



# Final Project Report

## London TB Service Review and Health Needs Assessment



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## Contents

EXECUTIVE SUMMARY and RECOMMENDATIONS .....	6
CHAPTER 1 - INTRODUCTION .....	23
1.1 Tuberculosis and London .....	23
1.2 Policy Context.....	25
1.3 Project Details .....	26
1.4 Report structure .....	27
CHAPTER 2 - EPIDEMIOLOGY .....	28
2.1 What this section contains .....	28
2.2 Principal patterns of incidence.....	28
2.3 Mortality .....	46
2.4 Treatment completion .....	61
2.5 Summary – what this chapter shows .....	68
CHAPTER 3 – LITERATURE REVIEW .....	72
3.1 What this chapter contains .....	72
3.2 TB treatment policies and strategies.....	72
3.3 Effectiveness of exemplar service models.....	81
3.4 Review of key areas of TB control & practice.....	86
3.5 What this chapter shows .....	91
CHAPTER 4 - TB SERVICES IN LONDON .....	92
4.1 What this chapter contains .....	92
4.2 Introduction .....	92
4.3 Geography .....	93
4.4 Reviewing London’s TB services .....	95
4.5 Service Review Questionnaire .....	95
4.6 Discussion – what this chapter showed.....	119
CHAPTER 5 – SERVICE PERFORMANCE .....	124
5.1 What this chapter contains .....	124
5.2 Hospital In-patient activity .....	124
5.3 Current rates of admission.....	132
5.4 Length of stay (LOS).....	134
5.5 Hospital Out-patient Activity .....	138
5.6 London TB Service Metrics.....	138
5.7 What this section showed .....	160
5.8 Conclusions.....	161
5.9 GP Prescribing .....	162
CHAPTER 6 – COMMISSIONING EXPENDITURE & FINANCING.....	166
6.1 Introduction .....	166
6.2 Methods.....	166

6.3 Results.....	166
6.4 Discussion.....	172
6.5 What this section shows.....	172
CHAPTER 7 – EXPERIENCE AND VIEWS OF SERVICE USERS .....	176
7.1 What this chapter contains .....	176
7.2 Methods.....	176
7.3 Results.....	178
7.4 Findings.....	180
7.5 What this chapter shows .....	187
CHAPTER 8 – DISCUSSION.....	189
8.1 Introduction .....	189
8.2 NHS Reorganisation .....	189
8.3 Epidemiology.....	189
8.4 Findings from the literature review .....	193
8.5 TB services in London .....	194
8.6 Services - Requirement for specialist care .....	198
8.7 Measuring, reporting and responding to performance .....	199
8.8 Centralised London-wide standards of care .....	200
8.9 Information on activity and finance .....	200
8.10 Patterns of need – expressed by users.....	201
8.11 A Board of TB Control for London.....	202
8.12 Controlling TB in London .....	204
CHAPTER 9 RECOMMENDATIONS.....	205
9.1 Central leadership and management .....	205
9.2 Standardisation of clinical policy and practice .....	206
9.3 Performance.....	207
9.4 Accessibility and responsiveness of services .....	208
9.5 Lead providers.....	209
Appendix A – Service mapping questionnaire .....	210
Appendix B - Service user interview questions/prompts.....	222

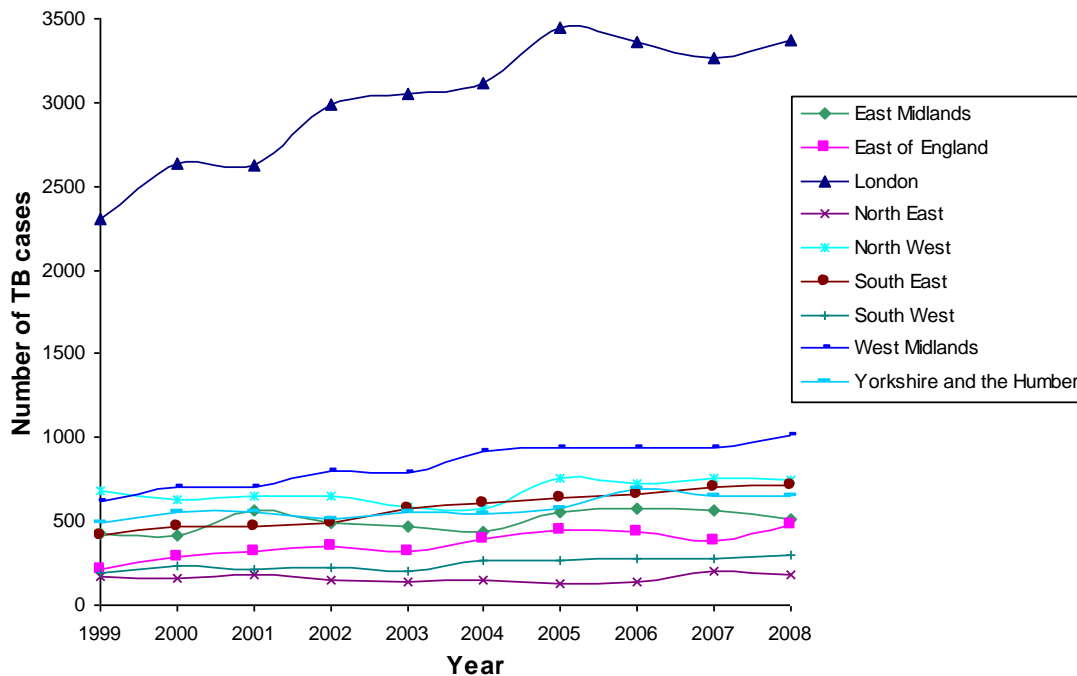
## EXECUTIVE SUMMARY and RECOMMENDATIONS

### Introduction (see Chapter 1)

Tuberculosis (TB) is an infectious disease that is both curable and preventable, but remains a major global killer, being responsible for 1.3 million deaths in 2008. In London, the incidence of TB has been steadily rising over the last few years and remains considerably higher than other regions in England.

**Figure A: Tuberculosis case numbers by region, England 1999 – 2008**

Sources: HPA: Enhanced TB Surveillance: ONS Mid-year population estimates



The escalating burden of TB in London needs to be seen against a background of helpful national guidance and policy development. The Health Protection Agency publishes regular updates on the epidemiology of TB. The CMO has published a national TB Action Plan (2004).<sup>2</sup> NICE Guidelines have been published on the clinical diagnosis and management of TB, together with measures for its prevention and control (2006).<sup>3</sup> A TB Commissioning Toolkit has been developed by the Department

<sup>2</sup> *Stopping Tuberculosis in England: an Action Plan from the Chief Medical Officer.* London: Department of Health, 2004.

<sup>3</sup> *Guidelines for the Management of Tuberculosis and its Control.* London: NICE, 2006

of Health (2007).<sup>4</sup> Earlier reports on TB in London have also highlighted local issues and made recommendations.<sup>5 6</sup>

30 main specialist TB services provide care for TB patients in the capital. Additionally, Great Ormond Street Hospital cares for children with complex disease. The *Find and Treat* team provides a further specific service (including a mobile X-Ray unit), funded by DH until March 2011, to work with hard to reach and excluded groups to promote engagement with services and to reduce losses to follow up.

Five sector-wide clinical networks have promoted good practice and supported the local commissioning of TB services. Nine metrics have been agreed to measure differing aspects of performance against local standards across London, and in 2009 the London TB Commissioning Board produced its *Vision and Commissioning Strategy for TB in London*.

Despite this context, the burden of TB in London each year continues to increase.

This project was commissioned by the London TB Commissioning Board as part of its work to deliver its commissioning strategy.

## Radical changes in the NHS

Our report must be considered against a background of significant further reorganisation in the NHS. Strategic health authorities and PCTs are to be abolished, with 80% of the NHS commissioning budget delegated to GP-led consortia by 2013. Transitional arrangements are still under development and it is currently unclear what the regional and sub-regional arrangements will be within the sphere of operation of the newly proposed NHS Commissioning Board.

The need to improve control of TB in London is sufficiently pressing that action needs to be planned now and implementation begun, despite organisational uncertainty.

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<sup>4</sup> Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high-quality services in England. London: DH, 2007.

<sup>5</sup> Tuberculosis in London, 2007. A report from HPA London and NHS London: HPA 2009.

<sup>6</sup> Hayward A. Tuberculosis control in London: the need for change. A report for the Thames Regional Directors of Public Health, June 1998.

## Epidemiology (see Chapter 2)

### ***General trends***

The number of new cases of TB in London reached a total of 3,450 in 2009, compared with 2,309 in 1999, an increase of nearly 50% in ten years. People born outside the UK account for about 85% of new cases of TB in London; this is not because of a recent influx of infected new entrants to the country: 80% of TB cases born overseas have lived in the UK for more than two years and over a third have lived here for more than ten years.

### ***Geographic distribution of cases***

London's TB caseload is widely spread across most boroughs. Nearly a third live in North West London. In 2009, 19 of the 30 TB services in London saw more than 100 new TB cases; three (Northwick Park, London Chest and Newham) notified more than 200 new cases. Only two services (Bromley and Queen Mary's, Sidcup) notified less than 50 new cases (21 and 8 respectively).

North West and North East London have both seen significant increases in TB incidence and caseload over the last ten years. The only PCT to have seen a steady fall in incidence is Southwark; this difference would be worth investigating.

TB is a disease strongly linked to certain communities, especially those ethnic minorities linked to countries with high TB prevalence, such as sub-Saharan Africa, the Indian sub-continent and Eastern Europe. TB is a feared and often stigmatised disease, so cultural context and health beliefs are important factors to understand when treating individual patients. These factors mean that TB services need to be well integrated into local communities, and accessibility and cultural sensitivity are important.

Given the numbers and distribution of patients currently needing treatment, and the number of times they need to see health professionals during long courses of antibiotics, suggests that the availability of *local* services is important to maintaining compliance with treatment, as well as preventing spread of disease. This is a strong argument for retaining the current number of TB services in London – provided they achieve quality standards.

### ***Outcomes – death from TB***

Deaths from TB are relatively rare; in 2008 a total of 3,376 new cases of TB were notified in London; in that year there were 69 deaths from TB.

Case fatality ratios (deaths vs cases notified) at PCT level suggest that there are relatively more deaths in some localities with fewer cases; this could be due to differences in age profile in these areas, but the issue deserves further investigation.



Cohort review across London using a standard methodology can provide more robust information on the risk of death from TB in London, as well as providing checks on service quality.

### ***Outcomes – drug resistance***

In 2009, 135 cases of Isoniazid resistant TB were identified in London, about 10% of all culture-confirmed cases (up from 7% in 2008). A third of Isoniazid resistant cases are treated in NE London and about a quarter in NW London. There were 19 cases of Multi-drug resistant TB (MDR-TB) across London and one case of extremely drug resistant TB (XDR-TB) (in Brent).

However, the drug resistant caseload of individual services is therefore small in contrast to their caseload of non drug-resistant TB.

### ***Risk factors associated with poor outcomes***

Drug resistant TB can develop if treatment is not taken regularly or stopped prematurely. Risk factors associated with poor compliance or failure to complete treatment (which can lead to recurrence of infectious TB or drug resistance) include: alcohol use, homelessness, drug taking, a previous history of TB, time spent in prison, and mental health issues. TB is already more common in these vulnerable and socially excluded groups because of their tendency to poor immune status and increased risk of exposure to infection.

Considerable information about individual TB cases is compiled on the London TB Register (LTBR), a web-based resource hosted by the Health Protection Agency. The recording of risk factors in the LTBR shows that a worryingly large proportion of patients do not have their risk factors recorded – in NW London, 9% of patients were reported to have an alcohol risk factor, but in 36% of cases this field in the LTBR was left blank.

Each service needs adequate administrative support to ensure that the LTBR can be completed in full for each patient. The process needs to be driven by a standard approach across London, supported by audit and cohort review.

### ***Use of Directly Observed Therapy (DOT)***

For those patients with risk factors, enhanced case management is necessary and for some of them DOT<sup>7</sup> is indicated. Our project shows poor correlation between the frequency of observed risk factors and the use of DOT. Some clinics clearly have a much lower threshold to trigger DOT than others. Where there is pressure on staffing there may be a risk that thresholds for DOT may become too high.<sup>8</sup> A standardised approach for London needs to be agreed.

### ***Outcomes – treatment completion***

Treatment completion rates across London vary considerably. Completion rates reported by the West Middlesex have been among the lowest in London for the last five years and in 2009 were only 61%. Low rates have also been reported for the Royal Free (73.6% in 2009).

Definitional issues<sup>9</sup> need to be resolved and standardised. Completion rates for fully drug-sensitive TB should be separately compiled and the current minimum standard of 85% should apply everywhere. Completion rates for drug resistant TB and other complex cases should also be considered separately.

This will require an agreed approach across the whole of London; data should also be collected centrally by the Health Protection Agency (or its successor body) and reported regularly as a performance metric.

### ***Outcomes – loss to follow up***

Losses to follow-up are a concern because of the risk of disease progression or reactivation (with the additional risk of infecting others), plus the possibility of drug resistance. In 2008, Newham, with the largest caseload in London, reported only one patient lost to follow up. By contrast, there were 8 lost each to Northwick Park and the West Middlesex and 7 to St Mary's.

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<sup>7</sup> Directly Observed Therapy (DOT). An enhanced degree of care involving direct observation by health workers, family members or community members of the taking of anti-TB medication by patients being treated for TB disease.

<sup>8</sup> Goodburn A, Drennan V (2000) The use of directly observed therapy in TB: a brief pan-London survey. *Nursing standard*; **14 (46)**: 33-38.

<sup>9</sup> The measurement of treatment completion is complex; for example, a patient dying within 12 months of disease notification is recorded currently as not completing treatment. The same can apply to complex cases requiring especially prolonged treatment.

A standard approach is needed to minimise losses to follow up, with an agreed threshold for referral to the Find and Treat service for advice and support. Changes of service models to incorporate more community based outreach work may help to reduce losses to follow up. Losses to follow up should be considered as a performance metric.

## Literature Review (see Chapter 3)

Our literature review examined key local, national and international sources of evidence of relevance to London, regarding:

- TB treatment policies and strategies – including service standards;
- Effectiveness of exemplar service models – including organisation & operation;
- Key aspects of TB control and practice – including treatment thresholds, contact tracing and new entrant screening.

The review showed that there is no shortage of current national and local strategy and policy guidance to inform commissioners of TB services and other stakeholders, including earlier reports with proposals for action in London. However, our project suggests that in some respects services in London may not always work in ways consistent with national guidance.

New York and from Amsterdam were studied as service model exemplars. Evidence from New York shows the extent to which local policy and practice has been centrally managed by the New York Bureau of TB Control. The New York model shows that centralisation of both coordination and accountability, with investment in a community based model of working, has led to a dramatic turnaround in the annual trend; each year's total of new cases is consistently less than the preceding year (see **Figure B**).

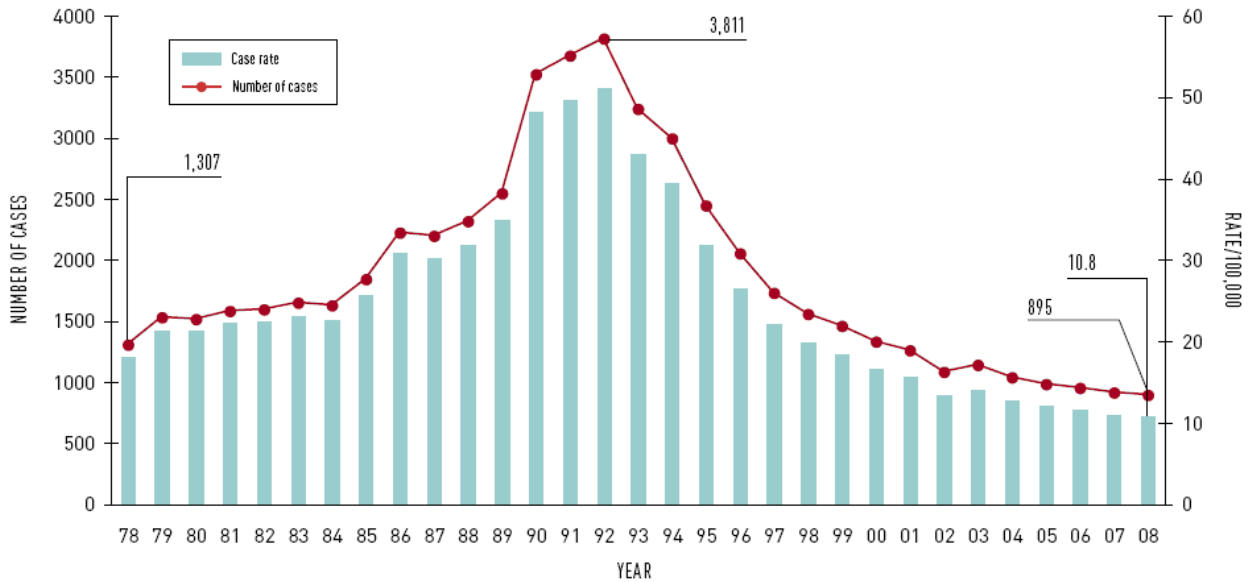
Agreed thresholds for the use of DOT (lower than those used in London) is held to have accounted for much of this reduction in incidence. An equally important influence may have been the central control and monitoring of TB treatment and prevention across the whole city.

The New York model is more community based than is the case in London. It is intentionally patient focussed, with field workers to provide DOT at locations convenient for patients; flexible clinic times include late evenings; the New York equivalent to London's Find and Treat team are integrated with medical and nursing provision, many working out of the clinics rather than from a separate site.<sup>10</sup> These models of working should be considered for London.

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<sup>10</sup> F. Dobniewski. Personal communication.

**Figure B: Tuberculosis cases and rates, New York City, 1978-2008**



Source: Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene (2008).

The New York Bureau of TB Control (there is currently no London equivalent) has published a 270 page manual containing care pathways, protocols and procedures for every possible clinical decision to be made in the care of patients with TB – including clinical care pathways, thresholds for DOT and protocols for TB prevention, including screening of new entrants and the contacts of identified cases.<sup>11</sup> This strong centralised commissioning approach needs to be adopted in London.

## TB services in London (see Chapters 4 and 5)

### General description

Specialist TB services in London are provided by 30 different hospital clinic services across the capital; all provide inpatient care if needed; 29 provide outpatient services

<sup>11</sup> <http://www.nyc.gov/html/doh/downloads/pdf/tb/tb-protocol.pdf>

as well as inpatient services. They are widely distributed geographically. This is appropriate, given the distribution of TB cases.

### ***Inpatient care (see Chapter 5)***

Many patients with TB experience an inpatient spell; we have shown that the ratio of the number of admissions to number of cases notified is around 1:2, suggesting that on average one in three patients with TB require a spell in hospital. For those needing inpatient admission, hospitals providing care tend to be those closest to where patients live.

It proved challenging to access and analyse good quality inpatient activity data. In turn this meant that length of stay and costs were difficult to examine with full confidence.

### ***Outpatient care (see Chapter 4)***

To understand patterns of outpatient care, we gathered more detailed service by use of a survey questionnaire. All 29 services responded.

#### *Service model*

The questionnaire showed that the current model of care provided to support TB patients out of hospital in London is predominantly a traditional one based on the outpatient clinic. Hours of availability are typically 9am to 5pm, Monday to Friday. No clinics were reported at weekends. Only two hospitals reported the use of a telephone helpline out of hours.

A few respondents mentioned the availability of an outreach service, and some services have staff able to go out into community settings, but these appear to be the exception. All services reported access to interpreting services; but not all have access to advocacy.

It is important for services to get closer to communities from whom TB cases are drawn; this requires a more proactive and imaginative approach involving community case workers, joint work with housing agencies and the local authority and providing care in settings other than the hospital outpatient block. Such examples seem to be rare.

#### *Workforce issues*

Broadly, the larger the case load, the bigger the stated nursing team and the greater the number of clinics held. The use of more generic case workers seems to be small.

All TB services in London must be able, as a minimum, to hit the traditional, pragmatic and evidence-based target that one specialist nurse is required per 40 notified cases of TB.<sup>12</sup> This particular benchmark has been in existence for over ten years and is a minimum standard; in London it is not universally met.

### *Conclusion*

The impression received is that of 30 services working in relative isolation, with little or no sharing of staff and limited work across or within sectors to share good practice. An exception may be the arrangement in North Central London, where all nurses work in one team and are employed by one hospital although deployed in several services across the whole sector. This model could be replicated elsewhere to achieve economies of scale and to create a workforce pool and this should be considered.

Improvements to the current outpatient model in use across London require a radical re-think. Consideration of moves toward the New York model would seem appropriate, empowering more generic community workers to take on some of the work currently tackled by a hard-pressed specialist nursing workforce.

### ***The Find and Treat service (see Chapter 8)***

It was not within our remit to evaluate the effectiveness and impact of the Find and Treat service team, currently based in a centre in Soho and funded (together with a Mobile X-Ray Unit) by the Department of Health until the end of March 2011. That evaluation is being performed by the Health Protection Agency.

TB clinic staff appear uniformly positive about the effectiveness of Find and Treat, and most have used it as some point. The model of care used by Find and Treat is important, because it is based on extensive outreach work in hard to reach, socially excluded or otherwise marginalised communities; Find and Treat have also developed an important role for peer educators working with these communities.

### ***New entrant screening (see Chapter 5)***

There is no one model for delivery of new entrant screening across London. Arrangements between Port Health, the Health Protection Agency and services seem to vary. Work needs to be done to agree a standardised model of new entrant screening across London.

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<sup>12</sup> The ratio should ideally be lower where the caseload is complex or where patients predominate from especially vulnerable or socially excluded groups.

### ***Screening contacts of cases (see Chapter 5)***

There is no standardised protocol for this and performance is not currently recorded as a TB metric. Comments from respondents suggest that if a service is hard pressed, then it may be difficult to devote as much time and energy to contact tracing and screening as is required.

One possible solution in London would be to contract with a specific service to provide contact screening across London. This option should be explored further.

### ***Service configuration (see Chapter 8)***

This needs assessment did not include a detailed organisational review of service configuration. However, some observation can be made.

A model of multiple TB services across the capital, each located close to patients, makes sense - provided services have good understanding of the needs of the local communities from whom the patients are drawn, and provided also that caseloads are large enough to ensure clinical quality.

We therefore believe that the current arrangement of around 30 TB services in London should be retained, provided that they are each able to perform to agreed quality standards, with appropriate staffing levels and delivering a more community based model of care.

The model is less appropriate for the management of complex cases, including those with drug resistant or MDR-TB, the numbers of which are currently very much smaller (see further below).

### ***Specialisation (see Chapter 8)***

#### ***Drug resistant TB***

The number of drug-resistant TB cases managed by individual TB services is small; some services may already be under pressure from the size of their overall TB workload. We have seen that the recording of risk factors and the frequency of use of DOT is also variable across London.

Within each sector, one provider could be designated to take the lead on drug-resistant TB, providing support to each local service, and ensuring that the most rigorous standards of individual care and contact screening apply. Because of the need to provide care close to where patients live (especially if they are in a socially excluded or vulnerable group), local services should be responsible for delivery of care. The role of the lead unit would be to provide clinical leadership, support and advice to ensure that standards of care are met.

### *TB in children*

A total of 5% of TB cases notified in 2009 were in children under 16 years. Ultra-specialist paediatric care is available for complex cases at Great Ormond Street, but for more routine cases of TB in children, clinicians have to rely on working relationships between TB consultants and paediatricians.

A lead paediatrician could be agreed in each network / sector to lead on care of children with TB. The arrangement could be similar to drug-resistant TB described above: leadership and support from one specialist team to ensure that paediatric clinical pathways are easily followed.

### *Services for renal, spinal and neurological TB*

We believe that it would be equally sensible for the care of renal, spinal and neurological TB (especially TB meningitis) to require a role for a lead clinician in each network / sector under a similar arrangement. This should be explored.

## ***Measuring, reporting and responding to performance (see Chapter 5)***

Nine performance indicators for TB services (the London TB metrics) were agreed by the Stopping TB in London group in 2005, to support the implementation of the CMO's Action Plan. We reviewed the utility of these metrics, how they had been used to assess service performance, and current performance against them.

Current arrangements are *ad hoc*. Two metrics have been universally achieved, but some metrics have no utility; others have not been systematically monitored. Two cannot currently be measured. The five sector networks have used different approaches, at differing time intervals, and there has been no evidence of coordinated action in response to the findings. The metrics as a whole need to be revised.

Neonatal BCG immunisation programmes also appear to be achieving poor coverage, especially in North West London. A minimum coverage rate needs to be agreed as a future metric. There are arguments in favour of universal neonatal BCG immunisation across all London's boroughs. However, given that this was not included for in-depth examination in the remit of this project, it appears appropriate that this should be considered as part of a detailed review of the BCG policy options for London.

Only 18 services appear currently to meet the agreed minimum standard of one specialist nurse per 40 notified cases.

Overall, there needs to be a standardised approach to metric measurement, content and timing, with collation at a central point (ideally, the Health Protection Agency or its successor body) and regular reviews of impact and utility.



### ***GP Prescribing (see Chapter 5)***

Unexpectedly, our analysis found that important volumes of anti-TB medication are being prescribed in general practice across London. The total cost of prescribing the four main anti-TB antibiotics in 2009/10 was £298,662.52. The largest volumes and total costs of GP prescribed anti-TB medication were in North West London.

The prescribing of these volumes of anti-TB drugs may be problematic, given their side effects, the unfamiliarity of most GPs to using them and the risks associated with poor compliance.

### **Information on activity & finance (see Chapters 5 and 6)**

Elements of the project examining NHS service activity (inpatient and outpatient) and finance (commissioning expenditure) demonstrated current constraints in the availability and analysis of data on these aspects of TB commissioning. It appears that helpful aspects of the DH TB Commissioning Toolkit have not been adopted to date.

Within these limitations we estimate that London PCTs are spending a total of around of £4 million on inpatient admissions (£933,000 elective admissions, £3.2 million non-elective). There is significant variability between PCTs, but those with the highest incidence seem to be spending the most on TB care.

If a more centralised model of TB commissioning for London is implemented (see below), improvements are required in these aspects in order for commissioners to be adequately well informed and for performance to be monitored and managed.

### **User Views (see Chapter 7)**

Interviews were conducted with a range of service users across London. The most commonly expressed opinion of users interviewed was that they would like to see better training for GPs and more awareness raising about TB for the public in general. GPs are often perceived as slow to recognise the symptoms of TB and slow to act. This provides an opportunity for TB services to develop their relationship with local GP teams, and for initiatives to increase diagnostic awareness and promptness of referral.

Clinic staff were reported to sometimes seem to lack empathy and understanding, although generally clinic services were appreciated and some TB patients felt a sense of social dependency. Interpreters are often available; less frequently available are patient advocates – an important aspect of care for socially marginalised groups.

For those patients attending hospital before a diagnosis has been made, diagnostic delay due to their being asked to return to their GP in order to be re-referred to a different hospital department appeared important.

This is avoidable. Tertiary referrals should normally be allowed where the symptoms of the patient are little changed, but where another opinion is required in order to form a diagnosis.

## Conclusions (see Chapter 8)

The management of TB in London needs to become more standardised and a greater degree of central control applied. There is currently a complete lack of standardisation of clinical pathways of care across London. A manual of protocols and pathways for London is needed (based on the New York equivalent<sup>13</sup>). The London TB metrics need extensive revision, performance monitoring needs to be centralised, and accountability for performance needs to be improved.

The current model of 30 geographically distributed services should be retained, subject to more rigorous performance monitoring. The five sector-wide clinical networks should also be maintained, but their role needs to be standardised and strengthened. Lead providers should be identified in each network for drug resistant TB, paediatric TB and for renal, neurological and spinal TB.

A London Board of TB Control should be established, whose prime objective should be to reverse the trend of year on year increase in TB incidence and in burden of disease. Membership of a future Board of TB Control would need to be drawn not just from the NHS, but also from the Department of (Public) Health, from local authorities, from the office of the Mayor of London, from users of services, and from the third sector.

TB is too specialised a topic, requiring broad public health action for the commissioning of TB services to be led by local GP commissioning consortia. The Board of Control will need to be viewed as the body fulfilling a specialist commissioning function for TB in London (although its terms of reference will be wider than this).

A Board of TB Control would deliver its objectives through:

- Standardisation of clinical care, of prevention and of performance measures;

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<sup>13</sup> *Clinical Policies and Protocols*. New York: Bureau of Tuberculosis Control, Department of New York Department of Health and Mental Hygiene, 2008.

- A robust and consistent management approach (including the commissioning of services across London);
- Transparency of performance;
- Accountability for delivery.

## Recommendations (see chapter 9)

This Report is submitted at a time of turbulent change in the NHS. The commissioning structures that existed when the work began are due to be radically altered.

Meanwhile, as a public health priority, TB in London needs to be brought under improved control. We believe that this can only be done by using a London-wide structure for leadership and decision-making.

The following recommendations should be considered by the London TB Clinical Reference Group and the London TB Commissioning Board (which commissioned the work), in consultation with senior colleagues in NHS London (including the Director of Public Health for London) and the Department of Health, with local authorities and with the office of the Mayor of London. The development of an agreed action plan should not be delayed by wider changes in the NHS.

### ***Central leadership and management***

- 9.1.1 Establishing a Board of TB Control for London should be considered. Similar to the approach adopted in New York, the Board would be responsible for achieving the overall objective of a year on year reduction in the incidence of TB in London. The Board would also be the central point of accountability of services for their performance against agreed standards of TB prevention, care and control.
- 9.1.2 A Board of TB Control would deliver its objectives through:
  - Standardisation of TB prevention, care and control, with agreed care pathways and performance measures;
  - A robust and consistent management approach, including the commissioning of TB services across London;
  - Transparency of performance;
  - Accountability for delivery.
- 9.1.3 Membership of a Board of TB Control for London should not be restricted to the NHS. It should comprise representatives of London's TB services, expertise in public health, specialist and GP commissioning, together with users, community and third sector representatives, local authorities and the office of the Mayor of London.
- 9.1.4 Robust clinical and managerial leadership should be identified, both for London as a whole and at network level. The current arrangement of five networks across the capital should be retained and strengthened.
- 9.1.5 TB services for London should be commissioned London-wide; commissioning of TB services should not be delegated to GP Commissioning Consortia.

- 9.1.6 Arrangements supporting the availability and analysis of information on NHS TB service activity (inpatient and outpatient) and commissioning expenditure should be reviewed, with reference to the DH TB Commissioning Toolkit.
- 9.1.7 The commissioning of TB services across London should involve local authorities, service users and the third sector.
- 9.1.8 A Board of TB Control for London should (in the future) work closely with GP Commissioning Consortia, with local Health and Wellbeing Boards and with Directors of Public Health to ensure that TB services in each network develop active and effective relationships with GP teams and with local communities.
- 9.1.9 The current arrangement of widely dispersed geographically accessible TB services should be retained, subject to more robust performance information, especially for those with small case loads. Relationships between services and local communities need to be substantially strengthened.

### ***Standardisation of clinical policy and practice***

- 9.2.1 Clinical policy and practice for TB prevention, care and control across London need to become standardised.
- 9.2.2 A manual of standardised protocols and procedures for the prevention, diagnosis, clinical management and control of TB across London (including assessment of lifestyle risk factors and thresholds of hospital admission) should be developed (similar to the *Clinical Policies and Protocols*<sup>14</sup> used in New York). This manual should be consistent with NICE and other Guidelines. From such a manual, care pathways and standards of care should be derived. Thresholds should be agreed and standardised for the use of Directly Observed Therapy (DOT) across London, with an agreed set of definitions as to what constitutes DOT. Protocols should include a pathway indicating where tertiary referrals are required for those patients who are suspected of having TB.
- 9.2.3 Standard protocols should be agreed for the delivery of the screening of new entrants from countries of high TB prevalence and of contacts of incident TB cases. In both instances, performance information should be made available (see below).
- 9.2.4 Standard protocols are also needed for screening of contacts of cases. Current arrangements for contact tracing and screening appear unsatisfactory. One possible solution in London would be to develop a specific service to provide contact screening across London. This option should be explored further.
- 9.2.5 We have established that there is widespread prescribing of anti-TB medication by GPs. This should be investigated.

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<sup>14</sup> *Clinical Policies and Protocols*. New York: Bureau of Tuberculosis Control, Department of New York Department of Health and Mental Hygiene, 2008.

- 9.2.6 Systematic Cohort Review should be introduced as a quarterly event in all networks, with representation across networks as well as from all providers within them. Cohort Review (including reviews of TB deaths) should be viewed as a multi-disciplinary team event and all disciplines should be represented. An overview of the principal issues arising from each Review should be made available.

### **Performance**

- 9.3.1 The nine current London TB metrics should be revised in the light of current context and performance against them across London.
- 9.3.2 Metrics concerning liquid culture (Metric 8) and sputum smear reporting (Metric 9) are no longer required. The metric regarding the interval between GP referral and seeing TB services (Metric 2) should be dropped. That concerning contact screening (Metric 7) should be dropped and later revised.
- 9.3.3 The coverage of neonatal BCG immunisation (Metric 1) is very patchy across London, especially in North West London. Where current policy is for *universal* neonatal BCG immunisation, action should be taken now to ensure proper reporting of uptake and coverage. A minimum coverage rate needs to be agreed as a future metric.  
The appropriateness of *selective* neonatal BCG immunisation in some London boroughs should be reassessed, and the case for adopting a programme of *universal* neonatal immunisation across the whole of London should be considered as part of a detailed review of the BCG policy options for London.
- 9.3.4 London requires each TB service to be adequately staffed with specialist nurses and administrative support. At sector level, this is a priority for North West London. All services should achieve the minimum standard of one specialist nurse per 40 notifications per year. Commissioners and service providers need to ensure that services are adequately funded to achieve this. Also, the replication of the integrated model of staffing such as seen in North Central London could be considered elsewhere to achieve economies of scale and to create a wider workforce pool.
- 9.3.5 New, effective metrics are required, having utility to clinicians as well as to commissioners and which can be easily measured. A group should be tasked to work up new metrics of proven utility. The Health Protection Agency (or its successor body) should be asked to collate TB metric performance using a standard methodology, with results reported to the London Board of TB Control as well as to networks.
- 9.3.6 New metrics could include the following areas:
- Documentation of individual patient risk factors;
  - Use of DOT (adjusted for/considering known risk factors);
  - Numbers and outcomes of those screened as new entrants;
  - Numbers and outcomes of those screened as contacts of incident cases;
  - Numbers of those lost to follow up who are found within an agreed period.
- 9.3.7 Treatment completion rates should also be measured separately for drug resistant or complex cases where completion within 12 months of notification,

with compliance, is unrealistic. Low treatment completion rates (less than 85%) of less complex cases should lead to remedial action in the services concerned.

### ***Accessibility and responsiveness of services***

- 9.4.1 All TB services should become more closely integrated into the local communities from whom most of their patients are drawn, with less dependency on patients attending the hospital outpatient department. Service models need to include outreach and community based provision, using a wider skill mix than specialist nurses, and with access not only to interpreting services, but also to patient advocacy.
- 9.4.2 All TB services should develop their relationships with local GP practice teams; this should include initiatives to increase diagnostic awareness of TB and to encourage prompt referral of possible cases. Advocates should be available as well as interpreters, especially in services with large caseloads.
- 9.4.3 The Find and Treat service provides a community based model of working which is valued by mainstream TB services. If its evaluation (currently ongoing) proves positive, learning from this should become integrated into the workings of all London TB services.
- 9.4.4 Clinic accessibility should be enhanced with more flexible hours of opening, including the availability of advice and support out of hours and at weekends. This is especially important for patients who have been able to return to work and may enable more to return to work.

### ***Lead providers***

- 9.5.1 A lead provider should be identified in each sector for the management of drug resistant TB. The lead provider would provide support to each local service on notification of a drug resistant case and would ensure that the most rigorous standards of individual care and of contact screening are applied.
- 9.5.2 We believe that it would be equally sensible for the care of renal, spinal and neurological TB (especially TB meningitis) to require a role for a lead provider in each sector under a similar arrangement. This should be explored.

## CHAPTER 1 - INTRODUCTION

### 1.1 Tuberculosis and London

#### 1.1.1 What is Tuberculosis?

Tuberculosis (TB) is an infectious disease that is both curable and preventable. Its causative agent (the mycobacterium *M. Tuberculosis*) is well understood. DNA fingerprinting can pinpoint how infection spreads between individuals and across different communities. TB, once diagnosed, can be effectively treated and cured using a combination of antibiotics, all of which are readily available on the NHS.

Despite the fact that it is curable, TB has remained a major global killer, being the second commonest cause of death from an infectious agent after HIV/AIDS. It killed around 1.3 million people in 2008.<sup>15</sup> It still kills Londoners (although the numbers are small).

#### 1.1.2 An old problem, but on the increase

In London, the number of cases of TB reported each year has been steadily rising. The popular press is inclined to describe TB as a Victorian disease on the way back. While it is true that numbers of cases of TB in London in the 21<sup>st</sup> century is very substantially less than a hundred years ago, TB never actually went away. TB has always been found in London, especially where there has been overcrowding, deprivation, poverty, and inward migration of people from parts of the globe where TB is especially prevalent. None of this is new.

What has happened in the last twenty years, however, is that the number of cases reported in London each year has surged steadily and is continuing to rise, with an increasing proportion of cases showing drug resistance.

#### 1.1.3 Key characteristics of TB

There are stigmas attached to TB, and these are important factors in some specific communities, where the disease is feared and having TB is associated with shame. The truth is that nobody can be to blame for catching TB. All that is needed is to be exposed to it, and to have a vulnerable immune system. However, stigma enhances both fear and prejudice, making prevention and control more difficult.

<sup>15</sup> World Health Organisation 2010.  
<http://www.who.int/mediacentre/factsheets/fs104/en/index.html>  
accessed 29 June 2010.

Anyone can catch TB, but some populations are at increased risk. They include those with increased exposure, either within their own communities if TB is prevalent there, or through travel to parts of the world where TB is common.

People who are homeless, have poor nutrition (e.g. through alcoholism), live in poor, overcrowded accommodation or who may have prolonged exposure (e.g. prisoners) are systematically at increased risk.

Those with good immune systems may still catch TB if exposed, e.g. in the workplace or in schools, and sporadic cases occur.

TB can lie dormant with no symptoms; a change in immune status can trigger disease activation, or a recurrence in someone with a history of previous TB. The disease is often insidious and difficult to diagnose in its early stages.

### **1.1.4 Challenges in diagnosing, treating and controlling TB**

TB is a multi-system disease and symptoms can sometimes be vague and non-specific. Although the symptomatology of TB is very well described, most primary care professionals (e.g. GPs) will only see an active case very occasionally. These factors often lead to delays in diagnosis or in referral to specialist services.

Control of TB requires action across a complex mix of different interventions. Prevention requires awareness at both community and health practitioner levels, so that TB infection can be diagnosed early and the likelihood of spread minimised. This includes the need to screen immediate household and other contacts of TB cases, so that others with the disease can be identified and treated. Those thought to be at increased risk of contracting it can be immunised or given chemoprophylaxis.

Prompt treatment with specific anti-TB antibiotics is usually curative, though having to take medication for up to six months can be a problem for some patients, and treatment may involve unpleasant side effects.

The prolonged nature of treatment, with the added difficulty of achieving full treatment completion in some patient groups, (e.g. discharged prisoners, homeless and other very mobile people) has led to increasing levels of drug resistance. Up to 10% of TB cases in London last year were resistant to the first line drug Isoniazid.

In recent years, the emergence of multi-drug resistant strains of TB (MDR-TB) has become an increasing concern across the globe and each year more of such cases are found in London. One case of extremely drug resistant TB (XDR-TB) was reported in London last year, and there are likely to be others.

As detailed in Chapter 3, there is no shortage of strategic advice to inform policy makers and clinicians. The Health Protection Agency publishes regular updates on the epidemiology of TB across the country, describing in detail those factors that are associated with increased risk and susceptibility. There is national guidance from NICE on the clinical diagnosis and management of TB, together with measures for its prevention and control. The Chief Medical Officer for England has published a



national TB action plan. A national toolkit has been devised for use by NHS commissioners for the planning, commissioning and delivery of high-quality TB services.

### **1.1.5 TB in London**

Despite all these resources, the fact remains that London continues to have the highest rates of TB in the country, and those rates are going up. The annual total of new cases notified in London also continues to rise. At the same time, the number of cases of antibiotic resistant TB in London is also increasing, presenting a specific challenge to clinicians attempting to treat and control this disease.

There are a number of reasons why London can be expected to have a larger burden of TB disease than smaller cities or rural communities. They include the capital's ethnic diversity and the association between susceptible communities and relative poverty (overcrowded living conditions, poor housing, poor nutrition). Communities with links to countries with high TB prevalence are at further increased risk of exposure to TB. People who are socially excluded, or whose lifestyles put them at extra risk of contracting or suffering a recurrence of TB (such as crack cocaine users and street homeless people) tend to live in London rather than in rural locations.

But all of this is well known, and there are already many initiatives in London to improve accessibility of diagnosis and treatment for these vulnerable communities.

### **1.1.6 TB in other metropolitan cities**

Other metropolitan cities in the world with complex and vulnerable communities have had to tackle the problem of increasing numbers of TB cases. Some of the initiatives employed in these cities are reviewed in this report. The most striking example is to be found in New York, where a massive initiative (with considerable financial investment and political will) was launched more than 20 years ago to turn the trend around. The rates and numbers of TB cases in New York are continuing to fall year on year.

In London, by contrast, despite all the guidelines and national and local action plans, the rates and numbers of TB cases are continuing, year on year, to rise.

It is against this background that this project was commissioned.

## **1.2 Policy Context**

This report was commissioned in March 2010. Since then the in-coming Coalition Government has proposed radical changes to the organisation of the NHS in

England. These proposals, announced in the NHS White Paper *Equity and Excellence: Liberating the NHS*,<sup>16</sup> include the abolition of strategic health authorities and primary care trusts and the transfer of responsibility for 80% of the NHS budget to GP Commissioning Groups under the supervision of a new NHS Commissioning Board. This report will show that TB in London is a problem that requires co-ordinated solutions across the whole capital, even if current London-wide NHS bodies cease to exist.

Stakeholders and policy-makers will need to work creatively and flexibly together, both within and around new NHS structures, to ensure that action is taken that will enable TB in London to be brought under improved control.

## 1.3 Project Details

### 1.3.1 Origin

The desirability of a comprehensive health needs assessment (i.e. incorporating service review elements) for TB in London was described by the London TB Commissioning Board in their *Vision and Commissioning Strategy* in April 2009<sup>17</sup>. As a result a detailed specification for such a project was agreed with PHAST in March 2010.

### 1.3.2 Approach and methods

Consistent with the model of epidemiological health care needs assessment described by Raftery and Stevens,<sup>18</sup> the agreed project specification sought, as far as information allows, to consider and triangulate the following aspects of TB in London:

- Epidemiology of TB needs and outcomes, showing patterns of incidence, prevalence, mortality, morbidity and other outcomes, including differential needs in geographical and ethnic population groups.
- Specialist TB service quality, capacity, range, resource use, and impact; with reference to evidence and experience from elsewhere.
- The experience and views of TB service users, especially with regard to health outcomes, service access, rapidity of diagnosis and use of therapeutic treatments.
- Expenditure and finance.

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<sup>16</sup> *Equity and excellence: Liberating the NHS*. London: Stationery Office Cm 7881, July 2010.

<sup>17</sup> *Vision and Commissioning Strategy for TB*. London: London TB Commissioning Board, 2009.

<sup>18</sup> Stevens A, Raftery J, Editors. *Health care needs assessment: the epidemiologically based needs assessment reviews*. Oxford: Radcliffe Medical Press; 1994.

## 1.4 Report structure

Based on this approach and methods, **Chapter 2** details the epidemiology of TB in London, including patterns of health outcomes.

**Chapter 3** describes the literature review conducted for this needs assessment, covering TB treatment policies and strategies, the effectiveness of exemplar service models within and outside the UK and key aspects of TB control.

**Chapter 4** describes TB services in London in terms of geography, workforce and models of care offered. The chapter is based on the findings of a service questionnaire completed by 27 of the 30 TB services in London.

**Chapter 5** describes recent service performance and covers inpatient hospital admissions, and performance against the current London TB metrics and patterns of GP prescribing.

**Chapter 6** describes commissioning expenditure and financial issues.

**Chapter 7** describes the experience and views of service users interviewed in TB services across all current sectors in London.

Finally, **Chapter 8** brings together the main issues from across all project elements, ultimately leading to specific recommendations to London's TB Commissioners on how best to improve treatment and control of TB in London (**Chapter 9**).

## CHAPTER 2 - EPIDEMIOLOGY

### 2.1 What this section contains

This section summarises the most recent epidemiology of TB infection across London.

The most recent review of epidemiology of TB across London was published in 2009 and contained data up to 2007.<sup>19</sup> This needs assessment has required an update of much of this information, up to and including 2009, using the latest data within the LTBR.<sup>20</sup> In addition, in this chapter we have studied the patterns of TB mortality across London.

### 2.2 Principal patterns of incidence

#### 2.2.1 Incidence of TB in London

London continues to have the highest incidence rates (new cases per 100,000 population) of any region in England.

**Figure 1** shows the incidence rate in London compared with other regions in England over the period 2000-2008. There have been increases in incidence in every region over the ten years; the rates in London have also steadily increased and remained substantially higher than anywhere else.

In 2009, the incidence rate had climbed to 45.7 per 100,000.

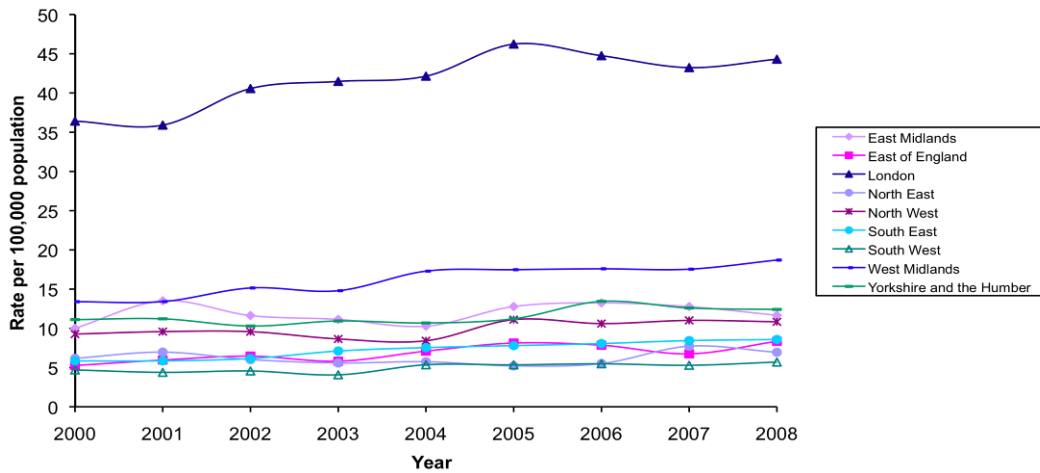
**Figure 2** shows the annual number of TB cases across the last ten years. In 2009 a total of 3450 new cases of TB were reported in London residents: this compares with a total of 2,309 in 1999, an increase of nearly 50%.

<sup>19</sup> *Tuberculosis in London, 2007. A Report from HPA London and NHS London.* London: HPA 2009.

<sup>20</sup> The London TB Register is an online database, held by the HPA, containing up to date information from individual TB patients receiving care from London NHS TB services in acute NHS trusts. The information it contains is as complete as the data that is uploaded on it by individual services.

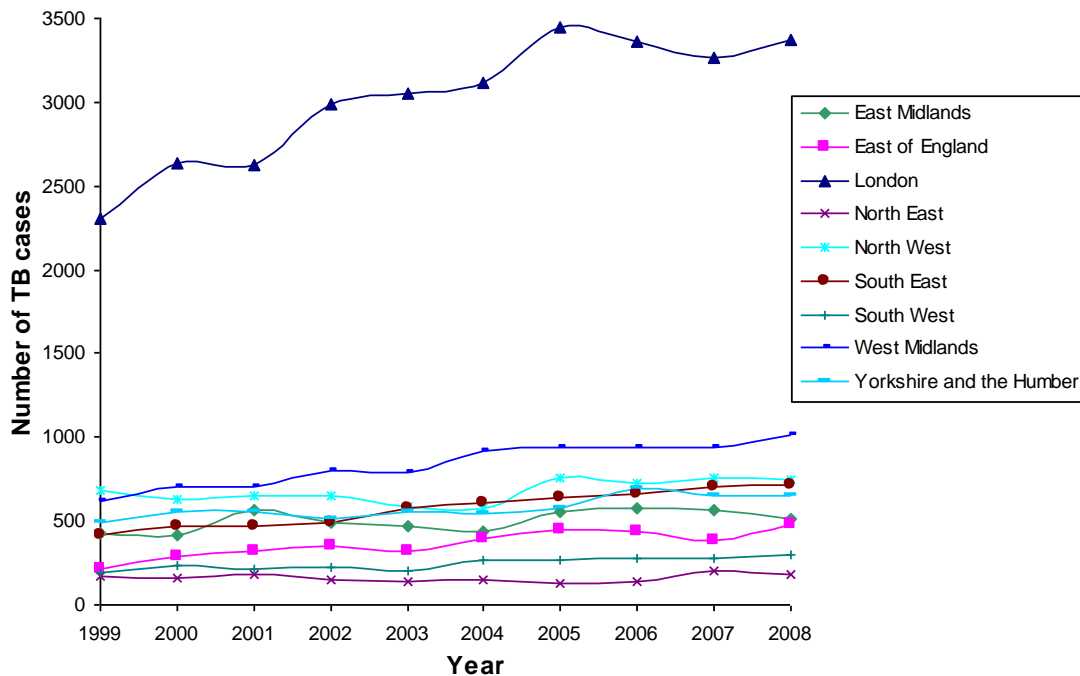
**Figure 1: Tuberculosis case rates by region, England 2000 – 2008**

Sources: HPA: Enhanced TB Surveillance: ONS Mid-year population estimates



**Figure 2: Tuberculosis case numbers by region, England 1999 – 2008**

Sources: HPA: Enhanced TB Surveillance: ONS Mid-year population estimates



**Map 1** shows the geographic distribution of TB incidence rates for the year 2009. The red dots on this and subsequent maps show the location of TB clinic services. The highest rates are in Newham, Brent and Hounslow, followed by Tower Hamlets, Ealing and Harrow.

Lowest rates are seen in Richmond & Twickenham, Bexley, Bromley, Havering and Kingston – all geographically outer London boroughs.

The patterns are broadly similar to those described in previous years, although the absolute rates are tending to increase in areas of high incidence, and to fall in areas of lower incidence.

**Map 1: Tuberculosis rate per 100,000 population, by PCT of residence, 2009. Red dots: location of TB clinics**

Source: HPA



**2.2.2 Numbers of TB cases by PCT of residence**

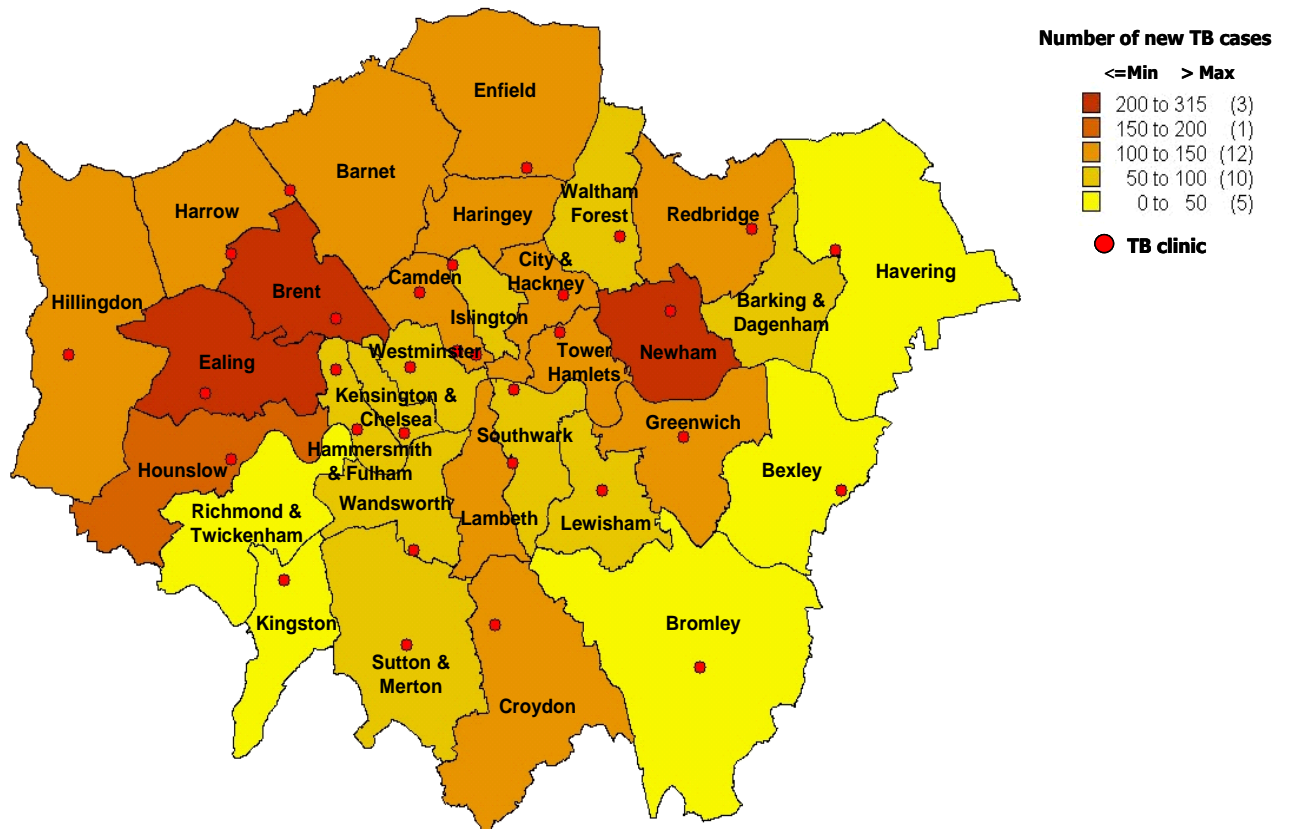
Map 2 shows the geographical distribution of numbers of new cases, by PCT of residence, notified in 2009.

