



# Tuberculosis in Birmingham



**A report from Overview & Scrutiny**







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## Tuberculosis in Birmingham

Further information regarding this report, and copies of the TB evidence report, can be obtained from:

Rose Kiely tel: 0121 303 1730, e-mail: [rose.kiely@birmingham.gov.uk](mailto:rose.kiely@birmingham.gov.uk)

Tony Green tel: 0121 303 1520, e-mail: [tony.green@birmingham.gov.uk](mailto:tony.green@birmingham.gov.uk)

Reports that have been submitted to Council can be downloaded from [www.birmingham.gov.uk/scrutiny](http://www.birmingham.gov.uk/scrutiny).



# Preface

By Cllr Deirdre Alden



When the subject of the vaccination programme for tuberculosis was debated at full Council last year, it generated a wide and sometimes emotional response as some Council Members related their own personal experiences of the disease.

The debate was followed by several members presenting petitions to Council, asking for the BCG vaccination programme for school children to be reinstated.

As a result of all the interest, the Health and Adults Scrutiny Committee decided unanimously that a review into the subject should be carried out. The suggestion was proposed by Cllr Anita Ward (who was at the time the Labour lead on the Committee) and supported by everyone, especially Cllr Graham Green who had proposed the motion at the October 2010 full Council Meeting.

Unfortunately Cllr Ward was unable to take any part in the review as this year she is serving as Lord Mayor. However I should like to take to take this opportunity to thank Cllr Ward for suggesting the topic, all those councillors who attended the Scrutiny meetings, the officers who worked so hard to collate the evidence and write the report, and the many expert witnesses who attended the evidence gathering sessions.

In the end, the evidence showed that reinstating the BCG vaccination programme in schools was probably not the best way forward. Nevertheless, the interest generated by the original Council motion and the petitions has been invaluable in raising awareness of a disease which most people probably thought had been eradicated, but which sadly is still affecting and – in rare cases - killing, people in Birmingham today.

You will see that the recommendations reflect the fact that responsibility for delivery does not fall solely to the City Council. Implementation will require close partnership working with the NHS and the drafting of the recommendations reflects the fact that the Cabinet Member will need to lobby the NHS Cluster to ensure that they are acted on.

The report takes account of the changes which are taking place in the Health economy and the existence of the newly formed Shadow Health and Well Being Board. The Board will include representation from Members and Officers of the City Council, from the PCT Cluster, from the clinical commissioning groups and from HealthWatch. It is chaired by the Cabinet Member for Adults and Communities. This should provide the structure to support the transition of public health activities from the NHS to the City Council, to manage the process for assessing population needs through the Joint Strategic Needs Assessment, to promote the integration of commissioning across Birmingham and to promote the use of effective pooled budget arrangements.

**Councillor Deirdre Alden**



# Tuberculosis in Birmingham

## Summary

Birmingham has one of the highest tuberculosis (TB) incidences of any European city and it is a significant public health problem, with a disproportionate impact on particular communities. Transmission is still happening in Birmingham: around a third of cases of TB diagnosed here are acquired here. In spite of the fact that the incidence of TB in the world is slowly dropping, the UK and especially London and Birmingham are bucking the general trend. People are still dying of TB in Birmingham in the 21<sup>st</sup> century.

Tuberculosis is a serious but curable infectious disease which can affect any part of the body but is most common in the lungs. The incidence of TB declined rapidly in the UK and other industrialised nations towards the end of the last century but never went away. It is quite difficult to catch. Most people who get TB have had a prolonged exposure to an infectious person, usually someone in the same household.

TB is curable with antibiotics but they must be taken for at least six months and compliance is important. Failure to complete the course of treatment not only fails to cure the disease but contributes to the growth of drug resistance. The patient needs to take the full course as prescribed to eliminate the infection. Modern anti-TB drugs are extremely effective and in nearly all cases after the first three weeks of medication TB sufferers are not infectious and feel much better, though they are not cured until they complete the whole course of treatment. TB in England came largely under control during the 1960s and 1970s, mainly through better nutrition and housing, milk pasteurisation, the introduction of effective drug treatments, effective public health programmes and BCG immunisation. From the early 1990s it re-emerged as a public health problem in England. Cases began to rise mainly as a result of increased migration of people from areas of the world where TB is more common.

Much concern has been expressed by the public and councillors in Birmingham have called for the reintroduction of BCG vaccination of school children. However during the course of the review it became clear to the Committee that BCG vaccination of school children and adults has only limited efficacy and does not target those most at risk of the severe forms of childhood TB. This is why it is not recommended by the Joint Committee on Vaccination and Immunisation (JCVI) or the National Institute of Health and Clinical Excellence (NICE) as a universal programme.

The expert advice from JCVI, NICE and the Department of Health's Green Book all express a similar line with regard to BCG policy. They all recommend that BCG vaccinations should be targeted at neonates (newborn babies) who are at high risk. None of these expert bodies and none of the expert witnesses who came to give evidence to the Committee recommended that children should be routinely vaccinated. All the available guidance supports the policy of selective immunisation of high risk groups using neonatal BCG as part of a wider TB strategy to control TB incidence.

This report discusses issues around defining the criteria for 'high risk'.



## Summary of Recommendations

	<b>Recommendation</b>	<b>Responsibility</b>	<b>Completion date</b>
R1	That TB commissioners ensure effective community awareness through a range of targeted means and channels, including community and clinical agencies. This will include appropriate information for elected members, community pharmacists and other appropriate agencies	Cabinet Member Adults and Communities to lobby NHS Cluster to ensure this happens	30 September 2012
R2	That an accountable TB Lead for Birmingham be appointed to lead a joint TB programme board and ensure progress against the TB Strategy including effective commissioning and provision	Cabinet Member Adults and Communities to lobby NHS Cluster to ensure this happens	30 September 2012
R3	That effective directly observed therapies be commissioned from appropriate agencies including community pharmacists and community organisations	Cabinet Member Adults and Communities to lobby NHS Cluster to ensure this happens	30 September 2012
R4	That the TB Lead, programme board and commissioners, including clinical commissioning group representatives, review the single multidisciplinary TB team with a view to strengthening its partnerships; the ratio of nurses to patients; and the banding, pay and responsibilities of the TB nursing service.	Cabinet Member Adults and Communities to lobby NHS Cluster to ensure this happens	31 December 2012
R5	That the TB Lead develop a plan for effective and integrated commissioning of TB and provision of services beyond new commissioning arrangements in April 2013	Cabinet Member Adults and Communities to lobby NHS Cluster to ensure this happens	31 December 2012
R6	That the JSNA include a section on TB	Cabinet Member Adults and Communities to direct the Joint Director of Public Health to ensure this happens	31 March 2012
R7	That progress towards achievement of these recommendations is reported to the Health & Adults Overview & Scrutiny Committee (HAOSC) in July 2012. The Committee will schedule subsequent progress reports thereafter, until all recommendations are implemented.	Cabinet Member Adults and Communities	July 2012 (Meeting date to be confirmed by HAOSC), and in further months as scheduled by HAOSC



