



All Party Parliamentary Group
On Global Tuberculosis

Turning UK TB policy into action: the view from the frontline

July 2009

**A report by the British Thoracic Society, Royal College
of Nursing TB Forum and the All-Party Parliamentary
Group on Global TB**



The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies. Forums exist in key areas with elected members from the UK to act as experts in their particular field to inform and lead activities of the forums. The current committee consists of Chair and 6 RCN members representing England (London, Birmingham, Sheffield and Manchester), Scotland and Wales. The Tuberculosis nursing forum has approximately 800 members who have registered interest in the work of the forum and regularly receive the forum newsletter. For more information please contact the Forum Chair: (malcolm.cocksedge@bartsandthelondon.nhs.uk).

The All-Party Parliamentary Group on Global TB was established in 2006 by Andrew George MP (Liberal Democrat – St Ives and Isles of Scilly), Nick Herbert MP (Conservative – Arundel and South Downs) and Julie Morgan MP (Labour – Cardiff North) who jointly chair the Group. The overall purpose of the APPG is to raise the profile of the global tuberculosis epidemic (which includes the growing incidence of TB in the UK) and to help accelerate efforts to meet international TB control targets. For more information please contact the APPG Co-ordinator: (Debbie@results-uk.org) or visit the website: www.appg-tb.org.uk

The British Thoracic Society (BTS) was formed in 1982 by the amalgamation of the British Thoracic Association and the Thoracic Society. It is a registered charity and a company limited by guarantee. Members include doctors, nurses, respiratory physiotherapists, scientists and other professionals with an interest in respiratory disease. All join because they share an interest in the Society's main charitable objective, which is to improve the care of people with respiratory and associated disorders. The BTS does this by:-

- promoting optimum standards of care
- promoting and advancing knowledge
- promoting and disseminating research

For more information, please contact tb@brit-thoracic.org.uk

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For more information on the report please contact the APPG (Debbie@results-uk.org) or BTS (TB@brit-thoracic.org.uk).

Foreword



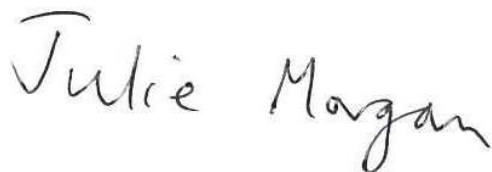
When I was first starting out in my career I was a social worker in a TB hospital TB rates were on the decline and when I left the hospital I honestly thought that that was the last I would see, or hear about TB in the UK.

I think that many of us, politicians and health care providers included, were at first complacent with regards to the resurgence of TB. TB was sorted, job done, box ticked. But TB wasn't defeated in the UK. Rates are now soaring and London is taking the dubious title of "TB Hotspot of the Western World".

It is clear that the UK Departments of Health are starting to take TB seriously. It was encouraging when five years ago the English Chief Medical Officer, Sir Liam Donaldson launched his TB Action Plan.

Policy is the first step in the process of change but on its own it is not enough. We, as the TB community in the UK, need to ensure that TB is made a priority at the local level and that TB policy is put into practice. In this climate of recession, where resources in the NHS are going to be even scarcer, we must ensure that TB services are well equipped and sufficiently staffed to deal with the TB epidemic. In debate, we must highlight the fact that TB is not only a disease of the individual but a public health issue and is thus crucial to control.

I warmly welcome this report containing the results of surveys of the Royal College of Nursing and British Thoracic Society members, and am glad that these important professional organisations are working together in the fight to end TB in the UK. My colleagues and I at the All-Party Parliamentary Group on Global TB will strive to keep TB on the political agenda and hope that TB will once again become a disease of the past.



Julie Morgan MP

Co-chair, All-Party Parliamentary Group on Global Tuberculosis

Abbreviations

APPG	All-Party Parliamentary Group
BTS	British Thoracic Society
CMO	Chief Medical Officer
DoH/DH	Department of Health
DOT	Directly Observed Therapy
GU(M)	Genito-Urinary (Medicine)
HPA	Health Protection Agency
ID	Infectious Disease
IGRA	Interferon Gamma Release Assays
LTBI	Latent TB Infection
MDR	Multi-Drug Resistant
MDT	Multi-Disciplinary Team
NICE	National Institute for Health and Clinical Excellence
PA	Programmed Activity
PCT	Primary Care Trust
RCN	Royal College of Nursing
SLA	Service Level Agreement
SpR	Specialist Registrar
WHO	World Health Organisation
WTE	Whole Time Equivalent

Message of Thanks

The BTS, RCN TB Forum and APPG would like to thank all of the nurses and consultants who took the time to take part in the survey, without whom this report would not have been possible.

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Executive Summary

- TB rates in the UK continue to rise with the HPA reporting a 2% increase in incidence in 2008. Now that healthcare is devolved, somewhat different approaches to TB management are being employed within individual UK countries based on local circumstances. The common factor is that much clinical guidance and policy has been published aimed at both commissioners of TB services and local service providers. Two surveys undertaken in the past three years by the BTS and APPG indicated that progress was needed in implementing policy and guidelines^{*}
- Among the important policies that have been released on TB in England is the Chief Medical Officers Action Plan. This set out the actions that should be taken if TB is to be brought under control. It used the successful control of TB in the USA as the underlying philosophy of how success can be achieved. The CMO set out 10 recommended actions including increased awareness, an expert workforce and well coordinated patient services. The BTS and APPG surveys of 2007 were completed in order to see what was happening at the local level with regard to the CMO's Action Plan.[†]
- This report sets out the results of two interconnected surveys of TB lead consultants and TB nursing staff. They were completed by BTS and RCN members between January and April 2009. The surveys sought to ascertain from frontline staff the degree to which central policy has been implemented and the outstanding barriers that prevent effective TB prevention and control.
- The results of the surveys are encouraging and highlight that much progress has been made. However, they also indicate that there are areas where more effort is needed if effective services for TB are to be developed.
- **TB nursing staff:** Three quarters of respondents to the BTS survey were aware that there was advice on matching nursing staff with TB caseload. 57% of RCN respondents stated that the number of TB nurses employed by their TB service had increased since the CMO's Action Plan was launched in England in 2004. The BTS survey also highlighted the relationship between TB burden and level of TB nurse specialist input – whilst over 75% of TB cases in areas seeing 150 or more new TB cases a year are treated by nurse specialists with sole responsibility for TB, this was the opposite in very low burden areas where no TB cases were treated by TB nurse specialists.
- **TB consultants:** 22% of BTS respondents stated that they were aware of guidance matching the number of consultant PAs to number of TB patients even though no official guidance has been produced. This is a major area of concern as Consultant job planning is now routine, yet there is no national standard to which doctors working in TB can refer to when mapping out their personal commitment or planning services appropriate for local need.

^{*} The surveys can be viewed on the BTS website at www.bts.org.uk

[†] While the Action Plan was published for use in health services in England, the surveys covered both England and Wales.

- **Administrative support:** Only 44% of BTS respondents stated that their TB service had a specifically funded admin or clerical post.
- **Data systems:** Only 52% of BTS respondents felt that they had a robust data recording system in place even though TB is a notifiable disease. This is an issue at all levels of TB burden and is consistent with the 2007 BTS leads survey (51%).
- **Multidisciplinary Teams:** In an improvement on the results reported in the previous study, 79% of respondents to the BTS survey stated that TB was managed within an MDT. However, these results contrast with those to questions about admin support, suggesting that this is often not included in an MDT. Also, results still show that 10% of clinics seeing more than 100 new cases of TB a year are not using MDTs. In addition, 47% of respondents to the RCN survey felt that they did not have the necessary skills and relationships in their service to adequately deal with patients with socially complex needs.
- **TB networks:** 68% of BTS respondents stated that the Trust within which they work is part of a TB network. This varies by TB burden with only a quarter of respondents in areas seeing fewer than 10 new cases of TB being part of a network. This is however an improvement from 2007 as the BTS leads survey indicated that only 54% of Trusts were within a TB network at that time.
- **TB-HIV co-infection:** Only a third of BTS respondents stated that the care of co-infected patients was shared between respiratory and genito-urinary consultants.
- **Paediatric TB:** Only 12% of BTS respondents stated that the care of paediatric TB patients was shared between respiratory physicians and paediatricians. In addition, the RCN survey showed that 32% of respondents did not feel that their TB service had the necessary skills to deal with paediatric patients.
- **Drug resistant TB:** 16% of BTS respondents stated that any consultant involved in TB care could treat MDR-TB patients. RCN respondents commented on the need for information sharing and an advice service for MDR-TB management. The BTS is leading in the development of such a national service (in line with recommendations of the TB Commissioning Toolkit) and will be actively encouraging TB staff to maximise their use of the advice network.
- **Awareness raising:** In a disappointing result, only 35% of respondents to the BTS survey indicated that there was a local programme aimed at raising awareness of TB in high risk areas. This is associated with TB burden; only 14% of respondents in areas seeing fewer than 10 new cases a year have a local programme. However, the Department of Health in England has funded the UK Charity TB Alert to assist PCTs in formulating effective awareness activities and also working directly with affected communities. It is hoped that, through TB Alert's engagement with local service providers and affected communities, local programmes will be implemented and levels of local awareness rise. It is envisaged that the next stage of this study – which will be the third BTS survey – will assess the impact of these activities.

- **TB in low incidence areas:** Responses to both the BTS and RCN surveys make it clear that TB policy and recommendations are often not being implemented in areas of low TB burden, whilst in some cases TB staff are not even aware that these policies exist.
- **Microbiology:** Only 54% of respondents to the BTS survey had access to a designated microbiologist who deals with TB. 72% of the respondents indicated that they use liquid culture for all specimens. 83% of respondents had access to IGRA with access levels very similar across disease burden areas. This is a major improvement on the 2007 BTS survey which found that only 39% had access to IGRA. However, only 65% of respondents with access to IGRA had the necessary funding to use them as required.
- **BCG:** Results show that BCG programme delivery varies from area to area. 68% of RCN respondents stated that TB nurses were responsible for giving BCGs but that school nurses, immunisation nurses and health visitors were also involved to a lesser extent. 69% of RCN respondents felt that routine BCG should be given by someone who is not a TB nurse.
- **TB Commissioning Toolkit:** It has now been exactly two years since the TB Commissioning Toolkit was launched in England. It is therefore disappointing that only 17% of RCN respondents stated that it had been fully implemented in their area. 45% in the BTS survey commented that TB services in their area were specifically commissioned by their local PCT. This is an improvement on the 2007 BTS survey results that showed only 33% had specifically funded TB services.
- **TB service standards:** 88% of BTS respondents stated that all TB patients with suspected pulmonary TB are seen by the TB team within two weeks of first presentation to health care. In addition, 89% of BTS respondents suggested that more than 86% of their TB patients successfully complete treatment.
- **Local priority:** 20% of BTS and 33% of RCN respondents regarded the priority given to TB by their PCT as excellent or good. A further 56% of BTS respondents and 41% of RCN respondents stated that the response was adequate but that it should be better. However, around a quarter of both BTS and RCN respondents regarded the priority given to TB by their local PCT as inadequate. Similarly, 26% of BTS and 34% of RCN respondents regarded the priority given to TB by their local Secondary Care Trust as excellent or good. But again, 18% of BTS and 19% of RCN respondents regarded the priority given to TB by their Secondary Care Trust as inadequate.
- Since the CMOs Action Plan was launched in 2004, 62% of BTS respondents have seen funding for TB stay the same or reduce, even though TB rates have been increasing. In addition, 73% stated that they were not expecting to see a change in resources for TB services. Worryingly, a third of BTS respondents in areas of over 150 new cases a year were expecting a decrease in resources for TB.
- **National priority:** 43% of BTS respondents gave the Department of Health in England a rating of poor or very poor in the priority they give to TB. The 2007 BTS survey saw 71% poor or very poor so this is a marked improvement. This reflects the increased priority

the Department of Health has given TB, with much service improvement attributable to Department of Health funded projects such as Restructuring TB Services - the multi-disciplinary team project undertaken by BTS.

- **The future:** 59% of BTS respondents were optimistic that TB services will have improved within two years even though 70% of respondents expect an increase in TB cases.

Recommendations

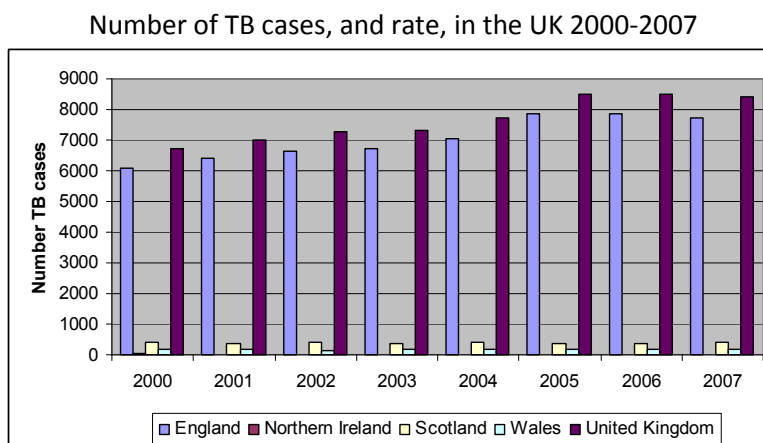
1. People who commission or fund TB services in all parts of the UK should ensure that those services are in line with the recommended 1:40/1:50 nurse to patient ratio and ensure all nursing staff treating TB in low incidence areas are adequately trained and that their skills are regularly updated.
2. Clear guidelines should be produced to govern the workload of consultants treating TB cases. It is especially important to be clear about:
 - the optimal ratio of consultants (or consultant PAs) to TB patients in line with that of TB nurses;
 - the optimal number of consultants that should be managing TB cases in low incidence areas; and
 - the amount of time a TB lead should have programmed into their work plan to allow them to carry out this role.
3. All Trusts should have robust data systems in place to ensure that TB incidence data is reported to the Department of Health - as a notifiable infectious disease it is a statutory requirement that TB data is reported to the 'Proper Officer'.
4. All TB services should be staffed by a multi-disciplinary team (including admin support) and all Trusts, irrespective of TB burden, should be part of a local clinical network that shares best practice and advice.
5. Current guidelines on the shared care of paediatric and TB-HIV co-infected patients must be implemented and all TB, HIV and paediatric staff should receive the necessary training to facilitate this.
6. All MDR-TB patients should be treated at designated specialist centres with effective communication between TB staff via the MDR-TB Advice Network.
7. Trusts should ensure that effective local awareness raising programmes are run in all high risk communities.
8. Adequate information and support should be given to areas with low incidence of TB to enable effective prevention and control services to be put in place and sufficiently resourced.
9. New technologies should not only be accessible but also adequately funded to allow optimum benefit to TB patients.
10. Clear guidelines should be produced indicating where responsibility lies for giving routine BCGs and the impact that this has on TB nurse specialist work load.
11. PCTs should specifically commission TB services and ensure that the TB Commissioning Toolkit is fully implemented. (As referred to below in the

introduction, HPA Scotland created guidelines based on the TB Commissioning Toolkit but adapted to reflect the local epidemiology of TB within Scotland.)

12. National Standards on TB should be agreed and implemented to allow local PCTs and service providers to be held to account on the services they commission and provide for TB patients.

Introduction

Whilst many people within the UK, from policy makers to the general public, believe that TB is a disease of the past, the reality is unfortunately far different. Over the last twenty years the number of new cases of active TB reported per year has risen by almost three-quarters. In 2007 there were 8417 notifications and provisional Health Protection Agency data suggest that TB cases have risen by 2.2% in 2008. Every day at least one person will die of TB in the UK even though this is a disease that is fully preventable and treatable.



Source: http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1225182912374?p=1204707145336

In many areas of the UK, TB is now concentrated in population subgroups - often those on the fringes of society or disengaged with the health system. The result is that TB services must be designed and funded specifically for its target population(s). Services must be appropriate and accessible with the necessary skill mix to ensure that all medical and social needs of patients are met.

Due to the devolution of responsibilities for health to each country within the UK, TB policy and practice differs. In England, the Department of Health and NHS have produced several policy and practice guidelines on TB.

In 2004, the Chief Medical Officer published his Action Plan[‡] setting out what England must do to control TB. It used the successful control of TB in the USA as the underlying philosophy of how success can be achieved. The CMO set out 10 recommended actions including increased awareness, an expert workforce and well coordinated patient services.

This was followed by the National Institute for Health and Clinical Excellence (NICE) clinical guidelines for TB in 2006[§]. These aimed to introduce best practice within England and to standardise services in order to ensure equity of care received by patients.

[‡] Stopping Tuberculosis in England: *An Action Plan from the Chief Medical Officer*: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4090417

[§] *Tuberculosis: clinical diagnosis and management of tuberculosis, and measures for its prevention and control*. <http://www.nice.org.uk/nicemedia/pdf/CG033FullGuideline.pdf>

The CMO's Action Plan and NICE guidelines set out clearly what to do to reduce TB but in the new world of health economics and local commissioning it did not make clear how services were to be set up and funded. The NHS in England therefore published a toolkit** in 2007 to assist both commissioners and service providers in establishing and maintaining a locally appropriate and effective TB Service.

To raise awareness of TB, the Department of Health in England has funded a campaign run by the UK charity TB Alert. This campaign has produced a series of materials (leaflets, factsheets, posters and info cards) designed to raise awareness about TB among the public and health professionals.

In March 2009 Health Protection Scotland published guidelines^{††} on treating TB and controlling the disease within its borders. The guidance was based on that published in England but adapted to reflect the local epidemiology of TB within Scotland.

The 2006 NICE guidance on TB is also in use in Wales. In addition, a Welsh Respiratory Alliance has been established which is monitoring the effects of re-organisation and lobbying Welsh Assembly politicians for improved respiratory services.

In Northern Ireland consultation has recently ended on a 'Service Framework for Respiratory Health and Well-being'. The framework will be supported by over £5million of investment, with £2.5million allocated by the Social Care Trusts and GPs to implement the framework.

Although policy on TB has been developed by central NHS and DH Departments, it is unclear the extent to which these guidelines are implemented at a local level. No national TB standards or indicators exist against which health care commissioners and providers are performance managed.

In 2007 the BTS completed a survey in order to see what was happening at the local level with regard to the CMO's Action Plan^{††}. The survey^{§§} of TB lead consultants found that 85% believed that their PCT should give TB more priority (75% said the same of their Trust) and 71% rated the Department of Health in England as poor or very poor in their role in TB prevention. In addition, a fifth of TB leads claimed that the priority given to TB by PCTs was inadequate.

The results of the BTS survey led to a joint study with the APPG of English PCTs in 2007/2008^{***}. Results indicated that only 50% of PCTs had an individual identified as their

** Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high-quality services in England. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075621

†† Tuberculosis: Clinical diagnosis and management of tuberculosis, and measures for its prevention and control in Scotland: <http://www.documents.hps.scot.nhs.uk/about-hps/hpn/tuberculosis-guidelines.pdf>

†† while the Action Plan was published for use in health services in England, the surveys covered both England and Wales

§§ British Thoracic Society survey of Tuberculosis Leads: http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Tuberculosis/BTS_TB_Lead_Survey_2007.pdf

*** Putting Tuberculosis on the local agenda: <http://www.appgtb.org.uk/documents/PuttingTuberculosisontheLocalAgendaFINAL.pdf>

TB Lead – an essential role if TB is to be made a priority. In addition, only 30% of PCTs had an SLA in place for TB (as suggested by the TB Commissioning Toolkit), and only half suggested that TB had been an agenda item at PCT board level.

In light of this, the current two joint surveys of TB nurses and lead medical consultants sought to determine the degree to which policy is being implemented and TB prioritised at the local level by reporting the experience of frontline staff. It seeks to assess whether (and how) things have changed since the policies were introduced, and what challenges remain.

The Royal College of Nursing, British Thoracic Society and All-Party Parliamentary Group on Global TB (hereafter referred to as 'we') are committed to working together with other TB organisations to further highlight the issues faced by TB front line staff in the UK.

Chapter 1 – BTS Survey

Methods

In 2007 the BTS undertook a national survey asking consultants across the UK to share their views and experience of TB care and management. The 2007 survey was reviewed and piloted by the BTS Specialist Advisory Group on Tuberculosis (TB SAG). The TB SAG is chaired by Dr Marc Lipman and is tasked with providing expert opinion on TB to the Society. In order to allow comparisons between the 2007 and 2009 surveys, the questions remained unchanged. One new question was added concerning working within multi-disciplinary teams. The BTS survey tool was used, allowing consultants to complete and return the survey electronically.

In August 2008, the BTS updated its TB leads database; this was used for the survey. All registered TB leads were sent an email on 3rd March 2009 inviting them to participate. The link to the survey was included, which allowed access to complete the questions, with no registration or log-in required. The link to the survey was also on the BTS website, along with a pdf of the questions that respondents could view. A reminder email was sent to all TB leads on 24th March 2009. The survey closed on 3rd April 2009.

Results

1. Response to the survey

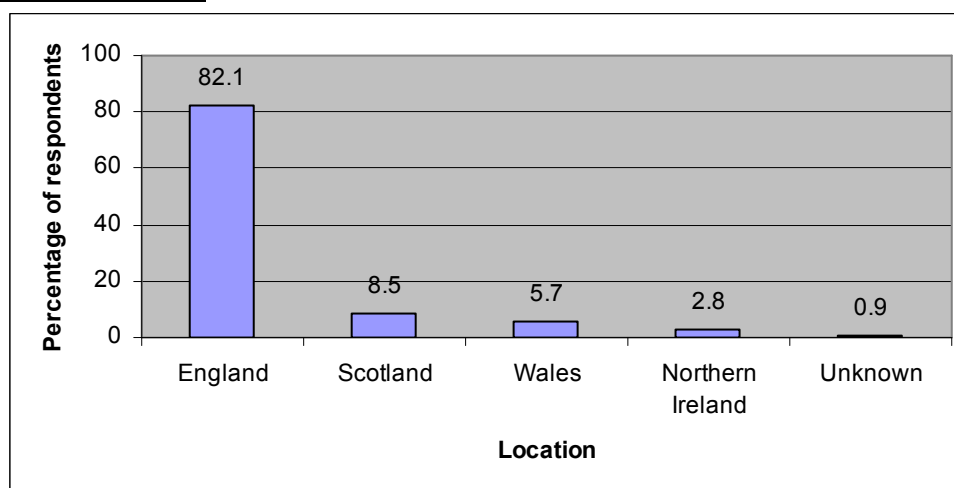
Response rate

- Survey went out to = 217
- No. of respondents = 124
- Response rate = 57.1%

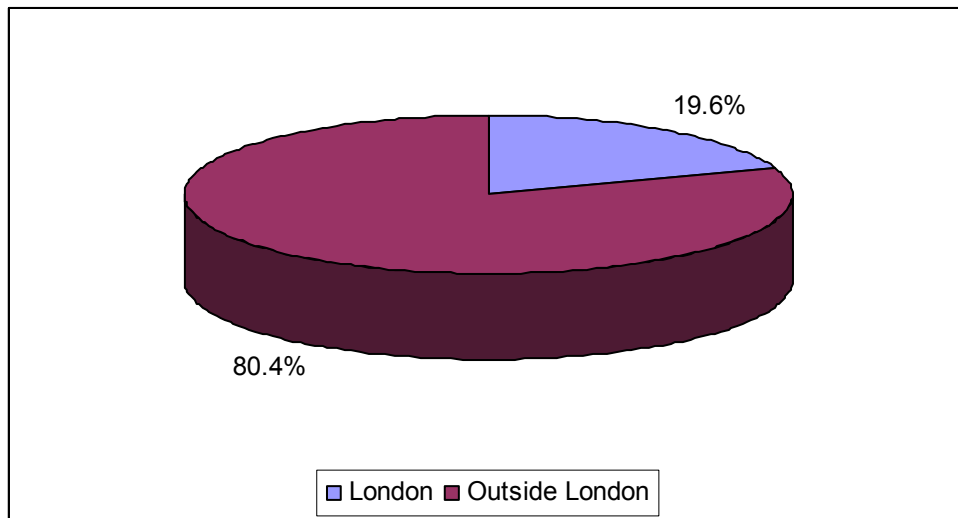
Responses used in analysis

- Among the responses were 4 duplications, 8 completely blank entries and 6 entries that had only the respondent's name and employer completed.
- These were deducted from the analysis resulting in 106 responses being analysed.