The largest numbers of new cases are to be found in residents of Newham (314), Brent (299), Ealing (225) and Hounslow (177). The smallest numbers are reported for residents of Richmond & Twickenham (21) and Bexley (17).

By and large, the PCTs with the largest numbers of cases are also the PCTs with the highest rates of TB cases per 100,000 head of population (see Map 1).

## Map 2: Numbers of new TB notifications, by PCT of residence, London, 2009

Source: HPA 2010



### 2.2.3 Numbers of cases by clinic

The numbers of cases reported by individual local TB services differ, reflecting flows into services from residents outside the borough where the clinics are sited. This is important to the understanding of clinic workloads. For example, although in 2009 there were 145 TB cases in residents of Tower Hamlets, the nearest service (London Chest Hospital) reported a caseload of 220 patients.

**Table 1** shows the number of new TB notifications by notifying clinic, 2004-2009. The largest reported TB caseloads are to be found in services based in the following hospitals: Northwick Park (259), Newham (247), London Chest (220), Ealing (189) and North Middlesex/Haringey/Chase Farm (189).

The impact of flows into specific services is important – whether due to proximity to work, transport links, clinical pathways or other factors relating to communities. It is the size of the caseloads of individual services, together with case complexity, that should determine their TB workforce requirements and provides the best denominator for measurement of performance.

**Table 1: Number of new TB notifications by notifying clinic, London 2004-2009.**

Source: HPA, 2010

Sector / TB service	2004	2005	2006	2007	2008	2009
<b>North Central</b>						
Barnet	49	80	82	74	69	70
Great Ormond Street	13	7	8	7	15	16
North Middlesex	203	190	192	122	167	189
Royal Free	111	103	107	86	91	114
UCLH	116	138	132	125	141	122
Whittington	92	71	100	87	87	94
<b>North Central Total</b>	<b>584</b>	<b>589</b>	<b>621</b>	<b>501</b>	<b>570</b>	<b>605</b>
<b>North East</b>						
Queens (BHRT)	19	37	45	50	65	84
Homerton	151	122	128	131	119	112
King George (BHRT)	108	133	142	124	155	153
London Chest (BLT)	185	211	213	234	218	220
Newham	198	212	215	225	220	247
Whipps Cross	108	119	119	102	129	109
<b>North East Total</b>	<b>769</b>	<b>834</b>	<b>862</b>	<b>866</b>	<b>906</b>	<b>925</b>
<b>North West</b>						
Charing Cross (ICHT)	56	65	63	50	58	64
Chelsea & Westminster	62	70	59	53	66	61
Ealing	194	175	179	189	153	189
Hammersmith (ICHT)	68	64	79	72	65	77
Hillingdon	87	101	105	105	129	101
Northwick Park (NWLTL)	223	300	249	235	287	259
Royal Brompton	-	-	6	3	0	2
St Mary's (ICHT)	151	166	139	148	143	135
West Middlesex	86	117	107	111	108	149
Central Middlesex (NWLTL)	138	174	123	129	129	158
<b>North West Total</b>	<b>1065</b>	<b>1232</b>	<b>1109</b>	<b>1095</b>	<b>1138</b>	<b>1195</b>
<b>South East</b>						
Bromley	24	22	29	23	15	21
Guy's & St Thomas's	148	191	153	125	163	153
Kings College	134	127	141	119	114	112
Queen Elizabeth	87	93	92	98	132	107
Queen Mary's	13	10	13	12	5	8
Lewisham	74	92	84	98	76	73
<b>South East Total</b>	<b>480</b>	<b>535</b>	<b>512</b>	<b>475</b>	<b>505</b>	<b>474</b>
<b>South West</b>						
Epsom St Helier	23	37	43	52	46	52
Kingston	30	37	42	32	42	59
Mayday	112	96	99	102	92	110
St George's	172	196	161	181	192	139
<b>South West Total</b>	<b>337</b>	<b>366</b>	<b>345</b>	<b>367</b>	<b>372</b>	<b>360</b>
<b>Non LTBR Clinics</b>	<b>4</b>	<b>15</b>	<b>7</b>	<b>9</b>	<b>6</b>	<b>12</b>
<b>London Total</b>	<b>3239</b>	<b>3571</b>	<b>3456</b>	<b>3313</b>	<b>3497</b>	<b>3571</b>



## 2.2.4 Trends in numbers and rates of new cases of TB

Trends in numbers and rates of new TB cases across London and its PCTs over the last five years are shown in **Table 2** and **Figures 3 – 8** below.

In many PCTs, the general trend has been for a gradual increase in both numbers and rates of new cases. The highest rates of new cases in London are north of the Thames, and case numbers there are increasing slowly year on year, especially in North East and North West London.

In SE and SW London, numbers seem more constant year to year. The only PCT in London in which numbers and rates are falling to any extent is Southwark. Examining the local factors explaining why this is the case may be valuable.

There are a few changes in the pattern since 2007:

### *NC London*

Haringey again has the highest rates, after a fall two years ago; numbers of cases are similar across all PCTs.

### *NE London*

Newham has far the highest rates and numbers of cases in both the sector and London as a whole, and both are continuing to increase.

### *NW London*

Brent and Ealing continue to have the highest rates and numbers of new cases. Brent's figures are increasing, while Ealing rates and numbers have slightly fallen.

### *SE London*

Greenwich has overtaken Lambeth with the highest rates and numbers of new TB cases, but the margin is not large. Only Greenwich has a notification rate higher than the London average. Numbers and rates in Southwark are falling, but nowhere else.

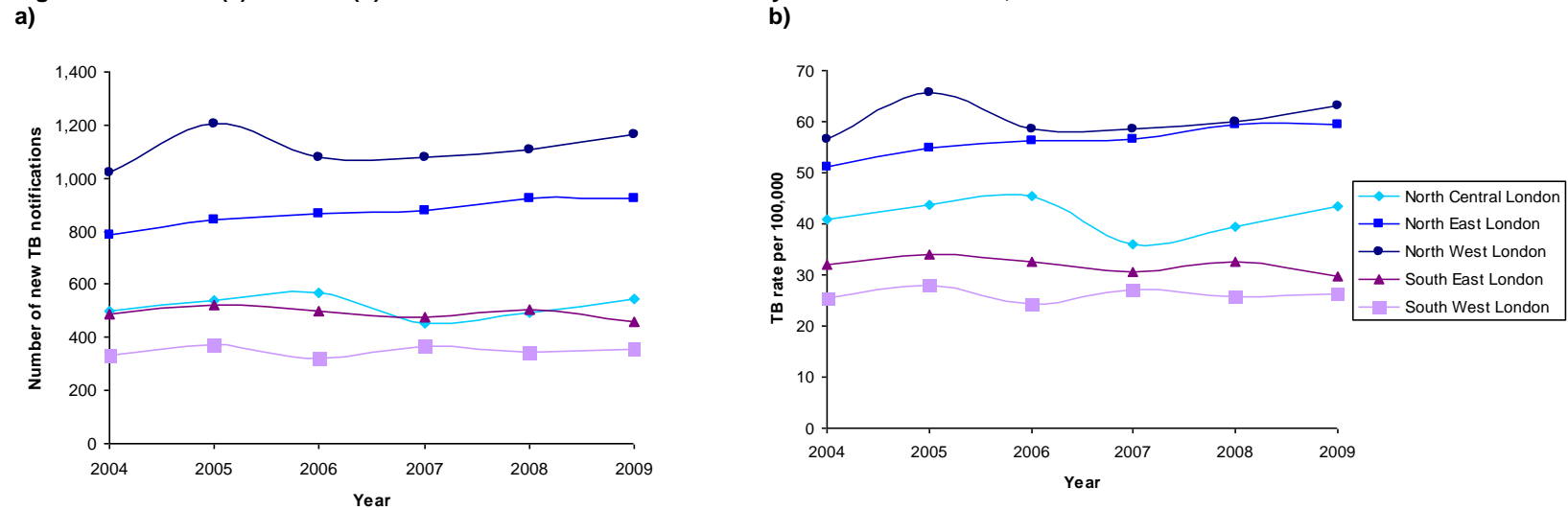
### *SW London*

Rates and numbers of cases in Wandsworth have fallen, while they have risen in Croydon; these changes are not profound – the general trend line is flat. All PCTs have rates lower than London as a whole.

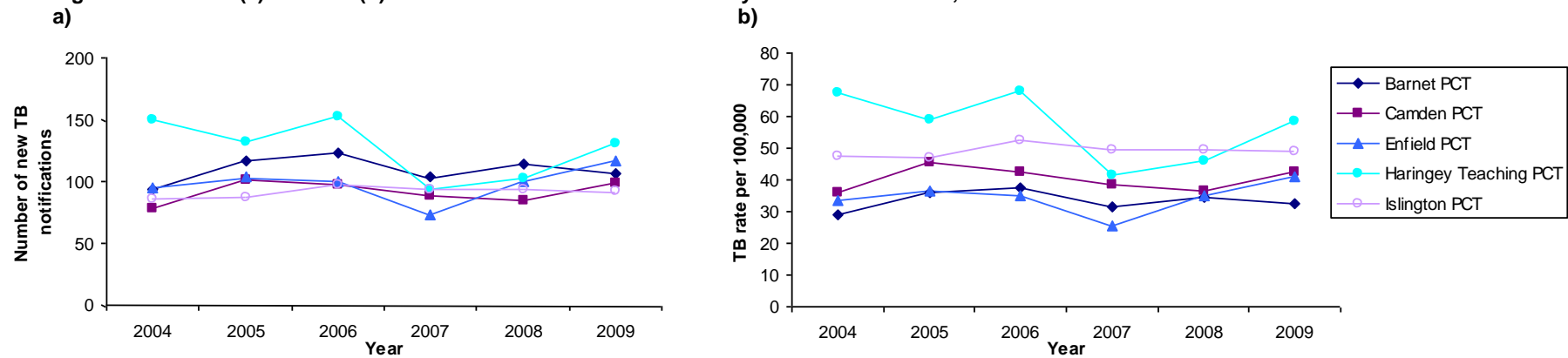
**Table 2: Number and rate of new tuberculosis notifications in London residents, by PCT of residence, 2004 – 2009.** Source: HPA

Sector / PCT		Number of new notifications of TB						Rate per 100,000 population					
		2004	2005	2006	2007	2008	2009	2004	2005	2006	2007	2008*	2009*
<b>North Central</b>	Barnet PCT	93	117	123	104	114	107	28.8	35.9	37.4	31.5	34.6	32.5
	Camden PCT	78	101	97	89	85	99	36.2	45.3	42.6	38.4	36.7	42.7
	Enfield PCT	95	104	100	73	100	117	33.7	36.7	35.1	25.6	35.1	41.0
	Haringey Teaching PCT	150	132	153	93	103	131	67.3	58.9	67.8	41.4	45.8	58.3
	Islington PCT	86	87	97	93	93	92	47.4	47.2	52.3	49.5	49.5	49.0
<b>North Central Total</b>		<b>502</b>	<b>541</b>	<b>570</b>	<b>452</b>	<b>495</b>	<b>546</b>	<b>41.0</b>	<b>43.6</b>	<b>45.5</b>	<b>35.9</b>	<b>39.3</b>	<b>43.4</b>
<b>North East</b>	City and Hackney Teaching PCT	160	132	137	143	124	118	74.8	61.5	63.4	65.7	57.0	54.2
	Havering PCT	12	30	23	16	20	30	5.3	13.3	10.1	7.0	8.8	13.1
	Newham PCT	241	257	261	277	287	314	95.7	102.9	105.1	111.0	115.0	125.8
	Redbridge PCT	109	120	144	135	163	149	44.1	48.2	57.2	53.1	64.1	58.6
	Tower Hamlets PCT	119	129	133	153	133	145	57.2	61.6	62.5	71.1	61.8	67.3
	Waltham Forest PCT	99	114	121	93	129	95	45.0	51.7	54.6	41.8	58.0	42.7
<b>North East Total</b>		<b>784</b>	<b>842</b>	<b>868</b>	<b>879</b>	<b>925</b>	<b>924</b>	<b>51.2</b>	<b>54.9</b>	<b>56.2</b>	<b>56.5</b>	<b>59.5</b>	<b>59.4</b>
<b>North West</b>	Brent Teaching PCT	230	286	240	274	307	299	85.6	105.8	88.4	101.5	113.7	110.7
	Ealing PCT	257	239	235	236	194	225	84.5	78.2	76.7	77.3	63.5	73.7
	Hammersmith and Fulham PCT	71	90	80	68	68	74	41.9	52.6	46.7	39.4	39.4	42.9
	Harrow PCT	99	133	124	122	128	136	46.7	62.1	57.8	56.8	59.6	63.4
	Hillingdon PCT	116	143	126	127	153	124	47.2	57.7	50.4	50.7	61.0	49.5
	Hounslow PCT	115	167	138	136	134	177	53.6	77.1	63.1	61.7	60.7	80.2
	Kensington and Chelsea PCT	48	49	53	32	53	50	28.0	27.9	29.8	17.9	29.7	28.0
	Westminster PCT	86	96	85	86	69	81	39.0	42.0	36.7	36.7	29.5	34.6
<b>North West Total</b>		<b>1022</b>	<b>1203</b>	<b>1081</b>	<b>1081</b>	<b>1106</b>	<b>1166</b>	<b>56.6</b>	<b>65.7</b>	<b>58.7</b>	<b>58.5</b>	<b>59.9</b>	<b>63.1</b>
<b>South East</b>	Bexley PCT	30	23	19	26	21	17	13.6	10.4	8.6	11.7	9.5	7.7
	Bromley PCT	29	29	41	35	19	32	9.8	9.7	13.7	11.6	6.3	10.6
	Greenwich Teaching PCT	89	88	98	105	138	124	40.4	39.7	44.0	47.1	61.9	55.6
	Lambeth PCT	127	145	134	104	127	117	47.2	53.6	49.3	38.1	46.5	42.8
	Lewisham PCT	78	99	85	100	84	76	31.0	39.1	33.2	38.7	32.5	29.4
	Southwark PCT	132	137	125	104	117	95	50.9	51.9	46.4	37.9	42.6	34.6
<b>South East Total</b>		<b>485</b>	<b>521</b>	<b>502</b>	<b>474</b>	<b>506</b>	<b>461</b>	<b>32.0</b>	<b>34.1</b>	<b>32.6</b>	<b>30.5</b>	<b>32.6</b>	<b>29.7</b>
<b>South West</b>	Croydon PCT	120	113	102	117	112	124	35.7	33.7	30.3	34.5	33.0	36.5
	Kingston PCT	22	29	25	29	29	31	14.5	18.8	16.0	18.4	18.4	19.6
	Richmond and Twickenham PCT	12	19	20	14	13	21	6.8	10.7	11.1	7.8	7.2	11.7
	Sutton and Merton PCT	86	86	93	90	81	93	23.0	22.7	24.3	23.4	21.0	24.1
	Wandsworth PCT	94	125	82	115	110	84	34.5	45.2	29.4	40.8	39.0	29.8
<b>South West Total</b>		<b>334</b>	<b>372</b>	<b>322</b>	<b>365</b>	<b>345</b>	<b>353</b>	<b>25.5</b>	<b>28.1</b>	<b>24.1</b>	<b>27.1</b>	<b>25.7</b>	<b>26.3</b>
<b>London Total</b>		<b>3127</b>	<b>3479</b>	<b>3343</b>	<b>3251</b>	<b>3377</b>	<b>3450</b>	<b>42.3</b>	<b>46.7</b>	<b>44.5</b>	<b>43.0</b>	<b>44.7</b>	<b>45.7</b>

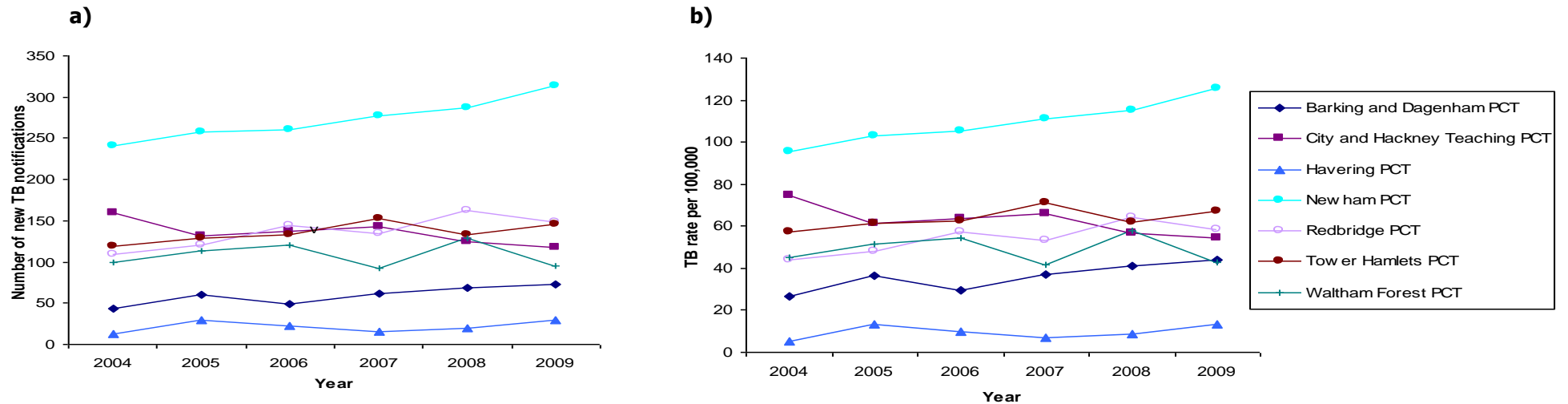
**Figure 3: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, London 2004 – 2009**



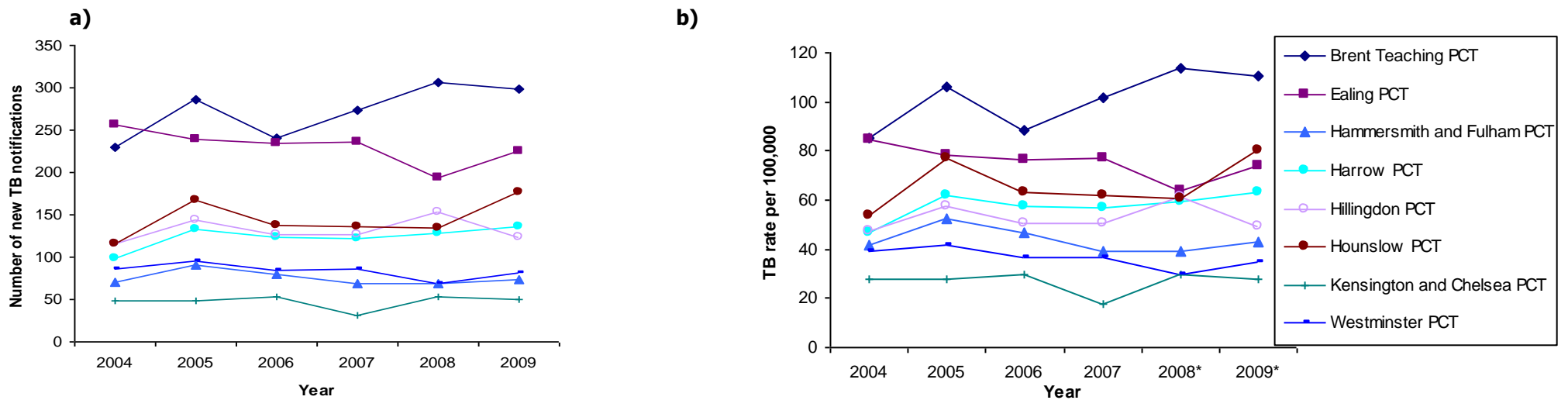
**Figure 4: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, North Central London 2004 – 2009**



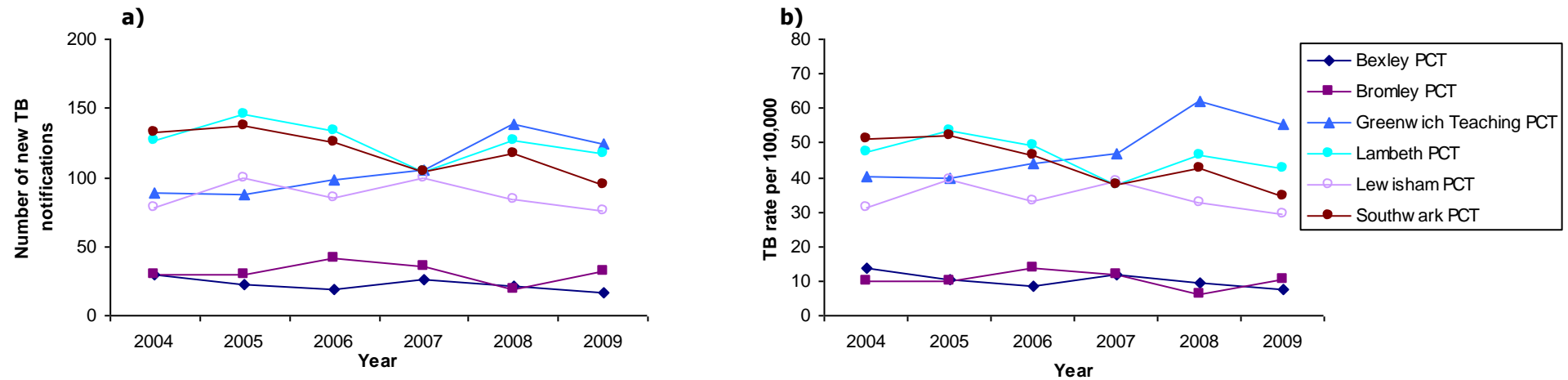
**Figure 5: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, North East London 2004 – 2009**



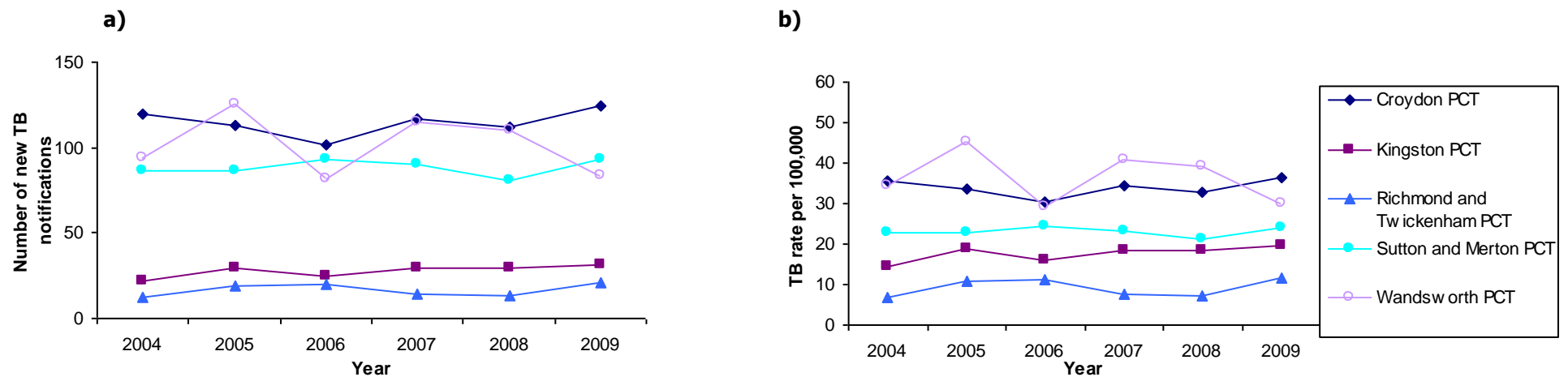
**Figure 6: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, North West London 2004 – 2009**



**Figure 7: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, South East London 2004 – 2009**



**Figure 8: Number (a) and rate (b) of new tuberculosis notifications by sector of residence, South West London 2004 – 2009**



### 2.2.5 What these trends show

The figures above show that the burden of TB disease in London shows no sign of reduction. Indeed, in those parts of London with the highest burden, the rates and numbers of new cases reported each year continue slowly and inexorably to increase.

### 2.2.6 Demographic issues

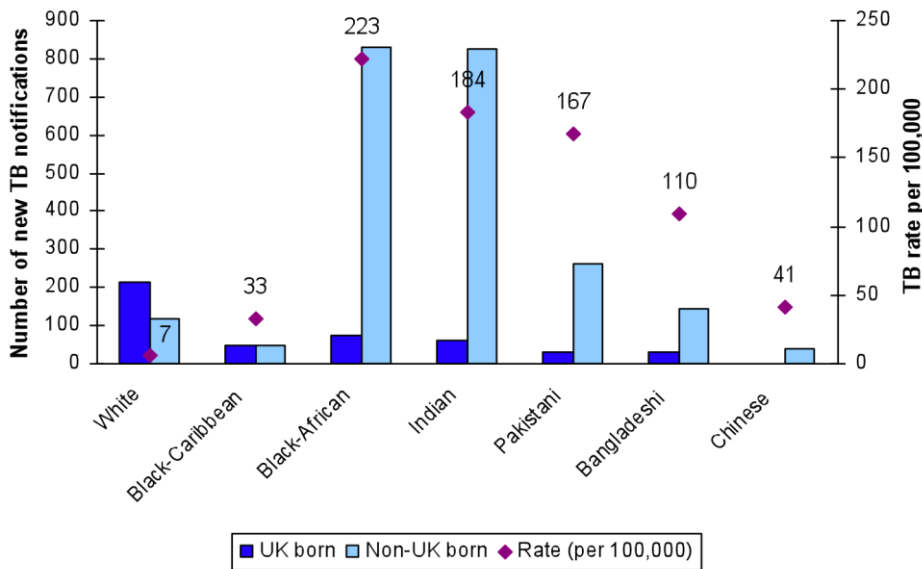
#### Country of birth and ethnicity

Most notified cases of TB occur in people born outside the UK. The proportion of TB cases born within the UK continues to decrease, accounting for 15% (down from 17% in 2007).

**Figure 9** shows the number of TB cases in London residents, broken down by country of birth and ethnic group in 2009.

**Figure 9: Reported TB case numbers and rates by place of birth and ethnic group, London residents, 2009**

Source: HPA, 2010



The most common ethnic groups are black African (28%, 930/3381 cases where ethnicity is known), Indian (27%, 922 cases) and White (17%, 340 cases). Rates are highest among black Africans (223 /100,000), followed by Indians (184 /100,000) and lowest (7 /100,000) among white individuals.

Over 40% of TB cases are black African in the following PCTs: Camden, Enfield, Haringey, Bexley, Greenwich, Lewisham and Southwark.

Over 40% of TB Cases are Indian in these PCTs: Redbridge, Brent, Ealing, Harrow and Hounslow.

Bangladeshi account for almost half of TB cases in Tower Hamlets. TB cases in Newham come from the widest range of ethnicity, consistent with the considerable ethnic diversity of Newham’s resident population.

These differences in ethnic origin are important for TB services provided to residents of these boroughs, since services need to be culturally responsive and sensitive to the needs, customs and health beliefs of these quite different local communities. Services also need to use interpreting and advocacy services across a wide range of languages.

*Site of disease*

In 2009, 49% of tuberculosis cases had pulmonary disease, a similar proportion to recent years.<sup>21</sup> This varied by sector from 45% in North East London to 58% in North Central London.<sup>22</sup>

*Age*

The 2009 report (figures to 2007) showed that the majority of TB cases in London are in young adults – 65% are aged 15-44 years, and this has been the picture since 1999.

This needs assessment (figures to 2009) shows that almost 5% of all TB cases are in children under the age of 16 years. The largest numbers of children with TB live in Camden (15) and Ealing (14), with 11 living in Brent.

The clinics reporting the largest caseloads of children under 16 years in 2009 are Ealing (18), Gt Ormond St (16) and St George’s (13). It is likely that some of these children have complex disease or co-infection with HIV.

Most TB services reported at least one child with TB in 2009, although for many the numbers of new cases are small.

These generally very small caseloads reinforce the need to ensure that all paediatricians work very closely with TB specialists in the management of TB in children, although this is not an issue specifically studied in this needs assessment.

*Risk factors*

Clinicians entering data on the LTBR can enter risk factors they have identified for individual TB patients, and which may affect the likelihood of treatment compliance or completion. The risk factors identified this way on the LTBR are five in number:

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<sup>21</sup> 48% in both 2008 and 2007, 51% in 2006 and 50% in 2005.

<sup>22</sup> Source: HPA, 2010

- History of drug use
- History of homelessness
- UK prison history
- Ability to self administer treatment affected by alcohol
- Mental health concerns.

Analysis of the LTBR returns for 2009 shows that 12% of all cases are reported as having one or more of these five risk factors. In North Central London, the figure was 18%.

The prevalence of these risk factors, as reported in the LTBR, varies very widely between clinics (see **Table 3**). Some with small case loads report 0%. Risk factor prevalence reported by services with larger case numbers ranges from 2.7% (West Middlesex, notified caseload: 149) to 24% (Homerton, caseload: 112)

Some of the low risk factor prevalence figures may be due to under-reporting. Some possible reasons for this are raised later below.

The commonest risk factor identified and entered into the LTBR is alcohol use (7% of patients overall). The reported prevalence of this risk factor varies widely by reporting clinic; from nearly 50% at King's (though small numbers) to 29% at the Whittington, 23% at the Royal Free and 18% at Northwick Park.

Mental health issues as a risk factor are reported for 5% of patients and 4% are reported to have problems with drug use and 3% are reported on LTBR to be homeless.

The differences in reported prevalence of risk factors between clinics should be interpreted with caution, as risk factors are probably under-reported in the LTBR by many clinics.



**Table 3: Risk factors\* among TB cases reported by treating clinic, London 2009**

Source: HPA 2010

Sector / TB service	Where one or more risk factor		Total notifications
	n	%	
<b>North Central</b>			
Barnet	4	5.7%	70
Great Ormond Street	0	0.0%	16
North Middlesex	41	21.7%	189
Royal Free	24	21.1%	114
UCLH	25	20.5%	122
Whittington	15	16.0%	94
<b>North Central Total</b>	<b>109</b>	<b>18.0%</b>	<b>605</b>
<b>North East</b>			
Queens (BHRT)	3	3.6%	84
Homerton	27	24.1%	112
King George (BHRT)	17	11.1%	153
London Chest (BLT)	29	13.2%	220
Newham	10	4.0%	247
Whipps Cross	4	3.7%	109
<b>North East Total</b>	<b>90</b>	<b>9.7%</b>	<b>925</b>
<b>North West</b>			
Charing Cross (ICHT)	11	17.2%	64
Chelsea & Westminster	10	16.4%	61
Ealing	9	4.8%	189
Hammersmith (ICHT)	6	7.8%	77
Hillingdon	5	5.0%	101
Northwick Park (NWLTL)	48	18.5%	259
Royal Brompton	0	0.0%	2
St Mary's (ICHT)	25	18.5%	135
West Middlesex	4	2.7%	149
Central Middlesex (NWLTL)	18	11.4%	158
<b>North West Total</b>	<b>136</b>	<b>11.4%</b>	<b>1195</b>
<b>South East</b>			
Bromley	2	9.5%	21
Guy's & St Thomas's	9	5.9%	153
Kings College	13	11.6%	112
Queen Elizabeth	17	15.9%	107
Queen Mary's	0	0.0%	8
Lewisham	5	6.8%	73
<b>South East Total</b>	<b>46</b>	<b>9.7%</b>	<b>474</b>
<b>South West</b>			
Epsom St Helier	5	9.6%	52
Kingston	2	3.4%	59
Mayday	14	12.7%	110
St George's	8	5.8%	139
<b>South West Total</b>	<b>29</b>	<b>8.1%</b>	<b>360</b>
<b>Non LTBR Clinics</b>	<b>1</b>	<b>8.3%</b>	<b>12</b>
<b>London Total</b>	<b>411</b>	<b>11.5%</b>	<b>3571</b>

\*Risk factors include: history of homelessness; UK prison history; ability to self-administer treatment affected by alcohol; mental health concerns.

### *Directly Observed Therapy (DOT) use*

The purpose of identifying risk factors for treatment compliance is to decide which TB patients may require special and additional support or resources to ensure they take all their medication and complete the course of treatment. In many cases, where patients are vulnerable with chaotic lifestyles, Directly Observed Therapy (DOT) may be indicated.

The LTBR contains a data field for reporting DOT usage. The frequency of reported DOT usage is seen in **Table 4** on next page.

The frequency of DOT usage (as reported in the LTBR) varies very widely, and the extent of its use does not seem to be related to size of clinic caseload. For example in SE London, at Kings it is only 1.8%, whereas at Queen Elizabeth Hospital it is nearly 20%. In SW London, at Mayday DOT is reported as used in 32% of cases, whereas in Kingston it is only used in 1.7%.

In NC London, the use of DOT appears to be more frequent than in other sectors, with those clinics having more than 100 TB cases all reporting use of DOT at rates of between 12% and 20%.

In NW London, the rates of reported DOT use are substantially lower, despite very large caseloads in general. Rates are mostly below 6% with the exception of Hillingdon, where DOT usage is at 16%.

In NE London, the Homerton reports using DOT in 17% of cases, whereas the London Chest Hospital uses it in only 4%.

These comparisons are not straightforward; where treatment changes to use of DOT after it has started it may not be recorded on the LTBR. DOT is also recorded as a binary variable: used or not used. In practice there are various regimes which are half way house methods towards DOT; they include the use of dosette boxes or use of family members as supervisors without necessarily directly observing the taking of medication.

What may be an important issue is standardisation of risk assessment and an agreed protocol to determine thresholds for the use of different methodologies to achieve treatment compliance.

These issues are picked up in the summary at the end of this chapter and in **Chapter 8**.

**Table 4: DOT usage reported to the London TB Register during 2009 (as at 18 May 2010)**

Source: HPA

Sector / TB service	On DOT during episode of care		Total notifications
	n	%	
<b>North Central</b>			
Barnet	4	5.7%	70
Great Ormond Street	1	6.3%	16
North Middlesex	22	11.6%	189
Royal Free	17	14.9%	114
UCLH	24	19.7%	122
Whittington	17	18.1%	94
<b>North Central Total</b>	<b>85</b>	<b>14.0%</b>	<b>605</b>
<b>North East</b>			
Queens (BHRT)	7	8.3%	84
Homerton	19	17.0%	112
King George (BHRT)	6	3.9%	153
London Chest (BLT)	8	3.6%	220
Newham	12	4.9%	247
Whipps Cross	11	10.1%	109
<b>North East Total</b>	<b>63</b>	<b>6.8%</b>	<b>925</b>
<b>North West</b>			
Charing Cross (ICHT)	3	4.7%	64
Chelsea & Westminster	3	4.9%	61
Ealing	3	1.6%	189
Hammersmith (ICHT)	2	2.6%	77
Hillingdon	16	15.8%	101
Northwick Park (NWLTL)	11	4.2%	259
Royal Brompton	0	0.0%	2
St Mary's (ICHT)	8	5.9%	135
West Middlesex	0	0.0%	149
Central Middlesex (NWLTL)	9	5.7%	158
<b>North West Total</b>	<b>55</b>	<b>4.6%</b>	<b>1195</b>
<b>South East</b>			
Bromley	0	0.0%	21
Guy's & St Thomas's	9	5.9%	153
Kings College	2	1.8%	112
Queen Elizabeth	21	19.6%	107
Queen Mary's	0	0.0%	8
Lewisham	10	13.7%	73
<b>South East Total</b>	<b>42</b>	<b>8.9%</b>	<b>474</b>
<b>South West</b>			
Epsom St Helier	7	13.5%	52
Kingston	1	1.7%	59
Mayday	35	31.8%	110
St George's	16	11.5%	139
<b>South West Total</b>	<b>59</b>	<b>16.4%</b>	<b>360</b>
<b>Non LTBR Clinics</b>	<b>0</b>	<b>0.0%</b>	<b>12</b>
<b>London Total</b>	<b>304</b>	<b>8.5%</b>	<b>3571</b>

*Drug resistance*

Drug resistance is an extremely important issue. Drug resistance solely to Isoniazid is termed single drug resistance. TB that is resistant to more than one drug (e.g. resistant to both Isoniazid and Rifampicin) is termed Multi-drug resistant TB (MDR-TB). MDR-TB takes longer to treat with second-line drugs, which are also more expensive and have more side effects.

Where further drug resistance is shown to any quinolone drug and also to at least one second line anti-TB injectable drug, that resistance is termed Extensively drug-resistant TB (XDR-TB).

The incidence of drug-resistant TB is rising each year, and is commoner in London than the rest of the country. About half of all notified cases of TB involve culture-confirmed diagnosis (cultures are needed to test drug sensitivity). In 2008, 1,875 culture confirmed cases were reported, 52% of the total. Of these, 135 (7.2%) were Isoniazid resistant, and 1% (19) were multi-drug resistant.

Provisional data for 2009 show these figures have risen. In 2009, as many as 10% of all culture confirmed cases reported in London were resistant to Isoniazid (compared to a UK average of 7%), and 2.2% were multi-drug resistant (compared to 1.3% across the UK).<sup>23</sup>

**Table 5** shows the pattern of notified drug resistant TB across London in 2008, which are the latest figures available by clinic. There are many more cases in North London than in South London. Most clinics had less than 10 cases per year; exceptions were the Homerton (15) and Whipps Cross (11).

Analysis of drug resistance by borough of residence (as opposed to notifying clinic) shows a very similar pattern, suggesting that on the whole this group of TB patients tend to be treated close to where they live.

Of 135 cases of Isoniazid-resistant TB, 42 (34%) were treated in NE London, and 37 (27%) in NW London.

The caseloads of MDR-TB are much smaller; those clinics which treated patients with MDR-TB saw only one or two cases and many appear to have seen none.

One case of XDR-TB was reported in 2009 (not shown in the Table).

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<sup>23</sup> Source: Health Protection Agency Centre for Infections: Enhanced TB surveillance and MycobNet.  
152 cases were Isoniazid resistant, and 34 multi-drug resistant, out of 1566 culture confirmed cases with drug susceptibility testing results for at least Isoniazid and Rifampicin.

**Table 5L Number of Isoniazid resistant and MDR-TB cases\* by notifying clinic, London 2008**

Source: HPA 2010

<b>Sector / TB service</b>	<b>Isoniazid resistant cases</b>	<b>Multi-drug resistant</b>
<b>North Central</b>		
Barnet	3	1
Great Ormond Street		
North Middlesex	9	
Royal Free	2	
UCLH	5	1
Whittington	5	
<b>North Central Total</b>	<b>24</b>	<b>2</b>
<b>North East</b>		
Queens (BHRT)	4	1
Homerton	15	1
King George (BHRT)	3	
London Chest (BLT)	5	2
Newham	4	1
Whipps Cross	11	3
<b>North East Total</b>	<b>42</b>	<b>8</b>
<b>North West</b>		
Charing Cross (ICHT)	2	
Chelsea & Westminster	3	
Ealing	5	
Hammersmith (ICHT)	2	
Hillingdon		
Northwick Park (NWLTL)	8	
Royal Brompton		
St Mary's (ICHT)	8	
West Middlesex	5	1
Central Middlesex (NWLTL)	4	1
<b>North West Total</b>	<b>37</b>	<b>2</b>
<b>South East</b>		
Bromley	1	
Guy's & St Thomas's	7	2
Kings College	6	
Queen Elizabeth	2	
Queen Mary's	1	
Lewisham	3	1
<b>South East Total</b>	<b>20</b>	<b>3</b>
<b>South West</b>		
Epsom St Helier		
Kingston	1	
Mayday	3	1
St George's	7	2
<b>South West Total</b>	<b>11</b>	<b>3</b>
<b>Non LTBR Clinics</b>	<b>1</b>	<b>1</b>
<b>London Total</b>	<b>135</b>	<b>19</b>

\*among culture confirmed cases with drug susceptibility testing results

## 2.3 Mortality

Most people who contract TB and are treated in London survive their episode of infection. However, a small number die every year. Some may die directly of their TB; for others TB may be a contributory cause but not the principal cause of death. Although the numbers of deaths may be small, understanding their pattern across London is important.

### 2.3.1 What this section contains

This section presents information on deaths from TB across London. This includes trends in death rates over the last 15 years for which information is available, both across the five sectors within London and the PCTs within them, all compared with London and England as a whole.

We also present rates and numbers of TB deaths in each PCT within each sector, averaged over the last three years, in comparison with all London PCTs and both London and national figures.

### 2.3.2 Limitations of information

It is important to remember that the accuracy of any information is only as good as the accuracy of its source. In the case of mortality data, much of the information is dependent on the accuracy and completeness of death certification.<sup>24</sup> In a later chapter we will be considering hospital activity, including admissions. This information is dependent on the completeness and accuracy with which a hospital admission spell is coded by the hospital concerned. This function has improved in all hospitals, but there remains a degree of variability.

As is usually the case, the information we have is far from perfect, but is the best that can be obtained from current data sources. It is best to assume (especially where the numbers involved are reasonably large) that the extent of any data inaccuracies or misclassifications is much the same in all boroughs and across London and England in general.

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<sup>24</sup> The format of the medical certificate of cause of death was laid down in 1927, and forms the basis for subsequent international recommendations up to the present time. The certifying doctor is required to enter the conditions which led directly to death in part I of the certificate, so that the disease or condition which started the sequence is in the lowest used line. Any other significant conditions which may have contributed to the death are put in part II. The cause section of coroners' certificates has had the same basic format since 1993, although other details are different. These certificates are used to code the cause of death to codes from the International Classification of Diseases. (<http://www.ons.gov.uk/about-statistics/classifications/international/icd-10/death-reg/index.html>)

### 2.3.3 Causes of death categorised as due to TB

ONS death datasets use a series of specific, internationally agreed codes to define death due to TB. These ICD-10 codes<sup>25</sup> are shown in the box below. It can be seen that deaths described as due to TB include deaths due to respiratory TB, TB of the nervous system and other organs as well as miliary TB<sup>26</sup>. Data used in other reports or sources may use more restricted range of ICD-10 codes, so it is important to ensure like-with-like comparisons.

**Box 1: ICD-10 codes for causes of death classified as due to tuberculosis**

A15	Respiratory tuberculosis, bacteriologically and histologically confirmed
A16	Respiratory tuberculosis, not confirmed bacteriologically and histologically
A17	Tuberculosis of nervous system
A18	Tuberculosis of other organs
A19	Miliary tuberculosis

### 2.3.4 Standardised death rates

Death rates show deaths as a proportion, expressed as a number of deaths per 100,000 head of population. The death rates presented below do not represent the risk of death in a population of TB patients, but the risk of death from TB in the population as a whole.

We have used rates that are standardised for age and sex, and therefore take into account differences in age and sex profile of the populations studied, compared with, say, London or England as a whole. Differences in standardised rates observed between different populations are therefore due to factors other than age or gender.

The strength of using age and sex-standardised death rates is that it is then easy to make comparisons between the risk of death in one population compared with another, excluding any differences in population size or in age and gender profile. We can therefore make valid comparisons between and across sectors or PCTs, and with national and regional comparators.

The other reason to consider rates is that it may then be possible to identify important inequalities of death risk in different communities. These are health inequalities, and on grounds of equity and fairness efforts should be made to reduce

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<sup>25</sup> International Classification of Diseases – 10. The latest version of the international classification of diseases.

<sup>26</sup> Miliary tuberculosis is a life-threatening condition that occurs when large numbers of tubercle bacilli spread throughout the body. Huge numbers of tiny tubercular lesions develop that cause weakness and weight loss, severe anaemia, wasting and death.

them. Reducing health inequalities has been mainstream health policy since the Acheson Report in 1998.<sup>27</sup>

### 2.3.5 Trends in TB death rates over the last 15 years

These trends are drawn from data compiled by the Office of National Statistics (ONS) from the principal causes of death described in death certificates lodged with the Registrar General. The information is drawn from the Compendium of Clinical and Health Indicators.<sup>28</sup> Deaths are ascribed to the borough of residence of the deceased, irrespective of where death occurred.

#### *TB mortality trends across London*

**Figure 10** shows the standardised mortality rate trend from TB in people of all ages in each sector, London and England between 1993 and 2008.

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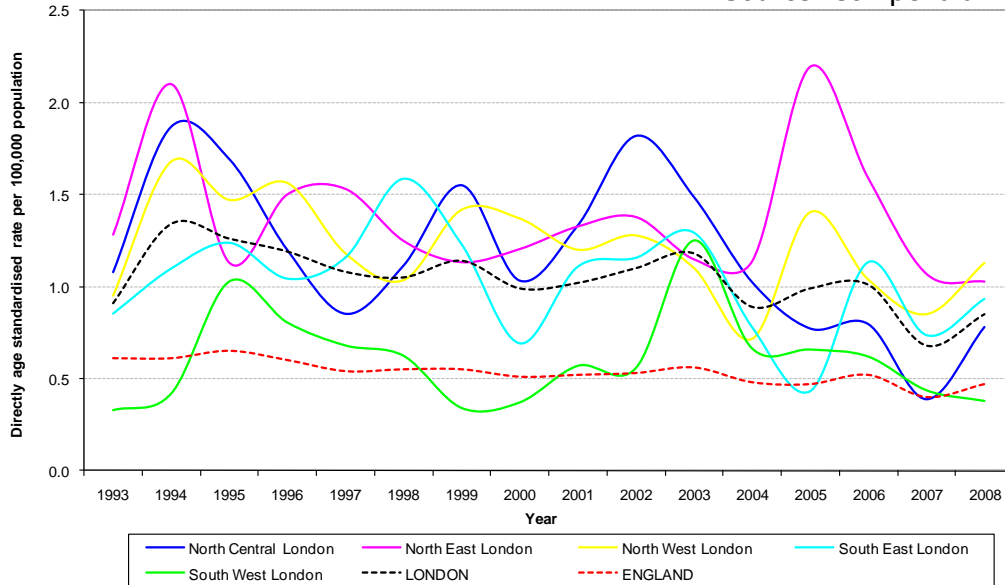
<sup>27</sup> *Independent Inquiry into Inequalities in Health*. (Chairman: Sir Donald Acheson). HMSO, November 1998.

<sup>28</sup> Compendium of Clinical and Health Indicators. Lakhani A, Olearnik H, Eayres D (eds). Clinical and Health Outcomes Knowledge Base. London: The Information Centre for health and social care / National Centre for Health Outcomes Development, 2008



**Figure 10: Annual standardised mortality rate from TB – Sectors, London and England, 1993 – 2008**

Source: Compendium<sup>25</sup>



All mortality rates can be seen to have fallen by 2008 compared to 1993, despite year to year variation in the 15 year period.

When the figures are smoothed by plotting three year rolling averages across the same period, the year to year fluctuations are reduced and a rather clearer trend can be seen (see **Figure 11**).

**Figure 11: Three year rolling average standardised mortality rate – TB, Sector, London and England, 1993 – 2008**

Source: Compendium

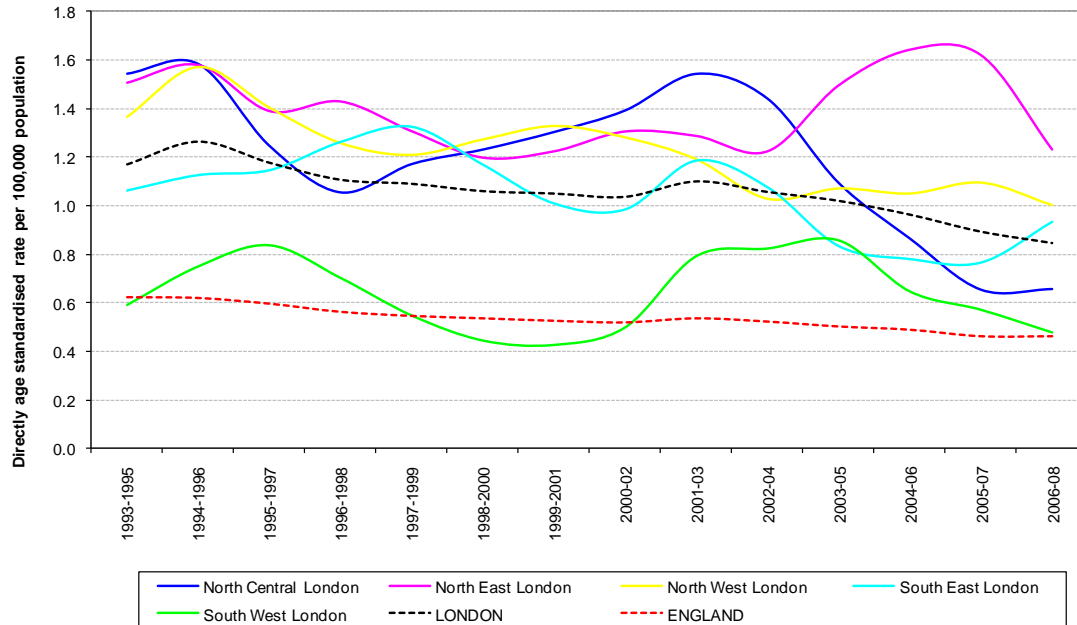


Figure 11 shows that the mortality trend for London as a whole over the last 15 years closely follows that of the national trend, which has slowly reduced over time. London has had consistently higher TB death rates than England. The reason for this is uncertain, but may be due to increased case complexity, co-infection with HIV, or delayed diagnosis.

### 2.3.6 Trends summary at sector level

NE London is the sector with the highest levels of TB mortality across the 15 years. SW London has been the only sector where the mortality rate has been consistently lower than the rate for London as a whole.

