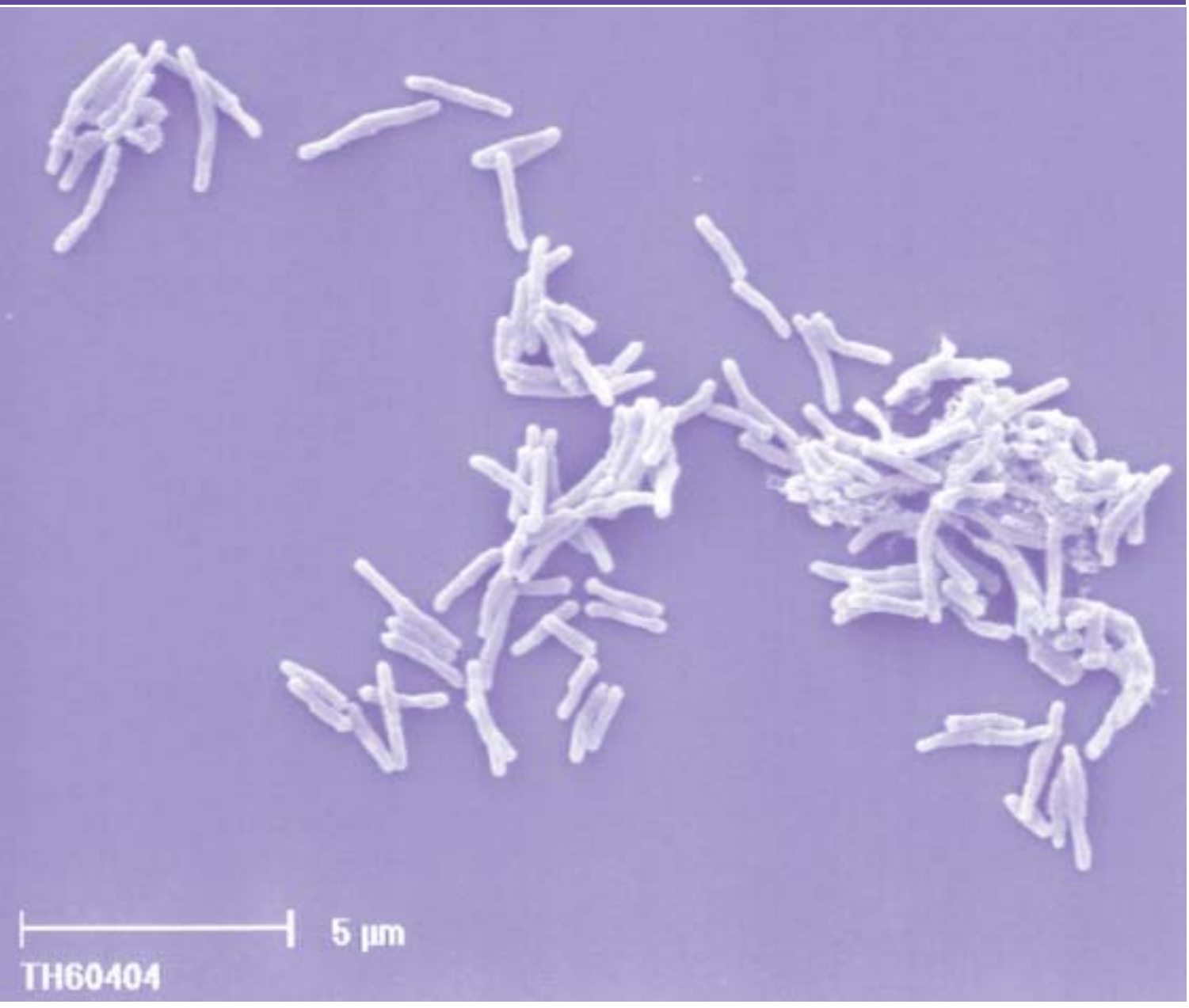
LONDONASSEMBLY

Health Committee

Tuberculosis in London

November 2003



Tuberculosis in London

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Chair's Foreword

After a century in decline, tuberculosis is making a worrying comeback in London. While rates of infection have flattened out or dipped across the rest of the country, increasing numbers of Londoners are contracting the disease. Fifteen years ago, the capital accounted for three out of twenty cases in the whole of England and Wales; now, almost half of them are in London.

This report, the product of a scrutiny by the London Assembly's Health Committee, looks into the implications of the resurgence of disease in the capital and explores some of the measures which are being adopted to tackle it. We hope our work will help those with the disease, who, in many cases, are already marginalised, and those who care for them.

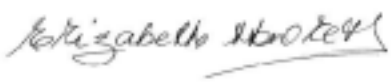
TB is, and always has been, a disease engendered by poverty. Our work confirmed that social and economic deprivation, particularly bad housing, is a breeding ground for *Mycobacterium tuberculosis*. Although the disease can be best controlled by early diagnosis, people most at risk are usually those with the most limited access to primary care.

The inquiries discovered that TB is putting new pressures on the National Health Service and other agencies in London. The disease, for example, is spread unevenly across the capital, hitting those areas were deprivation is high. Drug resistant strains of the disease are also becoming a growing problem in London, increasing the cost of treatment, in some cases, ten times.

The return of TB as a public health concern in London is similar to the rising incidents of the disease around the world. TB is killing more people worldwide than ever before, but screening people when they arrive at airports or on the dockside is not an effective method of controlling the disease. Far more effective, this report argues, is carrying out health checks in people's own communities, ensuring that agencies work together to tackle not only the medical but also the social aspects of TB and raising public awareness of the disease.

Although TB may be a particular problem for London, the rest of the country should not be complacent. London operates a TB Register. Despite the cost implications, we urge the NHS to extend the register across the country which will assist in the continuing health care of the population.

Finally, I would like to thank my colleagues on the Health Committee for their hard work and commitment, officers of the Greater London Authority who helped produce the report and the witnesses who gave so generously of their time to attend our meetings.



Elizabeth Howlett
Chair, London Assembly Health Committee

The Health Committee

The London Assembly's Health Committee was established in May 2002. It has a unique role, in that unlike local authorities and other organisations, it can identify and investigate health issues that are of concern to London as a whole. The Committee is flexible in its remit, and is not bound to issues emanating from individual localities or health authorities.

The Committee can also work across agency boundaries and encourage participation from the voluntary sector, the private sector and local people, ensuring that these diverse views are reflected in its work.

In May 2003, the Assembly agreed the following membership of the Health Committee for the year 2003/04:

Elizabeth Howlett (Chair)	Conservative
Meg Hillier (Deputy Chair)	Labour
Richard Barnes	Conservative
Lynne Featherstone	Liberal Democrat
Noel Lynch	Green
Diana Johnson	Labour

The terms of reference of the Health Committee are as follows:

- To examine and report from time to time on:
  - the strategies, policies and actions of the Mayor and the Functional Bodies; and,
  - matters of importance to Greater London as they relate to the promotion of health in London.
- To liaise, as appropriate, with the London Health Commission when considering the Health Committee's scrutiny programme;
- To consider health matters on request from other standing committees and report its opinion to that standing committee;
- To take into account in its deliberations the cross cutting themes of:
  - the achievement of sustainable development in the United Kingdom; and,
  - the promotion of opportunity;
- To respond on behalf of the Assembly to consultations and similar processes when within its terms of reference.

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Executive Summary

Tuberculosis (TB) is a global disease associated with deprivation and poverty. In the world today, more people are dying of TB than at any other time in history. There are approximately 2 million deaths globally from TB each year. The neglect of TB control in New York, led to a major TB epidemic in the 1980s and early 1990s. To reduce the levels of TB in New York required a massive re-investment in TB control, costing over 1 billion dollars.

London is currently experiencing increasing levels of TB. Over 40% of all TB cases in England and Wales now occur in London. The capital has the highest TB rate of any region in England and Wales. Whilst the level of TB in London is not at the same levels experienced in New York, we felt that there was an urgent need is to look at what is actually being done to bring TB in London under control.

TB is a complex disease. The drugs required to treat TB are relatively straightforward antibiotics, but treatment of the disease is complicated by social factors common to urban centres such as London. Social deprivation and marginalisation have a major impact on both the transmission of the disease and the effectiveness of treatment. As with so many other illnesses, those who are socially marginalised are those who are most vulnerable to the disease and yet face most difficulties in accessing and benefiting from appropriate health care.

We believe there is a need for a broader, more co-ordinated approach to TB control across the capital which must include non-health public services such as local authorities and voluntary sector agencies. We found that the structures needed to develop this approach are very much established at local levels. There has been a growing emphasis on partnership working and collaboration in health care policy over the last few years and a number of local planning processes have been developed in order to achieve it. Primary Care Trusts and local authorities work quite closely together and in some circumstances jointly, to provide a range of local health services. These existing structures must also be used to strengthen TB control methods.

The scrutiny shows that whilst the Department of Health, Health Protection Agency and the National Health Service are doing much to control TB in the capital, the level of TB remains high. More will need to be done to permanently reduce the level of TB in the capital. There is still a need for NHS organisations to work closely together, particularly with regard to ensuring the availability of facilities and treatment incentives for TB patients across London.

We recommend that a London TB plan be developed which will address the differences in the levels of service provision across the capital, and drive forward a partnership approach to TB control at local levels. It is only when such an approach that addresses both the social and medical needs of patients is established, that the levels of TB in London will fall.

1. Introduction

1.1 Tuberculosis (TB) is becoming of increasing concern to Londoners, with the media regularly highlighting alarming reports on the increasing incidence of TB in the capital. These reports are further fuelled by myths and misrepresentations as to how the disease is spread and why the level of TB in London has increased. TB is a disease associated with deprivation and poverty and has been prevalent in the capital for more than two centuries. The increasing levels of TB that London is currently experiencing are a cause for genuine concern.

1.2 The London Assembly is empowered by law to investigate issues of concern to Londoners. It is under this remit that we have undertaken the first London - wide scrutiny of TB. We hope to bring relevant facts, issues and data into the public domain. Our report highlights the various initiatives and methods of TB control that are currently being undertaken by the National Health Service (NHS) and the Department of Health. We have highlighted some of the issues that we are concerned about and we have made recommendations on how we believe these issues should be resolved.

The Scrutiny Process

1.3 As part of the scrutiny process we requested written evidence from a range of organisations including the NHS, Department of Health, voluntary sector and representatives from the London TB group. We held two public evidentiary sessions which covered several issues. A list of the organisations that submitted written evidence can be found at Appendix C. A list of those that attended the evidentiary hearings is at Appendix D.

1.4 In addition to the hearings we also visited Newham Chest Clinic, to meet both patients and staff. This provided us with the opportunity to hear at firsthand about the Newham TB scrutiny and the way the London Borough of Newham and Newham Primary Care Trust are working closely to improve the delivery of TB services in the borough.