Location of respondents



Breakdown of England based respondents

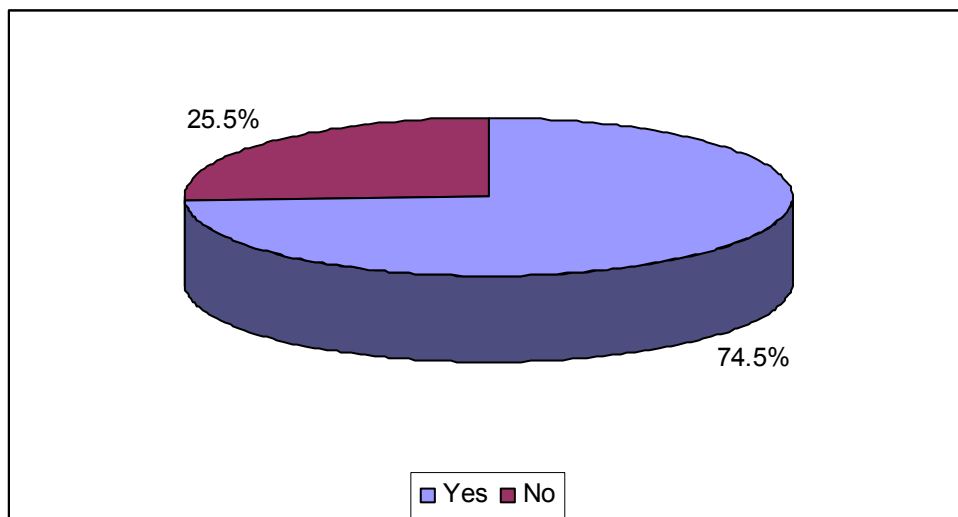


N=87

2. TB Service Workforce

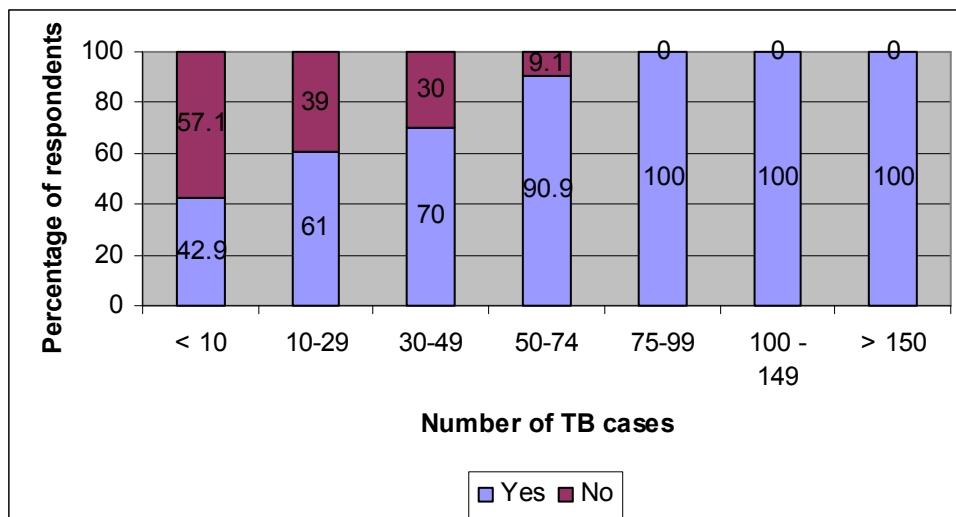
Nursing Staff

Are you aware of any advice which has been issued regarding matching numbers of TB Specialist Nurses to number of patients? (N=106)

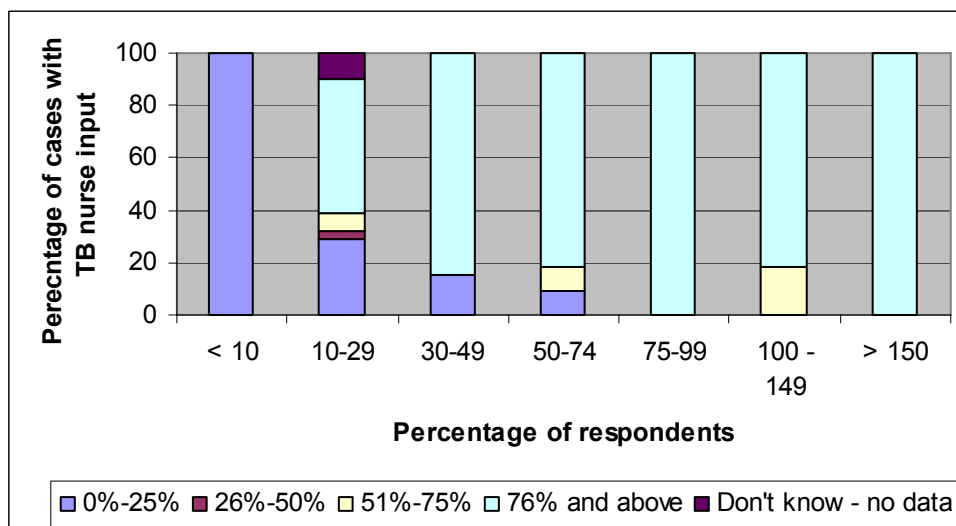


Please note: Throughout the report survey results are broken down by “number of cases”. This refers to the number of new cases seen in a year (as self-reported by the respondent). It is used as a crude indication of disease burden and workload.

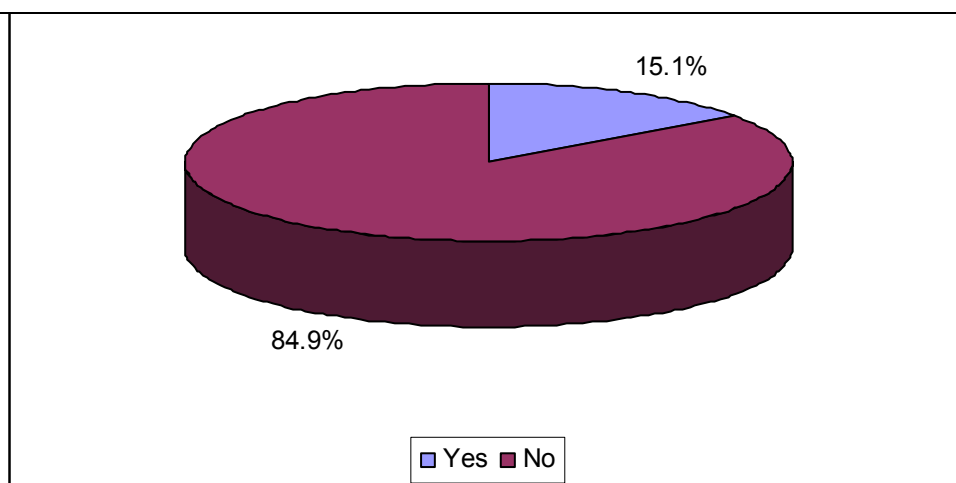
Breakdown by number of TB cases (N=106)



What percentage of your TB cases do you estimate are managed with input from TB specialist nurses with sole responsibility for TB? Breakdown by number of TB cases (N=106)



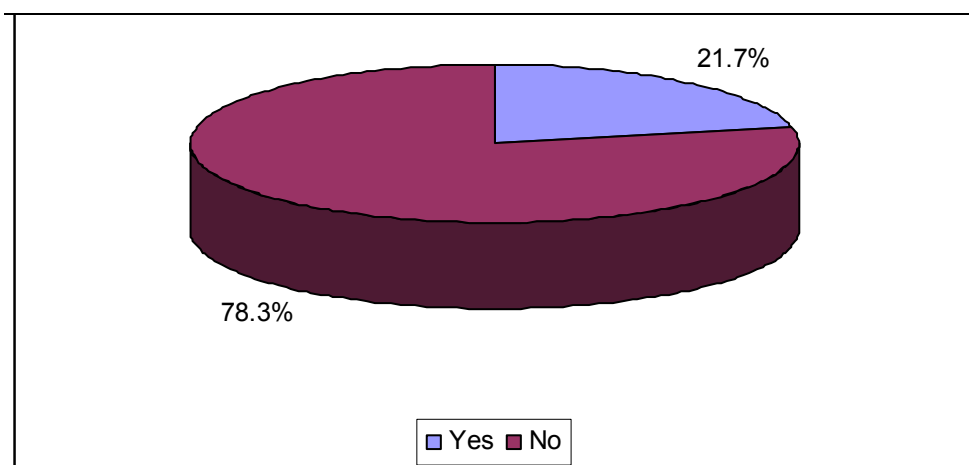
Are your TB nurse specialist posts under threat or review due to financial pressures? (N=106)



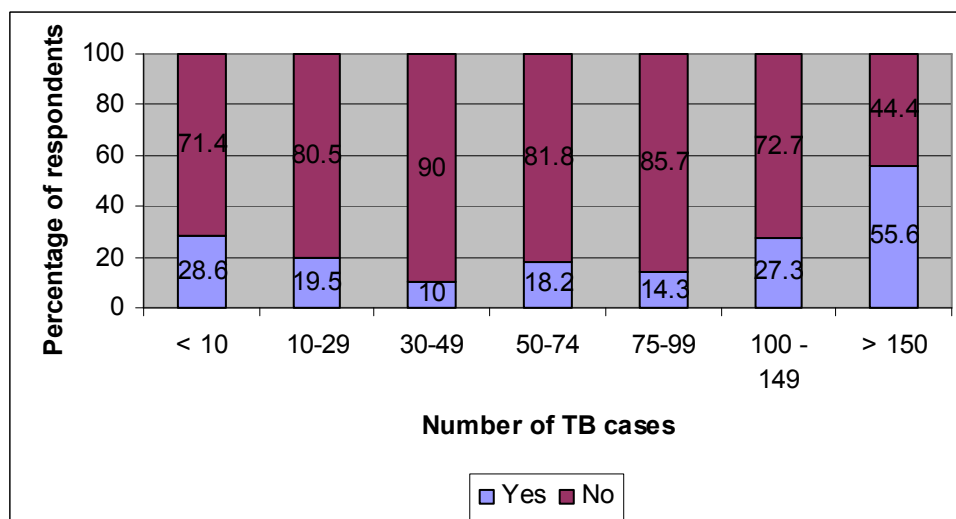
TB and Respiratory Consultants

“I am on an 8 PA contract of which perhaps 2 PA is for TB. The {other} physicians see few if any cases {of TB} and cannot spare time or SpR time to help me. Although I am clinical lead I am so snowed under that in 10 years I have been unable to attend a single regional or national TB meeting. We are completely under-resourced at this hospital and it is getting worse”

Are you aware of any advice which has been issued regarding matching numbers of Consultants’ PAs^{†††} of TB to number of TB patients? (N=106)

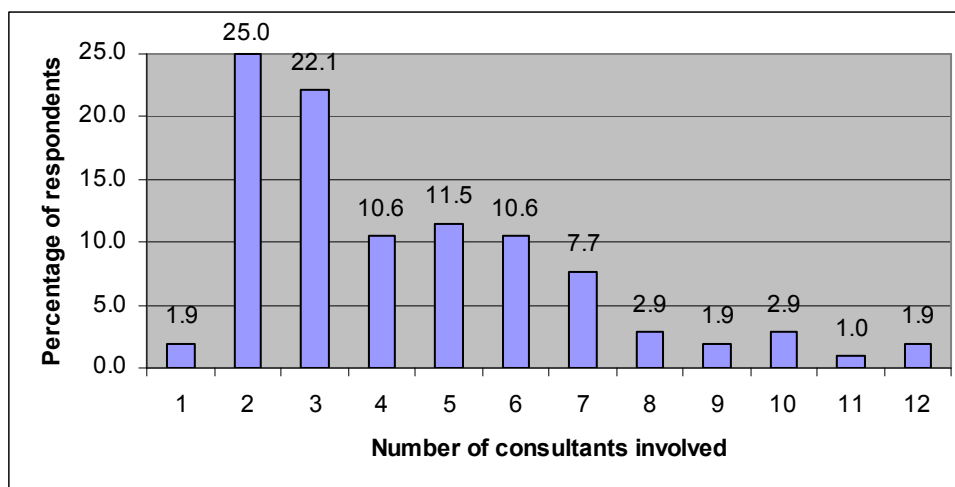


Breakdown by number of TB cases (N=106)



^{†††} Doctor’s contracts are divided into 4 hour slots which are each called programmed activities. In essence, a doctor may be contracted for 10 PAs (40 hours per week) and is supposed to do e.g. 7 PAs of clinical work and 3 PAs of supporting work (e.g. admin, training, sitting on boards etc.). Or, they might be contracted for 12 PAs (48 hours per week) – say, 5 clinical, 3 support and 4 research

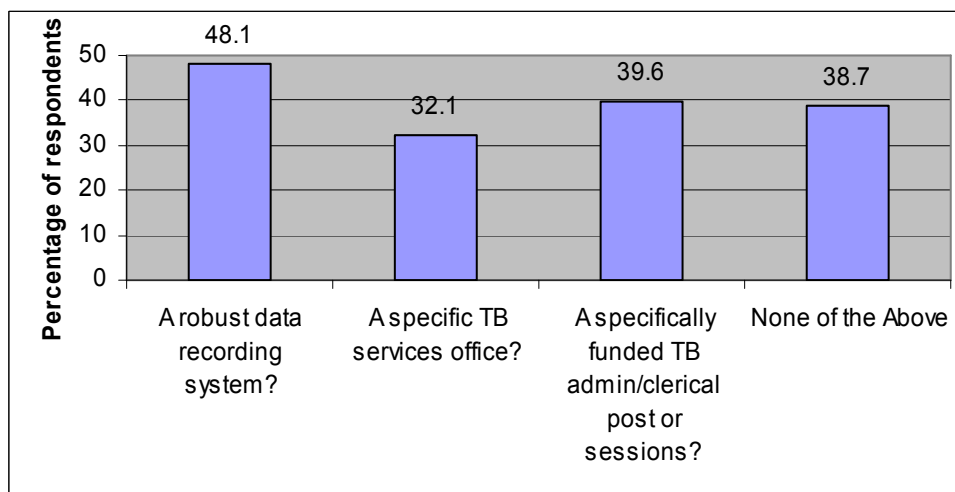
How many consultants are involved in the “critical care” of TB patients after initial diagnosis in your Trust, including paediatricians? (N=104)



Mean = 4.4

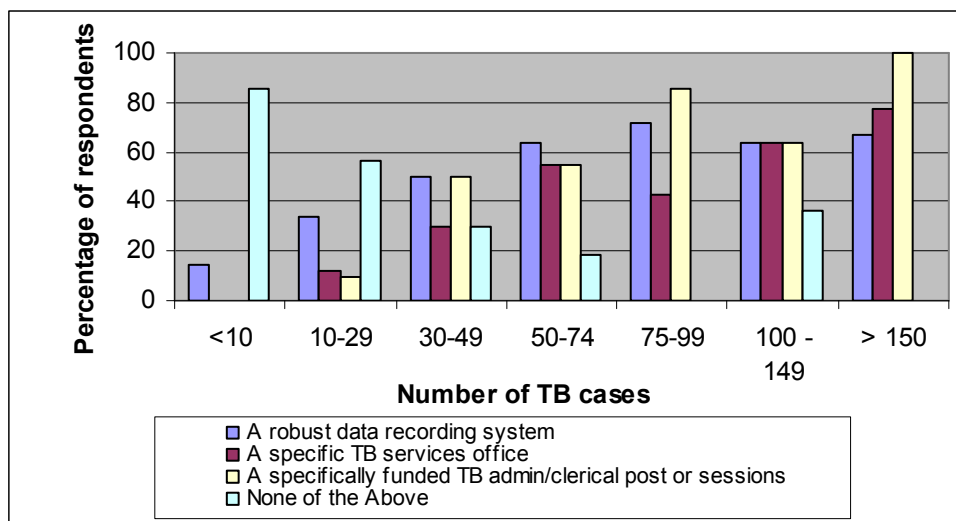
Administrative Support

Do you have a specifically funded TB admin/clerical post or sessions, specific TB services office, a robust data recording system?^{***} (N=106)



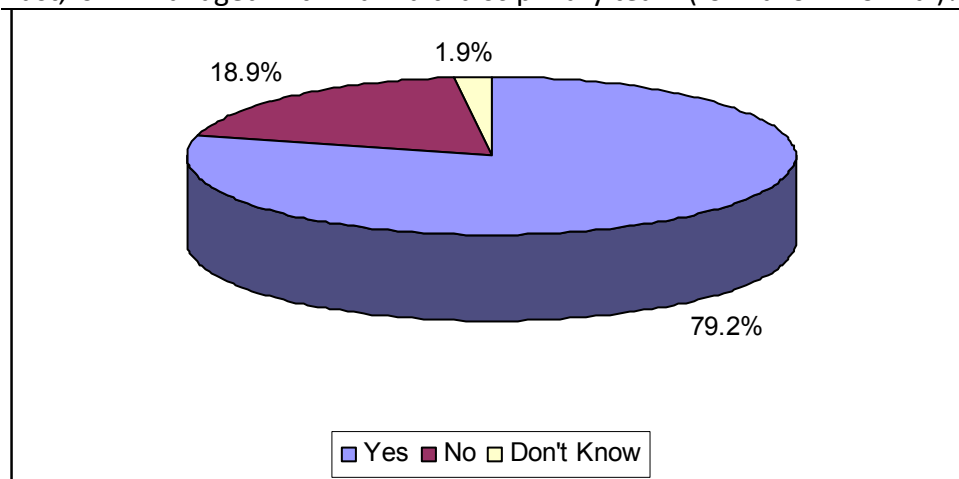
^{***} Please note, respondents can give more than one answer to this question

Breakdown by number of TB cases (N=106)

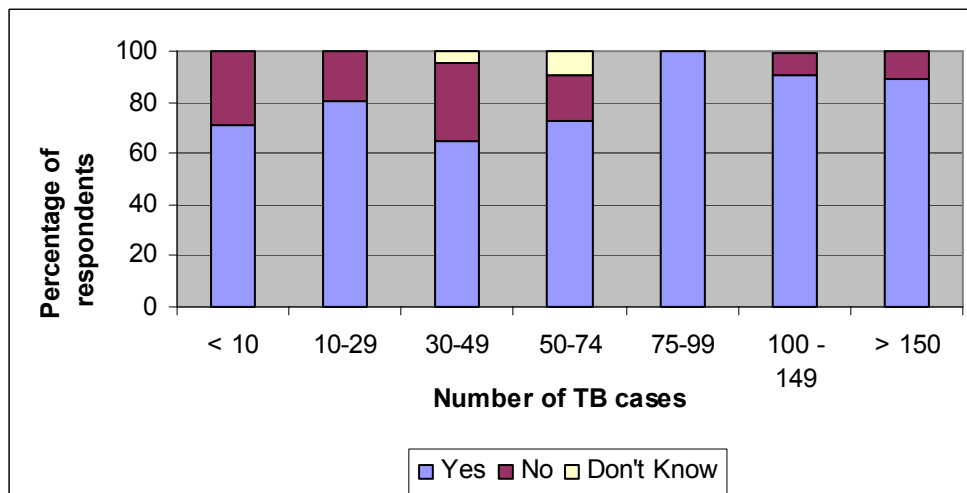


Multi-disciplinary Teams

In your Trust, is TB managed within a multi-disciplinary team (formal or informal)? N=106



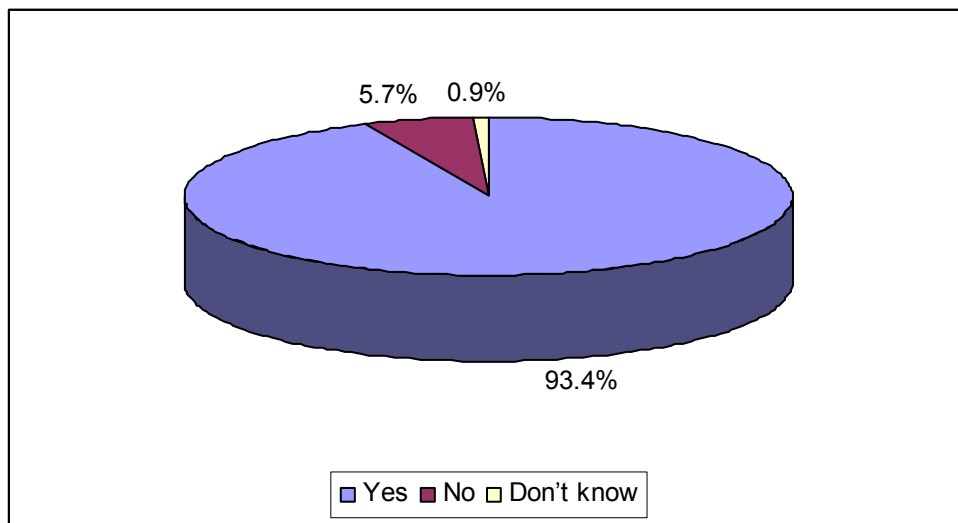
Breakdown by number of TB cases (N=106)



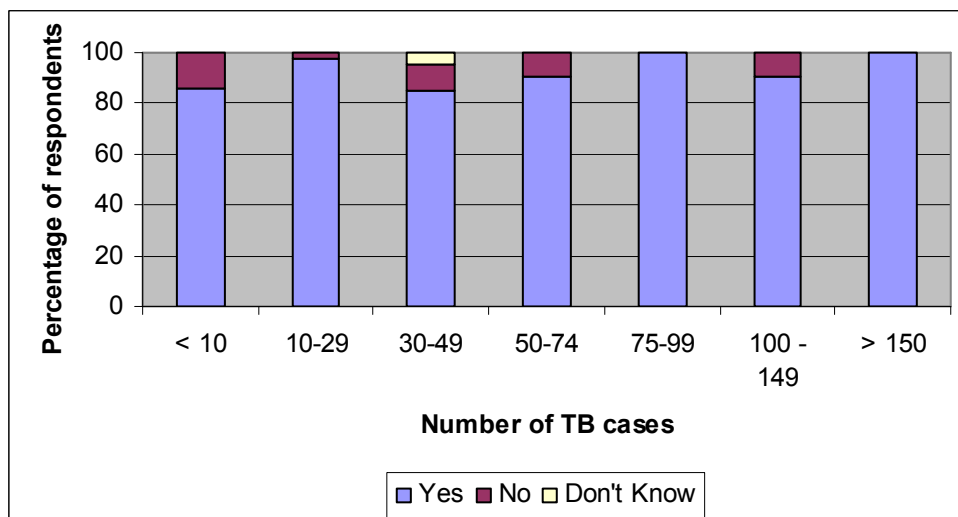
TB lead

“In the last 10 years I have been unable to attend a single sector meeting on TB - no time. I am so ashamed with the service that I have stepped down as lead, but there is nobody else to do it. We are on our knees, and the Trust has not the slightest interest in our situation”

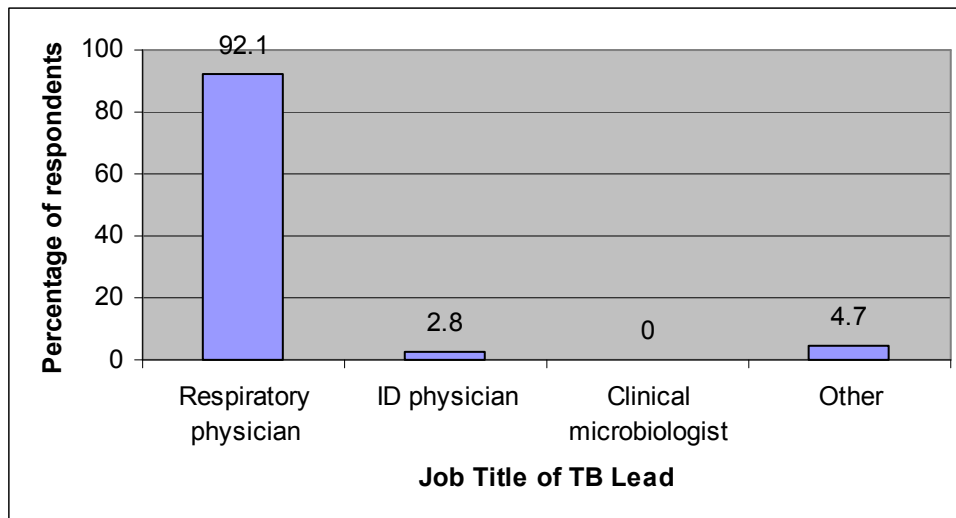
Does your Hospital Trust have a designated TB lead? (N=106)