## 1 Introduction

### 1.1 Some important facts about TB

- 1.1.1 Tuberculosis (TB) is a serious but treatable infectious disease commonly affecting the lungs, but which can involve any part of the body.
- 1.1.2 TB is quite difficult to catch. Prolonged close or repeated contact with a person with infectious TB, for example someone living in the same household, is usually required for the infection to be passed on. It is usually spread by the cough of an infected person.
- 1.1.3 People are at higher risk of TB if they have lived in parts of the world where TB is more common. The disease follows patterns of migration and is therefore more common in certain ethnic groups, especially in people who were born abroad.
- 1.1.4 Not everyone who is infected will develop serious symptoms. Around 90% of otherwise healthy people who have come into contact with and been infected with the TB bacteria will not develop the disease. Of the 10% who develop infectious disease, up to half will do so within the first two years while the remainder develop the disease later on. It may take many years before someone infected with TB develops the disease.
- 1.1.5 For the majority of people who become infected with TB, the bacteria become inactive without causing disease but they remain alive in the body and can become active later in life. This is called latent TB infection. Latent TB can become reactivated and cause TB later in life especially if a person's immune system becomes weakened through, for example, old age, some medical treatments, serious illness, poor diet, or through generally poor living conditions.
- 1.1.6 Compliance with treatment is important. TB is slow growing which means that because the TB lies dormant, short periods of antibiotic treatment can be ineffective. Therefore antibiotic treatment needs to be for at least 6 months and the patient needs to take the full course as prescribed to fully eliminate the infection. Lapsing on treatment will fail to cure the disease and may also contribute to the growth of drug resistance.
- 1.1.7 Three main factors increase the likelihood of non-compliance: firstly patients feeling better soon after starting the treatment and assuming they are cured; secondly the antibiotic dose being unpleasant to take, and in some cases bringing unpleasant side-effects; and thirdly social influences such as chaotic lifestyles or families being reluctant to acknowledge illness.
- 1.1.8 When people do not complete the course some of the infection remains. Where there is reason to think a patient will not complete the course it is advisable and sometimes possible to send someone to supervise the patient taking the antibiotic or to coach and assign a responsible family member to supervise it. This is called Directly Observed Therapy (DOT).



- 1.1.9 Drug-resistant TB takes longer and is more difficult and expensive to treat. Drug-resistant strains of TB infection or TB disease need a combination of antibiotics to be taken over a longer period – normally at least a year – to ensure the strains are destroyed so they cannot spread. Multi-drug resistant TB can result from inadequate or inappropriate treatment or from non-completion of treatment. Cases of multi drug resistant TB cost on average between £50,000-£70,000 to treat compared with £5,000 for active TB. Therefore there is a strong economic case to treat active TB promptly with the correct drug regime and to try to ensure that patients finish the course of treatment to prevent the development of multi-drug resistant TB.
- 1.1.10 Clinicians are legally required to report to the Department of Health (DH) all diagnoses of TB or suspected TB. The figures are collated and consolidated at DH level.