1.5 The terms of reference for this scrutiny are as follows:

- To consider the prevalence of TB in London including both current and future trends of the disease.
- To consider the effectiveness of strategies for the control of TB in London and how services for TB patients across London might be improved.
- To highlight the role of public health awareness in improving rapid diagnoses and ensuring successful treatment.

TB - The Global Health Challenge

1.6 TB is one of the three main health challenges facing the world today, the other two being HIV/AIDS and Malaria. These three diseases account for millions of deaths globally each year.[1] In 1993 the World Health Organisation (WHO) declared TB to be a global emergency. There are an estimated 8 million new cases in the world each year.[2] Together HIV and TB are a lethal combination, each speeding the other's progress. TB is a leading cause of death among people who are HIV-positive. Currently TB accounts for 11% of AIDS deaths worldwide.[3] More people are dying of TB in the world today than at any other time in history – approximately 2 million deaths each year.[4] *'An ancient disease is killing more people today than ever before. TB - which many of us believed would disappear in our lifetime - has staged a frightening comeback.'* [5]

1.7 TB is a problem that is a window on the world. Globally, one third of the population is estimated to be infected with TB. **The WHO has estimated that between 2002 and 2020, approximately 1,000 million people will be newly infected, over 150 million people will get sick, and 36 million will die of TB if control is not further strengthened.**[6] Nearly all countries in the world are now affected by the global resurgence of TB. It is a worldwide global problem that is having an impact on London and will continue to do so because of London's global position.

Why is TB an important issue for London?

1.8 London is one of the world's global trade centres. It is a city of 7.4 million people, the national capital and the centre of a major metropolitan region. London's life and economy are shaped by global forces, in particular the flow of trade, capital and labour. London is the UK's major destination for investment funds, students and workers from the EU and further afield. London is also a gateway to the rest of the UK, through its airports, road and rail links from the Channel ports. The flows of people into and through London in any one year are remarkable.

1.9 London ranks approximately equal with Paris as the world's most popular international tourist destination, with 13.1m tourist arrivals annually. In 2001, some 12.8m visitors from outside the EU were granted permission to enter the UK to study, work or for business or holidays. The majority come to or pass through London. In 2002, 108.6 million passengers flew from British Airport Authority's London airports at Heathrow, Gatwick and Stansted. This accounts for 58% of the total number of passengers using UK airports in that year.

1.10 The increasing mobility of people across the globe helps to spread TB as people travel from, or visit areas where TB is prevalent. Travel from the UK to exotic and remote places has become increasingly popular, with people travelling frequently to areas where TB is prevalent such as parts of Africa, Asia, Latin America and Eastern Europe. London is therefore vulnerable to high levels of TB because of its global position.

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[1] Getting Ahead of the Curve, Department of Health 2002
[2] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[3] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[4] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[5] Dr Gro Harlem Brundtland Director General, WHO (Getting Ahead of the Curve)
[6] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002

TB and Immigration

1.11 In the media, much blame has been placed on immigrants for bringing diseases such as TB and HIV into Britain. Much of this debate has been inflammatory and unhelpful, failing to take true account of the nature of the disease. These reports lead to misunderstandings about how best to control the disease. Dr John Hayward informed us that during the Newham scrutiny into TB in the borough, there was initially a general misunderstanding that TB was being brought into the borough from outside the UK and if that could be stopped the problem would effectively disappear.[7] Their scrutiny process has enabled Councillors and staff from the local authority and the primary care trust to develop an understanding of the way the disease is spread and how best to control it effectively.

1.12 The aim of this report is to highlight the nature of the disease, its impact on Londoners and current methods of TB control. We do not intend to focus on the issue of immigration and asylum at this time. The London Assembly Public Services Committee is considering the issue of Asylum Seekers and Refugees in London and will be reporting its findings later this year. We are not, however ignoring the issue of new entrant screening, and chapter three of this report considers this method of TB control.

What is Tuberculosis?

1.13 Tuberculosis, often referred to as 'TB' or 'consumption', is a curable infectious disease caused by the tubercle bacillus - also known as 'Mycobacterium tuberculosis or 'M.tuberculosis'. 'Mycobacteria' means spore-like bacteria. TB bacilli are slow growing and can survive in the body for many years in a dormant or inactive state. In these cases people are infected but show no signs of TB disease. When the bacilli is awake and dividing people are said to have 'active TB'. TB can affect any part of the body but is most common in the lungs and lymph glands.

How is TB spread?

1.14 Anyone can catch TB. Although TB is increasing in the UK , generally it remains quite rare (less than 7000 new cases in the year 2000) and is predominantly confined to the major cities. In the UK, people who are at most risk of developing TB disease are;

- Close contacts of an infectious case.
- Those who have lived in places where TB is still common.
- Those whose immune system is weakened by HIV or other medical conditions.
- Young people and very elderly people.
- People who experience chronic poor health through lifestyle factors such as homelessness, alcoholism and drug abuse.

1.15 People with active TB affecting the respiratory tract can infect others, but not all people with respiratory TB are infectious. Other forms of TB e.g. lymph or bone are not infectious. TB is spread when the microscopic bacillus attaches itself to an aerosol of tiny droplets of mucus and saliva produced when an infectious person talks, coughs or sneezes – other people then inhale these droplets. In poorly ventilated areas the

[7] Minutes: 20th May 2002

bacillus can remain suspended for several hours. Most people who get TB have had a prolonged exposure to an infectious person – usually someone in the same household. TB cannot be caught on the bus, tube or through spitting.[8]

1.16 Studies have demonstrated that only about 30% of healthy people closely exposed to TB will get infected. Young children exposed to TB are more likely to develop the disease than healthy adults. What happens to the TB bacilli once in the lungs is largely determined by the individual's immune response. 70% of healthy TB contacts will completely eradicate the bacilli and show no signs of infection, the remainder will become infected, but only 5%-10% will develop active TB.

1.17 When someone is diagnosed with TB a team of specialist health professionals will make an assessment of the infection risk posed to others. If TB bacilli are found in the sputum of the TB sufferer then their contacts will be investigated to identify others who may have been infected. Contacts are defined as "close" meaning household and close family and "casual" meaning friends, work colleagues, schoolmates etc. Casual contacts are only investigated if the TB sufferer is assessed to be a serious infection risk. If you are identified as a contact at risk from TB you will be invited for screening.

1.18 Screening consists of a skin test to determine if the immune system recognises TB. The skin test is done in one of two ways. The most common method is called the Heaf test which shows results within a week. The other is called the Mantoux test which can be interpreted after three days. Both tests are safe and involve a small and virtually painless injection into the skin of the forearm. If the skin test is strongly positive a chest X-ray may be required.

Symptoms of Tuberculosis

1.19 Because TB can affect almost any part of the body the symptoms are extremely varied.

The most common symptoms include:-

- Cough - lasting for more than two weeks and sometimes with blood streaked sputum
- Shortness of breath
- Loss of appetite and weight loss
- Fever and sweating – particularly at night
- Extreme fatigue and tiredness

Treating Tuberculosis

1.20 TB is now curable with antibiotics that must be taken for at least six months. Modern TB drugs are extremely effective and in nearly all cases TB sufferers are not infectious and feel much better after the first two weeks of medication. TB drugs are always prescribed in combination to reduce the risk of the TB bacilli becoming resistant to one or more of them. For this reason patients are started on three or four different drugs which should be taken daily or in certain situations can be taken three times a week on the advice of a specialist.

[8] Minutes of Evidence 20 May 2003

1.21 A course of TB drugs lasts for at least six months because the medicine is most effective against bacilli that are "active" and growing. Six months of TB medication has been demonstrated as the most effective duration to ensure that the dormant bacilli are also killed and cannot cause TB disease in the future. It is vital that the medication is taken as prescribed. Taking TB medication in the wrong dose, intermittently or for too short a time can result in the development of drug resistance making the disease much harder to treat and significantly increasing the risk of long term complications or death.

1.22 Some patients may require supervision of their treatment to ensure that they complete the course and that they take the treatment properly. This is known as Directly Observed Therapy (DOTs). Under DOTs health workers observe patients swallowing the full course of the correct dosage of TB medicine. DOTs is commonly provided by nurses, but others such as community workers can also be trained to provide this service.[9] DOTs was introduced on a global scale in 1991. Approximately 10 million patients have received TB medicine through this procedure. DOTs produces cure rates of up to 95% even in the poorest countries. It prevents new infections by curing infectious patients and prevents the development of drug resistance by ensuring that the full course of treatment is followed in the appropriate way.[10]

Challenges Presented by HIV

1.23 TB patients may suffer from a range of other conditions including drug and alcohol problems, HIV, diabetes, renal problems, psychiatric problems etc. As mentioned above global rates of TB have been accelerated by HIV. HIV weakens the immune system, thereby increasing susceptibility to TB. TB is a leading cause of death amongst people who are HIV positive. In their written evidence, the Health Protection Agency informed us that there are indications that TB co-infection with HIV is an increasing problem in London.[11] Recent reports from London hospitals suggest rates of co-infection as high as 17 to 25%.[12] In these circumstances it is necessary to treat both diseases and this necessitates a far more complex treatment regime. It is therefore important that people with TB be offered HIV counselling and testing so that appropriate treatment regimes can be initiated.

1.24 The NHS in London has developed five targets for the control of TB in the region which we discuss in Chapter three. One of these targets is that by April 2002 all patients presenting with/being treated for TB would be offered and recommended an HIV test. The NHS is currently working towards meeting this target on HIV testing.[13] We believe this is a crucial area. It impacts on the health of the individual and also on the health of the wider community. It is of particular importance because accurate diagnoses is vital in order to treat TB properly and to ensure that the right combination of drugs are given for the treatment of HIV. Both infections are life threatening and require a demanding regimen of drugs. The Health Committee will also be considering the issue of HIV and Aids.

[9] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[10] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[11] Memoranda: Health Protection Agency
[12] Memoranda: Health Protection Agency
[13] Memoranda: Health Protection Agency

Recommendation: 1

The NHS target on offering HIV testing and counselling for all TB patients, which we welcome, must be implemented across London as a matter of urgency. The Regional Public Health Team must inform us when the arrangements for HIV testing and counselling are in place in all TB treatment centres in London.

