

Tuberculosis - Identifying and managing tuberculosis among hard-to-reach groups

Expert testimony papers presented to the NICE PDG, 2010 to 2011

- Expert paper 1: 'Service user perspectives' anonymous.
- Expert paper 2: 'Socio-cultural factors influencing an understanding of tuberculosis within the Somali community in Sheffield' by Mubarak Ismail, Sheffield Hallam University.
- Expert paper 3: 'Screening international migrants for infection' by Anne Tunbridge, Royal Hallamshire Hospital, Sheffield.
- Expert paper 4: 'Primary care tuberculosis survey 2010' by Surinder Tamne, Health Protection Agency.
- Expert paper 5: 'Cohort review in practice' by Jacqui White, Royal Free Hospital.
- Expert paper 6: 'Hard to reach patients with, or at risk of, tuberculosis in immigration detention' by Frank Arnold, Medical Justice.
- Expert paper 7: 'Tuberculosis control, specifically among hard to reach groups in Rotterdam' by Rob van Hest, Municipal Public Health Service Rotterdam-Rijnmond.
- Expert paper 8: 'Tuberculosis case management – lessons from New York City (NYC)' by Sara Hemming, Royal Free Hospital.
- Expert paper 9: 'Health MOT in a hostel' by Stephen Davies, King George's Hostel, London.
- Expert paper 10: 'Managing a tuberculosis service in prison' by Sue Yates, Royal Free Hospital.
- Expert paper 11: 'The importance of housing homeless people with tuberculosis' by Sue Collinson, Homerton University Hospital.
- Expert Paper 12: 'Leicester model' by Philip Monk, Health Protection Agency.
- Expert paper 13: 'Strategies for managing tuberculosis in the chaotic community of rural Warwickshire' by Debbie Crisp, NHS Warwickshire.
- Expert paper 14: 'Tuberculosis in Scotland' by Oliver Blatchford, NHS Scotland.
- Expert paper 15: 'London Find & Treat' by Alistair Story and Joe Hall, Find and Treat London.
- Expert paper 16: 'Brief overview of prisons' by Claire Smith, Claire Smith Consultancy.
- Expert paper 17: 'Nurse led triage' by Malcolm Cocksedge, Bart's and the London NHS Trust.
- Expert paper 18: 'Nurse led service – Sandwell' by Jacqueline Nation and Imtiaz Ahmed, Sandwell General Hospital.
- Expert paper 19: 'Model of care – London tuberculosis plan' by Nick Relph, London TB Commissioning Board.
- Expert paper 20: 'What about the children?' by Fran Child, Royal Manchester Children's Hospital.
- Expert paper 21: 'Screening for tuberculosis and HIV in primary care' by Chris Griffiths, Barts and the London School of Medicine and Dentistry.
- Expert paper 22: 'The truth about tuberculosis awareness and advocacy programme' by Elias Phiri, TB Alert.

EP1: Service user perspective

Testimony presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by three service users

Manchester, 20 October 2010

1 Introduction

The PDG met for the first time on the 20th of October 2010 in NICE's Manchester offices. At this meeting, the group heard evidence from a review of the evidence around user experiences of relevant services. To supplement this review, the PDG also heard expert testimony from three service users – individuals who had been diagnosed with and treated for TB, and who had met the groups criteria for “hard to reach” at the time of their diagnosis and treatment¹.

2 The expert witnesses

Three services users provided testimony to the group. All three had been successfully treated for TB, following testing and diagnosis from a specialist service. All three now work (to different extents) as peer educators for a range of similar services. They were identified through the PDG and through the PDG recruitment process.

They were asked to talk about their experiences in relation to a set of questions, which mirrored those used to guide the evidence review. The questions were:

1. What were your personal circumstances at the time of your TB diagnosis?
2. What factors stopped you or made it difficult for your TB infection to be diagnosed?
3. What helped you get your TB diagnosed?
4. What difficulties did you face in accessing treatment?
5. What helped you to complete treatment?
6. What hindered you from completing treatment?
7. Thinking again about questions 1- 6, which do you think are the most important barriers and the most useful initiatives to help people to access services for the service users you work with?
8. What do you know about these issues from other service users?

Given the potentially sensitive and personal nature of some of the information, the decision was taken to keep all testimony anonymous.

3 This document

This document provides a summary of the testimony given to the PDG at the meeting, and the ensuing discussion. Following the summary are two appendices – written submissions to the PDG from two of the service users. The testimony will be used by the PDG to inform and develop the recommendations and guidance, in accordance with the NICE public health process and methods manuals².

4 Summary of expert testimony and discussion

The three service users took it in turn to talk about each of the questions set. One of the service users chaired the session. PDG members were invited to ask questions as each point was considered by the service users, and there was a wider group discussion at the end of the session.

What were your personal circumstances at the time of your TB diagnosis?

All three experts reported that their lives had been chaotic and difficult at the time of diagnosis. One had been an alcoholic and street drinker, one was homeless and using a range of illegal substances (sleeping at times in crack houses), and the third was homeless and using alcohol and substances.

What factors stopped you or made it difficult for your TB infection to be diagnosed?

The service users reported that a range of factors acted as barriers to their diagnosis.

One thought he simply had asthma, and so did not initially act on symptoms. Another reported that she had been hospitalised prior to her diagnosis with pneumonia, but had experienced prejudice from healthcare staff (e.g. comments about “you people wasting our resources”) and as a consequence, when discharged from hospital she had resolved not to ever go back. Finally, the third service user cited a range of lifestyle factors that meant he did not acknowledge or act on symptoms – a chaotic lifestyle, substance use (and sourcing supplies of these substances), and lack of a permanent address all contributed for the late diagnosis of his TB. TB symptoms (cough, weight loss, night sweats) had also been initially interpreted by all three service users as symptoms of alcohol or substance misuse. Two of the service users noted that they had received or heard of significant variation in attitudes and services depending on which part of the city you happened to be in.

What helped you get your TB diagnosed?

The three service users reached their TB diagnosis through different routes. One was diagnosed following a period in hospital (with pneumonia) – however, she had been treated by the same hospital two weeks previously for pneumonia. Another was diagnosed after several visits to primary and secondary care with TB symptoms – the first doctor he saw diagnoses a chest infection. He later had a chest x-ray but was not told the results – the results would be sent to his GP. However, he collapsed at the hostel he was staying at before he saw the GP again, and was admitted into hospital as an emergency. A key point made by two of the service users was the role that the knowledge and awareness of health and care professionals played in being diagnosed – their TB was picked up when the people they were living with or who were caring for them were aware of the symptoms of TB.

What difficulties did you face in accessing treatment?

There were a range of barriers reported on accessing diagnosis and treatment.

Barriers to diagnosis that were discussed included not recognising or being aware of symptoms, healthcare professionals not recognising symptoms, misinterpreting symptoms as something else, not having time or inclination to seek help, fear about the diagnosis (one service user reported that “to be told you have TB is like having the plague”) and perceptions about (and experience of) the attitudes of healthcare staff.

Barriers to treatment that were reported and discussed included the effects of the medication itself (*“I didn’t want to take the tablets at the start either – they made me feel awful”* – Service user C); and individual variation among practitioners and clinicians:

“Yes it varies by individuals. I had a rib problem and my Dr wouldn’t give me pain relief ‘cos he knew my history. They wouldn’t give me the x-ray results they wanted to send them back to my doctor and I remembered the last time – it really depends on the individual.”

What helped you to complete treatment?

Support for the duration of treatment was one issue reported by the service users as helpful. Service user A commented:

“I was one of the lucky ones with support. I was in a hostel. I had support from the hostel, from XX, from an outreach worker and a nurse. This physical and mental support helped with clearing up the TB all together.”

DOT (Directly Observed Therapy) also helped service user A to complete their treatment:

“DOT helped me complete my treatment. I think you should lock someone up that doesn’t take the tablets. You are a danger to yourself and everyone else.... I didn’t really get taking the tablets every day until DOT – I believe in it for certain types of treatment. I was having tablets and methadone together too.”

Service user B commented that having access to a specific TB nurse, including having the nurse’s mobile phone number, made a real difference.

Service user C spoke about support they had received from a clinic physician, who monitored them throughout treatment, visited them in hospital, and chased them up when needed. They also noted that enforcement had played a part:

“I missed one day in 15m and they threatened to section me. I took my methadone and pills at the hospital. Old bill would come round and make me take the pills.”

What hindered you from completing treatment?

Barriers to ongoing treatment that were mentioned included psychological barriers – user A, who had multi-drug-resistant TB and ended up on treatment for two and a half years, commented:

“I didn’t really get taking the tablets every day until DOT – I believe in it for certain types of treatment. I was having tablets and methadone together too.”

Other barriers included the physical effects of taking the medication (“they made me feel awful”). However, as all 3 service users had successfully completed treatment, they focused more on the things that had helped them.

Thinking again about questions 1- 6, which do you think are the most important barriers and the most useful initiatives to help people to access services for the service users you work with?

Service user B mentioned the other help they had received as a result of undergoing treatment for TB and said it made a real difference:

“It was the other help too – all the people I knew before that were street drinkers and my family weren’t talking to me and I could actually talk to (my TB nurse) and it was through her I got involved with find and treat I was with her and on treatment a year – so it did turn my life around.”

Other factors mentioned mirror those reported above: Support and access to that support; stable environment, supervision, and also incentives which were mentioned by service users A and C:

“Emotional and mental support. And the incentive payment.”

“The doctor was the only person who would visit me and she gave me a tenner too.”

What do you know about these issues from other service users?

Again, the issues discussed here are covered in the sections above.

Appendix 1: Written testimony from service user A

What were your personal circumstances at the time you were diagnosed?

Initially my circumstances were the hard to reach. So my next point is to iterate what category of hard to reach. So we have in our information pack that hard to reach groups have been defined as prisoners, problem drug and alcohol users, homeless or people in temporary accommodation, asylum seekers, refugees, recent immigrants, travellers and sex workers, but children were not defined for which I feel children from poor backgrounds etc etc should be considered.

Anyway I feel it requisite that we pinpoint the category of hard to reach in order to define and analyse our subjects.

So my personal circumstances were drug and homeless rough sleeper for 1 year, sleeping in crack houses. It is important to define and understand individual client's circumstances because that current situation will define their behaviour in terms of their healing especially without guidance.

What factors stopped you or made it difficult for your infection to be diagnosed?

What stopped and made it difficult to be diagnosed was primarily a chaotic lifestyle I was once asked why it took me so long to be diagnosed I found it hard to answer. After reflection, I remembered that I did not claim benefits and so I had to go hunting i.e. look for funds to purchase my narcotics instead of going to A and E. My TB was so advanced that I was down 2.6 stone and was on medication for 2.5 years.

What helped you to get your TB diagnosed?

Support was the main factor also I was living in a hostel the staff were concerned and they urged me to get a check up and some of them knew some of the symptoms. Finally I had cold sweats the paramedics were called staff went on hands and knees begging me to go to hospital still I refused until I had to go on oxygen.

What difficulties did you face accessing treatment?

Well I was one of the lucky ones – as I said before support but not just physical support – “here is your tablets eat them and everything will be ok” – emotional and mental support. With TB especially advanced TB all levels of the person have to be treated physical emotional and mental. All these factors contribute to our convalescence. Moreover I had three agencies dealing with my healing process.

What helped you complete your treatment?

Again support – I had three agencies – the Margarete centre, social work, outreach and nurse plus hostel staff plus DOT.

Because the support that I had which was quite unique, the things that hindered me were my own personal demand, lack of stability, lack of consistency, lack of knowledge about the dangers of not conforming with treatment, life stage and all the pastimes that are associated with drugs.

Thinking again about questions 1-6, which do you think are the most important barriers and the most useful initiatives to help people to access services?

Most important barriers: Chaotic lifestyle, ignorance of the dangers of TB, ignorance of symptoms, not conforming to treatment, misconception of how it spreads creates a barrier, people who have no way of accessing benefits.

Important initiatives: TB awareness, DOT for all hard to reach people, necessity of taking medication, and the fact that TB can come back aggressively and even be resistant.

Appendix 2: Written testimony from service user B

In around 2005-6, my life was very different to the life I lead now. I was an alcoholic, and a street drinker, through my 20's and 30's and found myself one night rushed to hospital with pneumonia. I had had various stints in hospital, and on this occasion the nurse while trying to find a vein to put me on a drip made various comments like “you people wasting our resources”.

I left that night thinking that the next time I went to hospital, it would have to be on a stretcher.

Two days later I was picked off the street by ambulance, unable to breathe. I was taken and kept in hospital, where I was found to have fluid on my lungs and patches in and around my heart. I was transferred to the heart hospital where I underwent a thoracotomy.

The day I left, I had a sputum sample taken, was given a big bag of tablets, and as I do say, discharged to the nearest off-license. They told me there was a chance I could have TB, and to start taking the tablets they gave me, till someone would contact me. Two weeks later a TB nurse took over and confirmed I had TB. I was put on about 10-12 tablets per day for six months. In this time the nurse was my rock and supported me. I was told the dangers of drinking and effects on my liver. I haven't drunk since.

At the end of 6 months, I was resistant to one of the TB tablets and so ended up on treatment for another 6 months, still seeing the nurse every other week. The symptoms were similar to my drinking, so it wasn't much different. I was vomiting from drink, sweating, diarrhoea, weight loss. The symptoms of TB are so similar.

Due to the fact I wasn't in close contact with my family, they never knew I had TB and they never needed to get tested. I thought TB was a thing of the past but four years on I find it to be very real and out on our streets. I have turned my life around from such a horrible illness, and that nightmare, and now can share and relate my experience into something positive.

Endnotes

- 1 "Hard to reach" groups are defined in the scope for this guidance as "children, young people and adults whose social circumstances or lifestyle, or those of their parents or carers, make it difficult to recognise the clinical onset of tuberculosis; access diagnostic and treatment services; self-administer treatment (or, in the case of children and young people, have treatment administered by a parent or carer) and attend regular appointments for clinical follow-up". The scope can be seen in full at <http://www.nice.org.uk/nicemedia/live/11978/48499/48499.pdf>
- 2 The NICE public health process and methods guides can be found here: [http://www.nice.org.uk/aboutnice/howwework/developingnicepublichealthguidance/publichealthguidanceprocessandmethodguides/public health guidance process and method guides.jsp](http://www.nice.org.uk/aboutnice/howwework/developingnicepublichealthguidance/publichealthguidanceprocessandmethodguides/public%20health%20guidance%20process%20and%20method%20guides.jsp)

EP2: Socio-cultural factors influencing an understanding of tuberculosis within the Somali community in Sheffield

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Mubarak Ismail (Sheffield Hallam University)

Manchester, 20 October 2010

The TB study sought to gain insight into the socio-cultural influences on how TB is perceived within the Somali community and how these perspectives affect the prevention, diagnosis and treatment of the disease. The study also gained an understanding of healthcare practitioners' perceptions of TB among the Somali community and their experiences of providing TB services to Somalis.

