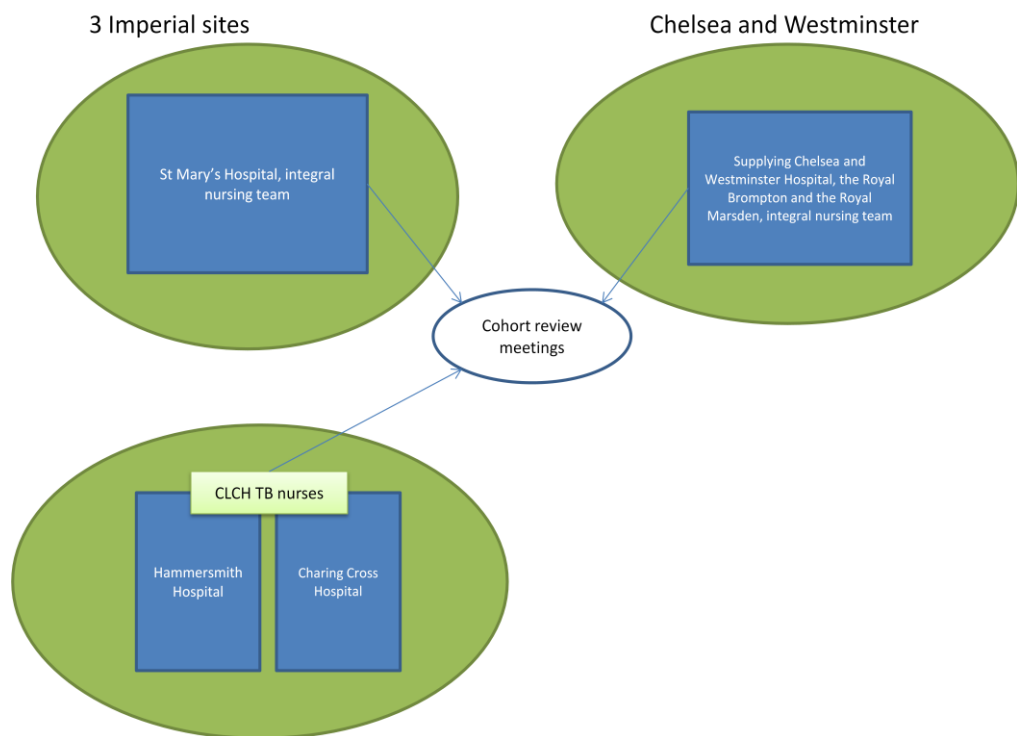
Provision of data for monitoring and quality control by the service providers to Public Health England (who take overall responsibility for TB monitoring) is also a requirement, while performance management falls to the commissioners. However, there are currently no formal arrangements or pathways for this.

Community work is covered more or less well by individual teams but lack priority in all settings, regardless of whether the service is commissioned through community nursing services or via the acute trust contract. Very few TB patients are managed as inpatients hence community work plays an important role in adequate TB management. The acute trusts are currently responsible for home visiting, managing access to social care and support in the community, and do outreach work in collaboration with community services such as pharmacies, community infection control, GP services, the councils and voluntary sector, although collaborative work with these organisations is rare and ad hoc at present.

There is no formal access to social funds to sort out temporary housing during DOT for example and is done on an individual basis, proving time consuming and inefficient. Linking the PHE and the councils particularly the housing department may be a solution and an opportunity with Public Health now being a responsibility of local authorities.

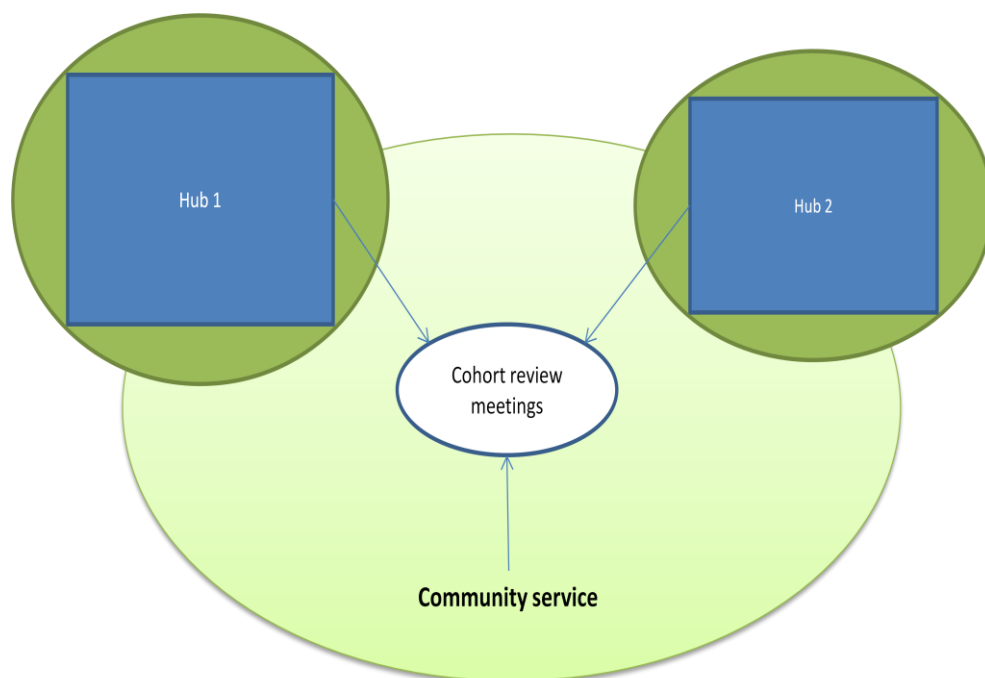


**Figure 3: Diagram of current organization of TB services in Triborough**



***\*Green shaded areas representing community outreach work from hospital***

**Figure 4: Diagram of possible re-organization of TB services**



### 3.6 Operational pressure on services

Economies of scale are needed for some clinics, for example the paediatric and HIV co-infection service needs to be offered frequently to ensure clinically appropriate rapid access but is not used to capacity and as such 'wasting' resources. Efficient use of resources while maintaining access to treatment is a challenge. Similar expertise is provided by the different TB services in tri-borough at present which is unlikely to be cost efficient.

