PUTTING TUBERCULOSIS ON THE LOCAL AGENDA

A REPORT BY
THE ALL-PARTY PARLIAMENTARY GROUP ON GLOBAL TUBERCULOSIS AND THE BRITISH THORACIC SOCIETY

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1. Executive Summary

This report is based on the results of a questionnaire which was sent to all Primary Care Trusts (PCTs) across England. The survey follows on from a British Thoracic Society (BTS) survey of secondary care tuberculosis (TB) services in March 2007 and the publication of:

- **Department of Health TB Action Plan** - Stopping Tuberculosis in England: An Action Plan from the Chief Medical Officer (October 2004)[1]

- **NICE Guidelines** - Clinical diagnosis and management of tuberculosis, and measures for its prevention and control – National Institute for Health and Clinical Excellence (NICE) tuberculosis clinical guideline (March 2006)[2]

- **TB Toolkit** - Tuberculosis prevention and treatment: a Toolkit for planning, commissioning and delivering high-quality services in England (June 2007)[3]

The survey was commissioned by the All Party Parliamentary Group on Global TB and the BTS (hereinafter referred to as "we").

The primary care questionnaire was designed to explore some of the themes of these policy documents and to ascertain the level of implementation which had been achieved by PCTs across the country. This report analyses the responses, gives a "score" or rating to each PCT according to the extent to which the policies have been implemented, and makes a series of observations and recommendations about the future of TB services in primary care.

- Overall response rate and scoring

Of the 152 PCTs contacted, 101 (66%) returned completed questionnaires. In those responding, there was little correlation between the overall 'score' received and the burden of TB within the PCT's catchment area. In other words, areas with a high incidence of TB generally failed to score better than areas of low incidence. However, there were significant variations in how PCTs scored when grouped in their Strategic Health Authority (SHA) regions.

- Population changes

86% of PCTs stated that they anticipated a change to their population demographic and 68% thought that this would lead to a rise in the local incidence of TB. Not a single respondent thought there would be a fall in TB in

[1] http://www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/Features/FeaturesArchive/DH_074748
[2] http://www.nice.org.uk/CG033
[3] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075621

their area. Given these responses, we were particularly concerned to note that 67% of respondents stated that they had no plans to deal with the expected rise in TB cases.

- TB lead within the PCT

The TB Toolkit recommends that each PCT should appoint a TB Lead. Only 50% of PCTs responding to our survey claimed to have an individual identified as their TB Lead, a role to be filled by an individual in a position to take strategic decisions and influence commissioning arrangements at board level. Of that 50%, many PCTs identified as their Lead, either a person who was not actually employed within the PCT (for instance, a consultant respiratory physician) or an individual who, whilst employed by the PCT (for instance, a TB nurse), seemed unlikely to be in a board level position to have the influence envisaged by the TB Toolkit.

- Screening for TB of new arrivals to the country

The screening of all new immigrants is part of the NICE guidelines, and is highlighted in both the Action Plan and the TB Toolkit. However, only 55% of all PCTs said a new entrant screening programme was in place. One PCT with a very high TB rate (over 50 new cases annually per 100,000 population) said that the new entrant screening programme had been scrapped.

Furthermore, the responses received almost universally said that information received from the port health service was scrappy, patchy, and insufficient to enable them to put in place the necessary screening mechanisms and processes.

- Defined Service Level Agreements

Only 30% of PCTs said that there was a Service Level Agreement (SLA) in place, despite this being a key recommendation in the TB Toolkit. In any event, we suspect that this is a substantial overestimate, confusing broader SLAs for medicine generally (within which TB is subsumed) with specific SLAs for TB.

- Funding

36% of responding PCTs stated that TB funding was specifically identified within the contracting process. However, given funding is often integrally tied into SLAs and this percentage represents a higher proportion than those who said there was a SLA in place, we would have to question the accuracy of this response.

Surprisingly, the proportion of PCTs in high TB incidence areas who had specific TB funding was no different from that in low incidence areas.

- Relationship with local partners

This is an extremely important area, especially from a financial management perspective, when a patient is using an expensive hospital bed because they do not have anywhere else to go. It is vital that PCTs are collaborating with local authorities and community social care services when managing a communicable disease like TB. However, 40% of responding PCTs stated they had done no work at all with this sector. Amongst those PCTs who said that there was ongoing collaboration, when the supplementary question asked for examples and further details, this was usually left blank.

- Raising awareness of TB

Awareness-raising about TB is one of the key issues in the TB Toolkit, but 41% of PCTs said they were not active in this area. 45% said they were, but when asked to give examples many simply stated that they had informed their population about changes in schools BCG vaccination policy. There appeared to be no difference in approach between high and low incidence areas. Only 6% of PCTs reported engagement with local media, and this was almost always reacting to reported TB cases and outbreaks rather than pro-active awareness-raising. There was, however, evidence of pockets of good practice around the country.

These findings from the primary care survey support the findings of last year's British Thoracic Society report, which found that two thirds of secondary care (hospital) TB leads claimed there was no local programme aimed at raising awareness of TB in their area.

- Setting Priorities

We asked how many times TB has been an agenda item for discussion, either at PCT board level or on the agenda of the Professional Executive Committee. 50% of respondents stated that it had never been an agenda item. 31% said that it had featured once or twice - but when asked to give details many simply said TB had featured in the Annual Report. Only 5% of PCTs said that they had discussed TB more than three times in the last two years.

- Conclusions

Not one of the PCTs which responded to our survey expects to see a fall in the number of TB cases in the future, yet they have generally not taken the necessary steps to deal with this growing problem.

A key recommendation of the TB Toolkit was for there to be a TB lead within every PCT; someone able to take strategic decisions about service planning and delivery, able to make recommendations at board level within the PCT, and able to enter into detailed commissioning negotiations. Almost half of PCTs think they have a TB lead but, in general, they do not have an individual fulfilling the role and remit envisaged in the commissioning TB Toolkit.

There are pockets of good – indeed excellent - practice which are highlighted throughout this report. We found instances where co-operation

between PCTs and service providers meant that centralised management of cases, contacts and new arrivals, with excellent support from laboratory staff and the Health Protection Unit, allowed for a cohesive and effective approach to TB.