Challenges Presented by Drug Resistance

1.25 TB can become resistant to treatment. When this occurs there is the need for more complex drugs which have to be taken for longer than the standard six months. Resistance to drugs develops where treatment is interrupted or is not taken in the correct way. Resistance can be developed to a single drug or to more than one of the drugs (multiple drug resistance). Multiple drug resistant TB is potentially life-threatening and is extremely expensive, both in terms of the types of drugs needed to treat it, and the need for long periods in hospital. Drug resistance is becoming an increasing problem in the capital.[14]

1.26 We were informed that the most common form of single drug resistance is to Isoniazid, which is the most effective of all the first line TB drugs.[15] In 1999 an outbreak of Isoniazid resistant TB in London, accounted for 8% of total London TB cases. This outbreak was associated with marginalised groups of people who also had other complex health needs. Many of these people found it difficult to adhere to their TB treatment.[16] **The Health Protection Agency informed us that multi-drug resistant TB is more common in London than anywhere else in England and Wales.[17]**

1.27 The treatment for drug resistant TB is complex and extremely expensive. It has been estimated that the cost of treating ordinary TB is £6,040 per patient. This rises to £60,000 for each patient with multiple drug resistant TB.[18] This increased cost has had an enormous impact on the budgets of the NHS in London. Although we do not have recent figures, in March 2001 the London TB Group estimated that in 1999 54.5% of the national total of multiple drug resistant TB cases were treated in London at a cost of £1 million to the London NHS.[19]

1.28 The money for the treatment of TB is part of the total financial resources allocated to Primary Care Trusts. There are occasions when the Department of Health is able to secure additional non- recurrent funding. We were informed that an additional £430,000 has been secured this financial year (2003/04).[20] This additional sum of money will be allocated across London according to the number of TB cases in an area.[21] Although this is a helpful amount and a large proportion of the financial

[14] Memoranda: Gini Williams City University
[15] Memoranda: Gini Williams City University
[16] Memoranda: Gini Williams City University
[17] Memoranda: Health Protection Agency
[18] TB Control in London - Next Steps London TB Group March 2001
[19] TB Control in London - Next Steps London TB Group March 2001
[20] Minutes of Evidence 20th May 2003

resources allocated nationally for TB, we were informed that it is not enough. There is no guarantee that additional funding will be secured in future.[22]

1.29 **There are alarmingly high rates of multiple drug resistant TB in Asia, parts of Eastern Europe and countries of the former Soviet Union. As a result of London's global position, the NHS in London must be prepared for a future Increase in the number of cases seen in the capital.[23] Given the total cost involved in treating these patients, it is essential that London treatment centres receive additional financial support for treating cases of multiple drug resistant TB.**

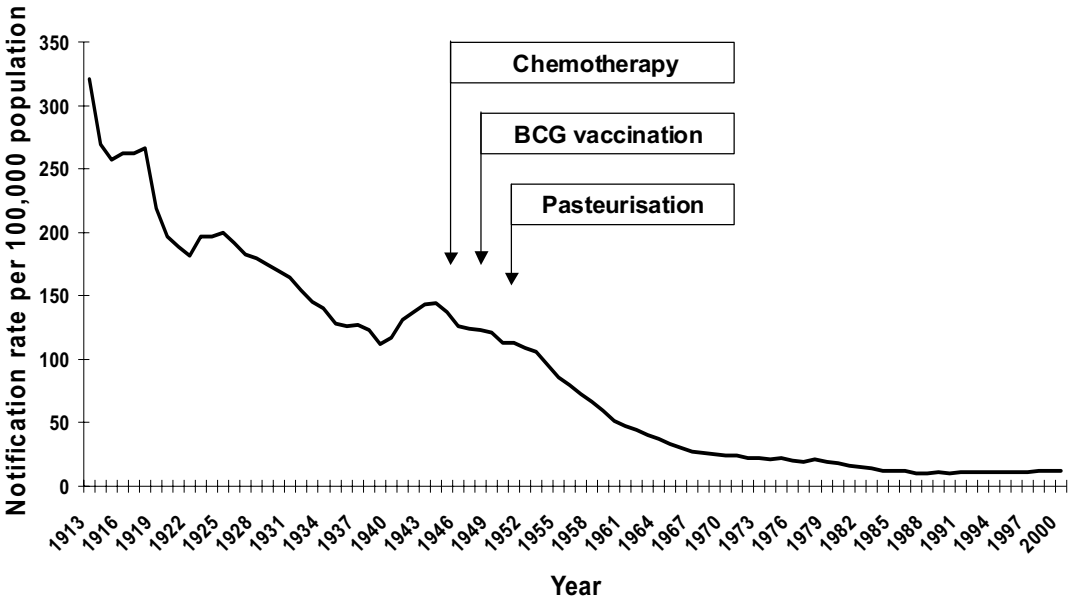
Recommendation 2:

We call upon the government to recognise the cost of treating multiple drug resistant TB and reflect this in the allocation of financial resources to London Primary Care Trusts.

[21] Minutes of Evidence 20th May 2003
[22] Minutes of Evidence 20th May 2003
[23] Memoranda: British Thoracic Society

2. Tuberculosis in London

Tuberculosis Notification Rates for England and Wales 1913-2000[24]



Tuberculosis in England and Wales

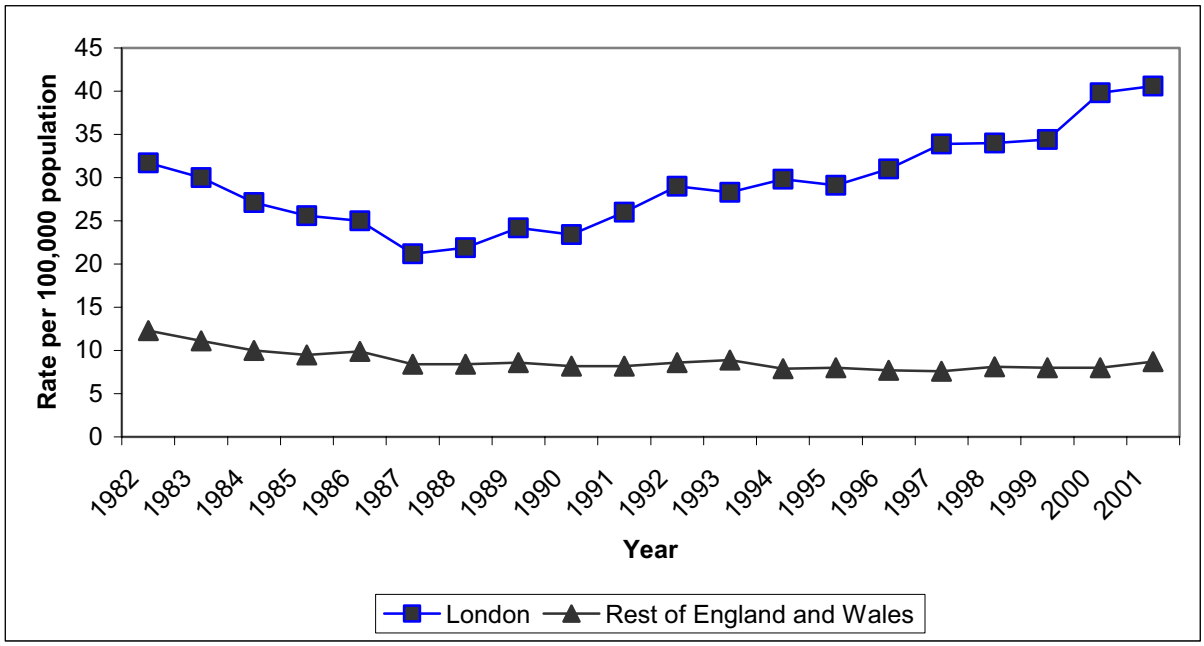
2.1 The table above illustrates that since 1913 rates of TB in England and Wales have fallen. In 1913, there were more than 100,000 new cases annually. By the mid 1980's there were between five and six thousand cases of TB per year.[25] The decline in TB was largely due to improved nutrition, social and environmental improvements, and the alleviation of absolute poverty.[26] This shows the impact social and economic factors can have on the treatment and transmission of the disease. Unfortunately these numbers have now increased. In 2002 there were 6891 new cases of TB in England and Wales.[27] TB is still an important cause of mortality. In 1999 there were 976 TB related deaths in England and Wales.

Tuberculosis in London

2.2 In 1987 TB cases in London accounted for only 14 per cent of the national total. Rates across the UK are now stable or in decline, but rates of TB in London have continued to increase.[28] **Over 40% of all TB cases in England and Wales now occur in London. This is the highest TB rate of any region in England and Wales. The incidence of TB in London is now three times higher than the national rate**.[29] The rates of TB cases for individual London boroughs can be found in Appendix A.

[24] Memoranda; Health Protection Agency
[25] Memoranda; Health Protection Agency
[26] Memoranda; Department of Health
[27] Memoranda; Health Protection Agency
[28] Memoranda; Health Protection Agency
[29] Memoranda: Health Protection Agency

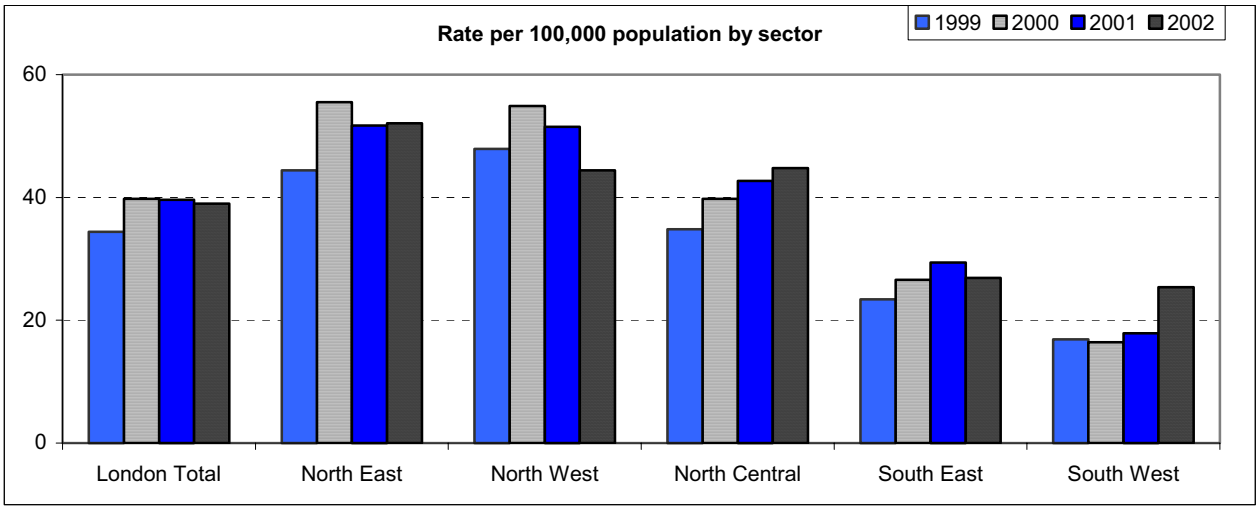
TB Notification Rates per 100,000 Population per Annum 1982-2001[30]