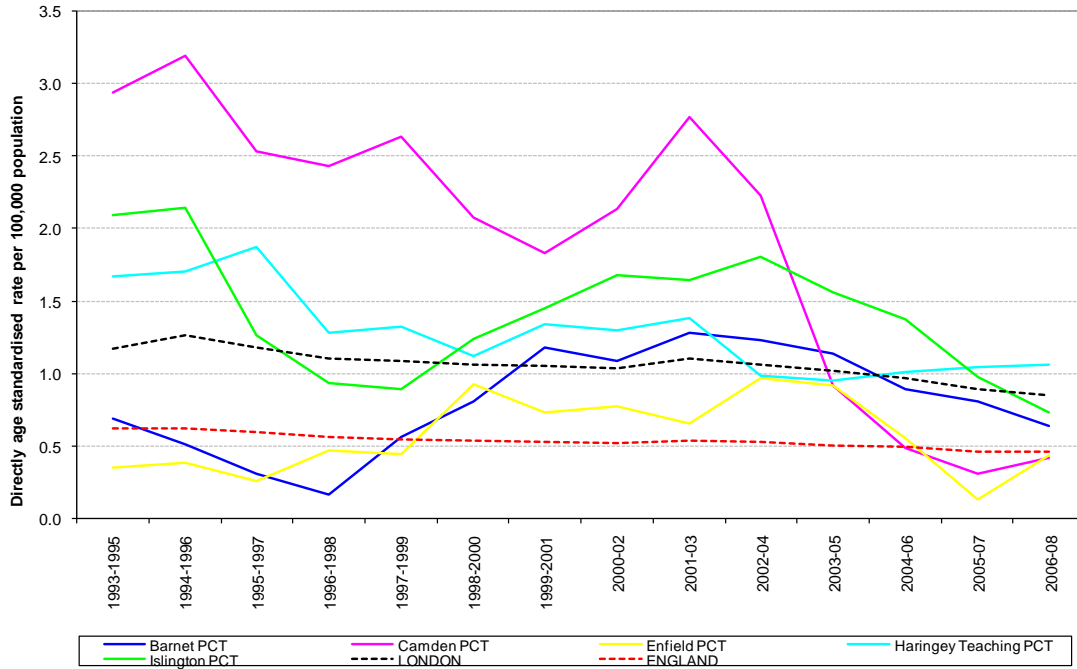
### 2.3.7 Mortality trends by PCT

*Mortality across all ages – PCT level*

**Figures 12 to 16** show the trends in mortality rates across all ages in the PCTs in the five sectors across London

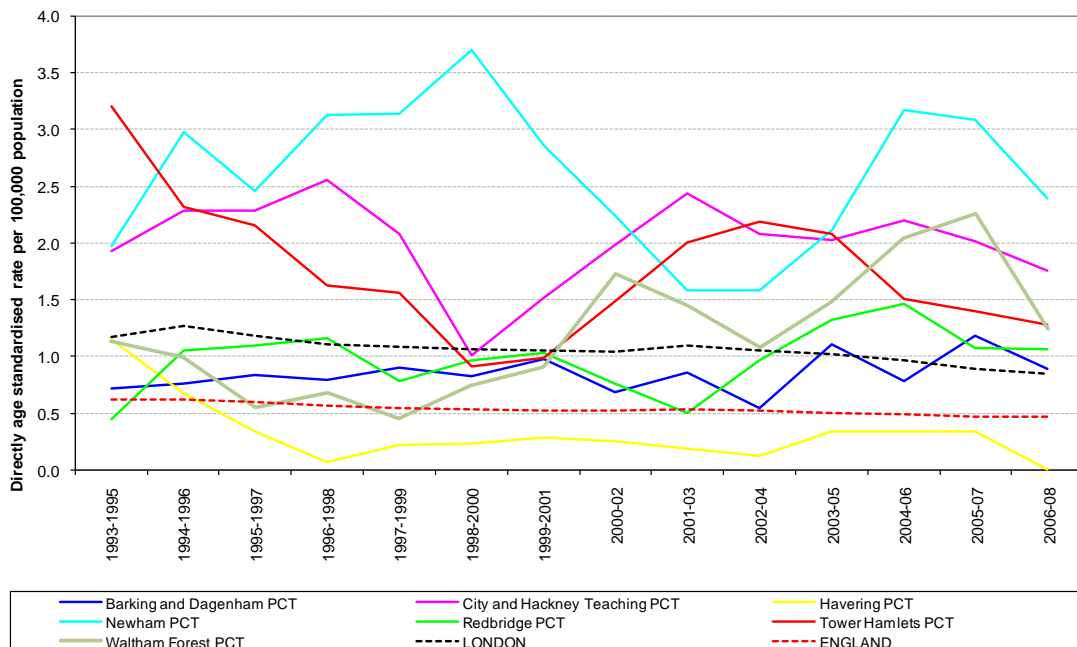
**Figure 12: Standardised mortality rate trend, TB all ages, NC London PCTs, London and England, 1993-2008**

Source: Compendium



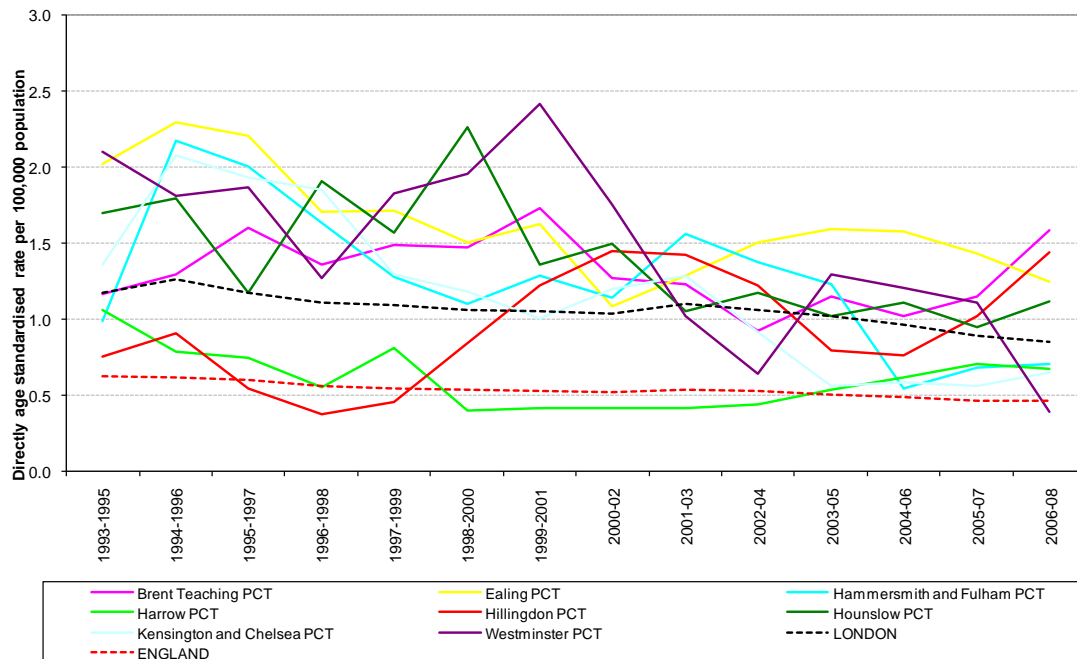
**Figure 13: Standardised mortality rate trend, TB all ages, NE London PCTs, London and England, 1993-2008**

Source: Compendium



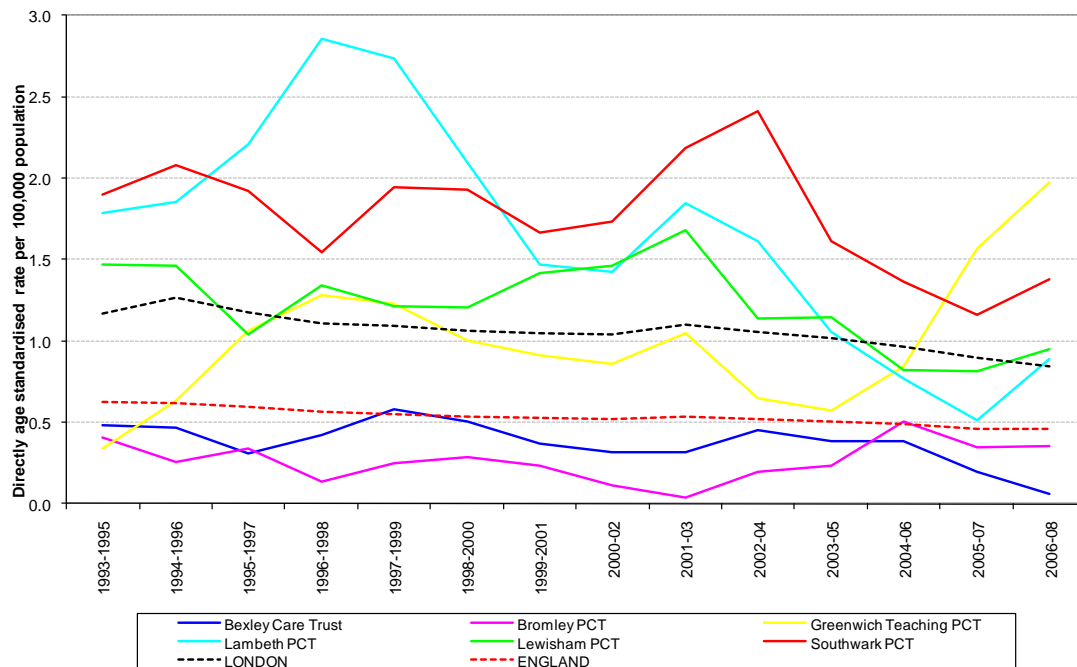
**Figure 14: Standardised mortality rate trend, TB all ages, NW London PCTs, London and England, 1993-2008**

Source: Compendium



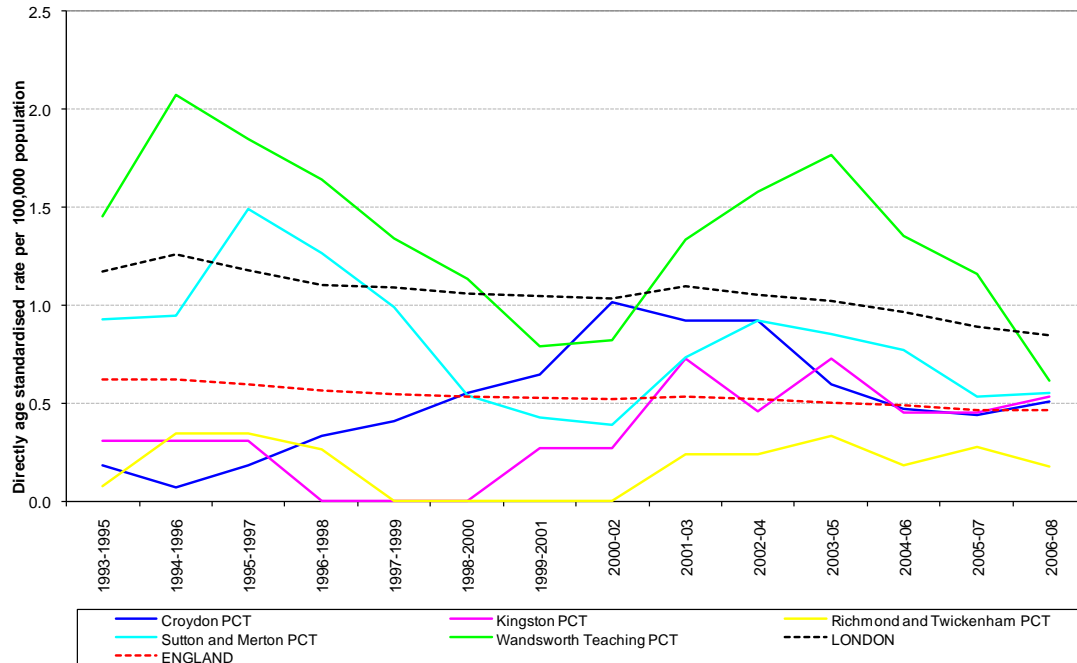
**Figure 15: Standardised mortality rate trend, TB all ages, SE London PCTs, London and England, 1993-2008**

Source: Compendium



**Figure 16: Standardised mortality rate trend, TB all ages, SW London PCTs, London and England, 1993-2008**

Source: Compendium



Despite smoothing the figures by using a three year rolling average, all the PCT trend lines show noticeable fluctuation. This is due to the smaller numbers of deaths, leading to more random variation. Only broad conclusions can therefore be drawn.

### 2.3.8 Summary of mortality at PCT level by sector

#### North Central London

From 1993 up to 2003, Camden had the highest mortality rates in North Central London (peaking at a rate of 3.65 per 100,000 population in 1994). In the last few years the death rates in Camden have fallen to the lowest in the sector. This is in contrast to the notification rates in Camden, which have remained broadly the same. All NC London PCTs have rates that have recently converged with values close to the London average.

#### North East London

Newham PCT has had the highest mortality rates for most of the 15 year period, peaking in 1998 with a rate of 4.19 per 100,000 and again in 2006 (4.43 per 100,000).

Havering PCT has had the lowest rates in North East London. Since 1994 Havering's death rates have remained below the London rate.

*North West London*

Death rates from TB have fluctuated markedly in the PCTs in North West London. Ealing PCT has tended to have the highest mortality rates (averaging at 1.63 per 100,000 over the 15 years) but Westminster PCT peaked with the highest rate in the sector in 1999 (3.06 per 100,000).

Harrow has had the lowest death rates in North West London.

*South East London*

Southwark PCT had the highest rate over the 15 years but Lambeth peaked above all the South East London PCTs between 1996 and 1999 (the highest being in 1998 with a rate of 3.35 per 100,000).

Both Bromley and Bexley rates have been consistently similar to those of London as a whole.

*South West London*

Wandsworth PCT had the highest rates in South West London, peaking in 1995 (2.48 per 100,000) and again in 2003 (2.12 per 100,000).

Richmond and Twickenham PCT has had the lowest rates in the sector.

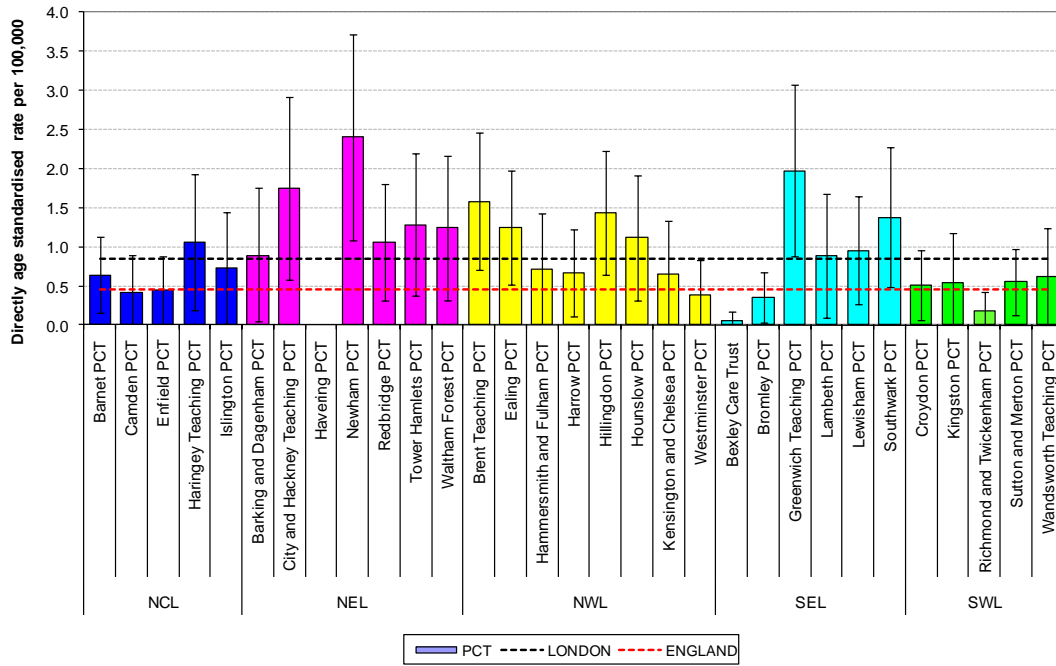
**2.3.9 TB mortality rates in comparison to other London PCTs**

The bar chart in **Figure 17** shows the death rates from TB for people of all ages across all 31 London PCTs, averaged across the last three years for which information is available (2006-08).

The rates of all PCTs can be compared, each bar representing the rate in one PCT. The rates are (as before) directly standardised for age and sex, to take account of the different age and sex distributions within the various PCTs. Each London sector is colour coded, London in black and England in red.

**Figure 17: Standardised TB mortality rates, all ages, London PCTs, London and England, 2006-08**

Source: Compendium



**2.3.10 How meaningful are differences between the rates of PCTs?**

The exact value of any rate can differ from its neighbour’s simply play of chance. We can be 95% certain that the true value for each of these rates lies within the limits shown by the symbol “I” extending across the top of each bar. When these “95% confidence intervals” across different bars overlap, differences between PCTs may not be significant. When PCTs’ values are so different that the confidence limits do not overlap, then the differences are statistically significant, and may actually be very important.

*What Figure 17 shows*

The 95% confidence levels around the values for most London PCTs overlap, meaning that the differences in rates between them are not significant.

However, there are exceptions. Newham has the highest death rate from TB in London, and Havering the lowest (no deaths attributed to TB in this period). The difference between these two PCTs is substantial and statistically significant. Death rates in Newham and Greenwich are significantly higher than both the national and London overall rates. By contrast, in Bexley and Richmond & Twickenham the rates are significantly lower than both the national and London overall rates. The rates

across North Central London are generally low. Those PCTs with the highest death rates from TB may be those whose cases have the greatest complexity or where they tend to present latest.

The only way to decide if some of these deaths could be prevented would be to make a brief study of each one, perhaps as part of Cohort Review.

### 2.3.11 Case fatality ratios

The most sensitive indicator of risk of death from TB is to study the number of TB deaths as a proportion of TB patients during a given time period. The best way to do this would be to look at figures by service, as part of Cohort Review. This information (by service) is not currently available.

Numbers of deaths certified as due to TB are, however, available by PCT of residence. The total number of TB notifications by PCT in any one year is also available. We therefore calculated **case fatality ratios** by comparing the number of deaths by PCT of residence to the number of TB notifications made in the same period. Because of small numbers of deaths in a single year, figures were aggregated across the five year period 2004-08.

The results are shown in **Table 6** below.

The figures must be interpreted with considerable caution. They are ratios, not (strictly speaking) direct proportions.

The ratios have also not been adjusted for age, gender, HIV co-infection, ethnicity or general case complexity.

Only very general conclusions can therefore be drawn.



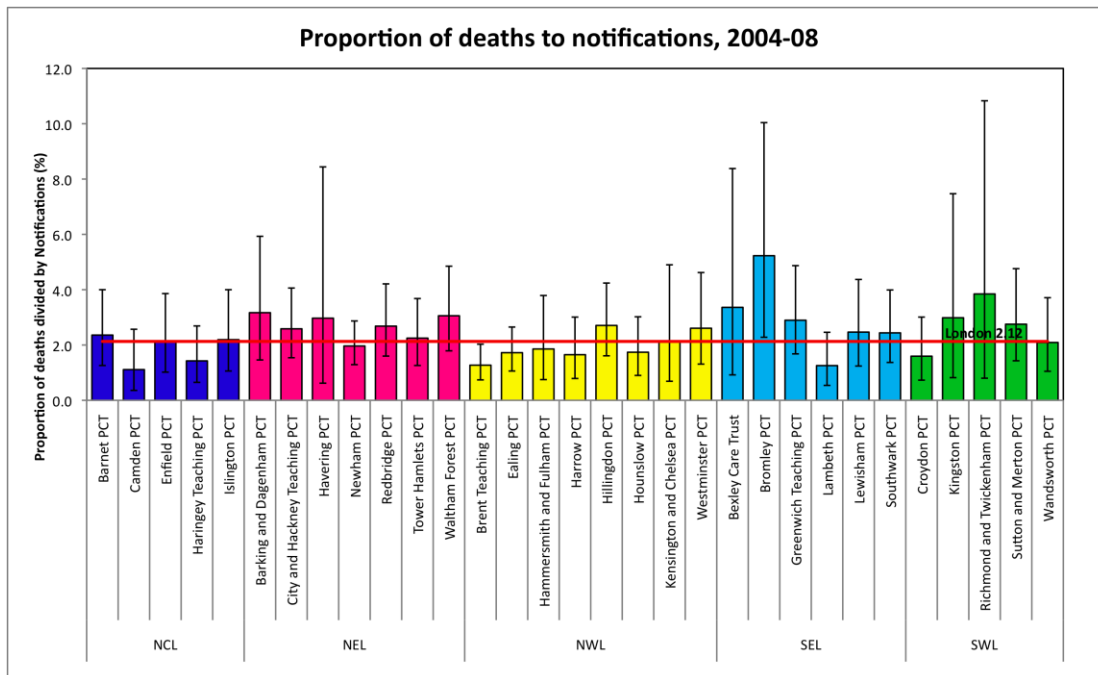
**Table 6: Case fatality ratios: TB deaths as a proportion of notifications (%) 2004-08**

<b>Sector</b>	<b>PCT Name</b>	<b>TB deaths 2004-2008</b>	<b>TB notifications 2004-2008</b>	<b>Proportion of deaths to notifications (%)</b>
NCL	Barnet PCT	13	551	2.36
	Camden PCT	5	450	1.11
	Enfield PCT	10	472	2.12
	Haringey Teaching PCT	9	631	1.43
	Islington PCT	10	456	2.19
	<b>TOTAL</b>		<b>47</b>	<b>2,560</b>
NEL	Barking & Dagenham PCT	9	284	3.17
	City & Hackney Teaching PCT	18	696	2.59
	Havering PCT	3	101	2.97
	Newham PCT	26	1,323	1.97
	Redbridge PCT	18	671	2.68
	Tower Hamlets PCT	15	667	2.25
	Waltham Forest PCT	17	556	3.06
	<b>TOTAL</b>		<b>106</b>	<b>4,298</b>
NWL	Brent Teaching PCT	17	1,337	1.27
	Ealing PCT	20	1,161	1.72
	Hammersmith & Fulham PCT	7	377	1.86
	Harrow PCT	10	606	1.65
	Hillingdon PCT	18	665	2.71
	Hounslow PCT	12	690	1.74
	Kensington & Chelsea PCT	5	235	2.13
	Westminster PCT	11	422	2.61
	<b>TOTAL</b>		<b>100</b>	<b>5,493</b>
SEL	Bexley Care Trust	4	119	3.36
	Bromley PCT	8	153	5.23
	Greenwich Teaching PCT	15	518	2.90
	Lambeth PCT	8	637	1.26
	Lewisham PCT	11	446	2.47
	Southwark PCT	15	615	2.44
	<b>TOTAL</b>		<b>61</b>	<b>2,488</b>
SWL	Croydon PCT	9	564	1.60
	Kingston PCT	4	134	2.99
	Richmond & Twickenham PCT	3	78	3.85
	Sutton & Merton PCT	12	436	2.75
	W&sworth PCT	11	526	2.09
	<b>TOTAL</b>		<b>39</b>	<b>1,738</b>
	<b>LONDON</b>	<b>353</b>	<b>16,577</b>	<b>2.13</b>

Figure 18 shows the same ratios as a bar chart. The 95% confidence intervals are also shown. Confidence intervals are widest where numbers are small.

Figure 18: Case fatality ratios, London PCTs 2004-08

Source: Compendium



Red line: London average

Across London there is some variation in the ratios; most sets of confidence intervals overlap, showing that apparent differences may not be significant.

There are low rates in Brent, Camden, Haringey and Lambeth. The rate in Bromley has wide confidence intervals (small numbers) but the rate is significantly higher than the London average.

This analysis does not suggest that areas of higher incidence (and large ethnic minority populations) have relatively higher death rates. However it does suggest that perhaps areas of lower incidence might have higher death rates. These differences could possibly be due to different age profiles. e.g. older patients in Bromley and / or younger patients in Brent or Lambeth.

The results suggest that cohort review (incorporating death review) is an important process to introduce into all parts of London so that these differences can be understood.

### 2.3.12 Age

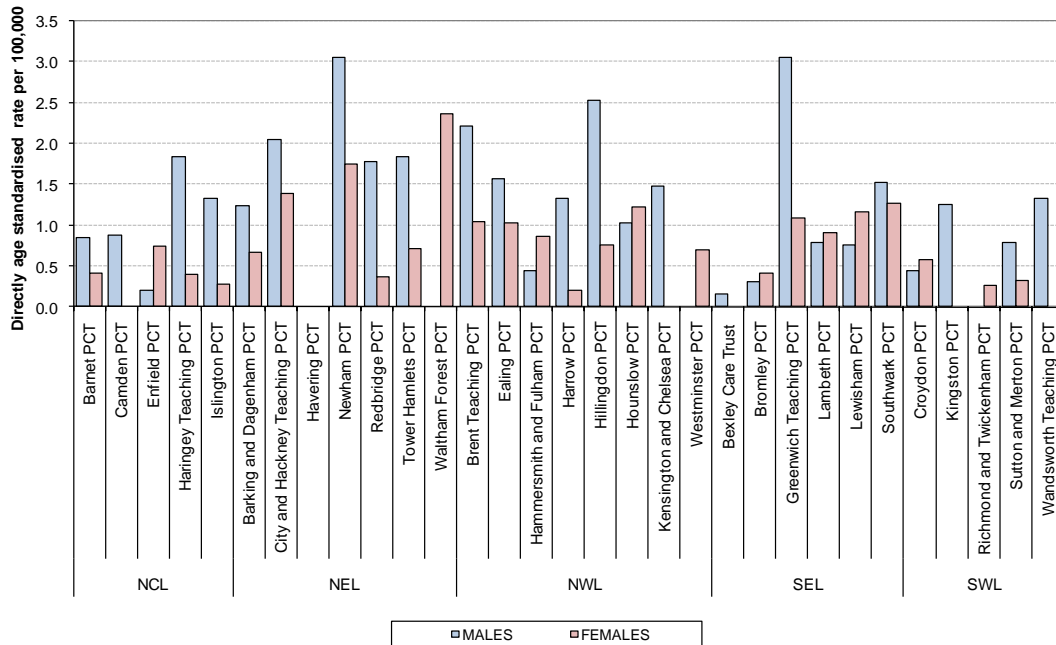
Nearly two-thirds of deaths from TB are amongst people under 75 yrs of age. In London there were 128 TB deaths in 2006-08 amongst this age group, accounting for 63% of all TB deaths.

### 2.3.13 Death rates in men and in women

Death rates in women and in men can be directly compared (see **Figure 19**). Rates are higher in men than in women (across all ages) in almost all PCTs in London.

**Figure 19: Age standardised mortality rates, TB, males and females, London PCTs, 2006-08**

Source: Compendium



Death rates in men exceed rates in women in over two thirds of PCTs across London. In Lambeth and Croydon the rates are very similar. In Waltham Forest, Westminster and Richmond and Twickenham there were no male deaths. In Enfield, Hammersmith & Fulham, Hounslow, Bromley, Lambeth, Lewisham and Croydon, the rates of female deaths exceeded those of males.

### 2.3.14 Numbers of deaths from TB

The previous section considered death *rates*. This section looks at total *numbers* of deaths from TB in each PCT within London.

Whereas death rates are adjusted for age and sex, there are no such adjustments to numbers of deaths. The total number of deaths in any area is a result of the combined impact of all the predisposing factors, such as deprivation, ethnicity,

access to and quality of local services, as well as the effects of age, gender and of population size.

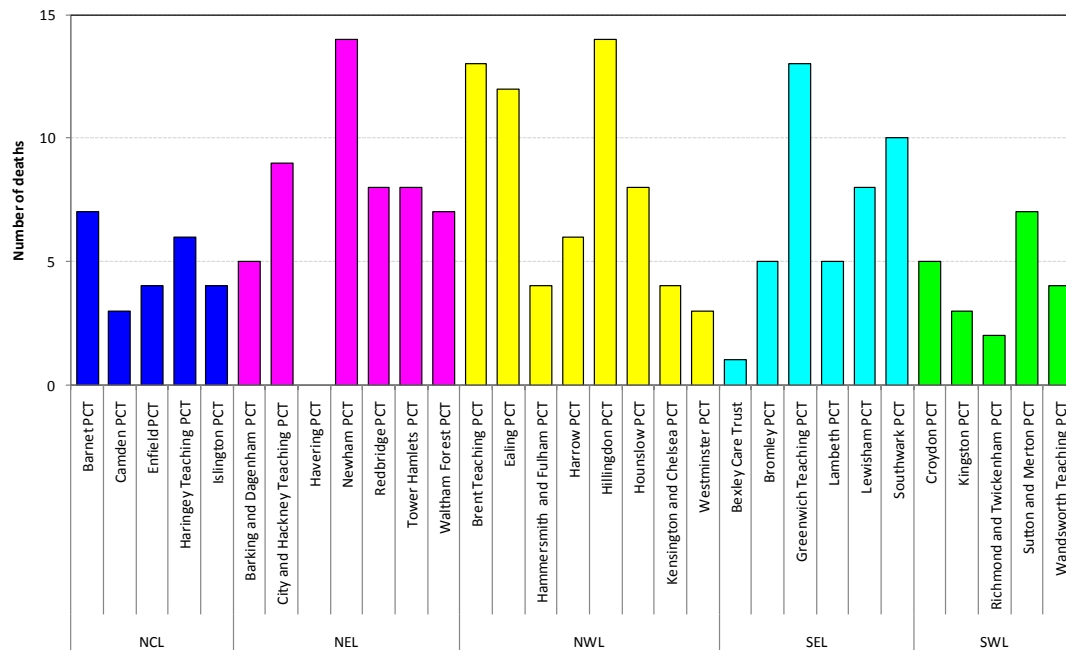
The number of deaths from TB in any one locality will (amongst other factors) reflect the size of the at-risk population living there.

In 2008 a total of 69 deaths in London were attributed to TB. Given that the number of deaths in any one year is relatively small in statistical terms, we examined deaths in London from TB across the three year period 2006 - 2008. A total of 202 deaths from TB were recorded across London as a whole in this period.

**Figure 20** shows the total number of TB deaths per year occurring to all residents of London PCTs, averaged across the three years 2006 – 2008 (i.e. totals for men and women of all ages combined).

**Figure 20: Number of deaths from TB, all ages, London PCTs, 2006-08**

Source: Compendium



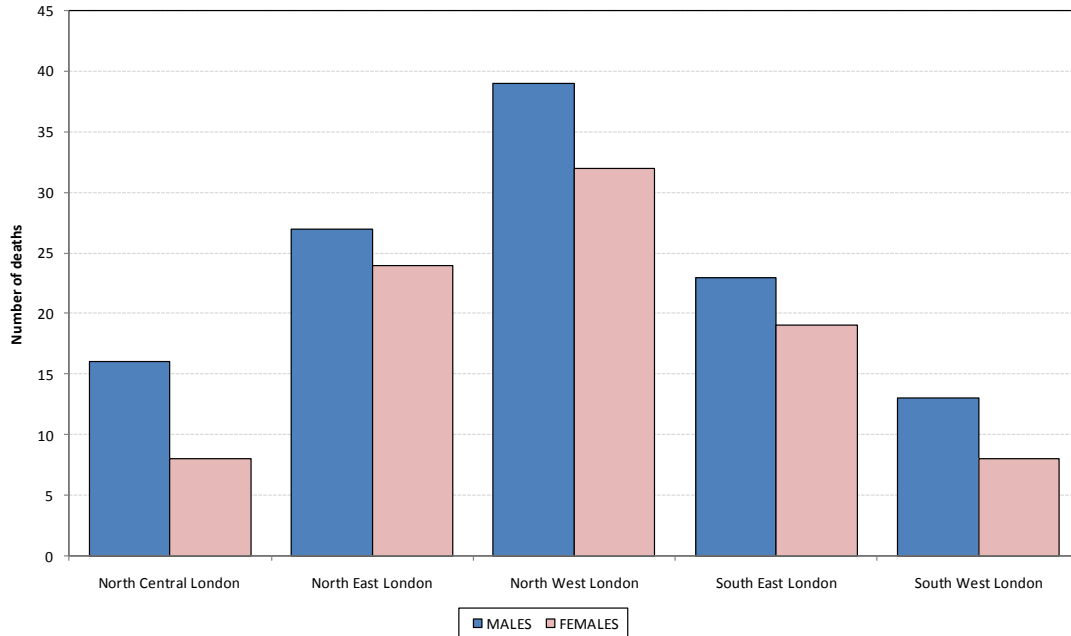
The pattern of death numbers shows a slightly different pattern from that of death rates, although as the numbers are small caution must be taken when interpreting these figures.

In London, the greatest number of deaths occurred to residents of Newham and Hillingdon, followed by Brent and Greenwich, all of which have high numbers compared with most London PCTs.

**Figure 21** shows the number of deaths from TB by gender in London by sector across the three years 2006-08.

**Figure 21: Number of deaths from TB by sex, all ages, 2006-08**

Source: Compendium



In all sectors, across all age groups, there are more deaths in men than in women. This is not entirely surprising, given that around 60% of all TB cases in London are in men. Further factors could include HIV co-infection. The gender difference is more marked in North Central London; however the majority of deaths are clearly within North West London.

**2.3.15 What this study of TB mortality shows**

Study of mortality from TB across London shows that those PCTs with the highest death rates are Newham, Greenwich, Brent and City & Hackney. Death rates are probably a reflection of TB incidence; these PCTs are known to have high TB notification rates. The PCTs with the lowest death rates (Havering, Richmond & Twickenham, Bexley) are all PCTs with low incidence and relatively small numbers of cases. A significantly high case fatality ratio, however, can be seen in Bromley; this may be age-related.

At sector level, the largest numbers of deaths are to be found in North West London, where the number of cases is also the highest in London.

**2.4 Treatment completion**

Treatment outcomes described below relate to TB cases notified during 2008, and therefore due to have completed treatment during 2009.

### **2.4.1 Definition – a source of difficulty**

Clinicians entering information on the LTBR must complete treatment status once 12 months have passed since initial notification of the case in question.

Treatment completion is simple in concept for an individual patient, but complicated when defined in a database such as the LTBR. The current LTBR definition also allows for some interpretation by the completing clinician, which can make comparisons between services misleading.

There are a number of reasons why treatment might not be completed. They include death of patient, transfers out of London or overseas, treatment stopped (not TB, de-notified) and losses to follow-up. Death is recorded as the outcome if it occurs before the patient completes treatment. In addition, if a patient has complex drug resistant TB it is possible that the full course of treatment will need to take more than 12 months following notification to complete; this instance still counts as treatment not completed.

These definitional issues make comparisons of rates between clinics more complex than ideal. However, all the information that follows has been derived from the LTBR by the HPA, using standardised definitions. This makes comparisons more valid, despite some of the definitional problems.

Losses to follow up are monitored as a separate outcome indicator.

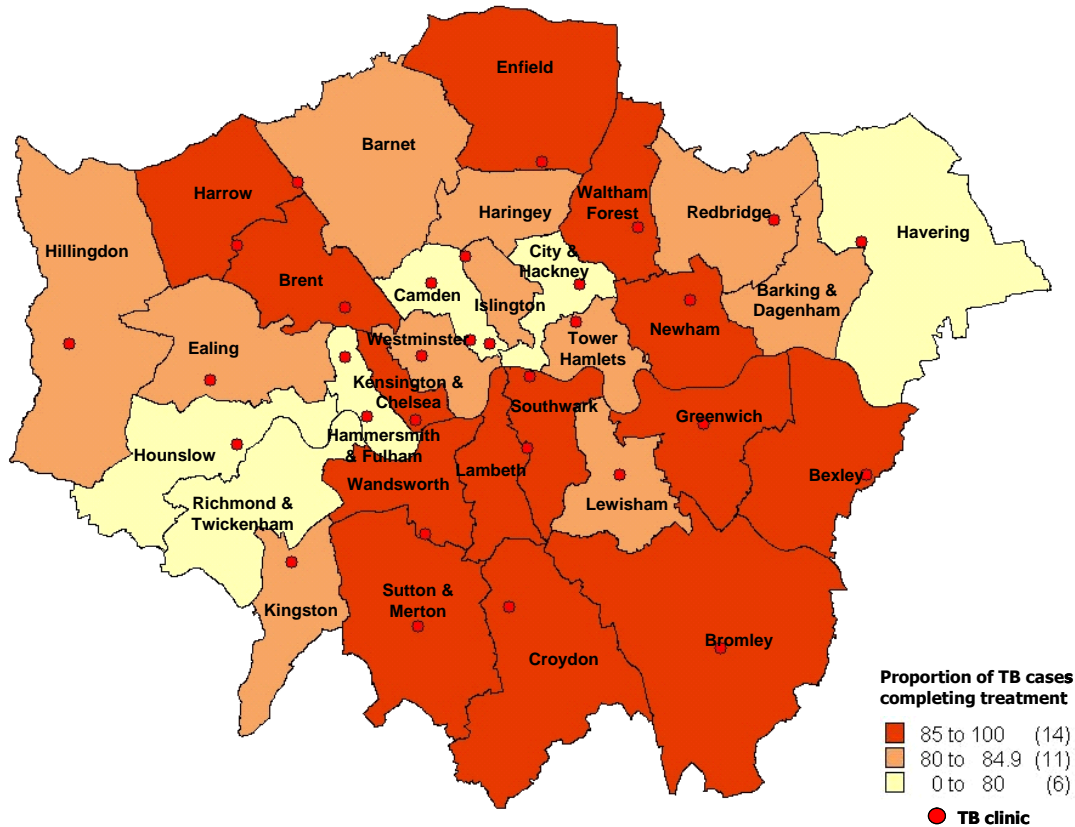
### **2.4.2 The standard**

Treatment completion rates should be higher than 85% (London TB metrics).

**Map 3** shows treatment completion rates across London by PCT of residence.

**Map 3: Treatment completion rates, London PCTs 2010**

Source: HPA



It can be seen that six PCTs reported treatment completion rates of 79% or less. The rates and numbers of TB cases in Richmond & Twickenham and Havering are among the lowest in London, so the potential public health impact of suboptimal treatment completion in these localities may be less than in PCTs such as Camden, City & Hackney and Hounslow. Case numbers here are relatively large, so the possible impact of low completion rates could be substantial in these localities. Some of the lower completion rates could be due to a higher proportion of cases being more complex or involving drug resistance.

**Table 7** shows the completion rates by notifying clinic between 2003 and 2008. The treatment completion rate for London as a whole is currently only 82.6%, although this is an increase on 2003-06.

**Table 7: Treatment completion numbers and rates, by clinic, TB cases reported 2003-2008.** Source HPA

Sector / TB service	Completed treatment within 1 year						% of all notifications completing treatment within 1 year						
	2003	2004	2005	2006	2007	2008	2003	2004	2005	2006	2007	2008	
<b>North Central</b>	Barnet	41	40	63	72	64	57	82.0%	81.6%	78.8%	87.8%	86.5%	82.6%
	Great Ormond Street	6	7	3	7	6	10	100.0%	53.8%	42.9%	87.5%	85.7%	66.7%
	North Middlesex	114	156	156	156	103	142	71.3%	76.8%	82.1%	81.3%	84.4%	85.0%
	Royal Free	96	89	87	94	66	67	78.0%	80.2%	84.5%	87.9%	76.7%	73.6%
	UCLH	108	82	108	110	98	111	77.7%	70.7%	78.3%	83.3%	78.4%	78.7%
	Whittington	69	77	57	83	77	69	69.7%	83.7%	80.3%	83.0%	88.5%	79.3%
	<b>North Central Total</b>	<b>434</b>	<b>451</b>	<b>474</b>	<b>522</b>	<b>414</b>	<b>456</b>	<b>75.2%</b>	<b>77.2%</b>	<b>80.5%</b>	<b>84.1%</b>	<b>82.6%</b>	<b>80.0%</b>
<b>North East</b>	Queens (BHRT)	15	16	26	32	39	55	78.9%	84.2%	70.3%	71.1%	78.0%	84.6%
	Homerton	121	116	97	107	116	95	82.9%	76.8%	79.5%	83.6%	88.5%	79.8%
	King George (BHRT)	105	87	116	117	104	121	81.4%	80.6%	87.2%	82.4%	83.9%	78.1%
	London Chest (BLT)	156	144	163	175	198	176	76.1%	77.8%	77.3%	82.2%	84.6%	80.7%
	Newham	175	168	179	177	194	192	83.7%	84.8%	84.4%	82.3%	86.2%	87.3%
	Whipps Cross	75	77	91	103	90	122	77.3%	71.3%	76.5%	86.6%	88.2%	94.6%
<b>North East Total</b>	<b>647</b>	<b>608</b>	<b>672</b>	<b>711</b>	<b>741</b>	<b>761</b>	<b>80.4%</b>	<b>79.1%</b>	<b>80.6%</b>	<b>82.5%</b>	<b>85.6%</b>	<b>84.0%</b>	
<b>North West</b>	Charing Cross (ICHT)	50	45	47	51	42	46	86.2%	80.4%	72.3%	81.0%	84.0%	79.3%
	Chelsea & Westminster	53	47	60	49	47	57	74.6%	75.8%	85.7%	83.1%	88.7%	86.4%
	Ealing	104	137	119	143	142	128	73.8%	70.6%	68.0%	79.9%	75.1%	83.7%
	Hammersmith (ICHT)	44	53	54	62	64	48	71.0%	77.9%	84.4%	78.5%	88.9%	73.8%
	Hillingdon	72	67	76	78	94	104	84.7%	77.0%	75.2%	74.3%	89.5%	80.6%
	Northwick Park (NWLTL)	191	170	244	216	205	251	68.5%	76.2%	81.3%	86.7%	87.2%	87.5%
	Royal Brompton	-	-	-	2	2	0	-	-	-	33.3%	66.7%	-
	St Mary's (ICHT)	118	115	135	121	127	113	80.3%	76.2%	81.3%	87.1%	85.8%	79.0%
	West Middlesex	20	42	66	64	85	66	38.5%	48.8%	56.4%	59.8%	76.6%	61.1%
Central Middlesex (NWLTL)	88	113	139	109	106	116	77.9%	81.9%	79.9%	88.6%	82.2%	89.9%	
<b>North West Total</b>	<b>740</b>	<b>789</b>	<b>940</b>	<b>895</b>	<b>914</b>	<b>929</b>	<b>73.4%</b>	<b>74.1%</b>	<b>76.3%</b>	<b>80.7%</b>	<b>83.5%</b>	<b>81.6%</b>	
<b>South East</b>	Bromley	18	16	16	21	19	14	69.2%	66.7%	72.7%	72.4%	82.6%	93.3%
	Guy's & St Thomas's	112	123	157	125	107	132	74.7%	83.1%	82.2%	81.7%	85.6%	81.0%
	Kings College	85	107	101	104	104	101	78.0%	79.9%	79.5%	73.8%	87.4%	88.6%
	Queen Elizabeth	61	70	73	78	67	115	88.4%	80.5%	78.5%	84.8%	68.4%	87.1%
	Queen Mary's	13	12	10	12	11	4	92.9%	92.3%	100.0%	92.3%	91.7%	80.0%
	Lewisham	53	64	73	78	75	64	77.9%	86.5%	79.3%	92.9%	76.5%	84.2%
<b>South East Total</b>	<b>342</b>	<b>392</b>	<b>430</b>	<b>418</b>	<b>383</b>	<b>430</b>	<b>78.4%</b>	<b>81.7%</b>	<b>80.4%</b>	<b>81.6%</b>	<b>80.6%</b>	<b>85.1%</b>	
<b>South West</b>	Epsom St Helier	32	17	30	36	48	38	84.2%	73.9%	81.1%	83.7%	92.3%	82.6%
	Kingston	26	24	28	31	23	32	78.8%	80.0%	75.7%	73.8%	71.9%	76.2%
	Mayday	85	96	80	88	81	78	82.5%	85.7%	83.3%	88.9%	79.4%	84.8%
	St George's	117	140	162	128	149	160	75.0%	81.4%	82.7%	79.5%	82.3%	83.3%
	<b>South West Total</b>	<b>260</b>	<b>277</b>	<b>300</b>	<b>283</b>	<b>301</b>	<b>308</b>	<b>78.8%</b>	<b>82.2%</b>	<b>82.0%</b>	<b>82.0%</b>	<b>82.0%</b>	<b>82.8%</b>
<b>Non LTBR Clinics</b>			<b>2</b>	<b>3</b>	<b>7</b>	<b>4</b>	<b>0.0%</b>	<b>0.0%</b>	<b>13.3%</b>	<b>42.9%</b>	<b>77.8%</b>	<b>66.7%</b>	
<b>London Total</b>	<b>2423</b>	<b>2517</b>	<b>2818</b>	<b>2832</b>	<b>2760</b>	<b>2888</b>	<b>76.6%</b>	<b>77.7%</b>	<b>78.9%</b>	<b>81.9%</b>	<b>83.3%</b>	<b>82.6%</b>	



The variation in reported completion rates is striking. Rates below 80% require some explanation.

Great Ormond Street Hospital reported a 40% fall in completion rates. This is probably related to case complexity, with small numbers of cases.

The treatment completion rate at the Royal Free (73.6%) however, and at the West Middlesex (only 61.1%) requires investigation.

It is not possible from these figures to be able to tell if low rates are due to losses to follow-up, poor patient compliance, case complexity, under-reporting into the LTBR, definitional issues or a combination of these factors.

This problem is picked up further in the **Discussion** chapter of this report.

### 2.4.3 Losses to follow-up

The LTBR also documents reported losses to follow up. These are clearly extremely important, although summary figures at the end of a year do not show whether the patient has been found elsewhere or has gone overseas and does not present an immediate risk of infection in London.

**Table 8** shows the number and proportion of patients lost to follow up in 2008, by PCT of residence. The largest total is in NW London (35), representing 3.2% of cases notified.

**Table 9** shows the number and proportion of patients reported as lost to follow up in 2008, by clinic. Again the largest total is in NW London.

In both tables, the figures can be compared year on year.

Comparisons are interesting: Newham, which has the largest caseload in London, reported only one patient lost to follow up in 2008. By contrast, there were 8 lost each to Northwick Park and the West Middlesex and 7 to St Mary's.

Without knowing the completeness of recording in the LTBR, and without knowing what action was taken to find those who have been lost, it is difficult to know whether remedial action is needed.

However, losses to follow up are sufficiently important that they should be discussed regularly and in detail at sector wide meetings, and certainly within regular Cohort Review meetings. It is not currently an indicator in the London TB metrics, although in practice it seems common for the figures to be reported to sector wide network groups.

**Table 8: Number and proportion of new notifications in London residents lost to follow-up within 1 year of starting treatment - reported to the London TB Register (as at 18 May 2010)**

Sector / PCT		Lost to follow-up within 1 year						% of all notifications lost to follow up within 1 year					
		2003	2004	2005	2006	2007	2008	2003	2004	2005	2006	2007	2008
<b>North Central</b>	Barnet PCT	2	1	3	3	0	1	2.0%	1.1%	2.6%	2.4%	0.0%	0.9%
	Camden PCT	1	1	0	1	0	2	0.9%	1.3%	0.0%	1.0%	0.0%	2.4%
	Enfield PCT	0	1	1	0	3	2	0.0%	1.1%	1.0%	0.0%	4.1%	2.0%
	Haringey Teaching PCT	10	12	7	6	2	1	7.8%	8.0%	5.3%	3.9%	2.2%	1.0%
	Islington PCT	2	3	2	2	2	3	2.1%	3.5%	2.3%	2.1%	2.2%	3.2%
<b>North Central Total</b>		<b>15</b>	<b>18</b>	<b>13</b>	<b>12</b>	<b>7</b>	<b>9</b>	<b>2.8%</b>	<b>3.6%</b>	<b>2.4%</b>	<b>2.1%</b>	<b>1.5%</b>	<b>1.8%</b>
<b>North East</b>	Barking and Dagenham PCT	0	2	2	1	0	2	0.0%	4.5%	3.3%	2.0%	0.0%	2.9%
	City and Hackney Teaching PCT	2	4	3	3	0	3	1.3%	2.5%	2.3%	2.2%	0.0%	2.4%
	Havering PCT	0	0	0	0	0	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	Newham PCT	6	1	9	5	3	2	2.4%	0.4%	3.5%	1.9%	1.1%	0.7%
	Redbridge PCT	5		3	5	1	1	4.5%	0.0%	2.5%	3.5%	0.7%	0.6%
	Tower Hamlets PCT	4	2	1	2	1	2	2.7%	1.7%	0.8%	1.5%	0.7%	1.5%
	Waltham Forest PCT	4	3	3	2	2		4.0%	3.0%	2.6%	1.7%	2.2%	0.0%
<b>North East Total</b>		<b>21</b>	<b>12</b>	<b>21</b>	<b>18</b>	<b>7</b>	<b>10</b>	<b>2.6%</b>	<b>1.5%</b>	<b>2.5%</b>	<b>2.1%</b>	<b>0.8%</b>	<b>1.1%</b>
<b>North West</b>	Brent Teaching PCT	7	11	13	8	9	13	3.2%	4.8%	4.5%	3.3%	3.3%	4.2%
	Ealing PCT	4	8	10	7	7	3	2.2%	3.1%	4.2%	3.0%	3.0%	1.5%
	Hammersmith and Fulham PCT	1	4	3	0	2	1	1.5%	5.6%	3.3%	0.0%	2.9%	1.5%
	Harrow PCT	5	2	4	1	3	3	4.3%	2.0%	3.0%	0.8%	2.5%	2.3%
	Hillingdon PCT	6	2	8	4	3	3	5.2%	1.7%	5.6%	3.2%	2.4%	2.0%
	Hounslow PCT	2	8	17	14	3	8	2.0%	7.0%	10.2%	10.1%	2.2%	6.0%
	Kensington and Chelsea PCT	0	0	0	0	0	1	0.0%	0.0%	0.0%	0.0%	0.0%	1.9%
Westminster PCT	2	5	4	0	3	3	2.2%	5.8%	4.2%	0.0%	3.5%	4.3%	
<b>North West Total</b>		<b>27</b>	<b>40</b>	<b>59</b>	<b>34</b>	<b>30</b>	<b>35</b>	<b>2.9%</b>	<b>3.9%</b>	<b>4.9%</b>	<b>3.1%</b>	<b>2.8%</b>	<b>3.2%</b>
<b>South East</b>	Bexley PCT	1	0	1	0	2	0	4.0%	0.0%	4.3%	0.0%	7.7%	0.0%
	Bromley PCT	0	1	3	1	0	0	0.0%	3.4%	10.3%	2.4%	0.0%	0.0%
	Greenwich Teaching PCT	2	6	3	1	2	1	2.8%	6.7%	3.4%	1.0%	1.9%	0.7%
	Lambeth PCT	3	4	4	1	5	4	1.9%	3.1%	2.8%	0.7%	4.8%	3.1%
	Lewisham PCT	2	2	3	2	0	1	2.5%	2.6%	3.0%	2.4%	0.0%	1.2%
	Southwark PCT	0	4	2	3	2	4	0.0%	3.0%	1.5%	2.4%	1.9%	3.4%
<b>South East Total</b>		<b>8</b>	<b>17</b>	<b>16</b>	<b>8</b>	<b>11</b>	<b>10</b>	<b>1.7%</b>	<b>3.5%</b>	<b>3.1%</b>	<b>1.6%</b>	<b>2.3%</b>	<b>2.0%</b>
<b>South West</b>	Croydon PCT	4	3	1	0	4	2	3.5%	2.5%	0.9%	0.0%	3.4%	1.8%
	Kingston PCT	0	0	0	1	3	0	0.0%	0.0%	0.0%	4.0%	10.3%	0.0%
	Richmond and Twickenham PCT	0	0	0	0	0	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	Sutton and Merton PCT	2	2	2	3	1	2	2.8%	2.3%	2.3%	3.2%	1.1%	2.5%
	Wandsworth PCT	3	3	3	2	4	3	3.1%	3.2%	2.4%	2.4%	3.5%	2.7%
<b>South West Total</b>		<b>9</b>	<b>8</b>	<b>6</b>	<b>6</b>	<b>12</b>	<b>7</b>	<b>2.9%</b>	<b>2.4%</b>	<b>1.6%</b>	<b>1.9%</b>	<b>3.3%</b>	<b>2.0%</b>
<b>London Totals</b>		<b>80</b>	<b>95</b>	<b>115</b>	<b>78</b>	<b>67</b>	<b>71</b>	<b>2.6%</b>	<b>3.0%</b>	<b>3.3%</b>	<b>2.3%</b>	<b>2.1%</b>	<b>2.1%</b>

**Table 9: Number and proportion of new TB notifications in London clinics lost to follow-up within 1 year of starting treatment by sector of notifying clinic and year of notification - reported to the London TB Register (as at 18 May 2010)**

Sector / TB service	Lost to follow-up within 1 year						% of all notifications lost to follow-up within 1 year						
	2003	2004	2005	2006	2007	2008	2003	2004	2005	2006	2007	2008	
<b>North Central</b>	Barnet	3	1	3	3	0	0	6.0%	2.0%	3.8%	3.7%	0.0%	0.0%
	Great Ormond Street	0	0	0	0	0	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	North Middlesex	7	13	6	5	5	3	4.4%	6.4%	3.2%	2.6%	4.1%	1.8%
	Royal Free	0	2	1	0	0	2	0.0%	1.8%	1.0%	0.0%	0.0%	2.2%
	UCLH	3	2	1	1	0	2	2.2%	1.7%	0.7%	0.8%	0.0%	1.4%
	Whittington	2	2	3	3	2	2	2.0%	2.2%	4.2%	3.0%	2.3%	2.3%
<b>North Central Total</b>	<b>15</b>	<b>20</b>	<b>14</b>	<b>12</b>	<b>7</b>	<b>9</b>	<b>2.6%</b>	<b>3.4%</b>	<b>2.4%</b>	<b>1.9%</b>	<b>1.4%</b>	<b>1.6%</b>	
<b>North East</b>	Queens (BHRT)	0	0	0	1	0	0	0.0%	0.0%	0.0%	2.2%	0.0%	0.0%
	Homerton	2	5	1	3	0	3	1.4%	3.3%	0.8%	2.3%	0.0%	2.5%
	King George (BHRT)	4	2	4	6	2	2	3.1%	1.9%	3.0%	4.2%	1.6%	1.3%
	London Chest (BLT)	7	3	3	4	2	4	3.4%	1.6%	1.4%	1.9%	0.9%	1.8%
	Newham	6	0	6	4	2	1	2.9%	0.0%	2.8%	1.9%	0.9%	0.5%
	Whipps Cross	4	4	5	2	1	0	4.1%	3.7%	4.2%	1.7%	1.0%	0.0%
<b>North East Total</b>	<b>23</b>	<b>14</b>	<b>19</b>	<b>20</b>	<b>7</b>	<b>10</b>	<b>2.9%</b>	<b>1.8%</b>	<b>2.3%</b>	<b>2.3%</b>	<b>0.8%</b>	<b>1.1%</b>	
<b>North West</b>	Charing Cross	0	1	2	1	1	3	0.0%	1.8%	3.1%	1.6%	2.0%	5.2%
	Chelsea & Westminster	2	1	3	1	0	0	2.8%	1.6%	4.3%	1.7%	0.0%	0.0%
	Ealing	3	7	8	9	7	2	2.1%	3.6%	4.6%	5.0%	3.7%	1.3%
	Hammersmith (ICHT)	1	1	3	1	1	1	1.6%	1.5%	4.7%	1.3%	1.4%	1.5%
	Hillingdon	1	3	5	3	2	2	1.2%	3.4%	5.0%	2.9%	1.9%	1.6%
	Northwick Park (NWLTL)	14	5	12	5	8	8	5.0%	2.2%	4.0%	2.0%	3.4%	2.8%
	Royal Brompton	-	-	-	0	0	0	-	-	-	0.0%	0.0%	0.0%
	St Mary's (ICHT)	0	7	1	0	3	7	0.0%	4.6%	0.6%	0.0%	2.0%	4.9%
	West Middlesex	2	10	14	9	4	8	3.8%	11.6%	12.0%	8.4%	3.6%	7.4%
Central Middlesex (NWLTL)	5	10	12	5	5	6	4.4%	7.2%	6.9%	4.1%	3.9%	4.7%	
<b>North West Total</b>	<b>28</b>	<b>45</b>	<b>60</b>	<b>34</b>	<b>31</b>	<b>37</b>	<b>2.8%</b>	<b>4.2%</b>	<b>4.9%</b>	<b>3.1%</b>	<b>2.8%</b>	<b>3.3%</b>	
<b>South East</b>	Bromley	0	1	1	1	1	0	0.0%	4.2%	4.5%	3.4%	4.3%	0.0%
	Guy's & St Thomas's	3	7	2	2	5	9	2.0%	4.7%	1.0%	1.3%	4.0%	5.5%
	Kings College	3	0	5	5	1	0	2.8%	0.0%	3.9%	3.5%	0.8%	0.0%
	Queen Elizabeth	1	5	4	1	4	1	1.4%	5.7%	4.3%	1.1%	4.1%	0.8%
	Queen Mary's	0	0	0	0	0	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
	Lewisham	1	3	4	0	1	0	1.5%	4.1%	4.3%	0.0%	1.0%	0.0%
<b>South East Total</b>	<b>8</b>	<b>16</b>	<b>16</b>	<b>9</b>	<b>12</b>	<b>10</b>	<b>1.8%</b>	<b>3.3%</b>	<b>3.0%</b>	<b>1.8%</b>	<b>2.5%</b>	<b>2.0%</b>	
<b>South West</b>	Epsom St Helier	0	0	1	1	0	0	0.0%	0.0%	2.7%	2.3%	0.0%	0.0%
	Kingston	0	1	0	1	2	0	0.0%	3.3%	0.0%	2.4%	6.3%	0.0%
	Mayday	3	3	0	0	4	2	2.9%	2.7%	0.0%	0.0%	3.9%	2.2%
	St George's	6	4	5	3	6	4	3.8%	2.3%	2.6%	1.9%	3.3%	2.1%
	<b>South West Total</b>	<b>9</b>	<b>8</b>	<b>6</b>	<b>5</b>	<b>12</b>	<b>6</b>	<b>2.7%</b>	<b>2.4%</b>	<b>1.6%</b>	<b>1.4%</b>	<b>3.3%</b>	<b>1.6%</b>
<b>Non LTBR Clinics</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0.0%</b>	<b>0.0%</b>	<b>6.7%</b>	<b>0.0%</b>	<b>0.0%</b>	<b>0.0%</b>	
<b>London Total</b>	<b>83</b>	<b>103</b>	<b>116</b>	<b>80</b>	<b>69</b>	<b>72</b>	<b>2.6%</b>	<b>3.2%</b>	<b>3.2%</b>	<b>2.3%</b>	<b>2.1%</b>	<b>2.1%</b>	

## 2.5 Summary – what this chapter shows

### 2.5.1 General trend

The trend of an increasing burden of TB in London, year on year, shows that improvement is needed in the control of TB in the capital.