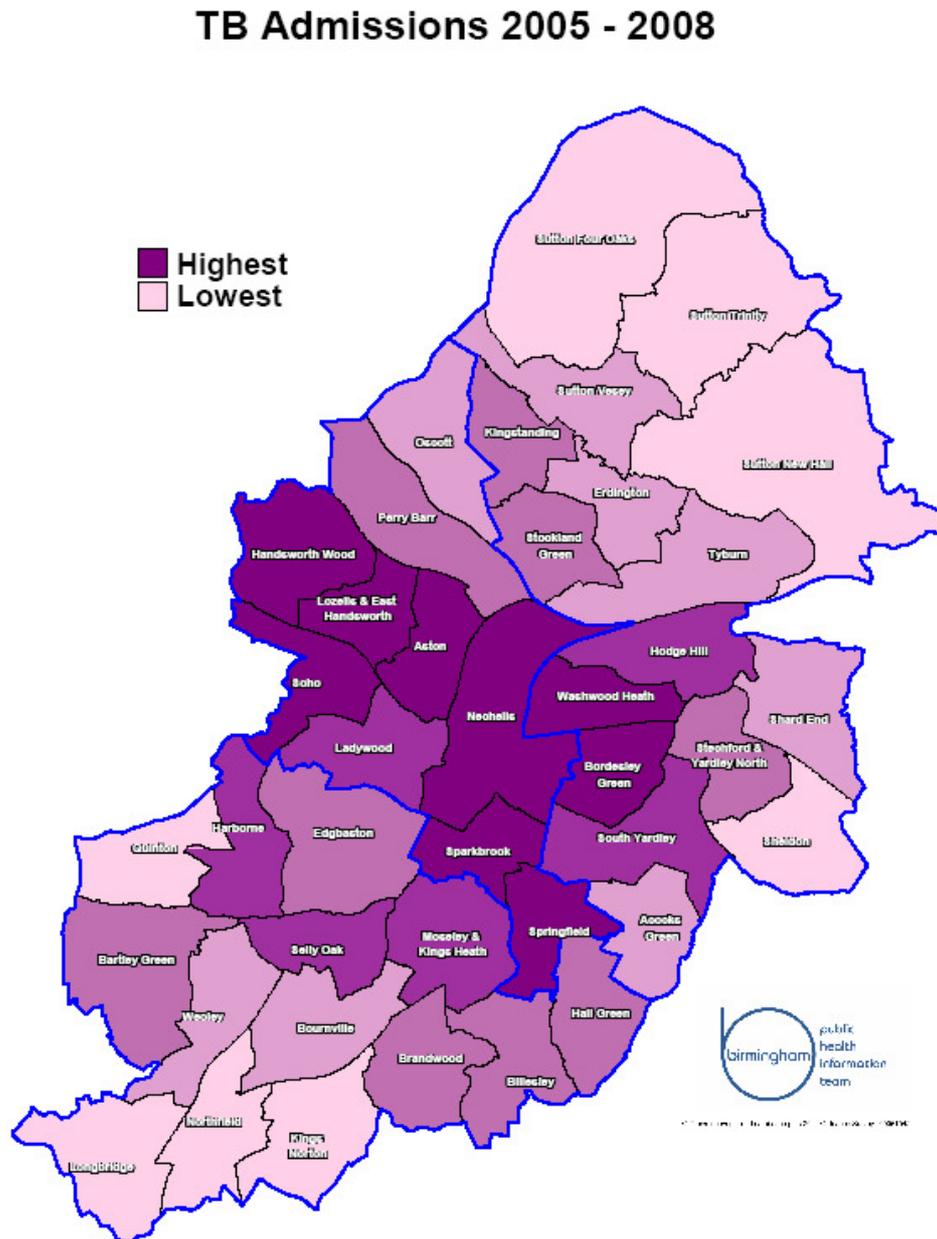
## 1.2 TB in Birmingham

- 1.2.1 Tuberculosis has been a public health problem in the UK for the past two decades and Birmingham has one of the highest TB incidences of any European city. In 2010 London had the largest number of cases and highest incidence per head of population across England followed by the West Midlands and the North West.
- 1.2.2 The incidence of TB is growing faster in Birmingham - by 107% between 1999 and 2009 – than in England as a whole, where it grew by 57% between 1987 and 2008. Transmission of TB is still happening in Birmingham with around one third of cases of TB diagnosed in Birmingham acquired in Birmingham.
- 1.2.3 As a result, TB is a significant public health problem in Birmingham, with a disproportionate impact on particular communities. Birmingham has one of the highest rates of TB in the West Midlands with 35 cases per 100,000 population (below the 40/100,000 rate often quoted as the threshold for declaring a “high rate area”). This rate is mainly due to very high rates in Heart of Birmingham teaching Primary Care Trust (HOBtPCT) area. The incidence of TB cases per 100,000 population varies from 27 in South Birmingham, to 43 in Birmingham East & North and 99.3 in the Heart of Birmingham, nearly 2.5 times the DH threshold.
- 1.2.4 Birmingham is at least three times the size of the average local authority and the DH ‘guidance’ is not a rule, so the CMO ‘40 per 100,000’ ratio could be applied independently to each of the PCT areas. If this were done, it would mean the Heart of Birmingham and Birmingham East & North being classed as high risk areas, so all neonates born there should be vaccinated. In the South Birmingham area, the decision as to which newborn babies are at risk would need to be done by clinicians based on their analysis of data from several sources. However, the guidance has not been applied in this way to date



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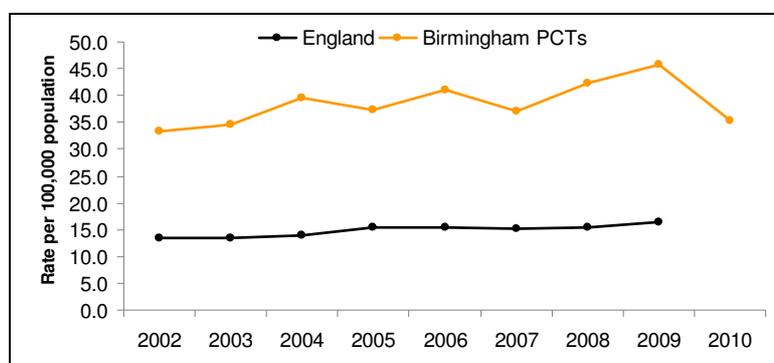
Figure 1: Map of the City showing the differing rates of TB admissions in electoral wards



1.2.4 Rates in Birmingham generally rose until 2009. In 2010 there were 363 cases of TB in Birmingham, a fall from 472 in the previous year.



**Figure 2: Graph of the TB case rate in Birmingham and England (2002-2010)**



- 1.2.5 Most cases are concentrated in a small number of wards with 73% born overseas where the place of birth is known. The overwhelming majority of cases, whether in adults or children, are in those from ethnic minorities with links to countries with high rates of TB, especially people of Pakistani, Indian or Black African ethnic origin.
- 1.2.6 There were 27 cases (aged 0-18) in children in Birmingham in 2010, a fall from the previous year. The higher numbers of TB cases in children in 2008 and 2009 was in part due to cases detected during contact tracing of other children with TB at schools.

## 1.3 Background to the review

- 1.3.1 There has been much concern expressed by the public and by Councillors in Birmingham around the issue of TB and much debate about the most effective course of action to prevent its spread.
- 1.3.2 On 12<sup>th</sup> October 2010, the City Council approved a motion moved by Councillor Graham Green expressing concern at the substantial increase in cases of TB within Birmingham and stating the belief that the decision to withdraw the Universal Program of Inoculation against TB was a retrograde step. The motion went on to call for the reintroduction of inoculation for all school children as soon as possible.
- 1.3.3 Subsequently, Councillor Mike Sharp presented a petition to the City Council on 7<sup>th</sup> December 2010 by calling on the City Council to lobby government to bring back TB vaccinations for all children and vulnerable adults whilst exploring improved protection against new strains of the disease.
- 1.3.4 A further petition was submitted to Council on 1<sup>st</sup> March 2011 by former Councillor Gwyn Neilly.
- 1.3.5 Whilst the overwhelming bulk of evidence the Committee heard suggested universal vaccination is not the best solution, the motion and petitions have been productive and extremely helpful in raising awareness of the disease, its symptoms and treatment.
- 1.3.6 The main health protection service for TB is provided by the Health Protection Agency (HPA). The HPA leads local and national TB control activities, including TB surveillance, data analysis and



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reporting. The overall functions of the HPA, including those related to TB control are expected to transfer to Public Health England (PHE) in 2012. The HPA advised that:

- In 2010 fewer people were diagnosed with TB in Birmingham than in 2009;
- Most childhood infection is in "at risk" groups;
- Children in an "at risk" group need to be vaccinated at birth to provide best possible protection, with a later "mop-up" when they start school;
- Later school-based vaccination is less effective for these groups; and
- Most disease in the UK-born population is not in children such that a school-based BCG programme does not make an effective contribution to protect this group.

1.3.7 The HPA report was very clear in saying that early recognition, diagnosis and treatment are the keys to preventing the onwards spread and thus to TB control. The key elements of any TB control plan are:

- Early recognition of possible cases;
- Early and reliable diagnosis;
- Effective treatment;
- Identification and treatment of people with latent infection; and
- Prevention through infection control and BCG.

1.3.8 In the light of this, the HPA advice was that a universal schools based programme would not be cost effective and that it would divert resources from effective control measures. Effective control measures focus on early diagnosis and effective treatment. For these reasons, the advice of the HPA was that a school-based BCG programme should not be reintroduced in the City.