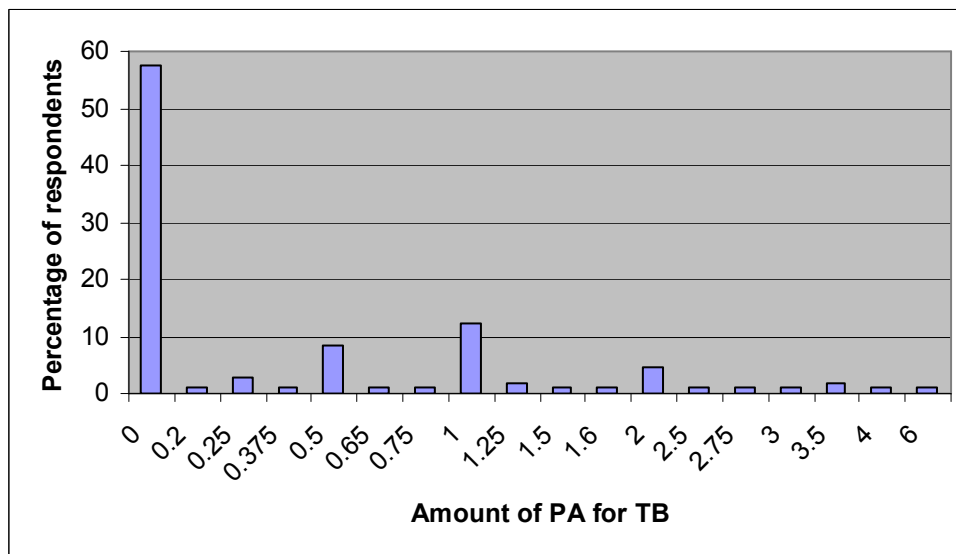
Breakdown by Number of TB cases (N=106)



If yes, is this lead a respiratory physician, ID physician, clinical microbiologist, other?
(N=101)



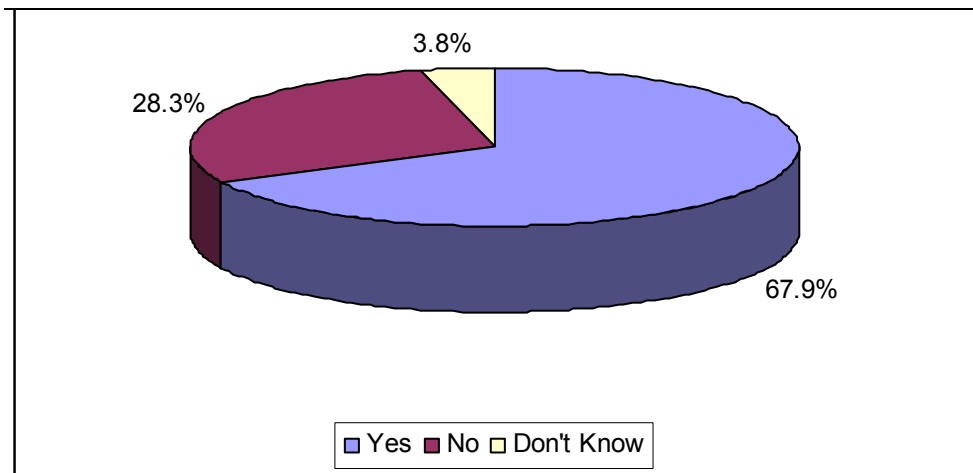
How much Programmed Activity (PA), if any, is identified in the lead's job plan specifically for TB services? (N=106)



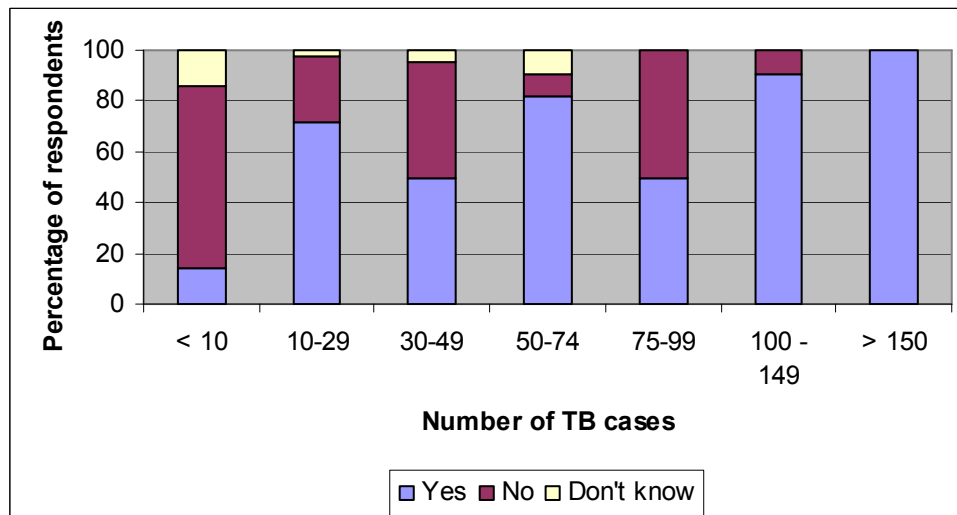
Mean = 0.6

TB Network

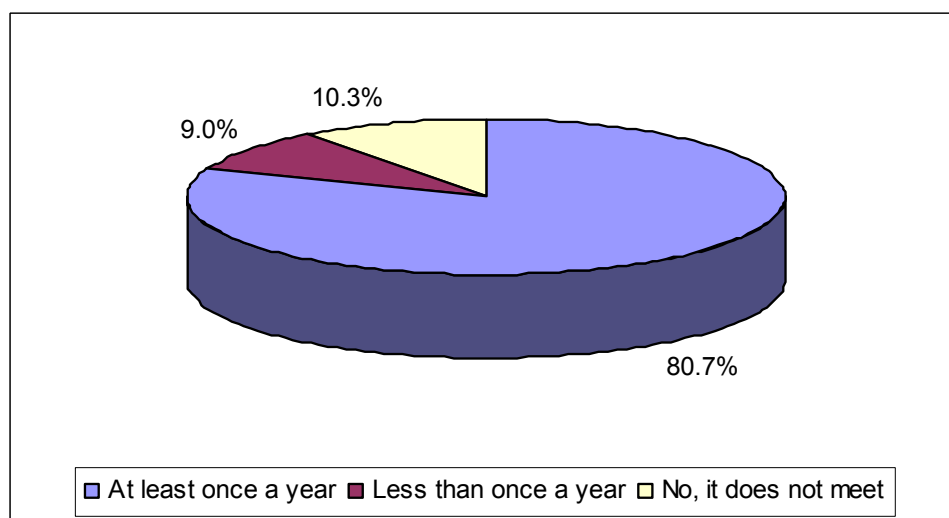
Is your trust part of a network crossing administrative boundaries with a designated named co-ordinator? (N=106)



Breakdown by number of TB cases (N=106)



If yes, how often does it meet? (N=78)



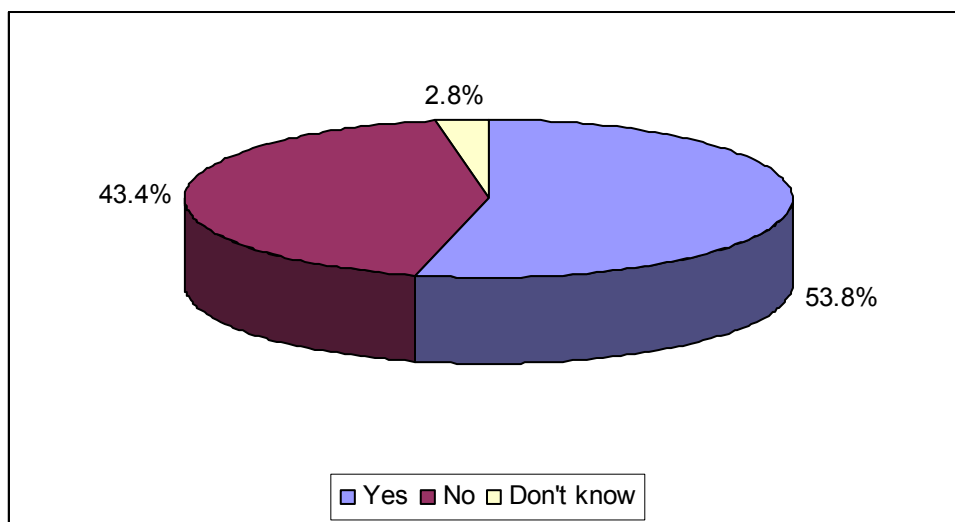
3. TB Services

“There isn't any local structured TB service in the trust. Two of us have great interest & experience in the field of TB & hence patients seem well sorted”

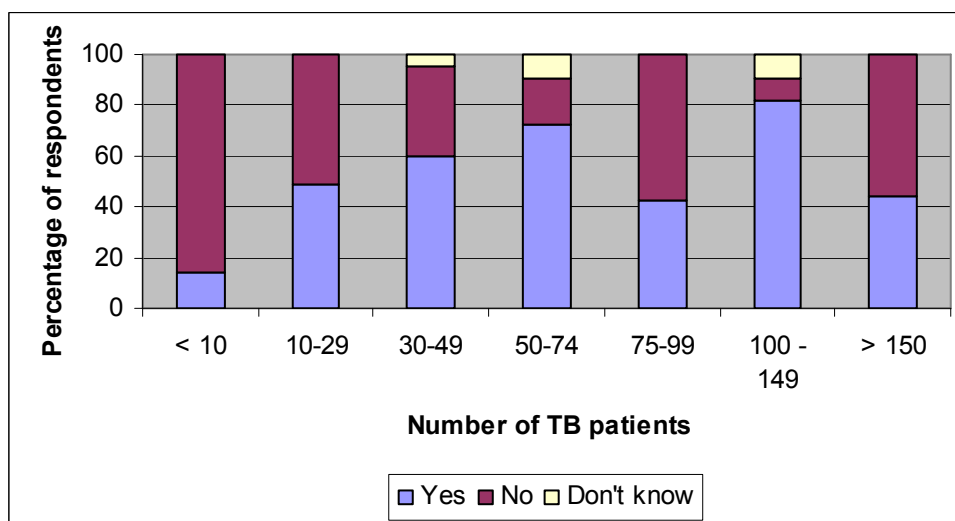
“With less than 20 new cases/year ... we are in a low prevalence area. There is still a significant amount of work e.g. screening new immigrants and students from high prevalence areas. Low prevalence tends to make GPs forget about the possibility of TB”

Microbiology

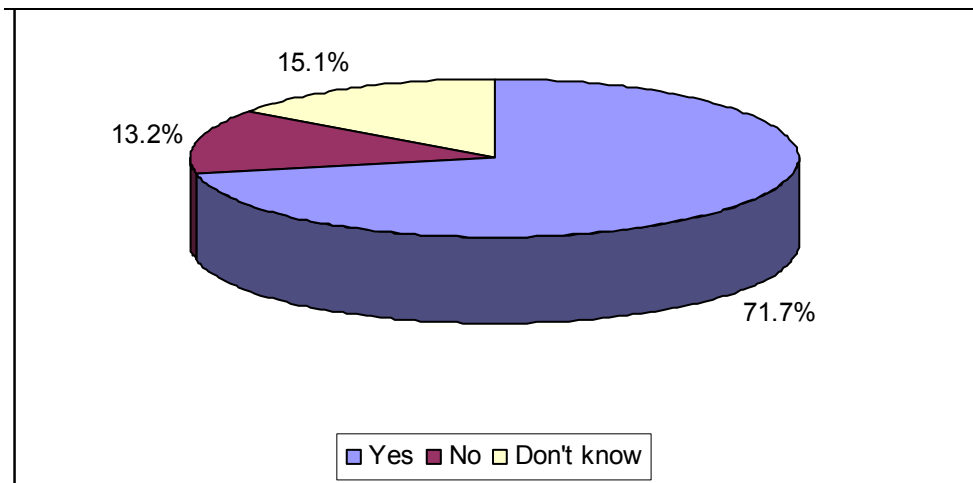
Is there a designated microbiologist who deals with TB? (N=106)



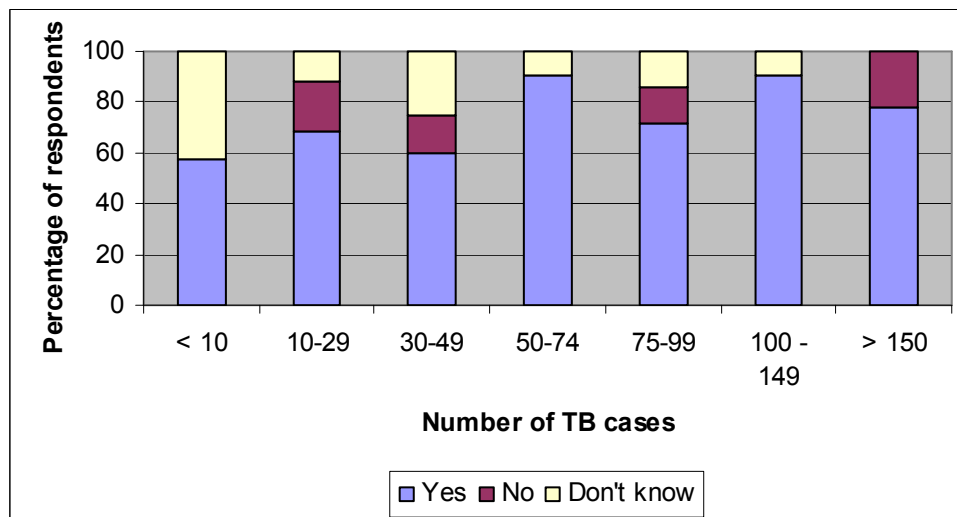
Breakdown by number of TB cases (N=106)



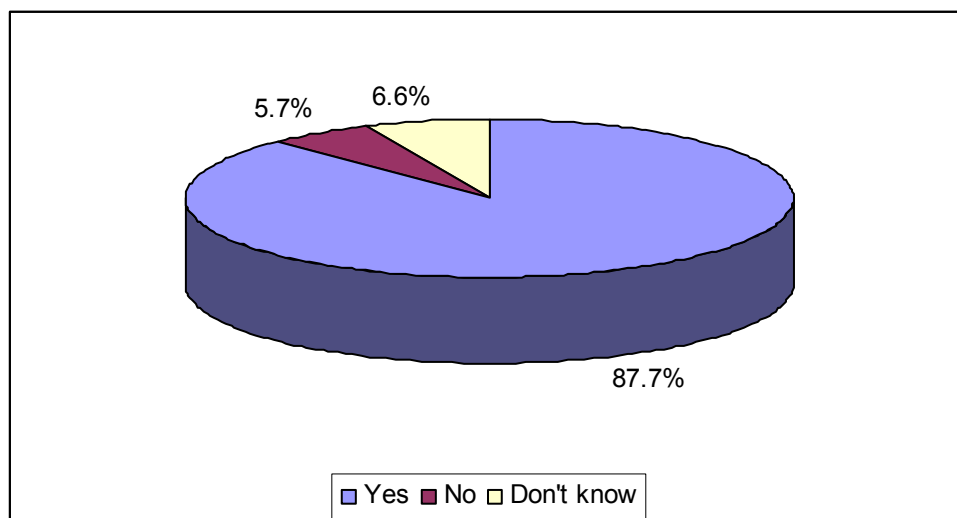
Are all microbiology specimens cultured in liquid media? (N=106)



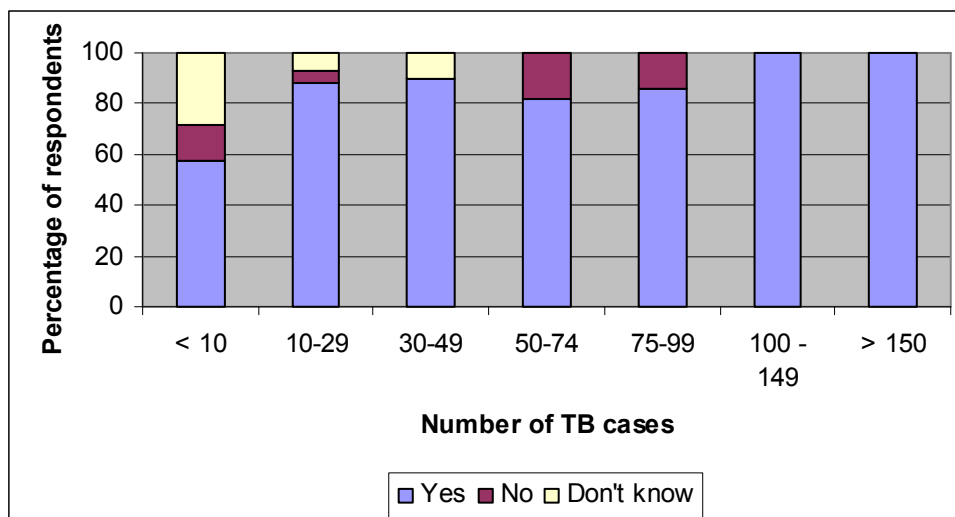
Breakdown by number of TB cases (N=106)



Can you readily obtain molecular probes for rifampicin resistance and species identification? (N=106)

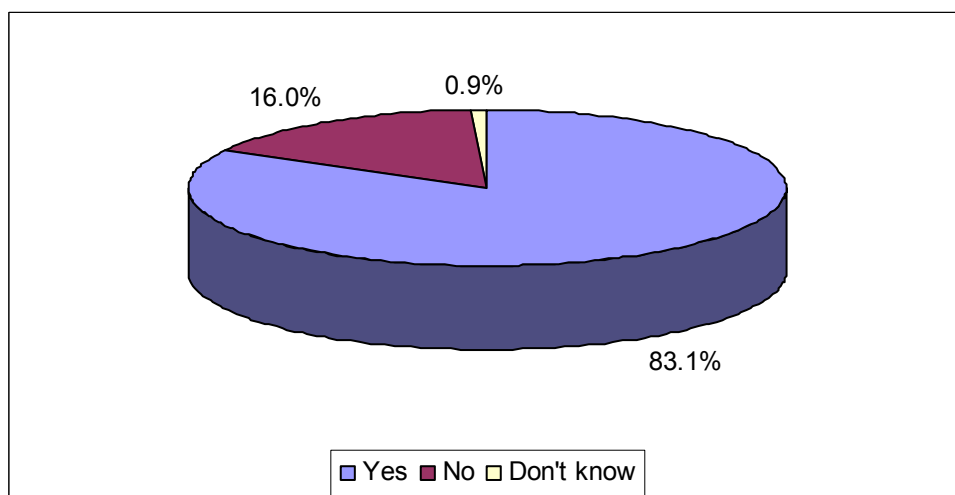


Breakdown by number of TB cases (N=106)

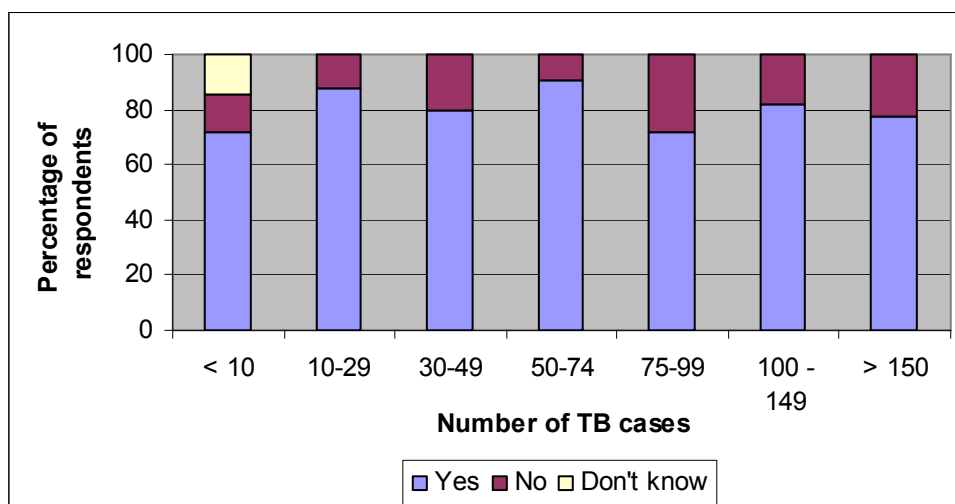


Interferon Gamma Testing

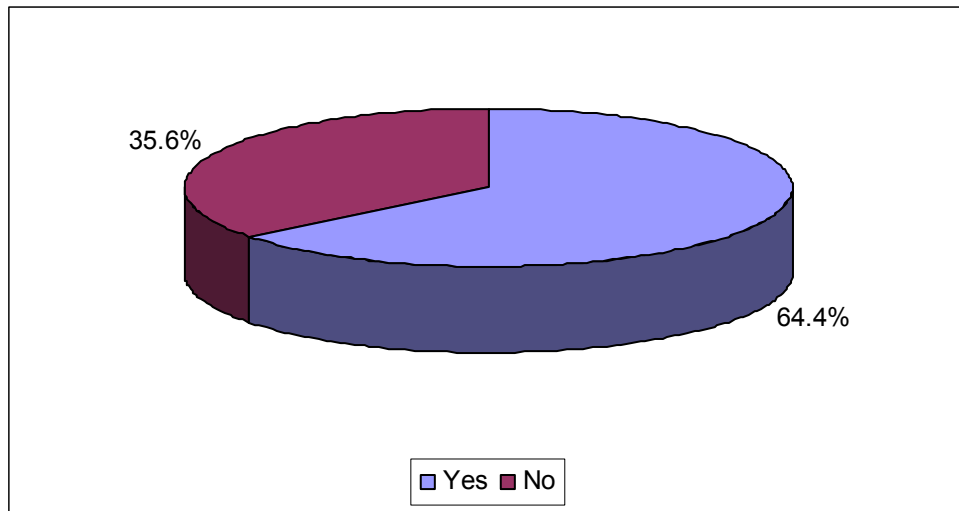
Do you have access to blood interferon gamma release assays (IGRA) to aid in the detection of latent TB, as recommended in the NICE guidelines? (N=106)



Breakdown by number of TB patients (N=106)

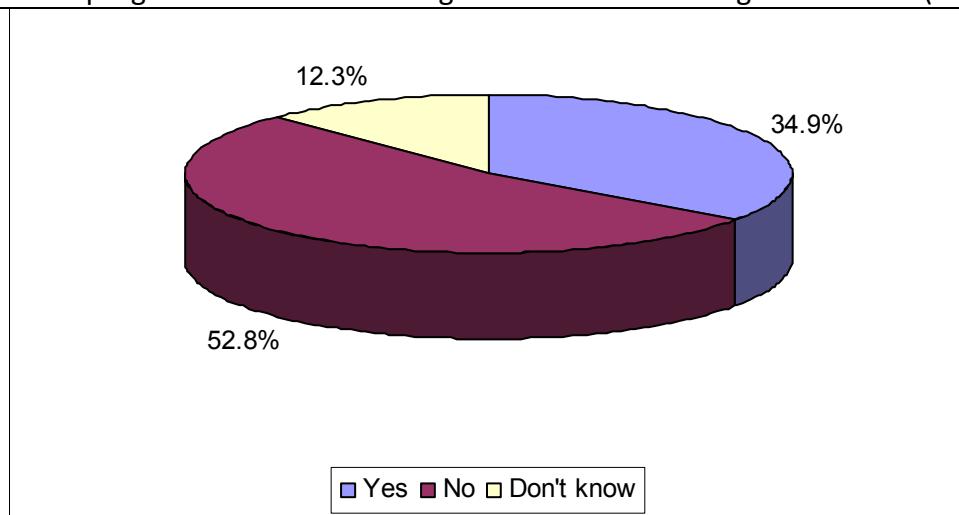


If you have access to IGRA, do you have funding to enable you to use them as needed? (N=87)