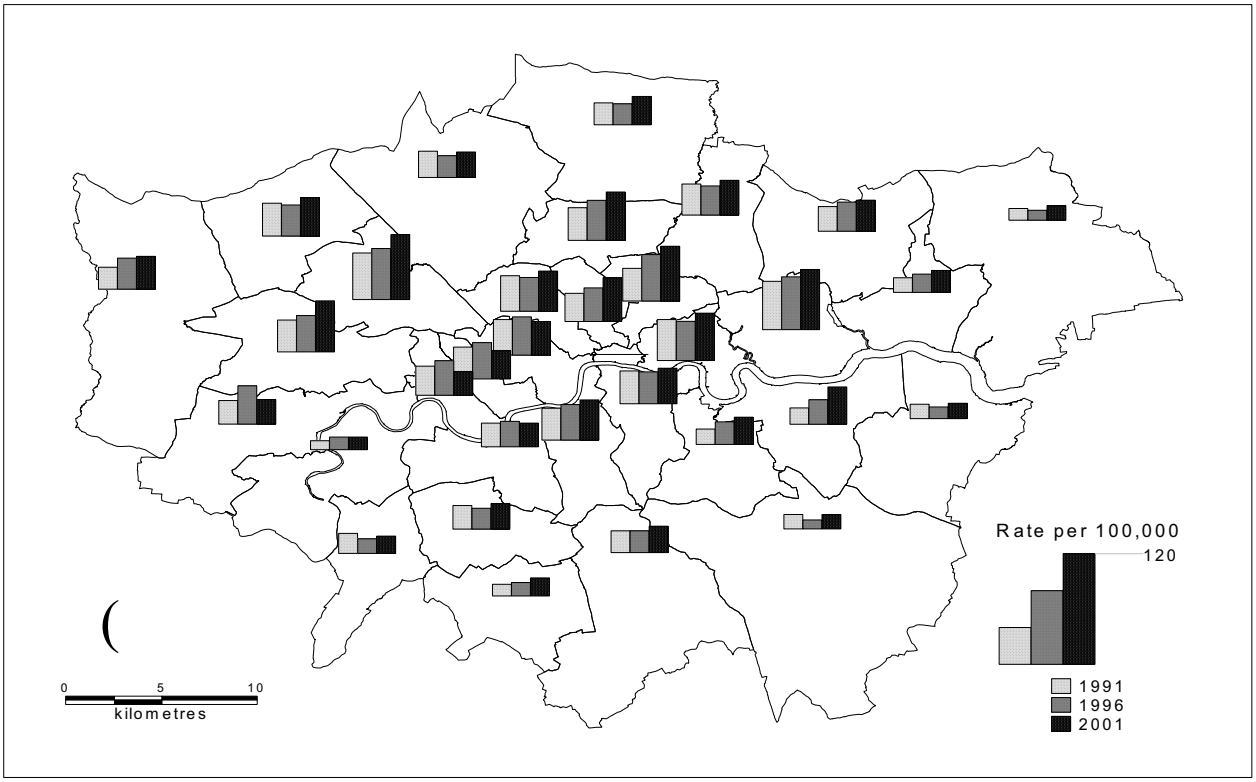
2.3 TB is concentrated in particular parts of London. In 2001, twelve London boroughs had TB rates of over 40 notifications per 100,000 of the population. Rates are greatest and rising fastest in the North East and North West NHS Sectors of London. (See Appendix E for the list of boroughs in each NHS sector) In the last decade rises have been up to fourfold in Hillingdon, Enfield and Greenwich. Cases have doubled in Barking, Ealing, Hackney, Islington, and Lewisham.[31]

[30] Memoranda: Health Protection Agency
[31] Memoranda: Health Protection Agency

Rates of TB Notification by London NHS Sector [32]



Changes in the Rates of TB infection by Borough Over the Last 10 Years [33]



[32] Memoranda: Health Protection Agency
[33] Memoranda; Health Protection Agency

The Social and Economic Aspects of TB

2.4 Certain population groups are far more susceptible to infection and disease than the general population, and are therefore at greater risk of catching TB. Groups at a higher risk of catching TB include homeless people, arrivals from high-prevalence countries, people whose immunity to disease is damaged through HIV infection, those suffering from drug or alcohol dependence, people with poor nutrition and prison populations.[34] These people are more likely to be found in urban centres such as London and are often socially marginalised. In our Access to Primary Care scrutiny we highlighted how people from these groups experience poor access to health services in spite of having complex and challenging health needs.[35] This social marginalisation makes it far more difficult to identify and treat people with TB from these high-risk groups.

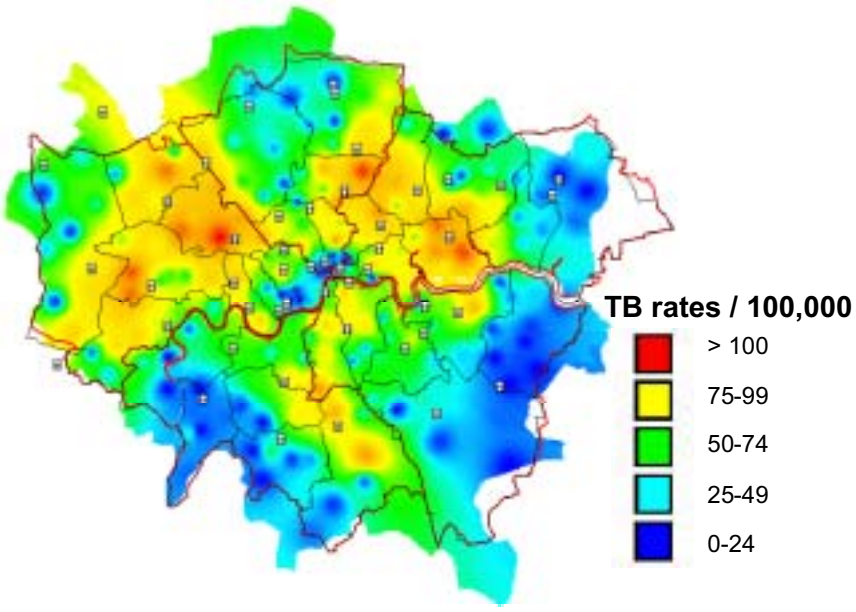
2.5 In London the areas where TB is prevalent closely correspond to those areas with high indices of deprivation, although some suburban areas also have high rates of TB. The red areas on the first map below indicate the areas in London where TB is prevalent. These areas correlate quite closely with the multiple indices of deprivation shown on the second map. **This demonstrates that there is an intersection between a medical problem (TB) and a social one (deprivation and poverty).[36]**

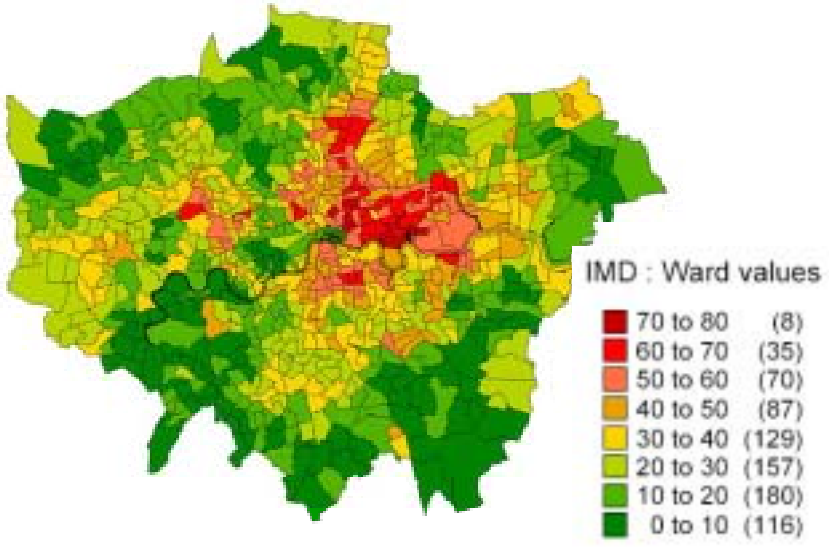
[34] Memoranda: Health Protection Agency, World Health Organisation Tuberculosis Factsheet 104 Revised 2002

[35] Access to Primary Care Report, Greater London Authority April 2003

[36] Minutes of Evidence 20 May 2003

Spatial Analysis of Tuberculosis Rates (2001) by Postal District and Index of Multiple Deprivation (IMD) 2000 – London Wards[37]





[37] Memoranda: Health Protection Agency (Provisional 2001 Enhanced Surveillance Data)

3. Existing Methods of Tuberculosis Control

London Region Targets for Tuberculosis Control

Target 1: 100% monitoring of outcome of treatment and treatment completion. (At least 90% by April 2001)

Target 2 Specialist TB nurses in post across each sector equivalent to one nurse per 40 notifications by April 2002.

Target 3 A comprehensive TB network in each sector of London

Target 4 By April 2002 all patients presenting with/being treated for TB to be offered and recommended an HIV test.

Target 5 All clinics to have full connectivity to NHS Net in order to link to the London TB register in 2001/02.

3.1 The successful prevention and control of TB in London depends on the implementation of methods of TB control across the city. For such methods to be effective the social and economic circumstances of patients must also be taken into consideration, both when developing methods of control and when initiating treatment of the individual. The Department of Health has recognised that TB is a problem for London, and has stated that the prevention and control of TB should be one of the four national priorities for serious infectious disease.[38] London is unique in having TB as an NHS Priority since 2001.

Responsibility for TB Control in London

3.2 In 2000 the then NHS London Regional Office set five targets for better TB control for the health service to achieve specifically within London.[39] Within the NHS, the Strategic Health Authorities manage the performance of Primary Care Trusts and Acute Trusts to ensure those Trusts meet the targets shown in the table above.[40] The Health Protection Agency, a new national organisation for England and Wales, was established on 1 April 2003 and is specifically dedicated to protecting people's health by a range of methods including the reduction of infectious diseases. The London branch of the Health Protection Agency is working alongside the NHS, providing specialist support in a range of areas including communicable disease and infection control. This includes the control of TB in the capital.

[38] Getting Ahead of the Curve: A strategy for combating infectious diseases (including other aspects of health protection). DOH: A report by the Chief Medical Officer. Jan.10.2002.
[39] Memoranda: Health Protection Agency
[40] Minutes of Evidence 20th May 2000

Surveillance of TB

3.3 Surveillance of TB is the term used for gathering and analysing information about the disease. This includes information about the numbers and rates of TB cases, where TB is occurring, who is affected, the factors affecting the spread of the disease, antibiotic resistance, and the outcome of treatment. This information is necessary to enable the health services control the disease. Surveillance is based on information from clinical and laboratory reports. [41]

3.4 We were informed that new systems of surveillance are planned at a national level in which London will participate. These will include surveillance of incidents and outbreaks of TB, and a new system for monitoring TB in prison populations.[42] Some of the different methods of surveillance and TB control are explained below.

Workforce Issues

Target 2: Specialist TB nurses in post across each sector equivalent to one nurse per 40 notifications by April 2002.