The TB burden in London remains significantly higher than in other regions in England. Both rates and numbers of new TB cases are continuing to increase across the whole of London (with the exception of Southwark). Within London, the PCTs with the highest notification rates in 2009 were Newham, Brent, Ealing, Tower Hamlets and Hounslow. The highest numbers of cases were seen in Newham, Brent, Ealing and Hounslow. Lowest rates (and numbers) were seen in Richmond & Twickenham and Bexley. This pattern is broadly similar to that seen in previous years, though the annual number of notifications has been increasing, especially in PCTs with already high incidence.

### 2.5.2 Age, gender and ethnicity

Only 15% of TB cases notified in 2009 were in people born within the UK. In those born outside the UK, TB is predominantly a disease of younger people; for those born in the UK there are more patients in older age groups.

Almost 5% of new TB cases are in children under 16 yrs. Relationships between paediatricians and TB clinicians are therefore extremely important.

There are more cases of TB in men than in women, a pattern that has been constant for some years.

In 2009, almost half of TB cases had pulmonary disease, a similar proportion to recent years.

The ethnicity of TB cases in London varies geographically; over 40% of TB cases are in people of Black African origin in Camden, Enfield and Haringey (NC London) and Bexley, Greenwich, Lewisham and Southwark (SE London). People from the Indian sub-continent account for more than 40% of cases in Redbridge, Brent, Ealing, Harrow and Hounslow. These patterns relate to the predominant ethnicity of local communities in these boroughs.

Services therefore need to understand the needs of these specific ethnic communities in their neighbourhoods. This requires good working relationships with local community and voluntary sector organisations, and knowledge of how most effectively to engage communities at increased risk of TB. Professionals delivering TB services will need to be actively involved in developing these essentially *local* relationships.

### 2.5.3 Clinic caseloads

The number of patients notified by each clinic is influenced by cross boundary flows in and out of the PCTs where they are located. The largest numbers of notifications are from clinics

at Northwick Park, Newham, London Chest, Ealing and the North Middlesex Hospitals. These appear to reflect local incidence of TB. The notified case load of these clinics, taken together (1,104), represents almost a third of London's total notifications for 2009.

Those clinics with the largest caseloads are likely to treat a greater number of more complex cases, though this is not quantifiable at present. Their clinical teams should be expected to be larger than elsewhere, with a wider skill mix, and to be leading on innovative services, models of care and the implementation of best practice.

### 2.5.4 Risk factor reporting

Certain factors and behaviours are known to be associated with a risk of non-compliance with the taking of anti-TB medication. The commonest risk factor reported in the LTBR is "the ability to self-administer treatment affected by alcohol" (at least 7% of patients overall across London).

There is substantial under-reporting of risk factors in the LTBR. The proportion of patients where the individual risk factor fields in the LTBR are uncompleted is high, especially in clinics with large numbers of notifications. For example, across all clinics in NW London, 77/772 patients (9.1%) were reported to have an alcohol risk factor. However, in 275 patients (36%) the alcohol field was left blank. This means that the reported 9.1% prevalence of alcohol as a risk factor in NW London is very much a minimum estimate.

This level of non-reporting makes it impossible to make meaningful comparison of the prevalence of individual risk factors between clinics or PCT populations.

It also raises the possibility that patients' need for supervised management, especially DOT, may be systematically underestimated. In NW London, this problem may apply in services caring for up to a third of London's caseload of TB.

It is also not possible to make a valid comparison between reported prevalence of risk factors and the use of DOT, either between different clinics or within / between sectors.

The probable reason for this (confirmed to us anecdotally by several stakeholders) is that the LTBR is not part of a clinical record system; high workloads may make it difficult for clinical staff to populate all the LTBR fields, especially where they need to be updated after initial notification is made. The need to complete the fields of the LTBR is an issue which needs to be picked up as a performance indicator; delivery will require clinics to have enough administrative support to enable this task to be fulfilled. (see **Chapter 8 and Recommendations**).

### 2.5.5 DOT usage

The use of DOT, as shown in records in the LTBR, appears to vary markedly between different clinics. This suggests that differing thresholds to trigger DOT may be in place, or that clinics are interpreting the definition of DOT in different ways.

The use of DOT, its varieties and how they are recorded is something that needs to be standardised across London.

### 2.5.6 Drug resistance

A total of 10% of all culture-confirmed TB cases notified in 2009, were resistant to Isoniazid, an increase from 7% in 2008. There are many more cases in North London than in South London. Most clinics report less than 10 cases of drug resistant TB per year.

MDR-TB is much less common; clinics reported none or only one or two cases each during 2009.

One case of XDR-TB was reported in 2009 (Brent resident – Northwick Park Hospital).

The relatively small case load of drug resistant TB in each clinic raises the issue in principle of critical mass of cases per clinic to assure quality of care. (see **Discussion Chapter** and **Recommendations**).

### 2.5.7 Outcomes

#### *Mortality*

Study of TB mortality within London shows that for more than 15 years London has had significantly higher death rates (the risk of death from TB per 100,000 general population) than other regions in England. Risk of death from TB (for the general population) appears to be directly related to incidence.

Death rates from TB in London are highest where the notification rates are highest, and lowest where notification rates are lowest. The greatest numbers of deaths in London are in those localities where there are the largest caseloads, and least deaths where there are least numbers of cases.

Study of case fatality ratios shows that deaths (as a proportion of notifications) are commoner in localities with low TB incidence, such as Bromley; the ratios are lower than average in localities with the highest numbers of cases. These patterns may be related to different age profiles in these different parts of London, but suggest that cohort review across all sectors should include a review of each TB-related death that occurs.

It is not possible from this data to know how much risk of death from TB is related to clinical complexity or delays in presentation. The pattern does, however, suggest that London TB services located in areas of high TB incidence may need clinical teams of the size and experience to be able to manage more complex TB cases.

Death rates are higher in men than in women, even when age is taken into account; this is unexplained but might be due to differentially late presentation or greater case complexity in men.

Understanding the extent to which any TB death might have been avoided is a clinical governance issue within trusts; but could also form part of the process of cohort review across sectors, so that best practice can be shared.

#### *Treatment completion*

The measurement of treatment completion is complex. It is partly a matter of definition. If the LTBR fields are not filled in, treatment is logged as not completed. If a TB patient on treatment is killed in a road accident, the reporting system logs their treatment as “not completed”, though the cause of death may also be logged as “unconnected”. If a patient with, say, spinal MDR-TB, (a clinically complex case) requires treatment to be taken for more than 12 months after their diagnosis was notified, treatment again is recorded as “not completed.” However, failure to complete treatment because the patient is lost to follow up really is a failure of treatment completion.

These and other definitional issues make comparison of treatment completion rates between clinics or PCTs problematic.

Table 7 showed the extent of variation in reported treatment completion rates by clinic across London. There are several relatively low rates in each sector. Treatment completion rates reported by the West Middlesex have been among the lowest in London for the last five years and in 2009 were only 61%. Low rates have also been reported for the Royal Free. This needs to be explained and any remedial action required taken.

Drilling down into the reasons for apparently low completion rates is an issue for each London sector to address, but an overview for London as a whole is also required. Getting into the issues behind the detail is a matter for clinical leadership.

The definitions need to be standardised in such a way that a meaningful figure can be compiled from the LTBR data, valid analysis made and remedial action taken if it is necessary. This issue is one for action in 2010/11.

#### *Losses to follow up*

Rates of losses to follow up appear to vary across London, being reported as high in some services compared with others. The relatively large number of losses to follow up reported by some clinics (e.g. West Middlesex, Northwick Park and St Mary’s) needs some explanation.

Losses to follow up are important. They need prompt action within each and every clinical service.

Referral to the Find and Treat team (see **Chapter 4**) and work to find patients within their communities needs to be prompt, with results reported within each network.

## CHAPTER 3 – LITERATURE REVIEW

### 3.1 What this chapter contains

This chapter describes the methods and findings of a focussed pragmatic literature review undertaken in order to identify key local, national and international sources of evidence on the following topics:

- TB treatment policies and strategies – including service standards;
- Effectiveness of exemplar service models – including organisation & operation;
- Key aspects of TB control and practice – including treatment thresholds, contact tracing and new entrant screening.

The findings on each of these themes are presented and discussed in the following sections in the context of TB in London with their relevance to improving TB control in the capital.

### 3.2 TB treatment policies and strategies

#### 3.2.1 Methods

A review of international literature (i.e. papers and reports) on the above themes published between 1<sup>st</sup> January 2000 and 1<sup>st</sup> April 2010 was conducted:

- Through the following electronic databases and websites: MEDLINE, EMBASE, HMIC, HEALTH BUSINESS ELITE, Google, National Electronic Library for Health, Public Health Observatories, Journal of Public Health.
- Using the following search terms: "tuberculosis" OR "tb" AND the following terms separately: "service model\*", "intervention", "model", "modelling exercise", "detection", "prevention", "screening", "treatment".
- Additional references were searched through reference tracking of key documents.

#### 3.2.2 Results

The literature search identified 11 papers and reports which were selected for initial assessment. Of these, six were found to include content on TB policy, guidelines, strategies or service models considered relevant to London.



An additional two relevant reports provided by stakeholders were also reviewed, as were a number of internal background papers supplied by the London TB Commissioning Board, including:

- Vision and Commissioning Strategy for TB in London, a working paper of the London TB Commissioning Board.<sup>29</sup>

### 3.2.3 Range of policy and strategy guidance found

Key UK sources identified include the following publications:

- Tuberculosis control in London: the need for change, 1998;<sup>30</sup>
- CMO's TB Action Plan 2004;<sup>31</sup>
- NICE / NCCCC TB Guidelines, 2006;<sup>32</sup>
- Stopping TB in London TB workforce group report, 2006;<sup>33</sup>
- The Tuberculosis Commissioning Toolkit, 2007;<sup>34</sup>
- An audit of Pan-London TB services and training needs, 2008;<sup>35</sup>
- BTS and RCN surveys of all TB lead consultants, nurses and PCTs, 2009;<sup>36,37</sup>
- Review of TB in London, 2007 (published 2009).<sup>38</sup>

#### *Tuberculosis control in London: the need for change (1998)*

In June 1998, Dr Andrew Hayward (Communicable Diseases Surveillance Centre, Colindale) produced a report: *Tuberculosis Control in London: the need for change* for the then Thames Regional Directors of Public Health. The report outlined the epidemiological situation in London and the problems with TB control and initiatives being taken to improve TB control. The report suggested minimum service requirements that commissioners should seek to purchase. The report also recommended greater provision of rapid diagnostic services and the establishment of a Greater London Tuberculosis Register.

<sup>29</sup> Vision and Commissioning Strategy for London. London, London TB Commissioning Board, April 2009.

<sup>30</sup> Hayward A. Tuberculosis control in London: the need for change. A report for the Thames Regional Directors of Public Health, June 1998.

<sup>31</sup> Stopping Tuberculosis in England: an action plan from the Chief Medical Officer. London: DH 2004.

<sup>32</sup> Guidelines for the Management of Tuberculosis and its Control. London: NICE, 2006

<sup>33</sup> Roberts W, Teasdale R. (on behalf of the Stopping TB in London group). Recommendations for the development of an appropriate workforce to deliver TB services in London, 2006

<sup>34</sup> Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high-quality services in England. London: DH, 2007

<sup>35</sup> Belling R et al. An audit evaluation of Pan-London TB Services and Training Needs. London South Bank University, 2008.

<sup>36</sup> Turning UK TB policy into action: the view from the front line. A report by the British Thoracic Society, Royal College of Nursing Forum and the All Party Parliamentary Group on Global Tuberculosis, 2009.

<sup>37</sup> Tackling tuberculosis in England: the PCT response to the challenge. Second national Tuberculosis Survey of English Primary Care Trusts. [APPG, BTS, RCN TB Alert], 2009

<sup>38</sup> Tuberculosis in London, 2007. A Report from HPA London and NHS London, 2009.

The report highlighted how TB service provision is greatly hindered by the fragmentation of services in London. Aiming at decreasing this fragmentation and to encourage the creation of effective teams, three possible structures for organising services were put forward:

1. Commissioning of specialist tuberculosis services on a pan London basis by the Greater London Region.
2. Commissioning three Greater London Tuberculosis Services (two in North London and one in South London)
3. Commissioning services at the level of the five Greater London Sectors.

The three above structures / models were not developed in detail in the report in order to allow scope for consultation on these and other models.

### *CMO's TB Action Plan (2004)*

In October 2004, the Chief Medical Officer published the *TB Action Plan*, where TB was identified as a serious threat which needing concerted action.<sup>39</sup> The Action Plan set out ten steps / actions which the Government, health services, and local communities needed to take in order to reverse the rise in TB:

- Increased awareness: aim to maintain high awareness of TB, particularly among health professionals, high-risk groups and people who work with them, teachers, and the public.
- Strong commitment and leadership: aim to create a strongly led, well co-ordinated and adequately resourced national TB programme, with all those working to deliver the programme having a clear focus on what needs to be achieved and best practice for doing these.
- High quality surveillance: aim to provide the information required to local, national and international levels to identify outbreaks, monitor trends, inform policy and the development of services, and monitor the success of the TB programme.
- Excellence in clinical care: aim to provide uniformly high-quality, evidence based treatment and care for patients with suspected and diagnosed TB, with all patients having their outcome of treatment recorded and at least 85 per cent successfully completing treatment.

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<sup>39</sup> *Stopping Tuberculosis in England: an Action Plan from the Chief Medical Officer*. London: Department of Health, 2004.

- Well organised and co-ordinated patient services: provide high-quality co-ordinated services for TB diagnosis, treatment and continuing care, which also meet the needs of individual patients.
- First class laboratory services: aim to provide laboratory services of consistent high quality which support clinical and public health needs, in keeping with the overall pathology modernisation programme.
- Highly effective disease control at population level: aim to increase the evidence base for, and the consistency of application of public health interventions for TB.
- An expert workforce: aim to ensure TB control has an appropriately skilled workforce and that physicians and nurses with expertise in TB continue to be recruited, trained and retained.
- Leading edge research: aim to increase our understanding of TB and its control; improve the evidence base for its control; and develop better tools for its diagnosis, treatment and prevention.
- International partnership: aim to contribute effectively to the global control of TB.

### *NICE TB Guidelines (2006)*

In March 2006, the National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Chronic Conditions (NCCCC) released the NICE guidelines *Clinical Diagnosis and Management of Tuberculosis, and Measures for its Prevention and Control*<sup>40</sup> to help the NHS identify, prevent, and treat people with TB in England and Wales. The new TB guidelines set the standard for a number of areas relevant to TB service provision in London:

- Vaccination: BCG vaccination should be considered for all new-born babies in areas with a high incidence of TB, for individuals at increased risk in other areas, and for selected new entrants from high incidence countries.
- New entrant screening: new entrants should be identified for TB screening, based on 'Port of Arrival' reports, new registrations with primary care, entry to education (including universities) and through links with statutory and voluntary groups working with new entrants.
- Active case identification: 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.

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<sup>40</sup> Guidelines for the Management of Tuberculosis and its Control. London: NICE, 2006

- Key worker: everyone with TB should have a named key worker who is easily contactable.
- Reduction of multi-drug resistance: all patients should have a risk assessment for adherence to treatment regimens.

The Guidelines also contain detailed recommendations on diagnosis and clinical management of TB, with examples of care pathways. Detailed algorithms covering various aspects of care are presented. For example, detailed guidelines are offered on drug treatment regimens that should be offered to patients with active respiratory TB who fall in various patient categories, such as children and HIV / non-HIV positive adults. With regard to new entrant screening, the Guidelines list the sources from where such entrants should be identified, and contain a detailed algorithm, but they stop short of providing an implementation strategy on how screening should be performed in practice.

The guidelines do not review different service models, and do not recommend how services should be configured or best delivered.<sup>41</sup>

### *London TB Workforce Group Report (2006)*

In October 2006, the Stopping TB in London group produced a report that aimed to build on existing work in four key areas relevant to TB services provision: baseline needs assessment, development of the current workforce, sharing of skills and expertise, and commissioning finance and budgets.<sup>42</sup> The report identified a number of short-term, medium-term and long-term issues and actions relevant to the four key areas.

The report suggested that a London wide event should be held in order to review the models of care available and to develop a shared vision that would lead to a redesign of TB services in London. With regard to the sharing of skills and expertise, the report recommends the development of better links between educational institutions and the London NHS in relation to TB. Regarding the development of the current workforce, it was recommended that a formal development programme be devised for TB nurses, in terms of career and educational development. This would be a process to be led by nurses. The report also recommended that a PCT chief Executive should be identified to lead the work on TB on behalf of all London PCTs.

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<sup>41</sup> Hayward J.A. NICE TB Guideline Development Group Co-Chair 2004-2006. Personal observation.

<sup>42</sup> Roberts W, Teasdale R. (on behalf of the Stopping TB in London group). Recommendations for the development of an appropriate workforce to deliver TB services in London, 2006.

### *The TB Commissioning Toolkit (2007)*

In June 2007, three expert working groups at the Department of Health supported by the Health Protection Agency developed a toolkit with the aim of offering commissioners of TB services in England a framework for assessing their local needs and for planning and commissioning high-quality services in order to implement the TB action plan.<sup>43</sup> Models of best practice aimed at TB service providers were included in the report, including laboratories and public health teams. The report provided key messages for commissioners and providers:

- For Commissioners:
  - Need to consider their local TB incidence and population demography, and potential changes to that demography, for example new demands as a result of population migration. Therefore, all PCTs should plan for TB services.
  - Every PCT should identify a named TB lead.
  - If the number of active cases within a PCT is likely to be low, commissioning TB services on a shared or amalgamated basis is a route to provide high-quality services.
  - A formal diagnosis should be best made by specialist service providers, reflecting the fact that TB is best diagnosed and managed by experienced specialists.
  - Primary care has an important role in providing support to the patient throughout the treatment period.
  
- For Providers:
  - TB (and suspected TB) must be investigated and managed by individuals who have comprehensive experience of the condition and who have ready access to the multidisciplinary services and skills necessary for a favourable outcome.
  - Best practice suggests that all TB services identify a lead clinician with overall responsibility for the diagnosis and possible treatment of TB with whom PCTs can liaise.
  - In areas where there is a low incidence of TB, transferred or shared management with more experienced centres or specialists needs to be considered.
  - A named key worker for each patient should be appointed.
  - High-incidence areas need to make provision for access to ECM.
  - Microbiology laboratories should be accredited and have sufficient throughput to maintain competency.
  - Reporting information should be in line with current national surveillance standards.

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<sup>43</sup> Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high-quality services in England. London: DH, 2007.

Overall, the toolkit provides a framework that PCTs can use to assess their local needs, and to plan and commission high-quality services. Additionally, the toolkit details recommended best practice for effective laboratory diagnosis of active TB, and current standards for surveillance.

### *Audit of pan-London TB services and training needs (2008)*

In 2008, the Institute for Strategic Leadership and Service Improvement at London South Bank University conducted an audit of pan-London tuberculosis (TB) services in relation to the range of services and expertise required to control and treat TB in London.<sup>44</sup> The audit looked at role development and training in regards to TB service provision and came to the following conclusions and recommendations in regards to the needs identified:

- A Pan-London TB services governing body is needed to support more consistent strategic planning, co-ordination, sharing of best practice and responsive delivery of cost effective, quality, sustainable services.
- New education and training must be developed which will be linked to roles, career paths, appraisal, personal development planning, for all TB staff, clinical and non-clinical.
- There is a need for GP training to remedy low index of TB suspicion impacting service access.
- Annually updated analysis of sector performance against quality targets is vital to aid decision making. This necessitates: i) a Pan-London agreement needed on quality standards development and, ii) support to enable continuous collection of information.

### *TB in London, 2007 (published 2009)*

In 2009 the Health Protection Agency and NHS London published a report bringing together a range of information relevant for the prevention and control of TB in London.<sup>45</sup> The information provided by the report related to key indicators of TB incidence and treatment, as at 2007. The key recommendation in the report was that commissioners and public health specialists consider the full range of data presented in the report when planning service configuration.

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<sup>44</sup> Belling R et al. An audit evaluation of Pan-London TB Services and Training Needs. London South Bank University, 2008.

<sup>45</sup> Tuberculosis in London, 2007. A Report from HPA London and NHS London, 2009.

### *Report of the British Thoracic Society and Royal College of Nursing with the All-Party Parliamentary Group, 2009*

This report focused on two concurrent surveys sent out in January 2009, to both TB Leads and TB nursing staff, with the aim of ascertaining the degree to which central policy had been implemented.<sup>46</sup>

The findings, which in London came from 16 respondents (representing different NHS Trusts) indicated that, although London is doing much better than the rest of the UK in terms of adherence to the TB guidelines, a number of areas were identified in which the NICE / other guidelines were not being followed:

- Multi-disciplinary team management of TB: In 15% of the London Trusts, respondents reported that TB was not managed within a multi-disciplinary team.
- TB patient contacts: Almost a third of the respondents from the London Trusts reported that the NICE guidelines on having access to blood Interferon Gamma release assays (IGRA), to aid detection of latent TB, were not met in their Trust.
- Implementation of policies / recommendations: In low incidence areas TB policy and recommendations are often not being implemented, while in some cases TB staff are not even aware that any such policies even exist.
- One of the London Trusts reportedly did not have a designated TB lead.
- Almost a third of the London Trusts were reported as not having available any local programme aimed at raising awareness of TB in high-risk areas.
- Half of the London Trusts were reported not to have available any local programme/s aimed at active case finding in high-risk groups.
- One Trust in London with more than 100 TB cases annually, reported having only one specialist nurse available specifically for managing TB patients.

### **3.2.4 International perspective on TB treatment policies**

In September 2007, the European Regional Office of the WHO released a report '*Tuberculosis in large cities*'.<sup>47</sup> The report included references to London and aimed to exchange experience through a recently established network of western European cities, to

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<sup>46</sup> *Turning UK TB policy into action: the view from the front line.* A report by the British Thoracic Society, Royal College of Nursing Forum and the All Party Parliamentary Group on Global Tuberculosis, 2009.

<sup>47</sup> World Health Organisation (WHO) (2007) *Tuberculosis in large cities*. Denmark: World Health Organization, Regional Office for Europe.

identify specific solutions to control TB in large European cities. This report made the following policy recommendations regarding TB service provision in large cities:

- National TB control programmes should ensure that there is a special focus on TB control in large cities. A health authority (TB working group bringing together people with different competences) should be identified and charged with TB control in the municipal or metropolitan area.
- Implementation of the [WHO] Stop TB Strategy should be ensured in all major European cities, including the setting up of quality-assured laboratories for anti-TB drug susceptibility testing, the provision of directly observed treatment (DOT) and the monitoring of treatment outcomes.
- A network should be created bringing together all current and potential TB care providers, including all public and private institutions, nongovernmental organizations for immigrants and refugees, and community associations.
- TB diagnosis and treatment services should be fully ensured for both legal and illegal immigrants and for all the socially disadvantaged groups commonly present in the main cities. Furthermore, these services should be culturally sensitive and include cultural mediators, educational materials translated to immigrants' languages, etc.
- Active TB screening should be organized among populations at increased risk of developing active TB within the municipality or metropolitan area.

### **3.2.5 Discussion – national and international TB policy**

The apparent inconsistency and geographical variability in the implementation of national TB policy raises the issue of whether service provision should be monitored by a central authority. The WHO European region report on TB suggests that variability in implementation should be tackled through one specific health authority being responsible for TB prevention and control of a whole city/metropolitan area. Such a centralised system of control and coordination has not yet been agreed for London.

The 2007 WHO European report suggests that any policy recommendations should place a special focus on large cities, potentially necessitating more intensive procedures and more stringent thresholds of policy/guideline implementation.

The review of policies on TB prevention also highlights the fact that the WHO strongly favours that a 'directly observed treatment, short course' (DOTS) strategy is adopted fully by



all countries. This is expected to be adopted in all countries within the European region as well as globally.<sup>48</sup>

This is acknowledged by stakeholders to be controversial, but it does raise the issue of having standardised thresholds to trigger the use of DOT in London.

### 3.3 Effectiveness of exemplar service models

The literature search for this section aimed to identify examples of TB service models that have been shown to be effective and which are of relevance to London.

#### 3.3.1 Methods

A literature search was performed for reports referring to exemplar service models in large cities relevant to London. None were found for other UK cities; the literature search therefore was widened to include the initial search terms plus additional keywords relevant to specific cities known to have applied successful service models in tackling TB: "New York", "NY", "Amsterdam", "Paris", "Berlin", "Rome".

#### 3.3.2 Results

The literature search identified no reports from other large UK cities. The search identified five reports / papers referring to service models in two large cities in developed countries and which share similar characteristics to London - New York and Amsterdam. The available evidence, reviewed below, highlights how the two particular service models implemented in New York and Amsterdam have proved to be effective in achieving an overall reduction in year on year incidence of TB.

#### 3.3.4 TB Service organisation in New York

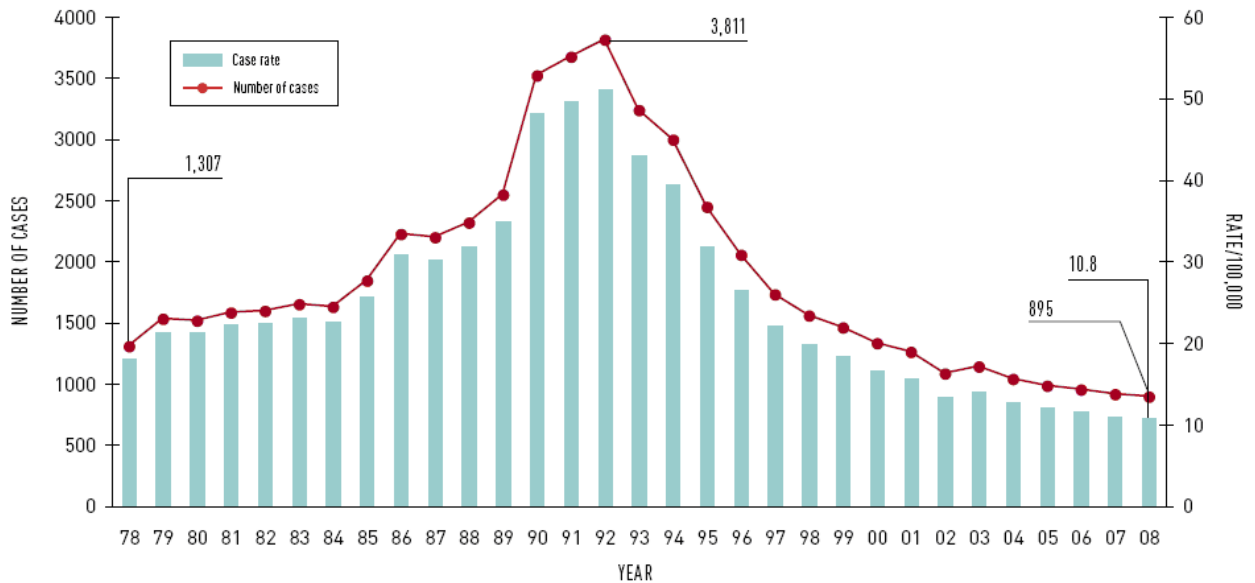
New York City provides an example of a successful model for other large cities to follow. Under its systematic programme for TB reduction, the number of TB cases has declined by 70% since 1992, and is still following a downward trend (see **Figure 22**).<sup>49</sup>

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<sup>48</sup> World Health Organisation (WHO) (2009) *Guidelines for treatment of tuberculosis. Fourth edition*. Geneva: World Health Organization.

<sup>49</sup> Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene (2008) *New York is Stopping TB: Annual Report 2008*.

**Figure 22: Tuberculosis cases and rates, New York City, 1978-2008**



Source: Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene (2008).

New York may be an optimal example for London to follow, as it shares common characteristics – it is a densely populous municipality (8.2 million residents compared to London’s 7.5 million), where the majority of TB cases are observed in immigrant populations, which are known to be difficult to identify, monitor and treat.

The large reduction in TB cases in New York is attributed to a number of initiatives that have been implemented, and which could be applied to a London setting. These are examined in the following sections.

*Centralisation*

In New York the TB control programme is managed and commissioned centrally through a pan-city approach through the Bureau of Tuberculosis Control (BTBC). A unified approach and adherence to TB protocols is ensured through notifying the BTBC of every patient who has received care from one of the NY clinics or of any private doctor. This centralisation of TB programme management includes the recording and monitoring of all clinic activities. This assists the provision of accurate data on numbers and outcomes of TB patients, supporting both surveillance and performance outcome monitoring and case management.

In comparison, London clinics do not routinely collect this data and information on actual clinic activities is incomplete (e.g. latent cases).<sup>50</sup>

#### *Legal powers and clinical accountability*

The centralised programme management and leadership also extends to the legal dimension, as the commissioner of health of NYC has the power to issue orders for implementation of DOT and also for detention of patients who are persistently non-adherent to TB treatment. The whole process involves legal representation and thorough investigation of all staff efforts to support adherence to treatment. In addition, health care professionals in New York are legally required to report illegal residents, whereas in London TB healthcare staff are under no such obligation.

#### *Contact tracing*

The centralised agency responsible for monitoring TB in New York also conducts follow-up investigations of people in contact with confirmed TB cases, with a ratio of 10 contacts to one TB case. Of the contacts investigated, 18% were found to have latent TB infection.<sup>51</sup>

#### *Additional case identification*

Hospitals are encouraged to implement voluntary in-house pharmacy surveillance. Pharmacy surveillance allows infection control staff to identify patients placed on anti-TB medications in instances when providers do not report them.

#### *Identification of TB clusters and community involvement*

As soon as a TB case is confirmed, laboratory tests take place with the specific aim to identify clusters from which the recent TB cases have risen. Then, once the specific community from which this clustering has been identified, an initiative starts with the aim of providing education and outreach to that high risk community. This is done also via increased partnerships with the specific NYC provider/s and the available community-based organizations. In addition, a number of congregate sites (such as school, day-care centres, work-places, health centres, etc) throughout the city, where previous TB cases had been known to attend, were routinely investigated and sites classified according to whether TB transmission would probable, possible, or unlikely.

#### *Provision of DOT to the homeless*

In 2007, a new initiative commenced - *Partners in TB Control*. This initiative was formed through a collaboration with the Department of Homeless Services and medical service providers. It involved screening and providing DOT (directly observed therapy) at 20 homeless shelters. As a result, in 2008, 2,175 homeless persons were screened.

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<sup>50</sup> Royal College of Nursing (2009) *Learning from success – TB case management in New York City (NYC)*. London: Royal College of Nursing.

<sup>51</sup> *New York is Stopping TB: Annual Report 2008*. New York: Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene, 2008.

### *Operation of chest centres*

Nine chest centres are operated, dispersed throughout the city. Each provides TB diagnostic testing, outpatient medical and nursing care, treatment for latent and active TB, social service assistance and HIV counselling and testing at no cost to the patient. These chest centres reported 8% of all confirmed TB cases and identified 18% of all patients suspected of having TB.

### **3.3.5 Costs attributed to New York model**

With support from the Centers for Disease Control and Prevention as well as the city and state governments of New York, the number of staff employed by the Bureau of Tuberculosis Control of the New York City Department of Health increased from 144 to more than 600 between 1988 and 1994; in the same period, the bureau's budget increased from \$4 million to more than \$40 million.

Overall, the response to the city's tuberculosis epidemic has cost well over \$1bn (£625m).<sup>52, 53</sup>

### **3.3.6 TB Service model organisation in Amsterdam**

The city of Amsterdam and the Netherlands overall provide another good example with similarities to the case of London. Currently, the Netherlands has achieved one of the lowest TB rates in the EU despite a significant concentration of illegal immigrants, homeless people, and illicit drug users, especially in Amsterdam.<sup>54</sup> The success story of Amsterdam is owed to a number of factors relevant to TB service model organisation and these are examined below.

#### *Centralisation of services*

In the Netherlands, TB control doctors, specialist nurses (who often also act as social workers) and practice assistants work under one roof. Hence, the TB clinic functions as a 'one-stop-TB-shop' for all basic diagnostic and treatment facilities. This model has been shown to be especially beneficial to socially excluded groups who often require intense management and DOT to prevent loss to follow-up.

#### *Close collaboration with community services*

TB is controlled through close collaboration between hospital based services and public health TB clinics in the community. These services are complemented by two former TB

<sup>52</sup> Frieden TR, Fujiwara PI, Washko RM, Hamburg MA (1995) Tuberculosis in New York City--turning the tide. *N Engl J Med* 333(4), 229-233.

<sup>53</sup> Coker R (1998) Lessons from New York's tuberculosis epidemic. Tuberculosis is a political as much as a medical problem-and so are the solutions. *BMJ* 317(7159), 616.

<sup>54</sup> Van Hest, R. and Story, A. (2008) Tuberculosis control among homeless persons in the European Union: more than words alone. *ENHW Newsletter*, Issue n°6.

sanatoria, now acting as tertiary in-patient TB treatment centers for patients with complex medical or psycho-social needs. In these settings, the consultants provide daily telephone expert advice service to TB professionals and medical specialists in the field. The hospitals concentrate on in-patient and clinical care, while the public health TB clinics work through a network of local health and social care agencies to provide preventive treatment, contact tracing, out-patient care and DOT, as well as active case finding among vulnerable populations.<sup>55, 56</sup>

#### *Focus on at-risk groups*

There has been a focus on at-risk groups with a high chance of treatment interruption. That is why (in 2004 for example) coverage levels of DOTS in key groups increased considerably, with 71% of drug users, 59% of homeless persons, 55% of prisoners and 47% of immigrants of undocumented immigrant status receiving DOTS. Treatment outcomes have improved considerably in these groups.

### **3.3.7 Discussion - service model exemplars**

Both examples identified by the literature search, as examples providing evidence for effective service model organisation of TB services in other metropolitan cities, highlight the importance of a centralised pan-city approach. Such an approach, in the cases of both New York and Amsterdam (and also Rotterdam), has been accompanied by substantial improvements in service provision, reporting and monitoring of outcomes and procedures, as well as in reaching out to the vulnerable populations which may slip through a more fragmented system.

Both systems place strong emphasis on reaching out to the communities at risk, largely through forming a close collaboration with them, in order to enhance both their treatment provision to these groups, as well as their ability to identify/trace potential new contacts and cases in these high TB-prevalence settings.

Finally, in the case of New York, the enhanced clinical accountability of health care professionals, as well as the provision of increased legal powers to the commissioner of health, has provided a strong mechanism of support to adherence to treatment. In the UK, the Public Health (Control of Disease) Act (1984) provides for restrictions or requirements to be enforced whereby, for example, a person can be medically examined or detained in hospital. This legislation appears to be used in rare cases. It is also clear that substantial resources were invested in tackling TB in New York.

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<sup>55</sup> DeVries, G., Van Hest, R.A. (2006) From contact investigation to tuberculosis screening of drug addicts and homeless persons in Rotterdam. *Eur J Public Health* 16, 133-136.

<sup>56</sup> DeVries, G., Van Hest, R. and Richardus, J.H. (2007) Impact of mobile radiographic screening on tuberculosis among drug users and homeless persons. *Am J Respir Crit Care Med* 176, 201-207.

### 3.4 Review of key areas of TB control & practice

This section focuses on evidence identified from the literature regarding three key areas of TB control and clinical practice:

- treatment thresholds for DOT;
- contact-tracing;
- new entrant screening.

#### 3.4.1 Methods

A literature search of reports or papers which referred to the three above specific areas (thresholds of operation, contract-tracing, new entrant screening) was undertaken. This included the initial search terms plus additional keywords relevant to the three specific areas: "thresholds", "contact", "trace", "tracing", "entrant", "screening".

#### 3.4.2 Results

The literature search identified 17 reports / papers referring to the three areas of interest. The evidence compiled from these reports / papers is presented for each specific area separately below.

#### 3.4.3 Findings

##### *Treatment thresholds for DOT*

A recent report from the Royal College of Nursing suggests that 'currently only half of patients who need DOT receive DOT in London'.<sup>57</sup>

Also, there is evidence suggesting that the proportion of patients in London who are given DOT from the onset, or at any time during their treatment, varies according to gender, ethnic group, migrant status, and also depending on whether the individual is homeless or in prison during treatment.<sup>58</sup>

The 2009 'Tuberculosis in London' report by the HPA and NHS London highlights large apparent differences in TB treatment completion rates by NHS Trust. This phenomenon may reflect variations in thresholds of implementation of DOT, considering the large London-wide differences observed by surveys of overall TB services provision.<sup>59</sup> This is not surprising if

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<sup>57</sup> Turning UK TB policy into action: the view from the front line. A report by the British Thoracic Society, Royal College of Nursing Forum and the All Party Parliamentary Group on Global Tuberculosis, 2009.

<sup>58</sup> Story, A., Murad, S., Roberts, W., Verheyen, M and Hayward, A.C. (2007) Tuberculosis in London: the importance of homelessness, problem drug use, and prison. *Thorax* 62, 667-671.

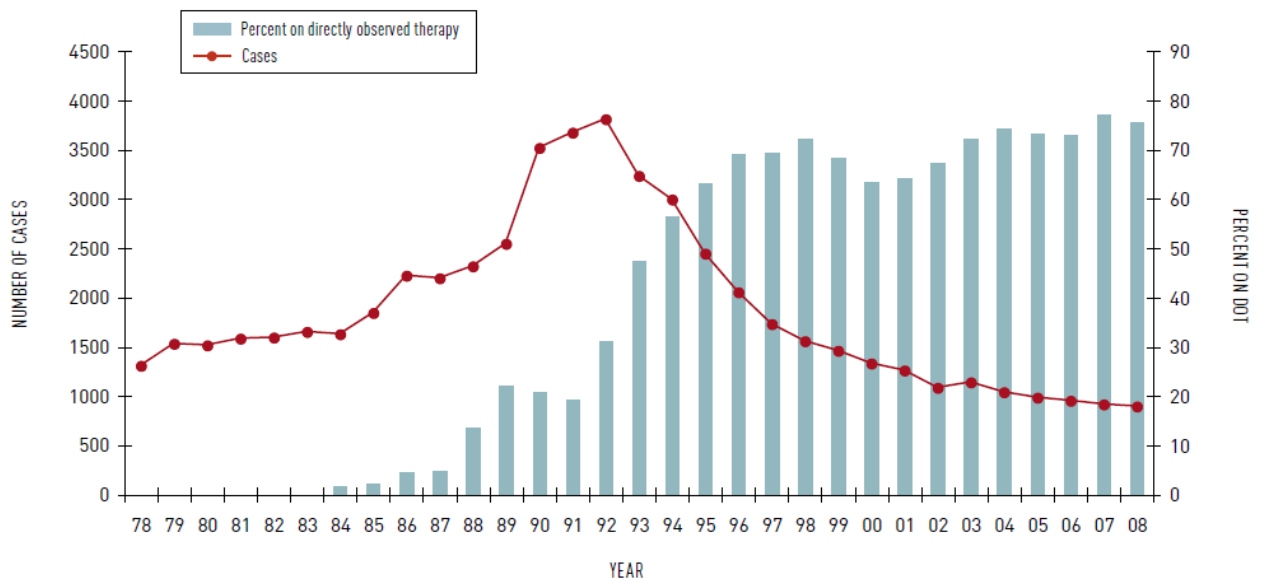
<sup>59</sup> Turning UK TB policy into action: the view from the front line. A report by the British Thoracic Society, Royal College of Nursing Forum and the All Party Parliamentary Group on Global Tuberculosis, 2009.

one considers that London’s TB services are comprised of around 30 separate clinics without strong centralised monitoring.

This variability in implementation of DOT is an important issue, since research suggests that if the DOTS program is incorrectly implemented the positive results it is usually associated with will not be observed. Elzinga and colleagues showed that a DOTs programme operates efficiently and accurately only once health providers are fully engaged.<sup>60</sup> This study also suggested a national certification system for DOTs coverage and community action to reinforce the value of DOTs.

Evidence provided by this literature search suggests that better outcomes are achieved in areas where a centralised system has been implemented across all TB sites/clinics with a clear set of indicators for clinical management of TB and thresholds of DOT implementation. In the case of New York, where The New York City Bureau of Tuberculosis Control and New York City passed regulations compelling an individual to complete treatment, to receive treatment under DOT, or to be detained for treatment, the proportion of eligible TB-cases for DOT rose from 57% to 76%. **Figure 23** highlights how this policy may have had a profound impact on TB case reduction in a city with many characteristics in common with London.

**Figure 23: Reduction of Tuberculosis cases as DOT implementation rises**



Source: Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene (2008).

<sup>60</sup> Elzinga, G., Raviglione, M.C. and Maher, D. (2004) Scale up: meeting targets in global tuberculosis control. *Lancet* 363 (9411), 814–819.

In addition, New York City actively provided DOT at homeless shelters. Evidence in 2007 highlighted how provision of DOT to the homeless in London was not sufficient,<sup>61</sup> suggesting that such a measure might potentially be of benefit to London.

### *Contact tracing*

Contact tracing has been considered an effective strategy to identify infected individuals for many years now, during which it has become an essential component of the TB control strategy in most low incidence countries, including the UK.<sup>62</sup>

The NICE / NCCCC 2006 TB guidelines suggest that differing practices in contact tracing and new entrant screening have different yields in detecting or treating latent TB, but there is no solid evidence revealing the ideal thresholds for implementation or the reach in this area of TB control.

Although how contact tracing should be performed has been outlined in detail by the NICE guidelines,<sup>63</sup> it appears that the guidelines may not currently be adhered to by all London NHS Trusts. Furthermore, as a study of homeless people, prisoners and drug users in London highlighted in 2007, contact tracing was largely failing 'hard to reach groups'.<sup>23</sup> This phenomenon has been observed also in other EU states.<sup>64</sup>

Recent evidence from a study of transmission rates among contacts in London suggests that not only should the recommended guidelines for contact tracing be strictly adhered to, but also that additional screening should be performed of casual contacts of smear-positive cases, and contacts exposed to more than one case, drug users or prisoners.<sup>65</sup>

In the case of the 'success story' of New York City, contact tracing is performed through a multifaceted approach, which entails conducting extensive follow-up investigations of contacts and congregate sites as well as strict reporting codes of contact evaluations by practitioners. In New York medical providers are required, under the New York City Health

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<sup>61</sup> London tuberculosis Nurses Network; Story, A., Murad, S., Roberts, W., Verheyen, M and Hayward, A.C. (2007) Tuberculosis in London: the importance of homelessness, problem drug use, and prison. *Thorax* 62, 667-671.

<sup>62</sup> British Thoracic Society (BTS) (2000) Control and prevention of tuberculosis in the United Kingdom: code of practice 2000. Joint Tuberculosis Committee of the British Thoracic Society. *Thorax* 55(11), 887-901.

<sup>63</sup> National Institute for Health and Clinical Excellence (2006) Tuberculosis: clinical diagnosis and management of tuberculosis, and measures for its prevention and control. *Clinical guideline 33*. <http://www.nice.org.uk/nicemedia/pdf/CG033niceguideline.pdf>

<sup>64</sup> Van Hest, R. and Story, A. (2008) Tuberculosis control among homeless persons in the European Union: more than words alone. *ENHW Newsletter*, Issue n°6.

<sup>65</sup> Neely, F., Maguire, H., Le Brun, F., Davies, A., Gelb, D. and Yates, S. (2009) High rate of transmission among contacts in large London outbreak of Isoniazid mono-resistant tuberculosis. *Journal of Public Health* 32(1), 44-51.



Code, to report to the Department of Health and Mental Hygiene, when requested, all information on the evaluation, testing and treatment of individuals who have been in contact with a person with active TB disease. Additional contacts are traced through the centralised agency responsible for monitoring TB in New York, performing follow-up investigations of people who were in contact with confirmed TB cases, with a 10 contacts to one TB-case ratio. Remarkably, of the contacts that are investigated, 18% have been found to have latent TB infection, suggesting that this approach may be highly efficacious.

In addition, a number of congregate sites (such as school, day-care centres, work-places, health centres, etc) throughout the city, where previous TB cases had been known to attend, are routinely investigated and sites are classified according to whether TB transmission would probable, possible, or unlikely.<sup>66</sup> This approach (of performing contact examinations in congregate settings) is considered to be one of the prime factors that has led to a reduction in TB cases in other large cities, such as Osaka, Japan.<sup>67</sup>

Evidence from urban areas in Canada suggests that such 'close-contact' investigation is highly cost-effective, results in net saving, and is more cost-effective than opting to screen immigration applicants and performing surveillance programmes.<sup>68</sup> More recent health-economic evidence from the US highlights how using sophisticated decision-analysis strategies to achieve targeted TB contact investigation can accrue substantial monetary savings without substantially compromising TB health outcomes.<sup>69</sup>

#### *New entrant screening*

Since a large number of UK TB cases involve individuals born outside the UK, screening of new entrants to the UK has been adopted. Such screening and evaluation may also identify individuals with latent TB infection (LTBI), for whom therapy could prevent future disease.<sup>70</sup> The early identification and management of TB among immigrants before they are dispersed within the UK is expected to prevent unnecessary transmission between recent immigrants and also guarantee a more equitable access to healthcare provision.<sup>71</sup>

<sup>66</sup> Bureau of Tuberculosis Control, New York City Department of Health and Mental Hygiene (2008).

<sup>67</sup> Shimouchi, A. (2009) Fight against urban tuberculosis problems and program effects in Osaka City] *Kekkaku* 84(11), 727-735.

<sup>68</sup> Dasgupta, K., Schwartzman, K., Marchand, R., Tennenbaum, T.N., Brassard, P., Menzies, D. (2000) Comparison of cost-effectiveness of tuberculosis screening of close contacts and foreign-born populations. *Am J Respir Crit Care Med* 162(6), 2079-2086.

<sup>69</sup> Pisu, M., Gerald, J., Shamiyeh, J.E., Bailey, W.C., and Gerald, L.B. (2009) Targeted tuberculosis contact investigation saves money without sacrificing health. *J Public Health Manag Pract* 15(4):319-327.

<sup>70</sup> Smeijja, M.J., Marchetti, C.A., Cook, D.J., Smail, F.M. (2004) Isoniazid for preventing tuberculosis in non-HIV infected persons (Cochrane Review). In *Cochrane Library* 2, Chichester, UK: John Wiley and Sons.

<sup>71</sup> Arshad, S., Bavan, L., Kajari, K., Paget, S.N.J. and Baussano, I. (2010) Active screening at entry for tuberculosis among new immigrants: a systematic review and meta-analysis. *Eur Respir J* 35, 1336-1345.

The NICE / NCCCC 2006 TB guidelines recognise the importance of implementing a comprehensive new entrant screening programme, although they stop short of providing a detailed strategy of how to perform this, apart from suggesting the sources from where such entrants could be identified. According to the guidelines, new entrants should be identified for TB screening based on 'Port of Arrival' reports, new registrations with primary care, entry to education (including universities) and through links with statutory and voluntary groups working with new entrants.

Highlighting the lack of evidence on which entrant-screening procedures would be the most optimal, Mulder and colleagues<sup>72</sup> state that 'there is an urgent need for a diagnostic tool to identify people with a recent latent infection that are at highest risk for developing active disease. This is especially relevant among foreign-born contacts.'

This literature search identified only one 'new entrant screening' service model which was performed in an area of London with a high concentration of immigrants and which underwent a systematic evaluation – an educational outreach programme that promoted screening for TB in people registering in primary care. This service model, which was evaluated through a randomised control trial published in the *Lancet*,<sup>73</sup> was performed in general practice settings in City and Hackney Teaching Primary Care Trust and involved verbal screening followed by tuberculin skin testing where appropriate. The reported findings suggested increased diagnosis of both active and latent TB cases by the intervention practices, as well as increased BCG coverage compared to usual care practices. Although such findings are encouraging in terms of what actions may be taken to improve new entrant screening procedures, the yield from the screening procedure in this study was low and it is questionable whether findings from a highly-committed research practice would be more widely applicable to London overall.

Recent evidence from a systematic review and meta-analysis supports the 2006 NICE guidelines that active screening for TB should be performed among new immigrants at the point of entry.<sup>34</sup> Also, recent health-economic evidence from the US suggests that a very cost-effective approach would involve supplementing the immigrants' overseas examination for TB with a domestic follow-up of those reported with active and inactive TB.<sup>74</sup>

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<sup>72</sup> Mulder, C., Klinkenberg, E. and Manissero, D. (2009) Review articles: Effectiveness of tuberculosis contact tracing among migrants and the foreign-born population. *Eurosurveillance* 14(11):1-7.

<sup>73</sup> Griffiths, C., Sturdy, P., Brewin, P., Bothamley, G., Eldridge, S., Martineau, A., MacDonald, M., Ramsay, J., Tibrewal, S., Levi, S., Zumla, A., Feder, G. (2007) Educational outreach to promote screening for tuberculosis in primary care: a cluster randomised controlled trial. *Lancet* 369(9572), 1528-1534.

<sup>74</sup> Porco, T.C., Lewis, B., Marseille, E., Grinsdale, J., Flood, J.M. and Royce, S.E. (2006) Cost-effectiveness of tuberculosis evaluation and treatment of newly-arrived immigrants. *BMC Public Health* 6, 157.

### 3.4.4 Summary - key areas of TB control

- There is evidence that existing recommendations / guidelines may not have been universally adopted or implemented by services in a large number of London PCTs, leading not only to reduced efficacy, but also to a wider geographical variability in policy implementation.
- Various sources, such as the WHO and the successful example of New York City, indicate that in large cities a pan-city approach should be followed, with a centralised system of control and coordination. This centralisation should include the recording of and monitoring of all clinical activities.
- Evidence from the New York model highlights how identification of TB clusters in a large city could be achieved in various targeted strategies as well as through community involvement.
- A common threshold for the use of DOT across London would be in line with evidence from New York and Amsterdam, where the use of DOTs is held to have contributed to reductions in TB incidence.
- There is evidence from a number of sources which suggests various successful strategies to enhance the current contact tracing situation in London. A multifaceted approach involving strict reporting codes and various follow-up investigations appears to be the most effective, and cost-effective, option.
- There is an urgent need for more detailed recommendations relating to new entrant screening strategies in London.

## 3.5 What this chapter shows

This literature review shows that there is no shortage of current and recent national and local strategy and policy guidance to inform commissioners of TB services and other stakeholders. There is persuasive evidence in the literature that current services may not always work in ways consistent with national guidance.