1.3.9 Based on this advice, the Joint Director of Public Health responded to the Council motion to the effect that BCG vaccination of school children and vulnerable adults has limited efficacy and does not target those most at risk and it is therefore, not recommended as a universal programme. He advised that a TB control plan was needed for Birmingham and that such a plan was in development as part of a Health Protection Strategy which would include a review of selective versus universal neonatal vaccination.

1.3.10 It was agreed that the lead Director for Public Health for health protection, Dr Chris Spencer-Jones, would bring a report to the Public Protection Committee. This report was subsequently presented to the Public Protection Committee on 17<sup>th</sup> June 2011 together with the draft TB control plan.



## 1.4 Evidence-gathering for the review

1.4.1 Councillor Graham Green recommended that the Committee should base its review on a 2004 Department of Health report "Stopping Tuberculosis in England: An action plan by the Chief Medical Officer" (CMO) that was aimed at driving a sustainable increase in local and regional TB prevention and control activities as well as stimulating the development and strengthening of TB services. The Scrutiny Committee therefore decided to structure its evidence gathering for this review to reflect the actions suggested in the CMO's 2004 report. These were:

- Increased awareness;
- Strong commitment and leadership;
- High quality surveillance;
- Excellence in clinical care;
- Well organised and co-ordinated patient services;
- First class laboratory services;
- Highly effective disease control at population level;
- An expert workforce; and
- Leading edge research.

1.4.2 The review group is grateful for the large volume of detailed and helpful evidence which was received from a variety of engaging and well-informed witnesses. The detail of the evidence gathered was too extensive to include in one report and so it has been summarised in a separate evidence report, copies of which are available via the scrutiny office.

## 2 BCG Immunisation

### 2.1 The history of BCG immunisation

2.1.1 The BCG immunisation programme was introduced in the UK in 1953. BCG vaccination was introduced for previously unvaccinated adolescents aged 10-14. Age 10-14 was selected for vaccination in 1953 because at that time, in what was nearly an entirely white UK-born population, TB was most common in those aged 15-29. Members of this cohort, now aged over 70, have the highest TB rates among white UK-born people. The rationale therefore was to give vaccination at this age to try to prevent acquisition of pulmonary disease before this peak and it became known as the 'Schools BCG Programme'.

2.1.2 TB rates fell through the 1950s and early 1960s and continued to fall until approximately 1987 since when there has been an increase. During the 1960s and 1970s, tuberculosis in England came



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largely under control after centuries of being one of our major killers. This was achieved through a variety of measures including better nutrition and housing, milk pasteurisation, the introduction of effective drug treatments, early detection through mass miniature chest x-ray programmes, public health programmes to detect and treat infection in contacts of people with newly diagnosed TB and the BCG immunisation programme. Over this time, both the proportion of cases and rates of disease in the white UK-born ethnic group continued to fall.

2.1.3 From the early 1990s, TB re-emerged as a public health problem in England. Cases began to rise mainly as a result of increased migration of people from areas of the world where TB is more common than it is in England. Reactivation of old TB as the established population aged, and TB in people with HIV infection, made small but important contributions.

2.1.4 However, in the 1960s, when TB rates in the indigenous population were continuing to decline, rates were shown to be much higher in new immigrants from high prevalence countries and their families. Recommendations were made therefore to protect the children of these new entrants, wherever they were born, at the earliest opportunity. As part of this, a selective neonatal BCG immunisation programme was introduced to protect infants born in the UK to parents from high-prevalence countries by vaccinating them shortly after birth.

2.1.5 In 2005, following a continued decline in TB rates in the indigenous UK population, the programme to vaccinate schoolchildren against TB with the BCG vaccine was stopped by the Department of Health. This was replaced by a targeted risk-based programme aimed at children shortly after birth. The key element is a neonatal programme targeted at protecting those children most at risk of exposure to TB. In Birmingham this programme is carried out in the hospital setting and ideally children identified as belonging to a high risk group are vaccinated.

## 2.2 Current expert guidance

2.2.1 Expert scientific guidance in relation to vaccination and immunisation in the UK is contained in various sources:

- The Joint Committee on Vaccination and Immunisation (JCVI) is the independent expert committee that advises Ministers on matters relating to the provision of vaccination and immunisation services. JCVI gives advice to Ministers based on the best evidence reflecting current good practice and/or expert opinion;
- The National Institute of Health and Clinical Excellence (NICE) also provides guidance on a range of issues including TB; and
- The Department of Health's Green Book is the popular name for "Immunisation against Infectious Diseases" which sets out the principles, practices and procedures of immunisation in the UK.



- 2.2.2 The aim of the UK BCG immunisation programme is to immunise those at increased risk of developing severe disease and/or of exposure to TB infection. The current policy which is in accordance with the current guidance is to vaccinate babies in high incidence areas only, rather than routine vaccination of adolescents who test negative for tuberculin. There are many reasons for this.
- 2.2.3 Distribution of TB has changed greatly since the BCG programme began. The annual risk of infection in the general population has declined significantly and the disease has become increasingly restricted to identifiable segments of the population and in particular to immigrant communities. Against this background routine vaccination of all children in schools is not cost effective because the number of cases in people born in the UK reached an all time low in 2003. The vaccine provides a reasonable amount of prevention for 10-15 years only if given to young babies, and protects for fewer years the later it is given. If given to adults it provides little or no protection. For these and other reasons scientific advice is that universal vaccination is not cost-effective. Research is currently being done on whether it would be cost-effective to vaccinate all babies irrespective of whether or not they are in high incidence areas.
- 2.2.4 JCVI, NICE and the Green Book express a similar line with regard to BCG policy. They all state that BCG vaccinations should be targeted at high risk neonates. None of these expert bodies and none of the expert witnesses who came to give evidence to the Members, recommended that children should be routinely vaccinated. There is no evidence to suggest that TB rates in children are increasing and expert opinion and the available guidance all support the policy of selective immunisation of high risk groups using neonatal BCG. Indeed, in relation to Birmingham there were 27 cases of TB in children (aged 0-18) in 2010, a fall from the previous year. The reintroduction of routine vaccination of all children in schools is not the answer. The solution is to ensure that infants in high-risk areas are protected and those in populations most at risk are progressively screened, treated and followed up.