3.5 Our evidence shows that since the introduction of this target, the number of TB nurses in London has increased. However there still remain areas where the ratio, as stated in the target, has not been met and staff are working to a much higher patient to nurse ratio. Some clinics are very well staffed while others are in need of additional funding or are having persistent difficulties recruiting. Some Primary Care Trusts (PCTs) are making substantial extra investment for 2004/5 to ensure that this staffing ratio for nurses is achieved.[43] **In London there are continuing difficulties in the recruitment and retention of health care workers from all disciplines, and we are pleased to see that despite these difficulties effort is being made to achieve this target.**

3.6 The role of the nurse in TB management is vital and there are opportunities for this role to be developed. Nursing staff account for the largest workforce in TB services and are the only group that focus entirely on the disease.[44] TB nurses provide a wide service. For TB patients the nurse is their constant link to the health service. Over a period of time patients build up a relationship with the nurse and feel able to confide in them. The TB nurse will often become involved in resolving some of the social needs of the patient. As well as focussing on the clinical aspect of the disease, TB nurses are heavily involved in issues such as housing, liaising with social services and other agencies, welfare advice etc. We discuss this further in the chapter on partnership working.

[41] Memoranda: Health Protection Agency
[42] Memoranda: Health Protection Agency
[43] Memoranda: Department of Health, Health Protection Agency
[44] Memoranda: London TB Nurses Group

3.7 The British Thoracic Society highlight the need for the more efficient use of respiratory physicians. They state that this could lead to improved waiting times and patient satisfaction. We were informed that most respiratory physicians do not deal exclusively with TB but have many other responsibilities. **The British Thoracic Society contend that in the light of increasing TB workloads, these staffing levels should be audited to ensure that the workloads are acceptable. The increased number of TB cases, leading to heavier workloads, means that waiting times for appointments and waiting times in clinics will continue to increase.**[45] Ensuring that there are adequate numbers of trained respiratory physicians would improve the quality of service to patients.[46]

Recommendation 3:

The Strategic Health Authorities (Workforce Development Confederations) should conduct an audit of the staffing levels within their TB treatment centres in order to identify accurately the numbers and types of staff required. Where numbers fall short of the identified targets, efforts must be made to recruit and retain staff so that patient care is improved.

Target 3: A comprehensive TB network in each sector of London

3.8 This target for London has been achieved. There are five NHS sector-based TB Networks in London. Geographically they mirror the boundaries of the five Strategic Health Authorities. Each sector has a steering group with a lead physician, nurse and consultant in communicable disease control and representatives from local trusts. Each sector has developed its own TB work programme. Most have produced joint protocols for patient diagnosis and care. Each sector network sends representatives to the meetings of the London TB Group.[47]

3.9 The London TB Group was established in 1999. It consists of representatives from each NHS sector as well as professionals from other organisations. The group has produced several reports and made recommendations to Government on the progress of TB control in London.[48]

[45] Memoranda: British Thoracic Society
[46] Memoranda: British Thoracic Society
[47] Memoranda: Health Protection Agency
[48] Memoranda: Health Protection Agency

Early Diagnoses

3.10 In their written evidence the Health Protection Agency informed us that early diagnosis and effective drug treatment of infectious cases is the single most important intervention to control tuberculosis.[49] This was also highlighted by a variety of organisations as being crucial to the prevention of transmission.[50]

3.11 Early diagnosis of TB is dependent upon:

1. Patient awareness of the disease.
2. Access to health services.
3. Early recognition of the disease by health care workers.
4. Diagnostic services.

Patient Awareness

3.12 Where the patient is aware of the symptoms of TB and seeks medical assistance this can aid early diagnosis and treatment can start, thereby preventing the transmission of the disease to others. Patient awareness is of particular importance amongst communities with a high prevalence of the disease. Stigma associated with the disease can sometimes be a factor preventing patients seeking help. There is a high degree of stigma associated with TB in many cultures, especially as it is so closely associated in Africa with HIV co-infection.[51] PCTs and Trusts should develop regular programmes to raise community awareness of TB and the available health services.

Access to Health Services

3.13 A patient cannot start treatment if they are unable to gain access to the health service. Our scrutiny into access to primary care highlighted the fact that the sections of the community with the greatest health needs often have the poorest access to the relevant health services, and encounter different types of barriers in accessing health care.[52]

3.14 Access to health services depends upon the availability of appropriate information, geographical location, ease of GP registration, availability of public transport, physical accessibility to the health service premises, health service opening hours and language support. Language support is also crucial not just in enabling access to health services, but in enabling the patient to take the medicine properly. Where complex or long treatment is required, such as for TB, language support is crucial. Directly observed therapy therefore has a vital role to play in enabling patients to adhere to the TB treatment regime, particularly where English is not the patient's first language.[53]

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[49] Memoranda: Health Protection Agency
[50] List of Written Evidence Appendix C
[51] Memoranda: Health Protection Agency
[52] Access to Primary Care, Greater London Authority, April 2003
[53] For an explanation of DOTs - see paragraph 1.22

Recognition by Health Care Workers

3.15 Early recognition of symptoms by doctors and other health care workers is an essential element of TB control. Although much attention is paid to high-risk groups, it is important to ensure that TB is recognised when it occurs in low-risk groups at the early stages of the disease. To prevent delays in diagnoses requires an increased awareness amongst staff within primary care, community, voluntary and statutory organisations.[54] The Department of Health should examine the issue of delayed TB diagnoses and ascertain how much of a problem this is in London.

Recommendation 4:

The Department of Health should examine the issue of delayed TB diagnosis and ascertain how much of a problem this is in the capital.

Diagnostic Services

3.16 Local diagnostic services including microbiology, radiology and histology are all essential to the prompt diagnosis of TB. Good communication between diagnostic services and TB services, with provision for the rapid feedback of results is critical.[55] This facilitates timely decisions about the treatment of patients (for example, whether a patient should remain isolated or not) and also allows the patient to start treatment early. Rapid feedback of results also allays patient fears.[56]

3.17 We asked witnesses how long it takes from the examination of a patient to diagnosis. We were told that in some situations it can take from six to eight weeks, whereas in others it may only take up to two weeks, although where there is a strong indication of TB, treatment will be started immediately.[57] One obstacle to rapid diagnosis is the lack of accurate diagnostic tools. The diagnostic tools that are currently used have been available for the last fifty years. There is a need to fund research into developing new, swifter diagnostic methods.[58]

3.18 We were also informed that a new liquid culture can be used which only takes two weeks to diagnose TB and so can lead to early treatment. Despite these obvious advantages, it is not widely available in London. We were informed that in one NHS sector which has rising levels of TB there are at least four Trusts that do not routinely provide or purchase this service.[59]

[54] Memoranda: Health Protection Agency, British Lung Foundation, TB Alert
[55] Memoranda: Gini Williams, City University
[56] Memoranda: Gini Williams, City University
[57] Minutes of Evidence; 10th June 2003
[58] Memoranda: St Marys NHS Trust
[59] Memoranda: Gini Williams, City University

Recommendation 5:

The Strategic Health Authorities in London must ensure that there are sufficient rapid and consistent systems for the early diagnosis of tuberculosis in the capital.

Notification of Tuberculosis

3.19 Notification of all cases of TB is a legal requirement. This is the statutory responsibility of the doctor. Notification is vital to TB control because the process yields information which is then used for epidemiological purposes. It is also vital for initiating contact tracing. In some areas where TB is not prevalent, TB nurses rely on the notification process to find out about local cases before they become involved in the care of the patient. Notification is also used to initiate contact tracing.[60] Notification is an extremely crucial stage of TB control. Where notification is inaccurate it may result in patients being denied access to care and the screening of those who have been in contact with the TB patient may then not take place.

Contact Screening

3.20 TB is spread through close contact. Close contact generally means those we live with, close friends and those we work with. Contacts of infectious cases are likely to become infected. The level of risk varies according to the amount of exposure and the individual's general state of health. 10% of tuberculosis cases are identified through contact tracing. Contact tracing of children is particularly important, as they are vulnerable to more serious forms of TB. [61]

3.21 Tracing close contacts of a person who has TB is generally the responsibility of the local TB clinic. Good co-ordination between clinics is needed when contacts live in an area not covered by the health service which is carrying out the tracing. If TB clinics have different approaches to contact tracing there may be duplication or some cases may be missed. We were informed that there are difficulties with contact tracing because many Trusts/TB clinics do not have the necessary nursing support to ensure the rapid and comprehensive screening of all contacts.[62]

[60] Memoranda: Gini Williams
[61] Memoranda: Gini Williams
[62] Memoranda: Gini Williams

The London TB Register

Target 5: All clinics to have full connectivity to NHS Net in order to link to the London TB register in 2001/02.

3.22 The London TB register was developed for use by London TB treatment centres in late 2001. It is a secure database designed to collect surveillance and treatment information on TB patients in London. The register allows TB treatment centres to share patient information, thus improving and co-ordinating the care of TB patients across London. Target 5 above has been met, and all London TB clinics are connected to the register, which now holds 4,800 patient records.[63]

3.23 Among other things the register:

- allows a clinician, nurse (or authorised member of staff) to determine quickly if a patient has had previous episodes of TB and if there were any management issues (e.g. poor compliance, high vulnerability or anti-microbial resistance).
- allows tracking of patients who move between districts and between clinics in London.
- allows alerts to be posted on the system (for example, for patients who have failed to attend their appointments whilst on drug treatment, for patients with known drug resistant TB or for patients who may be part of an outbreak).
- allows clinics, NHS sectors and the Health Protection Agency to obtain reports for their own areas. (Reports include episode outcomes, number of notifications and de-notifications, age group, ethnic group, site of disease, drug sensitivity, hospital admissions, smear results, case manager assignment etc).[64]

3.24 At the Newham Chest clinic we were given a demonstration of how the TB register operates. It is proving to be a very effective system for London. Our only concern is that this is not a national system. The TB register should be extended nationally, so that the care of TB patients can be monitored across regions. This is of particular importance for those communities at high risk, as these communities are highly mobile.

3.25 We recognise that this will have cost implications and for areas of the country where rates of TB are low it may not prove to be cost effective, but we are convinced that there are merits in the TB register being extended nationally. We feel that this is of great importance because high-risk categories such as the homeless are highly mobile and their TB treatment may be disrupted. It is also important that TB cases can be identified and contact tracing is carried out, even if it involves tracing patients and contacts to a PCT outside London.

3.26 The extension of the TB register also assumes greater importance when the impact of asylum seeker dispersal is taken into account. This would help situations where asylum seekers who are being treated for TB are dispersed to other areas of the country where the health services will not be aware of their stage of treatment. This is particularly important, as disrupted treatment might lead to drug resistance.

[63] Memoranda: Department of Health
[64] Memoranda: Department of Health

Recommendation 6:

A national TB register modelled on the London TB register should be developed.

BCG Vaccinations

3.27 In high prevalence areas of London, children are given the BCG vaccination immediately after birth. All children in London are given the BCG at adolescence.[65] We were informed that the effectiveness of the BCG vaccine in tuberculosis control is an issue of much debate. The Health Protection Agency informed us that in the UK, BCG has not proved to be very effective in preventing cases of pulmonary disease in the adult population, but prevents mortality associated with the more severe forms of tuberculosis in young children.[66] Whilst we are unable to debate the clinical merits of the BCG vaccination, we are pleased to note that it does provide some form of protection for young children.