Sadly, these positive findings are all too often outweighed by services struggling to cope. One PCT did not even trouble to respond itself, but simply passed the questionnaire on to the local TB service provider who stated: "*our medical resources are <50% of the recommended level, our administration is virtually non-existent, and our nursing resources are at about 50% recommended level*."

In publishing these responses and this report, we therefore call for three things as a matter of priority:

1. There should be a properly-funded national TB awareness campaign, tailored to local circumstances, aimed at healthcare professionals as well as the general public.

2. PCTs must ensure that there is a clearly identified individual within their organisation who is charged with developing strategies for service provision for TB and ensuring that provision of such services meets, at the minimum, the TB Guidelines for the National Institute for Health and Clinical Excellence.

3. PCTs should specifically identify and commission TB services, in accordance with the guidance set out in the DH Commissioning Toolkit[4].

[4] *Please note that we decided to just survey English PCTs because the TB Toolkit does not apply to Wales. Unlike English PCTs the Welsh Local Health Boards are not responsible for commissioning TB services. However, the All Party Parliamentary Group on Global TB did discuss the TB situation in Wales with Dr Lika Nehaul, Consultant in Communicable Disease Control from the National Public Health Service for Wales who has overall responsibility for TB services in Wales and there are plans to incorporate an audit of services in Wales in the near future.*

2. Recommendations

In publishing these responses and this report, we make three recommendations for priority action. These recommendations are made against a background of two stark findings:

- First, PCTs are responsible for commissioning TB services and yet not one of those responding believed that TB levels will fall in the near future.
- Secondly, in the earlier BTS survey of secondary care TB leads (responsible for delivering most TB services), 88% believed that the number of TB cases would continue to rise over the next 5 years.

Given these findings, it is a real concern to note that 67% of PCTs have no plans in place to manage or plan for the expected rise in then number of TB cases.

1. **There should be a properly funded national TB awareness campaign, tailored to local circumstances, aimed at healthcare professionals as well as the general public.**

   Our survey revealed that the majority of PCTs are not undertaking any proactive work to raise the level of awareness of TB, either amongst healthcare professionals or the public generally.

   Poor public and, particularly, professional awareness of TB means that diagnosis is often delayed. This has costs in terms of the public health, personal suffering, and consumption of NHS resources.

   We urge the government to provide public health money for a specific campaign to raise awareness of TB nationally, which could then be adapted by PCTs to meet local circumstances. We also urge the government to provide ring-fenced money for PCTs to run local awareness campaigns on TB.

2. **PCTs must ensure that there is a clearly identified individual within their organisation who is charged with developing strategies for service provision for TB and ensuring that provision of such services meets, as a minimum, the National Institute for Health and Clinical Excellence TB Guidelines.**

   Rapid changes in population demographics mean that this must be implemented in areas that currently have a low incidence of TB, as well as a high incidence.

3. **PCTs should specifically identify and commission TB services, in accordance with the guidance set out in the DH Commissioning Toolkit.**

   At present, TB service provision is almost invariably subsumed within bulk general contracts or SLAs which cover a wide range of medical services. There is rarely any specific provision made for TB services, let alone

allocated funding. The frequent consequence is that the allocation of resources to TB services is usually insufficient for local needs, and the costs of management and treatment increase overall because of a failure to take preventative action and/or diagnose cases early

3. Introduction to the Survey and Methodology

TB is a common and potentially deadly infectious disease caused by a bacterium. It most commonly affects the lungs, but can spread to any part of the body.

The TB Action Plan

'Stopping Tuberculosis in England: An Action Plan from the Chief Medical Officer,' was published in October 2004 in response to a dramatic rise in TB across England. At the time of publication TB in England had increased by 25 per cent since 1994. In the same time frame the disease doubled in London, leaving a few London boroughs with TB rates comparable with some developing countries. The then Secretary of State for Health, John Reid MP described TB as "on the march again".

The NICE guidelines

In March 2006, the National Institute for Health and Clinical Excellence (NICE) published a set of Guidelines, "Clinical diagnosis and management of tuberculosis, and measures for its prevention and control".

The TB Toolkit

This was followed up in June 2007 with the Department of Health publication of, "Tuberculosis prevention and treatment: a TB Toolkit for planning, commissioning and delivering high-quality services in England". The TB Toolkit was published in order to assist the NHS with implementing the TB Action Plan, by assisting PCT commissioners to plan and commission TB services for their local population.

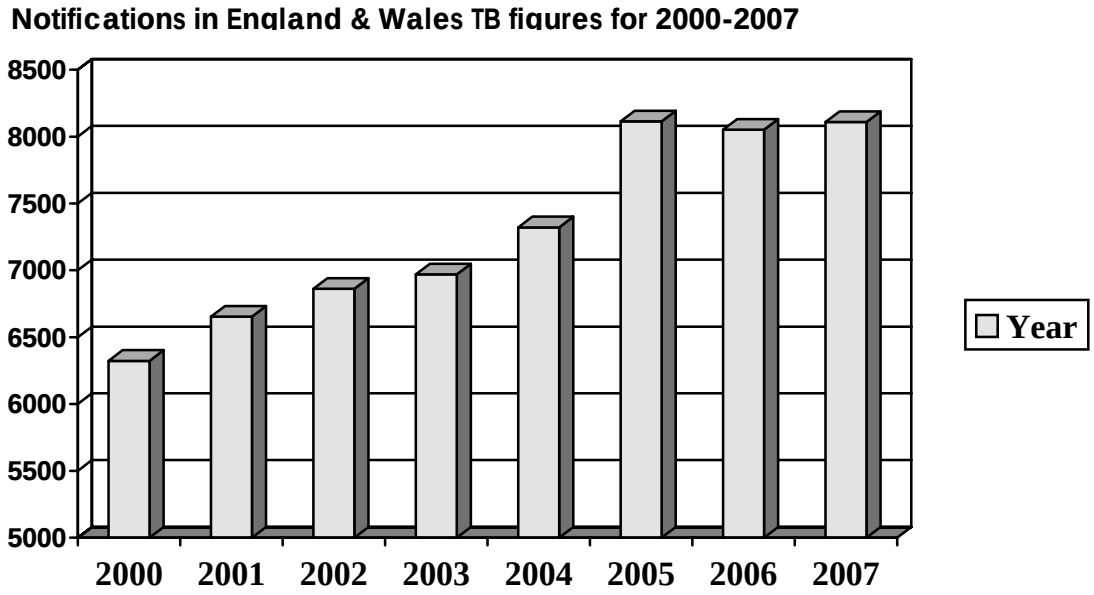
Amongst the key messages in the TB Toolkit were:

- All PCTs needs to be aware of TB regardless of whether you are in an area of high incidence or low incidence.
- Population shifts and pattern of workers migration also means that PCTs need to think about TB in the future and review local demography.
- There is an economic case for commissioning and delivering effective TB services. If PCTs do not treat ordinary TB cases properly it will have to deal with far more treating drug resistant cases later.
- All PCTs need to plan for local services. The TB Toolkit contains information to commissioners on how to work effectively within new NHS parameters such as the commissioning process, choice, choose and book.
- Every PCT should have a named TB lead
- TB is best managed in specialised services but PCTs play an important supportive role

- Increasing awareness is very important in tackling TB and evidence shows that local campaigns work better than national ones.

What is happening to TB?

However, despite these publications at national policy level, there has been a steady increase in the number of TB cases in **England and Wales** in recent years, as demonstrated by the graph below.



British Thoracic Society Survey of Secondary Care TB Leads

In March 2006 the British Thoracic Society (BTS), concerned by the lack of apparent urgency in tackling this major public health threat, conducted a survey of TB secondary care leads.

The results of the survey were presented to the All Party Parliamentary Group on Global TB (APPG) in June 2007 and are summarised in the box below.

Both the APPG and the BTS felt that the evidence was robust enough to conduct a survey of PCTs who, within the devolved healthcare system, are formally responsible for planning, commissioning and delivering TB services: PCTs are responsible for delivering local care according to local needs. However, a side effect of this has been the development of an accountability vacuum. This can partially be filled by Professional Membership Organisations and Parliamentary committees collaborating together to audit the effective delivery of healthcare.

This approach was recently supported by the Health Select Committee who stated in their report on NICE that "Greater involvement of the Royal Colleges

and other professional organisations in encouraging implementation could also increase the uptake of NICE guidance[5]."

Key Findings from the British Thoracic Society Survey of Secondary Care (Hospital) TB Leads - March 2007

Multi-Disciplinary Working: 'across the board' failure to implement local multi-disciplinary TB networks – a central plank of the TB Action Plan

Local resourcing of TB: Despite the publication of the Action Plan two and half years previously, 78% of TB leads have had no change in resources to implement the recommendations.

Financial pressures impact on Specialist TB Nurses: Over a third of TB leads stated that the specialist nurse position was under threat or review.

Insufficient medical time: Only a minority of TB units had appropriate identified time for TB management in the TB lead clinician job plan.

Waiting Times: Despite a central aim of the Action Plan being that "suspected cases of pulmonary TB are seen by the TB team within two weeks of first presentation to healthcare", a fifth of TB leads have stated that this is not achieved.

Laboratory Services: almost half of TB leads did not have access to a designated microbiologist with specific responsibility for TB. 39% did not have access to Gamma-interferon blood testing for detection of latent TB infection.

Screening and Contact Tracing: over two thirds of respondents said there was not a local programme aimed at raising awareness of TB in high-risk areas. Furthermore almost half of TB leads said there was not even a local programme carrying out active case finding in high-risk groups.

Local prioritisation of TB: 85% of TB leads believed that their PCTs should give TB more priority and 70% rated the Department of Health as poor or very poor in their role in TB prevention.

A fifth of TB leads claimed that the priority given to TB by PCTs was simply inadequate.

A worrying future for TB: over half of TB leads believed that TB care will not have improved two years from now and 88% of TB leads believe that the number of TB cases is set to rise over the next five years.

[5] House of Commons Health Select Committee, Fifth report of Session 2006-07, National Institute for Health and Clinical Excellence, 10th January 2007, page 78 http://www.publications.parliament.uk/pa/cm200708/cmselect/cmhealth/27/27.pdf

3. The PCT Survey - responses and methodology

Responses

On the 17th September 2007, we sent a self-completion postal questionnaire to 152 PCTs, requesting completion by 12th October. We sent a reminder letter to PCTs on 19th October 2007, extending the deadline for completion to 5th November 2007.

We received 98 responses.

Two of the responses were collaborative amongst PCTs:

- NHS South of Tyne & Wear responded on behalf Gateshead PCT, South Tyneside and Sunderland Teaching PCT
- Brent and Harrow PCTs also sent a joint response

In total, therefore, we received responses from 101 PCTs (66%) out of a total of 152 PCTs.

Design of the questionnaire

The questionnaire and its accompanying letters are set out at Appendix 1 (Page 28). The starting point for the questionnaire was the TB Toolkit, and the questions asked were designed to elicit the degree to which the key elements of that the TB Toolkit were being implemented by PCTs.

As the TB Toolkit is only applicable in England, this particular survey focussed on the responses of PCTs only. We do have plans to conduct a similar survey, appropriately tailored, to Local Health Groups in Wales in due course.

Criteria for judging performance

The survey questions were divided into the following categories

1) Incidence and population changes
2) PCT TB Lead
3) Testing and Screening
4) Treatment / Service Levels
5) Priority Setting
6) Awareness Raising
7) Collaborative Working

Some questions were designed to elicit responses that were necessarily qualitative in nature. These responses are extremely valuable in painting a picture of the approach of the PCT to TB, and will inform future targeted investigations, but are not readily amenable to direct comparative analysis. They have therefore not been included in the scoring process.

The majority of questions, however, did lend themselves to quantitative responses which could be used to generate a number of "points" for each answer given and used to "score" PCTs. We have expressed above our reservations about the accuracy of some of the responses (see the Executive Summary), but have taken PCTs at their word and have given them the benefit of the doubt when calculating their score.

Under the scoring system, the maximum points a PCT could earn was 44. A PCT scoring between 0 and 14 has been given one star (which we have called "poor"), those scoring 15 to 30 have been given two stars ("acceptable"), and 30 to 44 have been given three stars ("good").

Presentation of results

It is important to note that this is the first survey of its kind of TB services in primary care, that PCTs have had relatively little time to implement the TB Toolkit, that some respondents clearly misunderstood some of the questions, and that we have doubts about the accuracy of some of the responses.