Evidence from New York and from Amsterdam was studied as service model exemplars. Evidence from New York shows the extent to which local policy and practice has been centrally managed by the New York Bureau of TB Control. Thresholds for DOT are also clearly much lower in New York, and perhaps more consistent with an approach endorsed by the WHO.

Both New York and Amsterdam have shown the possible benefits of a centralised pan-city approach to TB control. In both cities, services appear to reach out to communities at risk, working closely in community settings. Lastly, there is central accountability for how effectively services are delivered.

A common approach to DOT across London would bring London more in line with current policy and practice in both New York and Amsterdam. Similarly a common approach may be needed across London to the delivery of screening for both TB contacts and new entrants.

## CHAPTER 4 - TB SERVICES IN LONDON

### 4.1 What this chapter contains

This chapter describes London's specialist TB services. The location and geographical distribution of TB clinics is shown. We describe the approach we have taken to a review of services, including the results of a specifically designed questionnaire to assess staffing, workload, accessibility, and characteristics of specialist TB services.

This chapter should be considered in conjunction with Chapter 5, in which we examine service performance across the whole of London, including performance against the nine TB metrics introduced to monitor service delivery.

### 4.2 Introduction

#### 4.2.1 Services over the years for a multi-system disease

London has provided services for people with TB for very many years. When TB was more prevalent than now, TB formed a considerable proportion of the workload of chest physicians (and surgeons).

TB is a multi-system disease; around half of all cases involve the lung (pulmonary TB) but many other organs can be affected, including the lymphatic system, renal system, bone (including the spine), the nervous system (including meninges) and the abdominal cavity. The disease can also present in a widely disseminated form.

#### 4.2.2 Care outside hospital

Although many patients may be sufficiently ill to require a spell in hospital as an inpatient, the majority of care is provided after discharge from hospital, as an outpatient. Because of the nature of TB treatment, which usually involves a course of several antibiotics over at least six months, most patients need to be seen in outpatients on many occasions before their disease can be said to have been treated satisfactorily and they can be discharged.

During this period, many will feel well enough to work and live normal lives, although they still need to take medication and progress will need to be carefully monitored. TB services need, if possible, to be located conveniently close to where patients with TB (and their families and contacts) live.

#### 4.2.3 Services accessible to local communities

This means that services need to be accessible to patients and their families in the widest possible way – not only in terms of clinic timing and frequency, but also in terms of cultural awareness, use of language, sensitivity to issues of stigma in communities, and approachability for those who think of TB as a stigmatising, frightening and killer disease.

The relationship between TB patients and the clinical team caring for them can therefore become more intense than is the case for many other infections, which can be cured relatively quickly.

Outpatient TB services for patients with pulmonary TB have traditionally been provided from “chest clinics”, originally hospital based, although some are now in community settings. Other specialities also see their TB patients for follow-up in clinics, and there are many examples where clinics are held jointly between specialities – e.g. with HIV/AIDS services, paediatrics, orthopaedic, renal or neurology services.

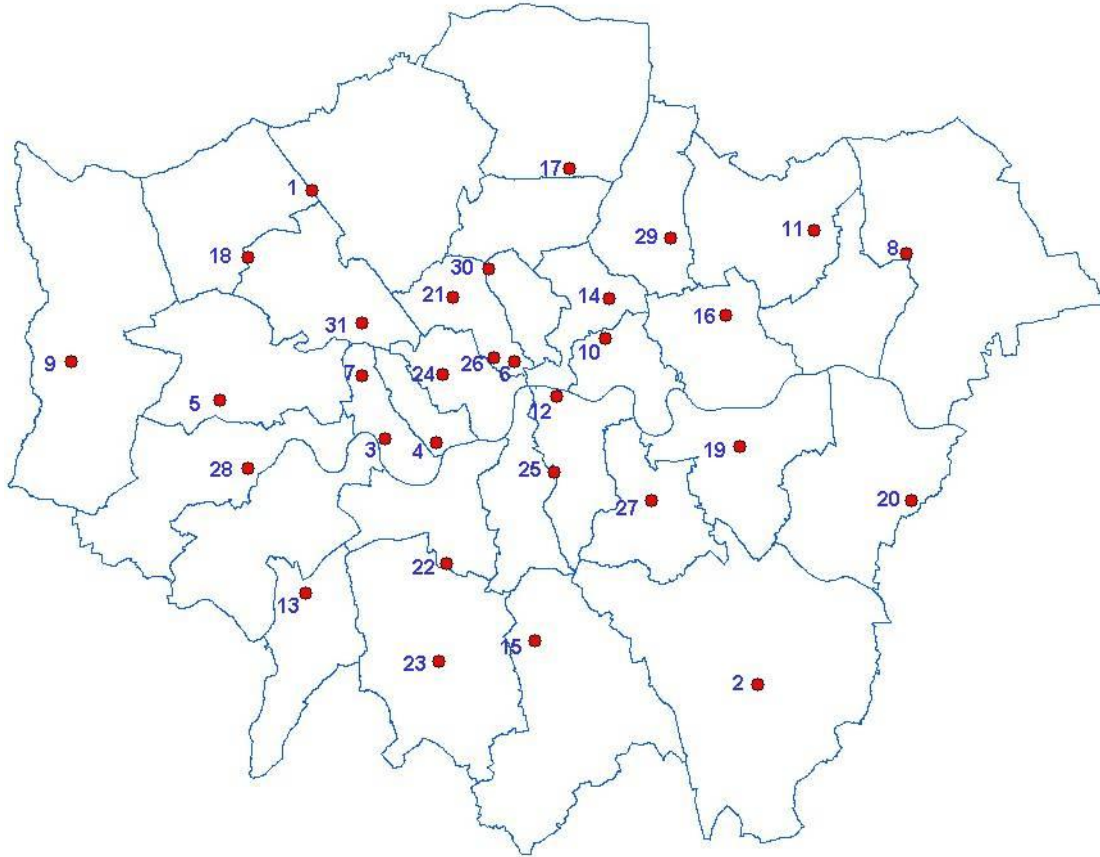
### 4.3 Geography

The location of TB clinics in London is shown in **Map 4** on the next page. There are 30 separate clinic services across the capital, roughly one per PCT. They are widely geographically scattered, with a good spread across the whole of London. This is appropriate, if it means better access for patients and good local relationships between clinical teams and the communities from whom TB patients are drawn.

NOTE: Since this Map 4 was prepared, the PHAST team has learned that outpatient and community TB care is no longer provided by the clinical team at Queen Mary’s Hospital, although inpatients with TB are treated there. Outpatient services are currently provided by the Greenwich Community TB team.

**Map 4: London TB clinic locations**

Source: HPA



Map reference	TB service	Clinic postcode	Map reference	TB service	Clinic postcode
1	Barnet	HA8 0AD	17	North Middlesex	N18 1QX
2	Bromley (SLHT)	BR6 8ND	18	Northwick Park (NWLTL)	HA1 3UJ
3	Charing Cross (ICHT)	W6 8RF	19	Queen Elizabeth (SLHT)	SE18 4QH
4	Chelsea & Westminster	SW10 9NH	20	Queen Mary's (SLHT)	DA1 4ER
5	Ealing	UB1 3HW	21	Royal Free	NW3 2QG
6	Great Ormond Street	WC1N 3JH	22	St George's	SW17 0QT
7	Hammersmith (ICHT)	W12 0HS	23	Epsom St Helier	SM5 1AA
8	Queens (BHRT)	RM7 0AG	24	St Mary's (ICHT)	W2 1NY
9	Hillingdon	UB8 3NN	25	Guy's & St Thomas's	SE1 9RT
10	Homerton	E9 6SR	26	UCLH	WC1E 6AU
11	King George (BHRT)	IG3 8YB	27	Lewisham	SE13 6LH
12	Kings College	SE5 8AZ	28	West Middlesex	TW7 6AF
13	Kingston	KT2 7QB	29	Whipps Cross	E11 1NR
14	London Chest (BLT)	E2 9JX	30	Whittington	N19 5NF
15	Mayday	CR7 7YE	31	Central Middlesex (NWLTL)	NW10 3RY
16	Newham	E7 8QP			

## 4.4 Reviewing London’s TB services

There has been no recent survey of the staffing, accessibility, workload or models of working of London’s TB services.

PHAST therefore reviewed services using the following approaches:

- A questionnaire administered across 30 clinics, in order to assess staffing, workload and accessibility of services;
- Analysis of inpatient hospital activity;
- Analysis of outpatient activity;
- Consideration of the London TB metrics;
- Analysis of GP prescribing.

This Chapter reports the results of the first aspect, and the following Chapter reports the remaining four.

## 4.5 Service Review Questionnaire

### 4.5.1 Introduction

The scoping phase of the project identified 30 TB services serving London, plus specialist paediatric services provided by Great Ormond St Hospital. One hospital – Queen Mary’s Sidcup – no longer runs a TB service clinic; the service is provided by Greenwich. A total of 29 general TB service clinics were included in the service review. Given the apparent diversity of their organisational and operational service delivery arrangements, it was agreed to gather detailed service information by use of a survey questionnaire across all service clinics.

### 4.5.2 Methods

A questionnaire was designed and agreed after piloting with the client and a senior TB service nurse. The questionnaire is attached as **Appendix A**.

The questionnaire sought to gather information on the following areas:

- Details of the service and organisation of that service
- Access and availability
- Staffing and capacity<sup>75</sup>

<sup>75</sup> The questionnaire asked one question about professional and clinical staff who provide the TB service, including their profession, whole time equivalent, and amount of time spent between TB and other services. Each service interpreted this question differently – e.g. not all included administrator time as part of the service.

- Funding of the TB service
- Interventions and therapies
- Other issues, such as risk assessment questionnaires for DOT thresholds, service level agreements between organisations, and local strategies for tackling TB.

The questionnaire was disseminated by email to named contacts, usually the lead TB Nurse, at all 29 TB service clinics included in the survey.

Clinic leads were asked to respond to the questionnaire within a three-week period, and for some this proved difficult with competing clinical demands. The response deadline was therefore extended by two weeks to allow for a higher response rate. Two further reminders were sent to the named contacts.

Questionnaire responses were extracted, summarised, and collated into an excel spreadsheet for analysis and reporting in brief (available separately). Both quantitative and qualitative findings from the questionnaire are reported in the following sections, aggregated by sector and for London as a whole.

### 4.5.3 Limitations

This was a pragmatic survey, designed to provide enough information about services (in limited time) to enable comparison between them and for broad strategic conclusions to be drawn.

The survey was not designed or intended to be a detailed audit of the whole TB service workforce.

As with all self-completed questionnaires, findings are potentially subject to responder bias, i.e. the answers given will be from the perspective of the person responding to the questions, and may therefore be unduly positive or negative. It is assumed that the information provided is accurate and correct, and reflective of the TB service.

### 4.5.4 Results

Overall, all 29 clinics (100%) responded to the questionnaire (see **Table 10**). This complete response rate suggests that those working in the TB clinics feel strongly about service improvement and development.



**Table 10: TB service by sector**

Sector	TB service
North Central <sup>76</sup>	UCLH Whittington Barnet Royal Free North Middlesex
North East	Queen's (BHRT) King George (BHRT) Homerton London Chest (BLT) Newham Whipps Cross
North West	Ealing Northwick Park (NWL) St Mary's (ICHT) Hammersmith (ICHT) Charing Cross (ICHT) Hillingdon West Middlesex Chelsea and Westminster Central Middlesex
South East	Bromley Queen Elizabeth Hospital <sup>77</sup> King's College <sup>78</sup> Guy's & St Thomas' Lewisham
South West	Mayday Kingston Epsom St Helier St George's

<sup>76</sup> The outpatient TB nursing service in North Central London is provided through one provider, the Royal Free, and all nursing staff are deployed to each individual service. All inpatient activities and consultant employment remain with the acute hospitals.

<sup>77</sup> TB clinic services provided by Greenwich Community TB service.

<sup>78</sup> Lambeth, Southwark, Lewisham Community TB Service provide the nursing staff for the TB services at King's, Guy's and St Thomas' and Lewisham and are deployed to the three sites as required.

## 4.5.5 Findings – London as a whole

### *Service and Organisation Details*

Across London as a whole there are 29 TB services/clinics. Some services (n=23) are provided from single locations; six run an additional service from a community based location.

In total, responders estimate that nearly 1600 patients are seen in TB clinics per week, and that of these the minority (less than 10%) are new contacts.

Four of the 29 clinics do not have specific TB clinics. TB patients are either seen as part of the infectious diseases clinic, the chest clinic or the respiratory clinic. Nearly all clinics offer a paediatric service, but two of the 29 clinics stated they did not have a paediatric TB service.

### *Access and Availability*

The number of clinics held per week ranges between one and seven. A total of 20 out of the 29 clinics stated that they are open Monday to Friday. Others are open between two and four days per week. No clinics are open during the evenings or at the weekend, though two clinics have a 24-hour answer phone service. However, staff are often flexible on an ad hoc basis with early morning or late evening appointments and for DOT when required.

All but one of the TB clinics have open access clinic arrangements. Those who have open access allow self referral, as well as referral from GPs and other hospital consultants. Some clinics work closely with the Port Health Authority and are sent referrals from that service. About half (n=16) of TB clinics report having an outreach service, seeing patients in community based settings such as pharmacies, as well as in their home. The level of this outreach may depend on staff capacity. All 29 clinics have interpretation services, and 21 have advocacy services available for patients.

### *Staffing and Capacity*

The number of consultants in each clinic varies between one and six. Not all consultant roles are solely dedicated to the TB service, and the service may involve those working in Infectious Diseases, HIV services, or Respiratory diseases. From the questionnaire responses it was not possible to determine what numbers of consultants (if any) across London are dedicated solely to TB services. All clinics have a TB clinical nurse specialist (CNS) attached to the service. The numbers of nurses deployed varies, in line with the number of patients seen, with more nurses employed at clinics who see larger numbers of patients.

The number of patients reported as seen every week by each clinic varies between over 100 to less than 20. Less than 20% (n=5) of all questionnaire respondents were unable to estimate the number of patients they saw each week. 30% (n=9) estimated they saw less than 40 patients in the clinics per week, whilst 20% (n=6) stated they saw over 100 patients per week – see **Table 11**.

**Table 11: Number of patients seen per week**

Number patients seen per week	Number of clinics reporting	Percent
More than 100	6	20
80-100	2	7
40-80	9	31
Less than 40	10	34
Unknown/not reported	1	3

*Links with other services*

All clinics reported 'good' access to the Find and Treat team. Three of the 29 clinics did not have any access to an HIV team. However, for the majority of respondents, access to an HIV team was stated to be good, with six holding joint clinics and multidisciplinary team meetings. All had good links with their health protection unit (HPU), and some access Port Health Authority through their HPU when needed.

*Funding*

The services (i.e. non inpatient care) are funded either via acute hospital Trusts (n=8), or PCTs/PCT Community Service providers (n=19). Two services did not state their funding route or were not sure (n=2). Seven stated that they were also in receipt of some fixed term funding.

*Interventions and Therapies*

Nearly all clinics offer DOT for their patients. Princess Royal University Hospital in Bromley is the only clinic that reported they did not have any patients on DOT.

Eleven clinics provide new entrant screening, two of which are for very specific populations – unaccompanied minors (Mayday Hospital, Croydon) and airport referrals (Ealing Hospital).

Contact tracing and screening is either done by the case managers, the lead TB nurses or any other member of the TB team, and is reportedly done according to NICE guidelines.

Neonatal BCG immunisations are offered across London, mostly as a universal policy (see Metrics section (Chapter 5) for detail) and usually provided by PCTs, e.g. by health visitors, school health, immunisation or community nurses. For 17 TB services it was reported that neonatal BCG immunisations were offered to all newborns (universal neonatal immunisation). The other services stated they offered it to newborns whose parents were from a country with TB rates more than 40/100,000.

Only six of the TB clinics (All North Central London Clinics - Barnet TB Service, North Middlesex, Royal Free, UCLH, Whittington - and Chelsea and Westminster) stated that they do not offer BCG neonatal immunisation. Seven TB services stated that midwives offered BCG neonatal immunisation. These were Whipps Cross, St Mary's (Imperial), Ealing, Northwick Park, North Middlesex, Hammersmith and West Middlesex.

### *Clinical Cohort Reviews*

Eleven clinics stated that they currently undertake cohort review or multidisciplinary team meetings about their patients (Mayday, UCLH, Barnet, Whittington, Royal Free, North Middlesex, St Mary's, Ealing, Charing Cross, Chelsea and Westminster and Homerton). The three clinics (Queen Elizabeth, Queen's and King George's) that stated that they perform audits do so on issues such as patient satisfaction, microbiology sensitivity and record keeping. Two other clinics stated that they are in the process of implementing regular cohort reviews for their patients.

## **4.5.6 Findings by sector**

### ***North Central London***

The clinics in North Central London are in a unique position, in that the outpatient nursing service is provided through one provider, the Royal Free.

Information was returned for all activity in North Central covered under the Service Level Agreement with the Royal Free and all other clinics. The North Middlesex returned a partially completed service questionnaire.

### *Service and Organisation Details*

As previously stated, all five services have one outpatient provider – the Royal Free. This is agreed via a service level agreement between the Royal Free and the four other clinics in the sector. TB nurses and admin support are employed by the Royal Free and are deployed to the clinic sites across the sector. Consultants remain employed by their acute trust.

All five services offer a specialist TB clinic. Three of the five reported also offering a specialist paediatric clinic. Of those that responded to the questionnaire, the number of clinics per week ranges from one to four.

### *Access and Availability*

It was reported that approximately 230 patients are seen per week in North Central London Sector. The services for UCLH and Barnet are open Monday to Friday 9am to 5pm. However the Royal Free has 24 hour access via their Accident and Emergency (A&E) department. No other services highlighted A&E as an access point for TB patients.

However, in terms of referral routes access to services appears less open than in other sectors, from responses given. Both Barnet and the Royal Free report mainly taking referrals from general practice, A&E, Find and Treat or from other hospitals. Self referrals seem not to be the norm. UCLH report having more open access arrangements. All services report having an outreach service, noted as being an outreach service for the sector. All offer interpretation and advocacy to their patients.

### *Staffing and Capacity*

The number of consultants involved in providing the TB clinics was only reported for the Royal Free. They have six consultants, four registrars and four senior house officers. They are not entirely dedicated to TB but have some input via infectious diseases, respiratory

medicine, HIV and paediatrics. All clinics except the North Middlesex have three nurses in each clinic. North Middlesex has five. All nurses are overseen by a band 8a TB nurse specialist, employed by the Royal Free and working across the North Central Sector.

#### *Links with other services*

All clinics that responded have reported good links with the Find and Treat team. All four state having access to an HIV team, with UCLH holding weekly meetings.

The HPU has good links to the clinics, but the clinics report very little access or links with Port Health.

#### *Funding*

As previously stated, the nursing staff is employed by the Royal Free. Funding for the NCL non inpatient TB services team comes from the provider arm of the PCTs as non tariff support. Each PCT's contribution is based on the rolling 3 year average number of TB notifications

None report being in receipt of any fixed term funding, such as research or voluntary sector grants.

#### *Interventions and Therapies*

DOT was reported as being offered at home, work, hostels, in the clinic or via a pharmacy. The Royal Free stated they would be as flexible as would clinically allow if it worked for the patient. Patients are stated to be assessed using a risk assessment tool.

Cohort review of all patients in the North Central sector started in June 2010 and will take place quarterly.

Responses from North Central London are summarised in **Table 12**.

**Table 12: Staffing levels, number of patients and clinics per week, by clinic in the North Central Sector**

<b>TB clinic</b>	<b>Number of consultants</b>	<b>Number of nurses</b>	<b>Number of case/support workers</b>	<b>Patients seen per week</b>	<b>Number clinics per week</b>	<b>Opening hours</b>
UCLH	Not stated	3.6 x WTE RCN 1 x WTE band 7 social care lead	1.5 x WTE admin	50-80	1 p.w. With docs 3 p.w. With nurses	Mon-Fri 9am-5pm
Whittington	Not stated	1 x WTE band 7 Lead nurse 1 x WTE band 6 CNS	1 x 0.5 WTE band 6 case worker shared with North Middlesex 1 x 0.5 WTE band 3 support worker shared with North Middlesex 1 x WTE admin	75	1 x consultant led 2 x nurse led 1 x contact clinic	Mon-Fri 9am-5pm
Barnet	Not stated	1 x WTE band 7 nurses 0.5 x WTE band 5 nurse (currently vacant)	1 x WTE administrator	25-30	1 p.w.	Mon-Fri 9am-5pm

<b>TB clinic</b>	<b>Number of consultants</b>	<b>Number of nurses</b>	<b>Number of case/support workers</b>	<b>Patients seen per week</b>	<b>Number clinics per week</b>	<b>Opening hours</b>
Royal Free	6 x medical consultants (not all F/T but work in respiratory, ID and HIV) 4 x medical registrars 4 x SHOs	3 x WTE Specialist TB Nurses	1 x WTE Administrator	55-60 p.w.	2 p.w.	all hours
North Middlesex	Not stated	1 x WTE band 7 lead nurse 3 x WTE band 6 CNS	2 x 0.5 WTE band 3 support worker shared with Whittington 1.5 x WTE admin	Not stated	Not stated	Not stated
NCL Sector		2 x WTE Band 8a NCL team leader/NCL lead nurse				

## **North East London**

Findings regarding the six clinics in North East London are summarised below.

### *Service and Organisation Details*

Five services have TB specific clinics. Queen's sees TB patients as part of the general respiratory clinic. All have a paediatric link for TB services. The number of clinics per week varies between six per week at the Homerton and one and a half at Whipps Cross. Newham has an open access clinic open Monday to Friday 9am to 5pm where a TB nurse is available to triage. This suggests that the number of booked clinics run from each clinic may not necessarily reflect the level of TB in the local area.

### *Access and Availability*

As a sector, a little over 400 patients are seen each week by the TB services. All services in the sector responded they are open Monday to Friday from 8am to either 5pm or 6pm, regardless of how many clinics are offered per week. None are open in the evenings or at weekends. Access to the services is open, with GP and self referrals as well as referrals from the Health Protection Agency. Only four of the six services in the North East sector offer outreach. All six offer interpretation and advocacy services for patients.

### *Staffing and Capacity*

Five clinics have one consultant attached to the TB service, including the Homerton, which has also has one research registrar. Newham did not provide details of consultant input to the TB service. Homerton, King George's, the London Chest and Queen's have case workers, while Newham and Whipps Cross apparently do not.

The case worker role involves working with individual cases and raising awareness of TB in hard to reach and high risk groups. All clinics have a TB clinical or specialist nurse.

### *Links with other services*

All services feel the Find and Treat Team are easy to access, though there are reports of inaccurate data reporting from Find and Treat to some services. All have good links to an HIV team, and King George's and Queen's have joint HIV clinics. Clinics have little direct contact with Port Health and most contact is made via the Health Protection Agency.

### *Funding*

Sources of funding within the sector vary between PCT and acute trust. Three are funded by the PCT (using top sliced funds from the PCT), two wholly by the acute trust in which they are located, and one is not sure how they are funded.

### *Interventions and Therapies*

Models of DOT described appear to vary between clinics. Some respondents have stated they offer DOT in hospital, pharmacy, and the patient's home. Others, such as Queen's and King George's, state that they offer DOT in the community, hospital, pharmacy, GP practices, work, psychiatric units, and others.



The North East London responses are summarised in Table 13

**Table 13: Staffing levels, number of patients and clinics per week, by clinic in the North East Sector**

TB Clinic	Number of Consultants	Number of Nurses	Number of case/support workers	Patients stated seen per week	Number clinics per week	Opening Hours
Queen's (BHRT)	1	5	1 outreach worker	64	2	Mon - Fri 8am - 5pm
King George's (BHRT)				23	3	Mon - Fri 8am - 5pm
Homerton	1 Plus 1 research registrar	4 clinical nurse specialists	1 support nurse	"Impossible to say!"	6	Mon - Fri 8am - 5pm
The London Chest (BLT)	1	1 Senior clinical nurse specialist 3 clinical nurse specialists 2 TB nurses		109	5	Mon - Fri 8.30am-5pm
Whipps Cross	1 x TB consultant 2 x F/T Chest consultant 1 x P/T chest consultant	3 x WTE band 7 nurses		60	1.5	Mon – Fri 9am – 5pm
Newham	Not reported	2 clinical nurse specialists 5 TB nurses		130-190	4	Mon 8am-6pm Tues 8am-6pm Weds 8am-6pm Thurs 8am-5pm Fri 9am-5pm

## **North West London**

Findings regarding the nine TB clinics in North West London are summarised below.

### *Service and Organisation Details*

TB specific clinics are run in eight of the nine services. Hammersmith Hospital and Charing Cross Hospital are part of Imperial College Healthcare NHS Trust with the 3 sites delivering TB care within the Imperial group as one TB service but with differences in TB CNS line management. The TB patients are seen as part of the Infectious Diseases clinics at Charing Cross. Paediatric clinics are offered at all services other than Charing Cross. The number of TB clinics held per week varies between two and seven across the sector.

### *Access and Availability*

Across the sector it was reported that approximately 500 patients were seen per week by TB services. Hillingdon and Charing Cross report only having limited opening hours to their service, i.e. three days per week. The remaining seven are all open Monday to Friday. The services are not open evenings or weekends, although the West Middlesex offers a 24-hour answer phone service for patients and the Hammersmith gives DOT via a 24 hour ward. The nine clinics that responded in the North West sector report they are open access, seeing patients who self refer as well as being referred by a health professional. Hillingdon reports receiving direct referrals from the Port Health Authority at Heathrow.

Northwick Park, West Middlesex, Central Middlesex and Chelsea and Westminster all stated they do not provide an outreach service. All services offer interpretation, but only half offer patients an advocacy service.

### *Staffing and Capacity*

The number of consultants reported per service across the North West sector ranges from one to five. St Mary's and Northwick Park reported the highest number of consultants, which may correlate to the higher number of patients seen per week (130 per week and up to 120 per week respectively). All clinics have a TB nurse specialist or clinical nurse. The number of nurses ranges between two and seven in the sector. Interestingly, West Middlesex reported it sees up to 90 patients per week and has only two nurses, but has up to five physicians.

### *Links with other services*

All nine clinics stated that the Find and Treat team are easy to access, with Hillingdon reporting that they aim to encourage attendance when the Mobile X-ray Unit is in the area. Hillingdon, Hammersmith and the West Middlesex TB services report they have no or little access to HIV teams. The remaining six report good access. All services report having good links with the HPU. Access to Port Health Authority is as required, with some services having more regular contact than others. Ealing, Hillingdon and West Middlesex all receive new entrant screening referrals from Port Health Authority at Heathrow airport, with the latter having one associate specialist sited with the Port Health Authority.

Responses from North West London are seen in **Table 14** below.

**Table 14: Staffing levels, number of patients and clinics per week, by clinic in North West London**

TB Clinic	Number of Consultants	Number of Nurses	Number of case/support workers	Patients seen per week	Number clinics per week	Opening Hours
<b>St Mary's (ICHT)</b>	1 x WTE HIV TB 1-2 x WTE Paediatric TB 3-5 x WTE Adult TB	1 x WTE Band 8a 2.4 x WTE Band 7 1 x WTE Band 6  1 x WTE Band 7 Community / new entrant screening	1 x WTE Band 3 non nurse TB outreach / DOT worker	130 p.w.	adults - 1 p.w. Paeds - 1 p.w. HIV - 1 p.w.	Mon - Fri 9am - 5pm
<b>Hammersmith (ICHT)</b>	Not stated	1 x FTE Band 6 TB Nurse - 1 x FTE Band 6 TB Nurse (2 P/T)	1 x FTE TB Administrator/DOT Worker (ie merged role)	24	6 p.w. nurse led 1 p.w. consultant led	Mon - Fri 9am - 5pm
<b>Ealing</b>	1 x WTE TB Associate Chest Specialist Doctor	1 x Band 7 TB Nursing Specialist Team Leader 3 x F/T Band 6 TB Specialist Nurses 1 x P/T Band 6 (33 hrs/4 days per week) TB Specialist Nurse	1 x Band 4 F/T TB advocacy/support worker 1 x P/T (2 days per week) TB advocacy support worker (funded by Choosing Health initiative) 1 x F/T Band 3 admin support worker	80-90	2 p.w. For chest clinic 2 p.w. Contact clinic 1 p.w. community clinic 1 p.w. ID clinic 1 p.mth community BCG clinic	Mon-Fri 8.30am-4.30pm
<b>Northwick Park (NWLTL)</b>	3x ID consultant	5.2 x WTE Band 7 TB Nurse Specialists	0.5 x WTE Band 3 administrator	100-120	7	Mon 9am-5pm Tues 9am-6.30pm Weds 8am-5pm Thurs 9am-5pm Fri 9am-6.30pm
<b>Charing Cross</b>	Not stated	1 x WTE band 8a nurse 1 x band 7 TB nurse 1 x WTE band 6 nurse		20-40	3 p.w. (1 new entrant, 1 nurse led, 1 contact and invest)	Mon 9am-4pm Tues 9am-12.30pm Weds 9am-1pm

TB Clinic	Number of Consultants	Number of Nurses	Number of case/support workers	Patients seen per week	Number clinics per week	Opening Hours
<b>Hillingdon</b>	1 x respiratory consultant (part time)	1 x TB Specialist Nurse (Full-time: PCT) 1 x TB Nurse (Full-time: PCT) 1 x TB Specialist Nurse (Full-time: Hospital)		PCT - 15 patients Hosp: 7-10 patients	1 p.w. at hospital 1 p.w. in community	Mon (hosp) 2pm-5pm Tues (hosp) 2pm-5pm Thurs (pct) 2pm-4.20pm Thurs (hosp) 2pm-5pm
<b>West Middlesex</b>	3 x Consultant Respiratory physicians 2 x Clinical Associate Specialists	2 x WTE Clinical Nurse Specialists 1 x WTE band 6 nurse		80-90 reviews	min 5 clinics p.w.	Mon- Fri 9am-5pm 24 hour answer machine service
<b>Chelsea and Westminster</b>	1 x F/T Consultant HIV Physician 1 x F/T Consultant Paediatric Physician 1 x P/T Consultant Respiratory physician (o/patients) 1 x F/T Consultant Respiratory physician (inpatients)	1 x F/T band 7 TB Clinical Nurse Specialist 1 x F/T band 8 Lead TB Clinical Nurse Specialist, 1 x P/T Band 4 TB service Coordinator		30-40 p.w.	4 p.w. Extra paed's occasionally	Mon- Fri 9am-5pm
<b>Central Middlesex (NWL)</b>	2 or 3 consultants in clinic 1 x SPR 1 x Lead consultant	3.2 WTE Band 7 nurses	1 x F/T admin	40 p.w.	1 TB Clinic (consultant led) 4 TB Screening clinic (nurse led) 2 TB Paediatric clinics monthly	Mon- Fri 9am-5pm

### *Funding*

The majority of the services are funded via PCTs or community services, via Service Level Agreements, or top slicing. Only three are wholly funded by the acute sector. No respondents reported being in receipt of fixed term funding, such as research grants or lottery funding.

### *Interventions and Therapies*

Across the sector, all respondent clinics reported that they provide DOT. From the responses, there are a range of models of DOT, including other health care providers (e.g. mental health), the workplace or the patient's home. The DOT threshold is assessed using a risk assessment tool for half of the clinics. St Mary's reported DOT can only be offered in normal working hours i.e. Monday to Friday 9am to 5pm. Outside of these times patients are asked to self administer. It was stated that district and twilight nurses are reluctant to undertake DOT. This issue was not raised by other services.

### ***South East London***

The findings regarding the five clinics in South East London are summarised in the following sections.

Bromley employs their own staff and run their own clinics. However, Queen Elizabeth's TB nurses, TB admin and case worker are employed by Greenwich Community Health, whilst Kings, Guy's & St Thomas' and Lewisham are supported by Lambeth, Southwark and Lewisham (LSL) Community Health. A similar arrangement to that in North Central London, the nurses are all employed by LSL community health and are deployed to the three sites as required. Kings, Guy's & St Thomas' and Lewisham hospital Trusts employ the consultants.

### *Service and Organisation Details*

Three of the five clinics offer a specialist TB clinic – Kings, Guy's & St Thomas' and Lewisham. Patients are seen as part of the general chest clinic at Bromley and the respiratory clinic at Queen Elizabeth. All have access to a paediatric service for young patients.

The number of clinics per week ranges from one to four (the four clinics at Bromley are offered over two sites, so could also be classified as two per week).

### *Access and Availability*

Across the South East of London, services suggest that a little over 200 patients are seen in their clinics per week. Only one service in the sector is open five days of the week, Monday to Friday, 9am to 5pm. This is the Queen Elizabeth. Bromley is open two days a week, and offers a service at another location another two days of the week (four days in total). King's is open three days per week for between two and three hours per day, Guy's & St Thomas' three days per week for between two and a half and four hours a day, and Lewisham only two days per week for a between two and four hours a day. Please see table below for details of opening times.

All referrals into the service in this sector are open, and come from a wide range of originators, including self-referral.

Only Queen Elizabeth reported an outreach service. All five of the clinics that responded offer interpretation and advocacy services to their patients.

### *Staffing and Capacity*

The number of consultants in each clinic ranges from one to three. Guy's & St Thomas' and Queen Elizabeth both have three consultants in their clinic. Lewisham and Bromley have only one each. The number of nurses per service ranges from one (Bromley) to five (King's). However it is Queen Elizabeth that reports seeing the highest number of patients per week. As with all sectors, every clinic has a TB nurse or nurse specialist.

### *Links with other services*

All clinics report having good access to the Find and Treat team, and LSL Community Health stated they had received referrals from them. Access to an HIV team is available for all clinics, and King's, Guy's & St Thomas' and Lewisham all have multidisciplinary team meetings. The clinics all have links with the HPU, who also provide their access to the Port Health Authority.

### *Funding*

All clinics in the South East sector report being funded by the local PCT. All TB nurses in South East London (plus admin staff and caseworkers) are employed by PCT provider services, with the exception of Bromley where the respiratory nurse, who also has a specialist TB nursing role, is employed by the PCT. None noted if they are in receipt of fixed term funding.

### *Interventions and Therapies*

The five clinics across the sector offer DOT to their patients, mostly in the home, clinic or where it works for the patient. For Bromley there are currently no patients on DOT, but the TB nurse there has previously used a community clinic to deliver the medication to the patient. All clinics use a risk assessment tool to assess the patient's best course of treatment.

Currently none of the clinics in the sector are performing cohort review of their patients.

Responses from South East London are summarised in **Table 15**.

**Table 15: Staffing levels, number of patients and clinics per week, by clinic in the South East Sector**

<b>TB Clinic</b>	<b>Number of consultants</b>	<b>Number of nurses</b>	<b>Number of case/support workers</b>	<b>Patients seen per week</b>	<b>Number clinics per week</b>	<b>Opening hours</b>
Bromley (general chest clinic)	1 x WTE chest consultant phys	1 x WTE TB CNS		10 to 20 p.w.	4 p.w. Across 2 sites (PRUH & Beckenham Beacon)	Monday pm (PRUH) Tuesday pm (BB) Wednesday pm (PRUH) Thursday pm (BB)
Queen Elizabeth (general chest clinic)	3 x chest consultant	1 x WTE band 7 TB CNS 1 x WTE band 6 nurse 2 x 0.5 WTE band 6 nurse	1 x 0.8 WTE Band 4 x support worker 1 x WTE band 2 admin	115	3 p.w. but likely to increase	Mon - Fri 9am - 5pm
Kings	2 x chest consultants	1 x WTE Band 8a TB nurse 1 x WTE Band 7 nurse 1x WTE Band 6 nurse 1 x WTE band 5 nurse	1 x WTE band 5 case worker 1 x WTE band 3 administrator 1 x WTE band 4 senior administrator	60-75 contacts across 3 sites  between 3-6 new index cases p.w.	1 p.w.	Mon 11am-2pm (paeds) Tues 2-4pm (HIV) Thurs 9am-12pm (adult TB)

Guy's and St Thomas'	3 x chest consultants	1 x WTE Band 7 nurse 2 x WTE Band 6 nurse	1 x WTE band 5 case worker 1 x WTE band 3 administrator		3 p.w.	Mon 9am-1pm (adult TB clinic) Mon 2pm-4.30pm (adult TB clinic) Mon 2pm-4.30pm (paeds TB clinic) Weds 9.30am-12.30pm (adult TB clinic) Thurs 9.30am-12pm (HIV)
Lewisham	1 x chest consultant	1 x WTE Band 7 nurse	1 x WTE band 3 administrator		1 p.w.	Mon 9am-1pm (adult TB clinic) Fri 9.30am-12pm (HIV) Fri 2-4pm (paeds clinic)



## ***South West London***

The findings for the four clinics in South West London are summarised below.

### *Service and Organisation Details*

All clinics offer specialist TB clinics, and two offer a paediatric clinic. The numbers of clinics run per week ranges from one to seven (Mayday run daily nurse-led clinics, with an additional two consultant led clinics per week).

### *Access and Availability*

Approximately 250 patients per week were reported as being seen by the TB services in South West London. All four clinics in the sector are open five days a week; Monday to Friday, 9am to 5pm or 6pm.

Access to the service is open in all clinics, including referral from HPU, School nurses and self referral. All TB clinics receive port of entry (POA) referrals as they are sent to the clinic nearest to where the new entrant says they will be living. Mayday is undertaking a project on the screening for TB in unaccompanied minors.

Two of the four clinics provide an outreach service - Kingston and Epsom St Helier offer a home visiting service and community DOT. St George's does not provide an outreach service; Mayday has one full time link worker who provides some outreach services.

All clinics offer their patients interpretation services, but only one offers an advocacy service via the TB case worker.

### *Staffing and Capacity*

The number of consultants in clinics in the South West ranges from five in St George's to one in Kingston. The number of nurses ranges from one and a half whole time equivalent at Kingston, to nearly three whole time equivalents at Mayday and St George's.

The highest number of patients seen per week in the sector is at Mayday, with up to 150 people being seen per week. They also have daily clinics held with TB nurses. In contrast, Epsom and St Helier see only 24 patients per week, run three clinics and have 1.66 whole time equivalent TB nurses.

### *Links with other services*

All four clinics state they have good links with the Find and Treat team. All have access to an HIV team, and links with the HPU. All TB clinics receive port of entry (POA) referrals as they are sent to the clinic nearest to where the new entrant says they will be living.

### *Funding*

Three TB services reported that they are funded via the acute trust and did not state if they are receiving funding from the PCT. St George's responded simply that they were NHS funded. None stated if they were in receipt of any fixed term funding.

### *Interventions and Therapies*

All clinics in the sector stated they offered DOT, in community settings, pharmacies, clinics and home. Patients were reported to be assessed against a risk assessment or adherence tool.

Mayday operate as part of the SWL multi-disciplinary TB meeting/teleconference which meets every few months to discuss difficult cases..

Responses from clinics in South West London are summarised in **Table 16**.

**Table 16: Staffing levels, number of patients and clinics per week, by clinic in the South West Sector**

<b>TB Clinic</b>	<b>Number of consultants</b>	<b>Number of nurses</b>	<b>Number of case/support workers</b>	<b>Patients seen per week</b>	<b>Number clinics per week</b>	<b>Opening hours</b>
Mayday	1	1 x WTE band 7 resp nurses 1 x WTE band 6 TB nurse 0.75 x WTE band 6 TB nurse	0.8 x WTE band 6 case worker	100-150	2 p.w. With TB cons; daily with TB nurses	Mon - Fri 8am to 6pm
Kingston	1 x cons respiratory physician	1 x WTE band 7 lead TB nurse specialist 0.5 x WTE band 6 TB nurse specialist	1 WTE band 3 Admin	45	2 p.w. With TB nurses 2 p.w. With resp cons phys	Mon - Fri 8am to 5pm or 6pm
Epsom St Helier	1.5 x WTE consultant chest physician	0.66 x WTE band 7 TB Nurse 1 x WTE band 6 TB Nurse	0.5 x WTE band 5 admin	24	3 p.w.	Mon - Fri 9am - 5pm
St George's	1 x chest clinic Consultant 5 x Infectious Diseases Unit (CIU) consultants on rota	1 x WTE band 7 TB nurse 1 x WTE band 6 nurse 1 x 0.8 WTE band 5 nurse	2 x part time admin staff	65	1 CIU chest clinics	Mon-Fri 9am-5pm

#### 4.5.6 Qualitative Findings

The final section of the questionnaire asked respondents if they had any further comments or additional information they would like to share. Many services forwarded reports of valuable work that had been done in their sector. Comments were also added, reflecting the experience of those working with patients.

A thematic analysis of these following according to the following four categories:

1. Staffing and resources
2. Organisational structures
3. Standardisation of guidelines, policies and procedures
4. Treatment populations.

Text taken directly from comments is shown in italics.

##### *Staffing and Resources*

Overall, there was a general opinion that TB services in London have been underfunded in the past. Despite this, new and emerging best practice is continuing to be integrated with current service provision across some areas of London (e.g. Cohort Review in North Central). However, there is concern that this best practice will require increased time and money to implement in services which are already stretched. Cohort review in particular was mentioned as an added demand on resources.

*Cohort review requires a large investment of resources, including staffing.*

*Need DOT workers as this is time consuming for specialist nurses who could devote more time to develop the services i.e. arrange education & awareness session in the community.*

*Once we have stepped up our staffing it will be great to be able to do more teaching, and raise awareness with groups.*

Along with comments on the increased workload, concerns were also raised about staff vacancies, and the pressure this added on an already stretched services.

*Lack of TB Lead Nurse*

*We need full-time admin support*

*I still feel we could do a lot more, e.g. health education etc in the community to all groups. But as we have no clerical/admin support staff we spend a lot of time doing paperwork.*

Staff vacancies in some areas mean that enhanced activities such as awareness raising and teaching are not undertaken, and - more of a concern - the ratio of nurses to patients was reported to be below the recommended ratio of 1:40.

*Nurse: patient ratio in some services [is] below recommendations.*

If staffing and resources were not an issue, then some services reported they would like to encourage innovative and new ways of working, especially in trying to reach the hard to engage groups.

*If this funding and resources could be available, the TB service could explore ways to enhance social aspects of TB care and improve the range of services we provide to the public.*

### *Organisational Structures*

It is clear from the questionnaire findings that there are different models of care in place across London. However, there are differing views as to where TB services might be located, in an acute setting, or in the community.

*TB services should continue to be provided from an acute setting.*

*Our service was hospital based, but since opening the community clinic and doing more home visits we case manage from the community...I still feel we could do a lot more e.g. health education etc in the community*

One service suggested that TB services had a part to play in all levels of care, from the local GP to the hospital:

*Need recognition that TB requires multidisciplinary team approach including GPs, local and secondary care.*

There are already examples of good practice and successful models of working when functions of the TB team have been separated out. For example, the Newham New Entrant Screening Service was reported as working very well.

*We work very well with the New Entrant Service ... team. This model works very well. It is the first time I have worked in a TB team that has a separate but designated and well established New Entrant TB Service.*

One service felt this could be extended further and that contact screening would be better provided in the community to stop the drain on hospital based services and clinics which inevitably impacts on patient care.

*Dedicated team for community based contact screening e.g. in schools, nurseries or workplace venue... resources [don't] need to be taken from the OP screening and TB CNS case management clinics [and] GP referrals, contacts etc are [not] delayed and those on treatment ... [do not] have their case management ... postponed.*

Many services reported having already identified gaps in the service and were in the process of making changes to address these.

*We are in the process of establishing an MDT meeting for discussion of complex cases.*

*We are formalising an urgent referral process for fast tracking urgent suspected cases from A+E in order to promote urgent diagnosis, rather than re-refer back via GP/local referral centres.*

When there are examples of best practice in other areas of London TB services, these should be shared with others, and should not go unrecognised.

*This appears to be a good opportunity to explore London TB Services and learn from each other in order to get the best practice for the service users and the local needs of the community that each clinic or service provides.*

There is also an acknowledgement that more could be done to make services more flexible for patients, giving them greater access and availability to TB services, no matter what level of support they require.

*Provision for DOT Mon – Sun and for twice-daily regimens.  
Outreach needs to be strengthened for most services.*

### *Standardisation of Guidelines, Policies and Procedures*

It was generally noted that there is no standardisation of the TB service policies across London.

*There is no uniformity/ standard / policies across all TB services*

*... services across London need to try and be more standardised. They can vary quite a lot. Some follow NICE to the letter, others use NICE plus+. We need a pan London approach that is operational as well as strategic.*

*London wide we feel that we should use same criteria for screening contacts and treating active cases.*

*Standardising cross boundary referrals (for both contacts and those on treatment moving across London) and having clear guidelines for responsibilities such as BCG, contact screening in outbreak cases across London would make each service more equitable.*

*Guidelines and Patient pathways need to be standardised.*

*Standardise TB nursing documentation in order that all TB nurses ask the same questions to gather accurate information.*

It was suggested that standardisation be widened to include staffing issues as well as policies and procedures.

*There also might be an opportunity for TB Nursing Services to have an equal banding pan London.*

A key development identified by one service and which could contribute to the improvement of TB services across London was to

*revise [the] metrics and the processes to ... be outlined as targets.*

### *Treatment Populations*

Two main treatment groups emerged as those needing the most support:

- those who are homeless, and
- those with no access to public funds.

For five of the TB services, losses to follow up are greatest around those patients with no access to public funds, such as homeless people and immigrants.

*One of the key issues ...[is] around loss to follow up and homelessness for group of client with no recourse to public funding.*

Some services suggested that these groups of patients should be provided with support. For one this support came in the form of welfare and money.

*Welfare support for those with no recourse to public funds*

Others identified the need for stable housing or secure accommodation, dedicated to those with TB (including those who are infectious).

*Secure unit / accommodation for homeless patients with TB or those with no recourse to public funds. The unit needs self contained facilities for those that are infectious.*

*Stable accommodation is essential when treating patients who are homeless, are here illegally, or who are experiencing both relative and absolute homelessness.*

*Need limited number of hostel places for difficult to treat cases where patients get maximum care and support to ensure completion of treatment.*

## **4.6 Discussion – what this chapter showed**

### **4.6.1 General findings**

The maximal response rate to our questionnaire (100%) implies considerable commitment to services by respondents, who appear to be enthusiastic advocates for their clinical work.

Services do not appear to be the product of rational planning, so that the pattern across any sector, and between different sectors, appears to be haphazard or fragmented. This probably reflects the history by which London TB services have developed within chest clinics in acute hospitals over the years – by a process of evolution and chance investment, rather than through any centrally managed and controlled initiative.

There is considerable variation in reported staff complement, consultant input, skill mix, banding of staff, and the extent of administrative support. Broadly, the larger the case load, the bigger the stated nursing team and the greater the number of clinics held (with some notable exceptions documented elsewhere). The use of case workers seems to be small.

Respondents have stated that the service is available outside the normal clinic schedule – implying “open all hours”. On enquiry, this usually has turned out not to reflect opportunities to be seen for a routine referral.

Most clinics operate within a hospital outpatient setting. Community settings are seldom used, although several respondents stated they would like to work more in community settings.

Outreach services are mentioned by only a minority of respondents.

All services have access to interpreters, and many have access to advocacy services.

New entrant screening programmes appear to vary, with different arrangements in place to deal with referrals from Port Health authorities. There is no standardised system across London. The only service dedicated specifically to new entrant screening in London is the Newham New Entrant Screening Service, funded and provided by Newham PCT.

#### **4.6.2 Standardisation**

Standardisation is an issue raised by respondents in a number of areas:

- implementation of NICE guidelines;
- how contacts are screened (including in TB outbreaks);
- cross boundary referrals;
- nursing documentation;
- pan-London banding for nursing staff.

The pragmatic minimum standard of one whole time equivalent specialist nurse for up to 40 TB notifications has not been systematically monitored (although we have calculated it for this report – see Metrics section); respondents expressed their concerns about perceived under-staffing of services; some enhanced activities such as awareness raising and teaching have not been possible in some services.

The issue of standardisation of quality of clinical management is a recurrent theme arising in this needs assessment.

#### **4.6.3 Service organisation**

Most sectors have entirely separate workforces. This means there is no common pool of nurses from which to draw if there are staff shortages or unfilled vacancies.



In the North Central sector, all TB nurses and associated administrative staff are employed by one organisation, with the nurses and administrative staff deployed across the current arrangement of hospital based clinics in the whole sector. There is a similar arrangement in part of South East London, where nursing staff at King's, Guys & St Thomas's and Lewisham work in one team, deployed across three sites.

There are strengths in this model, where need and demand of patients can be met by adapting capacity from a central work pool and it should encourage team work and sharing of best practice.

We have not heard of any examples of services sharing staff across sector boundaries.

#### **4.6.4 Settings in which services are delivered**

Most services are provided in and run by acute hospitals. Some respondents raised the need to provide more services in a community setting. Polyclinics may represent an opportunity to move services away from hospital outpatients, but other options should be explored, to find settings more accessible and less potentially intimidating for patients with a disease that is widely feared and stigmatised already.

Few services appear to offer community based outreach. This is an issue: only through reaching out into local communities will services be able to do more than react to a referred caseload.

Community settings are where prevention work can be done with local communities, in a way that might break down fears and prejudices. These options should be explored, especially where services have large caseloads; these services need to become centres of excellence for TB prevention and control as well as clinical management.

#### **4.6.5 Accessibility of services**

A lack of 24 hour access across London has implications for the service, especially as other NHS services are responding to patient demands for increased access to services outside of the normal working week (i.e. not simply Monday to Friday, 9am to 5pm). GP surgeries are offering longer opening hours and appointments at weekends. Yet across the whole of London, TB patients are expected to attend the clinic (usually in a hospital setting) between 8am and 6pm, Monday to Friday, regardless of how frequently these attendances are required.

A hospital based model of care, where most patients are seen in outpatients and supported through six months treatment, appears to be a very traditional and medical model of care, even where the front line clinicians are nurses, rather than doctors.

It is not a modern way of delivering a service for people recovering well from their illness, many of them back at work during the precise hours that the clinics offer their opening hours.

Fundamental changes require consideration.

#### **4.6.6 Administrative staff**

This review has not quantified administrative staff in a systematic way. However, their role may be pivotal to how nurses manage their workload. Many respondents stated that nursing time was often devoted to completing paperwork. This may also include entering data on the London TB Register (LTBR) – an important task but one that may have little apparent utility for busy clinical teams. This raises the issue of how to ensure enough administrative staff to free up nursing time away from what may be regarded as bureaucratic tasks.

The completion of the data fields in the LTBR is an important priority to enable changes of case mix to be identified, which in turn should enable an appropriate staff team to be commissioned. It also means that whoever fills in the LTBR needs to understand TB well enough for the information to be correct; some nursing supervision of this function is probably necessary, though that is different from the nurses finding they have to do everything themselves.

#### **4.6.7 Resourcing**

Respondents from six of the 29 services that responded (20%) stated that they felt under-resourced and unable to deliver the quality of care they would like to those most in need. This includes wanting to undertake further outreach and community based work, such as awareness raising, or more teaching. This is an important issue, especially for services with very large case loads related to specific communities, such as in North West and North East London.

Funding of individual services appears to vary, being a mixture of funding from within acute hospital budgets, with some examples of services or initiatives with direct ear-marked funding directly from PCTs. Very few staff are funded from other sources, such as community grants.

#### **4.6.8 Vulnerable groups**

The homeless and those with no access to public funds were described by five service respondents as those most difficult to engage. One issue is access to decent housing. This requires close joint working with local authorities so that homeless TB patients can be prioritised for housing; the Homerton has such an arrangement in

place with the London Borough of Hackney and a member of the TB service team to facilitate this.<sup>79</sup>

#### 4.6.9 Cohort Review

Cohort review is reportedly performed by 11 TB services in London. Two further services are working to implement cohort review and three clinics stated that they conduct regular audits of their services.

If cohort review is recognised as best practice (see *Literature Review – Chapter 3*), then sharing of good practice across sectors could begin to persuade those less keen to commit resources to gain the benefits. Examples of good and innovative practice are occurring all across London, and these should be celebrated and disseminated.

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<sup>79</sup> Dr Graham Bothamley, Homerton Hospital, personal communication.

## CHAPTER 5 – SERVICE PERFORMANCE

### 5.1 What this chapter contains

This chapter contains our analysis of hospital activity in the care of patients with TB across London. The patterns of inpatient admissions are presented and discussed, and the need to study outpatient data described. We also review performance of all London’s TB services against the nine London TB metrics which were designed for that purpose in 2005. Lastly, we analyse patterns of GP prescribing of the four main antibiotics used in TB treatment.

### 5.2 Hospital In-patient activity

We have studied demand for inpatient hospital care using information from Hospital Episode Statistics (HES) for all PCTs in London.<sup>80</sup> This section considers hospital admissions (technically defined as admission spells) across the capital.

#### 5.2.1 Numbers of hospital admissions

Numbers of admission spells in 2008/09 were studied, both by PCT of residence and by admitting hospital.

**Figure 24** shows numbers of admissions due to TB by PCT of residence across one year, 2008/09.

80 Hospital Episode Statistics (HES): a data warehouse containing details of all admissions to NHS hospitals in England. It includes private patients treated in NHS hospitals, and care delivered by treatment centres (including those in the independent sector) funded by the NHS. HES also contains details of all NHS outpatient appointments in England.