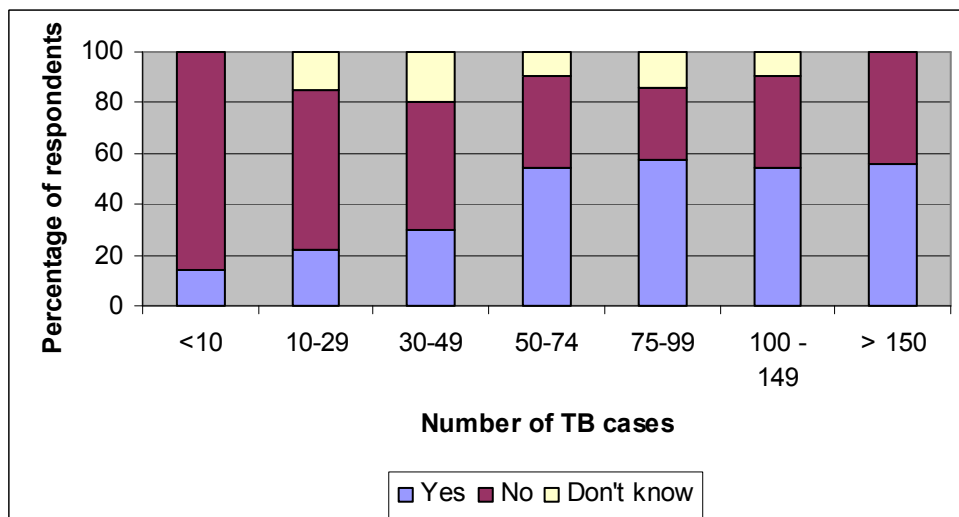


Awareness Raising

Is there a local programme aimed at raising awareness of TB in high-risk areas? (N=106)



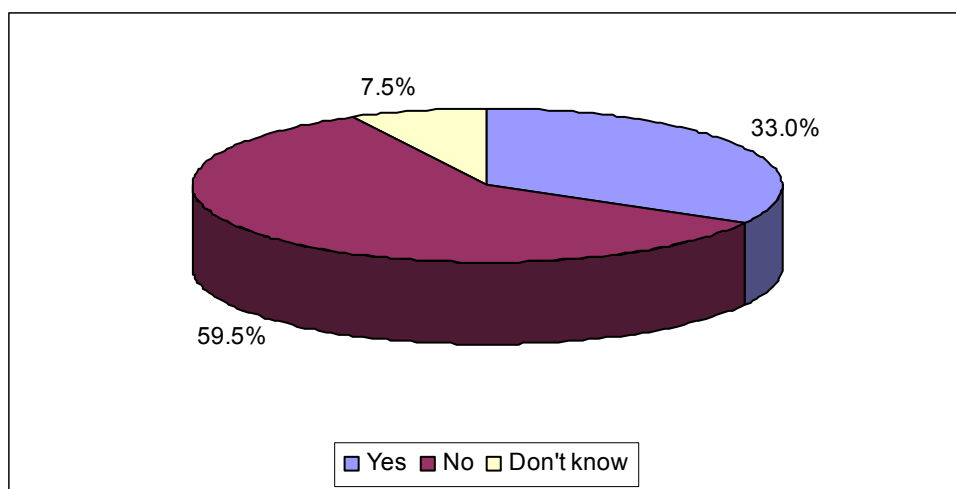
Breakdown by number of TB cases (N=106)



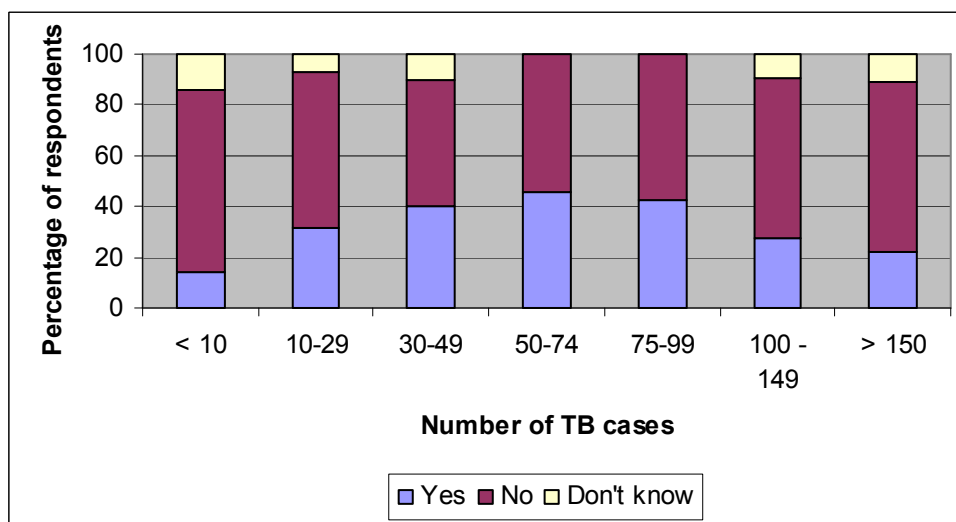
“Case numbers locally have fallen by 20% and increasingly the local emphasis is shifting to disease prevention. This will ultimately require additional resources and clear national strategies for new immigrant screening in particular”

Active Case finding

Is there a local programme aimed at active case finding in high risk groups (other than TB contacts)? (N=106)

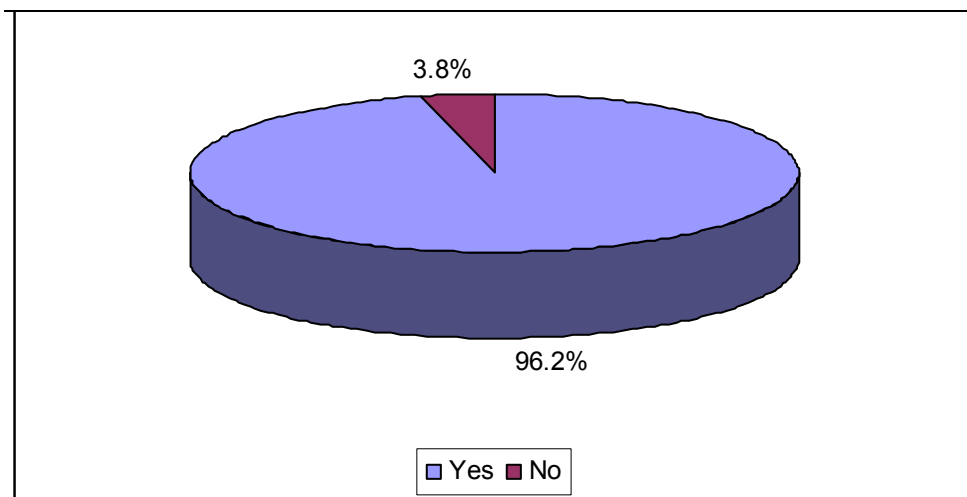


Breakdown by number of TB cases (N=106)



Contact Tracing

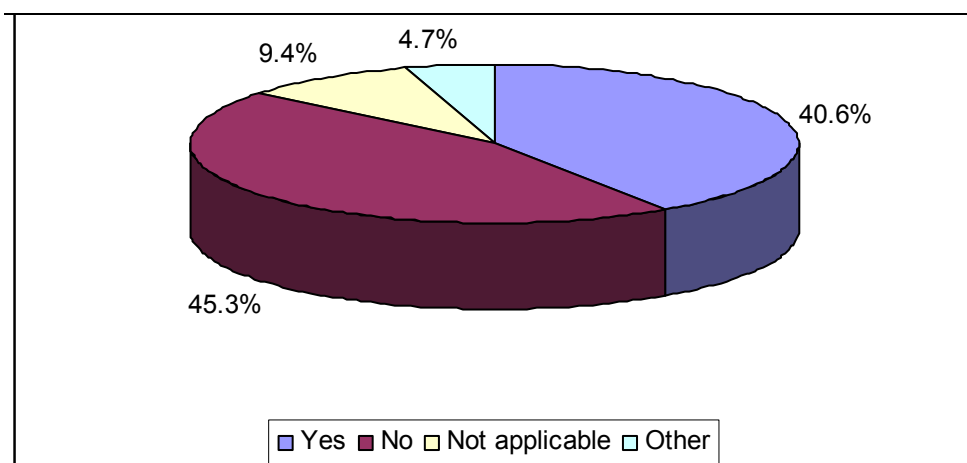
Do you have an agreed protocol for management of TB contacts/subjects at high risk of developing active TB? (N=106)



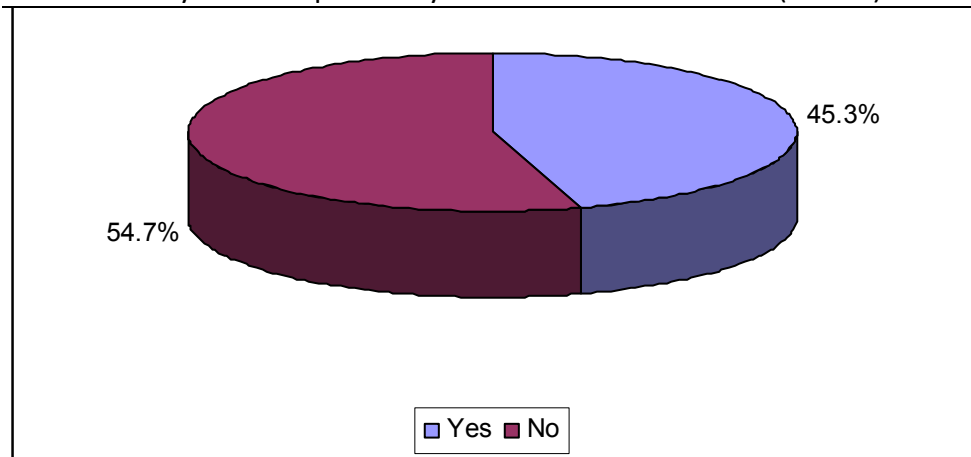
“We are a low incidence area however in the last 2 years {we} have had to manage the contact tracing in two schools & a prison. The advice from the HPA is excellent but they have no staff to support us (questioning, mantoux etc) & the PCT do not pay directly for contact tracing or in fact TB in general”

Choose and Book

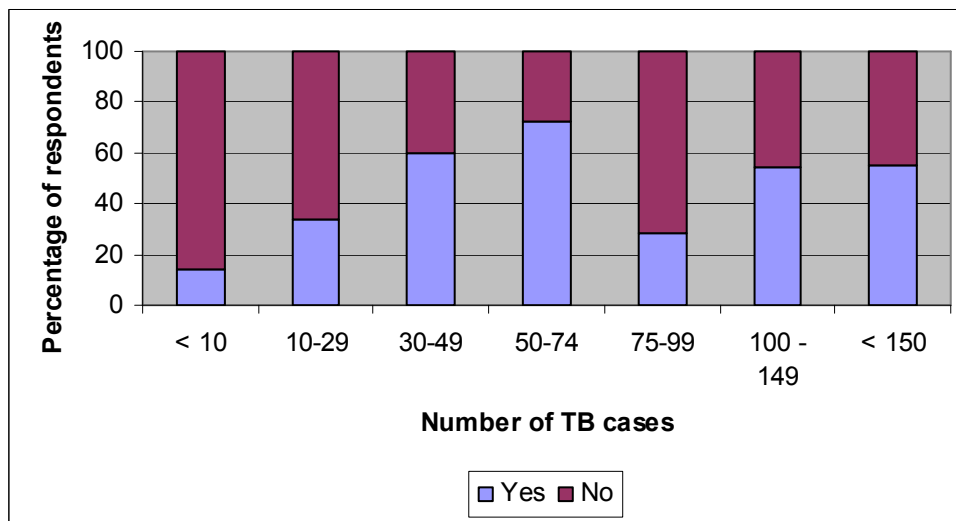
In your experience has the introduction of the Choose and Book system and negotiated appointments led to any difficulties? (N=106)



Does your PCT specifically commission TB services? (N=106)

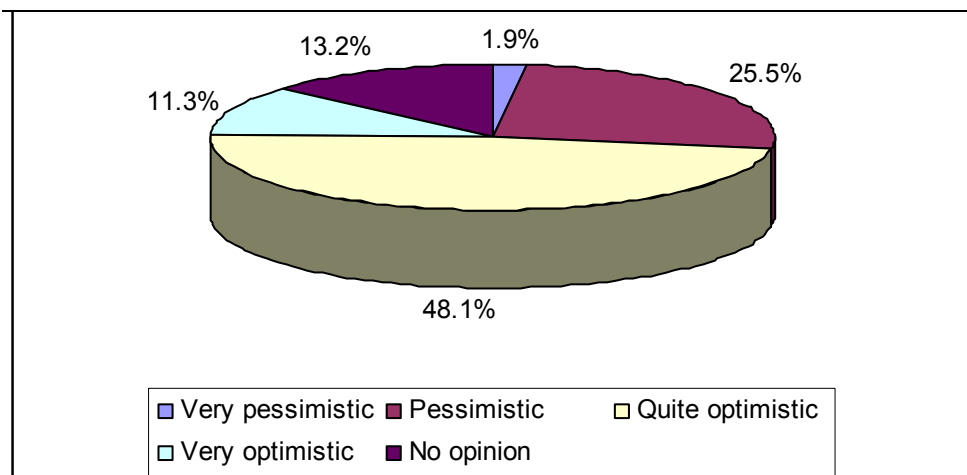


Breakdown by number of TB cases (N=106)

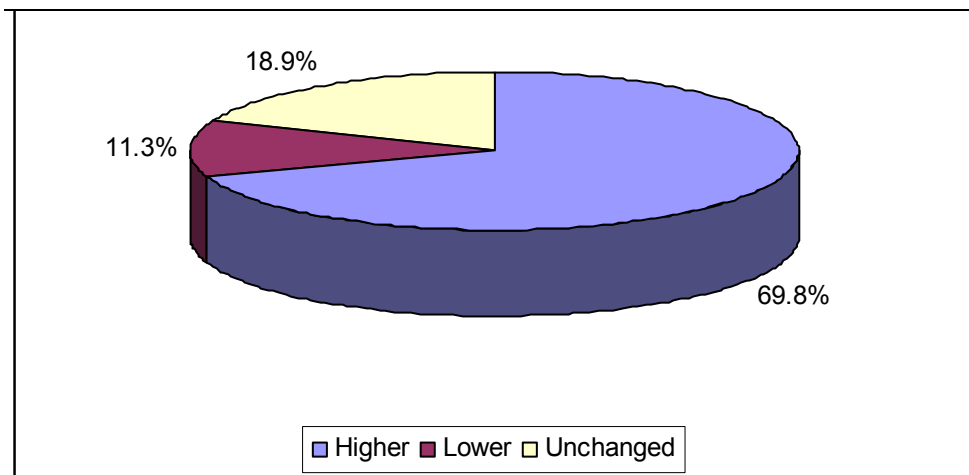


The Future

How optimistic are you that TB services will have improved within two years from now? (N=106)



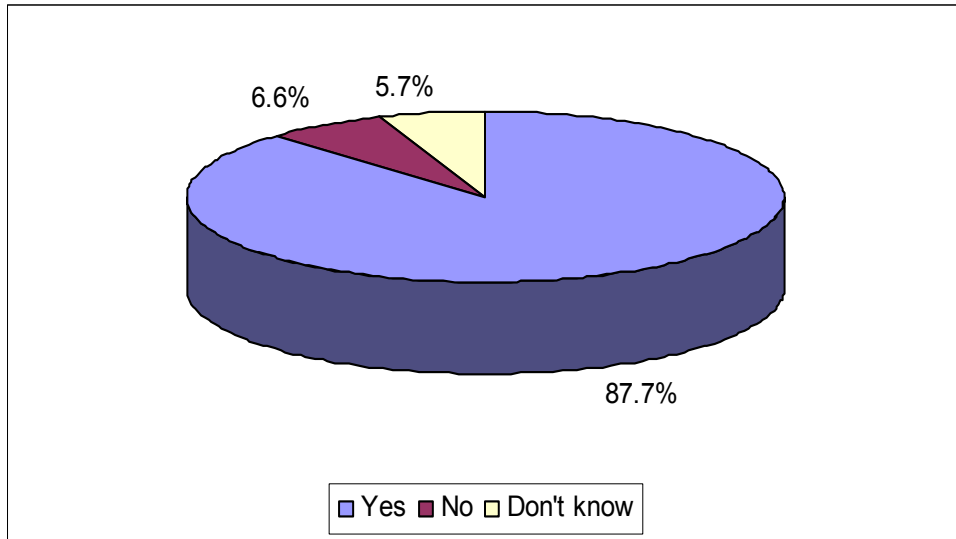
Five years from now what do you expect to have happened to the number of cases of TB in the UK? (N=106)



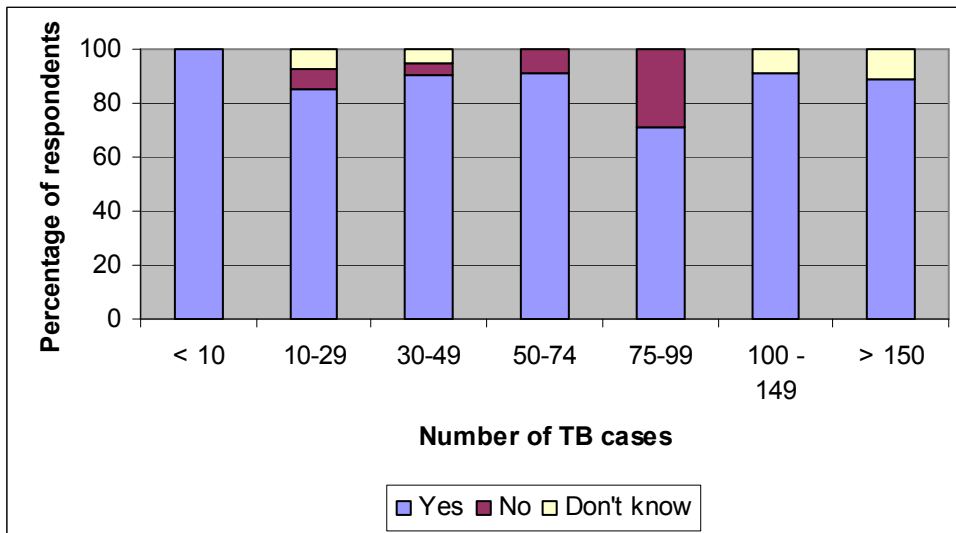
4. TB Standards of Care

Referral Time

Are all patients with suspected pulmonary TB seen by the TB team within two weeks of first presentation to healthcare (including those presenting to GP and A&E)? (N=106)

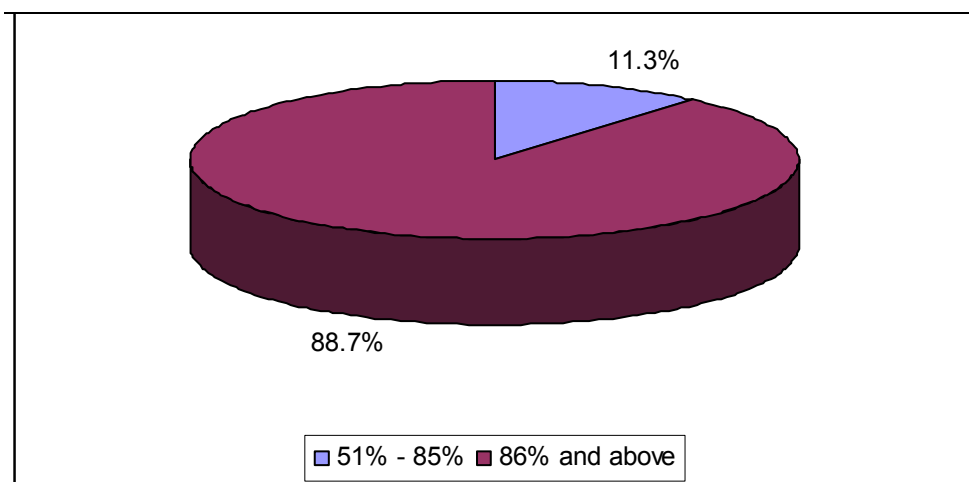


Breakdown by number of TB cases (N=106)

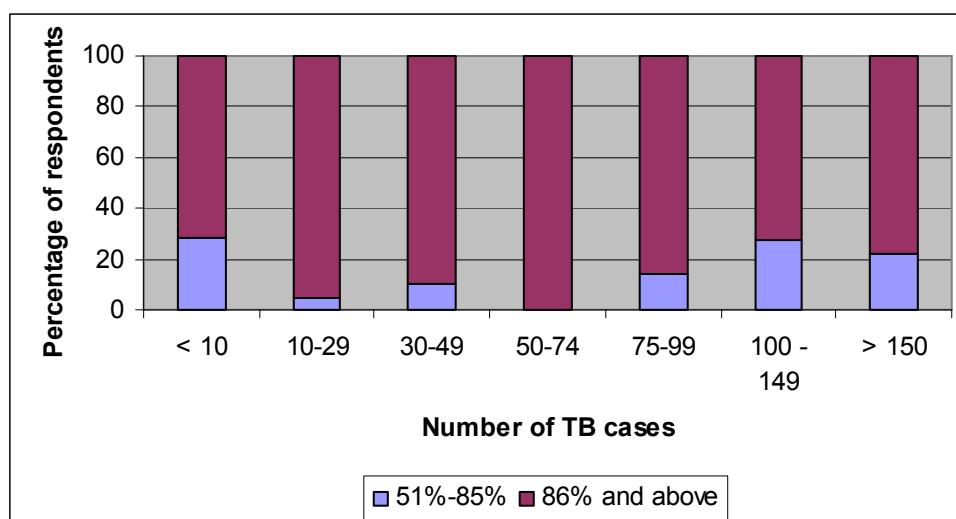


Treatment Outcomes

What percentage of patients successfully complete their treatment? (N=106)



Breakdown by number of TB cases (N=106)



5. Medically complex TB patients

TB-HIV co-infection

Who manages TB-HIV co-infected patients? (N= 106)

Answer	Percentage of respondents
ID or GU physician	32.1
Respiratory physician	15.1
Joint or shared care	34.0
Other	18.8
TOTAL	100%

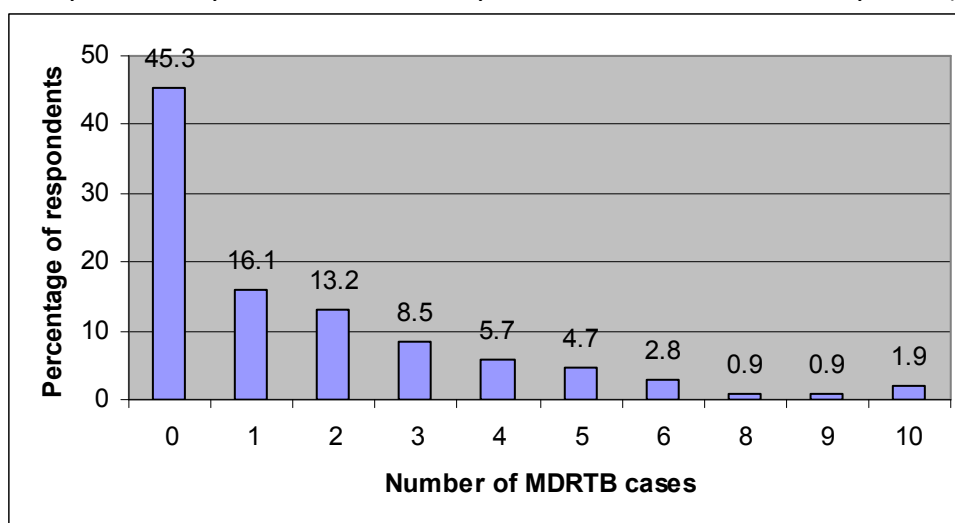
Paediatric TB patients

Who manages paediatric TB cases? (N=106)