For these reasons, we have decided not to publish the scores of individual PCTs. There is the possibility that PCTs may have been given, incorrectly, either very high, or very low, marks. However, the survey clearly provides enough information to identify the general extent of policy implementation and general trends, such as the marked differences across the country at Special Health Authority (SHA) level.

Accordingly, in this report we present the results at SHA (regional) level. The results for individual PCTs will be provided, together with a copy of this report, to the PCTs themselves and (for each PCT for which they are responsible) to the SHAs. The individual PCT scores will be used when this survey is repeated to see the extent to which improvements have taken place.

4. Survey Results

Response rates

Table of PCT responses by Strategic Health Authority				
Strategic Health Authority	**No of PCTs**	**Replying**	**Not replying**	**Percentage responding**
NHS East Midlands	9	5	4	56%
NHS East of England	14	6	8	43%
NHS London	31	24	7	78%
NHS North East	12	8	4	67%
NHS North West	24	18	6	75%
NHS South Central	9	7	2	78%
NHS South East Coast	8	3	5	38%
NHS South West	14	10	4	71%
NHS West Midlands	17	12	5	70%
NHS Yorkshire and the Humber	14	8	6	57%
TOTAL	152	101	51	

We have interpreted the overall response rates as one broad surrogate indicator of the importance which PCTs have attached To TB.

By SHA region, the highest levels of response came from NHS London, NHS North West and NHS South Central. NHS West Midlands (which has a very high incidence of TB) had a similar response to NHS South West (with a very low incidence of TB). NHS East of England and NHS South East Coast were conspicuously worse in terms of numbers of completed responses than other SHAs.

Overall PCT scores by Strategic Health Authority

The table below shows that the best performing SHA is NHS North East, where the average PCT in the region scored 29 points. Other SHAs that appeared to have an above average performance included NHS East Midlands, NHS East of England and NHS London.

The worst performing PCTs were from NHS South East Coast. It may be no coincidence that this SHA region also had a very low response rate to the survey overall and the highest increase in TB incidence rates compared to the previous year.

Other SHA regions which had poorly performing PCTs included NHS West Midlands (again with a poor response rate) NHS Yorkshire and Humber, NHS South West and NHS South Central.

It must be noted very carefully that a low score does **not** necessarily mean that the quality of TB service offered to patients is poor: this survey focused on the degree to which PCTs are fulfilling their responsibilities to ensure that TB services are good. We are aware of examples of high quality service provision despite there being little support from those charged with commissioning those services, and sometimes indeed in the face of attempts to reduce service provision and resource.

Table of overall PCT scores by Strategic Health Authority					
Strategic Health Authority	**No of PCTs responding**	**One Star**	**Two Stars**	**Three Stars**	**Average Score**
NHS East Midlands	5	0	4	1	26
NHS East of England	6	0	4	2	27
NHS London	24	3	14	7	25
NHS North East	8	0	6	2	29
NHS North West	18	4	10	4	22
NHS South Central	7	2	4	1	20
NHS South East Coast	3	1	2	0	18
NHS South West	10	2	7	1	20
NHS West Midlands	12	4	7	1	19
NHS Yorkshire and the Humber	8	1	6	1	20
TOTAL	101	17	65	20	23

PCT scores by Incidence of TB

As the table below clearly demonstrates, there is little difference in how PCTs fared when their burden of tuberculosis is considered. The PCTs with an incidence rate of 40 to 49.9 /100,000 population appeared to score better overall, but the number in this group is small and for the "high incidence" PCTs as a whole (40.0 or more new cases per annum per 100,000 population), the scores are not significantly better than the lower incidence PCTs.

Incidence of TB	No of PCTs responding	One star	Two Stars	Three Stars	Average Score
0-9.9	53	9	32	12	22
10-19.9	21	5	15	1	20
20-29.9	5	0	5	0	21
30-39.9	8	0	6	2	23
40-49.9	5	0	2	3	30
50+	9	3	4	2	23
TOTAL	101	17	64	20	n/a

Individual questions

Question One – Incidence and local population

1b) How many TB cases have been notified in the last year in your PCT?

Just over 50% of PCT respondents believed they had a rate of TB of between 0 and 9.9 (all figures are given as new cases per annum per 100,000 population). The next highest proportion, 21%, was between 10 and 19.9. The remaining 29% of respondents were equally spread across the classifications. Interestingly 30% of respondents believed that their incidence rates were either in one or two bands higher than figures from the Health Protection Agency show to be the case.

PCT	
Responses	101
0-9.9	53
10-19.9	21
20-29.9	5
30-39.9	8
40-49.9	5
50+	9

1c) Has your PCT forecast potential changes to your population demography?

86% of PCTs claimed to have forecast population changes to their area.

Response	Number of PCTS	% of PCTs
Yes	101	68
No	53	32

1ci) Are these changes likely to result in:

Response	Number of PCTS	% of PCTs
A rise in TB	61	68
No change	24	27
A fall in TB	0	0
Not known	4	5

68% of PCTs are expecting further increases in TB but not a single PCT was expecting a decrease. This view was also supported by the BTS survey of TB secondary care leads, 88% of whom believed that the number of cases was set to rise over the next five years.

1cii) Do you currently have an agreed TB related plan to react to this change:

Response	Number of PCTS	% of PCTs
Yes	12	20
No	19	32
In active Preparation	28	48

Of the 59 PCTs who were forecasting a rise in TB, only 32% had already made plans to manage that increase (as recommended by the TB Toolkit), whilst 47% claimed to have plans in active preparation.

Question Two – TB Lead

The role of the TB lead, as defined in the TB Toolkit, is; *coordinating development of the local plan for TB prevention and control; evaluating which elements of TB services need to be in place; developing partnerships with other organisations; and maintaining vigilance regarding potential outbreaks or rises in prevalence.*

One area of good practice was the North Central London TB Network whose TB Network Manager took the lead for all of the roles described in the toolkit, *in* addition to:

- Raising awareness
- TB education in the NHS, community groups and partner organisations
- Developing strategies for service provision that meet TB patients needs
- Working across the sector with PCTs and providers to co-ordinate TB commissioning and services
- Monitoring, reviewing and evaluating TB notifications and trends

2a) Does the PCT employ a TB lead?