Mobile Digital Chest Radiography Unit

3.28 The Department of Health informed us that it intends to strengthen TB control in London by targeted active case finding, using a mobile digital chest radiography unit, capable of safely screening 300 people a day.[67]

3.29 The programme will be hosted by one acute trust on behalf of all London primary care trusts and will be managed by a steering group. This programme will help develop a strategic approach to the management of infectious diseases amongst vulnerable groups such as prisons populations and rough sleepers. The unit will also be used to assist in the management of outbreaks. [68] We welcome this new development and ask that we be kept informed of the implementation of this new process. The progress of this method of TB control must be evaluated and its impact on the identification of TB cases in the capital (and its efficacy as a method of TB control) should be regularly evaluated.

Recommendation 7:

We welcome the use of the new Mobile Digital Chest Radiography Unit for targeted active TB case finding in London. We ask that the Health Protection Agency keep us informed of the implementation of this new process and that the efficacy of this method of TB control be regularly evaluated.

[65] Minutes of Evidence 20th May 2003
[66] Memoranda: Health Protection Agency
[67] Memoranda: Department of Health
[68] Memoranda: Department of Health

Screening of New Entrants

3.30 New entrant screening is a challenge to organise and has not been an effective method of TB control. *'With regard to the issue of screening of new arrivals, this is patchy as the port of entry scheme is regarded as being of extremely poor yield given the rapid movement of individuals and the current dispersal policy.*[69] The London TB Group set up a task group to consider this issue and they have made several recommendations including; improving access to primary care, the involvement of GPs in the screening process, developing national guidelines on new entrant screening and the need for research into effective methods of screening delivery.[70]

3.31 Although there is a clear need to screen people coming to settle in the UK, particularly those arriving from countries with a high prevalence of TB, a number of different approaches will be needed in order for new entrant screening to be effective as a method of TB control. New entrant screening should not just be focused at the ports of entry. Dr John Hayward of Newham Primary Care Trust, informed us that TB reflects an individual's susceptibility to catch the disease.[71] This susceptibility becomes greater for those who are deprived or impoverished. Therefore prevention and control of TB in the UK must be set in a wider context and not seen solely as the responsibility of port of entry officials,

3.32 Most new entrants who develop TB in the UK do so some time after arrival in the country. For some, this happens many years after arrival. For example, 56% of people develop TB at least five years after arrival, and 40% after ten years. It may be that the infection is present on arrival but latent for many years before developing into disease, or that the person is infected in the UK.[72] The implications of this are that screening prior to, or at the time of arrival is only part of the strategy to limit this occurrence of the disease. Raising awareness of the symptoms of the disease and ensuring that new entrants have prompt access to diagnosis and treatment are crucial in controlling its spread.[73] If screening takes place in a primary care facility in the new entrant's district of residence, this will enable not only TB screening, but also the delivery of other relevant health promotion and disease protection measures.[74]

3.33 It is clear that primary care has a greater role to play in the screening of new entrants. The Royal College of General Practitioners suggest that new entrant screening needs to be clearer with good communication to the GP.[75] In Newham the screening of new entrants to the UK is successful. The TB screening programme (New Entrant Screening) began in December 2001. Over 1400 clients were approached and invited for screening and 1367 (over 95%) agreed to be screened. Of these 83 (6.1%) were started on antibiotics for latent TB. Only one client from the 1367 was diagnosed with active TB. This screening service was made possible by a bid from Newham for Public Service Agreement (PSA) funding.[76]

3.34 There is a greater role that primary care services could play in the screening of new entrants. However this must be adequately resourced and based on research identifying

[69] Memoranda: St Mary's NHS Trust
[70] TB Control in London, The Next Steps, London TB Group March 2001
[71] Minutes of Evidence 20th May 2003
[72] Health Protection Agency
[73] Health Protection Agency
[74] Memoranda: British Thoracic Society
[75] Memoranda: Royal College of General Practitioners
[76] Memoranda: Professor Stephen Farrow, Newham TB Scrutiny Report

the best methods of such screening. Primary care based screening will also enable the diagnosis and treatment of latent TB and therefore prevent the reactivation of infectious TB. We are pleased to hear that the Health Protection Agency are currently conducting a modelling study to examine the issue of new entrant screening.

Recommendation 8:

We welcome the Health Protection Agency modelling study examining the issue of new entrant screening. The outcome of this study should lead to a clear strategy on new entrant screening which is supported by adequate financial resources, properly co-ordinated across all the relevant agencies and monitored for its effectiveness.

Treatment Completion

Target 1: 100% monitoring of outcome of treatment and treatment completion. At least 90% by April 2001.

3.35 The completion of TB treatment is essential for the control of the disease.[77] We were informed that the monitoring of treatment outcomes is now fully established across London and so this target has been met. Current results suggest around 79% of TB cases in London complete treatment.[78] The Health Protection Agency informed us that it is intended that the TB register will be used as a tool for monitoring treatment outcomes. This will include improving the baseline information used at local levels as well as improving the reporting mechanisms at regional and local levels.[79]

3.36 The level of treatment completion in London needs to be improved. WHO recommends 95% treatment completion rates.[80] WHO report that in some countries the use of directly observed therapy has produced cure rates of up to 95%.[81] We would like to see London achieving similar rates.

3.37 There are also other factors that will boost treatment completion rates.[82] These include:

- Providing TB drugs free of charge to TB patients across the capital.
- Ensuring that aspects of care for other issues the patient may have (such as HIV and substance abuse) are integrated in their treatment.
- Holding early multi-disciplinary case conferences for those patients with complex needs. These should involve local authorities as well as health services working in partnership together.
- Developing residential facilities for patients with TB who need high-level social support to be able to complete treatment.

We explore these issues in greater detail in the following chapters.

[77] Memoranda: Department of Health
[78] Memoranda: Health Protection Agency
[79] Memoranda: Health Protection Agency
[80] Minutes of Evidence; 10th June 2003
[81] World Health Organisation Tuberculosis Fact sheet 104 Revised August 2002
[82] Memoranda: Health Protection Agency

4. Improving The Patient Experience

The Issue of Stigma

4.1 For some people, stigma causes a fear and reluctance to admit that they have the disease. As a result there may be a delay in seeking medical assistance which can potentially cause the transmission of the disease to others. It is therefore important to allay the fears of people in the community and create a greater public awareness about TB. Treatment centres must reassure patients that they provide privacy and confidentiality. Local authorities and primary care trusts should ensure that adequate community information is available, particularly in areas of high prevalence.

Raising Awareness

4.2 We were informed that the health promotion of TB is severely lacking across the capital.[83] This is an important link in reducing the stigma that surrounds the disease. There are many popular misconceptions around the transmission of TB and false information regarding treatment. There is much scope to raise the awareness of TB across London.[84] Primary care trusts need to ensure that the negative media profile of TB be addressed as part of public health promotion strategies.

4.3 In Newham the local authority and the primary care trust produced videos for use amongst both the public and council staff in order to raise awareness of TB in the borough. The videos were also produced in the minority ethnic languages that are spoken in the borough. The council and the PCT have used this as a way of informing the community and dispelling some of the myths that surround the issue of TB.

The Housing Needs of TB Patients

4.4 TB patients often have difficulty with housing, particularly those who are single. Living in unstable accommodation or a poor quality environment not only determines whether you will get TB, it is also a factor that determines the chances of successfully completing treatment.[85] People with latent TB often develop infectious TB as a result of living in poor quality accommodation over a number of years.

4.5 TB nurses are often involved in trying to find patients stable accommodation. This is hampered by the fact that TB in itself does not give a patient automatic priority for local authority housing. We conducted a survey of London local authorities and this has shown that there is no systematic approach in deciding whether or not a patient will have priority for housing. Each case is decided on its merits and each local authority differs in its approach. This can only compound difficulties for TB patients and the nursing staff who try to help them. We were told that even if a patient could be given some form of temporary housing for the duration of their treatment, this would go some way to enabling them to complete their treatment.

[83] Memoranda: London TB Nurses Group
[84] Memoranda: London TB Nurses Group
[85] Minutes of Evidence 20th May 2002

4.6 We recognise that there is a strain on London public sector housing stock. We hope that all London local authorities will work closely with the NHS to ensure that where necessary TB patients are provided with some form of accommodation (albeit temporary) which will provide the stability needed for patients to complete their treatment.

4.7 Haringey and Enfield Primary Care Trusts reported that in response to the housing needs of TB patients, discussions have been held with appropriate local authority staff about the housing and support needs of patients. The primary care trusts felt this was crucial because although the number of TB patients with housing difficulties is small in number compared to the total TB patient population, they take up a disproportionate amount of staff time and resources, due to the complexity of their needs.[86] The trusts and the local authorities are providing a range of support depending on the needs of the clients. Networks are being set up with local groups including voluntary sector agencies, to assist with community support.

Treatment Regimes and Incentives

4.8 The treatment of TB presents a challenge for many TB patients. Patients may spend many weeks or even months in hospital, particularly if they have drug resistant TB. Treatment has to be planned on an individual basis and must be closely monitored. Full compliance is essential to prevent the emergence of further resistance.[87] Patients with ordinary TB generally cease to be infectious after the first two weeks of treatment. Although they can be discharged from hospital they will still need to take the TB drugs for at least six months. Patients could be taking up to eight tablets a day for the first two months of their treatment regime.[88] After discharge, maintenance of the complex drug regimen can be difficult and the patient may have to be observed taking their drugs (directly observed therapy).

4.9 In some cases incentives may become necessary in order to encourage the patient to adhere to their treatment. These incentives could include transport costs, refreshments or flexibility with regard to time and location of treatment.[89] Another incentive is the availability of free TB drugs. We were informed that there are inequities in services in different areas, particularly regarding the cost of treatment. [90] Most health care professionals believe that TB treatment should be provided free of prescription charges, but there are some instances where patients have to pay the prescription charge even though TB drugs are very cheap to produce, costing much less than the prescription charge.

4.10 A number of clinics have local arrangements and try to ease the cost for patients who have to pay prescription charges.[91] Where these arrangements are not in place some patients will be faced with the costs of paying for repeat prescriptions for the combination of drugs they need over a six month period. **Cost is a significant barrier to treatment and with an infectious disease such as TB it should not be borne by the patient.[92]** Where possible any barrier to completing treatment should be removed or at least minimised.

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[86] Memoranda: Haringey and Enfield Primary Care Trust
[87] Memoranda: British Thoracic Society
[88] Minutes of Evidence 20th May 2002
[89] Minutes of Evidence 10th June 2002
[90] Memoranda: Gini Williams
[91] Minutes of Evidence 10th June 2002
[92] Memoranda: Gini Williams

Recommendation 10:

NHS Trusts and Primary Care Trusts should enable patients to receive their TB drugs without charge, particularly for those on low incomes. The Department of Health should consider how this could be implemented across London.