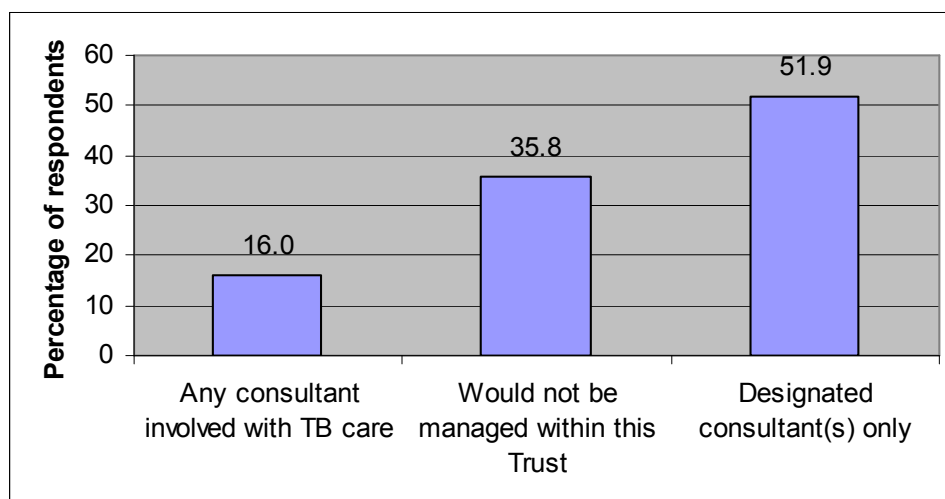
Answer	Percentage of respondents
Joint or shared care	12.3
Paediatrician	68.0
Respiratory physician	5.7
Other	14.0
TOTAL	100%

Patients with TB Drug resistance

Approximately how many MDR-TB cases has your service had in the last 2 years? (N=106)



Who would manage a case of MDR-TB diagnosed in your Trust?^{§§§} (N=106)



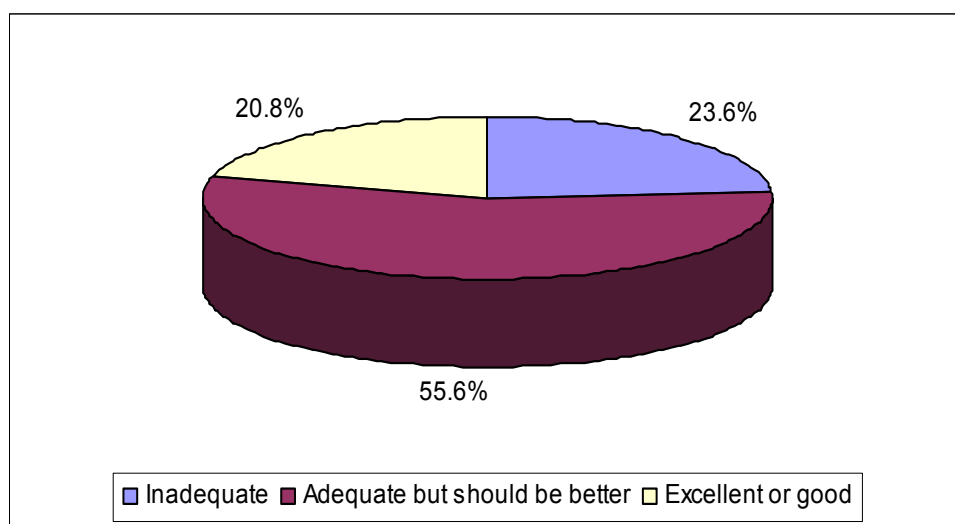
^{§§§} Please note, some respondents gave multiple answers to this question

6. The local response to TB

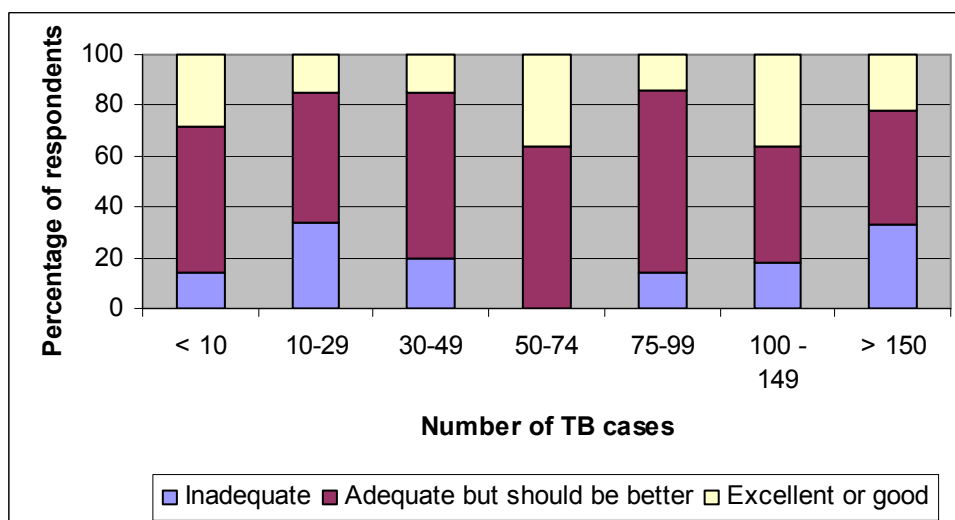
“We have a low incidence of TB. While this is good for patients it means that Commissioners give TB a very low priority, {they} have committed no new resources to it and put it to one side in planning healthcare. If we had an outbreak in a large group such as a big school we would struggle as there is insufficiently trained and experienced staff to deal with this”

“Inequity of access to TB services continues across London. More time is spent in managerial adjustments than in achieving change”

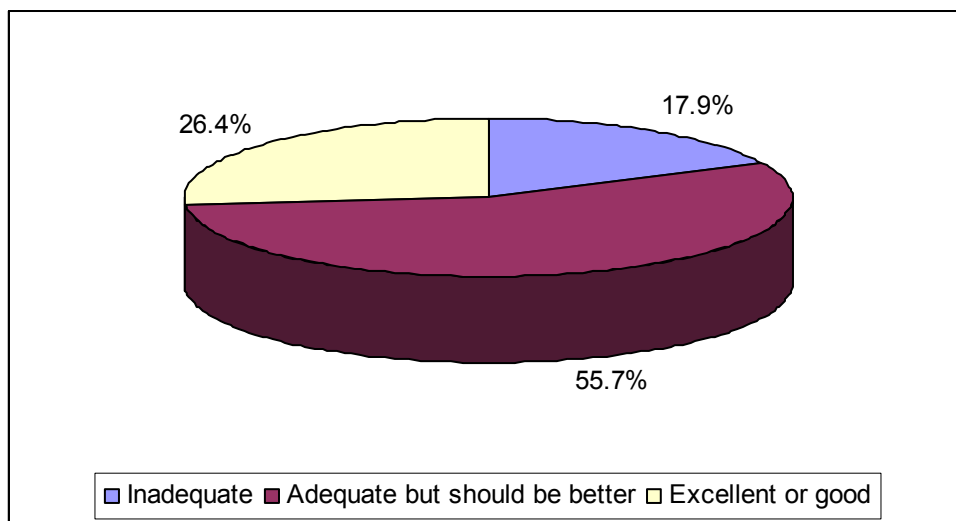
How do you regard the priority given to TB services by your local PCT? (N=106)



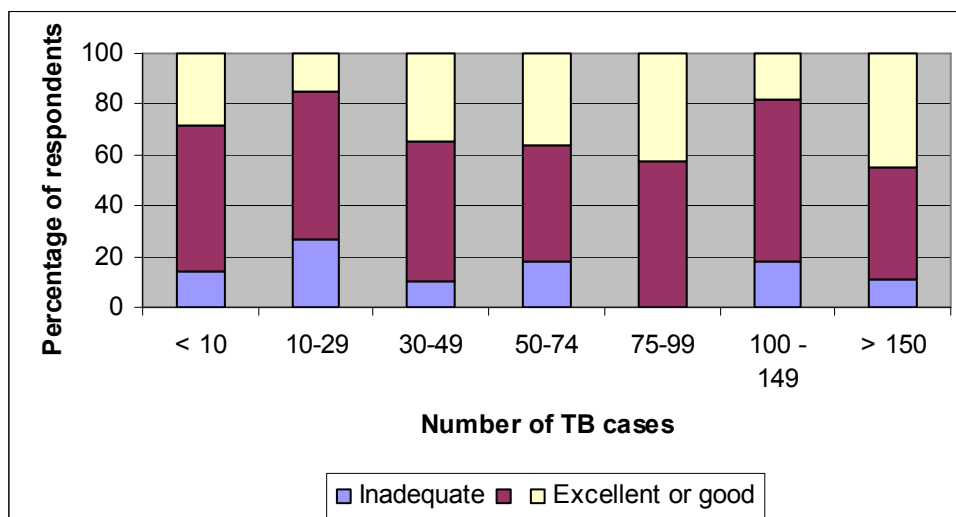
Breakdown by number of TB cases (N=106)



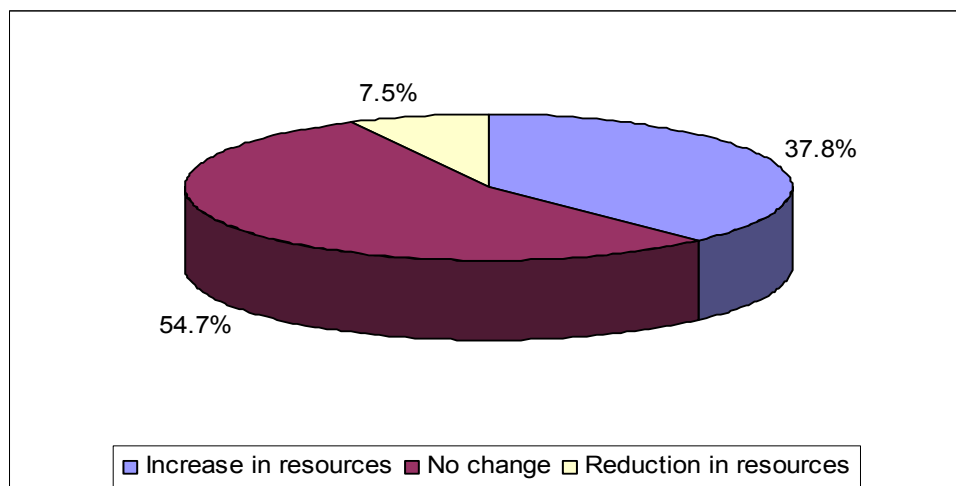
How do you regard the priority given to TB services by your Trust? (N=106)



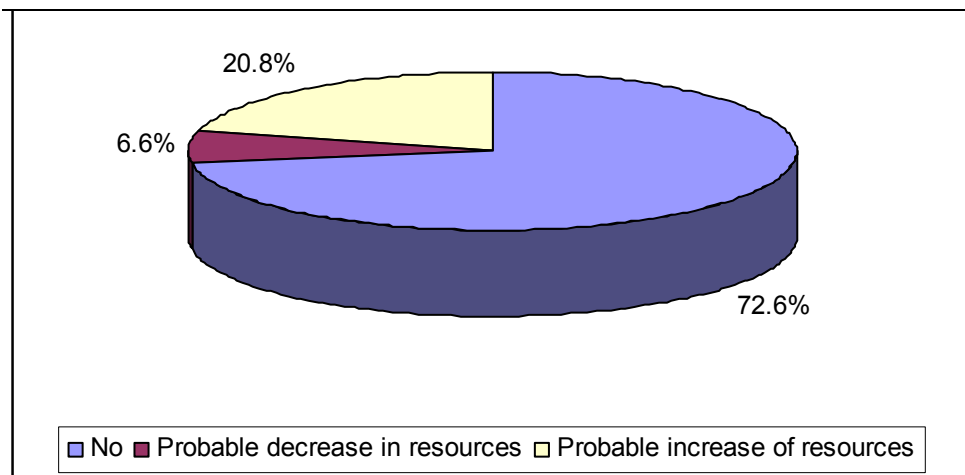
Breakdown by number of TB cases (N=106)



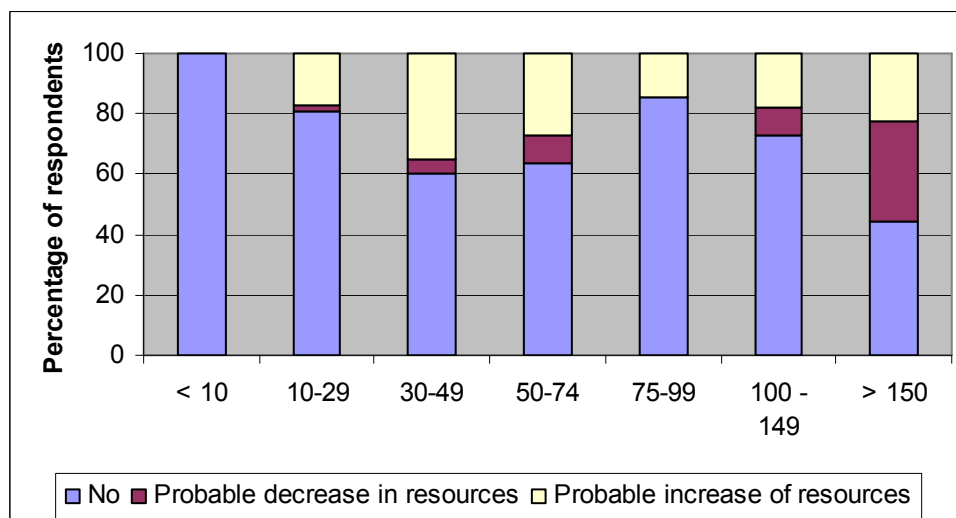
Has there been any significant change in resources for your TB services since the publication of the TB Action Plan? (N=106)



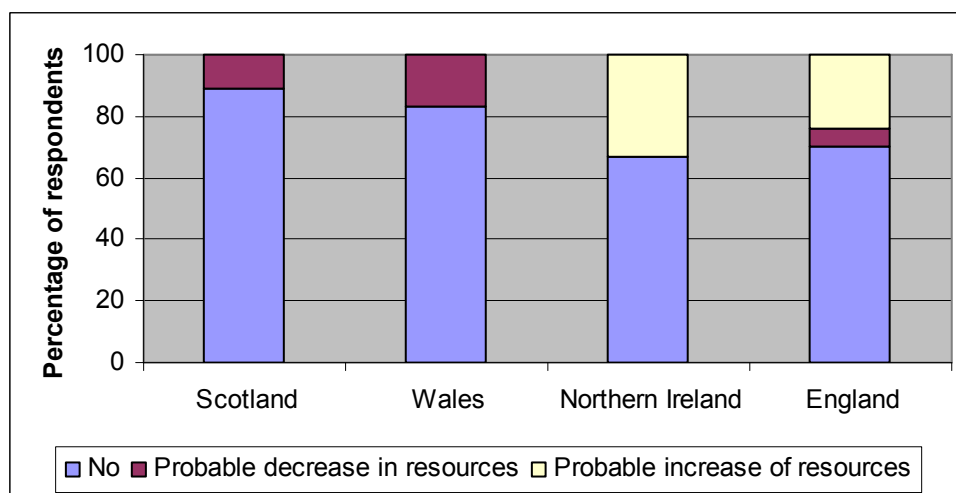
Is there any evidence or suggestion that there will be a significant change in resources for your TB service in the near future? (N=106)



Breakdown by number of TB cases (N=106)



Breakdown by country of employment (N=106)

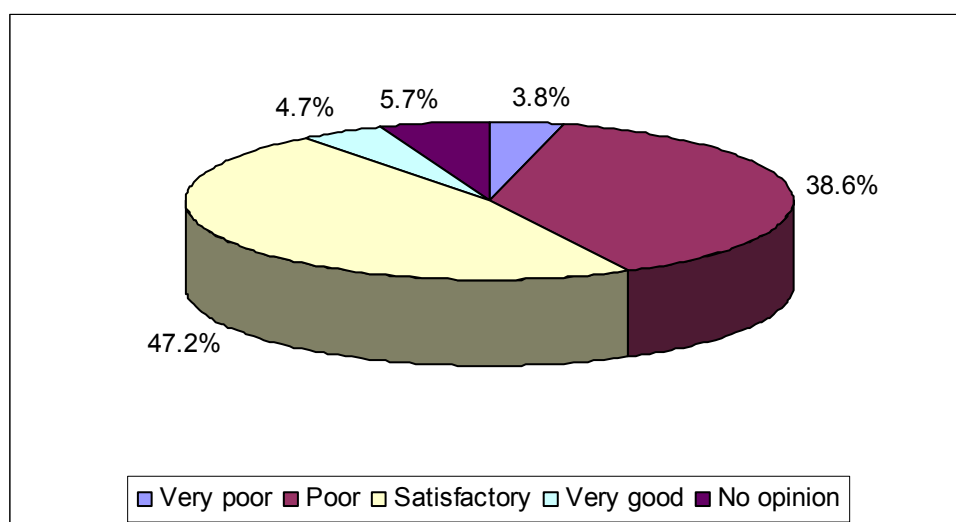


7. The national response to TB

“It is an increasing fight to maintain high standards of both TB clinical care and service administration in the NHS. This is not surprising given the problems that the NHS in general faces (and the potential for TB to be seen as a minority sport by many PCTs struggling with other Govt targets). Enhanced organisation of services both locally and regionally should help specific TB units; and also hopefully make TB more attractive to doctors, nurses and social care staff so that they train in this speciality”

“The DoH response to TB has been all words and no action, and particularly no money. I work with a well informed PCT who see TB as a priority and who support us well. Within the Trust TB does not have a great priority, probably because we do it so well and so there are no problems that management have to deal with”

How do you regard the priority given to prevention and control of TB by the Department of Health? (N=106)



“Nationally there needs to be much more joined up thinking so that services funded currently such as Find and Treat are able to translate into seamless working with local services in the future”

“Lack of DoH targets mean that PCTs and Acute Trusts will automatically give TB lower priority than conditions with targets (e.g. cancer)”

Chapter 2 – RCN Survey

Methods

The survey was written by the RCN TB Forum and the APPG secretariat. It was piloted by the RCN TB forum committee.

The survey was disseminated via email with an attached explanatory letter (to 60 nurses) on 6th January 2009 and in the delegation packs of the RCN TB Forum Annual conference (to 100 nurses) on 11th March. Reference to the survey was also put on the APPG website and included in APPG and RCN newsletters. An update was sent to the 60 emailed nurses on 23rd March. The survey closed on 27th March.

Survey results are confidential and non-identifiable. Respondents were asked for the name of their employer to assess the geographical spread of results but completing the name of the respondent was optional.

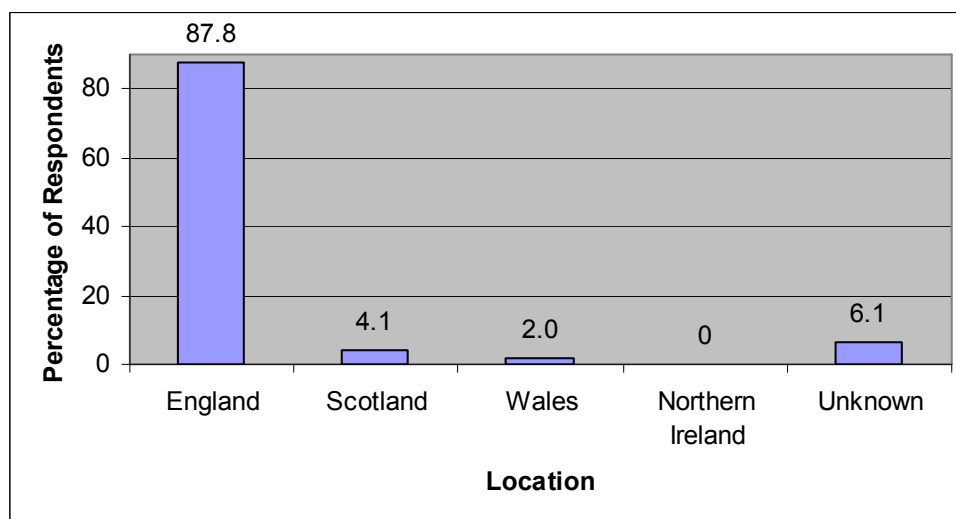
Results

1. Response to the survey

Response rate

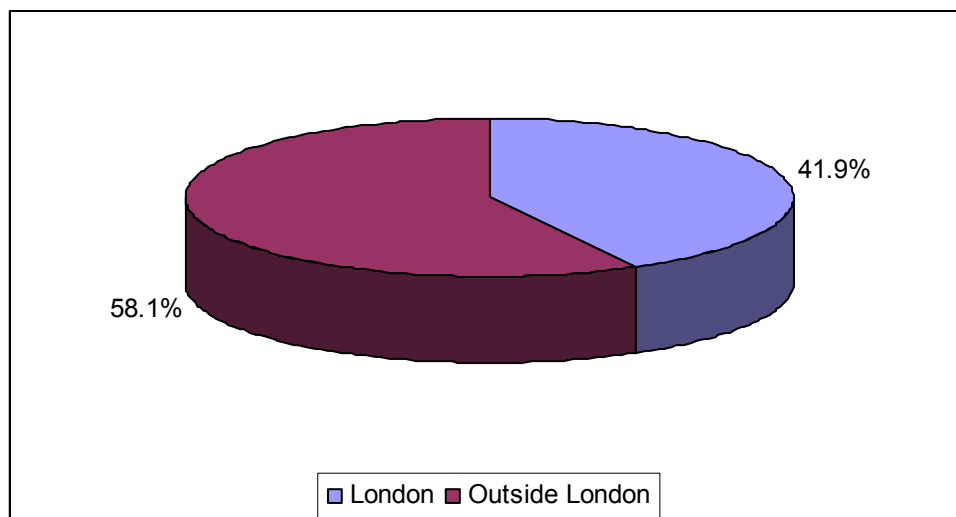
- Survey went out to = 160
- No. of respondents = 49
- Response rate = 31%

Location of respondents



N=49

Breakdown of England based respondents:



N=43

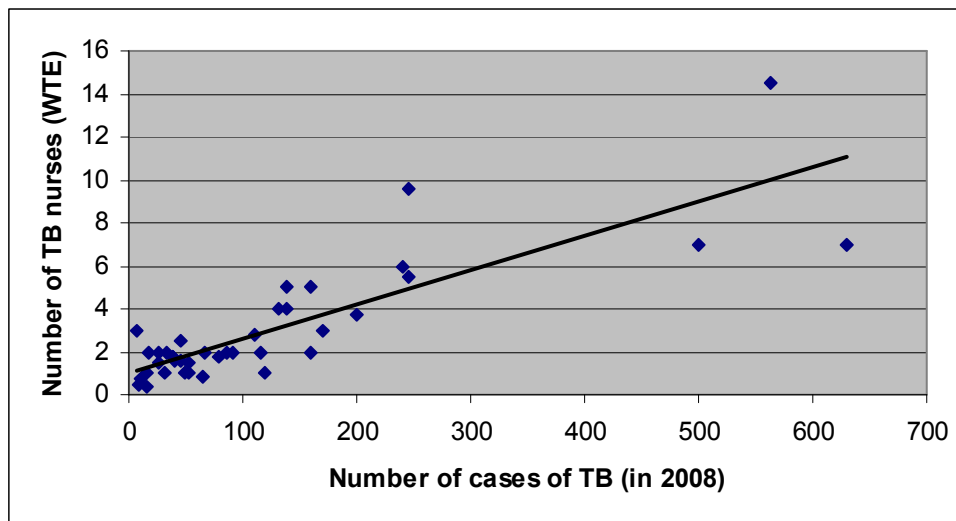
2. TB Service Workforce

Nursing Staff

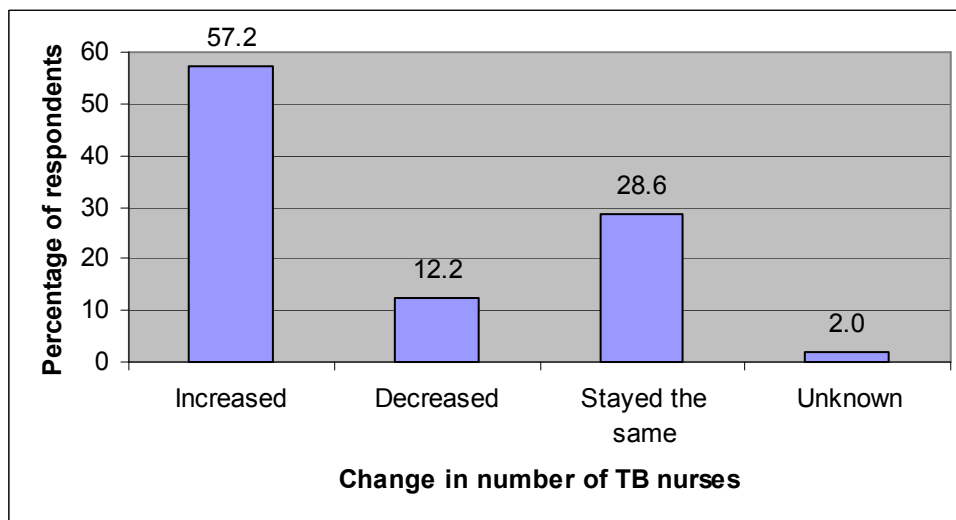
“Nurses are key to running TB services on a day to day level as well as driving development for the future...their expertise and commitment should be harnessed...and they should be allowed to practice the role to achieve the key objectives without fear of attack at every opportunity from managers who through no fault of their own (they too have demands they cannot meet) see TB nurses (and nurse specialists as a whole) as an easy target for staff reductions and redeployment. This will not happen until the government gets behind their talk with concrete developments that protect what is a massively important area of public health”