Response	Number of PCTS
Yes	51
No	50

Only 50% of PCTs claimed to have employed a TB lead – a key recommendation of the TB Toolkit. It is important to note that this does not mean an individual who was recruited as a TB lead in the first instance, but an individual who has been identified by the PCT as having primary responsibility for TB services.

It is of considerable concern to us that of the PCTs with a high incidence rate (above 30 per 100,000), 40% did not have TB Lead.

2ai) If the PCT does not have a TB lead in post please identify who, if anyone at all, undertakes the responsibilities

Job Title	Occurrence
Consultant in Communicable Disease Control	3
Consultant on Public Health	10
Consultant Physician & TB lead for Acute Trust	1
Deputy / Director of Public Health	11
Local Clinician	1
Health Protection Unit / Health Protection Agency	6
No one	11
Public Health Specialist	4
Public Health Nurse	1
TB Nurse	2

2b) Please provide the job title and affiliation of the TB PCT lead

Job Title	Occurrence
Deputy / Director of Public Health	12
TB Nurse Specialist	15
TB Network manager	5
Consultant on Public Health	7
Consultant in PH and Specialist nurse for county	1
Consultant in Communicable Disease Control	1
Consultant Chest Physician	1
N/a	1
Principal in Health Protection, Public Health Directorate	1
Public Health Manager / Specialist / Strategist	4
TB Specialist Lead	1
TB Specialist Health Visitor	2

It should be noted that although 50% of PCTs claimed to have a TB Lead within the PCT, when asked to state the job title of that person, many PCTs suggested that it was an individual such as a consultant respiratory physician (who is not, in fact, employed by or even part of the PCT) or a TB Nurse specialist/health visitor. Neither of the latter are in a position to take major strategic decisions and influence commissioning arrangements at PCT board level, which is the role of the TB lead envisioned by the TB Toolkit.

2c) How many hours per week does the TB lead spend exclusively on TB?

Those PCTs which have listed TB Nurses as their TB Lead are spending the most hours on TB. However, it is inevitable that this time will be spent on clinical care, not the responsibilities described in the TB Toolkit ("Coordinating development of the local plan; Evaluating elements of TB services needed; Developing partnerships, Maintaining vigilance regarding potential outbreaks.")

Directors, Consultants and Managers in Public Health were only able to spend a few hours a week dedicated to TB.

2d) Is the TB lead shared with other PCTs and if so how many?

Apart from in North Central London, there was little evidence of collaboration amongst PCTs in terms of sharing a TB lead. This is a key recommendation for low incidence areas in the TB Toolkit.

Question Three – Testing and Screening

3a) Does the PCT routinely screen high-risk groups?

Response	Number of PCTS
Yes	68
No	32
Did not answer	1

3c) Does the PCT have an agreed and active new entrant screening plan?

Response	Number of PCTS
Yes	55
No	15
In active preparation	26
Did not answer	5

Screening of new arrivals is a part of the NICE guidelines and of Home Office and Department of Health policy. However, only 55% of PCTs stated that a new entrant screening programme was in place. 15% of PCTs do not have an active new entrant screening programme (which includes half the PCTs with a rate of 50+). 26% stated that a screening programme is being prepared. One PCT, with an incidence rate of over 50+, stated that new immigrant screening had been stopped despite protest from local healthcare workers

3d) What information sources does the PCT use to identify new entrants for TB screening?

Information Sources most used by PCTs	Occurrence
Port Health	80
Registrations	33
Schools	9
Asylum	19
Occupational Health	7
Health Visitors and Community Nurses	7
Voluntary Groups, Local Authorities and other agencies	7
Home Office	3
Other	14
University	5

Port Health Notification forms were the information source most used by PCTs to identify new entrants. However 20% of PCTs failed to mention whether or not they used Port Heath. Some PCT expressed concern with the Port Health Notification forms, claiming that they were 'erratic' or 'infrequent'. The next most common information source was GP registrations, identified by 33% of PCTs. Other information methods employed by PCTs included the more ad hoc 'opportunistic', 'poor health', and 'word of mouth'.

In Nottingham details of new entrants are sent to the HPA Regional Microbiologist who passes them to the local TB service. The PCT have developed a questionnaire and algorithm to identify high-risk cases. They have developed a relationship with groups such as Refugee Action Group to also help alert them of high-risk groups. Nottingham University Hospital Trust has active links with practice nurses, school nurses and health visitors. An open policy is in force so that opportunistic screening is available at all times.

Question Four – Treatment / Service Levels

4b) Is an SLA [service level agreement] in place governing TB control and prevention services?

Response	Number of PCTS
Yes	33
No	33
In active Preparation	25
Memorandum of Understanding	5

The TB Toolkit recommends that a SLA should be put in place between the PCT and NHS Trust for the planning, commissioning and delivery of TB services.

25% of PCT respondents claimed that this SLA is in active preparation. A further 33% of PCTs said that an SLA was in place.

From discussions with service providers, we believe that these figures are substantial overestimates. We think it likely that PCTs have SLAs in place for medical services (as opposed to surgery) generally, that TB is subsumed within that overall agreement, and that PCTs are thus responding that they have an SLA in place for TB. This is not a SLA in terms of calculating the burden of TB, anticipating the number of new cases, the number of contacts needing following-up, and the amount of active case finding.

Some PCTs in their responses actually challenged the premise of the questions, arguing that it was incorrect for an SLA to be written for TB specifically.

4c) Has the PCT developed working relationships with partners in the local authority, the not-for-profit sector and voluntary organizations to help manage TB care?

Response	Number of PCTs
Yes	44
No	41
In active Preparation	12

The TB Toolkit makes clear that Commissioners should develop working relationships with partners in the local authority, the not for profit sector and voluntary organisations. It states "this is essential if a whole-system / multi-agency response is to be made in order to address the problems of our most challenging patients." 41% of PCTs had not developed these relationships.

Question Five – Priority

5a) Please state how many times TB has been on the PCT Professional Executive Committee board agenda over the last two years?

Response	Number of PCTs
0	44
1	19
2	12
3	1
4	4
Did not answer	20

We felt it was important to ascertain the priority given to TB by PCTs. One of the best ways we felt we could test this was by asking how many times TB had been an agenda item on the Professional Executive Committee board agenda. Almost half of all responding PCTs stated that it had failed to make the agenda. This included several PCTs with a high incidence of TB. 31% of PCTs had made it on to the board agenda once or twice, but this often was as part of the Annual Public Health report rather than an agenda item in its

own right. TB had only been a board agenda more than three times amongst 5% of PCTs.