A community participatory research approach was used which involved Somali community researchers and healthcare practitioners working in partnership with university researchers to design and conduct the research with the support of a community-based project advisory group. Data were collected by means of interviews and focus groups with Somali community leaders, patients suffering from TB, members of the wider Somali community, healthcare practitioners providing TB services and primary care practitioners.

The findings identified a general awareness of TB among the Somali community in terms of the signs and symptoms of pulmonary TB, its treatment and prognosis. There was less understanding of non-pulmonary TB among Somali participants and some healthcare practitioners. Many Somalis lacked detailed understanding of how the disease was spread. Established community beliefs, for example that TB was a hereditary disease, or that it could be acquired by sharing eating utensils proved difficult for healthcare practitioners to challenge.

Somali people spoke of how TB was perceived to be stigmatised within the Somali community. Whereas a person suffering from TB would generally share the diagnosis with their immediate family, concerns remained about the possibility of being ostracised by members of the wider community if knowledge of the disease became more widespread. This carried implications for

contact tracing. However, attitudes towards TB were changing. Community leaders emphasised that as people became more knowledgeable about TB then the stigma would diminish but it was acknowledged that deeply held beliefs about the causes and consequences of TB would take some time to change.

A number of barriers that hinder Somali people accessing TB services were identified. Some, like stigma, are embedded in cultural beliefs or are linked to socio-cultural activities such as chewing Khat.¹ A lack of trust and confidence in healthcare providers, especially some GPs arose from the protracted time it often took to diagnose TB. Healthcare practitioners lack of understanding of the Somali community and language barriers also hindered the uptake of primary care services.

Several avenues through which culturally appropriate strategies targeted at minimising the spread of the disease, ensuring timely diagnosis and effective management of TB were identified. These are captured in the recommendations arising from the study, which identify the need for a more proactive approach to raising awareness of TB within the Somali community and among primary care practitioners. Interpretations of TB are culturally bound and in order for TB services the better to meet the needs of the Somali community there is a need to develop greater awareness among healthcare practitioners of the needs of Somali patients and overcome linguistic barriers through improved access to interpreting services, especially in primary care.

Endnotes

- 1 "Khat" (also "Jaad" or "Qaat") is a green-leafed shrub that has been chewed for centuries by people who live in the Horn of Africa (Somalia, Ethiopia, Kenya) and Arabian Peninsula mainly (Yemen). Khat is not illegal to use, buy or sell in Britain.

EP3: Screening international migrants for infection

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Anne Tunbridge (Royal Hallamshire Hospital, Sheffield)

Manchester, 23 November 2010

Introduction

Why screen immigrants?

The United Nations predicts the UK population will include 6.5 million international migrants in 2010.¹ 70% of cases of tuberculosis (TB) and HIV in 2004 were non-UK born individuals, with similarly high rates of hepatitis B (HBV) and C (HCV).^{2,3} Disease transmission, morbidity and mortality is reduced in all these infections by early detection.³⁻⁵ The UK government has identified enhanced screening of sexually transmitted infections (STI) as a priority.⁶

The only current national screening programme for infection is for TB, through the Port of Entry scheme or at induction centres. However, many people bypass these channels, and rapid dispersal of asylum seekers and refugees can prevent appropriate follow up.^{7,8}

A hard to reach group

Asylum seekers and refugees come from diverse backgrounds, have complex psychosocial needs and often have poor English language skills. They are frequently moved at short notice by the UK Borders Agency (UKBA – previously NASS). In addition, failed asylum seekers lose any form of support, are not allowed to work and many are of no fixed abode.

The Mulberry practice

The Mulberry NHS General Practice was set up in September 2002 for newly dispersed refugees and asylum seekers to the city of Sheffield. This novel practice provides a nurse-led primary care service, focusing specifically on the needs of this diverse and challenging group. The practice

serves 1400 patients, which is approximately 2/3 of the asylum seekers in Sheffield. Due to the hyper-mobility of asylum seekers, the practice has an average yearly turnover of 39%.

Previous TB screening

Until 2005 the practice screened all new registrants for latent TB using Heaf tests, referring those with a reactive test to the local chest clinic. However, 35% of referred patients failed to attend. In 2005, the change from Heaf to Mantoux testing caused significant challenges in ensuring return for accurate test reading. Following a 6 month period in which only 7/120 tests were completed, Mantoux testing was discontinued.

Infection screening programme

All adult (aged over 16) patients seen in the new patient clinic were offered a blood test to screen for HIV, HBV, HCV and syphilis. TB screening was performed on blood samples, using the Quantiferon Gold In Tube assay (QFT-GIT), a new interferon gamma release assay (IGRA).⁹

Those testing positive for infections other than TB were referred to appropriate hospital departments. A regular infectious diseases (ID) outreach clinic, led by an ID Consultant (AJT), was established at the practice to assess patients with positive QFT-GIT results. Chest X-ray and blood profiles were obtained prior to clinical review; any suspicion of active TB prompted immediate referral to secondary care. Those diagnosed with latent TB were offered prophylaxis as per National Institute for Health and Clinical Excellence (NICE) guidelines.¹⁰ Patients were monitored during anti-tuberculosis prophylaxis by a general practitioner.

Results of programme audit January – December 2008

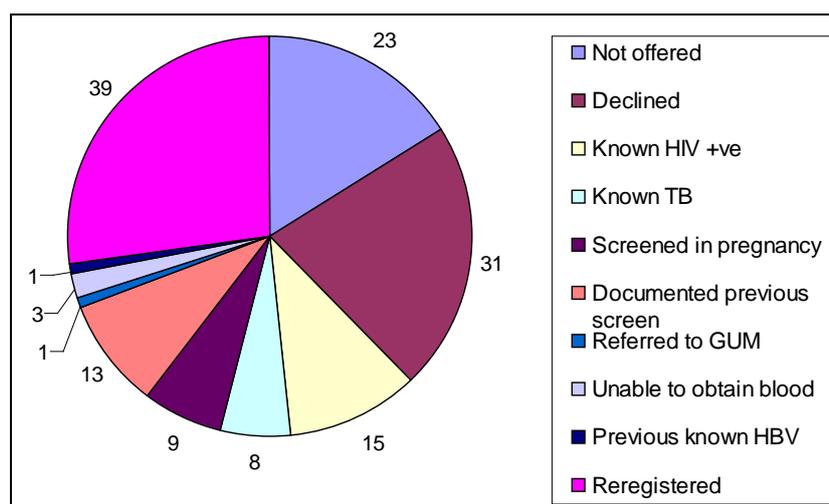
Patient demographics

In 2008, 376 patients from 41 different countries registered with the practice. 74% were male, with a median age of 30 years. 70% had been in the UK for more than 12 months; only 15% had documentation of any previous screening. 39 of 376 “new registrants” had actually previously attended the practice; they were not screened as they did not attend the dedicated new patient clinic. Thus 337 patients were eligible for screening.

Uptake of screening

70% of eligible new registrants (236/337) were screened for some or all of the designated infections. Reasons for not screening are shown in Figure 1. Two of those not offered screening were tested at later date and treated for latent TB.

Figure 1 – Results of TB screening



Results for the 220 of 236 patients who were screened for TB infection using the QFT-GIT are indicated in Figure 2. 56/220 (25.4%) had a positive result. One case of active TB was diagnosed of the five patients referred with abnormal chest X-rays. Of the 38 diagnosed with latent TB, 25 were offered anti-tuberculosis prophylaxis: 22 completed the full course. One patient who had a negative screen developed pulmonary TB 6 months later after contact with a known infectious case.

Cost comparison

The actual costs associated with this programme were compared with the theoretical costs of two alternative screening pathways (Table 1). Additional practice costs included nursing time and the price of the QFT-GIT; other assays were covered by a pre-existing block contract. Calculations were made from the Primary Care Trust perspective, thus secondary care costs include all tests and prescriptions.

Figure 2 – Results for patients screened using the QFT-GIT

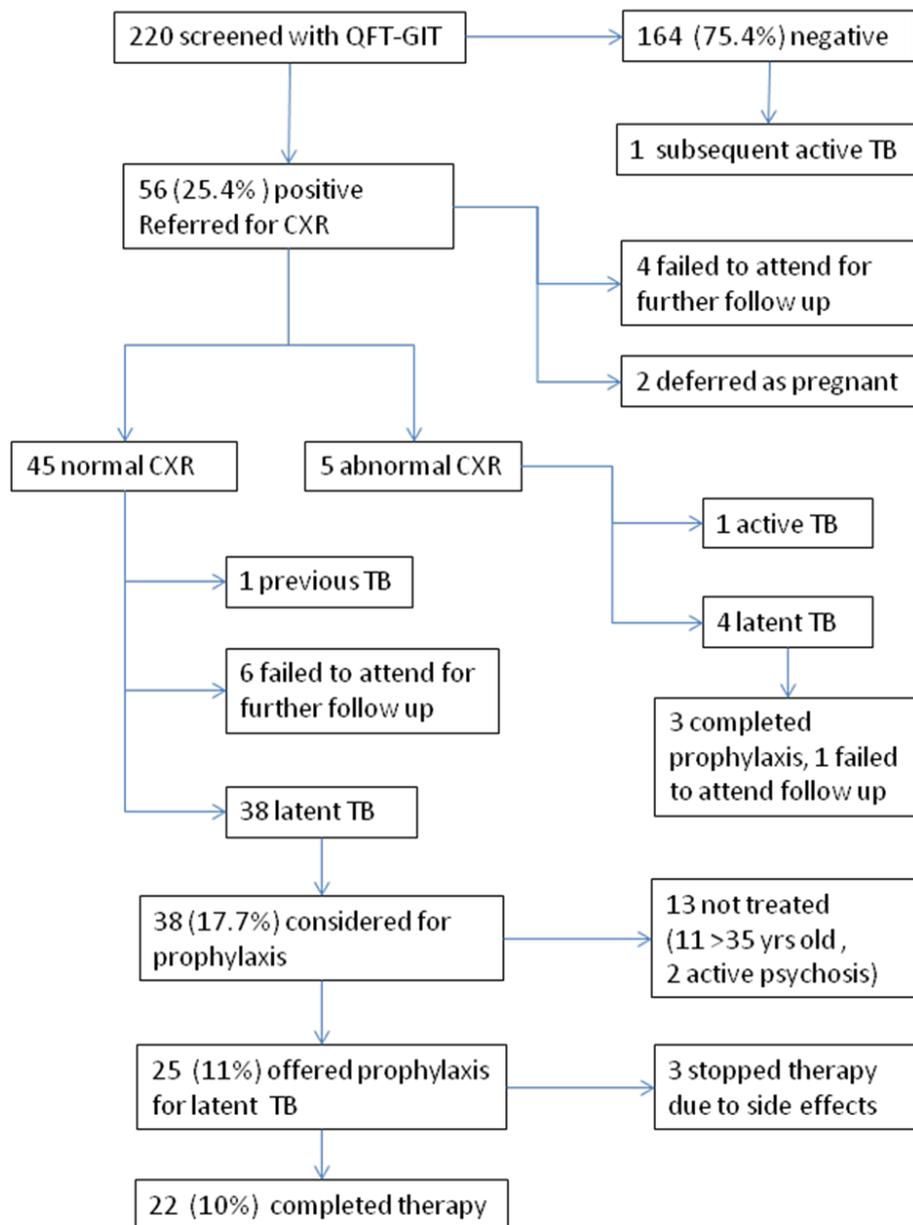


Table 1 – Actual costs compared to theoretical costs of two alternative screening pathways

	Actual cost of screening in primary care	Model 1: screening in secondary care	Model 2: TB screening primary care, GUM in secondary care
Total per patient	£64	£542	£251
Total for patient cohort (n=236)	£15,182	£127,912	£59,236

The comparative costs of latent TB treatment are shown in Table 2.

Table 2 – Comparative costs of latent TB treatment

	Mulberry Practice	Chest clinic	Screen in primary care, treat in chest clinic
Screening costs	£64	£321	£64
Review at in-house ID clinic	£60	N/A	N/A
2 further visits	£15 x 2	£104 x 2	£104 x 2
Drug costs	£66	N/A	N/A
Total cost per patient	£220	£542	£272

Discussion

Screening asylum seekers and refugees in primary care, as one point of access to all healthcare services, is cheaper and more accessible than multiple referrals to secondary care providers. Highly experienced staff are able to manage patients' other medical and social issues in addition to implementing screening. This scheme satisfies the UK national screening committee's criteria for appraising the viability, effectiveness and appropriateness of a screening programme.¹¹

The use of an IGRA test for TB screening offered clear operational advantages over skin testing, and is increasingly recognised as a cost-effective method for screening high risk populations such as asylum seekers.¹²⁻¹⁴ IGRAs are more specific than, and as least as sensitive as, Mantoux testing in detecting TB infection in this context.¹⁵ In this cohort, 25% had evidence of latent TB infection, of whom an estimated 10-20% will develop active TB during their lifetime.¹⁶ Since chemoprophylaxis reduces this risk by approximately two thirds, we assume that 1-2 cases of active TB were prevented as a result of this programme in 2008. In addition a case of asymptomatic pulmonary TB was detected early enough to prevent secondary cases.

National guidance states that TB should be managed by clinicians with specialist knowledge and experience of TB.¹⁷ For this practice a community-based consultant-led outreach clinic is feasible. However an appropriate option for practices with a lower prevalence of TB infection could be a referral pathway to the local chest clinic.

We believe that a screening programme based in primary care is the most efficient and cost-effective way to screen large numbers of individuals from populations with a high infection risk. Early diagnosis and treatment of these diseases offers clear benefit both to the individual and to the wider community through reduced transmission. An expansion of this programme has the potential for a significant impact on TB incidence in the UK.

Endnotes

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- 4 British HIV Association (BHIVA): *UK National Guidelines for HIV Testing 2008*. avail at: <http://www.bhiva.org/HIVTesting2008.aspx>
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http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1214808549127

EP4: Primary care tuberculosis survey 2010

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Surinder Tamne (Health Protection Agency, London)

Manchester, 22 March 2011

Introduction

Below are summarised responses to a survey (undertaken to determine the training and development needs of GPs and Practice Nurses on the prevention and care of TB in England), specifically the responses to Question 13 of the survey:

“What would help you diagnose TB earlier and aid in management of TB patients in your care?”