“As a TB nurse I enjoy working with a diverse range of people who are having treatment for TB. However, the role sometimes feels limited. I feel more creative service delivery could improve the TB service for patients and enhance job satisfaction for nurses”

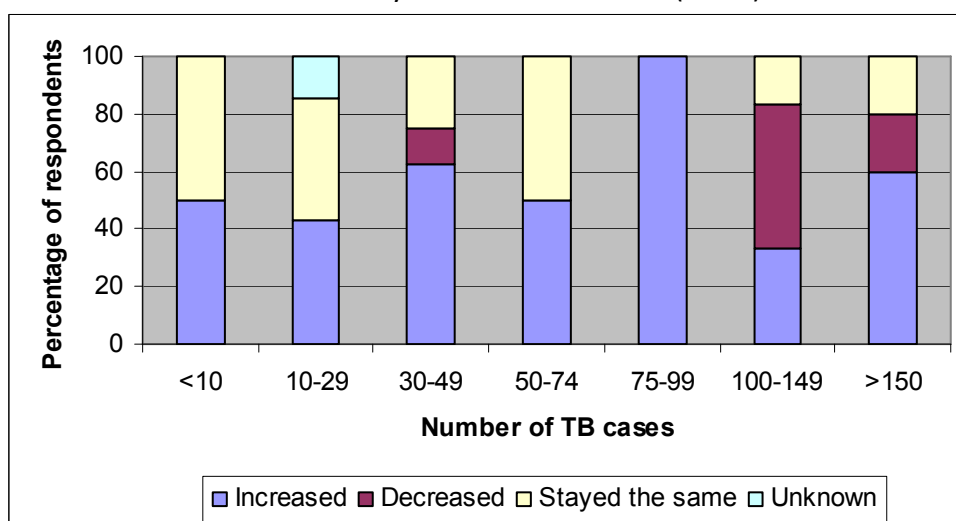
Relationship between number of TB nurses and TB caseload (N=39)



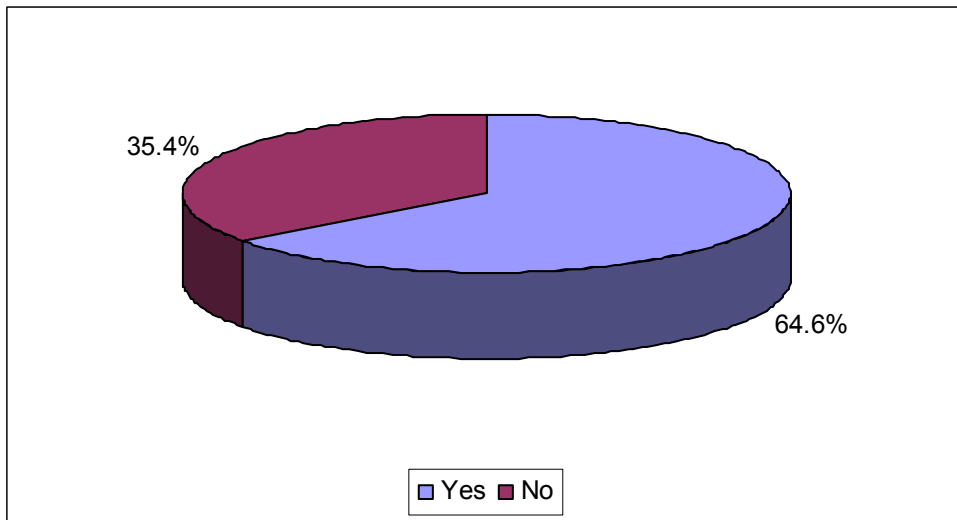
Has the number of TB nurses employed in your TB service changed in the past 5 years (Since the CMOs Action Plan)? (N=49)



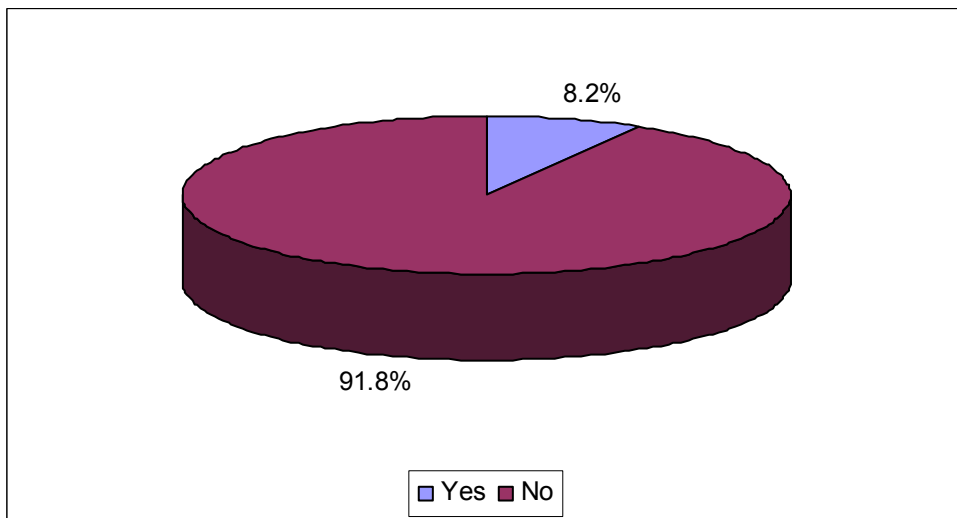
Breakdown by number of TB cases (N=40)



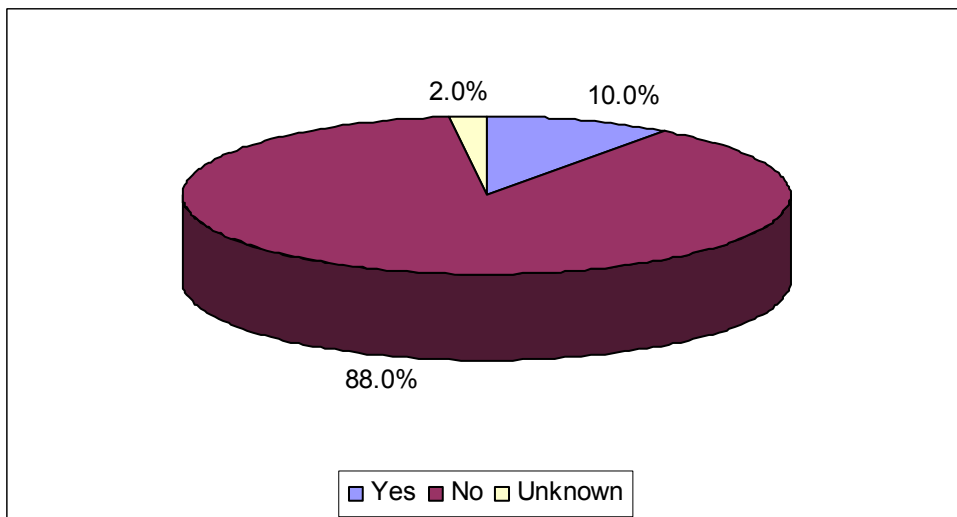
For the work that you personally carry out, do you feel that your post has been banded correctly? (N=48)



Does your TB Service currently have any vacant TB nurse positions? (N=49)



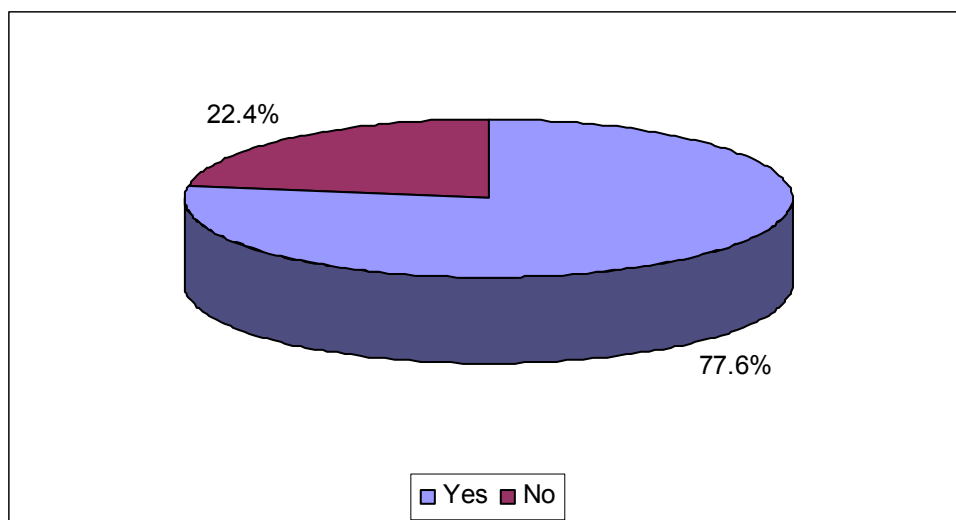
Are any TB nurse posts currently under threat or review in your TB Service? (N=49)



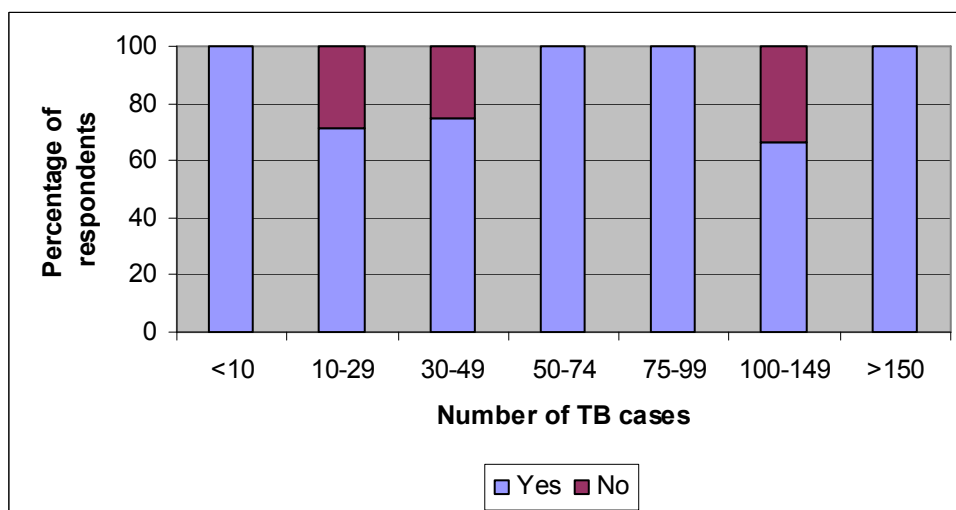
“There needs to be overall investment in school nurses screening to prevent outbreaks in schools. We have had two outbreak investigations. During these investigations the team has to fight for additional support for the clerical and nursing team. Also, many of our complex patients need directly observed therapy but we do not have the manpower to administer this”

Administrative support

Does your TB Service have administrative/clerical support? (N= 49)



Breakdown by number of TB cases (N=33)

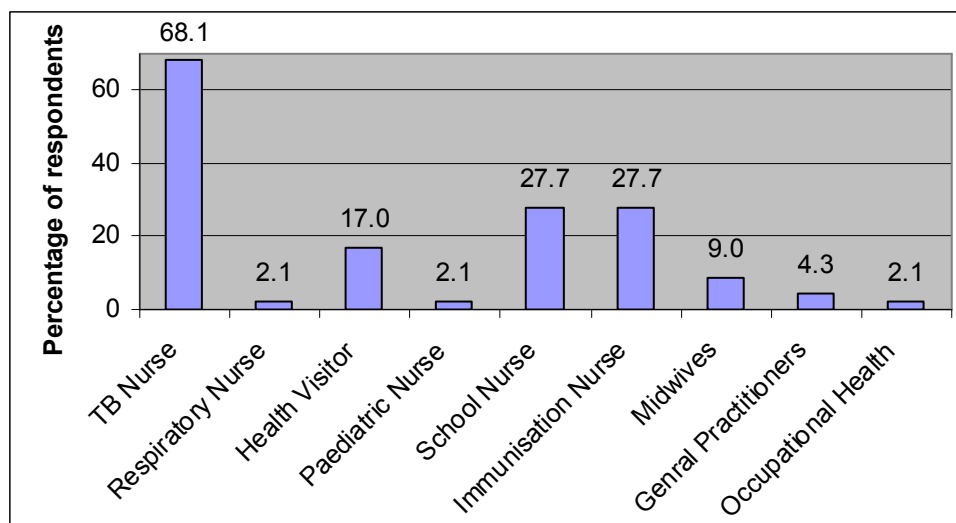


“We technically have admin support but they are on long term sick and we have no replacement”

“They are not dedicated TB admin support; they are part of the respiratory team”

3. TB Services - BCG

Who is responsible for BCG vaccinations in your local area? (N=47) ****

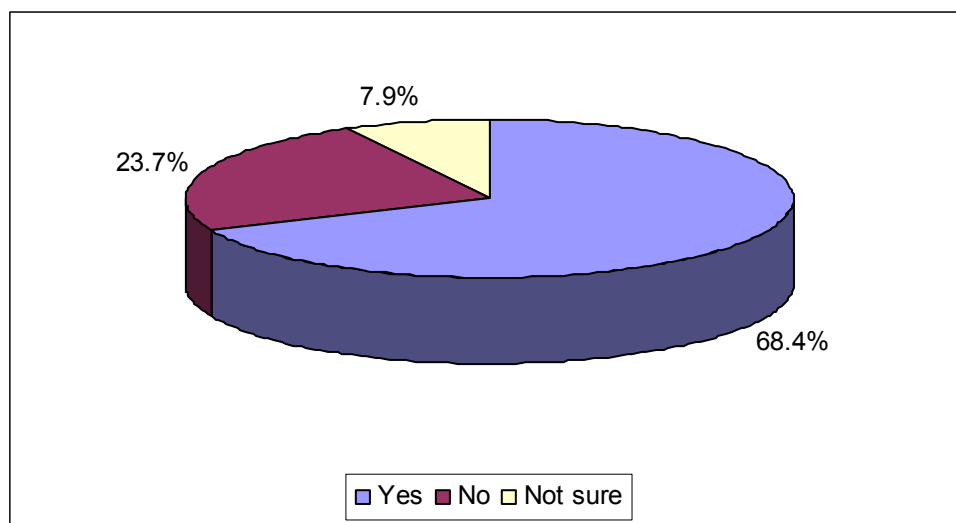


“I believe that BCGs should not be a duty for TB nurses-they need to utilise their time with TB patients-not in labour intensive BCG administration”

“It’s a complete waste of specialist time (but a good money spinner for the acute trust)”

“We {the TB Service} cannot meet demand – we have a waiting list of approx 500”

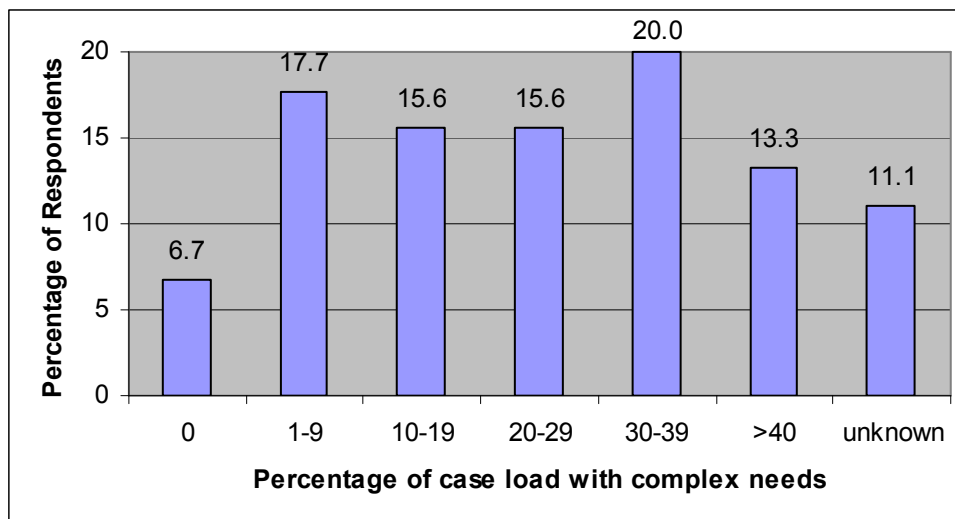
Do you think that BCG vaccinations in your area would be better carried out by other health care professionals or as part of another service? (N= 38)



**** Please note, more than one answer can be given to this question

4. Socially complex TB patients

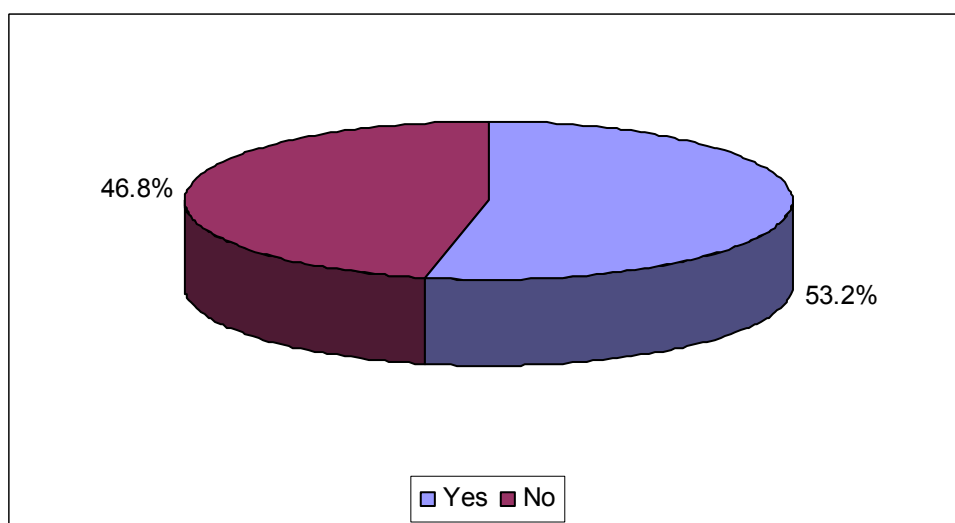
What proportion of the TB caseload treated by your TB service has 'complex needs' (defined as one or more of the following: homeless, drug misuse, alcohol misuse, prisoner during treatment, mental health problems)? (N= 45)



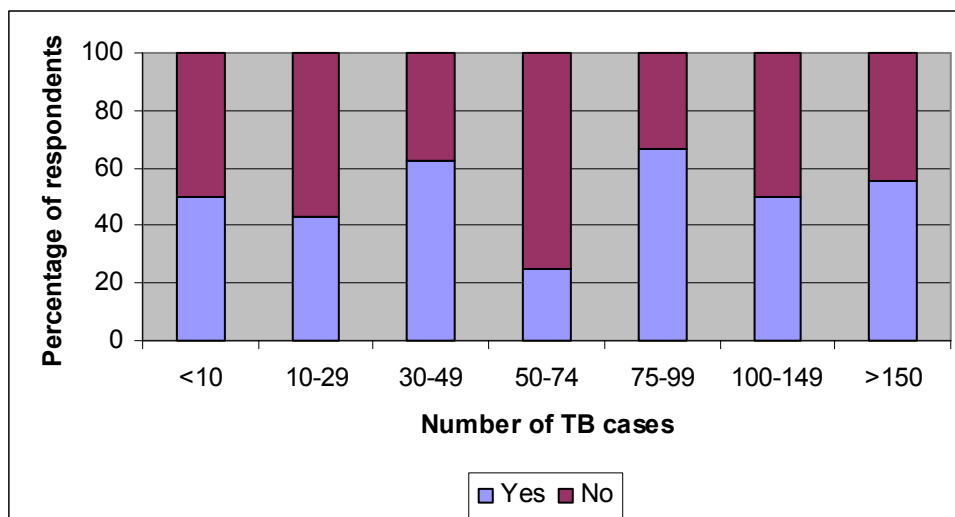
“There needs to be a provision of incentives from DH, HPA, PCT, Trust etc to use for difficult patients to aid compliance”

“On several occasions nurses have had caseloads of over 100 cases annually-the majority are complex cases that often need additional input. It has felt like a battle trying to get additional funds even though the numbers of cases continue to rise. The effect is a stressed team and little support from the PCT”

Do you feel your TB service has the necessary skills and relations with local social and housing services to adequately deal with “complex needs” patients? (N= 47)



Breakdown by number of TB cases (N= 39)



“A specialised case worker or social worker not scared of TB is needed”

“Certain patients do not have access to housing or other services. I’m not sure what can be done for them”

“We have a social care team-but need to move away from a medical approach which still dictates patient’s care; it needs to become much more holistic and integrated with health and social needs”

“We require training and multi-disciplinary working”

“Housing benefits and other social problems take up a considerable amount of time. The systems are so complex that often the nurses cannot sort it out”

“Because of the few patients requiring links to other agencies {it is} difficult to maintain established links. Often by the time we have dealt with an agency for one patient and need their services again people working in that service have moved on”

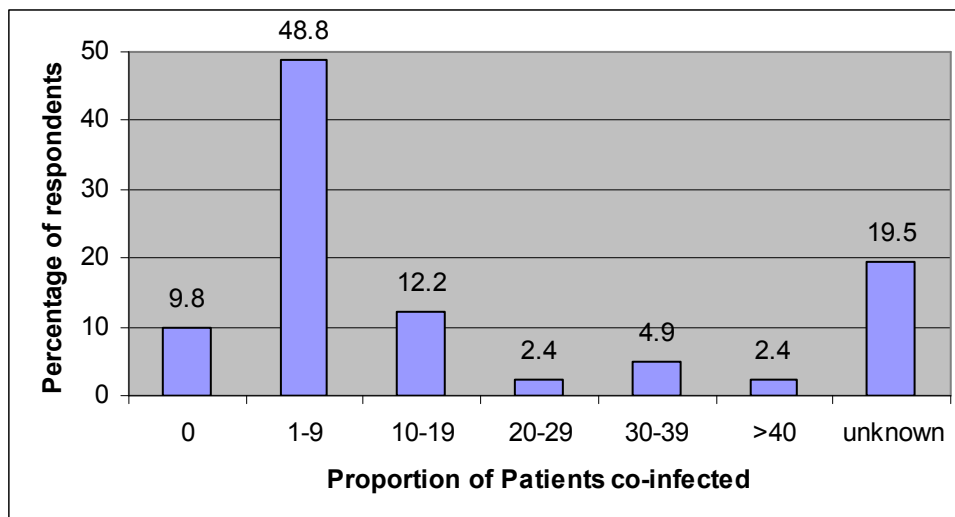
“I would like to see a named case worker within {the} social services department to deal with problems as they arise”