5b) Please indicate which government publications have informed the development of local TB services and commissioning arrangements.

Government Publications	
Action Plan	56
NICE guidelines	75
TB Toolkit	61
Other	39
All three	37
None	13

We were also keen to see the extent to which National Strategies and Guidelines on TB are registered by PCTs. 75% of PCTs identified NICE guidelines as a government publication that has informed the development of local TB services, but only 61% acknowledged the TB Toolkit and only 56% the Chief Medical Officer's TB Action Plan. This is despite the covering letter accompanying the survey mentioning all three publications.

5c) What specific funding has been allocated for TB in the last financial year?

Response	Number of PCTS
Yes – Specific funding	36
No specific funding	65

36% of PCTs claimed that TB had received specific funding. However, there did not appear to be any correlation between specific funding and the incidence of TB: high incidence areas appeared not to have received any more specific funding than low incidence areas.

5d) Has funding increased for TB services over the last three years?

Response	Number of PCTS
Yes	41
No	45

Probably a better indication of the lack of priority afforded to TB was the fact that 45% of PCTs had not allocated any extra funding over the last three years despite rates of TB increasing rapidly over that time period.

Question Six – Awareness Raising

6) Please describe how the PCT has engaged in active, locally targeted awareness-raising campaigns

Awareness raising campaigns	
None	41
BCG	16
World TB Day	22
Training Healthcare Staff	20
Awareness raising for healthcare staff	31
Raising awareness amongst high risk groups and the public through working with statutory organisations and / or community and voluntary groups	40
Local press	6
Production of targeted leaflets / online info or posters on TB	10

The TB Toolkit states that service providers should 'improve awareness of TB amongst the public, the professions and local authority agencies.' However, from our survey it is clear that 41% of PCTs are not partaking in any awareness raising programmes at all. The only awareness raising undertaken by 5% of PCTs was information regarding the change of the BCG vaccination programme in schools.

Some responses from PCTs suggested that there are pockets of good practice across the country, but these appear to be few and far between. For example, only 6% of PCTs had liaised with local media on TB, and this tended to be provoked by an outbreak of TB. PCTs with a high incidence of TB did no appear to undertake any more proactive awareness campaigns than those with a low incidence of TB.

It is worth noting the work of Croydon PCT in this area. This PCT has *"{worked with} the Homeless Health Team {to} place TB health information in the hotels in which they provide health services. b) Information leaflets on changes to the BCG programme include local awareness raising and were distributed to: local surgeries and clinics, social services drop ins, other health professionals, local press, head teachers. c) Information was also provided for the local school trawl in order to target children who are most likely to catch the disease and vaccinate them. Croydon is currently distributing leaflets on BCG vaccination to parents of children attending primary schools and will also leaflet secondary schools this year. d) PCT participated in World TB day local awareness raising campaign led by Chest Clinic. d) Targeted information/press releases on BCG and TB provided following correspondence between a parent and the local newspaper about changes to the child BCG programme. e) HPU funded case worker worked with local groups, including local mosque for duration of post."*

Question Seven – Collaborative Approach

7a) Does the PCT have any shared, or amalgamated TB agreements in place with other PCTs to manage TB care?

Response	Number of PCTS
Yes	26
No	75

A key message from the TB Toolkit is that, "If the number of active cases within a PCT is likely to be low, commissioning TB services on a shared or amalgamated basis is a route to provide high-quality services." However, only 17% of low incidence areas were adopting a collaborative approach, and there was a higher ratio of collaboration amongst PCTs in high-incidence areas. The most common areas of collaboration were amongst PCTs sharing service providers. A few PCTs were sharing a TB Nurse and a handful claimed they were sharing commissioning responsibilities.

Hounslow PCT established Hounslow Local Health Economy TB Steering Group in November 2004. The steering group is multi-disciplinary and multi-sectoral and includes the following representation: Hospital clinicians (I.e. consultant in respiratory medicine, TB nurse specialist, consultant microbiologist); CCDCs (NW London and North Surrey HPU); PCT Specialist in Public Health / Assistant Director of Public Health; Head of Prison Health Development - Feltham Young Offenders Institute; PCT service managers (i.e. Head of school nursing; specialist health visitor for homeless team); PCT commissioning manager; chief pharmacists (PCT and local hospital); local authority public health manager; local authority housing manager; sector-wide TB coordinator (NWLHPU)

7c) Does your PCT have a specific TB multi-disciplinary clinical network? Please provide the job titles and affiliations of those involved.

Response	Number of PCTS
Yes	67
No	34

67% of PCTs believed that there was a local multi-disciplinary clinical TB network. We know this not to be the case; few areas outside NHS London have such a network. Facilitating the development of such networks is part of a new DH/BTS initiative.

7e) Has the PCT lead actually met the clinical TB lead in your main TB secondary care provider in the last two years?

Response	Number of PCTS
Yes	73
No	18

We found this response difficult to reconcile with the response to the questions concerning whether there was a PCT TB lead in place at all.

5. Conclusions

This first survey of TB services in primary care has given us some very useful, thought-provoking and, in some cases, worrying insights into the current management and provision of TB services in England.

In some parts of the country, TB incidence rates continue to increase. Not one of the PCTs which responded to our survey expected to see a fall in the number of TB cases in the future. Despite this fact, a substantial proportion have not taken the necessary steps to deal with this growing problem.

A key recommendation of the TB Toolkit was that there should be a TB lead within every PCT: someone able to take strategic decisions about service planning and delivery at PCT board level, able to make recommendations and enter into detailed commissioning negotiations. Almost half of PCTs think they have a TB lead but, in general, they do not have an individual fulfilling the role and remit envisaged in the commissioning TB Toolkit. Resource allocation is inconsistent and the introduction of Service Level Agreements which address TB specifically is patchy and misunderstood.

The survey responses suggest to us a number of recommendations for follow-up and action. However, we will limit our recommendations to three key areas where we would like to see action as a matter of priority:

- There should be a properly-funded national TB awareness campaign, tailored to local circumstances, aimed at healthcare professionals as well as the general public.
- PCTs must ensure that there is a clearly identified individual within their organisation who is charged with developing strategies for service provision for TB and ensuring that provision of such services meets, at the minimum, the TB Guidelines for the National Institute for Health and Clinical Excellence.
- PCTs should specifically identify and commission TB services, in accordance with the guidance set out in the DH Commissioning Toolkit.