**Figure 24: Number of admissions due to TB by PCT of Residence, 2008/09 (London total = 1,801)**

Source: NHS Information Centre, HES

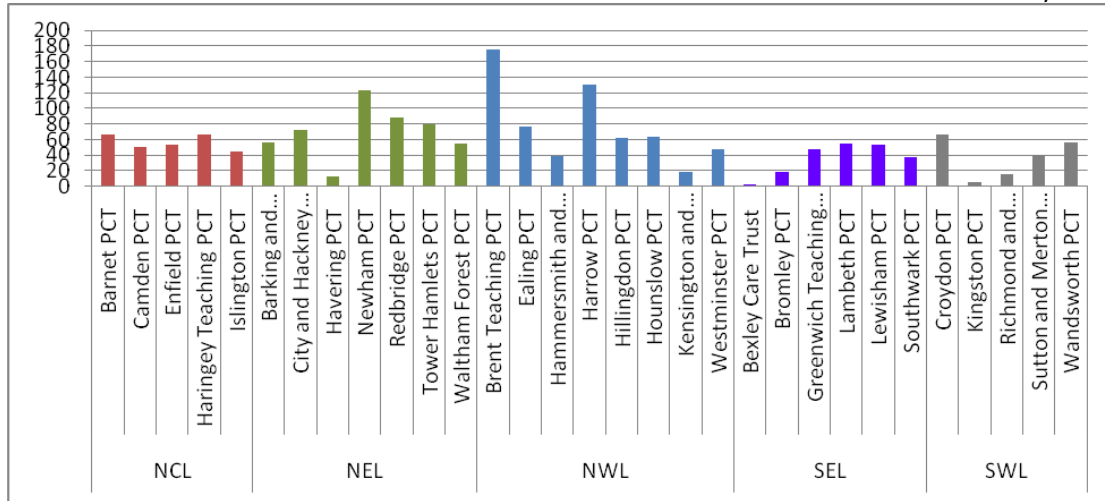


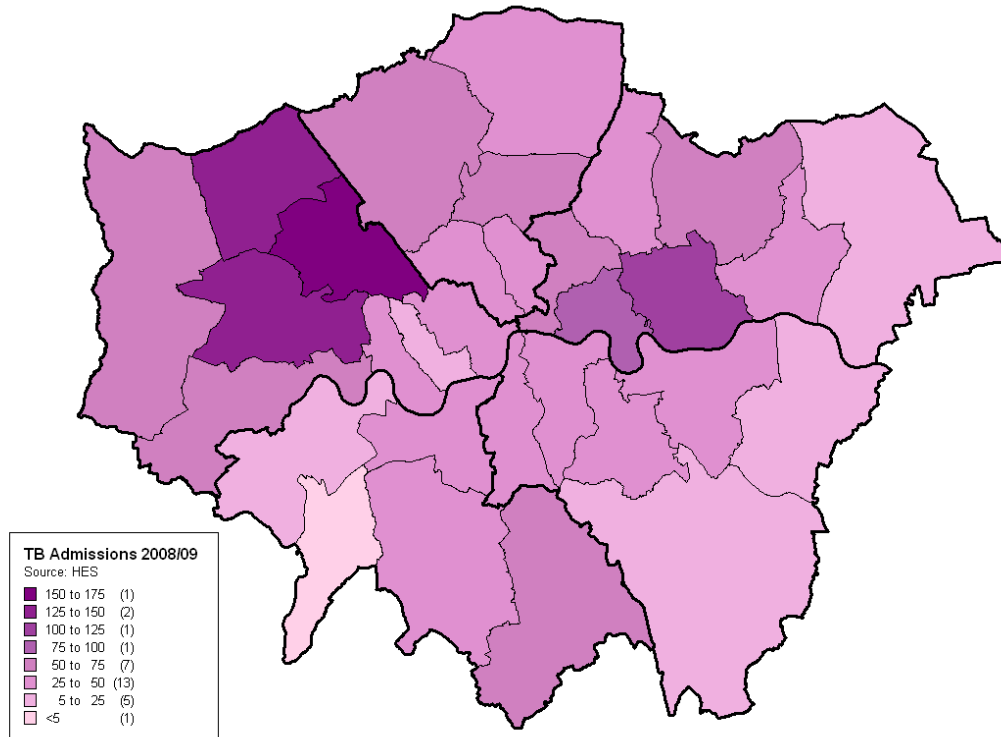
Figure 24 shows that there are more admissions of residents of NW London than elsewhere in London, followed by residents of NE London. This is probably related to the larger number of TB cases notified each year in these two sectors (compared with the others).

It is possible that TB patients in NW and NE London have greater case complexity or are more likely to have a delay in diagnosis.

The geographic pattern of need for hospital admission is shown below in **Map 5**.

**Map 5: Number of TB admissions by PCT of residence, 2008/09**

Source: NHS Information Centre, HES



The differences in total numbers of admission per PCT probably reflect the different sizes and demographic profiles of the various PCTs, differences in TB frequency and any differences there may be in admission thresholds or case complexity in different communities.

**5.2.2 Pattern of hospital admissions**

**Tables 17 to 21** show numbers of hospital admissions for TB by sector, the range of admitting hospitals used, and PCT of residence concerned. The tables show hospital admissions coded within the full range of ICD-10 TB diagnosis codes A15-A19 (as in Box 1 earlier).

Due to data restrictions, hospitals with fewer than 5 admissions were marked with an \* in the HES data. Where this was the case, 3 admissions were assumed.

For our purposes, inner and outer North East London are treated as one sector.

**Table 17: Number of spells of TB admissions, by hospital and PCT of residence, North Central London 2008/09**

Source: NHS Information Centre, HES

	Barnet PCT	Camden PCT	Enfield PCT	Haringey Teaching PCT	Islington PCT	Total
<b>North Central London</b>						
Barnet and Chase Farm Hospitals NHS Trust	25		9	3		37
Barts and the London NHS Trust					6	6
Camden PCT		3				3
Chelsea and Westminster Hospital NHS Foundation Trust				3		3
Great Ormond Street Hospital for Children NHS Trust	6	3	3			12
Homerton University Hospital NHS Foundation Trust	3		3	6	3	15
Imperial College Healthcare NHS Trust	6	9			3	18
Moorfields Eye Hospital NHS Foundation Trust	3					3
Newham University Hospital NHS Trust				3		3
North Middlesex University Hospital NHS Trust			20	27	3	50
North West London Hospitals NHS Trust	6	3				9
Royal Free Hampstead NHS Trust	14	14	6		9	43
Royal National Orthopaedic Hospital NHS Trust				3		3
The Whittington Hospital NHS Trust	3	3	6	12	12	36
University College London Hospitals NHS Foundation Trust		16	6	9	9	40
<b>Totals</b>	<b>66</b>	<b>51</b>	<b>53</b>	<b>66</b>	<b>45</b>	<b>281</b>

**Table 18: Number of spells of TB admissions, by hospital and PCT of residence, North East London 2008/09**

Source: NHS Information Centre, HES

	Barking And Dagenham PCT	City And Hackney Teaching PCT	Havering PCT	Newham PCT	Redbridge PCT	Tower Hamlets PCT	Waltham Forest PCT	Totals
<b>North East London</b>								
Barking, Havering and Redbridge University Hospitals NHS Trust	32		13	6	47			98
Barts and the London NHS Trust	9	9		27	9	70	6	130
Chelsea and Westminster Hospital NHS Foundation Trust				3				3
Ealing Hospital NHS Trust				3				3
Great Ormond Street Hospital for Children NHS Trust	3	6		3				12
Guy's and St Thomas' NHS Foundation Trust	3						3	6
Homerton University Hospital NHS Foundation Trust		43		3	3	6	6	61
Imperial College Healthcare NHS Trust							3	3
King's College Hospital NHS Foundation Trust		3				3		6
Newham University Hospital NHS Trust	6			58	9		3	76
North Middlesex University Hospital NHS Trust							3	3
North West London Hospitals NHS Trust					3			3
Queen Elizabeth Hospital NHS Trust				3				3
Royal Brompton and Harefield NHS Trust				3				3
Royal Free Hampstead NHS Trust				2	3			5
St George's Healthcare NHS Trust				6				6
Whipps Cross University Hospital NHS Trust		6						6
The Whittington Hospital NHS Trust		6			3		3	12
University College London Hospitals NHS Foundation Trust	3			9	12		28	52
<b>Totals</b>	<b>56</b>	<b>73</b>	<b>13</b>	<b>126</b>	<b>89</b>	<b>79</b>	<b>55</b>	<b>491</b>



**Table 19: Number of spells of TB admissions, by hospital and PCT of residence, North West London 2008/09**

Source: NHS Information Centre, HES

	Brent Teaching PCT	Ealing PCT	Hammersmith And Fulham PCT	Harrow PCT	Hillingdon PCT	Hounslow PCT	Kensington And Chelsea PCT	Westminster PCT	Totals
<b>North West London</b>									
Barnet and Chase Farm Hospitals NHS Trust	6			6					12
Barts and the London NHS Trust		6						3	9
Brent Teaching PCT								3	3
Chelsea and Westminster Hospital NHS Foundation Trust			9			3	6	9	27
Ealing Hospital NHS Trust	3	**		3	9	6			21
Great Ormond Street Hospital for Children NHS Trust	3	3			3				9
Guy's and St Thomas' NHS Foundation Trust	6							3	9
Imperial College Healthcare NHS Trust	21	23	30	6	6	9	12	23	130
North Middlesex University Hospital NHS Trust	3					3			6
North West London Hospitals NHS Trust	109	36		115	9	9			278
Royal Brompton and Harefield NHS Trust	3	3		3	6				15
Royal Free Hampstead NHS Trust	3								3
Royal National Orthopaedic Hospital NHS Trust	6								6
The Hillingdon Hospital NHS Trust		3			38	3			44
The Whittington Hospital NHS Trust	6								6
University College London Hospitals NHS Foundation Trust	9					3		6	18
West Middlesex University Hospital NHS Trust		3				34			37
<b>Totals</b>	<b>178</b>	<b>77</b>	<b>39</b>	<b>133</b>	<b>71</b>	<b>70</b>	<b>18</b>	<b>47</b>	<b>633</b>
<b>**Ealing hospital figures were omitted due to a coding error in the data.</b>									

**Table 20: Number of spells of TB admissions, by hospital and PCT of residence, South East London 2008/09**

Source: NHS Information Centre, HES

South East London	Bexley Care Trust	Bromley PCT	Greenwich Teaching PCT	Lambeth PCT	Lewisham PCT	Southwark PCT	Totals
Barking, Havering and Redbridge University Hospitals NHS Trust				3			3
Barts and the London NHS Trust			3		3		6
Bromley Hospitals NHS Trust		6					6
Chelsea and Westminster Hospital NHS Foundation Trust				3			3
Guy's and St Thomas' NHS Foundation Trust	3	3	6	20	6	21	59
Homerton University Hospital NHS Foundation Trust						3	3
Imperial College Healthcare NHS Trust		3					3
King's College Hospital NHS Foundation Trust		3	3	14	6	7	33
Mayday Healthcare NHS Trust				3			3
Queen Elizabeth Hospital NHS Trust			32		3		35
Royal Brompton and Harefield NHS Trust				3			3
Royal National Orthopaedic Hospital NHS Trust					3		3
St George's Healthcare NHS Trust		3		3			6
The Lewisham Hospital NHS Trust			3		29		32
University College London Hospitals NHS Foundation Trust				6	3	6	15
<b>Totals</b>	<b>3</b>	<b>18</b>	<b>47</b>	<b>55</b>	<b>53</b>	<b>37</b>	<b>213</b>

**Table 21: Number of spells of TB admissions, by hospital and PCT of residence, South West London 2008/09**

Source: NHS Information Centre, HES

	Croydon PCT	Kingston PCT	Richmond And Twickenham PCT	Sutton And Merton PCT	Wandsworth PCT	Totals
<b>South West London</b>						
Chelsea and Westminster Hospital NHS Foundation Trust					6	6
Epsom and St Helier University Hospitals NHS Trust	6			9		15
Guy's and St Thomas' NHS Foundation Trust					3	3
Imperial College Healthcare NHS Trust				3	3	6
King's College Hospital NHS Foundation Trust	3					3
Kingston Hospital NHS Trust		3	3		3	9
Mayday Healthcare NHS Trust	36	3		6		45
Newham University Hospital NHS Trust	3					3
North West London Hospitals NHS Trust			3		6	9
Queen Elizabeth Hospital NHS Trust				3		3
St George's Healthcare NHS Trust	12			19	32	63
The Lewisham Hospital NHS Trust	3					3
West Middlesex University Hospital NHS Trust	3		3		3	9
University College London Hospitals NHS Foundation Trust			6			6
<b>Totals</b>	<b>66</b>	<b>6</b>	<b>15</b>	<b>40</b>	<b>56</b>	<b>183</b>

*What these tables show*

By and large, people with TB in London requiring hospital admission are admitted to a hospital near to where they live. For example, most admissions of Camden residents are to UCLH or the Royal Free; admissions of Croydon residents are mostly to Mayday or St George's; admissions of Waltham Forest residents are mostly to Whipp's Cross.

The totals also reveal the extent to which the burden of TB admissions is distributed across the sectors. The highest totals of hospital spells of admission are from Brent PCT (178), of which the majority (109) were admitted to North West London Hospitals Trust.

### 5.3 Current rates of admission

Previous health needs assessments have shown that age and sex standardised hospital admission rates (per 100,000 head of general population) are difficult to interpret.<sup>81</sup> High apparent hospital admission rates usually simply reflect high local incidence of the disease in question.

Here, to crudely examine rates or ratios of admission to hospital for TB, we compared the number of hospital admission spells (irrespective of destination hospital) in 2008/09 to the number of TB notifications made the same year, by PCT.

This can only be an approximate indicator, given that some patients may experience more than one admission (which the dataset does not separate out), and there is no standardisation for age and sex, or adjustment for differences in case-mix.

The results are shown in **Table 22** below.

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<sup>81</sup> Hayward JA., Martin S. Health Needs Assessment: Stroke in North East London. London: PHAST, 2008

**Table 22: Ratio of hospital admissions (2008/09) to the number of TB notifications (2008)**

Source: NHS Information Centre, HES and London TB Register

<b>Sector and PCT</b>	<b>No of admissions 08/09</b>	<b>TB notifications 2008</b>	<b>Ratio of hospital admissions to notifications</b>
<b>North Central London</b>	281	495	1.76
Barnet PCT	66	114	1.73
Camden PCT	51	85	1.67
Enfield PCT	53	100	1.89
Haringey Teaching PCT	66	103	1.56
Islington PCT	45	93	2.07
<b>North East London</b>	491	925	1.88
Barking And Dagenham PCT	56	69	1.23
City And Hackney Teaching PCT	73	124	1.70
Havering PCT	13	20	1.54
Newham PCT	126	287	2.28
Redbridge PCT	89	163	1.83
Tower Hamlets PCT	79	133	1.68
Waltham Forest PCT	55	129	2.35
<b>North West London</b>	633	1106	1.75
Brent Teaching PCT	178	307	1.72
Ealing PCT	77	194	2.52
Hammersmith And Fulham PCT	39	68	1.74
Harrow PCT	133	128	0.96
Hillingdon PCT	71	153	2.15
Hounslow PCT	70	134	1.91
Kensington And Chelsea PCT	18	53	2.94
Westminster PCT	47	69	1.47
<b>South East London</b>	213	506	2.38
Bexley Care Trust	3	21	7.00
Bromley PCT	18	19	1.06
Greenwich Teaching PCT	47	138	2.94
Lambeth PCT	55	127	2.31
Lewisham PCT	53	84	1.58
Southwark PCT	37	117	3.16
<b>South West London</b>	183	345	1.89
Croydon PCT	66	112	1.70
Kingston PCT	6	29	4.83
Richmond And Twickenham PCT	15	13	0.87
Sutton And Merton PCT	40	81	2.03
Wandsworth PCT	56	110	1.96
<b>Grand Total</b>	1801	3377	1.88

Table 22 shows that the larger the numbers notified, the more admissions.

The commonest ratio is around 1 admission to 2.5 notifications. This suggests that a little more than a third of patients require an admission at some point in their illness. There are some exceptions; in Harrow the number of admissions is virtually the same as the number of notifications.

The lowest ratios may apply where cases are most complex – i.e. most in need of a spell in hospital. One conclusion to explain the extent of the variation could be that the thresholds for admission are different in differing parts of London, though this would require further exploration for a confident conclusion to be drawn.

## 5.4 Length of stay (LOS)

There are a number of length of stay (LOS) parameters that can be used to compare hospital activity – the most common being the average LOS (which uses the mean value of the interval between date of admission and date of discharge). However, here limitations on data mean that it was necessary to report minimum and maximum LOS.

### 5.4.1 Definitions and limitations

LOS is calculated as the difference in days between the admission date and the episode end date (duration of episode) or discharge date (duration of spell), where both dates are given. LOS is based on hospital stays and only applies to ordinary admissions, i.e. day cases are excluded (unless otherwise stated). Information relating to LOS figures, including discharge method/destination, diagnoses and any operative procedures, is based only on the final episode of the spell.<sup>82</sup>

LOS information is routinely classified under the following categories:

- Non-elective
- Elective
- Other

A large number of admissions is classified under 'other'. According to the NHS data dictionary, admissions coded as 'other' include the following:

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<sup>82</sup> A finished admission episode is the first period of inpatient care under one consultant within one healthcare provider. Finished admission episodes are counted against the year in which the admission episode finishes. Please note that admissions do not represent the number of inpatients, as a person may have more than one admission within the year.

- 22: GP Referral
- 23: Bed bureau
- 24: Consultant Clinic or Other Health Care Provider
- 28: Other (examples are:
  - admitted from A&E from another provider where they had not been admitted
  - transfer of an admitted patient from another Hospital Provider in an emergency)
- 31: Admitted ante-partum
- 81: Other hospital patient transfer

It was not possible to verify which types of 'other' admissions our TB activity analysis included.

Where hospitals had fewer than 5 admissions, the number of admissions is hidden to protect patient confidentiality.

We examined LOS data for TB admissions to London hospital trusts during 2008/09. Because information was available by trust, it was not possible to establish LOS for individual hospitals within trusts (e.g. Hammersmith, Charing Cross and St Mary's figures are contained with the total for Imperial College NHS Trust). The admission figures are totals irrespective of where patients live – TB admissions of patients outside London are therefore included. For that reason, figures are shown for the Brompton and Royal National Orthopaedic Hospitals, who do not provide a TB service for more than a handful of London residents.

### 5.4.2 Findings

Due to data restrictions, average LOS information was categorised by resident PCT instead of by hospital. **Table 23** shows the number of admissions by NHS Trust as well as the minimum and maximum LOS for each type of admission.

As individual data was unavailable, obtaining a mean LOS figure by admission type and hospital was not possible. However, by assuming each hospital with less than five admissions had three admissions, and by looking at the minimum and maximum mean LOS, some comparisons could be drawn.

For elective admissions, most hospitals manage a mean LOS between 0 (a partial day) and 20 days. Most of the outliers are probably caused by one patient being severely ill, thereby skewing the mean. Due to the nature of the data, it is difficult to draw a firm conclusion on this. Non-elective admissions also seem to have mean stays between 0-20 days, though there are more outliers (Barts, Guy's and St. Thomas', and Whipps Cross in particular). 'Other' admissions, which cover a variety of admission types, have slightly higher mean LOS figures than elective and non-elective. However, the numbers of admissions for 'other' are for the most part smaller than the other two admissions types, meaning that one or two people within these groups could be powering the increased LOS. Both North Central and North East London had higher levels of admissions for TB coded as "other" compared to those classified as "elective" and "non-elective".

<b>Table 23: Admissions by NHS trust and the minimum and maximum mean length of stay (LOS), 2008/09</b>									
<b>NHS Trust</b>	<b>Sum of elective admissions</b>	<b>Min elective LOS</b>	<b>Max elective LOS</b>	<b>Sum of non-elective admissions</b>	<b>Min non-elective LOS</b>	<b>Max non-elective LOS</b>	<b>Sum of other admissions</b>	<b>Min of other LOS</b>	<b>Max of other LOS</b>
Barking, Havering And Redbridge University Hospitals NHS Trust	22	3.8	5	63	1	15.33	16	19	51
Barnet And Chase Farm Hospitals NHS Trust	17	1	5	26	1	9	6	0.33	11
Barts And The London NHS Trust	44	2	5.5	59	6	53	48	0	20.33
Brent Teaching PCT	3	117	117						
Bromley Hospitals NHS Trust	3			3	10	10			
Camden PCT							3	228	228
Chelsea And Westminster Hospital NHS Foundation Trust	15	5	18	21	0	9	6	8	8
Ealing Hospital NHS Trust	9	5	12	12	3	15	3	2	3.67
Epsom And St Helier University Hospitals NHS Trust	6			3			6		
Great Ormond Street Hospital For Children NHS Trust	15	2.5	5				18	7	19
Guy's And St Thomas' NHS Foundation Trust	21	3	9	38	1	12.5	18	7.75	12
Homerton University Hospital NHS Foundation Trust	26	1	24	44	0	3.56	9	2	7
Imperial College Healthcare NHS Trust	48	3	16.33	74	0	34	38	0	75.13
King's College Hospital NHS Foundation Trust	9			24	1	6.33	9	8	13
Kingston Hospital NHS Trust				9	33	33			
Mayday Healthcare NHS Trust	14	56	56	31	20.13	20.13	3	15.75	15.75



Newham University Hospital NHS Trust	14	19.67	19.67	54	1	21	14	12	161
North Middlesex University Hospital NHS Trust	6	8	8	47	1	5.2	6	14.6	129
North West London Hospitals NHS Trust	144	1	5.2	71	0	10.33	84	3	34.33
Queen Elizabeth Hospital NHS Trust	8	3	3	30	5	5.89	3	4.25	4.25
Royal Brompton And Harefield NHS Trust	15	0	4				6	6	8
Royal Free Hampstead NHS Trust	9	4	4	24	0	28	18	0.75	51
Royal National Orthopaedic Hospital NHS Trust	6	1	1				6	4	154
St George's Healthcare NHS Trust	9	2.5	7	51	8	13	15	2	17.75
The Hillingdon Hospital NHS Trust	6	1	1	30	0	6.33	8	9.29	9.29
The Lewisham Hospital NHS Trust	6	13	33.5	23	12.33	12.33	6	10	26
The Whittington Hospital NHS Trust	6	5	5	24	6.5	12.4	18	1.33	12
University College London Hospitals NHS Foundation Trust	39	0	32.5	34	0.5	8	21	0.67	32
West Middlesex University Hospital NHS Trust	12	8	8	23	19.09	19.09	8	4.17	4.17
Whipps Cross University Hospital NHS Trust	9	1	1	30	3.5	122	13	6	9.67
Grand Total (1801**)	544			848			409		

\*Due to data restrictions, this table assumed an average of 3 admissions if hospitals had less than 5 admissions recorded.

\*\*Due to a coding error Ealing PCT's admissions to Ealing Hospital are not attributable to different types of admission and were excluded.

Source: NHS Information Centre, HES

## 5.5 Hospital Out-patient Activity

Outpatient services are an important aspect of TB care and examination of this was planned as part of the project specification. Volumes of activity are much greater than of inpatient spells. Most patients with TB can be cared for out of hospital and as we have seen in Chapter 4, the current model of service delivery is predominantly outpatient based.

However, obtaining robust information is not straightforward. A patient with renal TB who visits his urologist for follow-up may have that consultation coded under Urology. A patient with pulmonary TB may have a consultation coded as TB but it may also be coded under General Medicine. Each clinic uses a different code to identify it within each hospital.

Unfortunately it has emerged not to be feasible to overcome these obstacles in collating and analysing TB outpatient activity data within the timescale of the project.

Where necessary, the following have been employed as proxy indicators of workload and service burden:

- Numbers of notified cases;
- Inpatient admissions.

## 5.6 London TB Service Metrics

### 5.6.1 Origin

Following the publication of the CMO's Action Plan, the Stopping TB in London group was formed in 2005. Nine indicators were subsequently agreed, to monitor performance against the Plan across London.

These are the nine London TB metrics (see below).

All PCTs in London are now required to report to NHS London on just one of these metrics: their local rate of TB Treatment Completion.

The following sections review current performance against the metrics, and review the usefulness of the metrics themselves.

London TB Metrics

Metric	Detail	Status	Definitions	Threshold
1	Boroughs/PCTs with TB rates $\geq 40/100,000$ population to provide universal neonatal BCG. Neonatal BCG to be carried out within first year after birth. TB prevention in babies and young children: achieve as a minimum 70% coverage by 4 months, and 75% by 12 months, aspiring to 80% and 90% respectively.	Green	Universal neonatal BCG service in place and able to report minimum percentage take-up	70% at 4/12 , 75% at 12/12
		Orange	Universal neonatal BCG service in place	
		Red	No universal neonatal BCG service in place	
2	Access: each patient who is suspected by a GP to have pulmonary TB is seen by a specialist TB service within 2 weeks of referral by GP	Green	$\geq 90\%$ ?TB patients referred by GP are seen by TB services within 2 weeks of date on GP letter	$\geq 90\%$
		Orange	$\geq 75 - 89.9\%$ ?TB patients referred by GP are seen by TB services within 2 weeks of date on GP letter	$\geq 75 - 89.9\%$
		Red	$\leq 74.9\%$ ?TB patients referred by GP are seen by TB services within 2 weeks of date on GP letter	$\leq 74.9\%$
3	Prompt diagnosis: All TB samples should be processed using liquid culture technology	Green	Samples processed using liquid culture	65% pulmonary TB confirmed by lab culture Laboratories are accredited as described in the TB toolkit guidance
		Orange	Introduction of liquid culture planned and date of implementation within 08/09known	
		Red	Samples not processed using liquid culture	
4	Prompt diagnosis: all results on sputum smears should be available within 1 working day of the sample reaching the laboratory	Green	Results on sputum available within 1 working day of sample reaching laboratory	
		Orange	Results on sputum available within 2 working days of sample reaching laboratory	
		Red	Results on sputum available more than 2 days after sample reaching laboratory	
5	Identification of those with complex needs: a risk assessment, as defined by National Sureveillance Standard, is carried out on each TB patient to identify those at risk of not completing their TB treatment	Green	$\geq 90\%$ of notified TB patients have recorded risk assessment	$\geq 90\%$
		Orange	$\geq 80 - 89\%$ of notified TB patients have recorded risk assessment	$\geq 80 - 89\%$
		Red	$< 80\%$ of notified TB patients have recorded risk assessment	$< 80\%$
6	Treatment completion to achieve, as a minimum, 85% treatment completion rate (national target) using WHO equation $\% = (C/T) \times 100$	Green	Treatment completion $\geq 85\%$	$\geq 85\%$
		Orange	Treatment completion $\geq 80 - 84.9\%$	$\geq 80 - 84.9\%$
		Red	Treatment completion $< 80\%$	$< 80\%$
7	Prevention of further infection: all defined contacts of TB should be identified and screened as per NICE Guidelines. Services are able to report contact tracing specifically numbers seen, numbers offered chemoprophylaxis, numbers offered BCG and numbers diagnosed with TB	Green	Services able to report activity and outcome	
		Orange	Services able to report outcome	
		Red	Services unable to report activity or outcome	
8	Workforce: there should be a minimum of 1 specialist TB nurse for every 40 TB notifications and full clinic admin support in place	Green	1 specialist TB nurse per 40 TB notifications annually and 1 WTE/full-time admin worker	1 TB nurse $\leq 40$ TB notifications 1 WTE admin
		Orange	1 specialist TB nurse per 41 - 45 TB notifications annually and admin support	1 TB nurse = 41 - 45 TB notifications Admin support
		Red	1 specialist TB nurse per 46+ TB notifications annually OR no admin support	1 TB nurse $\geq 46$ TB notifications OR no admin
9	HIV: all TB patients, 16 years or older, to be offered HIV test	Green	$\geq 80\%$ TB patients, 16 years or older, are recorded as having been offered an HIV test	$\geq 80\%$
		Orange	$\geq 50 - 79.9\%$ TB patients, 16 years or older, are recorded as having been offered an HIV test	$\geq 50 - 79.9\%$
		Red	$\leq 49.9\%$ TB patients, 16 years or older, are recorded as having been offered an HIV test	$\leq 49.9\%$

## 5.6.2 Sources of information

The metrics do not rely on a single data source. The following section comments on the apparent current availability and collation of data for the metrics.

### *Metric 1 – Neonatal BCG*

Information on neonatal BCG immunisation rates is collected by PCTs who are responsible for childhood immunisation programmes.<sup>83</sup> This information has never been systematically collated in relation to TB control.

### *Metric 2 – Seen within 2 weeks of GP referral*

This information would need to be recorded by chest clinics. It is not, although it could be obtained from retrospective audit.

### *Metric 3 – Liquid culture*

Information can be obtained from providers.

### *Metric 4 – Speed of reporting of sputum smear results*

Information can be obtained from providers.

### *Metric 5 – Risk assessment for non-compliance with treatment*

The use and results of risk assessment can be estimated by information on risk factors extracted from the London TB Register (LTBR).

### *Metric 6 – Treatment completion*

Treatment completion rates can be extracted from the LTBR. Recently it has been agreed that this will be done by the HPA and reported to sectors, to ensure standardisation of the definitions used.

### *Metric 7 – Service ability to measure contact tracing*

Contact tracing information is not readily available and reporting from services has been patchy.

### *Metric 8 – No of nurses as a ratio of notifications made*

This information needs to be provided by services, requiring up to date workforce numbers.

### *Metric 9 – Offers of HIV test to all over 16 years*

Information on this metric is contained within the LTBR.

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<sup>83</sup> PCT provider services usually deliver neonatal BCG to babies around 6 weeks of age. In a few boroughs, neonatal BCG immunisation is delivered by midwives shortly after birth.

### 5.6.3 Reporting metrics performance – current arrangements

Currently, responsibility for monitoring performance of all TB services against the metrics is taken by the five London TB sector networks. Each sector has the boundaries of the five (former) London Strategic Health Authorities.<sup>84</sup>

We considered how performance against the metrics is reported by each sector from a review of their annual reports and from information provided by the sectors' TB network co-ordinators / managers.

The sectors report performance against the metrics in differing degrees of detail and over different time periods. Most sectors originally reported performance against all nine metrics, to the extent that it was possible to obtain the data. Most now consider only a selection of metrics.

Some metrics information can be derived from the LTBR. HPA London Region routinely (on a quarterly basis) provides data on treatment completion, by PCT and by provider service. However, for other metrics where the data is in the LTBR, sector coordinators have run their own data enquiries, in a way that is neither standardised, nor centrally coordinated.

- In SW London and in NE London, a scorecard is used for seven out of the nine metrics – excluding metrics 1 and 2 (*Neonatal BCG* and *"Seen within two weeks of GP referral"*).
- In NC London and in SE London, all nine metrics are reported annually, and treatment completion rates are reported quarterly.
- In NW London all nine used to be reported quarterly, but recently reports have been selective with special emphasis on treatment completion.

There is no systematic reporting of metrics performance across the whole of London, even though the metrics are performance indicators for London.

### 5.6.4 Current performance against the London TB metrics

Given the fragmentation and lack of coordination of metrics reporting across London, we have examined performance against all nine metrics across all five sectors in London for the most recent year for which figures can be obtained. The results reported in detail in the following sections below are therefore as up to date as possible. A summary table of performance is also included later in the chapter.

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<sup>84</sup> NE London has recently divided into two halves = inner and outer. For the purposes of this chapter, we treat NE London as one sector.

### **Metric 1**

*Boroughs/PCTs with TB rates  $\geq 40$  per 100,000 population to provide universal neonatal BCG. Neonatal BCG to be carried out within first year after birth.*

With the help of the HPA, we have examined the rates of BCG coverage in children under the age of one year, by PCT, as derived from the NHS Information Statistics Report 2008/09. This is a close proxy for immunisation rates provided within 6 weeks of birth; the number of infants being given BCG outside this neonatal programme is likely to be small.

#### *Results*

##### *a). PCTs with universal neonatal BCG policy*

Overall, among London PCTs with universal neonatal BCG policies, coverage of the population aged less than one year old was 64%. Excluding those PCTs where no BCG data were reported at all, this increased to 70%.

North Central London was the only sector with 75% coverage among its three PCTs with a universal BCG policy (Camden, Haringey and Islington).

In North East London, three PCTs had over 80% coverage (Newham, Redbridge and Waltham Forest), two had less than 70% (City and Hackney and Tower Hamlets), and no data were reported for Barking and Dagenham.

In North West London, although all PCTs have universal BCG policies, only two (Hillingdon and Hounslow) achieved 75% coverage. Of the others, Kensington and Chelsea PCT had particularly low coverage at 24% and Harrow had only 45%.

In South East London, Greenwich and Lambeth PCTs had over 75% coverage, but Lewisham only had 62% and no data were reported for Southwark PCT.

##### *b). PCTs with selective neonatal BCG policy*

PCTs with lower TB rates may immunise neonates selectively in high-risk communities.

Barnet and Enfield PCTs in North Central London had 37% and 22% coverage respectively. The only PCT in North East London with a selective policy, Havering, had no BCG data reported by the NHS Information Centre. In South East London, Bexley and Bromley have selective BCG policies: coverage in Bromley was 15%, and no data were reported for Bexley. All South West London PCTs have a selective policy, and coverage ranged from 6% in Wandsworth to 29% in Croydon.

#### *Comments*

Neonatal BCG immunisation rates across London are disappointingly low. The patchy performance across London highlights the lack of coordinated central reporting of this indicator, as well as an apparent lack of action to improve coverage rates. Action will be needed to ensure better coverage, especially in PCTs with universal neonatal BCG policies where coverage is poor.

Where neonatal BCG immunisation is selective, it is difficult to establish a denominator population and thereby measure coverage and uptake. However, the

absence of any data for several boroughs is a concern, and in Wandsworth (which notified as many as 110 TB cases in 2008) a neonatal immunisation rate of only 6% cannot be adequate. Selective immunisation policies in some PCTs need re-appraisal. An argument can be made for offering neonatal BCG immunisation to all babies in London. The issues this might help tackle include the following:

- Uptake and coverage of selective immunisation is difficult to measure;
- Londoners are very mobile: all children living in the capital may run the risk of exposure to TB;
- Children living in lower prevalence communities may go to school in higher prevalence areas (and vice versa);
- Immunisation targeted selectively at specific ethnic communities may be stigmatising.

Consequently, although consideration of BCG policy was not part of the remit for this report, it appears that a detailed review of options may be required, including the case for universal neonatal BCG immunisation across the whole of London.

**Metric 2**

*Access: Each patient who is suspected by a GP to have pulmonary TB is seen by a specialist TB service within 2 weeks of referral by GP*

This metric is not being measured. There is no information.

**Metric 3**

*Prompt diagnosis: all TB samples should be processed using liquid culture technology*  
The five sector coordinators have confirmed that all TB services in London have access to liquid culture.

Performance in London against this metric is no longer relevant.

**Metric 4**

*Prompt diagnosis: all results on sputum smears should be available within 1 working day of the sample reaching the laboratory.*

The five sector coordinators all have confirmed that prompt return of results of sputum smear examination is in place.

Performance in London against this metric is no longer relevant.

**Metric 5**

*Identification of those with complex needs: a risk assessment, as defined by National Surveillance Standard, is carried out on each TB patient to identify those at risk of not completing their TB treatment. [Target is 90%].*

The LTBR includes a record of information on patient risk factors, so this can be used as a proxy for whether a risk assessment has been done.

### *Results*

In London as a whole, 88% of TB patients notified in 2009 had information on the presence or absence of one or more risk factors recorded on the LTBR. This means that overall 12% of patients had no record entered to indicate whether or not a risk assessment had been done.

The recording of risk factors varies widely within London.

The North Central and North East London sectors both had risk factor information recorded on 96% of patients (at least 90% within each clinic). This shows it can be done.

In North West London, the overall level was 86%. However, only 43% of patients at West Middlesex University Hospital had this information recorded, and only 67% of patients at Hillingdon Hospital.

In South East London, risk factor information was reported on almost all patients at Bromley and Kings College Hospital, but only 36% of patients at Queen Mary's Hospital and 71% at Lewisham, so the overall proportion for South East was 70%.

Three of the four clinics in South West London reported risk factor information on more than 90% of patients, but St George's Hospital only had information for 73% of patients.

The full results by sector and reporting clinic are shown below in **Table 24**

### *Comments*

Risk factor documentation is unduly variable. The indicator is important, since the assessment is to determine risk of non-compliance with treatment, which can lead to treatment failure, return of infectious TB and possible drug resistance.

It is possible that patients have had their risk factors determined, but that the information has not been entered on the LTBR. Without an audit or cohort review process, it is impossible to know if this is the case.

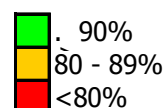
Where risk factor reporting rates are banded red, (see Table) prompt investigation is indicated. For example, it may simply be an issue of inadequate administrative support; alternatively, corners may have been cut.

The current metric is simply a measure of whether an assessment is recorded as done. A more important measurement would be the correlation between risk factors identified and whether or not patients with risks are in receipt of enhanced case management or DOT.



**Table 24: Sector / clinic performance against Metric 5: Proportion of patients reported to have risk factors.** Source: HPA, 2010

Sector / TB service	% with risk factor* information reported	
<b>North Central</b>		
Barnet	90%	
Great Ormond Street	100%	
North Middlesex	98%	
Royal Free	91%	
UCLH	98%	
Whittington	98%	
<b>North Central Total</b>	<b>96%</b>	
<b>North East</b>		
Queens (BHRT)	96%	
Homerton	99%	
King George (BHRT)	94%	
London Chest (BLT)	93%	
Newham	99%	
Whipps Cross	95%	
<b>North East Total</b>	<b>96%</b>	
<b>North West</b>		
Charing Cross (ICHT)	100%	
Chelsea & Westminster	98%	
Ealing	98%	
Hammersmith (ICHT)	97%	
Hillingdon	67%	
Northwick Park (NWLTL)	94%	
Royal Brompton	0%	
St Mary's (ICHT)	90%	
West Middlesex	43%	
Central Middlesex (NWLTL)	91%	
<b>North West Total</b>	<b>86%</b>	
<b>South East</b>		
Bromley	100%	
Guy's & St Thomas's	80%	
Kings College	98%	
Queen Elizabeth	88%	
Queen Mary's	36%	
Lewisham	71%	
<b>South East Total</b>	<b>70%</b>	
<b>South West</b>		
Epsom St Helier	98%	
Kingston	95%	
Mayday	98%	
St George's	73%	
<b>South West Total</b>	<b>88%</b>	
<b>Non LTBR Clinics</b>	<b>27%</b>	
<b>London Total</b>	<b>88%</b>	



Risk factor information reported includes all cases with at least one field completed (yes, no or unknown) in the LTBR.

\* Risk factors include: history of drug use; history of homelessness; UK prison history; ability to self-administer treatment affected by alcohol; mental health concerns.

## **Metric 6 Treatment completion**

*Treatment completion to achieve, as a minimum, 85% treatment completion rate (national target)*

Treatment completion rates by PCT of residence have previously been described in the Epidemiology section. Here we show performance against this particular metric at clinic level.

**Table 25** below shows the detail of treatment completion, by sector and service, for 2008.

Among tuberculosis cases notified by London clinics in 2008, 83% completed treatment within one year, but only 10 clinics achieved the treatment completion target of 85%. The proportion of patients still on treatment varied by clinic, from none to 27% (Great Ormond Street Hospital). This is probably an indicator of case complexity, where treatment may need to last longer than twelve months after notification.

The proportion of deaths recorded also varied, being as high as 11% at the Hammersmith Hospital and Epsom & St Helier NHS Trust, although the cause of some deaths may not have been related to TB.

Losses to follow up can also be seen to vary considerably.

Eleven clinics are scored "red" for this indicator.

### *Comment*

The definition of treatment completion is complex as well as unsatisfactory (see Epidemiology section).

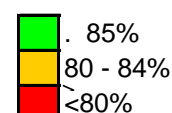
The extent of the variations seen is striking, though with small numbers, there may be wide confidence intervals around estimates. A completion rate of only 61% at the West Middlesex, where more than 20% of patients are still on treatment at 12 months, does suggest further investigation, especially as the proportion recorded as lost to follow up (7%) is the highest in the capital.

A central body is required to coordinate action in response to low reported treatment completion rates as well as to standardise the definitions and reporting metrics used in the future.

**Table 25: Proportion of new TB notifications in London clinics completing treatment within one year, by sector and notifying clinic, 2008**

Source: HPA, 2010

Sector / TB service	% completing treatment	Still on treatment	Died	Lost to follow up	Treatment stopped	Transfers without further info	Outcome unknown/null
<b>North Central</b>							
Barnet	83%	10%	1%	0%	0%	6%	0%
Great Ormond Street	67%	27%	0%	0%	0%	0%	7%
North Middlesex	85%	10%	1%	2%	2%	1%	0%
Royal Free	74%	8%	8%	2%	2%	5%	0%
UCLH	79%	8%	4%	1%	3%	6%	0%
Whittington	79%	12%	6%	2%	1%	0%	0%
<b>North Central Total</b>	<b>80%</b>	10%	3%	2%	2%	2%	0%
<b>North East</b>							
Queens (BHRT)	85%	6%	8%	0%	2%	0%	0%
Homerton	80%	8%	5%	3%	1%	4%	0%
King George (BHRT)	78%	9%	4%	1%	1%	6%	1%
London Chest (BLT)	81%	14%	3%	2%	1%	1%	0%
Newham	87%	6%	3%	0%	2%	1%	0%
Whipps Cross	95%	1%	2%	0%	0%	0%	2%
<b>North East Total</b>	<b>84%</b>	8%	4%	1%	1%	2%	0%
<b>North West</b>							
Charing Cross (ICHT)	79%	9%	4%	5%	2%	0%	0%
Chelsea & Westminster	89%	3%	3%	0%	0%	5%	0%
Ealing	84%	8%	4%	1%	1%	5%	0%
Hammersmith (ICHT)	74%	9%	11%	2%	0%	3%	0%
Hillingdon	81%	5%	6%	2%	0%	8%	0%
Northwick Park (NWLTL)	87%	1%	3%	3%	1%	1%	3%
Royal Brompton	-	-	-	-	-	-	-
St Mary's (ICHT)	79%	7%	3%	6%	1%	3%	1%
West Middlesex	61%	21%	5%	7%	0%	4%	2%
Central Middlesex (NWLTL)	90%	2%	2%	5%	0%	2%	2%
<b>North West Total</b>	<b>82%</b>	6%	4%	3%	1%	3%	1%
<b>South East</b>							
Bromley	93%	7%	0%	0%	0%	0%	0%
Guy's & St Thomas's	81%	6%	4%	6%	0%	2%	2%
Kings College	89%	2%	2%	0%	2%	3%	4%
Queen Elizabeth	87%	5%	5%	1%	1%	2%	0%
Queen Mary's	80%	20%	0%	0%	0%	0%	0%
Lewisham	84%	13%	0%	0%	0%	3%	0%
<b>South East Total</b>	<b>85%</b>	6%	3%	2%	1%	2%	1%
<b>South West</b>							
Epsom St Helier	83%	0%	11%	0%	2%	4%	0%
Kingston	76%	6%	8%	0%	0%	8%	0%
Mayday	85%	4%	3%	2%	0%	5%	0%
St George's	83%	4%	4%	2%	2%	2%	1%
<b>South West Total</b>	<b>83%</b>	4%	4%	2%	1%	3%	1%
<b>Non LTBR Clinics</b>	<b>60%</b>	0%	20%	0%	0%	0%	20%
<b>London Total</b>	<b>83%</b>	7%	4%	2%	1%	3%	1%



### **Metric 7**

*Prevention of further infection: all defined contacts of TB [sic] should be identified and screened as per NICE Guidelines. Services are able to report contact tracing, specifically numbers seen, numbers offered chemoprophylaxis, numbers offered BCG and numbers diagnosed with TB.*

This metric is not being measured and no information is currently available (see Discussion section).

### **Metric 8**

*There should be a minimum of one specialist TB nurse per 40 TB notifications and full clinic admin support in place*

The ratio of numbers of notifications / number of nurses was calculated, using the number of TB notifications made by each clinic for 2009, and the number of whole time equivalent (wte) clinic nurses given to PHAST in the Service Review Questionnaire. The results are shown below in **Table 26**.

**Table 26** below shows that the apparent nurse: notification ratio varies widely within each sector.

In NE London, the ratio of nurses to notifications at BHRT (where nurses operate across two sites) is low at 1:46 overall. Elsewhere the ratios are better than the 1:40 standard. Given the complexity of caseloads in NE London, this is appropriate.

NW London has more variable ratios. Northwick Park has the highest number of notifications in London (259 in 2009) but the ratio is only 1:50. The Central Middlesex also has a ratio of 1:50. Given that Brent has a very high incidence of TB, this is a cause for serious concern. The staffing at Northwick Park, Central Middlesex and the West Middlesex needs to be reviewed. The ratio at the West Middlesex is also too low at 1:50. Ratios elsewhere in NW London are lower than 1:40, so that the overall sector ratio appears reasonable at 1:37.

In SE London, Lewisham clinic has a ratio of 1:73 (only one WTE nurse), but otherwise in the sector the ratios are within the 1:40 benchmark.

In SW London, St George's has a ratio of 1:50, again suggesting not enough nurses, but other providers are within the benchmark.

**Table 26: Nursing staff numbers (2010) and TB notifications 2009**

Sources: HPA, PHAST Service Review Questionnaire returns

Sector / Clinic	Number of Nursing Staff, (WTE)	Notifications 2009	Nurses : Notifications
<b>NORTH CENTRAL LONDON</b>			
UCLH	4.6	122	1:27
Whittington	2	94	1:47
Barnet	1.5	70	1:47
Royal Free	3	114	1:38
North Middlesex	4	189	1:47
<b>NC LONDON</b>	<b>15.1</b>	<b>589</b>	<b>1:39</b>
<b>NORTH EAST LONDON</b>			
Queen's (BHRT)	5.1 <sup>a</sup>	84	1:46
King George (BHRT)		153	
Homerton	4	112	1:28
London Chest (BLT)	6	220	1:37
Whipps Cross	3	109	1:36
Newham	6.5	247	1:38
<b>NE LONDON</b>	<b>24.6</b>	<b>925</b>	<b>1:38</b>
<b>NORTH WEST LONDON</b>			
St Mary's (ICHT)	5.4	135	1:25
Hammersmith (ICHT)	2	77	1:39
Ealing	4.8	189	1:39
Northwick Park (NWLTP)	5.2	259	1:50
Charing Cross (ICHT)	3	64	1:21
Hillingdon	3	101	1:34
West Middlesex	3	149	1:50
Chelsea and Westminster	2.5	61	1:24
Central Middlesex	3.2	158	1:50
<b>NW LONDON</b>	<b>32.1</b>	<b>958</b>	<b>1:37</b>
<b>SOUTH EAST LONDON</b>			
Bromley	1	21	1:21
Queen Elizabeth	3	115	1:38
King's (LSL)	4	112	1:28
Guy's and St Thomas' (LSL)	3	153	1:51
Lewisham (LSL)	1	73	1:73
Queen Mary's Sidcup - Greenwich Community	*	<sup>b</sup>	*
<b>SE LONDON</b>	<b>12</b>	<b>474</b>	<b>1:40</b>
<b>SOUTH WEST LONDON</b>			
Mayday	2.75	110	1:40
Kingston	1.5	59	1:39
Epsom & St Helier	1.66	52	1:31
St Georges	2.8	139	1:50
<b>SW LONDON</b>	<b>8.71</b>	<b>360</b>	<b>1:40</b>
* Data unavailable			
<sup>a</sup> Nurses shared between King George and Queen's, thus the ratio calculated using 237 total notifications for two sites combined			
<sup>b</sup> Queen Elizabeth (Greenwich) notifications includes Queen Mary's Sidcup notifications			

*Comment*

The information presented above has been dependent on the workforce numbers presented to PHAST by respondents to the Service Review Questionnaire. If staff numbers are under-reported, then the ratios presented will be misleading.

Without any other recent survey of all staff in TB clinics, the responses to the PHAST questionnaire provide the most complete and up to date source of information about the nursing workforce.

Workforce numbers and skill mix in TB clinic teams is a vitally important issue. Without enough nurses and adequate administrative support, no TB service can be run safely without cutting corners.

There seems to have been no arrangement to coordinate action in response to these workforce issues. Some PCTs are known to have made substantial investment in local acute services in order to ensure that the performance standard of this metric is met; others clearly have not.

The proposed arrangements whereby the commissioning of TB services in London is performed London-wide, provides an opportunity to make certain that action is taken where it is needed to ensure that all services hit the 1:40 standard of this metric.

### **Metric 9**

*All TB patients, 16 yrs or older, to be offered HIV test.*

Information on this metric is obtainable from the LTBR. The HPA has analysed data for 2009. Proportions were calculated among all TB cases where information about the offer of an HIV test was recorded in the LTBR in 2009.

The data shows whether a test was offered (recorded as YES), not offered (recorded as NO), or previously offered. The data also reveals how often all these options were left blank (null = no record).

#### *Proportion shown null - no information recorded*

A quarter (26%, 867 /3399) of patients aged 16 or older had no information recorded on whether an HIV test had been offered. This varied by sector: clinics in North East London were missing information on only 8% of patients, while in South East London this was missing for almost half of all patients (44%).

At clinic level, there was substantial variation: the Royal Brompton (though few patients), West Middlesex, Guy's and St Thomas', Queen Mary's and St George's Hospital reported whether an HIV test had been offered on less than a third of their patients.

#### *Information recorded*

Among patients where the offer of an HIV test was reported (offered, not offered or previously offered), 89% were offered an HIV test in 2009 with a further 4% having been previously offered a test. Almost all London clinics offered 80% or more a test. Chelsea and Westminster only offered 45% of their patients an HIV test, but 31% had previously been offered a test. West Middlesex University Hospital only offered 54% of patients a test, with only a further 8% having previously been offered. Guy's and St Thomas' offered 71% of patients an HIV test, with 26% previously offered.

#### *Comment*

A high proportion of patients have no record of whether they have been offered an HIV test. This may be simply due to lack of administrative capacity, or it may show that HIV testing is not being offered when it should.

The picture again suggests that central monitoring of this metric is needed and initiatives put together to improve performance, especially in those clinics that have recorded the offer of an HIV test in less than a third of the patients under their care. The metric should probably be modified – see below.

### **5.6.5 Summary scorecard - metric performance by sector**

A summary scorecard to show performance against all nine metrics by sector is seen in **Table 27** below.