Comments from the free text box are presented.

We received 54% comments from the GPs (109/202), 38% (68/180) from Practice Nurses and 51% (23/45) from Nurse Practitioners.

General practitioners

The majority of the comments related to awareness raising, diagnosis and referral pathways. Interestingly GPs not only provided information on what they required but provided examples of good practice in their area.

a. *Raising awareness about TB among the GPs:*

“Awareness and feedback on incidence, how many we should expect to be diagnosing and what to look out for beyond the obvious signs and symptoms” summed up the information submitted in this

section. "Heightened awareness amongst health professionals" emphasised the need for raising awareness among this group.

Suggestions of methods by which this may be achieved included: "Regular updates or perhaps TB specialist nurse visiting practice for in house educational meeting"; "On site presentations by Chest Physicians" "Updates and talks"; and "local TB nurse talk". Good practice was highlighted as "We have just had a talk from specialist nurse and he was wonderful", Sheffield. "This helps to keep the awareness alive and the possibility of TB at the back of your mind."

b. Prompts while seeing the patients:

The GPs requested more "information on presenting symptoms of those found to have TB in UK". While diagnosing the patients any prompt would be helpful including "yellow flag system in my clinical computer system"; "alerted to the possibility of TB" and "I would have to remember to consider it in the differential diagnosis". The information requirement is "Clinical awareness of what is needed and in this practice hopefully always a diagnostic possibility".

c. Diagnostic Testing:

"Easy access to TB diagnostic testing" as well as updates on the most rapid, up to date and most appropriate diagnostic test for their patients was flagged up as a need. GPs requested "awareness of the diagnosis and ability to get tests done to confirm it".

d. Referral Pathways:

This section highlighted the need for clear referral pathways and good links between primary and secondary care. "Close links to the local services is considered crucial to diagnosis"; "More dialogue primary and secondary care Services available locally – their referral criteria" and "easy access to chest clinics if in doubt". Clarity of the referral pathway was emphasised by some GPs "clear idea of how and where to refer patients". "Easy access pathways locally and flow charts"

Good practice in their local areas was highlighted: "My experience in Southampton with the TB patients I have had over the years was actually good. Good communication with sec. Care."; and "we have a marvellous TB clinic next door to our practice & so getting our patients assessed / getting advice is very easy!"

e. At risk groups

GPs identified needing to: "Be aware of its various modes of presentation and which groups are particularly at risk, be up to date with best practice management."; "Remembering to consider it in higher risk patients" ; "Understanding of risk factors and relevance today" and "Update on clinical hx, signs and at risk groups."

f. Immigrant Screening

The requirement is for clear guidelines on *who* needs to be tested and *how* they need to be tested within the local settings. Also requests for results to be recorded and easily available to appropriate healthcare professionals. “At new patient checks many patients arriving from abroad, need to know when and who to x-ray”; “Better information about which immigrants have been screened (in the GP notes) so we know if they have not been screened” and “Greater awareness of at risk immigrant groups, access to appropriate investigations”.

Best practice example: “We are a specialised GP practice for refugees and asylum seekers in Coventry. We screen all our newly registered patients for TB using Mantoux testing and investigate/refer further according to protocol. We also administer BCG as necessary.”

g. Treatment

GPs had some specific information requirement about TB treatment as “Chest X-rays invariably take 2 weeks to be reported upon, that is such a long time as to be a disincentive for GPs to request X-rays at all. Too quick a report might encourage some GPs to over X-ray, exposing those with just a few days cough to unnecessary investigation.”; “information about TB clinics ...guidance of what to do if normal chest X-ray but still suspect TB”; “I know hospitals do quantiferon - but in some GP surgeries we are still doing AAFB - why?” and “Summary notes to have at hand”.

h. Epidemiology and Surveillance

All comments received emphasised the need to receive information about local TB incidence: “Local data on incidence and at-risk groups.”; “Alerts re local cases/increase in incidence”; and “Awareness of number of TB cases in our area”. “Feedback on current prevalence rates (locally and nationally) and how many would be expected to have TB in our practice.” “Who to screen and how.” “Who to test for on the basis of symptoms, and how.” “Knowing the difference between expected and actual prevalence in my practice and comparison with rates across locality.”

Good practice was highlighted as “Reasonably happy as we are - we have a population that is very healthy - mainly professional white British and very aware of health issues - we would see so much less TB than in other areas of Hammersmith and Fulham”.

i. Management of TB

There were few responses in this category, possibly because management of the patient was seen as the responsibility of secondary care. “Management is largely in the hands of the chest clinics in hospital.”; “We have dedicated TB nurse within the PCT who deals with all suspected cases, so we are all rather deskilled”.

j. See very few cases

A few GPs responded that they have very few cases in their clinic; “Considering it in my differential diagnosis and is my feeling that it is very rare in my patient group in fact true?? To my knowledge I have only been involved with 2 patients with TB in the past 15 years -not diagnosed by me” and “I have only had one active patient treated by the hospital and one contact patient in the last 5 years, so I can only hope that I am not missing cases!”

Practice nurses

Practice nurses gave fewer responses than GPs with most comments on how to raise awareness within their professional community in terms of identifying patients with symptoms of TB and clearly defined referral pathways in their settings. Raising awareness among the patient groups was also important to this group. Practice Nurses differed from GPs in making many more requests for training on clinical aspects of TB.

a. Raising awareness among practice nurses

Practice nurses requested up to date information and education in recognising TB: “A greater understanding of the disease and future developments/plans as to the future of TB vaccination”; “Efficient screening and knowledge of the disease”; “Education and training to better understand disease and risk factors”; and “Education and training to better understand disease and risk factors”.

b. Raising awareness among patients

The responses of practice nurses reflected that they have a responsibility to raise awareness among their patients for diagnosis of TB as well as compliance to treatment: “Educating patients with signs and symptoms so one can come during an early onset”; “Teaching on signs and symptoms, and then being able to tell pts what the process may be from initiating treatment to infection control and discharge.” and “understanding symptoms understanding treatment and meds to support/encourage adherence”.

c. Diagnosis of TB

Practice nurses wanted clear information on signs and symptoms of TB with a view to determining when they should refer a patient to a GP: “Be aware of alerting signs/symptoms for referral to GP”; “Just be aware of signs and symptoms so know when to refer to GP”; “Knowing the early signs and symptoms, diagnosis process and treatment.” and “Signs and symptoms those most at risk.”

d. Referrals and epidemiology

Practice nurses noted that more information about treatment and management pathway would be useful in the form of flow charts and would find it useful to be sent information about local incidents: “Being up to date with signs and symptoms and also to know of current outbreaks. Also knowing the correct referral pathway.”; “Diagnosis and treatment pathway in form of flow chart”; “Standardised protocol or flow chart “; and “More information locally, posters etc, regular emails regarding recent new cases”.

e. Training for Practice Nurses:

Practice nurses highlighted the fact that some have never had any formal training on TB and would welcome regular training: “Never had any training regarding TB, any information would be a great help”; “regular training in management of TB”; and “More up to date training”.

Nurse practitioners

a. Knowledge of symptoms and treatment

Nurse practitioners requested information on knowing what signs and symptoms alert diagnosis of TB along with information on treatment and side-effects of medication; “To feel up-to-date and knowledgeable about this area would make me generally more aware of it when managing patient consultations, particularly in at risk groups.”; “Updates on treatment would be useful, and interactions with other medications.”; “Clear pathways including regular updates of treatment” ; “Having up to date knowledge on prevalence in area, be fully aware of all signs & symptoms + when to suspect if symptoms are not clear cut.”

b. Patient support

Nurse practitioners were keen to raise patient awareness and support patients during course of their treatment; “Consistency, seeing one practitioner “Increase awareness of TB.”; “Support patients in their treatment plans to aid better concordance with treatment. Agree support that suits patient’s lifestyle.”; “Provide bullet point information in other languages for patients to enhance their knowledge base.

c. Training

Nurse Practitioners have requested some clinical training to be able to participate in the diagnosis of TB “Being able to perform Mantoux test myself.”; “Refresher training, statistical information.” and “provide more training”.

EP5: Cohort Review in Practice

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Jacqui White (Royal Free Hospital, London)

Manchester, 13 May 2011

Cohort review was first used in Tanzania, by Dr Karel Styblo, and was implemented in New York during the 1990s as a process to review treatment completion among TB cases. Along with the introduction of other control measures, cohort review contributed to an increase in completion rates, and a reduction in reported TB cases (particularly multi-drug resistant (MDR) TB).¹

Cohort review is a systematic quarterly appraisal of the management of every case of TB for treatment completion and contact investigation. The “cohort” is a group of cases counted over a specific time, usually three months. The case manager presents the cases for which they are responsible, giving the opportunity to bring up problems and difficulties in case management, reveal service strengths and weaknesses, and staff training needs.

The North Central London TB Service introduced cohort review in June 2010, as a means of systematically reviewing the case management and contact investigation of every case of TB notified in the sector.

We evaluated the impact of North Central London TB Service introducing cohort review after four cohort reviews had been carried out over the year to March 2011, with the aim of informing the future development and roll out to TB services nationally.

Key outcomes related to case management and contact tracing for a group of patients notified and treated prior to implementation of cohort review were compared with those notified post implementation.

Treatment completion rates improved after the introduction of cohort review, as did the offer of, and uptake of HIV testing among TB cases. The proportion of infectious TB cases who had at least

one contact identified increased substantially, and an increase was also observed in the proportion with five or more contacts identified.

Staff feedback on their experience of cohort review was also reviewed through an online questionnaire. A very positive response was obtained, with clear support for the process. Staff reported cohort review highlighted gaps and training needs within their service, and led to changes to their way of working.

Certain key TB service issues arose through cohort review, particularly around DOT provision and contact tracing. These are likely to reflect the experiences of TB services across London and elsewhere.

In conclusion, cohort review led to improved patient and contact outcomes in North Central London TB Service, and is an important tool in ensuring accountability for patient care relevant to TB services across the UK.²

Endnotes

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EP6: Hard to reach patients with, or at risk of, tuberculosis in immigration detention

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Frank Arnold (Medical Justice, London)

Manchester, 13 May 2011

The following observations are based on 5+ years personal experience of visiting and examining at least 500 people in 9 of the 11 UK immigration detention centres, and is supplemented by the findings of at least three medical colleagues.

Approximately 27,000 people are held in UK immigration detention centres annually for indeterminate periods ranging from days to years.¹ They are simultaneously at high risk of having or disseminating or contracting TB, a truly captive “audience”, and hard to reach for several reasons.

These problems arise largely from the trajectories of these patients' journeys. The ten commonest countries of origin of asylum seekers² and (probably other) detainees are all countries with very high incidence of tuberculosis (and HIV). Many have experienced imprisonment there, in very overcrowded conditions wholly suited to disease transmission and/or in extended close confinement with others while travelling to the UK. Those not detained on arrival will have spent weeks or years in conditions of severe poverty in this country, or may have been imprisoned before transfer to detention. Co-morbidities and drug misuse, including self medication for PTSD, are also common in this population. Linguistic and cultural differences inevitably increase the difficulties of providing good care to these patients.

While in detention, there is a potential for disease transmission between room mates (especially if the latter are HIV +ve or otherwise immuno-compromised) other detainees, staff and visitors. There have been numerous failures of timely diagnoses of communicable TB among detainees,

including at least two documented deaths in recent years³, and failures of contact tracing within and between detention centres, medically unplanned transfer being common.

Approximately half of all detainees are released into the community², some are returned to their countries of origin with limited supplies of medication and lack of plans regarding their means of obtaining the rest of required treatment. These factors constitute potential public health risks whether in the UK, or among the populations of countries to whom they are returned. In those released, problems are exacerbated by confusion at hospital level about whether “failed” asylum seekers are entitled to NHS care (even for conditions which are a potential risk to the public health).

Improvements will require attention to arrangements for governance and the nature of clinician-patient relations in detention. At present, healthcare in the 11 detention centres in the UK is the responsibility of the UK Borders Agency (UK BA - an arm of the Home Office) which outsources its responsibilities to or via private contractors in 8 privately run centres and PCTs in the rest. Although it was recommended by the Prisons Inspectorate that the commissioning of healthcare in detention be transferred from UK BA to the DoH⁴ and this appears to have been partially accepted by UKBA, visible progress has been slight to date. It may be relevant that the equivalent transfer of prison healthcare has resulted in major improvements.

Each detention centre appears to have developed its own written policies for TB management⁵, which agree neither with each other nor with national guidance from NICE (where there is overlap), so far without visible success. The total absence of any policy in at least one centre was noted by the Prisons Inspectorate in early 2010.⁶ Although the Department of Health agreed to improve and standardise guidance in mid 2010, their efforts have so far met with little success.

Relations between detainees and the clinicians responsible for them in detention are often strained by distrust from the former and dual loyalties on the part of the latter.⁷ Detainees frequently perceive the clinicians responsible for their care as putting the interests of their ultimate employers, UK BA, the authority responsible for their incarceration. When taken to hospital for investigation and initiation of treatment, male detainees are usually kept in restraint and denied privacy, sometimes despite strenuous objections from clinical staff. Detainees are frequently not permitted to keep hospital appointments for “administrative” and cost reasons.⁸ When set in the context of delayed diagnosis in a highly stressed patient and ill-informed perceptions of risk among other detainees and staff this becomes a recipe for mutual distrust which is incompatible with adequate clinical practice.

These factors pose high risks for patient incomprehension, non-compliance, delayed diagnosis and failure of contact tracing.

Specific recommendations:

- 1) The Department of Health should be offered and accept formal responsibility for the commissioning and governance of healthcare in immigration detention centres.
- 2) Guidance for the investigation of suspected TB, management of diagnosed cases, contact tracing and follow-up should be standardised across the detention estate and should comply with standard NICE guidance.
- 3) Notes from previous clinical encounters in the community and previous prisons and detention centres should accompany detainees or be sought within 24 hours. Difficulties in doing so should be logged and audited.
- 4) HIV+ and other immuno-suppressed patients should not be subjected to administrative and therefore discretionary detention. If patients with proven TB can not be offered adequate care, they should not be subjected to detention either, to protect their health and that of detainees and staff.
- 5) Detention centre doctors' are empowered to use of "medical hold" and other relevant clinical interventions to prevent continuing detention, transfer or removal of detainees under circumstances that would pose a clinical risk to their patients or others. The use of these powers should be audited and analysed, and used more extensively, for sound medical reasons. This may require a culture shift and protection for clinicians who may be required to inconvenience their employers' plans for detention and movements of detainees..
- 6) The causes of missed hospital appointments should be audited and addressed. The presumption should be that detainees are not restrained and permitted privacy and confidentiality during hospital appointments.