We propose repeating the survey on an annual basis, to benchmark the implementation of the TB Toolkit, and to ensure that SHAs and the Government are made accountable for the delivery of care. Furthermore, next year we will publish the league table of PCTs' respective scores.

We would like to thank all of the PCTs who took the time and trouble to complete the questionnaire and we look forward to working with SHAs, PCTs, healthcare professionals and the public to ensure that good quality, response, and well resourced primary care TB services are accessible and available to all .

APPENDIX 1

ALL-PARTY PARLIAMENTARY GROUP ON GLOBAL TUBERCULOSIS
Co-Chairs: Andrew George, MP; Nick Herbert, MP; Julie Morgan, MP

Chief Executives
Primary Care Trusts / Local Health Boards

11th September 2007

Dear Sir / Madam

The All-Party Parliamentary Group on Global Tuberculosis is conducting an audit of tuberculosis services across England and Wales to assess the implementation of recently published Action Plans and Guidelines for Tuberculosis.

These include a Department of Health Tuberculosis Action Plan for England, NICE Clinical Guidelines published in March 2006, and a Department of Health Tuberculosis Toolkit to aid commissioners in implementing the Action Plan and Guidelines in June 2007.

This audit will form part of a report to the Government.

To help us with the audit, we would be grateful if you would be kind enough to take the time to complete the attached short questionnaire and return it to the address below.

Any names supplied in your answers will not be published and will only be used to aid the All-Party Parliamentary Tuberculosis Group with mapping tuberculosis services.

Please return your completed questionnaire by 12th October 2007 to:

James Hollaway, All-Party Parliamentary Group on Global TB, 89 Albert Embankment, London, SE1 7TP

Yours faithfully

Julie Morgan MP
Co-chair, All-Party Parliamentary Group on Global Tuberculosis

ENCL: PCT Survey 2007

ALL-PARTY PARLIAMENTARY GROUP ON GLOBAL TUBERCULOSIS
Co-Chairs: Andrew George, MP; Nick Herbert, MP; Julie Morgan, MP

Chief Executives
Primary Care Trusts / Local Health Boards

22nd October 2007

Dear Sir / Madam

All-Party Parliamentary Group on Global Tuberculosis Audit of tuberculosis services across England and Wales

We have not had a reply to our letter of Tuesday 18th September which requested that either yourself or a relevant member of your staff completed the questionnaire to inform the All-Party Parliamentary Group on Global Tuberculosis audit of tuberculosis services across England and Wales. The audit is designed to assess the implementation of recently published Action Plans and Guidelines for Tuberculosis.

These include a Department of Health Tuberculosis Action Plan for England, NICE Clinical Guidelines published in March 2006, and a Department of Health Tuberculosis Toolkit to aid commissioners in implementing the Action Plan and Guidelines in June 2007.

This audit will form part of a report to the Government.

I have re-attached the audit to this email, and the Parliamentary Group would be very grateful if you would be kind enough to complete the attached short questionnaire as soon as possible and certainly before 5th November, and return it to the address or email below. Please accept my apologies if you have already responded.

Any names supplied in your answers will not be published and will only be used to aid the All-Party Parliamentary Tuberculosis Group with mapping tuberculosis services.

Please return your completed questionnaire by 5th November 2007 to:

James Hollaway, c/o Munro & Forster, All-Party Parliamentary Group on Global TB, 89 Albert Embankment, London, SE1 7TP. Tel: 020 7815 3951

Yours faithfully

Julie Morgan MP
Co-chair, All-Party Parliamentary Group on Global Tuberculosis

ENCL: PCT Survey 2007

HOUSE OF COMMONS
LONDON SW1A 0AA

All-Party Parliamentary Tuberculosis Group
PCT Survey 2007

Please note: all information provided in answering this survey will be treated in confidence. Please go directly to the next question in sequence unless directed otherwise. We would be grateful if you could complete and return the questionnaire by Friday 12th October.

1. Incidence and local population

a. What is the name and the population of your PCT area?

Name:……

Population:……

b. How many TB cases have been notified in the last year in your PCT?

Indicate which full year:……

Number of cases:……

c. Has your PCT forecast potential changes to your population demography?

Yes……..……..... ☐

No……..…….……..... ☐

i. Are these changes likely to result in:

A rise in the number of cases of TB……...……..…… ☐

No change……..……..……..…… ☐

A fall in the number of cases of TB……..……..…… ☐

ii. Do you currently have an agreed TB related plan to react to this change:

Yes …… ☐

No…… ☐

In active preparation…… ☐

iii. Does the PCT have a written plan agreed with the local HPU defining actions and responsibilities in the event of TB incidents or outbreaks

Yes …… ☐

No…… ☐

In active preparation…… ☐

2. PCT TB Lead

a. Does the PCT employ a TB lead?

Yes…… ☐

No…… ☐

Currently recruiting…… ☐

(If the PCT does not have a TB lead in post please identify who, if anyone at all, undertakes the responsibilities outlined below)

……

b. Please provide the job title and affiliation of the TB PCT lead

……
……

c. How many hours per week does the TB lead spend exclusively on TB?

……

d. Is the TB lead shared with other PCTs and if so how many?

Yes…… ☐

No…… ☐

If Yes, how many……

e. Please tick which of the following areas the TB lead is responsible for?

Coordinating development of the local plan for TB prevention and control…… ☐

Evaluating which elements of TB services need to be in place……..……. ☐

Developing partnerships with other organisations……..…… ☐

Maintaining vigilance regarding potential outbreaks or rises in prevalence……..…. ☐

Please specify any additional roles the TB lead is responsible for:

……
……
……
……

3. Testing and Screening

a. Does the PCT routinely screen high-risk groups?

Yes…….. ☐

No……...… ☐

b. On average how many contacts are examined per index case?

……

c. Does the PCT have an agreed and active new entrant screening plan?

Yes…….. ☐

No…….....☐

No, but in preparation……..☐

d. What information sources does the PCT use to identify new entrants for TB screening?