**Table 27: Summary of London TB Metric Achievements by Sector  
A: North Central London**

Primary Care Trust	Metric	Barnet PCT	Camden PCT	Enfield PCT	Haringey PCT	Islington PCT
	1. Neonatal BCG a) Universal BCG	--	77%	--	75%	75%
	b) Selective BCG	37%	--	22%	--	--
	2. Pulmonary TB patients seen by specialist TB service within 2 weeks of referral by GP	Not measured	Not measured	Not measured	Not measured	Not measured
	3. Liquid culture	Yes	Yes	Yes	Yes	Yes
	4. Speed of reporting of sputum smear results	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place
	6. Treatment completion	80%	74%	86%	82%	83%
7. Service ability to measure contact tracing	Not measured	Not measured	Not measured	Not measured	Not measured	

TB Clinic	Metric	Barnet & Edgware	GOSH	North Middlesex	Royal Free	UCLH	Whittington
	5. Risk assessment of non-compliance with treatment	90%	100%	98%	91%	98%	98%
	6. Treatment completion	83%	67%	85%	74%	79%	79%
	8. No. nurses as ratio of notifications	1:47	--	1:47	1:38	1:27	1:47
9. Offers of HIV test to >16years	84%	--	88%	98%	81%	96%	



## B: North East London

Metric		B&D	C&H	Havering	Newham	Redbridge	TH	WF
Primary Care Trust	1. Neonatal BCG a) Universal BCG	0	69%	--	81%	100%	68%	94%
	b) Selective BCG	--	--	0%	--	--	--	--
	2. Pulmonary TB patients seen by specialist TB service within 2 weeks of referral by GP	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured
	3. Liquid culture	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	4. Speed of reporting of sputum smear results	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place
	6. Treatment completion	81%	79%	75%	85%	80%	83%	91%
	7. Service ability to measure contact tracing	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured

Metric		Queen's	Homerton	King George	London Chest	Newham	Whipps Cross
TB Clinic	5. Risk assessment of non-compliance with treatment	96%	99%	94%	93%	99%	95%
	6. Treatment completion	85%	80%	78%	81%	87%	95%
	8. No. nurses as ratio of notifications	1:46*	1:28	*	1:37	1:38	1:36
	9. Offers of HIV test to >16years	97%	88%	87%	90%	92%	81%

\* Nurses are shared between King George and Queen's thus the ratio has been calculated by using 237 total notifications for the two sites combined

### C: North West London

Metric		Brent	Ealing	H&F	Harrow	Hounslow	Hillingdon	K&C	Westminster
Primary Care Trust	1. Neonatal BCG a) Universal BCG	70%	61%	51%	45%	75%	93%	24%	57%
	b) Selective BCG	--	--	--	--	--	--	--	--
	2. Pulmonary TB patients seen by specialist TB service within 2 weeks of referral by GP	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured
	3. Liquid culture	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	4. Speed of reporting of sputum smear results	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place
	6. Treatment completion	88%	82%	79%	88%	80%	66%	85%	84%
	7. Service ability to measure contact tracing	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured

Metric		Charing Cross	Chelsea & Westminster	Ealing	Hammer smith	Hillingdon	Northwick Park	Royal Brompton	St Marys	West Middlesex	Central Middlesex
TB Clinic	5. Risk assessment of non-compliance with treatment	100%	98%	98%	97%	67%	94%	0%	90%	43%	91%
	6. Treatment completion	79%	89%	84%	74%	81%	87%	--	79%	61%	90%
	8. No. nurses as ratio of notifications	1:21	1:24	1:39	1:39	1:34	1:50	--	1:25	1:50	1:50
	9. Offers of HIV test to >16years	92%	45%	92%	86%	94%	97%	--	81%	54%	99%

### D: South East London

Metric		Bexley	Bromley	Greenwich	Lambeth	Lewisham	Southwark
Primary Care Trust	1. Neonatal BCG a) Universal BCG	--	--	78%	94%	62%	0%
	b) Selective BCG	Unavailable	15%	--	--	--	--
	2. Pulmonary TB patients seen by specialist TB service within 2 weeks of referral by GP	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured
	3. Liquid culture	Yes	Yes	Yes	Yes	Yes	Yes
	4. Speed of reporting of sputum smear results	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place
	6. Treatment completion	90%	95%	88%	85%	82%	88%
	7. Service ability to measure contact tracing	Not measured	Not measured	Not measured	Not measured	Not measured	Not measured

Metric		Bromley (PRUH)	Guys & St. Thomas'	King's	Queen Elizabeth	Queen Mary's	Lewisham
TB Clinic	5. Risk assessment of non-compliance with treatment	100%	80%	98%	88%	36%	71%
	6. Treatment completion	93%	81%	89%	87%	80%	84%
	8. No. nurses as ratio of notifications	1:21	1:51	1:28	1:38	n/a*	1:73
	9. Offers of HIV test to >16years	81%	71%	90%	90%	100%	94%

\*The nurse to notification ratio for Queen Elizabeth includes all Queen Mary's Sidcup notifications

### E: South West London

Metric		Croydon	Kingston	R&T	S&M	Wandsworth
Primary Care Trust	1. Neonatal BCG a) Universal BCG	--	--	--	--	--
	b) Selective BCG	29%	27%	14%	12%	6%
	2. Pulmonary TB patients seen by specialist TB service within 2 weeks of referral by GP	Not measured	Not measured	Not measured	Not measured	Not measured
	3. Liquid culture	Yes	Yes	Yes	Yes	Yes
	4. Speed of reporting of sputum smear results	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place	Prompt return of results in place
	6. Treatment completion	85%	83%	69%	90%	86%
	7. Service ability to measure contact tracing	Not measured	Not measured	Not measured	Not measured	Not measured

Metric		Epsom & St Helier	Kingston	Mayday	St George's
TB Clinic	5. Risk assessment of non-compliance with treatment	98%	95%	98%	73%
	6. Treatment completion	83%	76%	85%	83%
	8. No. nurses as ratio of notifications	1:31	1:39	1:40	1:50
	9. Offers of HIV test to >16years	83%	85%	99%	88%

### 5.6.6 Utility and future reporting of individual metrics

There is no point in collecting metrics performance information, unless there is also utility in the results. We consider the utility of each metric briefly below and recommend whether / how the information should be reported.

*Metric 1 Neonatal BCG immunisation*

NICE Guidelines emphasise the protective effectiveness of neonatal BCG in areas of high local incidence (notification rates greater than 40:100,000). Neonatal BCG coverage rates are not systematically collected nationally, or locally in London. The indicator is important, but to date has not been reported since the TB metrics were invented. It is also very difficult to measure uptake and coverage of immunisation where the policy is selective.

The HPA analysis presented above is the closest we can get at present to directly measuring neonatal BCG uptake. The figures show too much variation for reassurance.

A reporting system needs to be put in place so that coverage rates can be systematically reported to the HPA, and performance consistently measured with transparent results. The HPA should, ideally, be able to report performance against this metric, by PCT, for the whole of London.

Performance against this metric is especially variable and poor in some localities.

A minimum coverage rate (perhaps 75%) should be agreed as a performance metric.

It appears that a detailed review of BCG policy options for London may be required, including consideration of the case for universal neonatal BCG immunisation across the whole of London.

*Metric 2 Seen by TB services within 2 weeks of GP referral*

This metric is not being measured. It is also a poor indicator: patients are often referred because they have complex symptoms and not necessarily because TB has been suspected by referring GPs. Indeed, it would seem that TB is often *not* suspected by GPs.

This metric should be abandoned.

*Metric 3 Liquid culture*

All services are now offering liquid culture in 2010. Performance against this metric should be monitored by exception reporting, with the expectation that the metric should be dropped by 2011.

*Metric 4 Speed of reporting of sputum smear results*

All sputum smear results are now being reported within 1-2 working days. Again, exception reports should be made, with the expectation that the metric can be dropped by 2011.

*Metric 5 Risk assessment for non-compliance with treatment*

This metric is important, since non-compliance is associated with risk of drug resistance or recurrence of active and possibly infectious disease.

Information should in future be extracted from the LTBR by the HPA (as has been done for this Report). Reporting should include completeness of data field completion. All patients must have a risk assessment conducted: at least 95% of patients (we suggest) should have had their risk assessment results entered in the LTBR.

*Metric 6 Treatment completion*

This is an important outcome. The HPA should continue to monitor treatment completion, from LTBR information, in a standardised way.

*Metric 7 Service ability to measure contact tracing*

This metric is not helpful. Ability to measure something is a poor indicator. What is required is information about the completeness of contact tracing.

From 2011, the national Enhanced TB Surveillance (ETS) system will take over the current functions of the LTBR. Like the LTBR, it uses a secure web-based on line system, with extra functionality<sup>85</sup> and will include a contact tracing module.

The HPA should report provider contact tracing performance, using information extracted from ETS once it is in use.

Until then, this metric should be abandoned.

*Metric 8 Number of nurses as a ratio of notifications made*

This is an important staffing metric, even though it only considers nurse complements in each clinic. Review of the sector scorecards (above) shows that 18 of the TB services currently appear to achieve the target of one nurse: 40 TB notifications.

The precise workforce of each TB service should be updated on a regular basis (perhaps quarterly).

Service providers should be asked to report any variations promptly, and where important gaps are identified, action must be taken to ensure they are filled.

This is a commissioning priority across London.

Workforce issues should not be seen as an isolated metric, but a critically important aspect of service delivery to achieve good TB management and control across London.

The London TB service workforce should be monitored by a London-wide body, and this task should not be delegated to individual sectors networks.

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<sup>85</sup> ETS will include capacity to upload TB drug sensitivities derived from culture results, so that any drug resistance is integrated into the database.

*Metric 9 Offers of HIV test to all over 16 years*

This is a useful indicator and the HPA should continue to report it centrally.

All patients should be offered the opportunity of having an HIV test. A more useful indicator would be the documentation of the results of an offer: test done/refused/not offered. (HIV status cannot be held on the LTBR.)

### **5.6.7 Future arrangements for the London TB metrics**

We believe that all reporting of TB performance indicators, whatever their content, should be standardised and conducted at agreed intervals for the whole of London at the same time and in the same way.

Where information can be derived from the LTBR, then the HPA should extract the data and provide the performance reports. Sectors should not be undertaking their own separate analyses.

*Reporting*

Performance against agreed metrics should be reported centrally to the London TB Commissioning Board and to the London TB Clinical Reference Group (or any similar successor bodies). It should be copied to sector networks.

*Taking action*

There is no point in measuring performance if poor results are not acted on.

Where performance is seen to be sub-standard, support must be provided and action taken, with the results fed back to the central London bodies.

*In summary*

- Metric 1 should be reported to the HPA by providers of neonatal BCG immunisation programmes; the details will need to be agreed and standardised, with a target coverage rate.
- Metrics 2 and 7 should be dropped now.
- Metrics 3 and 4 should be considered only as exception reports using information furnished direct by providers; it should be possible to drop them both by 2011.
- Metrics 5,6, and 9 should be reported by the HPA, using information extracted from LTBR.
- Metric 7 should be re-introduced in 2011; it should be reported by the HPA once ETS (with its contact tracing module) is introduced.
- Metric 8 should be reported by providers as part of a workforce profile update on a regular basis, perhaps quarterly.

*Future metrics*

Other useful performance indicators need to be developed, based on the use of standardised TB care pathways across the whole of London. Indicators should not be used unless they can also be accurately measured and have proven utility.

A group may need to be tasked to consider the development of new useful metrics; this will require representation from a range of stakeholders including (among others) the HPA, sector leads, commissioners and representatives of TB services.

New metrics could include the following:

- Documentation of individual patient risk factors;
- Use of DOT against known risk factors;
- Numbers / outcomes of those screened as new entrants;
- Numbers / outcomes of those screened as contacts of incident cases;
- Numbers of those lost to follow up who are found within an agreed period.

Treatment completion rates should also be measured separately for drug resistant or complex cases where completion within 12 months of notification, with compliance, is unrealistic.

## 5.7 What this section showed

Current arrangements for the nine London TB metrics are *ad hoc*. Some of the metrics have no utility; others have not been systematically monitored. Two of them cannot currently be measured.

The five sector networks have used different approaches, at differing time intervals, and there has been no evidence of coordinated action in response to the findings.

Performance against the metrics is patchy. Performance against Metric 1 (neonatal BCG immunisation programmes) has not been systematically measured. Our analysis, using a proxy indicator, suggests that neonatal BCG immunisation coverage is poor in many parts of London, including in North West London where there is the largest caseload of TB in the capital. A minimum coverage rate should be agreed.

It appears that a detailed review of BCG policy options for London may be required, including consideration of the case for universal neonatal BCG immunisation across the whole of London.

The achievement of two of the metrics (use of liquid culture technology and reporting of smear analysis within 1-2 working days) is now universal. This shows good progress has been made and that these two metrics can now be dropped.

We have reviewed achievement of metric 5 (identification of patient risk factors) and metric 6 (treatment completion) across London. Poor risk factor documentation is striking at Hillingdon and West Middlesex TB services (North West London) and at Lewisham and Queen Mary's Sidcup (South East London). Treatment completion rates are low in parts of all sectors except South East London. Accepting that there are difficulties over definitions which make some comparisons difficult, these variations clearly need to be worked through and an approach agreed across London to ensure high rates of treatment completion.

We have calculated the performance of metric 8 (One specialist nurse per 40 notifications) across London. This again shows patchy performance. The metric is mostly achieved in



North East London; the ratio is unacceptably high in parts of North West London, especially in Brent. The ratio is too high in a few providers in SE and SW London.

North West London has the highest TB caseload in the capital, so to have lower levels of specialist nurse staffing in that sector appears inequitable. The issue needs to be addressed.

## 5.8 Conclusions

There is limited utility in collecting metrics performance information unless it is systematically collated across London, and action taken where performance is in the “red” zone.

One priority is the apparently low levels of specialist nurse staffing in relation to numbers of cases notified across North West London. This must be addressed.

The delivery of neonatal BCG immunisation appears to be very patchy. Where immunisation is selective it is very difficult to measure uptake and coverage. A plan is needed to achieve higher coverage rates, especially in areas with high TB incidence and a minimum coverage rate should be agreed as a future metric. The possibility of moving to universal neonatal BCG across the whole of London should also be considered as part of a detailed review of the alternative policies.

There needs to be a standardised approach to metrics measurement, content and timing, with collation at a central point and regular reviews of impact and utility.

A standardised method of reporting risk factor assessment, and treatment completion need to be agreed, with measures put in place to ensure that higher rates are delivered across the whole of London.

The place for decision making is the body to which performance is reported. That body should have London-wide responsibility; within current arrangements, that body is the London TB Commissioning Board.

New metrics are required, which can help services understand performance and which are based on evidence-based care pathways. Whatever metrics are agreed in the future, decisions have to be made for London as a whole.

This requires one London-wide body to lead, both on metrics development, but even more importantly, on the action required to ensure all services deliver to common standards of performance. This is essential if TB in London is to be controlled more effectively.

Lastly, our analyses have shown that many metrics can be collated from information available to the HPA. The HPA should be asked to report metrics performance across London in a standardised way and on a regular basis to the London TB Commissioning Board as well as to the sector wide networks within London.

## 5.9 GP Prescribing

### 5.9.1 Introduction

The NICE guidelines do not address the issue of who should prescribe anti-TB medication. There is currently no central policy on this issue. GPs are entitled to prescribe anti-TB drugs. Anecdotally, however, many stakeholders have advised that all anti-TB medication should be prescribed by hospital specialists, because the drugs may have side-effects and interactions with which most GPs will be unfamiliar, and because non-compliance has particular risks, including reactivation of disease and drug resistance.

Anecdotally, most anti-TB medication is prescribed by hospital physicians and dispensed by hospital pharmacies, or by special arrangement with community pharmacies as part of DOT.

### 5.9.2 What this section contains

This section presents information on anti-TB drugs prescribed by general practitioners (GPs) in primary care across London. This is an area not previously studied, as far as we are aware. The section shows volumes and costs for the year 2009/10.

### 5.9.3 Methods

Data was obtained from ePACT.<sup>86</sup>

The four principal most commonly anti-TB drugs were extracted from this data. They are all drugs that are most commonly used to treat TB, rather than other conditions for which GPs routinely see patients.

- Isoniazid;
- Ethambutol;
- Pyrizinamide;
- Rifampicin (including the combinations: Rifinah 150, 300 and Rifater).

The accuracy of any information is only as good as the accuracy of its source. In this instance, the source of data is relatively unimpeachable.

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<sup>86</sup> ePact (electronic Prescribing And Cost) - a service for pharmaceutical and prescribing advisors, allowing real time on-line analysis of prescribing data held on the NHS Prescription Services' Prescribing Database.

### 5.9.4 Findings

**Figure 25** shows the total number of items of anti-TB drugs prescribed by GPs in each PCT in London in the year 2009/10.

An item can be any item on a script. A box of 20 tablets is one item; 2 boxes of 100 tablets on the same script is also one item.

Each PCT has been colour coded to reflect the sector of London in which they reside.

#### Key to Sector Colour Coding

North Central London	
North East London	
North West London	
South East London	
South West London	

**Figure 25: Volume of anti-TB drug items prescribed, by PCTs, 2009/10**

Source: ePACT

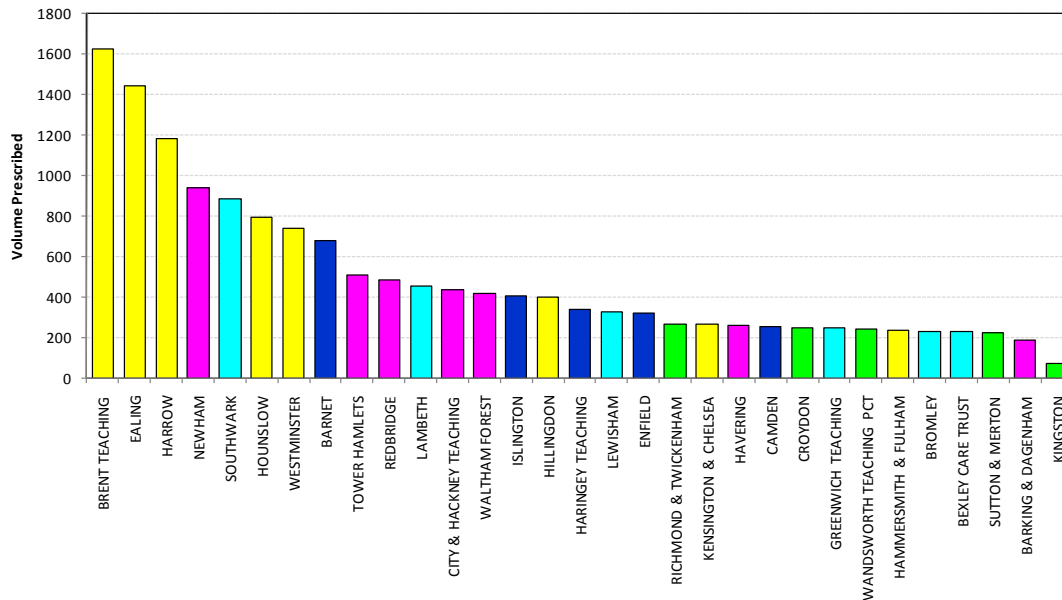
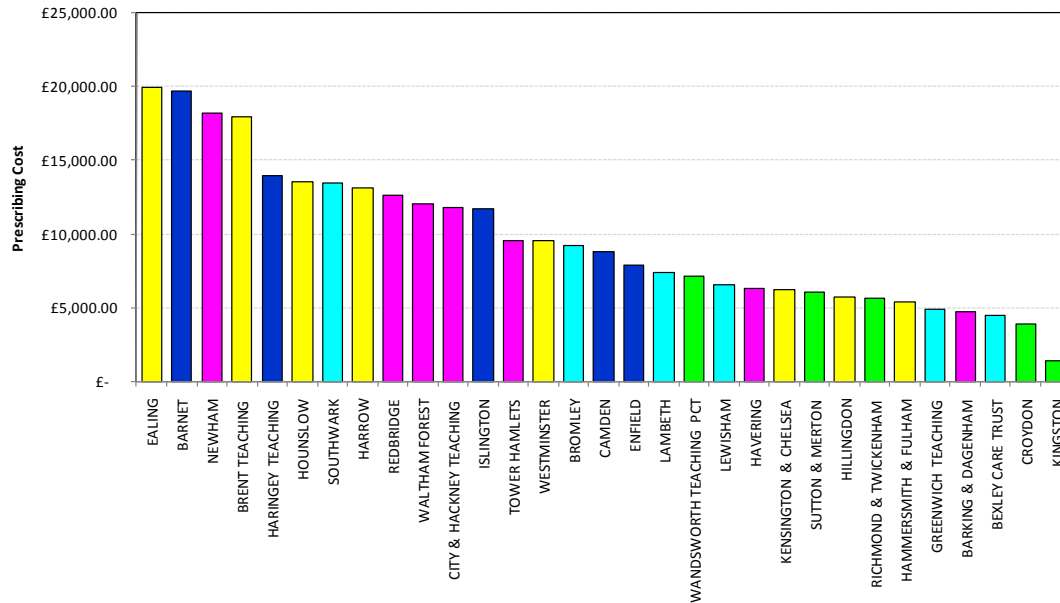


Figure 25 shows that there were many more anti-TB drug items prescribed by GPs in North West London compared to other sectors in London, with the largest volumes prescribed by GPs in Brent, Ealing and Harrow PCTs.

The total cost to the NHS of these four anti-TB drugs prescribed by GPs is shown in **Figure 26**.

**Figure 26: Total cost of anti-TB drugs prescribed by PCTs, 2009/10**

Source: ePACT



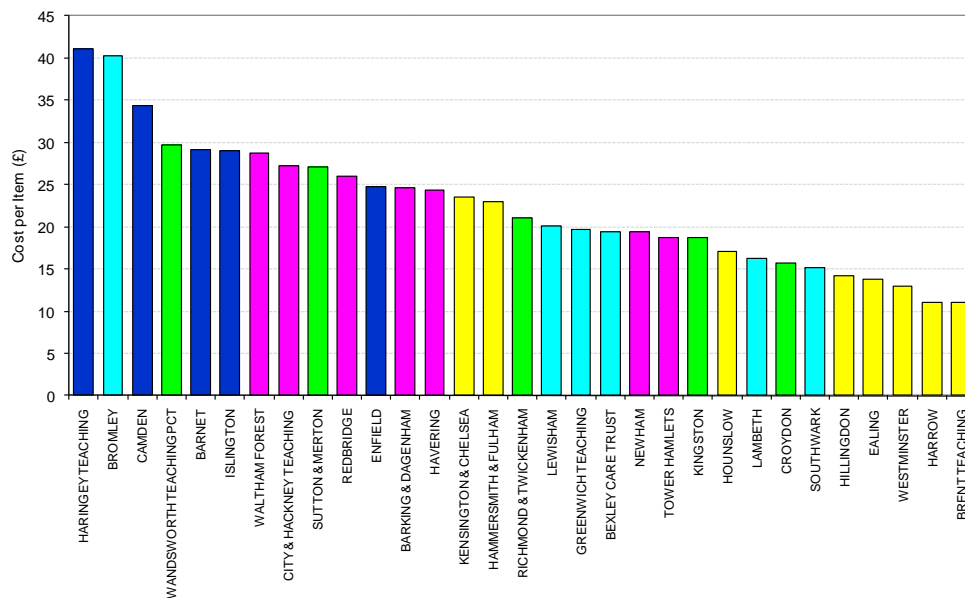
Ealing is ranked highest of the London PCTs, with items totalling £20,000 prescribed and dispensed in 2009/10. The lowest cost is seen in Kingston, with a value of £1,369.44.

The total value of anti-TB drugs prescribed by London GPs during the year 2009/10 came to £298,662.52.

When the cost per item is studied, a different picture is presented (**Figure 27**).

**Figure 27: Prescribing Cost per Item of anti-TB drugs, PCTs, 2009/10**

Source: ePACT



Again, a large range of values can be seen. Brent, which had the highest volume of items prescribed, had the lowest cost per item; Haringey the highest.

### **5.9.5 Discussion**

The issue of GP prescribing of anti-TB medication is not addressed in national policy guidance. It does not feature in the NICE Guidelines.

However, GP prescribing of anti-TB drugs may be problematic. The GP prescribing them thereby takes clinical responsibility for the impact of the medication on his/her patients, yet most GPs have little or no experience of treating TB and may be unfamiliar with the side effects and drug interactions associated with these drugs. Nor may they be aware of the consequences of poor compliance – drug resistance and / or recurrence of infectious disease.

Most consultant stakeholders interviewed for this needs assessment expressed the view that GPs should not be prescribing anti-TB medication, and many thought no such prescribing was happening.

### **5.9.6 What this section shows**

Important volumes of anti-TB medication are being prescribed in general practice across London. The total cost of prescribing the four main anti-TB antibiotics in 2009/10 was £298,662.52. The largest volumes and total costs of GP prescribed anti-TB medication were in North West London, though the cost per item was small. The range of volumes of items prescribed is large: from 1,624 items (GPs in Brent PCT) to only 73 (GPs in Kingston). The prescribing of these volumes of anti-TB drugs may be problematic, given the unfamiliarity of most GPs to using them and the risks associated with poor compliance.

The pattern of GP prescribing of anti-TB medication should be investigated.

## CHAPTER 6 – COMMISSIONING EXPENDITURE & FINANCING

### 6.1 Introduction

Gaining a fuller understanding of NHS expenditure on tuberculosis is key to:

- Considering the feasibility of ear-marked TB commissioning budgets;
- Examining the investment of resources to tackle TB needs across London;
- Examining the efficiency of TB services in London.

The scoping work identified that information on TB expenditure by commissioners and financial flows within and between providers for TB services was sparse, and raised key questions such as the overall spending and the nature and spending of ad hoc projects (such as community outreach workers).

Within the limitations of the current project it was decided to focus effort on determining commissioning programme budgets for TB across London PCTs.

### 6.2 Methods

A financial template was designed to capture information on TB expenditure for 2009/10 and planned expenditure for 2010/11 in London PCTs. Expenditure on a wide range of NHS TB activity was sought.

An excel spreadsheet was emailed to Finance Directors at all 31 London PCTs, who were asked to fill it in as completely as possible and return it to the PHAST team in 2-3 weeks. Two reminder emails were sent out to the financial directors, as well as supporting documentation. Returned templates were collated and analysed by the PHAST team.

Also, in-patient activity data for patients with a primary diagnosis of TB in 2008/09 was gathered from NHS Hospital Episode Statistics and costed, based on NHS inpatient PbR (payment by results) TB tariffs multiplied by the number of admissions (elective and non-elective). The data from the IC was coded with an \* if the number of admissions were less than five. For estimation purposes in these cases, the number of admissions was assumed to be three. The 'other' category of admissions (see Chapter 5) was ignored due to various types of admissions being included (but not disaggregated) in that category, making matching a tariff impossible.

### 6.3 Results

#### 6.3.1 TB expenditure by PCTs

Nine of the 31 PCTs (29%) returned the templates with at least some information entered. Information on spending by PCTs for the financial year 09/10 is shown in

**Table 28.** The paucity and incomplete nature of the data (for instance, only Tower Hamlets and Bexley reported any outpatient expenditure, and only Lambeth, Islington, and Newham reported any drug expenditure) makes drawing conclusions difficult.

However, it does seem clear that there are differences between boroughs on inpatient expenditure, with Bexley spending only £40,317 and Tower Hamlets spending £378,432. Outpatient services were much more difficult for respondents to collect, due to hospital information systems not identifying TB services specifically as a treatment code. However, Bexley identified £1,702 worth of outpatient activity and Tower Hamlets identified £391,291 spent on outpatients. It is likely that the other boroughs also have proportional spending on their outpatients, and therefore this will contribute significantly to the overall London TB expenditure.

Spending on TB screening and BCG immunisation also differs between PCTs. While some of the difference is probably due to the populations within the area, it is unclear whether some PCTs are running more efficient services than others, and therefore spending less.

Although less than a third of PCTs reported, it is clear that *ad hoc* projects make up a significant amount of TB expenditure in London. For example, Bexley employs a specialist nurse, Newham provides a New Entrant Screening Service (screening for incoming migrants), and Tower Hamlets employs several outreach workers to educate their population as well as follow-up on cases. Islington, like the other PCTs in North Central London, pays Barnet PCT to care for their patients. The PCTs indicated no spending on Non-PBR activities, non-GMS primary care, or research and development projects. Total expenditure reported was approximately £3.2 million. This is likely to be a severe underestimate given the lack of outpatient information.

**Table 29** reports planned expenditure for TB services in 2010/2011. The results are much the same as those for 2009/10, but have increased by approximately £200,000. The bulk of the increase seems to be coming from Newham expanding its local TB service to include more community outreach, as well as across the board increases in inpatient costs.

**Table 28: Expenditure on TB for financial year 2009/2010 by PCT and Sector**

Services	South East London				South West London	Northwest London	North Central London	Northeast London		Total
	Bexley	Lambeth	Lewisham	Southwark	Wandsworth	Westminster	Islington	Newham	Tower Hamlets	
<b>Inpatient services</b>	£40,317	£210,197	£155,679	£151,187	£174,400	£361,464	£0	£0	£378,432	<b>£1,471,676</b>
<b>Outpatient services</b>	£1,702	Not available	Not available	Not available	Not available	Not available	Not available	Not available	£391,291	<b>£392,993</b>
<b>TB screening</b>	£0	£0	£181,920	£0	£0	£0	£0	£52,217	£32,000	<b>£266,137</b>
<b>BCG immunisation</b>	£0	£19,746	£75,000	£0	£0	£65,000	£0	£0	£19,038	<b>£178,784</b>
<b>Community pharmacy</b>	£0	£0	£0	£0	£0	£0	£0	£10,000	£0	<b>£10,000</b>
<b>Pharmaceutical supplies</b>	£0	£0	£0	£0	£0	£0	£0	£0	£0	<b>£0</b>
Community	£0	£486,000	£0	£0	£0	£0	£11,673	£0	£0	<b>£497,673</b>
<b>Other (please list)</b>	£0	£0	£0	£0	£0	£0	£0	£0	£0	<b>£411,729</b>
Specialist Nurse	£53,844	£0	£0	£0	£0	£0	£0	£0	£0	
Pay to Barnet PCT	£0	£0	£0	£0	£0	£0	£147,559	£0	£0	
New Entrants Screening - Provider	£0	£0	£0	£0	£0	£0	£0	£123,326	£0	
Primary Care audit (Red Alert)	£0	£0	£0	£0	£0	£0	£0	£0	£7,000	
Community Outreach work	£0	£0	£0	£0	£0	£0	£0	£0	£80,000	
<b>Total Expenditure</b>	<b>£95,863</b>	<b>£715,943</b>	<b>£412,599</b>	<b>£151,187</b>	<b>£174,400</b>	<b>£426,464</b>	<b>£159,232</b>	<b>£185,543</b>	<b>£907,761</b>	<b>£3,228,992</b>



Service	South East London				South West London	Northwest London	North Central London	Northeast London		Total
	Bexley	Lambeth	Lewisham	Southwark	Wandsworth	Westminster	Islington	Newham	Tower Hamlets	
Inpatient services	£45,000	£215,452	£155,679	£151,187	£156,824	£361,464	£0	£0	£469,443	<b>£1,555,049</b>
Outpatient services	£2,500	Not available	Not available	Not available	Not available	Not available	Not available	Not available	£357,514	<b>£360,014</b>
TB screening	£0	£0	£184,000	£0	£0	£0	£0	£75,217	£32,000	<b>£291,217</b>
BCG immunisation	£0	£34,702	£75,000	£0	£0	£65,000	£0	£0	£31,608	<b>£206,310</b>
Community pharmacy	£0	Nil	£0	£0	£0	£0	£0	£21,000	£5,000	<b>£26,000</b>
Pharmaceutical supplies										
Community	£0	£491,000	£0	£0	£0	£0	£15,000	£0	£0	<b>£506,000</b>
Other (please list)										<b>£551,909</b>
Specialist Nurse	£55,000	£0	£0	£0	£0	£0	£0	£0	£0	<b>£55,000</b>
TB Manager for SW London	£0	£0	£0	£0	£11,000	£0	£0	£0	£0	<b>£11,000</b>
Pay to Barnet PCT	£0	£0	£0	£0	£0	£0	£166,583	£0	£0	<b>£166,583</b>
Staffing Costs	£0	£0	£0	£0	£0	£0	£0	£36,000	£0	<b>£36,000</b>
Outreach Cost	£0	£0	£0	£0	£0	£0	£0	£25,000	£0	<b>£25,000</b>
Nursing Costs	£0	£0	£0	£0	£0	£0	£0	£52,000	£0	<b>£52,000</b>
New Entrants Screening - Provider	£0	£0	£0	£0	£0	£0	£0	£123,326	£0	<b>£123,326</b>
Health promotion activities	£0	£0	£0	£0	£0	£0	£0	£0	£3,000	<b>£3,000</b>
Community Outreach work	£0	£0	£0	£0	£0	£0	£0	£0	£80,000	<b>£80,000</b>
<b>Total Expenditure</b>	<b>£102,500</b>	<b>£741,154</b>	<b>£414,679</b>	<b>£151,187</b>	<b>£167,824</b>	<b>£426,464</b>	<b>£181,583</b>	<b>£332,543</b>	<b>£978,565</b>	<b>£3,496,499</b>

### 6.3.2 Expenditure on mobile x-ray unit & find and treat team

There are two additional pan-London projects that provide an important part of London's TB services, funded in the short-term by the Department of Health: the Mobile X-ray Unit (MXU) and the Find and Treat (F&T) team.

The MXU provides screening for TB in hard to reach populations (e.g. homeless and ex-prison populations). The projected expenditure for 2010/11 was £804,313. The pilot of the MXU project was evaluated and the intervention was deemed a cost-effective option for screening hard to reach populations.<sup>87</sup> However, it was thought that the intervention would be more cost-effective coupled with an ability to follow-up patients seen by the van. Therefore, the Find and Treat team was put in place, to allow a small team to ensure follow-up with patients. The cost of the F&T team is estimated to be £566,950 for 2010/11.

### 6.3.3 Estimated in-patient TB treatment costs

Given the nature of the HES data (described in detail in Chapter 5) it was difficult to estimate the actual cost of inpatient stays. However, a tentative estimate can be made simply based on the number and type of admissions. As we could not identify the different types of 'other' admissions, it was decided to exclude that category from the analysis.

According to our analysis (seen in **Table 30**), in 2008/09 London PCTs spent an estimated £933,504 on elective admissions, and approximately £3 million on non-elective admissions, leading to a total estimated expenditure of £4,066,016.. This is based on tariffs for TB inpatient tariffs from NHS Reference costs 2008/2009 (Elective tariff £1716; Non-elective tariff £3694). These figures do not take into account Ealing PCT as the trust was excluded due to an administrative error in reporting the trust's inpatient figures.

There is significant variability between PCTs, with Bexley seeming to have no inpatient expenditure (although this excludes 'other' admissions) but most PCTs contributing between £100,000-400,000. Again, those London PCTs with the highest incidence of TB seem to be spending the most on TB care.

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<sup>87</sup> HPA (2007)/Jarrett J. (June 2010) Personal Communication.

**Table 30: Admissions and estimated costs to PCTs for inpatient TB care in 2008/09\***

Primary Care Trust	Sum of Elective Admissions	Total Cost Elective Admissions	Sum of non-elective admissions	Total Cost of non-elective admissions	Total cost for TB admissions**
<b>North Central London</b>	<b>68</b>	<b>116688</b>	<b>135</b>	<b>498690</b>	<b>615378</b>
Barnet PCT	17	29172	31	114514	143686
Camden PCT	12	20592	18	66492	87084
Enfield PCT	15	25740	23	84962	110702
Haringey Teaching PCT	15	25740	36	132984	158724
Islington PCT	9	15444	27	99738	115182
<b>North East London</b>	<b>130</b>	<b>223080</b>	<b>249</b>	<b>919806</b>	<b>1142886</b>
Barking And Dagenham PCT	12	20592	32	118208	138800
City And Hackney Teaching PCT	26	44616	35	129290	173906
Havering PCT	3	5148	7	25858	31006
Newham PCT	24	41184	72	265968	307152
Redbridge PCT	28	48048	39	144066	192114
Tower Hamlets PCT	25	42900	34	125596	168496
Waltham Forest PCT	12	20592	30	110820	131412
<b>North West London</b>	<b>249</b>	<b>427284</b>	<b>228</b>	<b>842232</b>	<b>1269516</b>
Brent Teaching PCT	50	85800	75	277050	362850
Hammersmith And Fulham PCT	10	17160	23	84962	102122
Harrow PCT	88	151008	17	62798	213806
Hillingdon PCT	12	20592	33	121902	142494
Hounslow PCT	18	30888	38	140372	171260
Kensington And Chelsea PCT	6	10296	9	33246	43542
Westminster PCT	19	32604	19	70186	102790
<b>South East London</b>	<b>53</b>	<b>90948</b>	<b>130</b>	<b>480220</b>	<b>571168</b>
Bromley PCT	6	10296	9	33246	43542
Greenwich Teaching PCT	11	18876	27	99738	118614
Lambeth PCT	18	30888	31	114514	145402
Lewisham PCT	12	20592	35	129290	149882
Southwark PCT	6	10296	28	103432	113728
<b>South West London</b>	<b>44</b>	<b>75504</b>	<b>106</b>	<b>391564</b>	<b>467068</b>
Croydon PCT	17	29172	34	125596	154768
Kingston PCT		0	6	22164	22164
Richmond And Twickenham PCT	3	5148	6	22164	27312
Sutton And Merton PCT	12	20592	22	81268	101860
Wandsworth PCT	12	20592	38	140372	160964
<b>Grand Total</b>	<b>544</b>	<b>933504</b>	<b>848</b>	<b>3132512</b>	<b>4066016</b>

- \* There is an assumption of 3 admissions where data was hidden due to confidentiality in NHS IC data where the total is < 5 admissions.
- \*\* 'Other' admissions and information from Ealing PCT were excluded. Bexley had 0 admissions so was excluded.

## 6.4 Discussion

Will Roberts carried out a study in 2007<sup>88</sup> which aimed to assess whether or not a universal TB tariff under the PBR system was appropriate for TB services. The author used a top down approach to identify trust income, using HES HRG data to identify inpatient episodes, but used a proxy measure (thoracic medicine outpatient appointment) and multiplied these by the appropriate PBR tariff. Roberts also included the cost of DOTs, BCG vaccinations, new entrant screening, and contact tracing. Roberts calculated expenditure by identifying data on staffing, bed days and hospitalisations, tests and investigations, drug costs and overheads from hospital records and attaching a national unit cost to the output. The results indicated that total acute trust income from TB services was approximately £4.9 million, whereas expenditure was approximately £4.4 million in 2005/06. Roberts concluded that the variability between centres meant that some had more income from PbR than expenditure, while others were unable to cover the cost of care.

From the PCTs that did report in our exercise as well as the inpatient admissions analysis, it is clear that spending for TB can vary significantly, echoing the findings of Roberts. Another striking comparison is the total spend for the 5 acute trusts in the Roberts study was considerably higher than the total spend from the 9 PCTs that reported in our study. This indicates that if there had been better reporting in our survey, our total expenditure figure would be significantly higher. The variability in expenditure and income, coupled with limitations on information makes the development of a London-wide commissioning and budgeting procedure difficult. Therefore, it is imperative that a clearer picture of spending on TB is gathered before effective management of commissioning can take place.

## 6.5 What this section shows

From this exercise, it would seem clear that there are no “top-down” TB commissioning budgets for most PCTs or sectors, nor is determining a “bottom-up” level of spending a straightforward process, due to the apparent limitations of coding and/or information systems in HES relating to TB outpatient services. Tower Hamlets was able to supply information on outpatients as they record TB as a separate clinic on the monitoring reports for a BLT contract (personal communication). Some difficulties were also experienced in costing total inpatient TB expenditure due to uncertainties over the ‘other’ category in the data supplied.

Due to the lack of response from many PCTs, the picture of TB spending in London is still unclear. It is clear, however, that the total expenditure from the nine

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<sup>88</sup> Roberts, W. What are the implications of introducing a national tariff to fund the provision of effective Tuberculosis treatment and control services? Dissertation. University of London, 2007

participating PCTs is likely to be a severe underestimate of total spending on TB in London. This is further illustrated with the analysis of the inpatient admissions data, as well as previous research by Roberts.

Commissioners having access to clear financial information is key to developing a coordinated, efficient commissioning and planning mechanism for TB services across London. This exercise has shown that there are still many stumbling blocks in access such information and that improvements are necessary (see **Recommendations**).

It is worth noting that as shown in the extracts below, the Department of Health 2007 TB commissioning toolkit<sup>89</sup> provides helpful detailed proposals on commissioning TB services - outlining an integrated tiered approach where PCTs or groups for collaborating PCTs play an important role. As shown in Tables **31** and **32** below, responsibilities for particular commissioning tasks and for commissioning specific TB service elements are mapped to organisations and population levels. However, it is important to note the caveat in the footnote regarding population size and PCTs in London.

**Table 31: Example of a tiered commissioning process (DH Toolkit)**

Organisation	GPs or groups of GPs	PCTs	PCT groups	Supra-regional
Possible population size <sup>1</sup>	50,000	1 million	5 to 8 million	8 million+
Planning	<ul style="list-style-type: none"> <li>Carry out needs assessment</li> <li>Service Improvement strategy</li> <li>Commission services for practice population</li> </ul>	<ul style="list-style-type: none"> <li>Carry out needs assessment</li> <li>Set up and operate governance arrangements</li> <li>Local forward planning</li> <li>Ensure that choice operates at an appropriate level</li> <li>Partnership planning with local authority and other stakeholders</li> <li>Maintain links with advisory bodies (eg Expert Patient Forum, TB Network)</li> <li>Liaise and co-operate with health protection unit</li> </ul>	<ul style="list-style-type: none"> <li>Provide strategic direction and leadership</li> <li>Anticipate future trends and develop appropriate policies</li> <li>Ensure supply and capacity</li> <li>Take action in case of failure</li> </ul>	
Finance and information management	<ul style="list-style-type: none"> <li>Manage care budget</li> <li>Ensure that all referral decisions are consistent with financial parameters</li> <li>Ensure that financial constraints are met</li> </ul>	<ul style="list-style-type: none"> <li>Set practice budgets</li> <li>Ensure financial stability</li> <li>Manage claims and disputes</li> </ul>	<ul style="list-style-type: none"> <li>Ensure that providers have sufficient capacity/competencies and financial stability</li> <li>Ensure contestability</li> <li>Performance manage PCTs</li> </ul>	<ul style="list-style-type: none"> <li>Information management</li> <li>Ensure adequate financial data is available to manage risk locally</li> <li>Claims management and/or reconciliation</li> </ul>
Care pathway focus	<ul style="list-style-type: none"> <li>Commission care package for individual patient</li> <li>Manage and support patient in choice of provider/booking</li> </ul>	<ul style="list-style-type: none"> <li>Ensure that local care pathways meet the needs of patients</li> <li>Support Expert Patient schemes</li> <li>Survey patient satisfaction</li> <li>Ensure that the majority of complaints are managed at local level</li> </ul>	<ul style="list-style-type: none"> <li>Negotiate framework for quality access and price</li> <li>Capacity planning and service mapping (with PCTs)</li> <li>Liaise with advisory bodies (eg a network of TB leads, TB Alert)</li> </ul>	<ul style="list-style-type: none"> <li>Commission very low-demand/high-cost services (eg long-term isolation facilities)</li> <li>Liaise with advisory bodies (eg NICE, British Lung Foundation, TB Alert, British Thoracic Society, Faculty of Public Health)</li> </ul>

<sup>1</sup> London is an exception to the PCT population size as London has been permitted to maintain its PCT structure.

<sup>89</sup> Tuberculosis prevention and treatment: a toolkit for planning, commissioning, and delivering high-quality services in England. London: Department of Health, 2007

**Table 32: Commissioning examples (DH Toolkit)**

GPs or groups	Who might commission which service?			Who might provide which service?
	PCTs	PCT groups	Supra-regional/national	
<ul style="list-style-type: none"> <li>• BCG</li> <li>• Health promotion (practice-based campaigns)</li> <li>• New entrant screening</li> </ul>	<ul style="list-style-type: none"> <li>• BCG</li> <li>• Health promotion (local campaigns)</li> <li>• Screening services (contact tracing, case finding, including new entrant screening)</li> <li>• TB consultants and nurses (case management), community-based services</li> <li>• BCG</li> <li>• Inpatient bed days</li> <li>• Inpatient infection control services</li> <li>• Investigation of suspected cases of TB</li> <li>• Negative pressure Isolation facilities (local hospital)</li> <li>• TB consultants and nurses (case management)</li> <li>• TB diagnostics (bronchoscopy, non-microbiology)</li> <li>• TB microbiology services</li> </ul>	<ul style="list-style-type: none"> <li>• Health promotion (regional campaigns)</li> <li>• Screening services (contact tracing, case finding, including new entrant screening)</li> <li>• TB nursing (case management), community-based services</li> <li>• Negative pressure Isolation facilities (regional treatment centre)</li> <li>• TB microbiology services (regional specialist centre)</li> <li>• TB nursing (case management)</li> </ul>	<ul style="list-style-type: none"> <li>• Health promotion (national campaigns)</li> <li>• Negative pressure Isolation facilities (national treatment centre)</li> </ul>	<p><b>Level one</b> GPs and/or other community-owned service providers</p> <p><b>Level two</b> Secondary care providers</p>
	<ul style="list-style-type: none"> <li>• Advisory bodies</li> <li>• Negative pressure Isolation facilities</li> <li>• Prison TB services</li> <li>• Surveillance</li> </ul>	<ul style="list-style-type: none"> <li>• Advisory bodies</li> <li>• Negative pressure Isolation facilities</li> <li>• Prison TB services</li> <li>• Surveillance</li> </ul>	<ul style="list-style-type: none"> <li>• Advisory bodies</li> <li>• Negative pressure Isolation facilities</li> <li>• Prison TB services (national treatment centre/prison)</li> <li>• Reference laboratory services</li> <li>• Screening services (port of entry services/mobile screening units)</li> <li>• Surveillance</li> </ul>	<p><b>Level three</b> Tertiary providers</p>

Some services, such as BCG and health promotion, are shown in more than one column or row. This is because they may be commissioned for different populations and provided at different levels dependent upon the local preferred service configuration. There is no 'one size fits all'. For example, BCG services for neonates from high-risk groups may be provided by either primary or secondary care providers.

As shown below in **Figure 28**, the toolkit also provides several examples of potential patient pathways and payment methods for complex TB patients and services. The findings of our work suggests that these approaches have not been widely adopted in the commissioning of TB services in London.

**Figure 28: Pathway and payments for patients with active pulmonary TB (DH Toolkit)**

Pathway and payments for patients with active pulmonary TB		PbR £	Local £
	Person (assume adult) with signs and symptoms of active pulmonary TB		
A	Patient attends GP. Referred to hospital. Admitted to hospital to a negative pressure room	(A) First outpatient appointment (thoracic medicine 340)	201
		Non-elective spell tariff (up to 34 days)	3,459
			Isolation facility local flexibility
B	Diagnostic tests for TB. Diagnosis of fully sensitive pulmonary TB confirmed	(B) Pathology and radiography included within relevant outpatient or admitted patient tariff	
C	Seen in outpatient clinic for follow-up appointment with consultant and TB nurse	(C) Second outpatient appointment	101
D	Home visit from TB nurse	(D) No tariff for community services	
			By local negotiation
E	Follow-up clinic appointment at 2, 3, 4, 5 and 6 months	(E) Follow-up appointments 5 x 101	505
F	Two home visits during treatment from TB nurse	(F) No tariff for community services	
			By local negotiation

## CHAPTER 7 – EXPERIENCE AND VIEWS OF SERVICE USERS

### 7.1 What this chapter contains

This chapter describes the findings of a qualitative interview survey of the views and experience of people using TB services in London, conducted as part of this health needs assessment.

### 7.2 Methods

Our initial view was that the most efficient way to obtain user views would be to run focus groups in a sample of TB clinics across London.

However, the scoping phase showed various concerns:

- Clinic patients might be unable or unwilling to spend a longer period of time at the clinic to participate in focus groups.
- Some patients might be uncomfortable about participating in group discussions, given the stigma and sensitivity often associated with TB.

Consequently it was decided that individual semi-structured interviews with service users would be more suitable.

A set of questions for the semi-structured interview schedule was agreed with the client and the London TB Clinical Reference Group (see **Appendix B**).

Patients were recruited from seven of those clinics who agreed to host the interviews. Clinics were drawn from all five sectors across London.

Patient interviews took place in clinics at the following hospitals:

- UCLH
- London Chest
- Greenwich
- Royal Free
- Mayday
- Ealing
- Northwick Park

It was agreed that the following would also be included in the sample:

- A mixture of contact tracing, undiagnosed, & diagnosed service users;
- A home visit to a user;
- An HIV-TB dual diagnosis clinic;
- Patients from a variety of ethnic groups, as far as would be feasible, determined by their level of spoken English or the availability of interpreters.



The interviews were planned collaboratively with clinic staff, and arrangements for the conduct of the interviews were necessarily flexible to the organisational, staffing, clinical, and practical arrangements in each.

Interviews were conducted as qualitative research in accordance with good practice standards for 'market research' methods for the collection of health care patient experience feedback by an experienced qualitative survey professional.

In each case the interviews were undertaken on a single day, with recruitment taking place from patients attending the TB/chest clinic on that day.

Prior to interviews, clinic attenders were provided with a letter (in English) detailing the purpose of the project and interviews. Some nurses chose to send out the invitation letters in advance while others handed them out on the day. On the day itself, clinic staff invited and encouraged patients to participate in interviews. The nurse (and in some cases the doctor) accompanied the patients to the room where the researcher was sitting, having gained their consent in advance. In six clinics interviews were held in private rooms close to the waiting area. In one hospital the interviews were conducted in the corner of a very large waiting room where conversations could not be overheard.

In addition to clinic interviews the researcher also attended:

- The launch meeting of a Somali project in Haringey
- A Find and Treat peer educators meeting
- A TB Action Group (TBAG) meeting, facilitated by TB Alert at their offices
- A home visit to a user from the London chest clinic.

### 7.3 Results

**Table 33:** below shows the gender, age and ethnicity of interviewees, together with the stated route of referral to the TB service used.

Clinic	Gender / age	Spoken English Good unless stated	Ethnicity / Nationality	Source of referral / other information
<b>UCLH</b>	M 49,		Pakistani	GP
	F 78		Burmese	Other clinic
	F 54	Interpreter	Somali	A&E
	M 29		Iranian	Other clinic
	M 68		White British	Other clinic
	M 72	Wife interpreted	Iraqi	Other clinic
	M 24		African	A&E
Total	7			
<b>London Chest</b>	F 27		Gujarati	Contact
	F 40	Limited	African	A&E
	M 32	Advocate/interpreter	Bangladeshi	GP
	M 29	Interpreter	Nepalese	Other clinic
[Home visit]	M 78	Daughter interpreted	Pakistani	GP (delayed referral)
Total	5			
<b>Greenwich</b>	F 30		Zambia	A&E
	F 57		Irish	A&E
	F 38		Asian	A&E (HIV+ve)
	M 43	Moderate	Lithuanian	A&E
	M 40		Punjabi	A&E
	M 27		Nepal	GP
	F 23		W. British	GP
	M 35		Nigerian	GP (suspected malaria)
Total	8			
<b>Royal Free</b>	F 36	Moderate	Sairra Leone	GP (HIV +ve)
	M 35	Moderate	Malawi	GP (HIV +ve)
Total	2			
<b>Mayday</b>	F 21		Carribbean	A&E - on DOT
	F 47		African	Walk in appt. - was started on DOT
	M 45	Moderate	African	A&E – inpatient
	F 66		Tanzania	GP - on DOT
	M 60	Limited	Asian	Walk in (inpatient)
	M 40		African	GP - on DOT
	F 45		W. British	Contact
Total	7			
<b>Ealing</b>	F 31		Indian	GP
	M 55	Limited	Kenyan	Contact
	F 55	Limited	Pakistani	GP
	M 52	Limited	Pakistani	Contact
	M 30	Limited	Poland	GP
	M 50	Limited	Nepal	Contact
	F 44	Limited	India	GP
	M 23	Moderate	India	Clinic abroad

	M 52	Moderate	Asedonia	Occupational health check
	M 50	Limited	Asian	GP
Total	10			
<b>Northwick Park</b>	M 25	Friend interpreted	Romanian	Clinic Abroad - Inpatient
	M 55	Limited	Asian	GP
	F 25		Asian	Clinic Abroad
	M 30		Indian	GP
	M 40		Indian	GP
	F 25		Asian	Contact
Total	6			
<b>Haringey Somali meeting</b>	F		Asian	GP ("delayed" referral)
	M	Moderate	Somali	GP
Total	2			
<b>Find &amp; Treat</b>	M 45 *		Black British	A&E
	M 41		White British	Other clinic
	M 56		Jamaican	Find & Treat
	F 41		Greek	A&E
	M			[meeting host]
Total	4 + host			
<b>TBAG (at TB Alert)</b>	F 59	Moderate	Philippines	A&E
	F 24		White British	Daughter
	F 28		Chinese	other clinic
	F 40		Indian	other clinic
	M 45		Indian	Husband
	M 45*		Black British	F&T
	F		British	meeting host
	M 52		Indian	travelled from W. Yorkshire
	F 25		British	travelled from W. Yorkshire
	F 24		British	GP
	F 57		British	A&E
Total	9 + host			
<b>Grand total</b>	<b>60</b>			

A total of 60 users of TB services were interviewed. Of these, 28 were women and 32 were men.<sup>90</sup>

<sup>90</sup> As shown in the table above one male attended both the Find and Treat and the TBAG meeting.

The main self reported ethnic groups / nationalities were as follows (numbers of each):

African	7
Indian	7
White UK	7
Asian	5
Pakistani	4
Black British	2
Nepalese	3

## 7.4 Findings

Findings have been aggregated by topic and stages of patient journey. Key themes in each section are highlighted in italics at the beginning of each sub-section.

### 7.4.1 Consulting the GP

*GPs were reported as being slow to recognize and act on symptoms.*

Of the 30 people who had consulted their GPs prior to diagnosis, only four gave an account of a prompt referral. Two of these had "lumps and bumps" (probably lymph node enlargement) and had been sent for biopsy; one was suspected of malaria.

A total of 12 users reported going to their GP on numerous occasions; two of these reported receiving at least two courses of antibiotics before being referred for further tests. In three cases, it was reported that GPs had not explored TB as an option even though told there was a history of TB in the family. One family told of their elderly father who went for years before being referred to hospital where he was found to have both cancer and TB. The daughter reflected that she *'wished they had been more persistent with their GP'*.

One woman who had repeatedly "pleaded with her GP for help" was persuaded by her niece in Canada to go back and tell him that her mother had had TB and demand to be tested.

Three patients who felt their stories were being repeatedly ignored by their GP went back to their home country for diagnosis. In these cases, the patients were diagnosed as having TB and had started treatment before they returned to the UK.

Six patients eventually were brought or came to A&E or a walk-in clinic.

Feelings expressed towards GPs ranged from frustration at slowness to act to anger at not being listened to.

### 7.4.2 Being diagnosed

*Diagnosis was described as a long process. The practice of not being allowed to be cross-referred between departments without going back to the GP first might have been a contributory factor to delay in diagnosis.*

Even once referred to hospital diagnosis was felt by those interviewed to take a long time and was not always confirmed before treatment started. Two patients described how their diagnosis was severely delayed when the biopsy department was unable to cross refer to the TB clinic without going back via the GP.

Six users described their or others' surprise at the discovery that they could have TB elsewhere than in the chest.

One woman described how, just after being told she had TB, a nurse shouted out that it was caused by '*unsanitised living conditions.*' This was deeply distressing for her, being '*someone who takes great pride in the cleanliness of her home.*'

Another woman, on being diagnosed was referred to as '*people like you.*'

Finding out that TB was suspected was a relief for three patients, since they were worried they had cancer.