Whilst staffing levels at St Mary's and Chelsea and Westminster hospitals are perceived as adequate there are issues in covering short term vacancies such as maternity cover or sick leave due to the difficulty of recruiting qualified staff. Staffing levels at H&F are perceived as inadequate but may be due to the fact that staff are split across two hospital sites and additional referrals to CLCH nurses for out of borough patients for whom no payment is received.

Case complexity is not linked to payment at present and this means that inadequate funding is made available over all. There is very little capacity for home visits and community DOT as there is no provision for an outreach worker apart from the TB service at SMH. Some Outreach work is provided by the TB nurses but is inconsistent due to capacity issues and hospital centricity.

H&F faces similar pressures to the other services such as little proactive community activity related to TB. It is the only service with an explicit service specification. However the existing service specification expired in 2010 and is in need of updating. Work specified in the service specification that is currently not carried out includes performance reporting, new entrance screening, providing adequate nursing time per index case and raising awareness of TB in the community.

There is insufficient staff capacity to carry out this work. Other work that is currently provided by the CLCH contract is the result of the collaboration with the hospital service and is not part of the original service spec. TB Nurses at Charing Cross and Hammersmith are frequently seeing patients for whom they are not commissioned to provide care. In 2012 there were 123 index cases managed by the two sites, however only 68 of those were resident at H&F. Consultants are able to cross charge for the care they provide but there is no equivalent agreement for TB nurses in place, even though duty of care demands that all patients are seen. Despite the service specification defining the target population as those registered in the borough ALL patients alerted to Charing Cross and Hammersmith hospital are currently seen by the service, providing full support whilst on treatment for both active and latent TB cases to ensure continuity of care. There is other work not currently commissioned that the service is providing such as liaising with local GPs to ensure adherence and continued care provision. The team provides TB screening for patients prior to Anti TB/ immunosuppressive therapy and work place screening as appropriate for staff who live outside the borough. Funding for CLCH staff is currently limited to staff costs

only and does not cover any other costs. However, there are no arrangements with the acute trusts at the Charing Cross and Hammersmith sites to provide consumables.

Historically CLCH were asked to provide the TB nursing service as they are ideally placed to strengthen the community aspect of the TB work. Theoretically clinics can be held in their own community settings to deliver DOT or see patients locally. CLCH has clinics in H&F that could be utilised to deliver screening and new entrant referrals or work alongside GPs to deliver more screening services. This is not done at present due to the lack of service level agreements and the way the service is organized and community work lacks priority in H&F similar to the services at St Mary's Hospital and the Chelsea and Westminster.

### 3.7 Active case finding

Active case finding includes contact tracing and screening high risk people such as those with social risk factors or from high prevalence countries. At present most new entrant referrals are from PHE/Immigration and very few are from GP practices even though recent evidence shows that GP practices are more effective at finding active and latent TB cases than any other services.

Acute trusts and PHE act in a specialist advisory capacity and are well placed to provide training for primary care staff and their own in house staff. This is however not a formal remit of the acute trusts at present. Raising community awareness through health promotion is not a priority for the acute trusts and there are established awareness programmes developed by TB Alert.

TB care for prison and custody sector was solely the responsibility of the prison health commissioner and is now the responsibility of NHS England.

Active case finding is an important part of containing TB infection in populations at high risk of contracting TB such as the homeless, drug abusers, alcoholics and prisoners. The acute trusts deal with the majority of contact tracing as part of active case finding. There is a London wide protocol for contact tracing. A minimum of 5 contacts per index case are recommended to be screened, which has been adopted from the NYC case management manual. Service providers work closely with PHE to determine their screening strategy.

Patients lost to follow up or non-compliant with treatment are the responsibility of the TB teams with support from the Find and Treat team (F&T team – a specialist outreach unit) and PHE. The F&T team and mobile x-ray unit based at UCLH deal with about 2% of TB cases in the minority of those with social risk factors, referred from other TB services for follow up, DOT or sorting out complex social issues. They work alongside over 200 NHS and third sector front-line services to tackle TB in people with social risk factors and scan over 10,000 high risk people annually as part of

targeted case finding. This service was set up the Department of Health in 2005 and since 2010 has been commissioned on a pan London basis. Camden CCG is now the lead commissioner on behalf of London's CCGs, as Find and Treat Services are now part of UCLH. It is operating in all London boroughs.

The TB Find and Treat (F&T) service supports the delivery of awareness raising activities among both hard to reach groups (with a higher risk of developing and transmitting TB) and front line care workers in frequent contact with these groups. It supports the early detection and diagnosis of TB among a population that would not be targeted for screening as part of the proposed screening programme. By seeking out people who have been lost to treatment and re-engaging them with services, Find and Treat supports the achievement of treatment completion indicators and reduces the risk of increasing rates of drug-resistant TB.