## 2.3 Implementation in Birmingham

- 2.3.1 The national guidance published by CMO in 2005 recommended BCG vaccine for "all infants living in areas where the incidence of TB is 40 per 100,000 or greater". An area was defined in the 2005 DH guidance as a local authority.
- 2.3.2 The joint report of the Directors of Public Health and the Health Protection Agency which went to the Public Protection Committee in June 2011 gives the three year average TB rate for Birmingham as published by the HPA nationally as 42 cases per 100,000 population (2007-9) i.e. borderline for the guidance. The latest figures show that currently, although Birmingham has the highest rates of TB in the West Midlands with 35 cases per 100,000 population, the rate is below the level for recommended universal vaccination.
- 2.3.3 In view of this fluctuation, the report says that a local review of implementation is needed to determine the most appropriate strategy for the future. This recommendation is reflected in the



draft strategy where one of the recommended lines of action is to review the BCG immunisation programme including an audit of the neonatal programme.

## 3 TB control plan for Birmingham

### 3.1 Public consultation

3.1.1 When this review was initiated, there was no overall TB control strategy for Birmingham. One of the aims of the review would have been to recommend that a strategy be developed and agreed between the City Council and all the relevant health organisations and to indicate some of its key aims.

3.1.2 Members were pleased that, as the review progressed, a draft TB control plan for Birmingham was produced and presented to the Public Protection Committee in June 2011. Public consultation on the tuberculosis strategy for the City of Birmingham 2011-2015 will be taking place between October and December 2011. A copy is appended to the evidence report, together with a final strategy that was approved by NHS trusts in November 2011.

3.1.3 The remainder of this report will focus on scrutinising the draft strategy which was being consulted over during the review.

### 3.2 TB control

3.2.1 The fundamentals of TB control are:

- Early recognition of possible cases;
- Early and reliable diagnosis;
- Effective treatment (especially supporting all those diagnosed to complete treatment);
- Identification and treatment of people with latent infection; and
- Prevention through infection control and BCG.

3.2.2 The most important and effective elements are the early diagnosis and effective treatment of those with TB because this reduces onward transmission.

3.2.3 The long term goal of any TB control programme is to bring about a reduction and ultimately complete elimination of TB in a country. The shorter term aims of the Birmingham strategy are to:

- Reduce the risk of people being newly infected with TB in England;
- Provide high quality treatment and care for all people with TB; and
- Maintain low levels of drug resistance, particularly multi-drug resistant (MDR) TB.



## 4 Evidence based interventions

### 4.1 Increased awareness

- 4.1.1 Members heard evidence about the importance of TB awareness programmes and work that is taking place with Primary Care Trusts, Local Authorities and the voluntary/third sector to raise awareness about TB among communities vulnerable to it.
- 4.1.2 The government recognises the role of third sector organisations (TSOs) in helping to reduce health inequalities. Members were told about the importance of the involvement of TSOs in developing initiatives to support local awareness-raising amongst high risk groups. Many TSOs already work closely with groups known to be at most risk from TB and are well placed to reach out to people who may have poor access to health services and to understand and help dispel the stigma and myths that make some communities reluctant to come forward for treatment. Those most at risk include substance mis-users, homeless people and people from ethnic minority communities. Through third sector involvement, patients will be diagnosed earlier, resulting in less impact on their health and welfare and reduced levels of onward transmission.
- 4.1.3 Since 2008 TB Alert, a charity, has worked with PCTs to encourage and support the development of relationships with third sector and local government, and to incorporate the social model of health – covering the wider socio-economic influences on health – into TB programmes. In 2010, TB Alert began to build the capacity of third sector organisations to fill this critical role and to provide evidence to demonstrate to TB commissioners the effectiveness of a local partnership approach.
- 4.1.4 One of the recommended lines of action in the TB strategy, under the category of increased awareness, refers to working with existing networks, local groups and national non-governmental organisations such as TB Alert, with a view to increasing community involvement in TB control. Evidence presented to the review group by TB Alert highlighted the need for better co-ordination with third sector organisations that are already funded by Birmingham City Council and the NHS to encourage them to incorporate TB awareness and support into their service.
- 4.1.5 It was suggested that we should consider adding TB to the services already commissioned in Service Level Agreements by stipulating that the relevant organisation will deliver a specified number of awareness-raising sessions a year. It was also suggested that we develop policies that support the involvement of TSOs in TB service design and delivery eg. prioritising Pakistani, Indian and Black African communities as well as homeless and drug mis-users.
- 4.1.6 Evidence was also presented that there is funding available from the Strategic Health Authority to pilot a West Midlands Group to commission TB awareness programmes at regional level.
- 4.1.7 Third sector and community organisations also have a role in supporting testing and treatment, as some communities may not respond to offers of testing or treatment unless it is provided or



facilitated by such organisations. Third sector and community organisations will need to work in partnership with health care providers to explore which services could be delivered in this way.

- 4.1.8 A framework has been developed to monitor and evaluate the role of TSOs with a view to commissioning TB awareness raising programmes in communities at risk of TB. (**Reference R1**)

## 4.2 Strong commitment and leadership

4.2.1 The strategy refers to the need to create a strongly led, well co-ordinated and adequately resourced TB programme and to facilitate this, recommends working with and providing appropriate technical advice to elected members. The importance of strong and well informed political leadership was also raised in the evidence presented to the Committee.

4.2.2 The importance of strong commitment and leadership is vital in providing a clear focus on what needs to be achieved and local councillors are in a good position to act as local champions in their communities. They can play a particularly vital role as local leaders in helping to de-stigmatise TB in certain communities in their capacity as ward councillors, by disseminating information to their local community, but they need to be provided with the appropriate technical advice and information to allow them to do this. (**Reference R1 and R2**)

4.2.3 The strategy mentions that a TB Commissioning Group has been established which is chaired by the Joint Director of Public Health and which should help to ensure consistent commissioning across all provider organisations and the effective involvement of clinicians in commissioning. The strategy also acknowledges the challenge of maintaining this group in a time of huge change.

4.2.4 In the course of the evidence presented to the Committee a more basic question was raised, namely whether the TB programme will be commissioned by the newly emerging clinical commissioning consortia or by the NHS Commissioning Board? Doubtless a decision about this will be made by the NHS Commissioning Board but Members were of the opinion that the importance of establishing this as a matter of priority should be raised with the Shadow Health and Wellbeing Board at the earliest possible opportunity. (**Reference R5**)

## 4.3 High quality surveillance

4.3.1 The 2004 CMO's report said that the aim of high quality surveillance is to provide the information required at local, national and international levels to identify outbreaks, monitor trends, inform policy, inform development of services and to monitor the success of the TB programme.

4.3.2 Current surveillance systems in England include:

- Statutory notifications of infection;
- Treatment outcome monitoring;
- Laboratory data;



- Strain typing;
- Incident and outbreak surveillance;
- Bovine TB surveillance (very few human cases are due to this bovine form but continued vigilance is required); and
- Mortality data.