### 7.4.3 Medication

*Patients were not always prepared for the side effects of medication.*

All those interviewed described difficulties in taking the tablets and side effects experienced. Beside the most commonly described side effects of sickness and tiredness, people complained that it affected their eyesight, gave them headaches and that they had pains in their joints.

Two people felt that their complaints about side effects relating to their eyes were not fully acknowledged, though these problems were dealt with separately even though they as patients insisted there was a connection.

While nearly everyone commented on the side effects, few reported changes in medication as a result of side effects.

One young woman who had suffered extreme side effects from tablets said she was now on injections for TB. She was informed that the risks for this are higher and seems to be having regular hearing tests. Her view is that she should have been offered a choice and told about the injections sooner. She felt there were '*lessons to be learned from the world of HIV in terms of giving patients more choice and control over their medication.*'

However, users in general did not appear to question what they were being given.

Where it was felt that people would be reluctant or have difficulty in taken medication, some hospitals used Directly Observed Therapy (DOT).

One young woman gave a very insightful description of her journey from DOT to self medicating. She said *'up till now I have relied on them to check I take my medicine - its time for me to do it on my own'*.

It was not always clear when talking to some patients if TB had been confirmed or just suspected. It appeared that some of those suspected of having TB were prescribed medication before the diagnosis had been confirmed. One person understood why this was the case, though others appeared not to have asked questions.

Four people with latent TB were advised to take precautionary medication. In the case of one young woman the side effects caused severe complications and she is now recovering from those before deciding whether and when to restart her treatment.

It was not clear therefore from the interviews the extent to which patients with latent TB or unconfirmed TB understood the strength of the medication and its side effects and had therefore made an informed choice about taking the medication. One man had limited spoken English felt that he had been *'advised rather than told to take the medication'* but he found it *'very strong'*

TB medication was understood by the patients to be free of charge. However, one person pointed out that medication for the side effects was not free and another (who was on DOT) pointed out her transport costs (3 modes of transport) to the hospital to collect the medication was high.

One young woman who had been diagnosed and initiated treatment in India reported that she was told to dispose of the medication she had bought and paid for in India even though it was the same medication she would be prescribed here because the hospital could not treat her if they did not prescribe the medicine themselves.

#### **7.4.4 Knowledge and behaviour of non - TB clinical staff**

*Comments by some patients suggested that 'non TB clinical staff' appeared to lack empathy and understanding when faced with a TB patient.*

One TBAG member reported that while pregnant that she had told a nurse that she had previously had TB in her liver. She said that the nurse laughed at her and then later having looked at her notes came back to apologize.

One man who was sent to hospital for an operation told how staff kept their distance from him and treated him *'like he was Bin Laden.'* This was made worse when the surgeon realized he was suspected of having TB because he was put at the end of the day's list (even though he was scheduled to be first). He explained this meant he was left without food all day. Given his experience he was too afraid to ask any questions.

One young woman described how a doctor from her GP clinic phoned her to tell her to come to the surgery to give her some test results. When he discovered that she was at work he *'started shouting at me over the phone that I should not be at work because I might have TB'*. On her arrival at the surgery *'he sat across the room from me' while he made the arrangements for me to be admitted to hospital'*.

#### **7.4.5 Emotional Impact of TB**

*TB clinics were seen as great sources of emotional and social as well as medical support, though there may be some danger of patients becoming dependent on clinics for support. However, there was some interest by patients in forming patient support groups. No expert patient programme currently exists.*

*Those with English as a second language appeared to benefit more from advocacy than just translation.*

*The psychological impact of being an inpatient in isolation should not be underestimated.*

While some people described the immense support from their family, others described the emotional strain of carrying the burden alone. Three reported that they had chosen not to tell anyone.

At least six patients with chaotic lifestyle reported that the clinic had become their main source of advice and support on a variety of issues. Two referred to the clinic as their family.

One man who had been rejected by his family said he would *'not give up on his treatment because the team had tried so hard to save him'*.

One hospital appeared to use Direct Observation of Treatment (DOT) with all their new patients as a way of ensuring that both medical and psychological support is available in the early stages of treatment.

It was not clear what would happen to some of these people once they are ready to be discharged from outpatients. Some of those living in hostels were previously in a drink and drug culture environment and could well find that without the constant psychological reinforcement of the clinic they revert to their earlier lifestyle.

While most other patients at clinics described the level of support as very good, at least 2 patients from the clinics specifically mentioned the need for hospital based support groups and individual counselling. Three people described their religious faith as the thing that has carried them through this traumatic time.

Those at Find and Treat acknowledged that while they had been attending TB clinics as patients the level of support they had received was the first time in a long time they had felt cared for or that anyone had believed in them.

The TBAG focus group at TB Alert emphasized most strongly the need for psychological support and the limited nature of this at the time of crisis. Some felt they would have liked support in how to actually cope with the nausea of the tablets, others said they joined TBAG because of the feelings of isolation. They all had been surprised to discover that there was no expert patient programme and only one national support group and that it only meets in London. (2 people had travelled that day from the West Yorkshire).

The issue of pain management was explored at the TBAG focus group but no one had any experience of it being offered. Occasionally physiotherapy or surgery was offered to deal with back pain.

The experience of being on an isolation ward was vividly described. Fear, loneliness and boredom were just of some of the emotions described for what could be up to two weeks and in one case months.

Some described experiences of having food effectively '*thrown into the room quickly and staff running out*', while other hospitals were described as very caring. The isolation situation meant there was no opportunity for social interaction and one person suggested that access to the internet would have been helpful.

It was not evident that these isolation experiences were subsequently counteracted with any psychological support.

One man who was being interviewed via an advocate/interpreter told the advocate that he had found the experience intimidating and had been feeling too sick and afraid to ask questions before. The interview being undertaken provided the catalyst for him to ask the advocate questions that had been worrying him for some time. This situation starkly highlighted the difference between an advocate and a translator as the advocate was in a position to answer many of the man's questions or explain to him where he could get further information.

#### **7.4.6 Housing, living arrangements and benefits**

*Availability of suitable accommodation for patients to move onto could affect bed management and readmission rates.*

Some of those interviewed in clinic who were living in rented accommodation found that having TB meant losing their job which meant no money for rent, loss of accommodation and a reliance on benefits.

Others who lived in hostels already on benefits found themselves having to juggle even more complex issues than previously, and the nurses or outreach workers where available found themselves acting as social workers to sort out housing for those leaving hospital.

As previously mentioned patients appreciate that TB medication is free from hospital but public transport costs (in one case 3 modes of transport) are prohibitive if the



patient is on DOT and not working. It was also reported that any medication required to counter act side effects is not free.

At the TBAG group some users mentioned that once they had been diagnosed as having TB they were taken through a type of lifestyle assessment. They felt this focused more on their living conditions (e.g. number of rooms in house) than on their family support structure. However both were felt to be factors in the vulnerability of those with TB.

#### **7.4.7 Being signed off treatment / avoiding a dependency culture**

*There does not appear to be a step down approach to weaning people off the social dependency on the clinic.*

Examples have already been reported of where the team and in particular the nurses had become the focal point of support for individuals. In some cases this looked to be extremely successful in others even with the level of support on offer patients described themselves as suicidal or not sure if they could carry on.

Patients from the Find and Treat Team recall the mixed feelings of being signed off treatment and welcomed the opportunity to join find and treat as a way of remaining part of the TB community.

It appeared that in some clinics which support large numbers of patients with chaotic lifestyle, that there may be in danger of developing a culture of dependency by not developing a phased psychological exit strategy for those who have completed treatment.

#### **7.4.8 Experience of contact screening**

*Those receiving contact letters via work appear to be more frustrated and angry about being at the clinic than those who came in with family members. These individuals felt that there was insufficient information in the contact letter about TB and the process they would need to go through.*

Those interviewed who were coming to contact clinic because a family member had been diagnosed with TB tended to be very appreciative of the opportunity and understanding of the reasons.

Those interviewed who had received a letter because of a work colleague had been diagnosed presented as more frustrated and sometimes angry. One woman said she was '*cross that TB had re emerged especially as she had had her BCG*'. She was now '*refusing to see her younger family members until she was sure she was safe*'.

At least two women described receiving the letter with an inadequate explanation of what TB was or what they should expect to happen at the clinic.

One young woman said she felt she had been *'left hanging for two weeks'* before her scheduled appointment with only the internet for information.

Another woman who was interviewed immediately after her initial contact meeting indicated that she might not attend the follow up appointment on the scheduled day because she was working independently and would lose a days pay. She said she had not yet informed the nurse of her decision not to attend. It later transpired that the nurse had not explained to her that she needed to have the follow up appointment within 72 hours for the test to be valid. In fact the nurse arrived very early at the clinic most morning and would by prior arrangement have seen her before work started.

#### **7.4.9 General public awareness**

*Patients feel that there needs to be more public awareness about TB.*

When asked about how TB services could be improved nearly all patients made reference to the need for more public awareness.

They mentioned the absence of any national campaigns on TB. This they felt was in contrast to stroke or flu outbreaks.

One young man highlighted the fact that *'information on TB is not available at the places that young people go'*. When asked what he meant he included GP surgeries, sexual health clinics, student union information centres and student accommodation offices.

One TB nurse said she had tried to talk to the local university about awareness sessions but they had refused preferring not to bring the topic into the open arena.

#### **7.4.10 Workforce issues**

*The knock-on effects of TB on patients mean that the TB service needs to be seen as a whole system not just a clinical team including social services, housing, outreach and advocacy.*

The added value of the advocate as opposed to a translator was demonstrated during one of the interviews when the patient started asking questions to the advocate he had previously been afraid to ask in the clinical setting.

Those in peer roles at Find and Treat described a strong desire to do more to help TB patients. They would like to see a career path develop so that they can go on to support those on medication, not just get people to be tested. One person from the find and treat project has gone on to become a paid worker on a community project.

### 7.4.11 Suggested areas of improvement from patients

*Patients wanted better training for GPs and more public awareness.*

When asked what they want to see improved, patients overwhelmingly said they could not think of any improvements in relation to the clinic but would like to see better training for GPs and more awareness raising for public. They felt that TB would benefit from the kind of profile given to stroke and HIV.

In terms of better awareness for the public suggestions included more information where young people go such as sexual health clinics and student information centres as well as information to be given out by nurses doing travel vaccinations.

Among the other ideas from one or two individuals were, research so that less tablets need to be taken and for less time, and shorter waiting times in clinics.

The TBAG group felt that NICE referring to TB as a disease of poverty was not helpful as it gave out the wrong messages about the current circumstances under which it can be caught in the UK.

## 7.5 What this chapter shows

In summary the key findings outlined in this chapter are that:

- GPs were reported as slow to recognize and act on symptoms.
- Diagnosis was felt to be a long and slow process.
- Referral between hospital departments was troublesome.
- Patients were not always prepared for the side effects of medication.
- Non TB clinical staff appeared to lack empathy and understanding when faced with a TB patient.
- TB clinics were seen as great sources of emotional and social as well as providing health care.
- There might be a danger of a dependency culture in some clinics.
- There was some interest in patient support groups.
- Those with English as a second language appeared to benefit more from advocacy than just translation.
- The psychological impact of being an isolation inpatient should not be underestimated.

- Availability of suitable accommodation for patients to move onto could affect bed management and readmission rates.
- There does not appear to be a step down approach to weaning people off the social dependency on the clinic.
- Patients receiving contact letters as a result of work related contact do not feel they have adequate information.
- The knock on effects of contracting TB mean that the TB service needs to be seen as a whole system not just clinical team including social services, housing, outreach and advocacy.
- Patients wanted better training for GPs and more public awareness.

## CHAPTER 8 – DISCUSSION

### 8.1 Introduction

This section provides an overview of what each of the earlier chapters have found. It then triangulates and considers collectively the main findings from each chapter in order to set out the overall conclusions of the project. Finally, **Recommendations** are made in **Chapter Nine**.

### 8.2 NHS Reorganisation

Our findings must be considered against a background of significant further reorganisation in the NHS. Strategic health authorities and PCTs are to be abolished, with 80% of the NHS commissioning budget delegated to GP-led consortia by 2013. Transitional arrangements are still under development and it is currently unclear what regional and sub-regional arrangements will be within the sphere of operation of the newly proposed NHS Commissioning Board.

The need to improve control of TB in London is sufficiently pressing that action needs to be planned now and implementation begun despite this uncertainty.

### 8.3 Epidemiology

#### 8.3.1 General trends

The number of TB cases reported each year in London continues to increase and is substantially higher than in other parts of the country. A total of 3,450 new TB cases were reported in London residents during 2009, compared with a total of 2,309 in 1999, an increase of nearly 50% in ten years. Around 5% of new cases are in children under 16 years of age.

People born outside the UK account for about 85% of new cases of TB in London; this is not because of a recent influx of infected new entrants to the country: 80% of TB cases in people born overseas have lived in the UK for more than two years and over a third have lived here for more than ten years.

TB is commoner in men than in women.

Drug resistance is an increasing problem. A total of 10% of all culture-confirmed TB cases in 2009 were resistant to Isoniazid (up from 7% in 2008). The number of cases of MDR-TB is also increasing (now 2.2%) and one XDR-TB case was reported in 2009.

### 8.3.2 Geographic distribution of cases

London's TB caseload is widely spread across most boroughs. Many patients live in outer London locations. Nearly a third live in North West London. This geographic spread means that in 2009, 19 of the 30 TB services in London saw more than 100 new TB cases; three services (Northwick Park, London Chest and Newham) notified more than 200 new cases. Northwick Park Hospital notified 259 cases (following a high of 287 in 2008). Only two services (Bromley and Queen Mary's, Sidcup) notified less than 50 new cases (21 and 8 respectively).

North West and North East London have both seen significant increases in TB incidence and caseload over the last ten years. The only PCT to have seen a steady fall in incidence is Southwark; this difference would be worth investigating.

TB is a disease strongly linked to certain communities, especially those ethnic minorities linked to countries with high TB prevalence, such as sub-Saharan Africa, the Indian sub-continent and Eastern Europe. TB is a feared and often stigmatised disease, so cultural context and health beliefs are important factors to understand when treating individual patients.

These factors mean that TB services need to be well integrated into local communities, and accessibility and cultural sensitivity are important.

The sheer scale of the number of patients currently needing treatment, and the number of times they need to see health professionals during long courses of antibiotics, suggests that the availability of *local* services is important to maintaining compliance with treatment, as well as preventing spread of disease.

This is a strong argument for retaining the current number of TB services in London – provided they achieve quality standards.

### 8.3.3 Deaths from TB

Deaths from TB are relatively rare; in 2008 there were 69 TB deaths in London compared with a total of 3376 cases notified. The risk of death from TB appears to be higher in those communities with high TB prevalence. Death rates (per 100,000 general population) in London are falling very gradually: rates are highest in NW and NE London where caseloads are greatest. About two-thirds of deaths from TB are in people under 75 years of age. More men than women contract TB and male death rates are also higher.

Current information does not enable us to determine precise case fatality rates at service level. Case fatality ratios (deaths vs notifications) at PCT level suggest that there are relatively more deaths in some localities with fewest notifications; this could be due to differences in age profile in these areas, but the issue deserves further investigation.

Cohort review across London using a standard methodology will provide more robust information on the risk of death from TB in London, as well as providing checks on service quality.

### **8.3.4 Drug resistance**

Patients with drug resistant TB need especially rigorous care. Drug resistant TB in London is an increasing problem, as it is everywhere in the world. In 2009, 135 cases of Isoniazid resistant TB were identified in London, about 10% of all culture-confirmed cases. A third of Isoniazid resistant cases are treated in NE London and about a quarter in NW London. There were 19 cases of MDR-TB across London and one case of XDR-TB (in Brent).

The drug resistant cases are spread across London, with a slight bias towards North East London (an effect of the Isoniazid-resistant TB outbreak over the last ten years). Most clinics reported less than 10 Isoniazid resistant cases in 2009 (except for the Homerton: 15, Whipps Cross: 11). Most clinics reported two, one or no cases of MDR-TB.

The drug resistant caseload of individual services is small, in marked contrast to their caseload of non drug-resistant TB.

Our report has shown (see also below) that the recording of individual patient risk factors appears patchy, and that thresholds for DOT are not standardised. There are no agreed London-wide protocols for contact tracing and screening. There are also no standardised systems to assure service quality. These are important deficiencies when dealing with drug resistant TB.

The treatment of drug resistant TB requires clinical leadership within each network. A lead provider should be identified in each sector / network (see further below – Lead Providers).

### **8.3.5 Patient risk factors associated with poor outcomes**

Drug resistant TB can be contracted from an infectious case, but it can also develop if treatment is not taken regularly or stopped prematurely. Risk factors associated with poor compliance or failure to complete treatment (which can lead to recurrence of infectious TB or drug resistance) include: alcohol use, homelessness, drug taking, a previous history of TB, time spent in prison, and mental health issues. TB is already more common in these vulnerable and socially excluded groups because of their tendency to poor immune status and increased risk of exposure to infection.

The recording of risk factors in the LTBR shows that a worryingly large proportion of patients do not have their risk factors recorded – in NW London, 9% of patients were reported to have an alcohol risk factor, but in 36% of cases this field in the LTBR was left blank. If risk factors were assessed (but only recorded in the clinical notes), there is no evidence for it within the LTBR.

Each service needs adequate administrative support to ensure that the LTBR can be completed in full for each patient.

The process needs to be driven by a standard approach across London, supported by audit and cohort review.

### 8.3.6 Use of Directly Observed Therapy (DOT)

For those patients with risk factors, enhanced case management is necessary and for some of them DOT is indicated. Our studies show poor correlation between the frequency of observed risk factors and the frequency of use of DOT. Some clinics clearly have a much lower threshold to trigger DOT than is the case in others. It is impossible at present to know which have got it right.

Where there is pressure on staffing (see later) there may be a risk that thresholds for DOT may become too high. This issue was revealed in a 2008 survey by the Find and Treat team,<sup>91</sup> in which respondents from 22 / 30 clinics stated that over-stretched resources was a common reason not to offer DOT to patients who might otherwise benefit from it.

There is no standard protocol across London for risk factor assessment or to determine what form enhanced management should take; there is also no agreed model for DOT across London, which has meant that whether DOT is offered and how it is provided varies considerably.

A common approach for London needs to be agreed. This requires centralised, robust clinical leadership and the support of all networks. The proportion of patients on DOT should be reported as a TB metric.

### 8.3.7 Treatment completion

Reported treatment completion rates vary across London. The definition of treatment completion is complex and does not always take adequate account of case complexity or the need for prolonged treatment.

The definitions of treatment completion require some work. Completion rates for fully drug-sensitive TB should be separately compiled and the current standard of 85% should apply. Completion rates for drug resistant TB and other complex cases should also be considered separately.

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<sup>91</sup> Goodburn A, Drennan V (2000) The use of directly observed therapy in TB: a brief pan-London survey. Nursing standard; **14 (46)**: 33-38.



This will require an agreed approach across the whole of London; data should also be collected centrally by the Health Protection Agency (or its successor body). Treatment completion figures should be reported regularly as a performance metric.

### 8.3.8 Losses to follow-up

Losses to follow up also vary across London. Again, a standard approach is needed to minimise them, with an agreed threshold for referral to the Find and Treat service for advice and support. Changes of service models to incorporate more community based outreach work may help to reduce losses to follow up. New protocols are needed, clarifying where the responsibility lies for trying to find patients who need treatment and who have apparently gone missing. Losses to follow up should be considered as a performance metric.

## 8.4 Findings from the literature review

The literature review showed that there is a mass of national and international policy guidance on TB control, including NICE Guidelines (which cover prevention as well as clinical management), a national action plan, a national TB commissioning toolkit and numerous surveys and reports.

However, a large survey in 2009 found that existing recommendations and guidelines may not have been universally adopted in London.<sup>92</sup> And it is clear that the year on year total of new TB cases in London continues to increase.

There are no service model benchmarks provided from experience outside London, elsewhere in the UK. This is probably because cities outside London have a total TB caseload equivalent to that of only one or two London boroughs.

A study of the approach used in New York shows that political commitment, with centralisation of coordination, performance management and accountability and investment in a community based model of working, has led to a dramatic turnaround in the annual trend; each year's total of new cases is consistently less than the preceding year. In London, the trend each year is one of a steady increase in burden of disease.

In New York, a set of agreed thresholds for the use of DOT (lower than those used in London) is held to have accounted for much of the reduction in annual TB

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<sup>92</sup> *Turning UK TB policy into action: the view from the front line.* A report by the British Thoracic Society, Royal College of Nursing Forum and the All Party Parliamentary Group on Global Tuberculosis, 2009.

incidence. It is possible that an equally important influence has been the central control and monitoring of TB treatment and prevention across the whole city. Whatever the views on the appropriateness of the DOT threshold level, the point is that they are standardised across the city.

The New York model is more community based than is the case in London. It is intentionally patient focussed, with field workers to provide DOT at locations convenient for patients; flexible clinic times include late evenings; the New York equivalent to London’s Find and Treat team are integrated with medical and nursing provision, many working out of the clinics rather than from a separate site.<sup>93</sup> These models of working should be considered for London.

The New York Bureau of TB Control (there is currently no London equivalent) has also published a 270 page manual containing care pathways, protocols and procedures for every possible clinical decision to be made in the care of patients with TB – including clinical care pathways, thresholds for DOT, and for prevention initiatives including screening of new entrants and the contacts of identified cases.<sup>94</sup>

This centralisation of approach has not been replicated in London.

London needs to consider a more centralised approach to commissioning TB services, to standardise care pathways and to ensure accountability.

## 8.5 TB services in London

### 8.5.1 General description

TB services in London are provided by 30 different clinic services across the capital; all provide inpatient care if needed; 29 provide outpatient services as well as inpatient services. They are widely distributed geographically (see Map 4). This is appropriate, given the geographical spread of TB cases (Map 2).

Many patients with TB experience an inpatient spell in hospital; we have shown that the ratio of the number of admissions to number of cases notified is around 1:2, suggesting that on average one in three patients with TB require a spell in hospital. For those needing inpatient admission, hospitals providing care tend to be those closest to where patients live.

A model of multiple TB services across the capital, each located close to patients, makes sense - provided services have good understanding of the needs of the local

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<sup>93</sup> F. Dobniewski. Personal communication.

<sup>94</sup> <http://www.nyc.gov/html/doh/downloads/pdf/tb/tb-protocol.pdf>

communities from whom the patients are drawn, and provided also that caseloads are large enough to ensure clinical quality.

We therefore believe that the current arrangements of dispersed TB services in London should be retained, provided that they are each able to perform to agreed quality standards, with appropriate staffing levels and able deliver a more community based model of care (see below).

The model is less appropriate for the management of complex cases, including those with drug resistant or MDR-TB, the numbers of which are currently very much smaller (see further below).

### **8.5.2 Model of outpatient care**

Our service review questionnaire showed that the current model of care provided to support TB patients out of hospital in London is predominantly a traditional one based on the hospital outpatient clinic. No clinics were reported at weekends. Only two hospitals reported the use of a telephone helpline out of hours.

The outpatient model offered most commonly to TB patients is based on their attending a hospital outpatient clinic which is open only during office hours, Monday to Friday, despite many patients being well enough to go to work. Most of these clinics are based at the main hospital site, though there are a few exceptions where full outpatient services including radiology are available at a community-based site.

A few service questionnaire respondents mentioned the availability of an outreach service, and some services have staff able to go out into community settings, but these appear to be the exception.

All services reported access to interpreting services, and most, but not all have access to advocacy.

It is important for services to get closer to communities from whom TB cases are drawn; this requires a more proactive and imaginative approach involving community case workers, joint work with housing agencies and the local authority and providing care in settings other than the hospital outpatient block.

The impression received is that of 30 services working in relative isolation, with little or no sharing of staff and limited work across or within sectors to share good practice. An exception may be the arrangement in North Central London, where all nurses work in one team and are employed by one hospital although deployed in several services across the whole sector. This model could be replicated elsewhere to achieve economies of scale and to create a workforce pool and this should be considered.

Improvements to the current outpatient model in use across London require a radical re-think. Consideration of a move nearer to the New York model would seem appropriate, empowering more generic community workers to take on some of the work currently tackled by a hard-pressed specialist nursing workforce.

Changes will require firm central management and support.

### **8.5.3 Workforce**

Workforce issues are critical to delivery of effective TB services. TB services are currently fragmented with little or no joint working across different services. This is probably because they have evolved without central direction – simply responding to local demand and need, or to local commissioning initiatives.

The service review questionnaire, which achieved a remarkable response rate of 100%, showed the extent of staff commitment to TB care. The richness of the detailed comments made by respondents is a further indication of the extent of their commitment to provide good care, and to consider ways services can be developed and improved.

However, it also showed considerable variation in staff complement, consultant input, skill mix, banding of staff, and the extent of administrative support. Broadly, the larger the case load, the bigger the stated nursing team and the greater the number of clinics held. The use of more generic case workers seems to be small.

At the same time the survey showed that services would like to extend further into community-based work, but were constrained by their existing clinic-based workload, or by financial limitations.

A radical re-think is required if these problems are to be ironed out across London. Somehow clinical and managerial leadership must break down traditional organisational barriers.

Meanwhile all TB services in London must be able, as a minimum, to hit the traditional, pragmatic and evidence-based target that one specialist nurse is required per 40 notified cases of TB. At present, according to our service review questionnaire, only 18 services appear to achieve this target. Staffing levels in NW London require particular attention. This particular benchmark has been in existence for over ten years and is a minimum standard; it is sufficiently important to TB control that it is surprising to find it is not universally met. The ratio should ideally be lower where the caseload is complex or where patients predominate from especially vulnerable or socially excluded groups.

All services now have access to liquid culture technology for the diagnosis of TB, but they do not all have enough nursing staff to provide a robust service for their patients.

Achieving this target will again require a firm central management approach, linked to commissioning.

### **8.5.4 The Find and Treat service**

It was not within our remit to evaluate the effectiveness and impact of the Find and Treat service team, currently based in a centre in Soho and funded (until the end of March 2011) by the Department of Health. That evaluation (including the Mobile X-ray Unit) is being performed by the Health Protection Agency and will be reported after this needs assessment is completed.

However, our Service Review Questionnaire included a question about the Find and Treat service. Respondents were uniformly positive about the effectiveness of Find and Treat, and most have used it as some point. We are unable to assess whether TB services use it to the most advantage, or in the most appropriate and timely way.

The model of care used by Find and Treat is important, because it is based on extensive outreach work in hard to reach, socially excluded or otherwise marginalised communities; Find and Treat have also developed an important role for peer educators working with these communities.

This model is similar in concept to some of the initiatives used in Amsterdam and in New York.

If the evaluation is positive, then it will be important not only to ensure their funding is picked up and continued through the mainstream, but to integrate Find and Treat more closely into the workings of all services. Learning from the Find and Treat model should be widely applied across London's TB services. Find and Treat could provide training opportunities for service teams as well as providing specialist support to those services finding it difficult to work well with complex groups of especially vulnerable TB patients.

### **8.5.5 New entrant screening**

There is no one model for delivery of new entrant screening across London. Arrangements between Port Health, the Health Protection Agency and services seem to vary. The Newham New Entrant Screening Service provides a dedicated service in that borough, receiving referrals direct from Port Health, but it is an exception.

Given the important role played by migration in the epidemiology of TB, this situation cannot be allowed to continue.

Work needs to be done to agree a standardised model across London. A TB metric could be devised to measure performance and ensure equity of access to screening for all new entrants to the capital who come from countries with high TB prevalence.

### **8.5.6 Screening contacts of cases**

The service review questionnaire showed that an important part of the clinic nurses' workload is the screening of contacts of TB cases. However, there is no standardised protocol for this and performance is not currently recorded as a TB metric. Comments from respondents suggest that if a service is hard pressed, then it may be

difficult to devote as much time and energy to contact tracing and screening as is required.

This situation is not sustainable and a new approach is needed. Standards of contact screening need to be agreed across London and a metric agreed to monitor performance.

In New York, contact screening is carried out by a designated team, with a yield of 18% for latent infections.<sup>95</sup> One possible solution in London would be to contract with a specific service to provide contact screening across London. While this report was in preparation, such a proposal was submitted to PHAST as part of the feedback from the draft of this report. A contact screening service could also carry out outbreak and cluster investigations, in the light of universal molecular typing for all culture confirmed TB cases.

## **8.6 Services - Requirement for specialist care**

### **8.6.1 Role of a lead provider**

TB occasionally can be a very complicated disease, especially when diagnosed late in its course, in cases where there is serious multi-system involvement, or when there is a co-existing condition like HIV/AIDS. Spinal or renal TB and TB meningitis may require specialist centres for their treatment; all of these are available in London.

But for the majority of more routine cases, effective care should be available close to where patients live. We have shown that the pattern of hospital admissions already shows that the largest numbers of admission spells are to hospital services closest to where patients live.

The situation is different, for example, from cardiovascular surgery (currently offered in only a limited number of specialist sites across London to maintain quality and safety). It does not appear to us currently necessary to limit routine TB care to a small number of expert providers, except in certain clinical situations (see below).

### **8.6.2 Drug resistant TB**

The number of drug-resistant TB cases managed by individual TB services is small; some services may already be under pressure from the size of their overall TB workload. This leads us to suggest that within each sector, one provider should be designated to take the lead on drug-resistant TB, providing support to each local service, and ensuring that the most rigorous standards of individual care and contact screening apply.

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<sup>95</sup> Maguire H. Personal communication.

Because of the need to provide care close to where patients live (especially if they are in a socially excluded or vulnerable group), local services should be responsible for delivery of care. The role of the lead unit would be to provide clinical leadership, support and advice to ensure that standards of care are met.

This role would need to be formalised. It might also involve sharing of staff to ensure there is capacity to do what needs to be done. In situations where the nursing staff are already employed by one organisation (e.g. in North Central London, the Royal Free Hospital) this should be possible to organise centrally and should ideally be a function of clinical networks.

### 8.6.3 TB in children

A total of 5% of TB cases notified in 2009 were in children under 16 years. Ultra-specialist paediatric care is available for complex cases at Great Ormond Street, but for more routine cases of TB in children, clinicians have to rely on working relationships between TB consultants and paediatricians.

We believe that a lead paediatrician should be agreed in each network / sector to lead on care of children with TB. The arrangement could be similar to drug-resistant TB described above: leadership and support from one specialist team to ensure that paediatric clinical pathways are easily followed.

### 8.6.4 Services for renal, spinal and neurological TB

We believe that it would be equally sensible for the care of renal, spinal and neurological TB (especially TB meningitis) to require a role for a lead clinician in each network / sector under a similar arrangement. This should be explored.

## 8.7 Measuring, reporting and responding to performance

We have shown that the current arrangement whereby nine indicators (the London TB metrics) are used to measure TB service performance is *ad hoc*. The metrics need to be reviewed to provide a more useful set of indicators – useful to clinical teams as well as to commissioners or others assessing service performance. A number of new metrics are suggested, all of which could be derived from the LTBR.

We have shown that current performance against all nine metrics across London is patchy. The five current sector networks have used different approaches at differing time intervals, and we found no evidence of coordinated action in response to the findings. This is not sustainable.

More rigorous central monitoring of performance is required across the whole of London, to ensure that standards of care are met and action taken when they are not. This will also require a central system of performance reporting. The best placed organisation to collate performance information (where the information is available

from the LTBR) is the Health Protection Agency (or its successor body, following future reorganisation), which is the guardian of the information in the LTBR.

The robustness of screening of new entrants and of TB contacts, in particular, appears weak. These are important areas for action to improve performance.

Neonatal BCG immunisation programmes also appear to be achieving poor coverage, especially in North West London. A minimum coverage rate needs to be agreed as a future metric. There are arguments in favour of universal neonatal BCG immunisation across all London's boroughs. However, given that this was not included for in-depth examination in the remit of this project, it appears appropriate that this should be considered as part of a detailed review of the BCG policy options for London.

Overall, the reporting and monitoring of TB metrics in London needs to be standardised and centralised with greater accountability. Where performance is consistently poor, firm action must be taken by commissioners.

There is good evidence from New York that cohort review, when regularly performed and bought into (as a process) by all members of clinical teams, can lead to improved processes of care and lessons being learned when things go wrong. Cohort Review (already piloted in some sites) should be rolled out across all five sector-wide networks as a priority.

## **8.8 Centralised London-wide standards of care**

Although there are extensive NICE guidelines on the clinical diagnosis, management, prevention and control of TB, there are currently no agreed pathways of care London-wide to ensure their consistent implementation in practice.

We believe that a London version of the New York manual (see 8.4.4 above) would prove an invaluable tool to the development of city-wide standard protocols and pathways of care.

## **8.9 Information on activity and finance**

Elements of the project examining NHS service activity (inpatient and outpatient) and finance (commissioning expenditure) demonstrated current constraints in the availability and analysis of data on these aspects of TB commissioning. It appears that helpful aspects of the DH TB Commissioning Toolkit have not been adopted to date.

If a more centralised model of TB commissioning for London is implemented (see below), improvements are required in these aspects in order for commissioners to be adequately well informed and for performance to be monitored and managed.



## 8.10 Patterns of need – expressed by users

This needs assessment included specially conducted interviews with a range of service users across London. The most commonly expressed opinion of users interviewed was that they would like to see better training for GPs and more awareness raising about TB for the public in general. GPs are often perceived as slow to recognise the symptoms of TB and slow to act.

Clinic staff sometimes seem to lack empathy and understanding, although generally clinic services were appreciated and some TB patients felt a sense of social dependency. Interpreters are often available; less frequently available are patient advocates – an important aspect of care for socially marginalised groups.

For those patients attending hospital before a diagnosis has been made, an important factor has been diagnostic delay due to their being asked to return to their GP in order to be re-referred to a different hospital department.

This is avoidable. Tertiary referrals should normally be allowed where the symptoms of the patient are little changed, but where another opinion is required in order to form a diagnosis.

Patients attending contact clinics often felt there was insufficient information in the letter they had received about TB and the process that they would have to go through to be screened. Contact tracing letters need to be culturally sensitive and be drafted in the knowledge of the stigma often attaching to TB.

### 8.10.1 Awareness raising and training for general practice teams

Most GPs encounter an acute case of TB relatively rarely. Three users told us they had travelled to their country of origin specifically in order to achieve a diagnosis, returning to the UK to complete their treatment. Others told us that they believed GPs and other primary care professionals needed training to develop their knowledge and skills in diagnosing TB.

Local services could have an important role in working more closely with general practice teams to increase awareness of TB and its diagnostic features.

This role should be developed alongside a new programme being developed by TB Alert and the HPA to improve the awareness of TB in general practice teams.<sup>96</sup>

Local services could also link to other initiatives to increase awareness of TB within their local communities.

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96 Phiri E. (TB Alert) personal communication.

The whole issue of awareness raising, both in communities and in general practice teams, is one which could be picked up and developed by local GP Commissioning Consortia.

### 8.10.2 Awareness raising in local communities

The issue of community awareness raising is outside the scope of this report, but has been highlighted by several stakeholders. TB Alert is currently contracted by DH to provide an awareness raising programme nationally, targeted at high risk groups. This programme needs to be taken into account and actively developed in London appropriate to the characteristics of local communities.

### 8.11 A Board of TB Control for London

TB control cannot be delivered without excellence of central management and accountability. TB control requires action needed to protect public health as well as that required to ensure effective services for people with TB.

While a range of options exist, the possibility of creating a Board of TB Control for London should be considered, using expertise from both the London TB Clinical Reference Group and the London TB Commissioning Board.

The approaches adopted in New York provide a successful reference-point, and a London Board of TB Control could adopt similar objectives to those set-out by the Bureau of Tuberculosis Control in New York:

- *To identify all individuals with suspected or confirmed TB disease and ensure their appropriate treatment.*<sup>97</sup>
- *To ensure that individuals who are at high risk for progression from latent infection to active disease (e.g., contacts of active cases, immunocompromised individuals, recent immigrants from areas where TB is widespread) receive treatment for latent TB infection and do not develop disease.*<sup>98</sup>

These two objectives cover all functions of TB control, from clinical policy and epidemiological surveillance to performance management, with the exception of primary prevention through the use of neonatal BCG immunisation. This would need to be added for London.

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<sup>97</sup> The New York objectives also state: "...ideally on a regimen of directly observed therapy."

<sup>98</sup> <http://www.nyc.gov/html/doh/html/tb/tb.shtml> accessed 3 July 2010.

A Board of TB Control would deliver its objectives through:

- Improvements in the availability, analysis, and monitoring of NHS information on service activity and finance relating to TB services;
- Standardisation of clinical care, of prevention and of performance measures;
- A robust and consistent management approach (including the commissioning of services across London);
- Transparency of performance;
- Accountability for delivery.

The Board of TB control would be the central body to react to intelligence concerning service range, quality and impact (including evidence from epidemiology, cohort review and from performance metrics) and would take tough commissioning decisions when required.

A Board of TB Control for London would need to be accountable, through the NHS, to the (future) NHS Commissioning Board and ultimately to the Secretary of State.

A Board of TB Control could also report to the Mayor for London.

Membership of a future Board of TB Control would need to be drawn not just from the NHS, but also from the Department of (Public) Health, from local authorities, from the office of the Mayor of London, from users of services, and from the third sector.

A Board of TB Control for London would need to assume the functions of the current London TB Commissioning Board; but as its title implies, the central body responsible for getting a grip on London's TB will need to have a membership and function that is wider than that of NHS commissioning. The terms of reference and membership of a future London Board of TB Control will need to be agreed without delay, during the transition period in which the NHS undergoes further reorganisation.

### **8.11.1 Commissioning**

Our proposal that a Board of TB Control for London should be established comes at a time when future NHS commissioning arrangements in London are in a state of uncertainty and transition – given the proposed abolition of PCTs and regional health bodies and the development of GP commissioning consortia.

TB is not a condition seen regularly in general practice by GPs and other primary care health professionals. Indeed, we have seen in Chapter 7 that GPs' relative lack of familiarity with the presenting symptoms of TB cases has contributed in some cases to important diagnostic delay.

In our view, the commissioning of TB services for London should continue to be performed by a London-wide body, such as a Board of TB Control. TB is too complex and specialised a topic, and requires wide and consistent policies and joint action, for the commissioning of TB services to be decided by local GP commissioning consortia.

The Board of Control will need to be viewed as the body fulfilling a specialist commissioning function for TB in London (although its terms of reference will be wider than this including wider public health activity).

### **8.11.2 Working at sector / clinical network level**

The current arrangement for TB services in London, with five managed clinical networks operating within the boundaries of previously identified sectors, has much to be said for it. The number of service providers within each is manageable (between 4 and 7) and the arrangement is appropriate for tertiary specialist care as there is at least one major tertiary centre within each network. Networks have a multi-disciplinary membership and are well set up to undertake peer review and cohort review, although to date their commissioning impact may have been limited.

The current arrangement of five managed clinical networks across London has appropriate economies of scale and we believe that it should be retained.

What will need to be different, however, is the expectation placed on each network to deliver a level of joint working and overall performance which is substantially greater than at present; to be the delivery arm of the Board of Control, working with local stakeholders (including local authorities, users of service and local GP Commissioning consortia), so that the Board of Control's objectives can be achieved across the capital, reaching into each sector's various local communities.

The membership, and possibly management capacity of each network will need to be reviewed in the light of the objectives of a new Board of TB Control for London and to reflect the reorganisation of the NHS.

### **8.11.3 Leadership for TB control in London**

Leadership across London is crucial to the delivery of more effective ways of working. This will require both managerial and clinical leadership, and political will in London.

Lead roles (such as those, perhaps, of Clinical Director and Nursing Director) may also need to be identified in each of the five sector-wide networks.

## **8.12 Controlling TB in London**

Based on these considerations a series of recommendations are set out in the following Chapter. The recommendations in this report should, if accepted, enable an Action Plan to be developed which could ensure progress to substantially improve the control of TB in London.

## CHAPTER 9 RECOMMENDATIONS

This Report is submitted at a time of turbulent change in the NHS. The commissioning structures that existed when the work began are due to be radically altered. Strategic health authorities and primary care trusts will be abolished; 80% of the NHS budget will be transferred to GP commissioning consortia by 2013. The minimum size of these consortia is to be determined and transitional arrangements are still being worked out.

Meanwhile, as a public health priority, TB in London needs to be brought under improved control. We believe that this can only be done by using a London-wide structure for leadership and decision-making.

The following recommendations should be considered by the London TB Clinical Reference Group and the London TB Commissioning Board (which commissioned the work), in consultation with senior colleagues in NHS London (including the Director of Public Health for London) and the Department of Health, with local authorities and with the office of the Mayor of London.

### 9.1 Central leadership and management

- 9.1.1 Establishing a Board of TB Control for London should be considered. Similar to the approach adopted in New York, the Board would be responsible for achieving the overall objective of a year on year reduction in the incidence of TB in London. The Board would also be the central point of accountability of services for their performance against agreed standards of TB prevention, care and control.
- 9.1.2 A Board of TB Control would deliver its objectives through:
- Standardisation of TB prevention, care and control, with agreed care pathways and performance measures;
  - A robust and consistent management approach, including the commissioning of TB services across London;
  - Transparency of performance;
  - Accountability for delivery.
- 9.1.3 Membership of a Board of TB Control for London should not be restricted to the NHS. It should comprise representatives of London's TB services, expertise in public health, specialist and GP commissioning, together with users, community and third sector representatives, local authorities and the office of the Mayor of London.
- 9.1.4 Robust clinical and managerial leadership should be identified, both for London as a whole and at network level. The current arrangement of five networks across the capital should be retained and strengthened.

- 9.1.5 TB services for London should be commissioned London-wide; commissioning of TB services should not be delegated to GP Commissioning Consortia.
- 9.1.6 Arrangements supporting the availability and analysis of information on NHS TB service activity (inpatient and outpatient) and commissioning expenditure should be reviewed, with reference to the DH TB Commissioning Toolkit.
- 9.1.7 The commissioning of TB services across London should involve local authorities, service users and the third sector.
- 9.1.8 A Board of TB Control for London should (in the future) work closely with GP Commissioning Consortia, with local Health and Wellbeing Boards and with Directors of Public Health to ensure that TB services in each network develop active and effective relationships with GP teams and with local communities.
- 9.1.9 The current arrangements of widely dispersed geographically accessible TB services should be retained, subject to more robust performance information, especially for those with small case loads. Relationships between services and local communities need to be substantially strengthened.

## 9.2 Standardisation of clinical policy and practice

- 9.2.1 Clinical policy and practice for TB prevention, care and control across London need to become standardised.
- 9.2.2 A manual of standardised protocols and procedures for the prevention, diagnosis, clinical management and control of TB across London (including assessment of lifestyle risk factors and thresholds of hospital admission) should be developed (similar to the *Clinical Policies and Protocols*<sup>99</sup> used in New York). This manual should be consistent with NICE and other Guidelines. From such a manual, care pathways and standards of care should be derived.

Thresholds should be agreed and standardised for the use of Directly Observed Therapy (DOT) across London, with an agreed set of definitions as to what constitutes DOT. Protocols should include a pathway indicating where tertiary referrals are required for those patients who are suspected of having TB.

- 9.2.3 Standard protocols should be agreed for the delivery of the screening of new entrants from countries of high TB prevalence and of contacts of incident TB

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<sup>99</sup> *Clinical Policies and Protocols*. New York: Bureau of Tuberculosis Control, Department of New York Department of Health and Mental Hygiene, 2008.

cases. In both instances, performance information should be made available (see below).

- 9.2.4 Standard protocols are also needed for screening of contacts of cases. Current arrangements for contact tracing and screening appear unsatisfactory. One possible solution in London would be to develop a specific service to provide contact screening across London. This option should be explored further.
- 9.2.5 We have established that there is widespread prescribing of anti-TB medication by GPs. This should be investigated.
- 9.2.6 Systematic Cohort Review should be introduced as a quarterly event in all networks, with representation across networks as well as from all providers within them. Cohort Review (including reviews of TB deaths) should be viewed as a multi-disciplinary team event and all disciplines should be represented. An overview of the principal issues arising from each Review should be made available.

### 9.3 Performance

- 9.3.1 The nine current London TB metrics should be revised in the light of current context and performance against them across London.
- 9.3.2 Metrics concerning liquid culture (Metric 8) and sputum smear reporting (Metric 9) are no longer required. The metric regarding the interval between GP referral and seeing TB services (Metric 2) should be dropped. That concerning contact screening (Metric 7) should be dropped and later revised.
- 9.3.3 The coverage of neonatal BCG immunisation (Metric 1) is very patchy across London, especially in North West London. Where current policy is for *universal* neonatal BCG immunisation, action should be taken now to ensure proper reporting of uptake and coverage. A minimum coverage rate needs to be agreed as a future metric.

The appropriateness of *selective* neonatal BCG immunisation in some London boroughs should be reassessed, and the case for adopting a programme of *universal* neonatal immunisation across the whole of London should be considered as part of a detailed review of the BCG policy options for London.

- 9.3.4 London requires each TB service to be adequately staffed with specialist nurses and administrative support. At sector level, this is a priority for North West London. All services should achieve the minimum standard of one specialist nurse per 40 notifications per year. Commissioners and service providers need to ensure that services are adequately funded to achieve this. Also, replication the integrated model of staffing such as seen in North Central

London could be considered elsewhere to achieve economies of scale and to create a wider workforce pool.

9.3.5 New, effective metrics are required, having utility to clinicians as well as to commissioners and which can be easily measured. A group should be tasked to work up new metrics of proven utility. The Health Protection Agency (or its successor body) should be asked to collate TB metric performance using a standard methodology, with results reported to the London Board of TB Control as well as to networks.

9.3.6 New metrics could include the following areas:

- Documentation of individual patient risk factors;
- Use of DOT (adjusted for/considering known risk factors);
- Numbers and outcomes of those screened as new entrants;
- Numbers and outcomes of those screened as contacts of incident cases;
- Numbers of those lost to follow up who are found within an agreed period.

9.3.7 Treatment completion rates should also be measured separately for drug resistant or complex cases where completion within 12 months of notification, with compliance, is unrealistic. Low treatment completion rates (less than 85%) of less complex cases should lead to remedial action in the services concerned.

## 9.4 Accessibility and responsiveness of services

9.4.1 All TB services should become more closely integrated into the local communities from whom most of their patients are drawn, with less dependency on patients attending the hospital outpatient department. Service models need to include outreach and community based provision, using a wider skill mix than specialist nurses, and with access not only to interpreting services, but also to patient advocacy.

9.4.2 All TB services should develop their relationships with local GP practice teams; this should include initiatives to increase diagnostic awareness of TB and to encourage prompt referral of possible cases. Advocates should be available as well as interpreters, especially in services with large caseloads.

9.4.3 The Find and Treat service provides a community based model of working which is valued by mainstream TB services. If its evaluation (currently ongoing) proves positive, learning from this should become integrated into the workings of all London TB services.

9.4.4 Clinic accessibility should be enhanced with more flexible hours of opening, including the availability of advice and support out of hours and at weekends. This is especially important for patients who have been able to return to work and may enable more to return to work.



## 9.5 Lead providers

- 9.5.1 A lead provider should be identified in each sector for the management of drug resistant TB. The lead provider would provide support to each local service on notification of a drug resistant case and would ensure that the most rigorous standards of individual care and of contact screening are applied.
- 9.5.2 We believe that it would be equally sensible for the care of renal, spinal and neurological TB (especially TB meningitis) to require a role for a lead provider in each sector under a similar arrangement. This should be explored.

## Appendix A – Service mapping questionnaire

The London TB Commissioning Board has commissioned the Public Health Action Support Team (PHAST) to carry out a health needs assessment and service review for TB across London. A brief project description is attached separately.

The work includes 'service mapping' to determine the extent and nature of current specialist TB services available, including:

- Service design & organisational details;
- Access & availability;
- Staffing & capacity;
- Links with other services;
- Funding;
- Interventions & therapies.

This questionnaire is an important part of this service review. The information gathered will be handled sensitively and used solely for the purpose of the project as governed by the London TB Commissioning Board.

*We would be grateful if you could please complete the questions below with as much detail as you can. The questionnaire should take no more than 30 minutes to complete. Once completed, please email the finished questionnaire and any supporting documents to [kerrycrabb@gmail.com](mailto:kerrycrabb@gmail.com). We should like to receive your completed questionnaires **by 31 May 2010 at the latest**.*

*If you have any queries, please don't hesitate to contact Dr John Hayward at [jhayward50@googlemail.com](mailto:jhayward50@googlemail.com).*

Name of Person completing questionnaire: \_\_\_\_\_  
Title: \_\_\_\_\_  
Department: \_\_\_\_\_  
Trust: \_\_\_\_\_  
Telephone number: \_\_\_\_\_ Email: \_\_\_\_\_

<b>Service &amp; Organisational Details</b>	
<b>1</b>	What is the clinic/service name? Which organisation is the clinic and/or service hosted and managed by? Are you networked to any other services or clinics?
<b>2</b>	How would you describe your service – e.g. what are the key roles and contributions to TB control and treatment? What are the TB services provided? Is there anything that is unique to your service?
<b>3</b>	Do you have a specific TB clinic or are patients seen as part of the general chest clinic?  Is there a dedicated service/clinic or links with paediatric teams? Please give details.

<p><b>4</b></p>	<p>What is the geographic catchment area (i.e. PCTs &amp; neighbourhoods) for your service?</p>
<p><b>4a</b></p>	<p>Does your service serve a particular population or client group?</p>
<p><b>5</b></p>	<p>Do you run any additional joint services, projects or initiatives (e.g. housing/homelessness projects, working with communities or voluntary groups, social care/welfare support etc)?</p>

<b>Access and Availability</b>	
<b>6</b>	What is the main location of the TB service (please provide full addresses including postcodes)?
<b>7</b>	Is the service also delivered in other locations? If so, please could you provide details (full addresses including postcodes)?
<b>8</b>	How many times in one week would you hold a TB clinic? Would this change if there was an increase in demand?
<b>9</b>	<p>What are the opening hours at the locations included in 6 and 7?</p> <p>Monday            Friday            Tuesday        Saturday            Wednesday    Sunday            Thursday</p>
<b>10</b>	How do clients access the service – e.g. Open-access, referrals from other organisations/professionals (please specify)?

<b>11</b>	<p>Do you have an outreach service? Yes/No</p> <p>If yes, what is the specific role and details?</p>
<b>12</b>	<p>Do you offer interpretation services to your patients? Yes/No</p> <p>Do you offer advocacy services to your patients? Yes/No</p> <p>If yes, please could you provide details of the interpretation and/or advocacy services.</p>



<b>Links with other services</b>	
<b>15</b>	What links does your service have to the Find and Treat team?
<b>16</b>	Do you find it easy accessing the Find and Treat team?
<b>17</b>	<p>What links does your service have to a HIV team/service?</p> <p>Please could you provide details of how you link with the HIV team?</p>



<p><b>18</b></p>	<p>What links does your service have to the Health Protection Unit?</p>
<p><b>19</b></p>	<p>What links does your service have to the Port Health Authority?</p>
<p><b>Funding</b></p>	
<p><b>20</b></p>	<p>How is your service funded – i.e. by which organisations &amp; through what mechanisms/budgets?</p>
<p><b>21</b></p>	<p>Do you have any services which are funded from fixed term funding, e.g. neighbourhood grant, community fund, innovation or research funding? If so, please specify.</p>

<b>Interventions and Therapies</b>	
<b>22</b>	<p>What different models of Directly Observed Therapies (DOT) do you offer your patients e.g. via pharmacies, in the home, at work?</p>
<b>23</b>	<p>Do you have agreed criteria or thresholds for deciding whether to use DOT? Please give details</p>
<b>24</b>	<p>Who has responsibility for new entrant screening?</p>
<b>24a</b>	<p>What is your model of delivering this screening – who does it and how?</p>



<b>Other</b>	
<b>29</b>	Do you have a regular programme of audit which might include healthcare and non healthcare professionals? For example detailed reviews of your patients with social care? Please could you provide details?
<b>30</b>	Do you have a strategy, service level agreement or business plan? Yes/No (if yes please attach to the email with a copy of the completed questionnaire)
<b>31</b>	<p><b>Other comments:</b></p> <p>This section is for any comments you might like to make on current TB services across London, such as what you see as the key developments for a London TB service, any gaps you have identified in your or any other TB service.</p>

*Thank you for your time in completing this questionnaire.*

*Once completed, please email the finished questionnaire and any supporting documents to [kerrycrabb@gmail.com](mailto:kerrycrabb@gmail.com).*

*If you have any queries then please don't hesitate to contact Dr John Hayward at [jhayward50@googlemail.com](mailto:jhayward50@googlemail.com).*

**Kerry Lonergan**  
**Research Associate, PHAST**

**Dr John Hayward FFPH MRCP MRCGP**  
**Consultant in Public Health, PHAST**

## Appendix B - Service user interview questions/prompts

1. Introduction including purpose of study and confidentiality
2. Can you tell me the story of what happened when you first came to realize that you had TB?
3. Who helped you?
4. What services/support were you able to use at that time?
5. How did you find out about them?
6. Were they easy to access?
7. How did they help?
8. What would have made things easier?
9. What services do you use now
10. How do they help?
11. How could they be improved?
12. If you were advising someone who just heard that they had TB what would you advise them to do?
13. Do you have any other feedback you would like to give to the project team?
14. Thank you