Endnotes

- 1 In practice the numbers held in detention centres at any one time are held to about 2700 by bed capacity. An additional 500-700 people are held under administrative powers (eg discretionary, not sentence).
- 2 UK BA data. On their website, cited in my PowerPoint slides (as supplied).
- 3 Report of Steven Shaw, the Prisons and Probation Ombudsman for one case (online), patient-anonymised personal communications between FWA and the then Immigration Minister available on request from me.
- 4 Supplied to me by UK BA and available to NICE on request.
- 5 HMIP report on Healthcare at Yarl's Wood 2006.
- 6 HMIP report on Harmondsworth 2010. Letter to FWA from UK BA available on request from me.
- 7 As confirmed by UK BA in a letter to FWA, available on request from me.
- 8 The costs of transport and guards are borne by UK BA. The costs following from the missed appointment are presumably borne by the hospitals.

EP7: Tuberculosis control, specifically among hard to reach groups, in Rotterdam

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Rob van Hest (Municipal Public Health Service Rotterdam-Rijnmond)

Manchester, 8 June 2011

Introduction

The changing epidemiology of tuberculosis (TB) across the EU is characterised by a concentration of disease in certain sub-groups of the metropolitan population. Large cities harbour a disproportionate number of socially excluded inhabitants belonging to risk groups for TB, specifically immigrants, homeless persons, illicit drug users, alcoholics, street dwellers with psychiatric co-morbidities and persons with a history of imprisonment. These risk factors commonly overlap and are especially over-represented in prison populations.¹ The prevention and control of TB among these risk groups is complicated by delayed diagnosis, onward transmission and poor treatment adherence leading to the development of drug resistant forms of TB. A recent international study on risk factors for TB transmission in low-incidence countries highlighted homelessness, injection drug use and alcohol abuse as the main factors associated with uncontrolled TB transmission in the community.² In 2002 and 2003 one out of six of all notified TB patients was homeless, illicit drug user or an (ex)prisoner in Rotterdam, the Netherlands, and London, United Kingdom, respectively.³⁻⁵

Many homeless persons and illicit drug users have poor access to health care or delay seeking help early and their lifestyle may also camouflage TB-related symptoms (“hard-to-find” groups). Therefore TB in homeless persons and illicit drug users more frequently progresses to advanced and infectious forms of disease before it is diagnosed. Homeless people and illicit drug users commonly share confined air spaces in poorly ventilated congregate settings such as hostels, day centres, methadone dispensing posts or safe drug consumption rooms. The problem is further compounded because their general health is poor, compromising immunity to TB. Collectively

these factors exacerbate one another resulting in major outbreaks of TB involving homeless persons and illicit drug users. Such outbreaks have been documented in many (future) EU member states where extremely high rates of TB have been consistently demonstrated (500 and 1500 TB patients per 100,000 persons).¹⁻¹⁶

Once diagnosed, poor adherence with treatment and loss to follow-up care is common among homeless persons and illicit drug users (“hard-to-treat” groups). Poor treatment adherence leads to further transmission and is the cause of drug resistant strains of the disease. The concentration of TB in socially excluded and vulnerable groups also effects staff working with these groups and the general population.^{5,6}

TB control model

TB is not only a medical disease but has strong social roots and components.¹⁷ The evidence to date suggests it is not possible to control TB among hard-to-reach and hard-to-treat vulnerable populations through a solely biomedical hospital based approach. Hospital services must be complemented by public health community based TB initiatives tailored to the needs of vulnerable groups. The success of the Rotterdam TB control model provides an example where TB is controlled through close collaboration between hospital based services and public health TB clinics in the community. These services are complimented by two former TB sanatoria, now acting as tertiary in-patient TB treatment centres for patients with complex medical or psycho-social needs who provide a daily telephone expert advice service to TB professionals and medical specialists in the field. The hospitals concentrate on in-patient and clinical care while the public health TB clinics work through a network of local health and social care agencies to provide contact tracing; out-patient care, DOT and preventive treatment; and active case finding among vulnerable populations with appropriate targeted interventions, such as mobile digital X-ray screening.⁵ The public health clinics also have epidemiological responsibilities for surveillance and outbreak investigation. In the Netherlands TB control physicians, specialist nurses (who often also act as social workers) and practice assistants work under one roof and the TB clinic is a one-stop-(TB)-shop for all basic diagnostic (tuberculin skin testing, chest-X-ray and smear microscopy) and treatment facilities. This model is especially beneficial to socially excluded groups who often require intense case management and DOT to prevent lost to follow-up. The Netherlands has one of the lowest TB rates in the EU despite a significant concentration of homeless people and illicit drug users and in the major cities of Amsterdam and Rotterdam where vulnerable groups are periodically and successfully screened.^{3,4,18} In Rotterdam 90% of the hard-to-treat TB cases identified in a mobile X-ray screening programme completed their treatment.⁵ DNA fingerprinting data supported interruption of TB transmission among vulnerable groups in Rotterdam. The number of hard-to-

reach ad hard-to-treat TB cases in Rotterdam have reduced from approximately 30 per year in the beginning of this century to an average of 3-5 case per year in recent years.

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EP8: Tuberculosis case management – lessons from New York City (NYC)

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Sara Hemming (Royal Free Hospital, London)

Manchester, 6 July 2011

This talk was about a visit to the New York Bureau of TB Control (BTBC) in 2009. Money was obtained from the Royal College of Nursing Travel Award to visit NYC with four other colleagues from London to learn from their successful TB management.

Background

In the 1980's and early 1990's NYC had a major TB epidemic with a peak of 3811 cases in 1992. The increase in cases was highly associated with social deprivation, drug use and homelessness with high levels of HIV co-infection and MDR disease (441 in 1992).¹

Through major reinvestment, restructuring of TB services and implementation of standardised guidelines, NYC managed to control the epidemic with a 59% decrease in cases between 1992 and 1998. The control has been sustained, in 2010 711 TB cases were verified (82% decrease since 1992), and there was a 98% decrease in MDR cases between 1992 and 2009 (411 to 8 cases).²

What made it work?

The success was achieved broadly by improved infection control in institutional settings, improved service coordination and improved adherence through expanded community DOT programmes. Below are some of the NYC key components relevant and applicable to improving TB control in a UK/London context. For further information, see the complete NYC guidelines.³

Political commitment

Political commitment to combat the epidemic was a key factor in their success. In NYC, the TB budget increased from \$4 to \$40 million, the number of staff increased from 144 in 1998 to over 600 in 1994.⁴

The current budget for TB services in NYC is \$18 million. Forty percent of this comes from federal government, which provides a strategic overview and guidance on issues that are considered public health activities such as DOT, contact tracing and outbreak investigations. The NYC State government provides 15% of the budget and the rest (45%) comes from local NYC government and includes commissioning of clinical TB services.⁵

Public Health Focus and Pan-city commissioning

In the US, the overall responsibility for TB control and prevention rests with the public health system.⁶ The Bureau of TB Control is part of the New York City Department of Health and Mental Hygiene (DOHMH). The DOHMH is responsible for all public health activities in New York, and is headed by a Commissioner appointed by the Mayor of New York, who in turn is directly elected by the people of the City to run City government. This includes formulating strategies for public health, and promulgating public health laws (as long as these are in line with federal laws). The work is overseen by a Board of Health consisting of members from industry, public health, the community and clergy who approve all new public health laws, who ensure new public health laws are sound.

DOHMH has several divisions, each led by a Deputy Commissioner, that oversee broad public health areas. The Bureau of TB Control is part of the Division of Infectious Diseases, and is responsible for TB management and control all across the city.⁷

The focus on public health underpins all work within the Bureau, including extensive identification and treatment of latent TB infection, and identification and reporting of all individuals with suspected as well as confirmed tuberculosis.⁸ The responsibility for successful treatment in is assigned to the provider (e.g. the public health programme), not to the patient, and every treatment plan should stress the use of DOT and a commitment to collaborate – *“by coordinating care with local public health authorities, physicians are more likely to achieve better outcomes for their patients”*.⁹

Coordinated service provision and case management

The BTBC provides a pan-city service from 9 community centres. TB care and management is provided in the same way across the city, using pan-city guidelines and standards of care adhered to by all staff.¹⁰ Components and definitions for case management are well defined, and include expected time frames and interventions such as for non-adherence, treatment interruptions, treatment outcomes, contact tracing etc. Each patient is assigned a case manager and multidisciplinary team (MDT) that address both the medical and psychosocial needs of patients, and include suspected and confirmed TB cases as well as their contacts.^{11,12} The first interview with patients should take place within 1-3 (preferably 1) working day for all AFB smear positive cases and within 3 days for all culture positive cases . A contact index of at least 5 is required for all respiratory cases. Most of the care is provided in the community and cases discussed at weekly MDT meetings. Roles and responsibilities are clearly defined between the PHAs, TB nurses, treating doctors (private), and Bureau doctors. This ensures timely identification of problems and management according to TB guidelines. The case manager is the primary person responsible for coordination of patient care, and can be either a TB nurse or a Public Health Adviser (PHA). More than 50% of the BTBC staff are PHA's. PHA's are non-clinical staff with a minimum of a batchelors degree.¹³

Flexible DOT – “field” DOT

DOT was introduced as the standard of care in 1993.¹⁴ Guidelines provide an extensive list of who should be particularly encouraged, including people that are homeless, substance misusers, have MDR disease or a history of previous TB treatment to name a few.¹⁵ Almost all DOT is provided through flexible community outreach, mainly by PHA's, who visit patients at their home, workplace, hostel, park bench, “crack den” or wherever is convenient for the patient.^{16,17} The number of patients eligible, and the number receiving DOT is monitored through the Cohort Review. For example, all patients with MDR TB, and at least 80% of patients with sputum smear-positive respiratory samples should be on DOT. In 2008, 76% of all eligible patients were receiving DOT.¹⁸

Training & Education

To tackle the epidemic from an educational aspect, the BTBC provided an extensive training programme for staff, allied services and risk groups for TB. All staff in hospital as well as community clinics received TB training, and a booklet with information, precautions and referral process for TB. All new BTBC staff also receive formal training in interview techniques to elicit optimal information about social settings and habits, contacts etc as well as information about TB.^{19,20}

The use of non-clinical staff (PHA's) enables recruitment from a wider range of backgrounds, including from groups with an increased risk of TB, and awareness raising within these groups. Outreach training was also provided to risk groups such as in homeless hostels, including in some instances specific outreach TB clinics.

Accountability and performance management

BTBC and other TB providers' adherence to the TB guidelines and standards of care are monitored through quarterly Cohort Review of TB cases, where each case is presented and measured against the set standards. TB Cases from all five NYC districts are reviewed using the same criteria, enabling monitoring of progress within each district as well as comparison on a pan-city basis. All TB cases are reviewed by the same Medical Reviewer to ensure impartiality and equity in the cohort review process.

In short – recommendations for the UK:

- 1) Political commitment and leadership
- 2) Pan-city/large area commissioning
- 3) TB should be the responsibility of Public Health
- 4) Report number of suspected cases
- 5) Case management from point of referral (especially for hard to reach groups)
- 6) Standardised guidelines
- 7) Formalise training about TB guidelines and case management
- 8) Expand use of flexible community DOT
- 9) Expand use and extend roles of non-clinical staff
- 10) Accountability in case management cohort review

Endnotes

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EP9: Health MOT in a hostel

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Stephen Davies (King George's Hostel, London)

Manchester, 23 November 2010

King George's is a 68 bed hostel in Westminster, London. We provide support and accommodation for 68 men who have slept rough in the borough, targeting those who continue to use drugs and who present challenges to other services. People will stay for up to 2 years before moving on. The service is funded by a local authority Supporting People grant and housing benefit.

We have a team of 15 support staff who have a keywork relationship with 3 – 8 clients. Formal or professional qualifications are not a requirement for support workers.

The client group is:

- Over 90% white British
- Vast majority have been in prison within the last 10 years.
- Average age is 40 with around 10% under 30 and 10% over 50.
- Average over 15 years of problematic drug use.
- Average over 10 years of sleeping rough and accessing homeless services.
- Currently there are 3 clients at King George's who we know have been treated for TB in the last 8 years, all are native born white British poly injecting drug users.
- Rates of hepatitis C are 55 – 60% with 5 people completing treatment in the last year.
- 4 clients are known to be HIV+ all co infected with hepatitis C.
- All clients who have previously had TB have tested positive for hepatitis C.
- 1 person is hepatitis C+, HIV+ and has previously been treated for TB.

The London Delivery Board set up in 2009 to end rough sleeping by the end of 2012 identified 205 people sleeping rough whom they considered to be the most entrenched and hard to reach, we accommodate a number of this group.

Twice a year we are visited by the Find and Treat mobile X-ray unit (MXU), and for the last 3 years we have maintained screening rates of over 90%. We have tried a variety of models to engage people in screening but all with the same foundation – prioritise and organise.

We launched the first screening session by offering supermarket vouchers; we have run a rewards card system, a prize draw to give out burger and chips – all with the same uptake rates. The one thing that has not changed is the organisation of the screening day, the entire staff team with the help of the Find and Treat peers are involved in ensuring that everyone is screened.

Following our successful rates of screening, last year in partnership with the Westminster DAAT, Turning Point (our local substance misuse service) and the Find and Treat team we piloted our health MOT model. We decided that the effort it took to engage a hard to reach group in a single health outcome was a wasted opportunity when there were many other health concerns we wanted to address. We decided to “bolt on” as many services as possible during the week the MXU arrived.

We now invite as many health related services as possible to our MOT week, they include; stop smoking services, lung function testing, BBV screening, flu vaccinations, podiatry services and sexual health screening.

The last 3 MXU screening sessions have each required follow up tests for 3 individuals, a severe chest infection, an ongoing investigation involving further tests and awaiting the results of sputum tests.

Whilst always aiming for 100% screening rates on the MXU there has always been a handful of clients who refuse on the day, the most common trends for refusal are often related to delusional conspiracy theories in people we know have issues with mental ill health, the nature of their mental ill health often means they are more socially isolated from their peers and receive greater staff support.