- 4.3.3 Statutory notifications of infection (NOIDS) have been required from clinicians since 1913. Notification has to be to a Proper Officer of the local authority, who is normally the Consultant in Communicable Disease Control. It includes both confirmed and suspected cases. It is timely and allows interventions to be put in place and is useful for case-finding and outbreak detection but it is incomplete, lacks key information such as risk factors, and is unverified. As such it is not ideal for measuring trends and identifying policy or service needs.
- 4.3.4 Enhanced TB Surveillance (ETS) was introduced in 1999 with subsequent developments. It is run by the Health Protection Agency (HPA) with local partners including Birmingham Chest Clinic. Duplicate checks are made to verify diagnosis and improve accuracy. It includes more details on the case (age, sex, ethnicity, place of birth etc), risk factors, clinical picture and microbiology. It is useful for subgroup analysis (policy, service planning) and monitoring some elements of service effectiveness.
- 4.3.5 Treatment Outcome Monitoring was added to ETS in 2002. TB needs long term treatment and where patients are poor compliers there may be complications. Data is collected 12 months after diagnosis and start of treatment. It monitors whether treatment completion has been recorded and the proportion of patients who successfully complete treatment.
- 4.3.6 Laboratory data (MycobNet) collects data from TB Reference Laboratories. It provides details on TB species and antibiotic sensitivity and is linked to ETS centrally. Its main use is in measuring drug resistance but it also identifies bovine TB cases for enhanced surveillance.
- 4.3.7 TB Strain Typing is a new service introduced by HPA Reference Laboratories. It examines 24 specific areas of the organism's DNA. It aims to spot cases that might be linked, based on the similarity of organisms at DNA level. Potential clusters are reported to the local laboratory and the local Health Protection Unit for investigation. The aim is to identify common sources and unscreened contacts and it can also rule out links in suspected clusters.
- 4.3.8 Incident and Outbreak Surveillance is a recently introduced system. Incidents would be cases of potential exposure to an infectious case in an educational setting, prison, healthcare setting, an aircraft etc. This often requires a major effort to screen all possible contacts. An outbreak is two or more linked cases in a non-household setting. The aim is to collect data to inform an evidence base for preventing and managing incidents.
- 4.3.9 The HPA provides annual reports on TB surveillance findings at national, regional and city levels and the data can be analysed by PCT area or by ward. Provisional HPA data shows that in 2010



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half the TB cases in Birmingham were in just seven out of the 40 wards; that TB cases in England and Wales had reduced from 118,000 in 1913, to 52,000 in 1945, to 10,000 in 1969, and to 5,000 in 1989, but had then increased to 6,000 by 2009; and that in Birmingham there were 329 TB cases in 2002, and this peaked at 470 in 2009, but reduced again to 358 in 2010.

4.3.10 HPA data showed wide differences between ethnic groups in Birmingham in the rate of TB cases per 100,000 population. 70 % of those with diagnosed TB had not been born in the UK. The incidences were as shown in figure 3.

**Figure 3: TB cases in Birmingham by ethnic group**

<b>Ethnic group</b>	<b>TB cases per 100,000 population</b>
Black African	280.2
Pakistani	142.3
Indian	112.8
Black Other	50.8
Bangladeshi	43.1
Black Caribbean	41.5
Mixed Other	33.7
Chinese	17.5
White	5.0

4.3.11 In the Heart of Birmingham area, 62 % of those patients with TB who were not born in the UK were born in South Asia (mainly in the sub-continent) and 21 % were born in sub-Saharan Africa. The next table (Figure 4) shows the 187 TB cases in the Heart of Birmingham analysed by certain risk factors.

**Figure 4: TB cases by risk factor**

<b>Risk Factors/DOT, 2010</b>	<b>Yes</b>	<b>No</b>	<b>Unknown</b>	<b>Blank</b>	<b>Total</b>
Previous notice	16	163	1	7	187
BCG vaccinated	64	60	39	24	187
Drug use	2	168	5	12	187
Alcohol use	5	163	2	17	187
Homeless	1	171	3	12	187
Prison	6	152	3	26	187
DOT	4	30	0	153	187

So excluding those who couldn't remember or gave no information, more than half who have TB had had the BCG vaccination and almost a tenth of the patients were catching TB for the second time.

4.3.12 The 2004 report set the following six measurable targets for TB control and reduction.

- A progressive decline in rates (of at least two per cent per year) of tuberculosis in population groups born in England. This is being achieved.



- A reduction in incidence of tuberculosis in those who entered and became resident in the country within the previous five years. This is being achieved.
- No more than seven per cent of new cases resistant to one drug and two per cent multi-drug resistant. This is being achieved.
- All patients with suspected pulmonary tuberculosis are to be seen by the tuberculosis team within 2 weeks of first presentation to health care. The HPA presentation did not cover whether this target is being achieved.
- At least 65 per cent of patients with pulmonary tuberculosis have the diagnosis confirmed by laboratory culture. This is being achieved.
- All patients with tuberculosis to have outcome of treatment recorded and at least 85 per cent successfully complete their treatment. This is being achieved.

Thus five of the targets are being achieved and no evidence was received about the sixth.

- 4.3.13 The Committee finds it encouraging that all, or all but one of the targets set in 2004 have been achieved. However it holds the view that it is time to set new, more stretching targets, particularly in respect of the percentage of patients with pulmonary TB whose diagnosis is confirmed by laboratory culture, and the percentage of patients who successfully complete their treatment.
- 4.3.14 There is a national system of reporting of infectious diseases in prisoners. Her Majesty's Prison in Birmingham takes part in a DH funded project, covering symptom screening, then if screening is positive, a chest X-ray.
- 4.3.15 In strain typing the current situation is that all isolates are typed; there are both local and national identification of clusters, and local meetings are held to review the clusters.
- 4.3.16 The next steps are to increase TB cluster investigation, ensure close working with TB cluster investigators; improve techniques for social network analysis; improve national and local collation of TB incidents; and in respect of neonatal BCG vaccination, to agree a maternity contract with all relevant parties; and to achieve the incorporation of BCG vaccination into the new child health information system.

## 4.4 Excellence in clinical care

- 4.4.1 The aim of excellence in clinical care is 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% successfully completing treatment.
- 4.4.2 Members were told about what constitutes excellent TB services:
- An excellent TB service is a dedicated one with a separate weekly or more frequent outpatient clinic; staff who have regular and continuing experience; ready access to multi-disciplinary services; and a full array of diagnostic services including clinical, radiological and



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laboratory testing. The service must be holistic, focusing on each patient's circumstances and needs.