An evaluation of TB F&T by the Health Protection Agency was commissioned by the Department of Health in 2011. It compares the cost of operating the F&T service with the costs that would be incurred by the NHS if the service did not exist. The evaluation found that the F&T service is cost effective. It found that F&T has an incremental cost effectiveness of £6,100 - £10,000 per QALY gained. It obtains the same rate of successful outcomes as normal care, despite the greater complexity of cases. In addition, it reduces disease transmission by identifying cases before they become smear positive. 36% of MXU cases were asymptomatic on detection and would not have presented for treatment without the MXU. The F&T team provides a flexible outreach approach to care allowing opportunities to link services provided by numerous organisations into one individual package of care. It offers a unique pan-city co-ordination service. The liaison work F&T does with numerous allied agencies across the city is very important for finding hard to reach patients and keeping them on treatment.

F&T screen on average 930 homeless people per year in Westminster, over 25 TB peer supported screening sessions per year and around 10 training events and briefings for frontline third sector staff. F&T provide case management support and work with an average of 34 socially complex confirmed and suspected TB cases annually in Westminster alone. The main reasons for referral are to help locate patients lost to follow up care, to arrange housing (including admission to the TB Hostel set up by F&T for destitute patients), tracking patients through the criminal justice system and other social care interventions.

The team consists of 1 Clinical Lead, 1.5 WTE Reporting Radiographers, 1 social worker, 1 nurse, 2 Outreach workers, 1 mobile x-ray unit, 1 admin person. It is currently the only service dedicated to active case finding and has cultivated excellent relationships with hostels, TB hostels, GPs, homeless services, 3<sup>rd</sup> sector, SMH and ChelWest. It is the only consistent link between the homeless team and GPs for the homeless. There are 4 homeless outreach teams with links to Dr Hickey and Dr Reeds practice. They carry out regular hostel visits and rely on the F&T team for

support and expertise as contact tracing difficult. There is pooled funding for a mental health worker among the homeless teams. It could also be a vehicle for near patient spot testing for HIV, Hep C and deliver immunization in the future.

Prisons have recently been taken out of the remit of the mobile x-ray team even though x-ray units at the prisons are currently not operational. Previously this was part of the F&T work. Currently no TB screening takes place in prisons where TB rates are high because new dedicated x-ray equipment installed in the prisons are not operational. This needs to be addressed urgently.

### 3.8 Incident management

Incident control is a major part of active case finding and falls into the remit of the hospital teams in collaboration with PHE (or specifically the former HPA now part of PHE) in an advisory capacity. PHE is well placed to coordinate incidence control, review cases and liaise with service providers. It is also able to invoke the law on compulsory treatment. PHE maintains good relationships with all services but there is confusion over the role of PHE as funding source for incident control.

Funding of incident control falls to the service providers as part of the public health element of TB services, however there is no explicit contract for TB services, rather it is part of the acute trust contract or the CLCH community respiratory contract. This makes it difficult to agree responsibilities and funding arrangements in the absence of specific service specifications. Flexibility and structure are both needed for preparedness in the case of a suspected outbreak: flexibility because of complexity of cases and lack of boundaries, structure because there needs to be a defined pathway of action and funding to react quickly and adequately.

H&F dealt with a 186 potential exposures and 133 were screened in 2012 in 3 work places, 1 hospital, 1 congregation, 1 school, 1 custodial institution and 2 colleges. Corresponding figures for RBKC and Westminster were 38 identified and 33 screened and 395 identified, 112 screened. In Westminster 5 Food outlets were implicated in Westminster along with 2 schools, 1 college, 5 work places and 1 hospital. In RBKC 1 hospital and 2 work places were involved (figures provided by former HPA).

All teams have limited capacity to respond to potential outbreaks and responses require diversion of resources from the main service delivery (i.e. case management of known latent and active cases, their contacts, managing adherence, DOT, etc). There is no coordinated approach. Funding of extra capacity to manage an incident as advised by PHE is not formally in the budget. Whilst any incident needs a degree of flexibility at the moment it is ad hoc and much time is spent on finding resources in terms of funding and personnel by the team and PHE. Prevention and community incident assessment lack priority. Outpatient clinic appointments are offered to contacts identified through their workplace etc but if numbers are high contacts are referred to the TB clinic local to their area of residence.

### 3.9 TB prevention (via BCG vaccination)

The BCG is provided at birth by acute trusts (midwifery service during delivery) or by catch up clinics in the community provided through the CLCH health visiting service.

A universal BCG offer is now in place across the capital, with Chelsea and Westminster having recently started this as part of a CQUIN. The uptake is good at around 70- 90%, however there is no co-ordinated programme or even defined pathway for parents who decline to have the vaccination at the time of birth, are not offered it (rarely) or those who are born at home or outside the boroughs. The HPA has previously advised that London as a totality is an area of high risk even if TB rates fall under 40/100,000 hence universal BCG vaccines should be offered London-wide to provide TB protection in a mobile city with pockets of very high prevalence. However, recent national JCVI guidelines and PHE do not support this view.

Vaccine is hospital based and the vaccine is predominantly administered by midwives or obstetric nurses. At Westminster parent education at antenatal appointments to prepare them for the decision and hopefully increase uptake has been trialled by the school health nurse who's remit includes neonatal BCG delivery (personal communication Gillian McKormack February 2013) but nothing has been put in place formally. H&F trialled health visitor input for vulnerable women during antenatal visits.