……
……
……
……
……

4. Treatment / Service levels

a. Does the PCT undertake a risk assessment for adherence to TB treatment, and is directly observed therapy (DOT) provided for those who have adverse factors on their risk assessment?

No the PCT does not undertake a risk assessment…….. ☐

*Yes, the PCT does undertake a risk assessment but DOT **is not** provided*……... ☐

*Yes, the PCT does undertake a risk assessment and DOT **is** provided*…..……. ☐

b. Is an SLA in place governing TB control and prevention services?

Yes…….. ☐

No……..…. ☐

No, but in preparation……..… ☐

c. Has the PCT developed working relationships with partners in the local authority, the not-for-profit sector and voluntary organizations to help manage TB care?

Yes……... ☐

No……..…… ☐

No, but in active preparation……... ☐

5. Priority setting

a. Please state how many times TB has been on the PCT Professional Executive Committee board agenda over the last two years?

……

b. Please indicate which government publications have informed the development of local TB services and commissioning arrangements.

……
……
……
……

c. What specific funding has been allocated for TB in the last financial year?

No specific funding…….. ☐

If specific funding has been allocated please indicate how much:……

d. Has funding increased for TB services over the last three years?

Yes…….. ☐

No……...…… ☐

6. Awareness Raising

a. Please describe how the PCT has engaged in active, locally targeted awareness-raising campaigns

……
……
……

7. Collaborative working

a. Does the PCT have any shared, or amalgamated TB agreements in place with other PCTs to manage TB care?

No agreement…….. ☐
Formal agreement with nearby PCT(s) (please indicate how many)……...….

b. If you do have agreements with other PCT, please very briefly explain the nature of and reason for the agreement

……
……
……

c. Does your PCT have a specific TB multi-disciplinary clinical network? Please provide the job titles and affiliations of those involved.

……
……
……
……
……

d. How often has the TB clinical network met in the last two years?

No, has not met…… ☐
Yes, has met……*times in the last 2 years*

e. Has the PCT lead actually met the clinical TB lead in your main TB secondary care provider in the last two years?

Yes…….. ☐

No……...…… ☐

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.
PLEASE RETURN THE REPLY TO:

James Hollaway
All Party Parliamentary Tuberculosis Group
c/o Munro & Forster
89 Albert Embankment, London
SE1 7TP

OR BY FAXING TO 020 7815 3999

PLEASE PROVIDE YOUR CONTACT DETAILS BELOW IF YOU WOULD LIKE TO RECEIVE A COPY OF THE FINAL REPORT

YES, I WOULD LIKE TO RECEIVE A COPY OF THE FINAL REPORT ☐

NAME: _____

PCT: _____

I WOULD PREFER TO RECEIVE IT

BY POST **Please provide details of postal address:**

_____
_____
_____
_____

BY E-MAIL **Please provide details of your e-mail address:**

_____

APPENDIX 2 – SCORING MECHANISM

Section 1. Incidence and local population	Yes	No	In active preparation
Has your PCT forecast potential changes to your population demography?	2	0	
Do you currently have an agreed TB related plan to react to potential changes to your population demography?	2	0	1
Does the PCT have a written plan agreed with the local HPU defining actions and responsibilities in the event of TB incidents or outbreaks	2	0	1
Maximum score for this section = 6			

Section 2. PCT TB Lead	Yes	No	Currently recruiting
Does the PCT currently employ a TB lead?	2	0	1

	Less than 5	Between 5 -10	More than 10, less than 15	More than 15, less than 20	More than 20	1 option ticked	2-3 options ticked	4 or more options ticked
How many hours per week does the TB lead spend exclusively on TB?	1	2	3	4	5			
Which of the following areas is the TB lead responsible for?						1	2	3
Maximum score for this section = 10								

Section 3. Testing and Screening	Yes	No	In active preparation
Does the PCT routinely screen high risk groups?	2	0	
Does the PCT have an agreed and active new entrant screening plan?	2	0	1
	1-2 Sources	3-5 sources	More than 5 sources
What information sources does the PCT use to identify new entrants for TB screening?	1	2	3
Maximum score for this section = 7			

Section 4. Treatment & Service levels	No	Yes	In active preparation
Does the PCT undertake a risk assessment for adherence to TB treatment and is DOT provided for those who have adverse factors on their risk assessment?	0	2	
Is an SLA in place governing TB control and prevention services?	0	2	1
Has the PCT developed working relationships with partners in the local authority, the not-for-profit sector and voluntary organisations to help manage TB care?	0	2	1
Maximum score for this section = 6			

Section 5. Priority Setting	No times	1-2 times	3 times	4 or more times
Please state how many times TB has been on the PCT PEC board agenda over the last two years?	0	1	2	3
Maximum score for this section = 3				

Section 6. Awareness Raising	None	Engaged in 1 initiative	Engaged in 2-3 initiatives	Engaged in 4 or more initiatives
Please describe how the PCT has engaged in active locally targeted awareness campaigns?	0	1	2	3
Maximum score for this section = 3				

Section 7. Collaborative working	No	Yes, formal agreement(s) in place	Yes	
Does the PCT have any shared or amalgamated TB agreements in place with other PCTs to manage care?	0	2		
Does the PCT have a specific TB multi-disciplinary clinical network?	0		2	
has the PCT lead met with the clinical TB lead in your main secondary care provider within the last 2 years?	0		2	
	Has not met at all	**Has met once**	**Has met 2-3 times**	**Has met more than three times**
How often has the TB clinical network met in the last 2 years?	0	1	2	3
Maximum score for this section = 9				

Abbreviations

APPG	All Party Parliamentary Group
BTS	British Thoracic Society
BCG	Bacille Calmette-Guérin
NHS	National Health Service
NICE	National Institute for Clinical Excellence
PCT	Primary Care Trust
SHA	Strategic Health Authority
SLA	Service Level Agreement
TB	Tuberculosis

All-Party Parliamentary Group on Global Tuberculosis
Officer of Andrew George MP
House of Commons
London SW1A 0AA
United Kingdom

www.appg-tb.org.uk

The All-Party Parliamentary Group on Global Tuberculosis was formed in 2006 to demonstrate cross-party concern for the growing scale and impact of the TB epidemic. The purpose of the Group is to raise the profile of the global TB problem and to help accelerate efforts to meet international TB control targets.

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