- TB services provided in high-incidence areas should include TB-specific outpatient clinics attended by the multidisciplinary TB team.
- A lead clinician should have overall responsibility for the diagnosis and possible treatment of TB.
- Each patient should have a TB nurse as their key worker.
- There should be a TB network in the hospital to ensure effective diagnosis, liaison and treatment.
- There should be adequate isolation facilities for hospitalised patients including high-quality negative pressure isolation facilities to minimise the risk of spreading infection. There may be three types of isolation facilities, namely an isolation room, an isolation room in an isolation ward, and a negative pressure isolation room in or out of an isolation ward.

4.4.3 The national target to have at least 85% of TB patients completing their treatment has been used as one of the recommended indicators in the draft strategy. Between 2002 and 2009 compliance in Birmingham has varied between 81.3% and 87.2%. Birmingham was above the target in 2007 and 2008 but below in other years. The main cause of non-compliance is that patients return to their home country and are lost to follow-up.

4.4.4 All patients with smear-positive pulmonary TB are seen in five working days, and contacts are screened within two days. All patients with smear-negative pulmonary TB are seen in five working days and contacts are screened within two to three weeks.

4.4.5 Details of all patients and their treatment outcomes are entered in a local database and treatment is managed in accordance with NICE guidelines. The new Birmingham database called 'Dendrite' is unique in the UK in the range of information it holds, which includes data about work place, school, as well as clinical data such as HIV status. Data is collected for all active and latent TB cases for 20 years.

4.4.6 The chances of a successful outcome are improved if continuing care is supervised routinely and more use is made of Directly Observed Therapy (DOT). Members were told that currently there are patients who would benefit from DOT if resources allowed. Where DOT would be beneficial but cannot be resourced the use of dosset boxes gives some support for compliance. They have doses marked by day so the patient can check whether or not the day's medicines have been taken. Each box contains a week's doses. The case manager may need to work closely with housing and social services to ensure their staff know about the need for the patient to maintain treatment compliance.

4.4.7 The draft strategy identifies the need to identify more resource to undertake DOT as one of the challenges in Birmingham and includes a recommended indicator about increased numbers of



patients on DOT. Evidence presented to the members suggested that more use could be and needs to be made of third sector and community organisations and community pharmacists to be DOT supervisors. DOT is sometimes needed every day, but in other cases it can be effective if only done three times a week. ( **Reference R3**)

- 4.4.8 At Birmingham Chest Clinic and Birmingham Heartlands Hospital TB consultants, nurses, Health Protection Agency staff and sometimes a microbiologist meet weekly to discuss all TB cases and contacts. There is also a monthly multi-disciplinary typing meeting; a weekly discussion of all active TB cases diagnosed at the Clinic or the Hospital, and a quarterly MDT discussion of complex cases including multi-drug resistant TB cases. A City-wide cohort review is being established.
- 4.4.9 Quarterly meetings of the clinical reference group are attended by TB lead consultants, TB consultants, TB microbiologists, TB pharmacists and HPA staff. The group develops clinical care pathways and develops protocols for the management of active TB. It also advises on the management of patients requiring preventive chemoprophylaxis according to NICE guidelines.
- 4.4.10 A Birmingham protocol for TB contact screening has been developed by TB consultants in consultation with the HPA, TB nurses and TB microbiologists. It is adapted periodically according to recent best evidence and NICE guidelines. Data from TB skin test and interferon gamma release assays (IGRA) test results (which are more reliable than a TB skin test) is audited every 3-6 months.
- 4.4.11 The strategy currently refers to a centralised TB nursing service but evidence to the Committee suggested that there should be a higher proportion of TB nurses to TB cases than there is at present. The cost of investing more in TB nursing is much less than the overall cost of not making that investment. ( **Reference R4**)

## 4.5 Well organised and co-ordinated patient services

- 4.5.1 The aim is to provide high quality co-ordinated services for TB diagnostics, treatment and continuing care, which also meets the needs of individual patients.
- 4.5.2 Evidence was presented about the rapid access which is enabled to the TB clinic at Heart of Birmingham and at City Hospital. There is direct referral from the radiology department to the rapid access TB clinic. Patients seen by A&E or a GP with abnormal radiology are referred directly to the clinic. Patients are seen within 7 days of referral or within 48 hours if they have suspected smear-positive TB.
- 4.5.3 All drugs are free of charge, including anti-emetics and other drugs related to TB treatment. There is a TB pharmacist at Birmingham Chest Clinic.



## 4.6 First class laboratory services

- 4.6.1 The aim is to provide laboratory services of a consistent high quality which support clinical and public health needs. Evidence was presented from the Midlands Regional Centre for Mycobacteriology that the three reference laboratories in England are in London, Birmingham and Newcastle upon Tyne.
- 4.6.2 TB incidence rates per 100,000 population vary greatly in England. They are highest – above 80 – in Heart of Birmingham PCT area and the two London PCT areas of Brent and Newham. This is based on a three-year average case rate from 2006 to 2008 by PCT area. The highly variable distribution of disease is a challenge for diagnostic services.
- 4.6.3 TB laboratory services in Birmingham are at:
- Birmingham Heartlands: for local GPs, Heartlands, Chest Clinic, Good Hope, Solihull and University Hospitals.
  - City Hospital: for local GPs, City and Sandwell Hospitals.
  - Birmingham Children's Hospital: for Birmingham Children's Hospital and the Women's Hospital
- 4.6.4 It was explained that molecular strain typing is used to identify epidemiological links between TB patients to detect and control outbreaks rapidly by trying to identify where a patient might have caught TB. It has been used to:
- Manage outbreaks and incidents;
  - Assist infection control in healthcare settings;
  - Assist in the management of difficult patients;
  - Decide who to screen in difficult or complex settings; and
  - Reduce contact screening because the index case is known.

## 4.7 Effective disease control at population level

- 4.7.1 The issue of screening those at risk is complex and remains a significant challenge to the capabilities of the system.
- 4.7.2 It was clear from the evidence presented to the Committee that checks or screening at the port of entry are not effective in picking up on TB disease or latent TB infection in high risk groups, including new entrants. Port health arrangements mean that notifications of risk are sent to the local NHS but by the time they are received the person may have moved. The port health arrangements are widely believed to be ineffectual and cumbersome for the yield of positive cases



they return. Moreover, testing and screening for TB under current technologies means that repeated diagnostic testing is needed to confirm cases which are negative.