The community BCG programme for all three boroughs is provided by Central London Community Healthcare (CLCH). Children who do not receive BCG at birth in hospital are supposed to be signposted to community BCG clinics by the health visitor service during the new birth visit (first two weeks after birth). Health visitors discuss BCG with parents during the new birth visit and subsequent contact visits in clinics until the child is 12 months old. An appointment is made for the child to receive BCG at a local BCG clinic.

Until the age of 1 the BCG can be given in the community by specifically trained nurses. The reason for the age cut-off is purely from a capacity point of view and the fact that after the first year it interferes with the routine immunisation schedule. Guidelines recommend that children in high prevalence areas, parents or grandparents born in a high prevalence country, unvaccinated immigrants from a high prevalence country should be vaccinated. There is no systematic process for identifying and screening new entrants from high-incidence countries, which is a national issue. Identifying children in 'at risk' categories falls largely to primary care but it's not clear how this is done. There is no dedicated service in the tri-borough to vaccinate children older than 5 years old.

Only Westminster has a programme for children older than 1, although future funding is uncertain. This comprised a community nurse post for catch up immunisations and case finding in 5 year olds through the school health

questionnaire. In 2012, 1215 questionnaires were sent along with the health questionnaire by school nurses to all reception aged children in Westminster and 349 were returned. Out of these, 147 met the screening criteria (having a parent or grandparent born in a high risk country with >40/100,000 TB cases), 5 had a BCG vaccine reported on RIO, 147 were excluded as having had the BCG after phoning parents (documentation in red book or BCG scar), leaving 101 children to be screened. Ten clinics were held in two venues (Lisson Grove health centre and Bessborough centre). 38 children did not attend, 31 were found to have BCG scar at visit and 32 were given the vaccine. Children who did not attend are not followed up further but are able to rebook. The most recent audit of this service showed that less than 1% of all children actually received the BCG vaccine. Eleven immunization clinics a month are offered in Westminster. The TB questionnaire is now sent out as part of the school entry health questionnaire in all 3 boroughs.

## 4. Summary

- TB is currently stable in the Tri-borough. The TB service needs to be seen as a service to exclude a TB diagnosis as well as diagnosing TB. Case finding and exclusion are resource intense and often complicated by being intermeshed with social care and affecting vulnerable adults. TB crosses boundaries and those most at risk of contracting TB are highly mobile. TB requires a flexible approach due to the nature of the disease but needs a more formal structure and pathways than currently exist.
- The service currently works very well together but draws on good will and relationships. There is generally a pragmatic, flexible and sensible approach to challenges and there is voluntary work force pooling. However, the current system cannot cope with increase in demand or respond adequately to outbreaks due to the flux in workload and segregation of services.
- Contact tracing and DOT is pragmatic rather than based on need, with SMH the only service offering an outreach DOT worker. Outbreak investigation and management needs to be formalised across boroughs and providers and finance planned proactively. The existing TB service is hospital centric with important community activities such as contact screening, DOT, follow up having lower priority than management of active cases.
- Latent TB is currently not addressed adequately and latent TB screening needs to be planned and sufficiently funded to deliver results. Guidance on the testing for and management of latent TB in primary care is currently lacking and GP engagement and education needs to be improved. The third sector is not sufficiently utilized.
- Using the Find and Treat team to screen vulnerable populations and find people lost to follow up is an effective way of controlling TB in these patient populations but the service needs to be reliably funded and supported. The prison population is currently not screened at all even though prisoners present an important source of TB, particularly in its multi-drug resistant form. This needs to be addressed urgently.
- In terms of BCG vaccination there is a universal neonatal offer in place with good uptake. However there is a lack of community engagement and education, particularly in the antenatal period. There is lack of clarity and structure for vaccination after the age of 1 and 5.



## 5. Next steps

- A geographical analysis of patient location and distance to sites to determine the best location for the hubs and unification of Imperial services under one contract
- A cost gathering exercise to quantify costs associated with the TB service (including incidence management, community work for which there is currently no budget identified)
- Unbundling the TB service from the acute and community respiratory contracts to allocate appropriate funds out of the overall acute and community budgets
- Formulate a clear primary care strategy and identify funding needs for screening of latent TB in new entrants in primary care
- Address the lack of screening in prisons and allocate this service/ address the reason for lack of use of existing equipment

## References

- (1) Tuberculosis in the UK: Annual report on tuberculosis surveillance in the UK, 2013. London: Public Health England, August 2013.
- (2) Clinical diagnosis and management of tuberculosis, and measures for its prevention and control. Nice clinical guideline 117. NICE 2011.
- (3) Royal College of Nursing. Tuberculosis case management and cohort review. Guidance for health professionals. 2012.
- (4) Old Disease- New Threat, APPG report. April 2013.
- (5) Clinical diagnosis and management of tuberculosis, and measures for its prevention and control. Nice clinical guideline CG33 now replaced by 117. NICE 2006.