“Social service allocation is slow. We would benefit from some dedicated social worker time. As nurses we spend a lot of time on social issues”

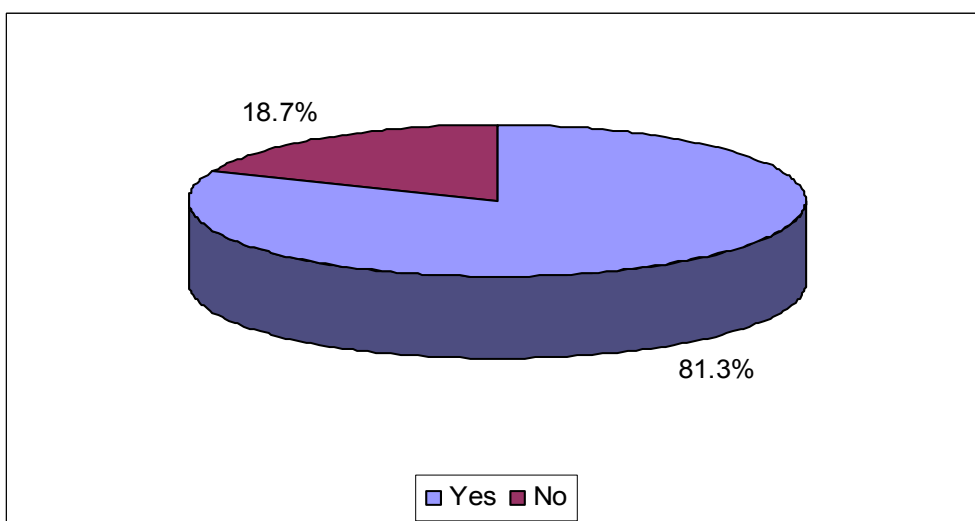
5. Medically complex TB patients

TB-HIV co-infection

What proportion of the TB caseload treated by your TB service is co-infected with HIV?
(N=41)



Do you feel that your TB service has the necessary skills to deal with co-infected patients?
(N=48)



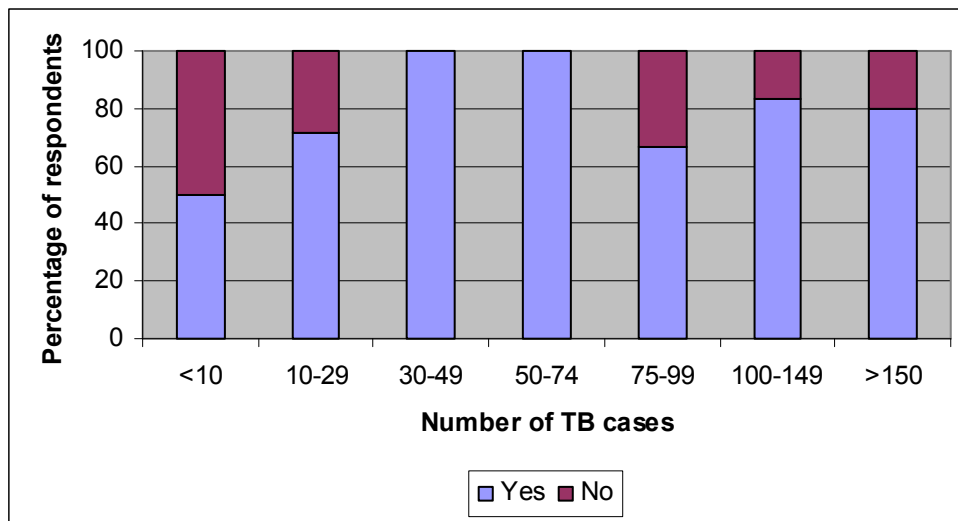
“Better coordination with GUM clinic and access to their results would enhance the service.”

“Need more patient focused care rather than disease focused”

“The HIV and TB services need to share skills more readily. They are two isolated services at present”

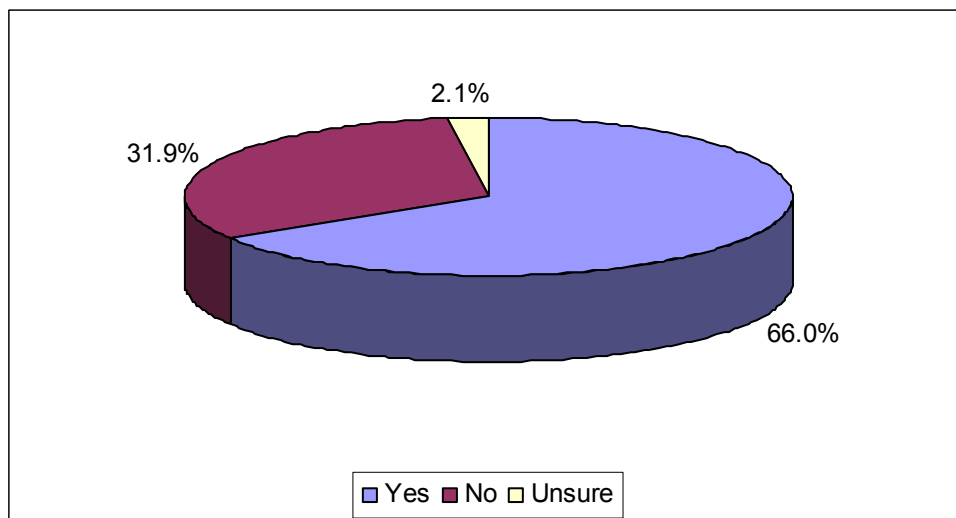
“Need to look at integrating services, still quite separate. Possibly develop the role of HIV-TB nurse”

Breakdown by number of TB cases (N=40)



Paediatric TB patients

Do you feel that your TB service has the adequate skills and facilities to deal with paediatric patients? (N= 47)



“The paediatrician is overloaded so it is hard to get urgent appointments with him”

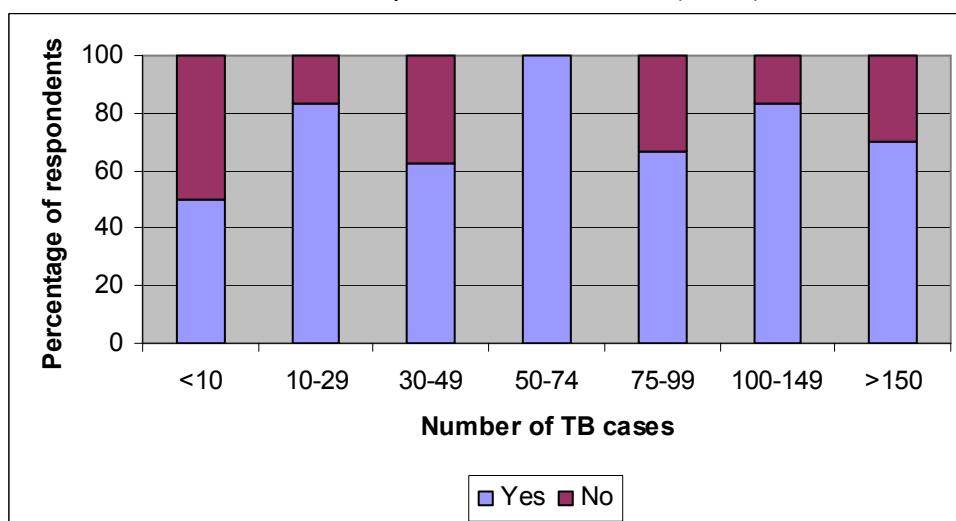
“We need to have a paediatric nurse who has dedicated responsibility for TB work”

“I would like to develop a TB/paediatrician role. There is also the need for family services”

“Our respiratory consultants don’t cover paediatric cases and paedes see so few {TB cases} that their expertise is minimal”

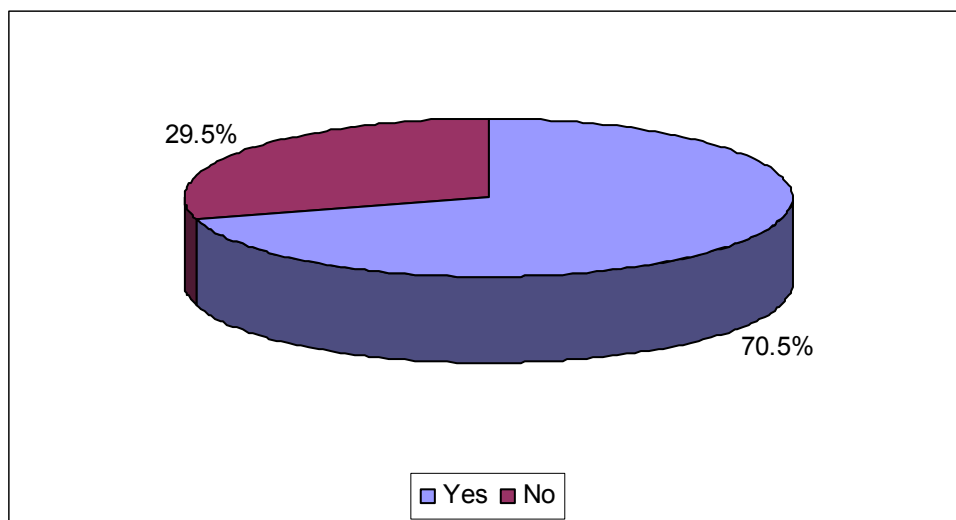
“There is a lack of experience in the {respiratory} nurses and in the paediatric department due to sporadic nature of the cases. Expert resource is needed”

Breakdown by number of TB cases (N=39)

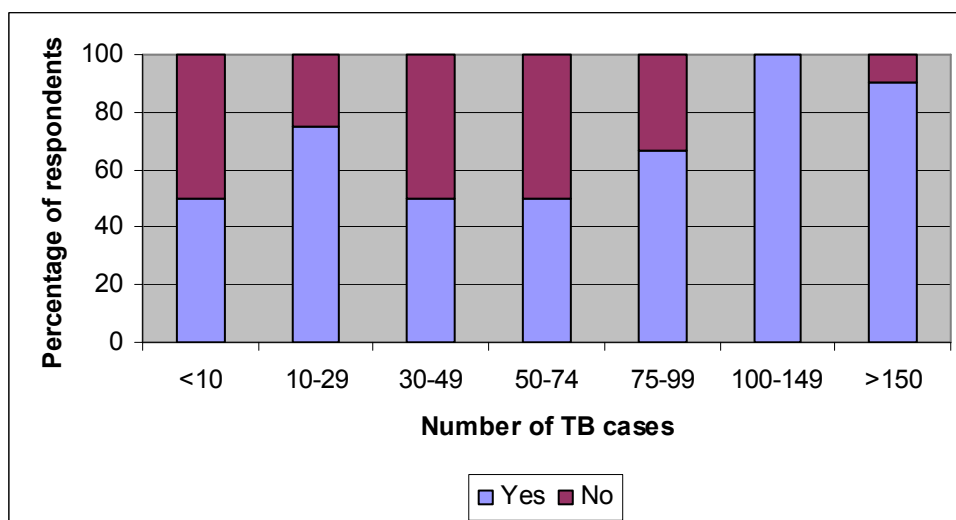


Patients with drug resistance

Do you feel that your TB service has the adequate skills and facilities to deal with TB patients resistant to TB drugs? (N= 44)



Breakdown by number of TB cases (N=37)



"{We} have lack of experience as small percentage {of patients are} drug resistant"

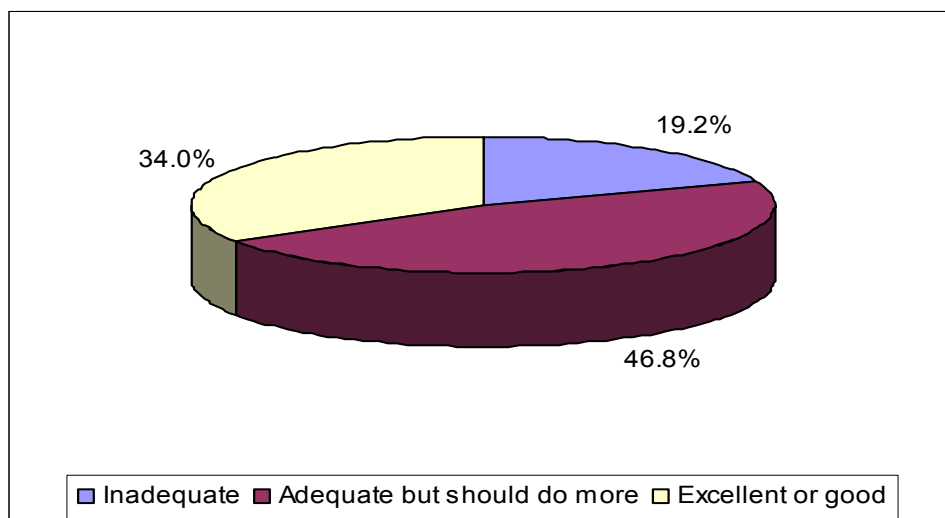
"We have no negative pressure facilities that we are able to use. We need improved lab resources to ensure all smear positive patients have a rapid gene probe assay"

"We need to improve the nurse patient ratio in line with NICE guidance so that the nurse can spend enough time to give observed treatment"

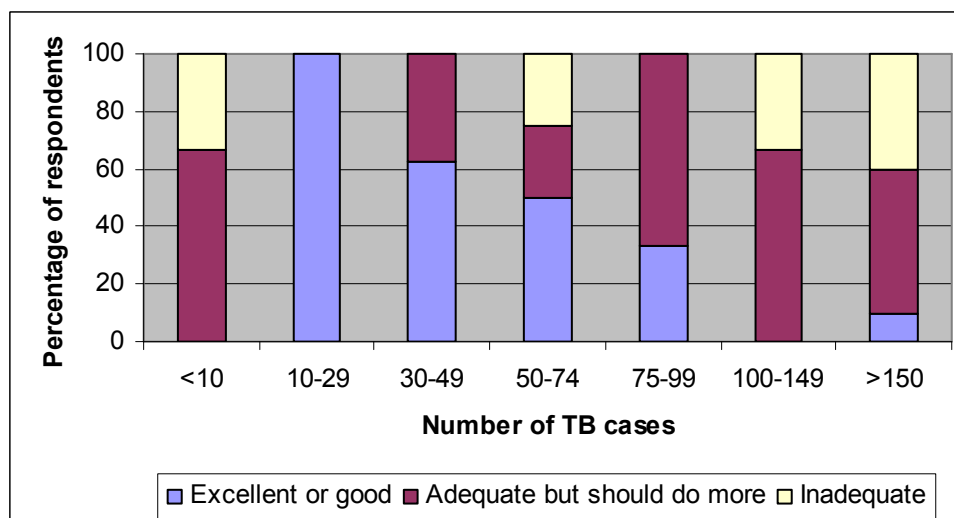
"Need to be able to consult with those who have experience. There needs to be an expert team available for advice/support"

6. The local response to TB

How do you regard the priority given to TB by your employer? (N=47)



Breakdown by number of TB cases (N=39)



“They have no appreciation of complex cases”

“We cover the basics but will need more qualified staff to provide a better service”

“They will not support DOT. They are always keen to cut secretarial hours and they would like us to become generic respiratory nurses”

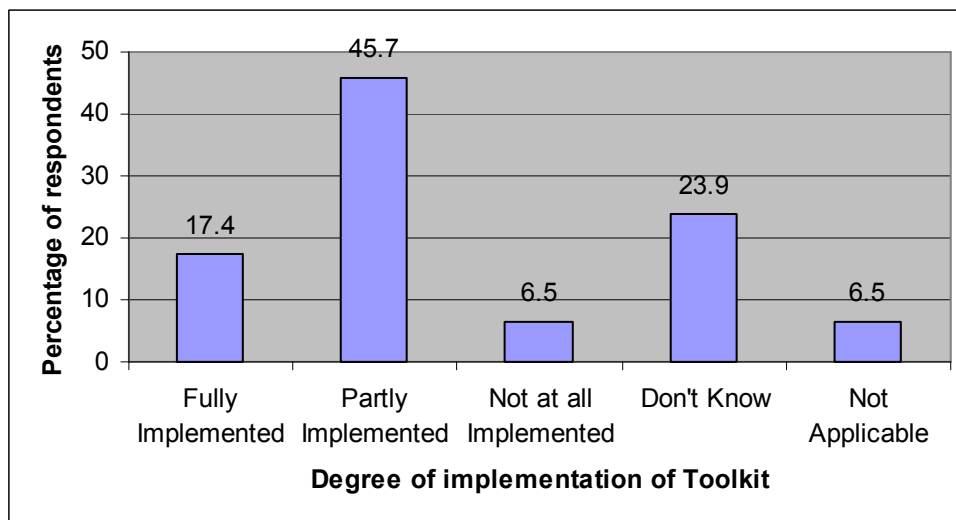
“TB is treated as a second class service. Note is only taken when there is a crisis e.g. outbreak or workload is so high it is unmanageable”

“The Trust has higher items on their agenda i.e. infection control targets. TB is way down the list”

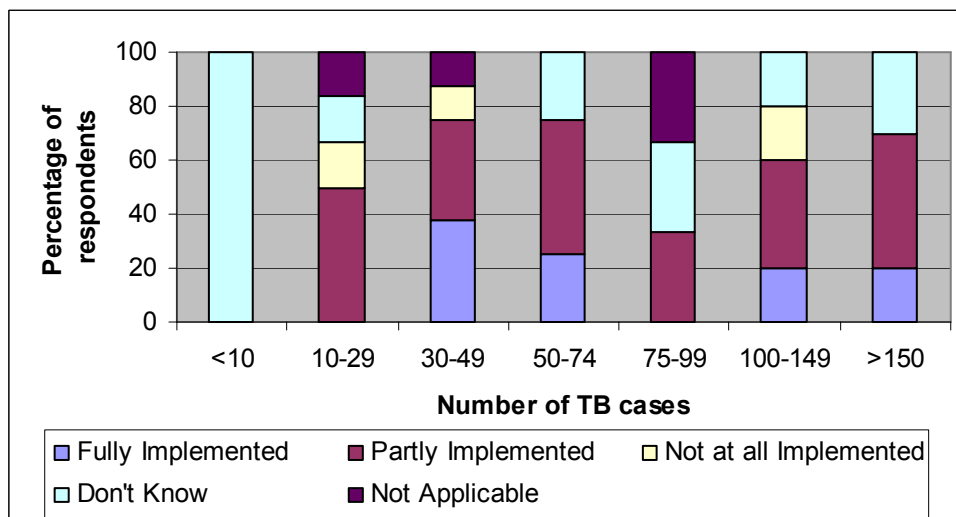
“There is a lack of understanding of complexity of issues surrounding the role. It leads to the supposition that when shortfalls occur elsewhere in the trust, nurse specialists (not only TB) can fill the gap. Particular problems within the TB service are completely washed over as a priority given that there is no ‘target’ to achieve i.e. two week wait in cancer”

“Adequate in the sense that we have a TB service but inadequate as there is no forward planning and no admin support”

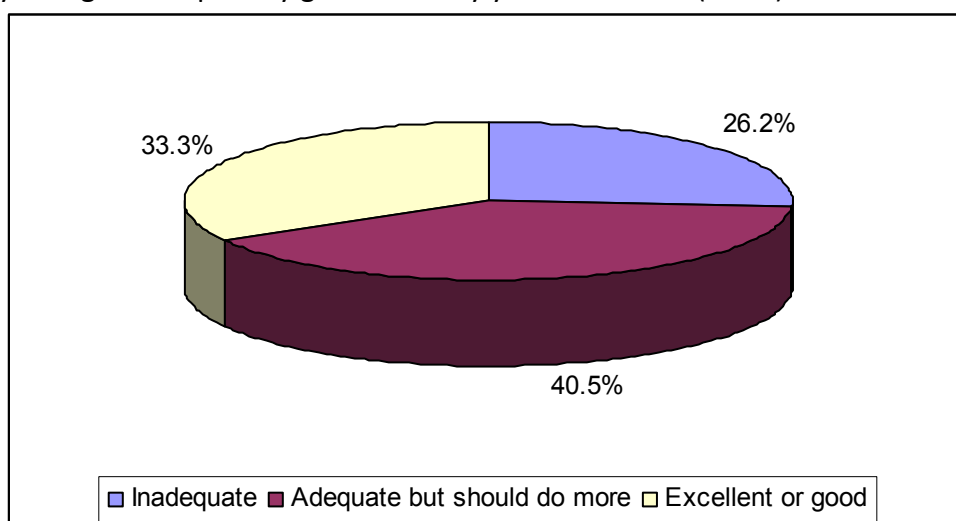
How well do you feel that the TB Commissioning Toolkit is being implemented in your area? (N=46)



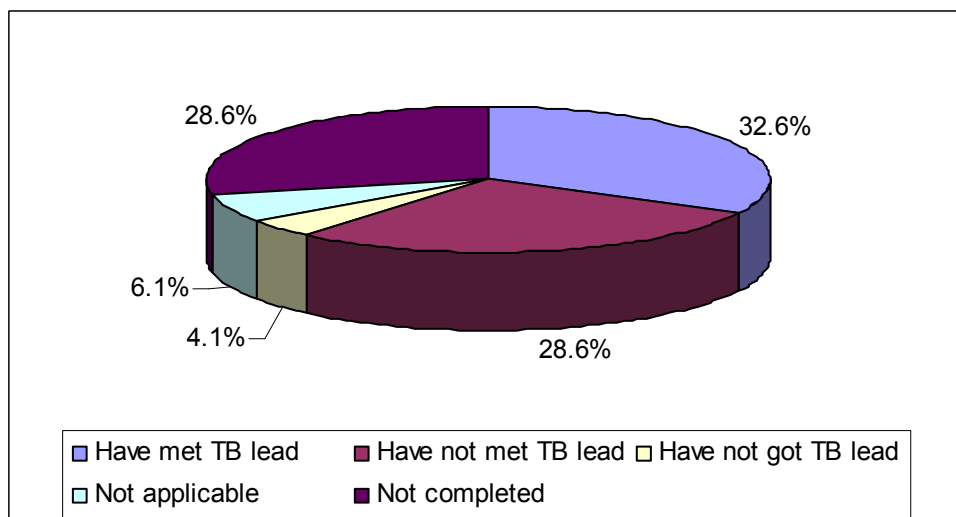
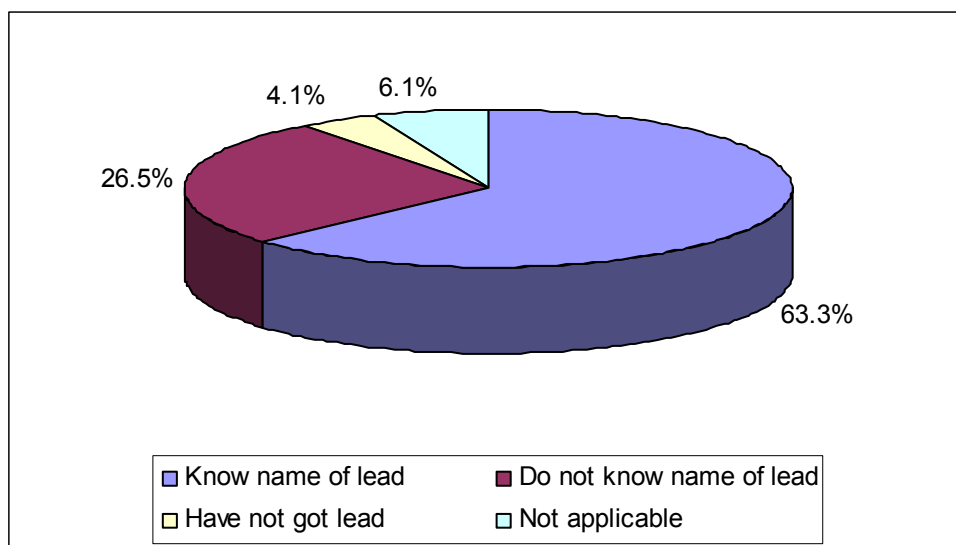
Breakdown by number of TB cases (N=38)



How do you regard the priority given to TB by your local PCT? (N=43)