EP10: Managing a tuberculosis service in prison

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Sue Yates (Royal Free Hospital, London)

Manchester, 22 March 2011

This talk is based on my five years experience of working in a large London male prison, with an average population of 1250, and with a high turnover. In this prison there are high levels of substance misuse, approximately half needing detoxification on arrival, high levels of homelessness and high levels of illiteracy.

During five years there were 55 TB patients, 75% were pulmonary and 39% had drug resistant TB (one multi-drug-resistant tuberculosis [MDR-TB]).

Whilst recognizing that security takes precedence over health in the prison setting, imprisonment is also an important opportunity to provide healthcare to some of the most vulnerable people in society who do not find it easy to access healthcare in the community.

Access

The importance of access and in-reach cannot be stressed enough, security clearance and access to keys facilitates this. Booked clinics, access to healthcare and prison IT systems and an understanding of prison communication systems are a prerequisite.

TB Awareness

A TB policy agreed between the local TB service and the prison must be in place. A lead for TB in the prison and a lead in the community are helpful. Clear referral pathways must be part of the TB policy.

Staff training and regular updates are important to ensure staff recognize and refer possible TB cases; this includes raising awareness amongst discipline staff and prisoners as well as healthcare staff.

Screening

Prisoners should be screened on arrival, preferably with a chest x-ray but as a minimum with a symptom screen (though this will mean cases are missed); use of IGRA testing should also be considered. IT systems and using templates are helpful. Screening on arrival is also an opportunity to raise awareness and make sure the prisoner knows how to report symptoms should they develop.

Contact screening is managed between the TB team, the prison and the HPU.

Case Management

All prisoners suspected of having TB, on TB treatment or preventative TB treatment must be case managed by the local TB service and treatment must be given as Directly Observed Treatment (DOT).

Transfer and Discharge planning

Prisoners being investigated for and on TB medication should be on medical hold so that possible transfers take place in a managed way. A discharge plan must be in place including housing provision, and close liaison between the prison, TB team and others involved in the prisoners care will facilitate continuity of care.

EP11: The importance of housing homeless people with tuberculosis

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Sue Collinson (Homerton University Hospital, London)

Manchester, 8 June 2011

There is an increasing body of evidence that demonstrates the importance of the provision of housing to support treatment completion for TB, which also points out that long-term homelessness is fundamentally an issue of health.^{1,2,3} By definition, homeless people often have chaotic lives, as their priorities are very different from housed people: finding a place to stay, or a place to get a free meal, on a daily basis. In addition, many have to fund drug or alcohol dependencies. Homeless people typically have no access to primary care, but are more vulnerable to both chronic and acute health problems than people in stable housing. The average age of death for homeless people in the UK is between 40 and 44 years old. Homeless people attend A&E six times as often as the housed population, are admitted four times as often and stay twice as long. UK wide, the homeless population generates secondary care costs of £85 million annually. Homeless patients stay twice as long in hospital, because they are twice as sick, by the time they are admitted. A recent HPA report noted that of 6,343 TB cases with known social factors recorded, 2.6% “were currently homeless or had a history of homelessness”.⁴

Current emergency provision for housing does not include TB as a specific priority risk factor (see Figure 1 below) and does not provide for persons such as asylum seekers, undocumented migrants or illegal overstayers.⁵

Figure 1 – Priority risk factors

The Office of the Chief Analyst notes the “priority need” groups for housing within existing legislation:

- pregnant women
- persons with dependent children
- a person who is vulnerable as a result of old age, mental illness, mental disability, physical disability or other special reason
- a person aged 16 or 17 who is not owed a duty under the Children Act 1989
- a person aged 18-20 who has previously been looked after, accommodated or fostered
- a person aged 21 or over who is vulnerable as a result of having been looked after, accommodated or fostered
- a person who is homeless, or threatened with homelessness, as a result of an emergency such as flood, fire or other disaster⁶

Cost of homelessness to health services

Current arrangements for housing homeless TB patients appear to be *ad hoc* and very dependent upon the attitude and capacity of local authorities. Anecdotal reports indicate that there is widespread reluctance on the part of local authorities to pay for emergency housing for patients with TB. As Hewett and Halligan point out, “*one consequence of the failure to treat and prevent the health outcomes of homelessness is increasing expenditure in secondary care...homeless patients attend six times as often as the housed population, are admitted four times as often, and stay twice as long*”. The result is unscheduled secondary care costs that are eight times those of housed patients.⁷ Furthermore, the Office of the Chief Analyst has shown that the lengths of admissions of homeless people are “generally appropriate for the admitting condition. In other words, homeless patients stay twice as long in hospital because they are twice as sick”.⁸ In the case of homeless TB patients, their TB can be quite advanced before they seek treatment, while the length of treatment (minimum 6 months) is very difficult for them to adhere to, not least because many suffer from co-morbidities over and above their homelessness, such as drug and alcohol dependency, BBVs, HIV, mental illness and other chronic conditions. It is not easy to address any of these when the patient is homeless. This reinforces the argument that investing in a flexible accommodation resource on a London-wide basis is both cost effective and humane, as other problems can be addressed while the housed TB patient is in accommodation.

Housing homeless TB patients

Chronic homelessness is a red flag symptom, marking a significantly increased risk of ill health and premature death.⁹ By definition, homeless people often have chaotic lives, as their priorities are very different from housed people: finding a place to stay, or a place to get a free meal on a daily basis. When a homeless person has TB, and must complete a minimum of six months treatment in order to be cured, adherence can become an insurmountable problem. An example of a model for housing homeless TB patients has been developed in Hackney, east London and has now been running successfully for over two years. It has proved both cost effective and has also benefitted patients in a range of ways over and above helping them complete TB treatment.

Most local authorities in England have very strict criteria as to who they are able to house. In Hackney, an inner city borough with a high density of population and a very limited, poor quality housing stock, the housing department is known as a fierce gate keeper. Any homeless applicant who fails even one of their five eligibility criteria will be refused accommodation:

1. Are you homeless?
2. Are you eligible? (Immigration status)
3. Are you in priority need?
4. Are you intentionally homeless?
5. Do you have a local connection?

In the experience of the Homerton TB team, criteria 2 and 5 were the ones that our homeless TB patients tended to fail. "Eligibility" addresses the question of immigration status (asylum seeker, non-EU citizen, undocumented migrant), and whether the patient has recourse to public funds. Number 5 asks for evidence of a local connection within LBH. If the homeless person has been squatting, or sofa surfing, this is very difficult to prove.

Examples of ineligibility from our case notes:

1. Male, 47, found out that he was a Jamaican citizen, although he had lived continuously in the UK since the age of 7 years, and had assumed that he was a British citizen.
2. Male, 53, EU citizen, but from an A8 country and not registered under the Workers Registration Scheme (WRS), therefore had no recourse to public funds.
3. Male, 65, Albanian citizen, living with his son, who had married a British citizen.

We have found that the majority of homeless, ineligible TB patients are single and male, though the TB team at Homerton did work with a couple, only one of whom had TB, as well as 3 single women.

Bed blocking

The outcomes for patients who are ineligible for local authority housing are not good. One is bed blocking: not discharging a patient because they are at risk of being lost to follow up. Bed blocking is unpleasant for ward staff, the patient, and the TB team. Ward staff understandably resent having to look after a patient for weeks or even months, when they know that he is fit to be discharged, and that he is being kept in hospital for “social” reasons. The patient senses the feelings of the ward staff. He also gets bored, especially when he has poor English. He will tend not to have visitors, and will probably abscond from the hospital out of frustration. The TB team have to make a case for keeping the patient in hospital by demonstrating that if the patient is discharged back to the streets, he will almost inevitably drop out of treatment and disease will reactivate, in which case:

1. He may have to restart treatment from the beginning
2. He may develop drug resistant TB
3. He may infect < 12 others
4. He may die

A recent, additional burden has been placed on resources by the influx of a large number of EU accession state citizens into the UK, especially the inner cities. We were treating a 47 year-old Polish male in a squat with DOT. He was evicted, we lost contact with him, and he died about 2 months later. The TB team felt that the death of the Polish patient was unacceptable. A series of meetings took place between the TB team, the local PCT as commissioners, and the head of Hackney’s Homeless Persons Unit. The team made a strong financial case: e.g. 1 day spent in the Homerton = 1 week in temporary accommodation (£350.00).

We also demonstrated the cost of one successful treatment completion (£5,000.00) versus the start, restart, admit, readmit pattern that is typical of trying to treat a homeless person, which can cost up to £55,000.00. Furthermore, the part-treated patient is likely to infect others, which again escalates cost.

The Service Level Agreement (SLA)

This is commissioned by City and Hackney Primary Care Trust (CHPCT) and delivered by the London Borough of Hackney's Homeless Persons Unit HPU). The terms of the SLA are:

1. Any patient with TB will be housed by the HPU, regardless of eligibility.
2. This accommodation will be paid for by CHPCT.
3. It will provide for a maximum of 6 patients, for 6 months, per annum.
4. It will be provided for the duration of the patient's TB treatment.

This is not a perfect arrangement. A patient still has to feed and clothe himself, and if he has no recourse to public funds, money remains a big issue. The TB team has some money in a joint bank account, held by the lead nurse and the case worker, but this will not last for ever, and we have to think of ways to raise more money, whilst trying to address this issue through the proper channels. This is not a recommendation to other teams!

To date the TB team has used the SLA 15 times. Outcomes so far are in Table 1 below.

Table 1 – Outcomes

Patient	Circumstances	Outcome
1 and partner	Lithuanian national and Russian partner	DOT. Completed treatment.
2	Male Jamaican	DOT. Compliance declined and thus lost his accommodation. Remanded in prison. Upon release smear and culture –ve, thus was not restarted.
3	Male Albanian	Completed treatment.
4	Black British male	Deceased.
5	Black African male from Guinea	DOT. Completed treatment.
6	Male Portuguese national	DOT. Completed 2010
7	Ghanaian female and child	Has completed treatment
8 and family	Male of Nigerian origin, wife and children	Has completed treatment
9	Teen from Afghanistan	DOT. Completed treatment
10	Portuguese adult	DOT. Completed treatment.
11	Undocumented migrant from Vietnam	DOT. Completed treatment.
12	Overstayer from KwaZulu Natal	DOT. Completed treatment
13	Male of Ghanaian origin	DOT. Fully compliant. Has completed treatment.
14	Portuguese female adult	DOT. Completed treatment.
15	Male from St Lucia	DOT, and generally adhering to treatment. Restarted work and a proposal to have a senior member of staff there to do DOT at the workplace.

While patients such as these have numerous, complex problems, experience tells us that housing is both the most intractable issue when it is lacking, but also a key element in maintaining patients

on treatment when it is available to them. Risk assessment tells us that a majority of the patients we have housed would very probably have been lost to follow up, if we had not been able to provide them with stability in the form of their own accommodation.

An additional benefit of housing high risk (i.e. homeless) patients has been that the TB team has been able to work closely with other health and social teams and thus address some of the patients' other needs. Examples include referrals into the local Specialist Addictions Unit, Department of Sexual Health, Open Doors sexual health project, specialist midwives, learning disabilities service, the mobile vet unit, English classes, emergency dental services and many, many more.

Endnotes

- 1 *LA TB Control Manual 2007*
- 2 *New York TB Control Manual 2008 Edition (4th)*
- 3 *Fair society, healthy lives: strategic review of health inequalities in England, post-2010*. London: The Marmot Review, 2010
- 4 *Tuberculosis in the UK (2010)*. Report on tuberculosis surveillance in the UK 2010: 15.
- 5 *Healthcare for single homeless people*. March 2010. Office of the Chief Analyst. Department of Health: p. 5.
- 6 *Ibid.* p. 3.
- 7 *Leicester Homeless Primary Health care Service. Annual Report 2007/8*. Leicester: Leicester City NHS Community Health Service; 2008
- 8 Hewett and Halligan, Homelessness is a healthcare issue. *J R Soc Med* 2010; 103: 306-7. DOI 10.1258/jrsm.2010.10k028
- 9 *Ibid.*

EP12: Leicester model

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Philip Monk (Health Protection Agency, Leicester)

Manchester, 23 November 2011

Background

This report is based on the experience of the Leicester TB team. Leicester and Leicestershire have about 270 cases of TB a year. The majority of cases of TB in Leicester come from people either from the Indian Sub Continent or whose ethnic origin is South Asian.

The hard to reach groups in Leicester are:

- Homeless, rough sleepers (not a significant problem at this stage because most live in hostels and have access to a medical service for the homeless)
- People with alcohol problems (not a significant problem for TB)
- People who are here illegally (mostly from Africa and Asia) who work as caterers (India / Pakistan Philippines and Thailand [also Sikh Priests and Muslim Imams] and in the sex trade Philippines and Thailand) and those who are not working (mostly Zimbabwe). People who are here on student visas but who also work through agencies to fund their studies (and who have often overstayed their student visas) also pose a significant problem. Many of these people are not registered with a GP and are difficult to trace as they have no permanent address.
- People from Somalia
- Prisoners – these do not present a great TB problem in Leicestershire.

Which interventions are effective and cost effective at identifying and managing TB among hard-to-reach groups?

In the experience of the Leicester TB team, identifying patients with TB has been improved through the use of a rapid access service. This is assisted by having a specialist GP service for the homeless and street dwellers.

The rapid access service consists of:

- All reports of x rays with TB as a diagnosis are copied to the TB nurses. The Consultant Respiratory Physician sees the x ray and if he agrees that TB is the likely diagnosis, then patient is seen in a rapid access clinic (within 1 week). This has the benefit that any hard to reach patient is seen quickly.
- GPs can refer any patient suspected of TB for rapid assessment by TB nurses
- Prisons refer any patient suspected of TB for rapid nurse assessment

Managing TB

The most significant tool that supports the management of TB is the multi disciplinary forum where the management of all cases is considered by a multi disciplinary team from clinical care, public health and linking in to social services and the homeless GP project.

Which case management tools are most effective and cost effective at identifying those who may need support to complete treatment?

We consider that the North East London assessment tool is the most useful available tool in helping to decide the optimal management for each person with TB, especially in deciding on the use of Directly Observed Therapy.

Which service models and organisational structures are most effective and cost effective at supporting TB diagnosis and treatment among hard-to-reach groups?

The Leicester team believe that the following elements of their approach to TB care for hard to reach groups are effective in reaching and treating people with TB in hard to reach groups:

- Rapid access service
- Good links with prisons, homeless, voluntary sector
- Culturally integrated nurses
- Local Standard Operating Procedures (we believe that these are very important in shaping the service. They are agreed in a multi- disciplinary forum and are based on national guidance on the management of TB but translated into a local protocol of what is done and when)

What factors help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups, for example the acceptability of different testing modalities. How can the barriers be overcome?