## Appendix 1: Characteristics of the TB services in Tri-borough

Characteristics	St Marys Hospital	Chelsea and Westminster Hospital	Charing Cross/ H&F
Description	Tertiary referral centre for MDR and HIV TB and invasive sampling	Tertiary referral centre for TB	Tertiary referral across two hospital locations provided by CLCH nurses and acute trust ID consultant at Charing X and respiratory consultant and ID consultant at HH
Staffing	4.4 WTE TB Specialist Nurses (Case Managers) x1 Band 8a Lead nurse for TB at St Mary's (complex cases) x2.4 Band 7s Case management (complex cases) x1 Band 6 Case management (non complex cases) 1 WTE Specialist Community (New Entrant Screening) Nurse Band 7 vacant Outreach worker 1 wte Admin 1.6 wte (0.6 wte covered by agency)	Lead TB Clinical Nurse Specialist (band 8a)  TB Clinical Nurse Specialist (band 7)  TB Service Co-Coordinator (Band 4)	Charing Cross site: 2 nurses  Hammersmith site: 2 nurses (x1 Band 8a Lead nurse for TB for complex cases, x1 Band 7 case management nurse for complex cases, 2 Band 6 case management nurses for non-complex cases)  1.6 (HCA / outreach / admin)
Expertise	Management of complex TB cases (MDR-TB), paediatric TB, renal, spinal or neurological TB including links with the renal team, co-infection with HIV, nominated leads in HIV and paediatrics	HIV co-infection MDR TB	
Catchment area	Westminster residents  SMH informally covering W10 and 11 even though RBKC	Chelsea and Westminster, The Royal Brompton, Royal Marsden (Fulham rd site) via service level agreements SW10, SW1, SW1W, SW1X, SW3, SW5, SW7, W10, W11, W8 and part of W14.	H&F residents
Services	diagnosis, treatment, screening, infection control advice, incidence control coordination, case management and follow up	rapid diagnosis, treatment, screening, infection control advice, incidence control coordination across ChelWest, Royal Brompton and Royal Marsden, case management and follow up	Diagnosis, screening, active treatment, case management and follow up
Organisation		Weekly team meetings, monthly local MDT meetings with radiology and microbiology, quarterly sector cohort review meetings and Imperial MDT	Consultants refer into TB nursing services – sees adults and children even though initial CLCH service spec for adults only
Finance	Via acute block contract	Via acute block contract	Via acute block contract for consultants Plus via CLCH community respiratory contract for TB nurses
DOT	The team at SMH is the only team in Tri-borough with a TB dedicated outreach worker  DOT provided in hours only	DOT provided by the TB nurses for selected patients (based on risk assessment and MDT). For patients who receive DOT good relationships with GPs, pharmacies and hostels to develop other options for DOT provision are essential	DOT provided in hours only by TB nursing team where necessary
Negative pressure facilities	31: Bronchoscopy suite (x1) Chest clinic (x1) HIV outpatient clinic (x1) A&E (x1) paediatric ward(x2) adult wards(x17) HDU/ITU (x8)	13: HIV in patient ward (x10) respiratory ward (x2) ITU (x1) A&E (x1) HIV day unit (x3)	14 across two hospitals rooms across 4 wards at Charing X (x6) (another 2 not in use) Infectious disease ward HH (x8)

## Appendix 2: Activity data from TB service sites

	St Mary's Hospital	Chelsea & Westminster	Hammersmith & Charing Cross
5 yr av TB notifications (2008-2012)	121.4	59.6	123.4
Treatment completion rate 2011 pts	86.7%	90.9%	82.0%
UK born (Westminster) sector av 9.3% (2012)	17.5%	18.4%	16.3%
Av no TB pts with risk factors* (2008-2012)	19.3%	12.1%	9.7%

## Appendix 3: Clinics across the TB service sites

	Imperial: SMH		Chelsea & Westminster		Imperial: H&F			
Day					Charing X		Hammersmith	
	am	pm	am	pm	am	pm	am	pm
<b>Mon</b>	Outreach DOT (9-5) Case management On call nurse 9-5 (ward and urgent referrals)	TB Screening Clinic (follow ups) 2 nurses	Directly Observed Therapy (DOT) Hospital and/or Community Telephone clinics	Home Visits  Telephone clinics	Screening Clinic 08.30-16.00 X 2 nurses		Home visits, complex reviews (DOT)	Medical Clinic MDT X 1 nurse X 1 HCA
<b>Tue</b>	Adult Joint Medical/Nurse Clinic 3-4 doctors 2-3 nurses Home visits to DNAs, urgent referrals, weekly reviews (9-5)	HIV/TB Joint Medical/Nurse Clinic alternate weeks	Telephone clinics	HIV/TB Clinic and nurse follow up clinic	Nurse led clinic 08.30-18.30 X 2 nurses		Paediatric and Family Screen  09.00-17.00 X 2 nurses	
<b>Wed</b>	MDT Paediatric Joint Medical/Nurse Clinic alternate weeks Outreach DOT (9-5) On call nurse 9-5 (ward and urgent referrals)	Adult case manager (follow-up) clinic Evening LTBI clinic monthly	DOT – Hospital and/or community  Telephone clinics	Contact Clinic	Medical Clinic X 2 nurses X 1 HCA  Screen Reading X1 nurse	MDT	Adult Screen  09.00-13.00  X 1 nurse X 1 HCA	Nurse Led  13.00-17.00  X 1 nurse X 1 HCA
<b>Thurs</b>	TB Screening Clinic (2 nurses - news) Home visits to DNAs, urgent referrals and weekly reviews	Ward round Home visits to new cases and paediatric latent and active cases	Paediatric TB Clinic and nurse follow up Clinic	Medical TB Clinic and nurse follow up clinic	Nurse Led Clinic / Ward patient reviews  Open day , home visits X2 nurses		Paed & Family Read  X 1 nurse X 1 HCA	MDT
<b>Fri</b>	Adult case manager (fup) TB treatment clinic Outreach DOT(9-5) On call nurse 9-5 (ward and urgent referrals)	Case management	DOT – Hospital and/or community  Telephone clinics	Contact Clinic.  Monthly BCG clinic  Telephone clinics	MDT (complex)	Home visits/ admin X 1	Adult Read X1 nurse morning only	