Do you know the name of, and have ever met with, the TB lead in your local PCT? (N=46)

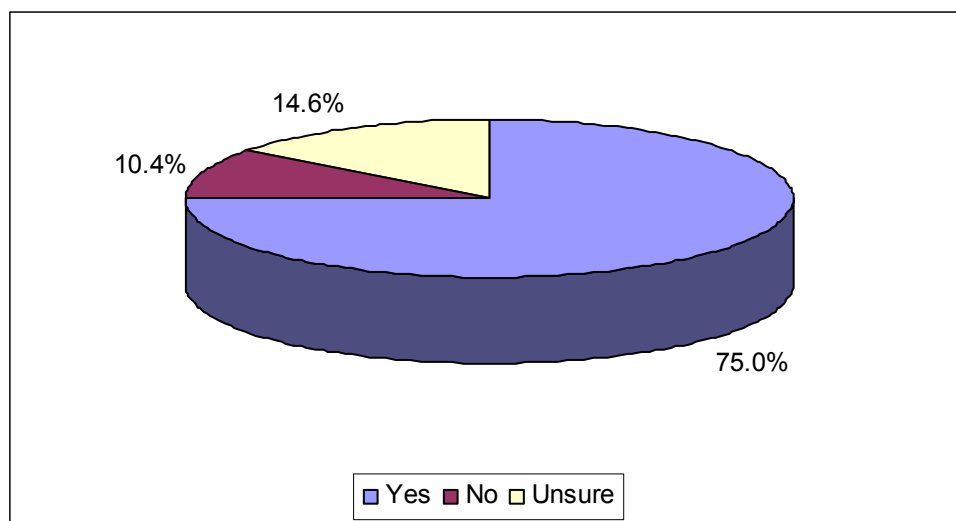


“They are not interested unless there is a problem”

“The PCT has a great number of patients with TB yet they have neglected the service by not investing. A recent report found they have existed on the good will of the nurses”

“{TB is} not a regional priority and because the PCT is divided there are different people driving the agenda”

Do you feel that TB services in your area will improve within the next 2 years? (N=48)



"We are regularly asked to provide information regarding our work justifying our time, nurses etc"

"It will only improve if the right person is involved"

"I have to remain hopeful. We are seeing more people moving to the area who have been born in high incidence countries with an increased number of cases in these groups. The local vulnerable groups are also at risk but we are yet to see a problem there. It is a time bomb. We lost our TB consultant last summer who had been very supportive and are waiting for a permanent appointment. He had initiated a gap analysis of the services when the NICE guidelines were issued but the work that came out of that has been sidelined by pressure of day to day work and no clinical lead to take it forward"

"Now that staffing levels have improved we can concentrate on moving the service to the next level"

"The PCT is working on it"

"I hope so. A business case is being put forward to request more clinic and office space"

"We have a forward thinking PCT and excellent support from our local HPA"

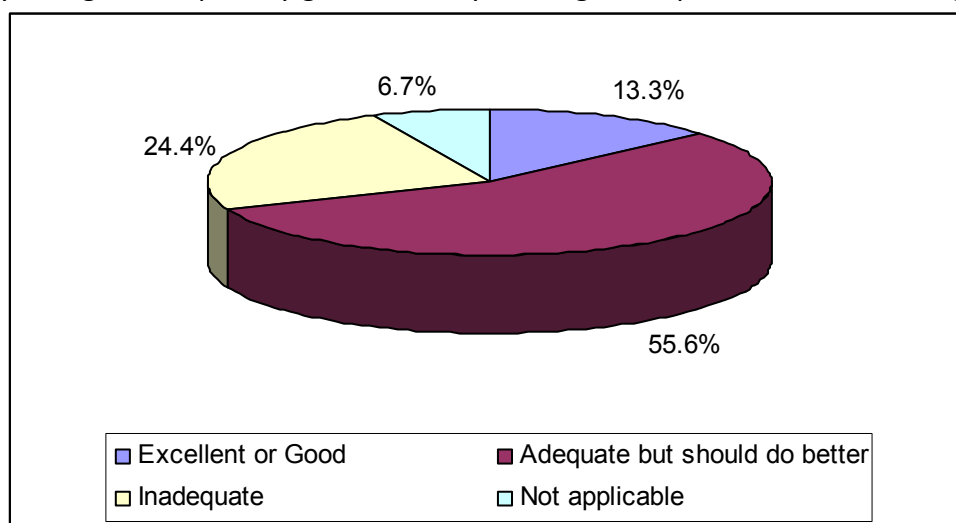
"The service is now adequately staffed and the manager keen to move service forward"

"It will only improve if current interest by the PCT and Trust results in additional input of full time admin and outreach worker"

7. The national response to TB

England

How do you regard the priority given to TB by the English Department of Health? (N=45)



“Despite the national action plan there has been no funding for services. There is no commitment to following through action plan/toolkit and ensuring PCTs comply”

“I have grave misgivings with regard to NICE guidelines relating to new entrant screening. I feel more should be done and NOT rely on individuals contacting and registering with GPs if they have a problem. Too many LTBI are missed which potentially could/will develop into TB if allowed to go undetected. Prevention rather than cure”

“There has been an improvement in recent years but services {are} still patchy. They have relied heavily on good will of staff to deliver under resourced services”

“It strikes me that the coordination of TB across the country could be much better. Every organisation seems to do different things in different ways. There is no single contact list for TB professionals or database like there is in infection control. Some organisations/TB teams do school screening/new entrant screening and new TB patient work while others only do some of this or one element which makes no sense”

Scotland

How do you regard the priority given to TB in Scotland? (N=2)

Response	No. Respondents
Adequate but should do better	1
Excellent or Good	1

Wales

How do you regard the priority given to TB in Wales? (N= 1)

Response	No. Respondents
Excellent or good	1

Comparison of 2007 and 2009 BTS survey results (refers to percentage of BTS survey respondents)

Indicator	2007 BTS result	2009 BTS result
Percentage aware of advice matching numbers of TB specialist nurses to number of TB patients	78%	75%
Percentage with nursing posts under threat or review	35%	15%
Percentage with robust data recording system	51%	48%
Percentage with specific office for TB	29%	30%
Percentage with a specifically funded TB admin/clerical post or sessions	43%	40%
Percentage with a designated TB lead	91%	93%
Mean amount of PA identified in the leads job plan	0.2 PA	0.6 PA
Percentage of Trusts that are part of a clinical network	54%	68%
Percentage with a designated TB microbiologist	56%	54%
Percentage who culture all microbiology specimens in liquid culture	90%	72%
Percentage who can readily obtain molecular probes for rifampicin resistance and species identification	92%	88%
Percentage with access to IGRA	61%	83%
Percentage with a local TB awareness raising programme	31%	35%
Percentage with a local active case finding programme	51%	33%
Percentage who have had difficulties due to the Choose and Book system	41%	41%
Percentage that see all suspected pulmonary TB cases within two weeks of first presentation to healthcare	80%	71%

Percentage with successful treatment completion rates of 86% or above	91%	89%
Percentage whose PCT specifically commissions TB services	33%	45%
Percentage that regard priority given to TB by local PCT as excellent or good	14%	21%
Percentage that regard priority given to TB by local Trust as excellent or good	28%	26%
Percentage who have seen an increase in resources for TB services since the CMOs TB Action Plan	16%	38%
Percentage who expect to see an increase in resources in the near future	14%	21%
Percentage who expect cases of TB to increase within the next five years	88%	70%
Percentage who are quite or very optimistic that TB services will improve within the next two years	37%	59%
Percentage who regard the priority given to TB by the Department of Health as satisfactory or very good	22%	52%

Discussion

TB nursing staff: Nursing staff are an essential part of a successful TB service. The BTS code of practice recommends that nursing staff should be maintained at one WTE nurse (or health visitor) per 50 TB notifications per year outside London, and 40 per year in London. Three quarters of respondents to the BTS survey were aware that there was advice on matching nursing staff with TB caseload. Knowledge was closely correlated with TB burden. While 100% of respondents from areas seeing more than 75 new TB cases a year were aware of the guidance, this figure was only 43% in very low incidence areas.

Regarding actual numbers of employed nurses, 57% of respondents to the RCN survey stated that the number of TB nurses employed by their TB service had increased since the CMO's Action Plan was launched in 2004. However, this was not uniform across incidence areas. A third of respondents in areas seeing 100 or more new cases of TB yearly have seen the number of TB nurses decline in the last 5 years. 15% of respondents to the BTS survey and 10% of respondents to the RCN survey suggested that at least one nursing post was currently under threat or review. This is significantly lower than the BTS 2007 survey which indicated that 35% of respondents had at least one nurse specialist post under threat or review.

The responses to the BTS survey highlighted the correlation between TB burden and level of TB nurse specialist input – over 75% of TB cases in areas seeing 150 or more new TB cases a year are treated by nurse specialists with sole responsibility for TB, whereas in very low burden areas no TB cases were treated by TB nurse specialists. While it is understandable that areas of low incidence may employ general respiratory nurses to treat TB patients, it is vital that skills and knowledge remain at a level where professional competence is uniform across the country. This is especially relevant, given some of the recent increases in TB in regions that were previously low incidence areas.

Recommendation 1: People who commission or fund TB services in all parts of the UK should ensure that those services are in line with the recommended 1:40/1:50 nurse to patient ratio and ensure all nursing staff treating TB in low incidence areas are adequately trained and that their skills are regularly updated

TB consultants: 22% of BTS respondents stated that they were aware of guidance matching the number of consultant PAs to the number of TB patients. This is the same result as the 2007 BTS lead survey. In his Action Plan, the CMO stated that advice should be issued on “*matching consultant ... posts to the TB burden in the population being served*”. Although 22% of respondents said that they were aware of advice, no official guidance has been produced and this is a major area of concern.

Recommendation 2: Clear guidelines should be produced to govern the workload of consultants treating TB cases. It is especially important to be clear about:

- **the optimal ratio of consultants (or consultant PAs) to TB patients in line with that of TB nurses;**
- **the optimal number of consultants that should be managing TB cases in low incidence areas; and**
- **the amount of time a TB lead should have programmed into their work plan to allow them to carry out this role**

Administrative support: Only 44% of respondents to the BTS survey stated that their TB service had a specifically funded admin or clerical post. This was generally positively associated with TB burden but some variations exist; while 85% of respondents in areas seeing between 75 and 100 new cases of TB a year had admin support, this was only 63% in areas seeing 100-150 new cases per year. This is in line with the results of the 2007 BTS survey which reported that 43% of services had admin support. This figure was higher among RCN respondents, 78% of whom stated that they had admin support. However, some respondents to the RCN survey pointed out that although someone was technically in post, they were on long term leave and the Trust had not provided cover; the result being that day-to-day the TB team is without admin support. In addition, the question did not distinguish admin support “specifically for TB” so in some cases, this may relate to general admin support.

Data systems: Only 52% of respondents to the BTS survey felt that they had a robust data recording system in place even though TB is a notifiable disease. This seems to be an issue at all levels of TB burden and is consistent with the 2007 BTS leads survey (51%). In line with the CMO’s Action Plan, the Health Protection Agency is carrying out work in this area including the launch of an updated London TB Register and roll out of an electronic data system to other areas of the country. It will be interesting to see if these systems give TB staff more confidence in the data that they collect and record.

Recommendation 3: All Trusts should have robust data systems in place to ensure that TB incidence data is reported to the Department of Health - as a notifiable infectious disease it is a statutory requirement that TB data is reported to the ‘Proper Officer’

Multidisciplinary Teams: Many TB patients have multiple medical diagnoses and suffer from complex social issues or chaotic lifestyles. 65% of respondents to the RCN survey stated that at least 10% of their TB patients had complex social needs. TB services must therefore be structured to reflect this, with both medical and social workers forming a multidisciplinary team (MDT) – the result being that each member of the team can fulfil their specialism and the team as a whole benefits. The BTS has carried out much work in establishing MDTs. The result is that 79% of respondents to the BTS survey stated that TB was managed within an MDT. However, results still show that 10% of respondents in

areas seeing more than 100 new cases of TB a year are not working within an MDT. In addition, although MDTs are in place, only 53% of RCN respondents felt that they had the necessary skills and relationships in their service to adequately deal with patients with socially complex needs. This is uniform at all levels – with services in high burden areas as ill-equipped as those in low burden areas. Many respondents called for a specialised case worker or a social worker to be employed within their service.

TB networks: The CMO’s Action Plan states that local TB clinical networks should be created. These will help to co-ordinate the local response to TB and will work across organisational boundaries. 68% of respondents to the BTS survey stated that the Trust within which they work is part of a TB network. This varies by TB burden with only a quarter of respondents in areas seeing fewer than 10 new cases of TB a year and 95% in areas with over 100 new annual cases having a network. This is however an improvement from 2007 when the BTS leads survey indicated that only 54% of Trusts were within a TB network.

Recommendation 4: All TB services should be staffed by a multi-disciplinary team (including admin support) and all Trusts, irrespective of TB burden, should be part of a local clinical network that shares best practice and advice

TB-HIV co-infection: TB-HIV co-infection is a major issue globally. As UK TB trends follow international trends, it is likely that more co-infected patients will be seen in the UK. Both the CMO’s Action Plan and TB Commissioning Toolkit suggest establishing joint services and shared management of co-infected patients ensuring adequate input by both TB and HIV specialists. However, only a third of respondents to the BTS survey stated that the care of co-infected patients was shared between respiratory and genitourinary consultants. This is a significant reduction from the 2007 BTS leads survey which indicated that 65% of co-infected patients are jointly cared for by respiratory and GU specialists. The limitation is that the BTS survey was unable to distinguish between infectious disease specialists who are able to treat both diseases. However, we must also remember that shared management includes nursing staff. This is highlighted in the RCN survey as 19% of respondents felt that their TB service did not have the necessary skills to deal with co-infected patients. This was linked to poor communication between TB and GU services and lack of access to HIV results. One RCN respondent summed it up by saying – *“We need more patient focused care rather than disease focused”*.

Paediatric TB: The CMO’s Action Plan suggested *“developing services for children in line with the Children’s National Service Framework but integrated with the TB service as a whole”*. In addition, the TB Commissioning Toolkit states that TB staff should ensure shared management with paediatric colleagues for children with TB. However, only 12% of respondents to the BTS survey stated that the care of paediatric TB patients was shared with respiratory physicians and paediatricians. This is a halving of the result of the 2007 BTS leads survey which showed that a quarter of paediatric patients were treated under shared care. Again it is necessary to stress that the survey could not distinguish paediatricians specialising in TB or infectious diseases. BUT again we must

remember that shared care includes TB nursing staff and effective communication. The RCN survey showed that 32% of respondents did not feel that their TB service had the necessary skills to deal with paediatric patients. Respondents' comments were often around the lack of shared care at consultant level with many calling for the establishment of a joint TB (or infectious disease)/paediatrician role.

Recommendation 5: Current guidelines on the shared care of paediatric and TB-HIV co-infected patients must be implemented and all TB, HIV and paediatric staff should receive the necessary training to facilitate this

Drug resistant TB: One of the aims of the CMO's Action Plan is to maintain low levels of drug resistance (particularly MDR-TB) with the wanted outcome of less than 7% of new TB cases being drug resistant. The TB Commissioning Toolkit recommends that MDR-TB patients are treated at specialist TB centres and that referral to these centres occurs where clinicians do not have the experience of treating drug resistance. However, 16% of respondents to the BTS survey stated that any consultant involved in TB care could treat MDR-TB patients. RCN respondents commented on the need for information sharing and an advice service for MDR-TB management. The BTS has established such a service (in line with recommendations of the TB Commissioning Toolkit) and is actively encouraging TB staff to maximise their use of the advice network.

Recommendation 6: All MDR-TB patients should be treated at designated specialist centres with effective communication between TB staff via the MDR-TB Advice Network

Awareness raising: Awareness among high risk groups was highlighted as a major area of activity in the CMO's Action Plan. In addition, the TB Commissioning Toolkit states that *"it is recommended that service providers aim to improve awareness of TB among the public, the professions and local authority agencies"*. However, only 35% of respondents to the BTS survey indicated that there was a local programme aimed at raising awareness of TB in high risk areas. This is associated with TB burden; only 14% of respondents in areas seeing fewer than 10 new cases a year have a local programme. This is consistent with the 2007 BTS survey that found only 31% of respondents had a local awareness programme. We congratulate the Department of Health in England for taking the initiative and funding the UK Charity TB Alert to assist PCTs to formulate effective awareness activities and work directly with affected communities. It is hoped that, through their engagement with local service providers and affected communities, local programmes will be implemented and levels of local awareness will rise.

Recommendation 7: Trusts should ensure that effective local awareness raising programmes are run in all high risk communities

TB in low incidence areas: Throughout the results of both the BTS and RCN surveys it was clear that TB policy and recommendations are often not being implemented in

areas of low TB burden, while in some cases TB staff are not even aware that these policies exist. For instance, only 43% of respondents to the BTS survey in very low burden areas were aware of advice matching TB nursing levels to TB patients. The TB Commissioning Toolkit states that areas with low incidence of TB should be putting in place effective TB control and prevention services. Knowing guidance on nursing levels may help these areas to fulfil this task. In addition, local TB clinical networks are essential in low incidence areas for the sharing of information and support in managing TB cases. However, only a quarter of respondents in areas seeing fewer than 10 new cases of TB a year are part of a network. In addition, even though the emphasis should be on prevention in these areas, only 14% of low burden areas have a local TB awareness raising programme in place.

Recommendation 8: Adequate information and support should be given to areas with low incidence of TB to enable effective prevention and control services to be put in place and sufficiently resourced

Microbiology: Only 54% of respondents to the BTS survey had access to a designated microbiologist who deals with TB. This is consistent with the 2007 BTS survey (56%).

The CMO's Action Plan, NICE guidance and the TB Commissioning Toolkit state that liquid culture should be used for all TB microbiology specimens. 72% of respondents to the BTS survey highlighted that this was in use. This is a decrease from the 2007 BTS survey which found that 90% of respondents had access to liquid culture. 88% of respondents to the current BTS survey had access to molecular probes for rifampicin resistance and species identification (again a reduction from the 2007 BTS survey results of 92% with access).

Interferon Gamma testing (IGRA) is an important new technology in use for the diagnosis of latent TB. The BTS survey indicated that 83% of respondents had access to IGRA with access levels very similar across disease burden areas. This is a major improvement on the 2007 BTS survey which found that only 39% had access to IGRA. However, only 65% of respondents with access to IGRA had the necessary funding to use them as required. Such a powerful tool in the fight against TB is important and thus funding should be made available to ensure IGRA testing can be used whenever needed.

Recommendation 9: New technologies should not only be accessible but also adequately funded to allow optimum benefit to TB patients

BCG: Since the change in BCG policy in 2005, BCG vaccinations are now given to neonates in high incidence areas, contacts of TB patients, new entrants and, in some high incidence areas, school children as part of a catch up scheme. Although NICE guidelines provide recommendations on who should and shouldn't be given BCG, it does not make clear where responsibility lies for giving these vaccinations. The result is that routine BCG programme delivery varies from area to area. 68% of RCN respondents stated that TB nurses were responsible for giving BCGs but that school nurses,

immunisation nurses and health visitors were also involved to a lesser extent. In order to save the time of highly trained specialist TB nurses, 69% of respondents to the RCN survey argued that BCG should be given by someone who is not a TB nurse. One respondent stated *“It {BCG} is a complete waste of specialist time (but a good money spinner for the acute trust)”*.

Recommendation 10: Clear guidelines should be produced indicating where responsibility lies for giving routine BCGs and the impact that this has on TB nurse specialist work load

TB Commissioning Toolkit: It has now been exactly two years since the TB Commissioning Toolkit was launched in England. It is therefore disappointing that only 17% of respondents to the RCN survey stated that it had been fully implemented in their area. In addition, a quarter of respondents were unaware of the toolkit or the extent to which it had been implemented. A major part of the toolkit is the need for a TB lead within the PCT who ensures that the local TB response is coordinated and appropriate. Only 63% of respondents to the RCN survey knew the name of their local PCT lead and only 32% had ever met with the lead.

Providing a TB service as part of a discrete Service Level Agreement (SLA) is another key aspect of the TB Commissioning Toolkit as it allows predictable and sustainable funding for TB services. 45% of respondents to the BTS survey stated that TB services in their area were specifically commissioned by their local PCT. This is variable with only 31% of respondents in areas seeing fewer than 30 new cases of TB a year and 55% in areas seeing more than 100 new cases having a discrete TB SLA. Nevertheless this is an improvement on the 2007 BTS survey results which showed only 33% had specifically funded TB services.

Recommendation 11: PCTs should specifically commission TB services and ensure that the TB Commissioning Toolkit is fully implemented

TB standards: In his TB Action Plan, the CMO states that *“all TB patients with suspected pulmonary TB should be seen by the TB team within two weeks of first presentation to health care”*. When asked in the BTS survey, 88% of respondents stated that this occurred. This was variable across disease burden areas and is an improvement on the 2007 BTS survey that found only 80% of patients see the TB team within two weeks of referral.

Both the World Health Organisation and the CMO assert that treatment completion rates should be at least 85%. 89% of BTS respondents suggested that more than 86% of their TB patients successfully complete treatment. This is a slight reduction on the 2007 BTS survey result of 92%.

Local priority: In the forward to the TB Commissioning Toolkit, Sir Liam Donaldson states that *“It is critical that PCTs engage with the current challenge if we are to contain the return of a disease we once had under control. To this end, we strongly recommend*

that all PCTs plan for TB service provision.” A quarter of respondents to the both BTS and RCN surveys regarded the priority given to TB by their local PCT as inadequate. A further 56% of respondents to the BTS survey and 41% of respondents to the RCN survey stated that the response was adequate but that it should be better. In 2007, the BTS leads survey found that 20% of respondents reported that the response of their local PCT was inadequate and a further 65% deemed it adequate but should be better.

Similarly, 18% of respondents to the BTS survey and 19% of respondents to the RCN survey regarded the priority given to TB by their Secondary Care Trust as inadequate. A further 56% of BTS respondents and 47% of RCN respondents stated that the response was adequate but that it should be better. In the 2007 BTS survey, 19% of respondents reported that the response was inadequate and another 54% considered it inadequate but should be better.

Since the CMO's Action Plan was launched in 2004, 62% of respondents to the BTS survey have seen funding for TB stay the same or reduce, even though TB rates have been increasing. In addition, 73% stated that they were not expecting to see a change in resources for TB services. A third of respondents to the BTS survey in areas of over 150 new cases a year were expecting a decrease in resources for TB. In 2007, the BTS survey found that 84% of funding had stayed the same or reduced, 71% were expecting no change in resources and 14% a decrease.

Recommendation 12: National Standards on TB should be agreed and implemented to allow local PCTs and service providers to be held to account on the services they commission and provide for TB patients

National priority: 43% of respondents to the BTS survey gave the Department of Health in England a rating of poor or very poor in the priority they give to TB. The 2007 BTS survey saw 71% poor or very poor so this is a marked improvement. This reflects the increased priority the Department of Health has given TB, with much service improvement attributable to Department of Health funded projects such as Restructuring TB Services - the multi-disciplinary team project undertaken by BTS.

56% of respondents to the RCN survey believed that the priority given by the Department of Health in England was adequate but that they should do better. They highlighted the lack of funding that was released with central policy on TB and the lack of accountability at local and national level.

The future: 59% of BTS respondents were optimistic that TB services will have improved within two years even though 70% of respondents expect an increase in TB cases.

The CMO's Action Plan exclaimed that public health efforts need to be better organised:

“There is much good practice but TB control is not consistent across the country and activities are not well co-ordinated”

This statement is as true today as it was nearly five years ago when the Action Plan was released. Since the Action Plan we have had NICE guidelines and the TB Commissioning Toolkit – the policy and guidance is written but, as the surveys have shown, it is not always being put into practice. Some Trusts and PCTs are responding well and have established model services but others have not. Effective TB services are a public health good as TB is not confined to the patient alone. It is not enough that healthcare organisations are talking about TB; they must now start to put this rhetoric into solid, sustainable actions and save the nearly 500 patients that are lost each year to TB.