What helps?

We consider that the integration of services between primary, secondary care and the voluntary sector with good links between providers is essential on managing people with TB in hard to reach groups.

In terms of service models, we consider that our rapid access model serves us well as does having walk in X-ray at all 3 acute hospital sites.

What hinders?

We acknowledge we don't do well with people from Somalia and that we struggle to provide services to people who are here illegally.

EP13: Strategies for managing tuberculosis in the chaotic community of rural Warwickshire

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Debbie Crisp (NHS Warwickshire, Warwick)

Manchester, 22 March 2011

The Warwickshire TB service aims to successfully treat patients with TB and prevent further spread of the disease. The TB nursing service, comprised of two full time TB nurse specialists, is community based. It recognises the holistic needs of the patient to deliver evidence based, patient centred, quality service; as well as addressing the wider determinants of public health; health promotion, prevention and health protection, all necessary elements to control TB.

TB is everyone's business and the TB nursing service demands collaborative partnership work with primary, secondary and tertiary health care as well as the essential input from third sector organisations, local authority, police and health protection agency to name a few.

Warwickshire has seen a rolling outbreak of TB occur among its "hard to reach community"¹ since 2001. The risk factors commonly seen among this population are alcoholism, drug abuse and homelessness all leading to chaotic unhealthy lifestyles that do not conform to the structured services claiming to be available to them. To address these problems and take control of the situation, the TB service has used the social marketing model to access this community. Through partnership working, individualised care plans can be agreed, meeting the clients needs; necessary for treatment completion.

Where there have been failures, lessons have been learned. Success has been achieved as a result of dedicated expert nurses available to give the necessary time, commitment, understanding and persistence required for their clients to realise the trust and respect necessary for the desire and belief to be cured. New challenges face the Warwickshire TB service as it merges with a

neighbouring team, with a contrasting epidemiology and population need; however the merge provides an opportunity to build links, re-focus and develop new ways of working to manage and control TB.

Endnotes

- 1 Story et al. (2007) TB in London; the importance of homelessness, problem drug use and prison; *Thorax* 62; 667-671

Other reading

Docherty, A (2008) *Review of TB in hard to reach groups; Behavioural Approaches to enhance adherence*. Unpublished; HPU West Midlands East
Health Protection Agency (2005) *TB and homeless: guidance for homeless service managers*. HPA; Colindale

EP14: Tuberculosis in Scotland

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Oliver Blatchford (NHS Scotland, Glasgow)

Manchester, 23 November 2011

TB guidance in Scotland

The Scottish Office guidance document *The Control of Tuberculosis in Scotland (1998)* has been replaced by the Health Protection Network Tuberculosis guidance. This was adapted (with permission) for Scottish use from the NICE TB guidelines. Adaptations were mainly to account for differences in legal systems and for different NHS structures in Scotland, as well as clarifying some clinical issues.

The revised document was reviewed using the AGREE methodology and was then adopted by the HPN steering group. The work of NICE on the original document has been welcomed.

Scottish TB Action Plan

The incidence of TB in Scotland had been stable before 2000, but around 2006, there was evidence that the TB incidence was now rising. This has accelerated. In early 2009, The Scottish Government therefore established a TB Action Plan Group. The 2009 influenza pandemic led to suspension of work on the TB action plan. The work was resumed in 2010 and it is expected that here will be a Scottish TB Action Plan early in 2011. This is anticipated to be a strategic document which recognises the changed constraints on Scottish healthcare systems.

The work of the action plan has mainly been conducted through four working groups covering the following areas:

- Clinical Services
- Public health and screening
- Surveillance
- Laboratory services

Managing TB in hard to reach groups in Scotland

Scotland has different NHS structures to England, in that NHS boards have direct management and responsibility for the delivery of acute and community health care services. Public health and health protection services are integral parts of the NHS boards.

Primary care services in Scotland are linked to local authorities in the delivery of services through Community Health Partnerships (CHPs) or Community Health Care Partnerships (CHCPs). These enable closer working of community services for both clinical and social care services.

NHS Greater Glasgow and Clyde has a dedicated TB nursing support team, which is part of the Public Health (Health Protection) unit. This comprises 5 TB outreach nurses, with around 210 TB patients annually, including screening the contacts of these cases. The service also provides BCG and TB screening for at risk groups.

NHS Greater Glasgow and Clyde has an established multiagency support project for asylum seekers. This operates through a CHCP. Details are at:

http://www.glasgow.gov.uk/en/Residents/Care_Support/AsylumSeekers/ApplyingforAsylum/index.htm#Gass

EP15: London Find & Treat

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Alistair Story and Joe Hall (Find & Treat London)

Manchester, 23 November 2010

London Epi Background

- Highest TB rate of any capital city in Western Europe
- 10% of cases drug resistant
- Largest outbreak of drug resistant TB documented in Western Europe. (UK birth, problem drug use, prison, homelessness and people in contact with these groups)
- >400 linked cases to date, 12 are known to have become multi drug resistant (MDR) so far
- Minimum of 12% of cases socially complex – LTBR 2009 (homeless, prisoners, problem drug/alcohol users)
- Profile study - 17% socially complex (Thorax. 2007 Aug;62(8):667-71)

Mobile X-ray (MXU) Pilot commenced March 2005

Concluded:

- Two-thirds less likely to be smear + on diagnosis Adjusted OR 0.35 (0.15-0.81) $p < 0.001$
- One-third duration of symptoms Adjusted HR 0.35 (95% CI 0.21-0.59) $p < 0.0001$
- Less clinically severe disease
 - Weight loss on diagnosis Adjusted OR 0.31 (0.14-0.70) $p = 0.005$
 - Fever on diagnosis Adjusted OR 0.31 (0.12-0.75) $p = 0.01$

BUT

- Need to...

- reduce LFU
- target
- increase uptake

Find&Treat funded by Department of Health in 2008 to implement the HPA recommendations of the MXU evaluation and strengthen TB control among hard to reach groups in London

- Pan-London - Multidisciplinary
- Work alongside
 - All (30) London TB services
 - 223 front-line allied services in every Borough
 - 84 Hostels
 - 56 Day centres / Drop-in
 - 83 Community drug and alcohol projects

Services provided by F&T

1. Active case finding (MXU)
2. Case management support
3. Locate and re-engage LFU patients
4. Link prison health and TB services
5. Specialist training and advice (national)
6. Peer Education programme

F&T case management model

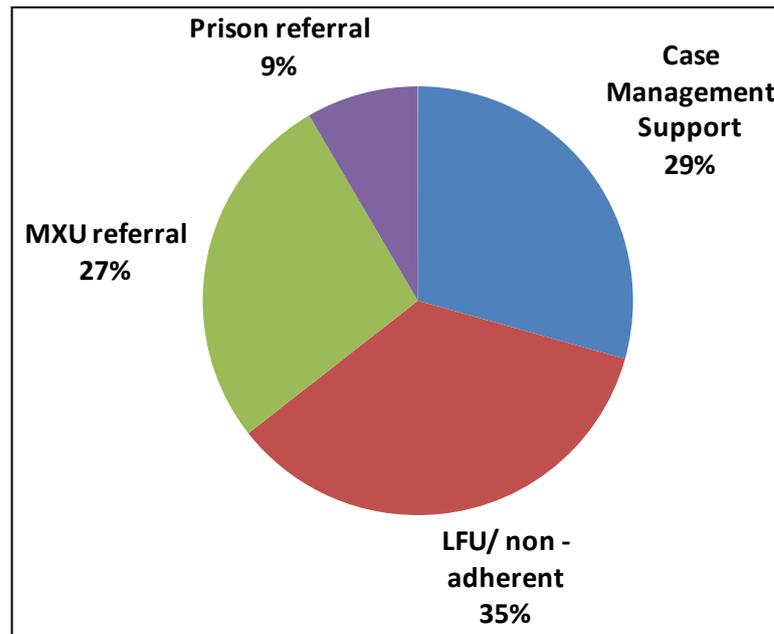
- Starts from suspected TB
- Package of health AND social care
- Community based – MDT
- DOT for all

F&T activity

- 844 referrals (up to April 2011)
- 530 active TB cases

- 32% of confirmed cases drug resistant
 - 36 have MDRTB
 - 1 has XDRTB
 - 68 are mono-resistant

Figure 1 – Route of referral



Active case finding - MXU activity

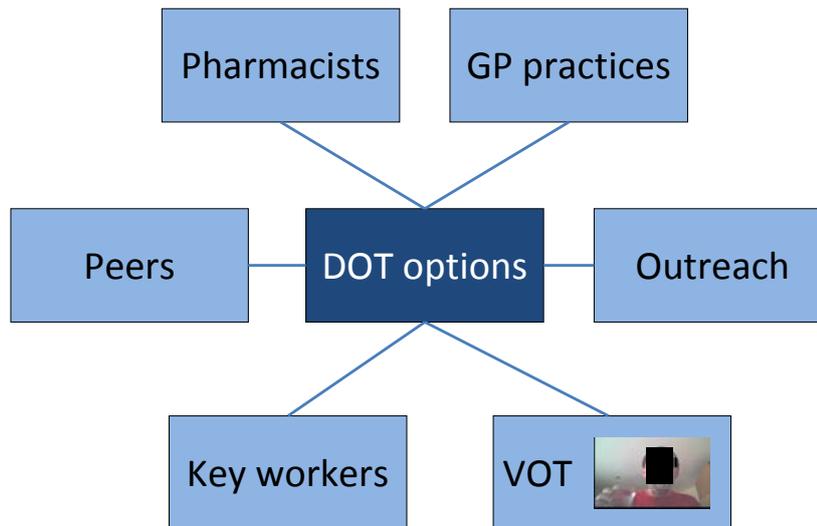
- Screen 8,000-10,000 per year
- Detection rate 251 per 100,000 population
 - Sensitivity 82% (95% CI 67.3 - 91.8%)
 - Specificity 99.3% (95% CI 99.1-99.3%)
- Peers support team to engage
- Reduced LFU pre-diagnosis from 53% to 7%

DOT – Survey of London clinics 2009 (>1800 patients surveyed)

- Half who need DOT (19%) get DOT (9%)
- Lack of staff resources is the main reason sited
- Proportion of cases on DOT by clinic varies between 0% to 69%.

- Variance suggests that either-
 - variation in the “complexity” of the caseload by centre
 - capacity to provide DOT
 - very different approaches to assessing who should get DOT

Figure 2 – Increase DOT through community partnerships



Actively manage lost to follow up cases

- **Principle** to identify confirmed (diagnosed) cases, LTBI treatment cases and suspected cases who could potentially harm either themselves or others by not completing prescribed treatment or relevant investigations.
- **Purpose** to trigger RTS action following missed doses of medication and/or missed follow up appointments.

Definitions of LFU to trigger Return to Service (RTS) action

- SAT - Not contacted within 10 working days of 1st missed OPD
- DOT - Not contacted within 10 working days of 1st missed DOT

RTS results first three years

- 228 Active LFU TB cases referred
- Located and re-engaged (168)

- Treatment completed (62)
- Dead (8)
- Treatment stopped – deemed too chaotic to treat (20)
- Transferred out – deported (9)
- On treatment (58)
- Treatment not restarted as too chaotic (10)
- Not located (60)

EP16: Brief overview of prisons

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Claire Smith (Claire Smith Consultancy, Doncaster)

Manchester, 22 March 2011

1 Different types of prisons

These prisons can be publically or privately owned

- Local Prisons
- Training prisons
- Young offender institutions
- High Security Prisons

Open prisons – These are prisons where there is more freedom than other prisons to move around and do things.

Closed prisons – Most people in prison are in closed prisons. These prisons are more secure

2 Security categories for adults

Category A. High risk of escape and causing harm

Category B. Risk of escape but don't really have the means i.e. money connections

Category C. Not likely to escape, but cannot be trusted in an open prison.

Category D. Can be trusted to be in an open prison.

3 **Prison Service Orders (PSO) and Prison Service Instructions (PSI)**

These explain the prison regulations (rules) and the way prisons do things.

4 **People who work in a prison**

- **The governor** is in charge of the prison
- **Prison officers** - work in lots of jobs around the prison
- **Offender supervisor** - offender supervisor will work with your offender manager on sentence planning.
- **Personal officers** - this is a prison officer who will write reports on your progress.
- **Probation officer** – works with the prisoner to help them not re-offend after you leave prison.
- **Psychologists** - make assessments and work with other staff to run offending behaviour courses.
- **Chaplains** - will help you practice your religion.
- **Education and workshop staff** - run classes and workshops.
- **Healthcare staff** - these are nurses, doctors, dentists etc.
- **CARAT workers** - help prisoners with drug problems.
- **IMB members** - are people who check prisons are run fairly. They are volunteers from the local area.
- **Official prison visitors** - these are local people who visit prisoners

5 **Challenges**

- Victorian buildings not fit for purpose
- High turnover of prisoners and staff
- Competing priorities

6 **Discussion**

EP17: Nurse Led Triage

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Malcolm Cocksedge (Bart's and the London NHS Trust)

Manchester, 22 March 2011

There is a lot of evidence suggesting that the early detection and treatment of TB can bring down the rates of it in areas.

Doctors are not solely responsible for TB patients, they also have a caseload of other respiratory or HIV patients, they also have a relatively set working week based on sessions.

On the other hand TB nurse in many areas are more flexible and are uniquely placed to ensure that referrals are processed in order to ensure that patients with TB, especially smear positive pulmonary TB, are investigated and treatment commenced appropriately. (In many places TB nurse are only responsible for the TB patient caseload).

The aim was of the presentation was to inform the group how to safely and effectively undertake Nurse led Triage.

Nurses who are required to under take triage should have the correct supervision, training as well as being on an appropriate band.

The protocols for the clinic must ensure that nurses do not operate outside the Nursing Midwifery Council Guidelines, link to NMS given.

The initiative needs to be accredited within the trust framework ensuring that the protocols fit within the governance framework.

Protocols should include pathology ordering and CXR ordering, with the relevant training.

There is a need to have clear pathways for referral to the service from GP's and the 3rd sector which are easy to use and well disseminated via all local communication systems.

Nurse do not have clinical freedom in the same way as medics, it is therefore important that algorithms are produced that have a clear end path for the patient.

If these steps are followed the aim should be achieved.