## Appendix 4: Service specification for TB services

Only the contract with CLCH specifies the scope of TB nursing services (but not TB consultant services, which are part of the acute block contract with Imperial) within the service specification for respiratory services from 1<sup>st</sup> April 2009 to 31<sup>st</sup> March 2010. The TB Nurse Specialists commissioned through CLCH should deliver the following:

### *Patients diagnosed and referred in from Imperial consultants*

- Ensure completion of TB treatment and chemoprophylaxis in pts referred from Imperial clinicians
- TB cases diagnosed will be seen same day within 2 working days
- Offer chemoprophylaxis to those under 35, over 35s chest x-ray at 6 and 12 months
- Offer DOT to TB patient based on risk assessment
- Provide case management to patients with TB and an identified group of those at risk of developing TB through case finding and referral from key stakeholders
- Give education and advice to those with TB diagnosed by consultant and those closely associated with them

### *Patients referred in from GP with suspected TB*

- Consultant clinic for every symptomatic child or adult within 5 working days
- Index case and their contacts: full assessment including history, Mantoux test and interpretation 48 to 72 hours later (2 appointments)
- Timely screening of those who have been exposed to TB (contact tracing – appointment should be made within 10 working days)
- Further investigation (blood, sputum, chest x-ray) and consultant appointment within 2 working days if positive Mantoux and symptomatic
- Further investigation (blood, sputum, chest x-ray) and consultant appointment within 3 weeks if positive Mantoux and asymptomatic
- Vaccination of children with BCG after repeat Mantoux at 6-8 wks if indicated, vaccination of adults if indicated by work place

### *Pro-active case finding and management in the community*

- Participate in diagnostic screening for in/out patients
- Screen new entrants (Primary care referrals)
- Raise awareness of TB throughout the borough
- work in partnership with other health and social care providers to plan patient care

- play a central role in assessment, care planning, implementation, co-ordination, including case management and evaluation of care
- education programmes for prison services, hospital and community staff

*Performance monitoring*

TB Services will participate fully in the clinical governance arrangements to support clinical effectiveness and performance. Including allowing access to the service for audit and inspection purposes. Monthly performance reporting.

## Appendix 5: Comparison of TB services by elements of service specification for TB services

Service specification	SMH	ChelWest	H&F
Patients diagnosed and referred in from consultants/ GPs: Ensure completion of TB treatment and chemoprophylaxis in pts referred from clinicians	yes	yes	Patients diagnosed with TB actively followed up by the Specialist Nurse thereby reducing the new to follow up ratio of consultant outpatients.
TB cases diagnosed will be seen within 2 working days for outpatients	for cases diagnosed on wards and in clinic (but not on the weekend) 2 days reasonable for outpatient work (i.e. weekends are clearly an exception)	yes	All patients starting treatment as an outpatient are seen on the same day. All inpatients are seen within 2 days of starting treatment.
Offer chemoprophylaxis to those under 35, over 35s chest x-ray at 6 and 12 months	yes according to protocol chest x-ray follow up is 3 and 12 months	yes	Yes Currently 8 patients on DOT for TB
Offer DOT to TB patient based on risk assessment	yes	Based on risk assessment offering patient choice i.e community or hospital DOT, or other methods like video assisted DOT (VOTS).	
Provide case management to patients with TB and an identified group of those are at risk of developing TB through case finding and referral from key stakeholders	all suspected active cases case managed	Yes, all suspected, active and chemoprox cases are case managed	Partially carried out
Give education and advice to those with TB diagnosed by consultant and those closely associated with them	yes	Provide education and advice to patients diagnosed with TB and TB chemoprophylaxis and for those closely associated with them. i.e. family/friends/work colleagues (if required).	yes
For patients referred in from GP with suspected TB: Consultant clinic for every high likelihood symptomatic child or adult within 5 working days as defined by imaging or symptom complex	yes if index of suspicion is high and with results from screening in nurse led clinic	5 working days not realistic to see a consultant physician	Nurses see new symptomatic referrals within 2 working days or 24 hours for those with suspected pulmonary TB. Patients are then seen by a physician within 1 week.