- 4.7.3 The TB strategy recognises that there is a need to develop and implement a more effective service for screening new entrants including refugees and asylum seekers. One of the recommended lines of action in the TB strategy refers to the need to develop and implement a service for screening new entrants including refugees and asylum seekers, in accordance with NICE guidance.
- 4.7.4 There is evidence that most new migrants register with a GP within a year of arrival. Given that many of the cases in Birmingham are detected after arrival, it seems likely that a screening service which is targeted in primary care ie. GP-based new entrant screening, could lead to early treatment for a substantial proportion of new migrants.
- 4.7.5 This needs to be raised with the newly emerging clinical commissioning consortia and consideration needs to be given as to whether arrangements to put this in place can be incorporated into the new commissioning systems to give GPs an incentive to do this.

**( Reference R5)**

## 4.8 An expert workforce

- 4.8.1 The aim is to ensure that TB control has an appropriately skilled workforce with the numbers of staff and skills to be able to cope with the TB workload, and that physicians and nurses with expertise in TB continue to be recruited, trained and retained.
- 4.8.2 Clearly the need to maintain and appropriately resource the TB nursing service is paramount and this is reflected in the draft strategy. Members were told that the Department of Health (DH) recommends a TB nurse to patient ratio of 1:40 in London and a ratio of 1:50 elsewhere.
- 4.8.3 The specialised TB team covering Birmingham comprises one pay band 7 team manager based at Birmingham Chest Clinic, eight band 6 TB specialist nurses, one band 5 staff nurse, one band 3 support worker, one band 3 clerical staff manager and four band 2 clerical staff. Members were told that the bandings for the team, in particular the team manager and the TB specialist nurse, need to be reviewed (and indeed the banding for the nursing service is referred to in the draft strategy). **(Reference R4)**
- 4.8.4 At the time the evidence was presented, the TB team was dealing with 13 TB incidents – cases of active TB occurring in a school, college or workplace where many contacts have to be followed up and screened – compared to only three to four per year in the last three years. Between June 2010 and June 2011 there were 435 cases of live TB, of which 121 were being treated by Birmingham Chest Clinic, 114 at City Hospital, 100 at Heartlands, 80 at UHB, 8 at Birmingham Children’s Hospital, 5 at Good Hope, 2 at Solihull Hospital and 1 at Priory Hospital. 4 other cases are being treated elsewhere.



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- 4.8.5 Eight TB specialist nurses currently cover 435 TB cases, so on average each TB nurse has just over 54 cases, which is higher than the DH ratio. When the fact that each patient has five to ten contacts that need to be followed up is taken into consideration, the volume of cases and contacts being dealt with by the TB team is self-evidently heavy. Extra pressure is put on the team by the number of cases which require additional input because they have multiple problems and/or are challenging. In 2011 there were 78 active cases needing additional input because they had multiple problems or were challenging. They included 9 patients with MDR TB, 5 with aggressive behaviour, 6 with drug problems, 11 on DOT, 6 with a weekly dosset box, 14 others with poor compliance, 5 with mental illness, 6 needing double visits and 12 needing treatment for over a year.
- 4.8.6 Members were told by a Consultant Respiratory Physician and TB Lead in Heart of England Hospitals NHS Foundation Trust that " They (the TB specialist nursing team) absolutely cannot cope with the volume of work". Members were also told by the North Central London TB Network Manager & London TB Projects Lead that the 1:40 ratio set by the DH for London is too high and that she is currently working towards a more effective ratio of 1:30. **(Reference R4)**
- 4.8.7 The skill mix of the team includes leads for prison services, paediatric services, TB typing, contact screening, education, refugees, unaccompanied young adults and supported living. At Birmingham Chest Clinic there are TB nurses, pharmacists, clerical support staff, consultants, microbiologists and radiologists all specialising in TB. To maintain and adequately resource the team the skill mix and resource needs to include an adequate number of clerical support staff, A TB multi-disciplinary team (MDT) co-ordinator (there is already an MDT co-ordinator for lung cancer but not yet one for TB) and a TB project manager to liaise with the third sector including community engagement programmes. **(Reference R4)**

## 4.9 Leading edge research

- 4.9.1 The aim is 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.
- 4.9.2 The problem is that Birmingham has one of the highest tuberculosis incidences of any European city; around one third of cases of TB diagnosed in Birmingham were acquired in Birmingham and people still die of TB in Birmingham in the 21<sup>st</sup> century.
- 4.9.3 The solution is to better understand how TB is transmitted in Birmingham, to understand different communities' perceptions about TB and address any barriers to accessing health care.
- 4.9.4 The gaps are that in many cases we are unsure of the links between people who acquire TB in Birmingham and we do not fully understand the places that put people at risk of acquiring TB.
- 4.9.5 The rate of TB incidence per 100,000 population is higher in Birmingham than in London, Brussels, Barcelona, Paris, Rotterdam, Amsterdam, Milan, Stockholm or Berlin. In Birmingham the incidence rate rose steeply from 2002 to 2008, while the incidence rate in most of the other nine declined.



- 4.9.6 Improvement is achievable. For example the incidence rate per 100,000 population in Barcelona steadily reduced from 67 in 1992 to 24 in 2008. In contrast in Birmingham the rate was 29 in 1992 but increased to 51 by 2008.
- 4.9.7 Social network analysis explores the links between people and places. It can be used to link people who may have common risk factors for acquiring TB. It is used to link people and places in time, and identifies possible routes of spread of TB.
- 4.9.8 Often TB links can be found at previously unsuspected parts of the social network. For example contact tracing has sometimes identified that the same strains of infection occurred in several homes with seemingly no contacts between the families, either in visits to each other, or at work, school or places of worship. Further detective work is needed until a common link – perhaps an infectious relative or friend who visits each home often but lives elsewhere – has been found. Only when the full network of contacts is discovered can the treatments be sure to stop further spread. This strengthens the case for more extensive contact tracing.
- 4.9.9 Whilst most TB transmission occurs at home, it can also occur in any other location where people meet and often come into sustained contact with someone who is infected.

## 5 Conclusion

### 5.1 Addressing TB in Birmingham

- 5.1.1 The immediate aims of the national TB programme which are incorporated into the draft Birmingham strategy are to:
- Reduce the risk of people being newly infected with TB in England;
  - Provide high quality treatment and care for all people with TB; and
  - Maintain low levels of drug resistance, particularly multi-drug resistant (MDR) TB.
- 5.1.2 TB can be controlled by:
- Promptly recognising and treating people with the disease;
  - Ensuring that people with TB complete their treatment. Non compliance with treatment not only fails to cure the disease but contributes to the growth of drug resistance;
  - Identifying and treating people with early infection, to prevent them later developing the full disease; and
  - Prevention through BCG immunisation of high-risk newborn babies.
- 5.1.3 To achieve these objectives a plan has now been developed for Birmingham based around the steps which the government, the health services and local communities need to take to reverse the rise in TB.