Patients Who Are Difficult to Treat

4.11 There remains a small but significant number of individuals who are 'hard to treat' and do not comply with treatment. Between 5-7% of patients are hard to treat, but these numbers are increasing.[93] We were informed that although these patients can be detained under sections 37 and 38 of the Public Health Act (1984) they cannot be forced to take TB drugs.[94] Patients who fail to comply with treatment often have other complex problems such as drug or alcohol dependency. A medical ward in an acute hospital is not an appropriate place to detain patients with challenging social problems.[95] The British Thoracic Society felt that a facility capable of being both voluntary and secure is needed in London to cope with this small number of difficult to treat patients. A therapeutic environment where medical and social problems can be addressed simultaneously would be ideal.[96]

4.12 The London TB Nurses Group supports the idea of providing a therapeutic environment for hard to treat patients. In their evidence they state that this would provide physical and psychological support in a pleasant environment. The facility would only need to provide a small number of places and offer a service to the whole of London. It could be used for individuals detained under the Public Health Act or those who voluntarily request to be admitted.[97] *'This category of 'Hard to treat' patients overwhelmingly involves some of the most vulnerable individuals and therefore the services provided must reflect this. The aim of such a facility would be not only to treat the disease but also give people an opportunity to reflect and to access other services, which might benefit them.* '[98]

Meeting the Diverse Needs of Patients

4.13 The Government's paper, 'Getting Ahead of the Curve' (DoH 2002) addressed the increased incidence of tuberculosis, emphasising the importance of adopting a more patient-centred approach to help patients through their treatment. Initiatives such as the London TB Register and the adoption of a more patient-centred approach to treatment will certainly encourage services to be more responsive to local needs.[99] We were informed that the addition this year of socio-economic as well as clinical profiling of patients will facilitate this response. In 2001 a profile of patients was piloted and this indicated the need for more joint planning with non-medical services in order for the diverse needs of patient to be met.

[93] Minutes of Evidence 10th June 2003
[94] Memoranda; British Thoracic Society
[95] Memoranda; British Thoracic Society
[96] Memoranda; British Thoracic Society
[97] Memoranda; London TB Nurses Group
[98] Memoranda; London TB Nurses Group
[99] Memoranda; Gini Williams

5. The Need for Partnership Working

5.1 We were informed that generally in dealing with TB in the capital, there has been a tendency to focus (quite correctly) on the medical aspects of the disease.[100] This approach works well for people who can easily access health care, but as highlighted in the previous chapter, the rising levels of TB, coupled with the complex needs of patients require a strategy to be developed that takes into account the social needs of patients. Unless patients problems such as homelessness, loss of work, drug or alcohol addiction etc are addressed it will be difficult to control TB in London.

5.2 In addressing the needs of the patient in a more holistic way, not only will TB be treated, but some of the underlying social needs will also be addressed. This requires all the necessary organisations to work in partnership with each other. It is necessary to diversify the skills involved in TB care (i.e. drug misuse workers, homeless services, benefit advice etc.) to reflect the wider needs of TB patients in the capital. Depending on the local circumstances it may be appropriate to incorporate these diverse roles into TB services, or develop links locally with different organisations.[101]

5.3 In our Access to Primary Care Scrutiny (April 2003) we highlighted the benefits that patients derive from the presence of welfare advisers within the health care setting. We highlighted research showing that where advice workers are placed within health settings patients benefit through reduced stress and increased well-being.[102] We saw this principle in action on our visit to the Newham Chest Clinic. Although the nurses there are still involved in resolving some of the social concerns of patients, a welfare rights adviser visits the clinic in order to assist with some of these issues. This relieves some pressure from the nursing staff and enables them to focus on treatment, as well as addressing the social needs of the patient.

5.4 Finding and treating infectious cases is also an area where there is a need for a partnership approach. Other agencies have a vital role to play both in identifying cases and helping patients to access and complete their treatment. Organisations that provide services to high-risk groups should, in partnership with the local NHS, provide training for their staff in symptom recognition and supporting clients to gain access to health services. Such agencies might include social services, education services, voluntary organisations, prisons and the police, amongst others. The roles of these organisations should be agreed and integrated into the planning of awareness campaigns and screening programmes.[103]

Recommendation 11:

The Health Protection Agency should develop a specific set of guidelines which will help other public sector agencies identify possible cases of TB and refer people to the appropriate health service.

[100] Memoranda: Gini Williams, City University
[101] Memoranda: London TB Nurses Group
[102] Access to Primary Care Report, Greater London Authority April 2003
[103] Memoranda: Health Protection Agency

Three Boroughs Primary Healthcare Team (Lambeth PCT) [104]

Within the Three Boroughs Primary Healthcare Team (Lambeth PCT) a joint TB/Homeless post is funded. This post brings together the two specialities to provide a seamless service. Through screening and education of local hostel staff and homeless workers, TB symptoms are diagnosed and referred appropriately and quickly. The post also provides expert case management to this vulnerable group. This can mean working in hostels, day centres and 'on the street' to ensure that treatment is taken in full.

Enfield and Haringey Primary Care Trusts[105]

Links have been made with a number of voluntary groups. This is to ensure appropriate opportunities for increasing public awareness and to work with these groups on the most appropriate way that health promotion and public awareness of TB can be improved.

5.5 The importance of partnership working in the treatment and control of the disease cannot be overemphasised. We recognise that there are often budgetary constraints at local levels, but we wish to emphasise the importance of joint work in this and other areas of the health service. There has been a growing emphasis on partnership working and collaboration in health care policy over the last few years and a number of local planning processes have been developed in order to achieve it (e.g joint investment plans, locality health and social care partnership boards, health improvement and modernisation programmes). Primary Care Trusts are now responsible for commissioning services for TB care and control and are best placed to develop local mechanisms for partnership working.[106]

[104] Memoranda: London TB Nurses Group
[105] Memoranda: Enfield and Haringey Primary Care Trust
[106] Memoranda: Gini Williams

6. A Strategy for London

Fragmentation of Services

6.1 It is not only partnership work with non-NHS organisations that needs to be developed. There is still a need for NHS organisations to work closely together, particularly with regard to the availability of facilities for TB patients. One of the issues we considered was that of fragmentation. It was felt by some respondents that services in London are fragmented and that there are inconsistent approaches, which have been developing in different areas. This needs to be addressed, services need to be equitable as well as locally appropriate.

6.2 This fragmentation includes the variation in London of the availability of facilities such as negative pressure isolation rooms.[107] We were told that different hospitals have different types of rooms, which may not, strictly speaking, meet the criteria of a negative pressure isolation room. For example they may not have a lobby or en suite facilities and the extractor fan may not be filtered. Some hospitals can offer isolated patients TV and telephones and others do not. These facilities ease the boredom and frustration of isolation for patients. Overall the co-ordination and consistency of services within and between the NHS sectors needs to be improved. There must be adequate service across the whole of the capital.

6.3 **One of the reasons for this fragmentation has been the absence of ring fenced money and this has meant that TB has had to compete with other priorities.** In addition the disease has never been identified as a target for which the PCTs should be allocating funding. We were informed that the commissioning process for TB services is unclear and therefore this leads to poorly funded services. This process is complicated further by the many different organisations (PCTs and Acute trusts) which are involved in providing TB services locally.[108]

6.4 We were told that the most successful way of reducing fragmentation is to have much stronger guidelines. This would mean that at London Strategic Health Authorities would have to demonstrate how they are actually going to meet the guidelines and show how they were going to commission services. This process would go some way to ensuring that the NHS was providing the same quality of service across the capital.

6.5 The London caseload has increased annually for fifteen years and resources have not kept pace with this increase. Adequate resources for TB control need to be deployed within each London sector. Both primary care and acute trusts need to allocate adequate funding for recruiting and training adequate staff for TB control within their districts. This not only includes doctors and nurses but also health care assistants and administrators.[109]

[107] Negative pressure isolation rooms are where infectious TB patients are placed, especially those with multi-drug resistant TB. They are ordinary hospital rooms that have special air filtration which create negative pressure inside the room to reduce the likelihood of transmission.
[108] Memoranda: London TB Nurses Group
[109] Memoranda: Health Protection Agency

A Strategy for London

6.6 The increase of TB in London is a reflection of a global crisis and it is clear that there have been serious efforts by the Department of Health and the NHS to respond to the increasing levels of TB in London. We must not forget the sterling examples of dedicated work provided through the chest clinics and primary care facilities across the capital. These doctors and nurses are stepping out of their traditional medical roles and offering social support to patients by engaging the relevant agencies and ensuring these agencies provide services meeting the diverse needs of TB patients. We have also seen sterling work from the voluntary sector namely through TB Alert, both to raise awareness of TB and encourage an awareness of the global implications of the disease. It is very important that we do not lose sight of the global nature of TB particularly in view of London's global position.

6.7 The treatment of TB, though apparently straightforward, presents a clear challenge both to medical and non-medical staff. We would like to see the development of strategic partnerships across the capital which involve public agencies such as local authorities. There is still an overwhelming need to reduce levels of TB in the capital. Current statistics show that the level of TB is static in some areas and increasing in others. The current activity in London is just holding TB back and not reducing it to a great extent. There is an overriding need to ensure that reducing TB remains a priority across London even in areas of low prevalence.

6.8 We were informed that the government is to publish a national TB action plan in the autumn. We would like the Health Protection Agency and the London NHS to use this plan as a basis for developing a London specific plan. We would expect the London TB plan to take account of the nature of London's diverse communities and encourage the development of services that are culturally appropriate, with the aim of raising awareness and dispelling the myths and stigma associated with TB. London has a highly mobile population with increasing difficulties in gaining access to primary care. We would expect a London wide strategy to take this into consideration.

6.9 We would also expect a London wide strategy to build upon the work of the London TB Group, extending organisational boundaries to include partnership roles for London local authorities and the voluntary sector. There must be strong partnerships at local levels such as in Newham. The Newham scrutiny shows that not only can this be done, but it can be done in a way that yields real improvements for local people.

Recommendation 12:

The Health Protection Agency Local and Regional Services should develop a specific TB action plan for London that is based on the forthcoming national action plan. We would expect the London TB plan to take account of the nature of London's diverse communities and encourage the development of services that are culturally appropriate with the aim of raising awareness and dispelling the myths and stigma associated with TB.