Service specification	SMH	ChelWest	H&F
Index case and their contacts: full assessment including history, Mantoux test and interpretation 48 to 72 hours later (2 appointments)	Patients are screened according to specific algorithms for symptomatic individuals and contacts and these include full history/ Mantoux/IGRA and imaging – the timelines are implicit within the algorithm and test modality.	Index case and their contacts: full assessment includes full history, Mantoux/IGRA/radiology / Sputums within specified timelines	Nurses take full history and risk assess each index case to determine contacts. Only those under 35 get a Mantoux test (not index cases as Mantoux can not diagnose active disease). Patients given a MT are followed up 48 -72 hours later. And / or IGRA testing and chest x-rays
Timely screening of those who have been exposed to TB (contact tracing – appointment should be made within 10 working days)	Contacts are prioritised according to risk (e.g. pulmonary versus extra-pulmonary and those most at risk e.g. children), as far as I am aware there is no specific mandate to screen all contacts within 10 working days	All patients are prioritized and given appointments according to date of exposure and risk.	Screening offered to contacts – for pulmonary Smear + contacts this is within the 10 day period and followed up at 3 months. For non smear + index cases appointments offered within 4 weeks, capacity unable to provide all contacts within 10 days.
Further investigation (blood, sputum, chest x-ray) and consultant appointment within 2 working days if positive Mantoux/IGRA/ symptomatic	Patients screened to specific algorithms and these further investigations are done at the initial visit rather than waiting for Mantoux results, patients are appointed to clinic within 1-2 weeks depending on index of suspicion.	Screened by the TBCNS if referral is urgent and patient is symptomatic. Two working days to see a consultant physician not realistic.	Yes. New GP referrals / contacts that symptomatic seen within 24 hours by TBNS. Consultant appointments are weekly, however access to registrar within same time frame as TBNS.
Further investigation (blood, sputum, chest x-ray) and consultant appointment within 3 weeks if positive Mantoux and asymptomatic	Those that are asymptomatic with positive TST / IGRA may be appointed within 1-4 weeks (evening LTBI clinic, those waiting to commence anti TNF are usually appointed sooner 1-2 weeks 3 weeks arbitrary, a month ok	Symptomatic patients get priority, however if clinic appointments available these will be offered to this group. Otherwise wait can be between 2-4 weeks.	
Vaccination of children with BCG after repeat Mantoux at 6-8 wks if indicated, vaccination of adults if indicated by work place	SMH provide BCG to contacts and NE (and as defined by NICE), not routine BCG for children, workplace travel etc	BCG given to patients that are screened through contact clinic or children 'at risk' on an individual basis	Only since April 2012 have BCGs been given to children. Employee Health commissioned to do work place BCGs for Health care workers.
Pro-active case finding and management in the community: Participate in diagnostic screening for in/out patients	yes	Yes	Patients are seen as contact. No pro active case finding happening. All cases are reactive from contacts.

Service specification	SMH	ChelWest	H&F
Screen new entrants (Primary care referrals)	Yes, if referred but these are ad hoc	Yes, only if referred by primary care	No, this is not taking place on the scale required. We only see referrals from PHE / Immigration. Very few come from GPs
Raise awareness of TB throughout the borough	Not part of an acute service specification and would be best encompassed by a strategic overview for public health	No, this would not be considered the remit of secondary care.	No teaching for any HCPs is taking place.  No proactive sessions for patients or hard to reach groups.
Work in partnership with other health and social care providers to plan patient care	yes	Yes	Work closely with all health care providers to ensure TB patients receive appropriate care.  Not working with enough GPs / Community Health Care Providers to improve and promote the service.
Play a central role in assessment, care planning, implementation, co-ordination, including case management and evaluation of care	yes	Yes	yes
Education programmes for prison services, hospital and community staff	not applicable to SMH team yes around WTBD and in response to requests annually response to requests from CLCH HIV forum	No prison in RBKC, Occasional requests from community groups. Hospital in-house education for medical and nursing staff	no
Governance Improving Productivity Increase in Case Management caseload Increase numbers of new entrants screened from 2008/9 baseline 40 index cases to 1 TB Nurse New Entrant Screening Target 4 week wait	New entrant screening is currently occurring on an ad hoc basis as the provision of new entrant screening will have to be strategically decided on and funded – the current view is that this should occur in primary care with IGRAs and referral into local service as per an agreed algorithm. This is currently not funded within inner NWL	We adhere to the 2/52 target for GP referrals for suspected Pulmonary cases must have an appointment within 2/52 of being referred by the GP, have to be seen and assessed by a member of the TB team.  New entrant screening occurs when a GP sends a referral (this is adhoc).	This target would be for New Entrants, BCG and screening patients as index patients - new TBs are seen within 2 working days.

Service specification	SMH	ChelWest	H&F
<p>Keeping patients in TB Treatment</p> <p>Lost to follow up reduced</p> <p>Completion of TB treatment improved</p> <p>Active DNA follow up / reduction in DNA's / DNA policy, Reduction from 2008/9 baseline, Evidence from audit &amp; LTBR</p>	<p>All these aspects are certainly an issue to measure and are published but for a service do not necessarily relate to any borough and should be measured per service</p>	<p>Some of this data is available via LTBR and some would need to be collated locally for each service. C&amp;W team make a huge effort to improve on the listed aspects of care continuously.</p>	<p>1.6 band 3 Vacancy posts currently out for recruitment. Mix HCA / admin roles to reflect need of service and allow reaction to demand of outreach worker. DNA rate has reduced from 34% to 4% in 6 months</p> <p>Currently no Lost to follow ups.</p>
<p>The TB Service will participate fully in the clinical governance arrangements to support clinical effectiveness and performance. Including allowing access to the service for audit and inspection purposes.</p>	<p>Via the cohort review process</p>	<p>Via the cohort review process</p>	<p>Via the cohort review process</p>
<p>Performance Reporting</p> <p>Performance reporting will be monthly, the key to reporting is that it provides analysis of the information</p>	<p>no</p>	<p>C&amp;W performance team request certain data quarterly</p>	<p>no</p>

## Appendix 6: Question guide for service providers

Location of service (if on multiple sites, please indicate)

Type of commissioning: part of block contract, individual contract

Is there a service specification for your service?

Outline the services you provide

Referral- how do patients access your service(s) – e.g. Open-access, referrals from other organisations/professionals (please specify)?

Outreach work

Screening- Do you deliver it? Who do you screen? How are they referred to you? How do you deliver screening?

Contact tracing- What is your role in risk assessment and contact tracing?

Advice to other clinicians in hospital

DOT- do you offer it? How? What models do you use?

Immunization- do you offer it? How is it delivered and to whom?

How do you collaborate and interface with other services?

Is there anything that is unique to your service?