EP18: Nurse led service – Sandwell

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Jacqueline Nation and Imtiaz Ahmed (Sandwell General Hospital, West Bromwich)

Manchester, 13 May 2011

Sandwell is located on the West of Birmingham and is a part of Black Country which also includes Wolverhampton, Dudley & Walsall. Our catchments' population is 290,000 which has a diverse ethnic mix. We have no prisons – but do have ex – prisoners. It is a socially deprived area with low education attainment. High numbers of individuals are known to abuse alcohol and drugs.

Historically TB was part of the general respiratory service. In mid 90s we saw an increase in the number of TB cases and there was a demand for a Rapid as well as an Open Access to TB clinics. A dedicated TB service was developed with an increasing role of TB Specialist Nurses in the setting of Nurse Led Clinic

A clear plan was made for clinical Supervision for Nurse Led Clinic and it was ensured that the service is established within the framework of Clinical Governance. Training needs of nurses were addressed which includes Radiation hazard training and clear guidelines made for requesting chest x-ray (CXR) and Bloods. Staff were encouraged to go for HIV courses.

The current team consists of 3 TB Nurses, 1 Clinical support. They are doing the clinics on three days of the week; Monday, Wed and Friday. This has allowed us to offer rapid access of TB service to radiologists, GPs, other health professionals, microbiologists, pharmacologists as well as patients.

Table 1 – Number active TB cases per year in Sandwell

Year	TB cases
2007	117
2008	112
2009	111
2010	102

The Incidence Rate over the past 3 - 4 years has been around 36 per 100,000.

Table 2 – Ethnic distribution of active TB cases in 2010

Ethnic category	Number
Indian	47
White	25
Pakistani	9
Other	9
Black African	9
Black Caribbean	2
Bangladesh	1

The clinics have been a great help to manage difficult cases especially hard to reach group. Every effort is made to meet individual client needs. All patients have a named case manager. There is a comprehensive partnership working with not just primary & secondary care but other stakeholders like mental health, HPA etc. The service is proactive to find cases and provide rapid access for early treatment. Its continuous feedback and audits have been instrumental in improving the TB service for the local population. For example its audit of all the active case load in 2003 showed there were 47 drug errors in 174 total cases mainly related to patients due to lack of understanding and side effects of medications leading to poor compliance. There were problems with pharmacy like dispensing wrong drugs or dosage and forgetting to order or deliver medications when arranged. We centralised the prescribing and dispensing. Handfuls of pharmacy were identified to support our patients. Communications with GPs were improved with the timely, accurate / informative typed clinic letters. Many patients receiving TB treatment could speak or read very limited or no English. Visual aids in the form of charts and leaflets were designed to assist both prescriber and patients

.In order to raise awareness, we have tried to access different cultural / ethnic communities e.g Places of worship, Afro-Caribbean Day Centres, Yemeni resource centre, Local shopping centre, Terence Higgins Trust, PPI groups. Not only did we acquire knowledge of different cultures but also gained acceptance within the local communities.

Our current Joint project with PCT & BME CHN includes a programme to disseminate information about TB throughout the mixed population.

It is important to dispel myths / alleviate stigma, improve awareness about TB and give a positive message that it is a treatable condition. We are going to use local radio like Raj Radio and prepared Podcast – to be interpreted.

Nurse led clinics recognise the holistic need of the patients. These clinics deliver evidence based and patients centred service. At the same time it could extend its role to address wider issues of public health to control TB like health promotion, prevention and health protection.

EP19: Model of Care - London tuberculosis plan

Presentation to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Nick Relph (London TB Commissioning Board)

Manchester, 13 May 2011

[A paper was requested. None was submitted, and the slides formed the basis of committee discussion]

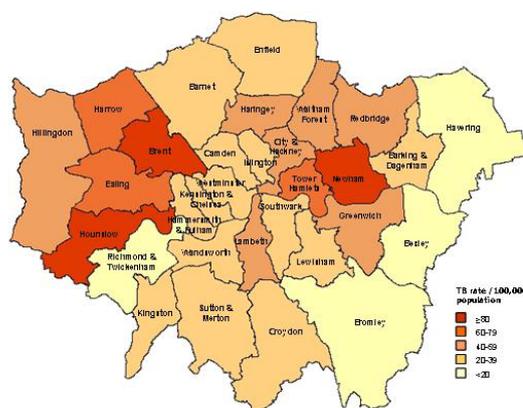


Why do we need a Model of Care?

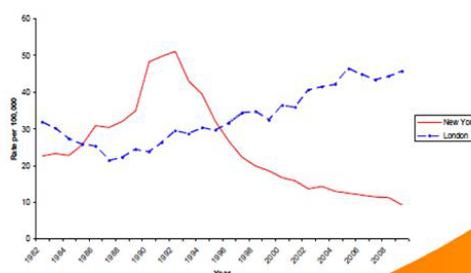
- London hasn't met the 2004 CMO National TB Action Plan challenges
- Following NICE guidelines
- Highest rates and numbers of TB for a West European city
- Are we getting good quality outcomes for the investment?
- Do we have a workforce that has the functions and skills to meet the needs of the patient pathway?

The Model of Care uses:

- London TB Service Review and Health Needs Assessment (2010)
- Epidemiology
 - TB rates high 42.6 per 100,000 in 2010
 - 3,302 new cases 2010
- Comparison with New York City
- Current services review
- Key elements of TB control and recommendations for changes to services



How do we compare to others:
London versus New York



Source: LTBR and New York City Health Department

What are the key elements of TB control?

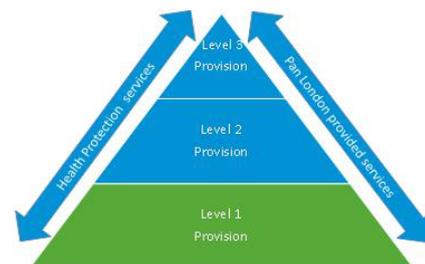
- Awareness-raising and education
- Ensure infectious cases detected early
- Ensure TB patients complete treatment
- Robust contact tracing
- Targeted testing and treatment of latent TB

By

- Pan London commissioning
- Standardisation of services and service provision

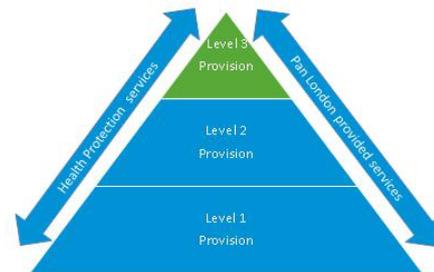
Level 1 services

- Increased active case finding
- Testing and treatment of latent TB – new entrants/recent entrants
- Use of community pharmacy/3rd sector for DOT
- Universal neonatal BCG in all boroughs



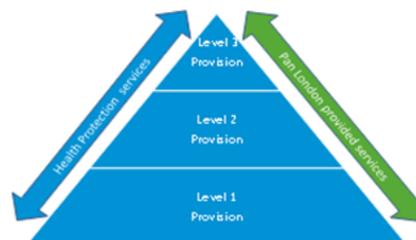
Level 2 & 3 services

- TB services open for extended times
- Level 3 services
 - Medically complex patients - paediatric TB, MDR TB, XDR TB
 - Clinical management advice and support for Level 2 patients with
 - renal impairment
 - spinal TB
 - neurological TB
 - HIV/TB co-infection
- Latent TB - increased contact tracing, testing of HIV patients for latent TB



Pan London provided services

- Awareness raising and education
- Accommodation
 - London TB CB to manage central fund for homeless patients while on Rx
- Persons with social risk factors
 - Outreach work: identify cases
 - Re-engage patients lost to follow up
 - DOT
 - 3rd sector / community organisations to support patients



EP20: What about the children?

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Fran Child (Royal Manchester Children's Hospital)

Manchester, 13 May 2011

Scale of the problem

Eight hundred and sixty children \leq 19 years of age were notified to have tuberculosis (TB) in the UK in 2009.¹ This comprises 10% of all TB notifications.¹ The circumstances which predispose children to TB, such as poverty, overcrowding and poor sanitation are similar to those seen in many hard to reach groups of children, yet little data exists in the UK regarding the incidence of TB in hard to reach children.

Following exposure to *Mycobacterium tuberculosis* (*M.TB*), the risk of developing TB disease is higher in children than in adults and increases with decreasing age. Thus, following *M.TB* infection a child has up to a 50% risk of developing TB disease compared to a 10% risk in an adult.² Young children also have an increased risk of miliary TB and TB meningitis, both of which have associated high morbidity and mortality. Between one and seven children die each year from TB in England and Wales.³

70% children with TB are identified via contact tracing. Many of these have early or preclinical disease and, with appropriate treatment, will never become unwell. The remaining 30% present with symptoms and, even with treatment, some will develop debilitating problems which affect them for the rest of their lives. The literature suggests that 40-60% children hospitalised with TB could have been identified with better contact tracing.^{4,5}

Difficulties in diagnosis and management

The diagnosis of TB can be difficult in children. The pauci-bacillary (few bacteria) nature of childhood infection makes isolation of *M.TB* more difficult than in adults. The interpretation of tuberculin skin tests in children can also be challenging with different guidelines recommending different thresholds for a positive test results in different groups of children.^{6,7,8} The interpretation of chest X-rays can be difficult even for experienced paediatric radiologists.

The treatment of TB in children is hampered by a lack of suitable combined drug preparations. Such combination therapies are used widely in adults as an aid to multi-drug compliance. Children frequently have to rely on multiple single suspensions or crushed tablets which are less well studied and which often have short shelf lives. Hard to reach families frequently have multiple children, adding a further layer of complexity to already difficult poly-pharmacy situations.

Many groups of children struggle to access TB services. These include the children of “hard to reach” adults, children who are themselves homeless or in prison, traveller families, children in asylum seeking or refugee families, unaccompanied minors and looked after children.

Potentially Hard to Reach Children

Substance abuse is common in children in the UK. Data from the Office for National Statistics suggests 18% children aged 11-15 years drink alcohol more than once a week with an average intake of 9-11 units per week. 29% of 15 year olds have used illegal drugs within the last year of whom 4% will have used a class A drug.⁹ In terms of accessing services, however, parental substance abuse is more of a problem for children than their own illicit activities. Parental substance abuse is one of the commonest reasons for neglect of a child in the UK. 250,000 and 920,000 children in the UK live with parental drug and alcohol abuse respectively.¹⁰

80,000 households were defined as officially **homeless** in 2009.¹¹ Half of these contained dependent children with ethnic minority families 3 times as likely to be homeless as white Caucasians.¹² There is little data regarding children sleeping rough in the UK but 100,000 children aged < 16 years run away from home every year of whom a sixth will sleep rough at some time. The London Centrepoint service provides hostel beds for young homeless people. In 2005, one in five of these beds was occupied by a young person aged 16-17 years.¹³

100,000 children aged 10-17 years were known to the youth justice service in 2009-10. Of these, 2,400 were **in custody**, 32% of whom were from ethnic minority groups. 90% and 75% reported recent drug and alcohol use respectively. 23% had a sexually transmitted disease and 10% had a history of being paid for sex. 4% children were discharged from youth custody without appropriate accommodation provision and were therefore homeless.¹⁴

There are currently approximately 100,000 **asylum seeking children** in the UK¹⁵ of whom 10% are **unaccompanied minors**.¹⁶ An unaccompanied minor is an individual <18 years who enters the country without someone who can provide parental responsibility. 3,400 such minors entered the England in 2009.¹⁷ Some of these children are sent to the UK because their parents perceive them to have health problems, such as TB, that cannot be met in their home country.

Children entering the UK illegally may be held in **immigration detention** centres either with or without other family members. Some report up to 1,000 children per year may be held in this way.¹⁸

There are 20- 30,000 **travellers** in the UK of whom two thirds are children. Travellers are a socially isolated and marginalised group many of whom live in poverty in overcrowded camps with poor sanitation. Several groups exist within the travelling community, some of whom come from Eastern Europe where multi-drug resistant tuberculosis is more common than in the UK.¹⁹

Why are these children hard to reach / treat?

Children in these groups share many common characteristics. Many do not speak English and their parents may also struggle to communicate with health professionals. Families entering the UK from overseas often have a poor understanding of health and social care services in the UK. This is likely to be an even greater problem for unaccompanied children. Past experiences in war-torn countries or with parental abuse or neglect lead to a fear of authority and may also lead to mental illness, particularly post-traumatic stress disorder. Hard to reach children are typically highly socially mobile and therefore have no regular GP or school. This precludes them from accessing standard health care services, particularly the school health service which is ideally placed to identify child health problems early. They frequently lack effective parental advocacy and, even when this is present, struggle to overcome prejudice from health care personnel when they do present with medical problems.

Looked after children

Approximately 480,000 children were known to child protection services in England in 2009. Of these 375,900 were defined as children in need, 39,100 were subject to a child protection plan and 64,400 were “looked after children”.¹⁶ The commonest reason for children to be taken into care is parental neglect, frequently secondary to parental substance misuse. These children may be malnourished, living in squalor and poverty and be at increased risk of TB exposure from their parent’s social contacts.

Unaccompanied minors entering the UK also fall into the “looked after children” group and as such undergo a medical assessment within 28 days of entering the care system. The RHA-YP and IHA-C Health Proformas.^{20,21} completed have specific prompts for BCG vaccination in children under 10 years but makes no other reference to tuberculosis. Children diagnosed to be at risk of TB at this assessment will be referred to the relevant local TB service.

Looked after children are highly mobile. 25% will be placed more than 10 miles away from their point of entry into the care system.¹⁶ On-going placement instability is also common and is associated with a lack of continuity of health and education services. This represents a challenge to the provision of optimal TB treatment with frequent missed appointments, loss of health information and interrupted treatment schedules.

The configuration of TB services for children

The provision and standard of care for children with tuberculosis varies across the country. There is widespread acceptance that both adults and children with TB should receive care from a local TB team. In addition NICE guidelines 2011⁷ recommend that children should be managed either by a paediatrician with specific training in tuberculosis or by a TB physician with input from a paediatrician. The care of children with TB is not always straightforward, however, and the relatively small number of children diagnosed with TB across the UK means that few doctors will have the opportunity to develop expertise in this area.

There is little doubt that children with TB from hard to reach groups struggle to access services. They have complex needs including the need for robust clinical expertise and appropriate pharmacy support. Care should be provided in a non-threatening child-friendly environment with access to specialist psychology and dietetic input. Children also require effective support from social services, housing and education. These services must be accessible and close to home.