6.10 We believe that such a plan must be supported by additional resources from central government. For real progress to be achieved increased funding is unquestionably necessary. **Over 1 billion dollars were needed to bring TB under control in New York. We have not yet reached that crisis point in London and we must ensure that we do not. Failure to heed the rising rates in London and to ensure adequate TB control now could result in major problems and expenditure in the future, particularly with the emergence of multi- drug resistant strains. Additional resources are needed to reduce levels of TB in the capital.**

Appendix A TB Notifications per Borough

Local Authority	*1982*	*1983*	*1984*	*1985*	*1986*	*1987*	*1988*	*1989*	*1990*	*1991*	*1992*	*1993*	*1994*	*1995*	*1996*	*1997*	*1998*	*1999*	*2000*	*2001*	*2002**
Barking & Dagenham	26	26	21	24	13	12	11	23	18	12	22	18	22	27	19	22	37	32	40	28	46
Barnet	70	68	47	67	67	49	92	86	73	75	98	85	68	66	57	63	77	50	71	77	93
Bexley	22	37	16	19	15	13	19	14	18	18	14	13	24	13	14	18	17	22	17	21	22
Brent	266	216	193	175	179	133	116	138	95	162	178	129	162	193	190	195	163	211	287	293	226
Bromley	25	22	22	29	19	17	5	9	16	26	11	17	12	13	12	21	13	26	28	26	9
Camden	69	62	58	53	60	48	49	50	64	73	80	67	115	78	72	105	103	78	81	100	125
City of London	7			1		1	1				2		1	1				2	1	1	2
Croydon	61	68	56	41	55	42	51	64	60	55	57	85	64	47	60	64	83	87	92	85	108
Ealing	172	146	107	86	119	95	85	93	87	96	109	125	117	127	130	162	212	197	238	240	261
Enfield	29	41	32	32	21	19	19	30	25	45	43	59	47	48	43	45	68	63	83	79	111
Greenwich	28	38	34	25	25	21	22	32	30	23	34	34	46	30	45	54	70	59	59	91	98
Hackney	61	68	71	66	56	55	59	88	78	67	104	97	102	106	129	117	121	96	180	176	138
Hammersmith & Fulham	52	51	52	35	64	42	40	46	41	45	47	33	39	40	60	54	59	49	75	34	10
Haringey	68	70	51	72	58	44	58	65	65	77	102	80	73	92	111	145	99	135	158	158	79
Harrow	80	120	119	69	76	67	83	78	66	73	69	73	71	79	67	64	73	75	89	99	124
Havering	31	20	16	16	15	17	14	18	8	14	11	20	15	16	11	19	6	12	27	21	15
Hillingdon	58	43	46	33	46	22	34	24	32	40	59	65	70	56	78	75	98	79	86	93	98
Hounslow	76	65	49	59	74	65	45	62	37	41	59	73	88	74	97	74	79	105	104	45	24
Islington	51	54	50	41	41	44	39	61	44	47	58	48	67	57	66	77	84	93	93	106	112
Kensington & Chelsea	49	51	42	38	34	36	28	38	38	50	35	45	37	38	68	51	43	64	45	47	36
Kingston upon Thames	14	14	12	13	16	19	9	3	13	20	13	13	10	15	12	10	17	15	12	17	18
Lambeth	83	98	80	94	66	75	54	68	77	85	97	118	94	104	110	94	102	100	126	137	98
Lewisham	57	35	59	52	27	2	54	41	46	24	34	38	37	38	46	57	78	68	68	64	82
Merton	34	32	23	31	29	20	19	20	27	34	33	31	23	24	29	39	21	30	40	43	65
Newham	164	122	113	130	103	125	126	123	133	154	132	137	206	194	186	174	213	237	290	238	228
Redbridge	59	52	49	49	48	41	43	37	41	51	66	53	51	74	66	100	70	71	58	73	91
Richmond upon Thames	18	16	18	15	15	17	10	9	8	6	3	11	14	12	13	9	14	16	9	14	16
Southwark	94	61	87	72	79	59	66	82	75	81	103	89	73	56	79	75	61	74	102	98	69
Sutton	6	13	3	14	11	6	9	14	17	10	10	9	20	16	13	23	18	15	14	23	31
Tower Hamlets	89	95	71	89	78	87	63	80	94	88	99	109	103	97	87	136	104	107	120	128	151
Waltham Forest	37	54	59	57	48	53	49	61	53	71	90	64	64	57	65	94	93	93	102	87	93
Wandsworth	97	91	85	68	85	55	56	40	70	54	64	50	70	64	61	70	67	59	51	55	87
Westminster, City of	93	78	92	76	59	44	58	49	54	77	67	71	72	90	94	105	81	89	92	89	73
London Total	***2146***	***2027***	***1833***	***1741***	***1701***	***1445***	***1486***	***1646***	***1603***	***1794***	***2003***	***1959***	***2077***	***2042***	***2190***	***2411***	***2444***	***2509***	***2938***	***2886***	***2839***

* 2002 provisional

Source: Statutory Notifications to The Communicable Disease Centre.

All forms of Tuberculosis. Corrected Notifications. Data excludes chemoprophylaxis. Data excludes Port Health Authorities. Population denominators ONS

Appendix B List of Recommendations

Recommendation: 1

The NHS target on offering HIV testing and counselling for all TB patients, which we welcome, must be implemented across London as a matter of urgency. The Regional Public Health Team must inform us when the arrangements for HIV testing and counselling are in place in all TB treatment centres in London.

Recommendation 2:

We call upon the government to recognise the cost of treating multiple drug resistant TB and reflect this in the allocation of financial resources to London Primary Care Trusts.

Recommendation 3:

The Strategic Health Authorities (Workforce Development Confederations) should conduct an audit of the staffing levels within their local TB treatment centres in order to identify accurately the numbers and types of staff required. Where numbers fall short of the identified targets, efforts must be made to recruit and retain staff so that patient care is improved.

Recommendation 4:

The Department of Health should examine the issue of delayed TB diagnosis and ascertain how much of a problem this is in the capital.

Recommendation 5:

The Strategic Health Authorities in London must ensure that there are sufficient rapid and consistent systems for the early diagnosis of tuberculosis in the capital.

Recommendation 6:

A national TB register modelled on the London TB register should be developed.

Recommendation 7:

We welcome the use of the new Mobile Digital Chest Radiography Unit for targeted active TB case finding in London. We ask that the Health Protection Agency keep us informed of the implementation of this new process and that the efficacy of this method of TB control be regularly evaluated.

Recommendation 8:

We welcome the Health Protection Agency modelling study examining the issue of new entrant screening. The outcome of this study should lead to a clear strategy on new entrant screening which is supported by adequate financial resources, properly co-ordinated across all the relevant agencies and monitored for its effectiveness.

Recommendation 10:

NHS Trusts and Primary Care Trusts should enable patients to receive their TB drugs without charge, particularly for those on low incomes. The Department of Health should consider how this could be implemented across London.

Recommendation 11:

The Health Protection Agency should develop a specific set of guidelines which will help other public sector agencies identify possible cases of TB and refer people to the appropriate health service.

Recommendation 12:

The Health Protection Agency Local and Regional Services should develop a specific TB action plan for London that is based on the forthcoming national action plan. We would expect the London TB plan to take account of the nature of London's diverse communities and encourage the development of services that are culturally appropriate with the aim of raising awareness and dispelling the myths and stigma associated with TB.

Appendix C List of Written Submissions

British Lung Foundation

British Thoracic Society (Joint Tuberculosis Committee)

City University, St Bartholomew School of Nursing & Midwifery (Gini Williams)

Department of Health

Enfield and Haringey Primary Care Trusts

Health Protection Agency

London TB Nurses Group

NHS London

Public Health Direct

Royal College of General Practitioners

St Mary's NHS Trust

South West London Strategic Health Authority

TB Alert

Appendix D List of Hearings

20 May 2003

Valerie Aston - TB Project Manager, Department of Health

Penny Bevan - Deputy Director of Public Health, Directorate of Health and Social Care London

Paul Sommerfeld - Chair, TB Alert

Dr Jane Jones - Consultant Epidemiologist, Health Protection Agency (Communicable Disease Surveillance Centre)

Dr John Hayward- Director of Public Health Newham Primary Care Trust

Alistair Story - TB Nurse Specialist and Scientific Advisor to TB Alert

10 June 2003

Dr Helen Booth - Consultant in Thoracic and General Medicine, University College London Hospitals NHS Trust

Gini Williams - Senior Lecturer in TB and Public Health, City University

Julie Glyn-Jones - Chair, London TB Nurses Network

Dr Deepti Kumar - Consultant in Communicable Disease Control, Ealing Primary Care Trust

Appendix E London NHS Sectors

North East Sector	South East Sector	North West Sector
Local Authorities	**Local Authorities**	**Local Authorities**
Barking and Dagenham	Bexley	Brent
City of London	Bromley	Ealing
Hackney	Greenwich	Hammersmith & Fulham
Havering	Lambeth	Harrow
Newham	Lewisham	Hillingdon
Redbridge	Southwark	Hounslow
Tower Hamlets		Kensington & Chelsea
Waltham Forest		Westminster

South West Sector	North Central Sector
Local Authorities	**Local Authorities**
Croydon	Barnet
Kingston	Camden
Merton	Enfield
Richmond	Haringey
Sutton	Islington
Wandsworth	

Appendix F Health Committee Publications

The Health Committee has also produced the following scrutiny reports, which can be downloaded free at: http://www.london.gov.uk/assembly/reports/health.jsp

GP Recruitment and Retention: the Crisis in London
June 2003

Access to Primary Care
A joint London Assembly and Mayor of London Scrutiny Report
April 2003

Infant immunisation
January 2003

Smoking in Public Spaces Report
April 2002

Appendix G Principles of Scrutiny

The powers of the London Assembly include power to investigate and report on decisions and actions of the Mayor, or on matters relating to the principal purposes of the Greater London Authority, and on any other matters which the Assembly considers to be of importance to Londoners. In the conduct of scrutiny and investigation the Assembly abides by a number of principles.

Scrutinies:

- *aim to recommend action to achieve improvements;*
- *are conducted with objectivity and independence;*
- *examine all aspects of the Mayor's strategies;*
- *consult widely, having regard to issues of timeliness and cost;*
- *are conducted in a constructive and positive manner; and*
- *are conducted with an awareness of the need to spend taxpayers money wisely and well.*

More information about the scrutiny work of the London Assembly, including published reports, details of committee meetings and contact information, can be found on the GLA website at http://www.london.gov.uk/assembly/index.jsp

Appendix H Orders and Translations

For further information on this report or to order a bound copy, please contact:

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London SE1 2AA
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tel. 020 7983 4397

If you, or someone you know, needs a copy of this report in large print or Braille, or a copy of the summary and main findings in another language, then please call 020 7983 4100. You can also view a copy of the Report on the GLA website: http://www.london.gov.uk/approot/assembly/reports/index.jsp.

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Ti o ba [illegible] ti o ba nilo [illegible] ede [illegible] ni ede ti abinibi won, ki o kansiwa lori ero ibanisoro. Nomba wa ni 020 7983 4100 tabi ki e kan si wa lori ero assembly.translations@london.gov.uk Ako ni gbowo lowo yin fun ise yi.

Haddii adiga, ama qof aad taqaanid, uu doonayo inuu ku helo koobi ah warbixinta oo koobab iyo talooyinka [illegible] ama farta qofka indhaha la' loogu talagalay, ama luuqadooda, oo bilaash ah, fadlan nagala soo xiriir telefoonkan 020 7983 4100 ama email-ka cinwaankiisu yahay assembly.translations@london.gov.uk

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