Commissioning- are the current commissioning arrangements clear? Who is the lead commissioner for your service? Do you meet regularly with them? Do you have clear lines of communication with the commissioners? How do you interact with the commissioners? What would help improve the current arrangements

Configuration- Are the current configuration of TB services effective and fit for purpose? What would help improve them?

Staffing- Is the current staffing adequate? If not, what would improve the current staffing- new roles, more wte in existing roles?

Standards and targets- Do the current standards and targets capture the essence of the service? Are they Specific, Measurable, Accurate, Relevant, Timely? What changes should be made?

Community outreach- Are you satisfied with the current arrangements for community outreach? If not, what should change?

DOT- Are the current arrangements for DOT clear? Are they satisfactory? If not, what

should change?

Immunisation: Are the current arrangements for BCG immunisation fit for purpose?

If not what should change?

Prevention

Housing

Incident management: Are the current arrangements for BCG immunisation fit for purpose? If not what should change?

Pathways- Are the current pathways for TB treatment, immunization and outbreak management in the Tri-borough area clear? If not, what elements need clarification? What would you recommend?

Any other comments/suggestions

I, today, found out from a friend about your investigation tomorrow at City Hall and thought you might be interested in my case of TB in 2011. I was in an induced coma and hospitalised for four months. If it wasn't for the excellent consultant, I would not be here today.

If you would be interested in hearing more at this late stage, I would be happy to furnish you with more information. I have plenty to tell! Unfortunately, I am out today at a funeral, but can respond this evening to any queries you may have.

Regards

Dear Health Committee

I was in extremely close contact on a daily basis, with someone who contracted TB and nearly died.

We both attended the same day centre.

We had been on holiday together prior to her diagnosis and hospitalization.

Neither I nor anyone else at the centre were screened as far as I am aware.

I have been extremely ill since November 2012 without a diagnosis.

## Tuberculosis by Patient Y

I almost died after being diagnosed with TB in 2011, but my story began a couple of year's before that, which eventually led to my hospitalisation at Croydon University Hospital, Croydon from May to September 2011.

I would, on and off, have a high temperature over the space of a couple of years or so and had blood tests at my doctor's surgery, but they could not find anything wrong with me and told me to go to A&E if it got worse.

Unfortunately, I suffer from Bi-Polar and during a particularly stressful time, fell really ill and at the same time, unbeknown to anyone, I contracted TB. 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.

A few days later, my parents called an ambulance for me and it was discovered that I had low blood pressure and was taken to A&E. It was about a week later that I was diagnosed with TB and sepsis and placed into intensive care. My parents were informed during the first six weeks that I may not make it – the TB was very advanced. My consultant said to me a few months after leaving hospital, when I returned to the chest clinic for a check up, that she had seen better patients with TB upon being admitted to hospital compared with my condition leaving hospital four month's later! She said she was surprised when I was admitted to hospital that I could breathe because I was so ill!

In hospital I had a low white blood cell count and had several transfusions, the cultures taken took six weeks to develop and the antibiotics were not sufficient to fight the TB. I had a tracheotomy and was put onto a ventilator for most of my four month stay in hospital and was also put into an induced coma for two weeks and eventually, with the aid of multiple antibiotics and steroids, along with an assay of medication, they started to work. Then I caught a virus and fell dangerously ill again. I was also diagnosed with pneumonia. Once I had been put into isolation I started to improve again and was home convalescing after four months, mostly in intensive care. I also developed a pressure sore in the early days in hospital, which then went down to the bone which was agonising and I also received morphine for back spasms. My hair all fell out and I was skin and bones. I very slowly recovered and received physiotherapy. Being laid up for four months in hospital, I had to learn to walk again and then was sent to my parent's home to convalesce – a very long two year plus process.

ITU at Croydon University Hospital was second to none and the staff there were excellent, especially Dr Anne Dunleavy, my consultant, who literally saved my life.

You ask for people's thoughts on what could be done to improve the awareness of TB. My doctor's surgery did not recognise any of my TB symptoms. Had they, I would have been treated two year's earlier by simply putting me onto a simple six month course of antibiotics. Apparently, I was the first patient at my surgery to contract TB, but I was angry and extremely concerned that not one doctor was aware that TB was and is prevalent in the UK, especially since, at the time I went into hospital, there were thousands of cases reported across London alone. In fact by the end of 2011 there were 8,963 cases reported across the UK.



I was considering suing my surgery for negligence – as I have a mental illness the three year limit may not apply to me and my mental state seemed to override any physical ailments that I had.

I notice that you have to be screened now from certain countries if coming here for more than six months. Has anyone thought about medically screening immigrants and refugees for TB, as a matter of course, even if their stay is under six months? I know they do so in America and Australia and before they even enter the country. I used to attend and volunteer for a social club run by Mind in Croydon and a lot of migrants go there that suffer from mental health problems. The only place I could have caught TB was at this club and I reported it to the chest clinic at Mayday Hospital, when requested, but never found out if they did any checks. I believe TB is a notifiable disease.

I am not fully recovered four year's later as I have numb toes and fingers, permanent lower back pain, coughing fits and I feel sick every morning without fail. The doctors, consultants and physiotherapists have no idea as to why, except the coughing as my lungs are permanently damaged.

By the way, I found this quote from the Lancet in a government document online which is a bad indictment for the UK...

Quote .....

"The UK has been labelled by some the "western capital for tuberculosis" (Lancet vol 377 January 2011 "The white plague returns to London") and TB in people born abroad is a factor commonly quoted"..... End Quote.

Pity my surgery did not pick up on this at the time.

By Patient Y  
1 August 2015