In areas of high TB incidence where services are configured across a relatively small geographical area (such as London) specialist expertise in paediatric TB is relatively easy to access and maintain. But most strategic health authorities cover much larger areas with tertiary children's services sitting 60 miles or more from a child's home. Coupled with a lower incidence of TB in many of these areas, appropriate paediatric TB expertise may be difficult to access.

Other children with "rare" diseases frequently receive care either in a regional centre or in a local district general hospital with visits or input from a tertiary specialist team. These children typically differ from those with TB in that they have chronic illnesses lasting for years.

It is difficult to set up similar services for children with TB in low incidence areas because the child only requires treatment for 6-12 months and there may not be another case for months or even years. It is clearly unrealistic, however, to expect children from hard to reach groups to travel 60 miles or more to attend clinic appointments.

One solution may be to develop networked TB services across geographical areas similar to those currently covered by strategic health authorities. This would link services with paediatric TB expertise to services where TB is seen less commonly. The development of regional guidelines and care pathways would allow children to receive care close to home, whilst ensuring they had ready access to appropriate specialist advice and support where necessary. The addition of cohort review may further enhance the quality of care provided.

Endnotes

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- 3 Office of National Statistics Mortality Data 2005-2009
- 4 Schaaf HS, Marais BJ, Whitelaw A, Hessling AC, Eley B, Hussey GD, Donald PR. *BMC Infectious Disease* 2007(29);7:140
- 5 Lobato MN, Mohle-Boetani JC, Royce SE. *Pediatrics* 2000;106(6):E75
- 6 Treatment of Tuberculosis. Joint Statement of the American Thoracic Society, CDC and the Infectious Disease Society of America. *AJRCCM* 2003;167-603:62
- 7 *Clinical diagnosis and management of tuberculosis, and measures for its prevention and control*. Clinical Guideline 117. National Institute of Clinical Excellence, London UK 2011
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- 13 Consortium for Street Children 2005
- 14 Ministry of Justice data from 2009-10
- 15 Arnot et al. Research Consortium on Education of Refugee and Asylum Seeker Children. University of Cambridge 2003
- 16 Ministry of Justice data 2010
- 17 Department of Education data 2010
- 18 Royal College of Psychiatrists position statement 2011
- 19 Gypsy/Traveller numbers in the UK – a general overview: www.article12.org/pdf/GYPSY%20TRAVELLER%20NUMBERS%20IN%20THE%20UK.pdf
- 20 *Statutory Guidance on Promoting the Health and Well-Being of Looked After Children*. Department of Health

- 21 British Association for Adoption and Fostering. *Forms IHA-C and RHA-YP*. Looked after Children Review Health Assessment 2004

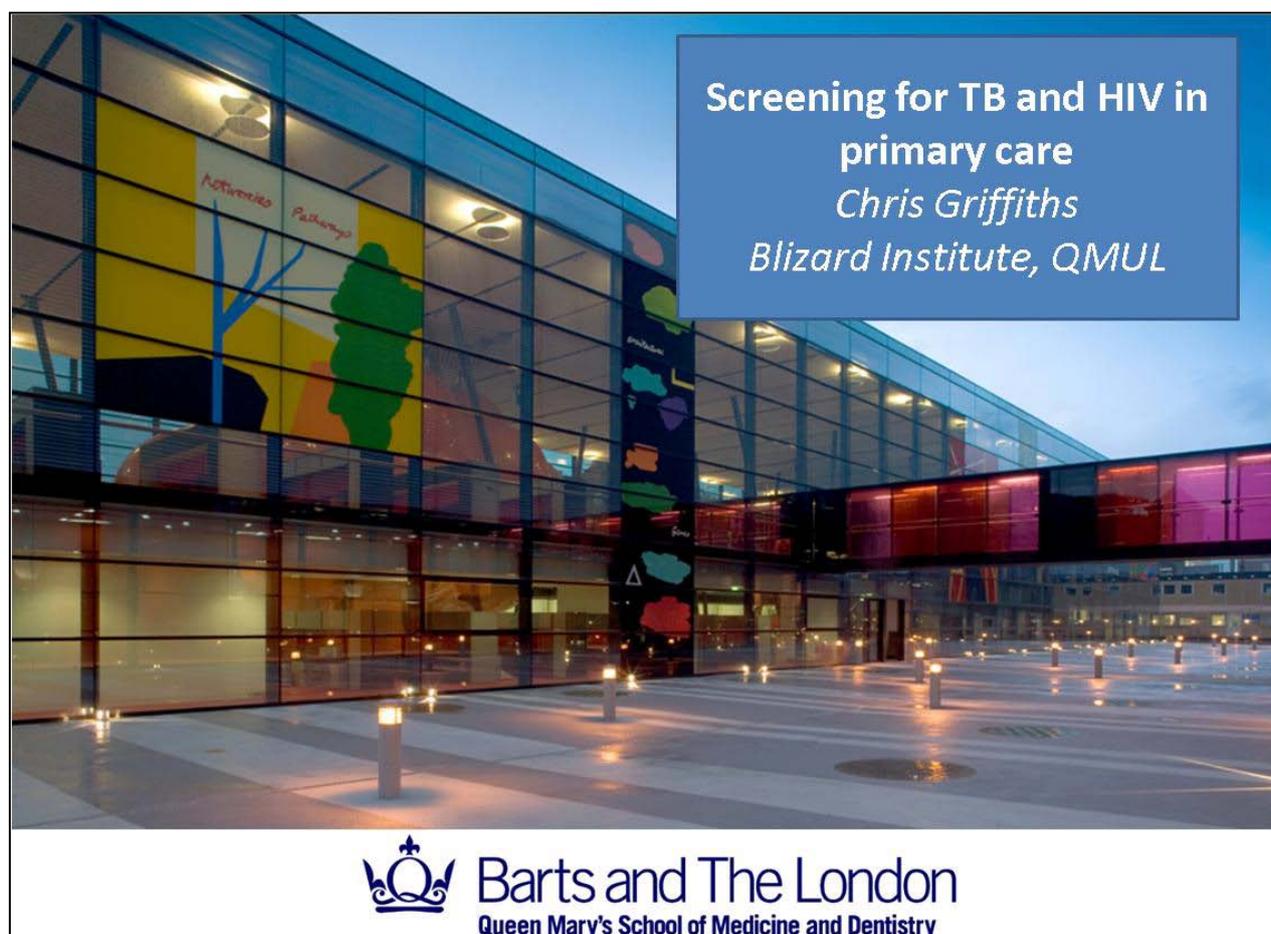
EP21: Screening for tuberculosis and HIV in primary care

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Chris Griffiths (Barts and the London School of Medicine and Dentistry)

Manchester, 8 June 2011

[A paper was requested. None was submitted, and the slides formed the basis of committee discussion]





Overview

- Screening trial
- Whom does it reach?
- Is screening effective?
- Is screening acceptable?
- Phase IV roll out – local enhanced service
- Screening for HIV

Griffiths 2007 Lancet.pdf - Adobe Reader

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Articles

✦ Educational outreach to promote screening for tuberculosis in primary care: a cluster randomised controlled trial

**Chris Griffiths, *Pat Sturdy, Penny Brewin, Graham Bothamley, Sandra Eldridge, Adrian Martineau, Meg MacDonald, Jean Ramsay, Suresh Tibrewal, Sue Levi, Ali Zumla, Gene Feder*

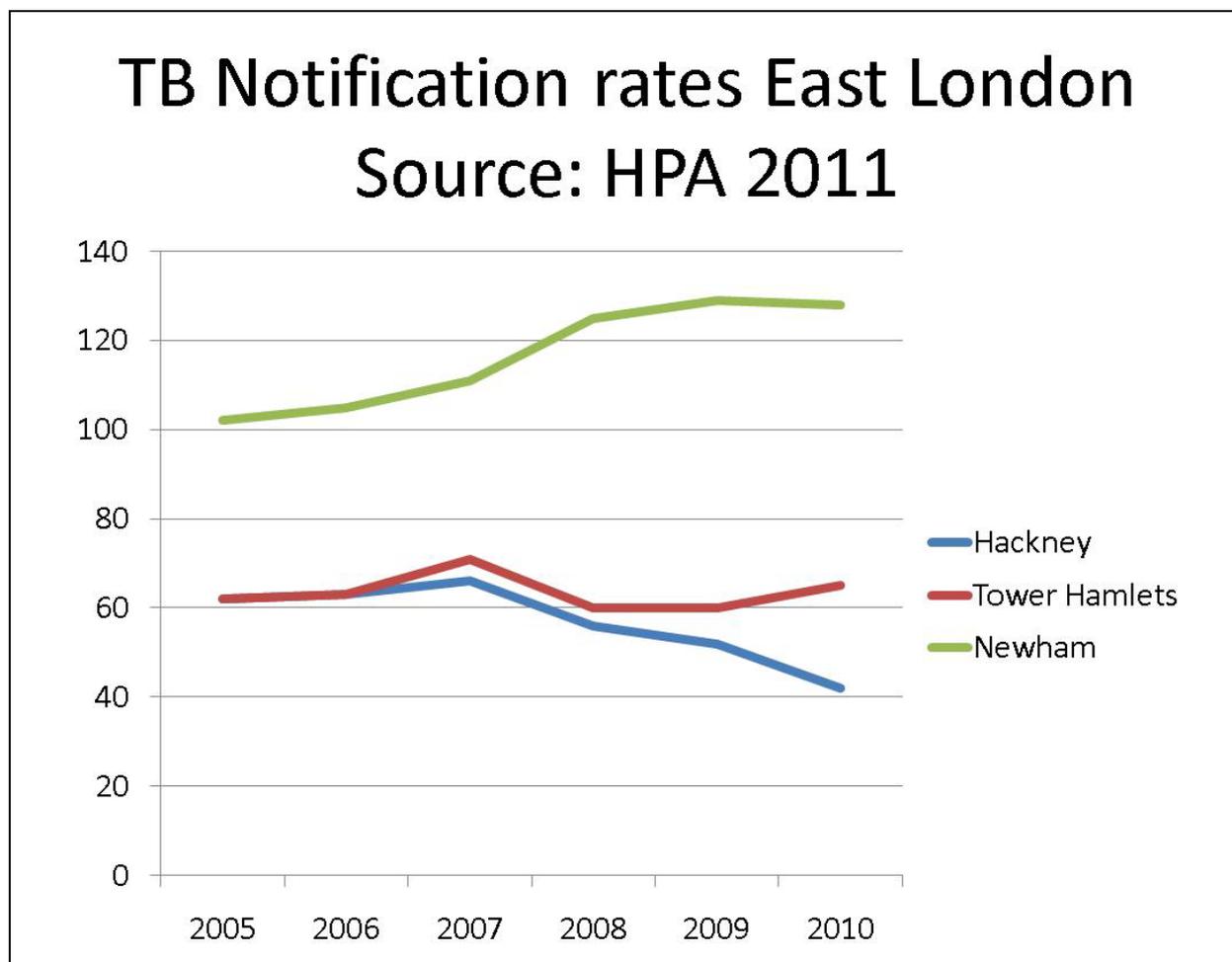
Summary

Background Tuberculosis is re-emerging as an important health problem in industrialised countries. Uncertainty surrounds the effect of public-health control options. We therefore aimed to assess a programme to promote screening for tuberculosis in a UK primary health care district.

Methods In a cluster randomised controlled trial, we randomised 50 of 52 (96%) eligible general practices in Hackney, London, UK, to receive an outreach programme that promoted screening for tuberculosis in people registering in primary care, or to continue with usual care. Screening was verbal, and proceeded to tuberculin skin testing, if appropriate. The primary outcome was the proportion of new cases of active tuberculosis identified in primary care. Analyses were done on an intention-to-treat basis. This study was registered at clinicaltrials.gov, number NCT00214708.

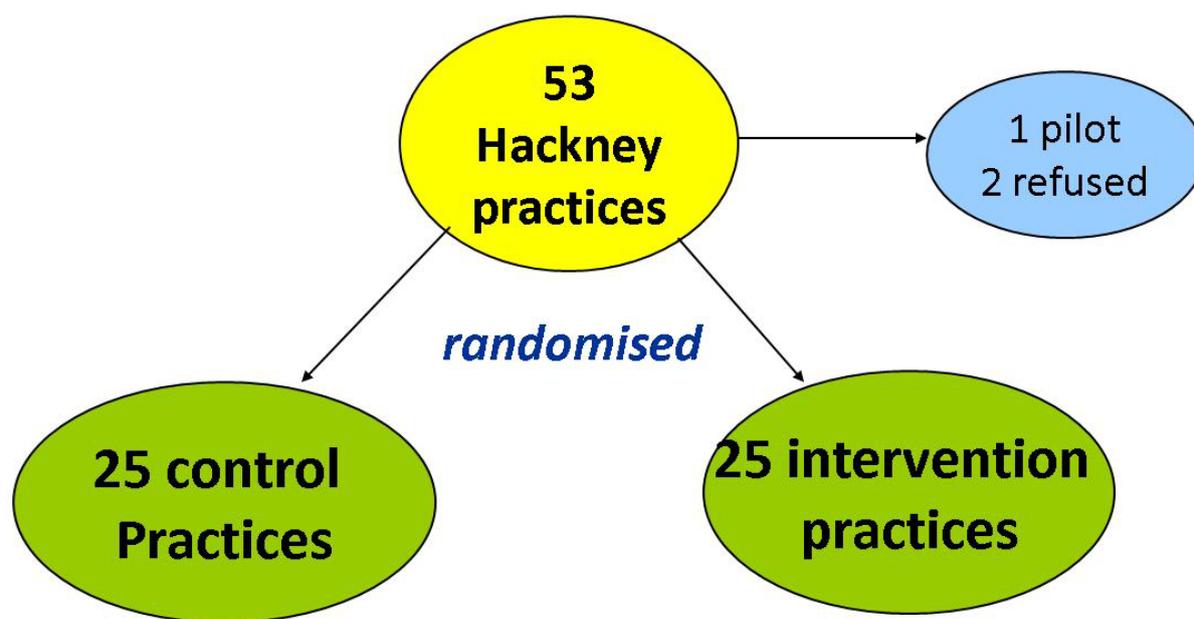
Lancet 2007; 369: 1528-34
 See [Comment](#) page 1493
 * Contributed equally to the study

Centre for Health Sciences, Barts and The London, Queen Mary's School of Medicine and Dentistry, London, UK
 (Prof C Griffiths FRCP, P Sturdy PhD, S Eldridge PhD, A Martineau MRCP, J Ramsay PhD, G Feder MD); Department of Respiratory



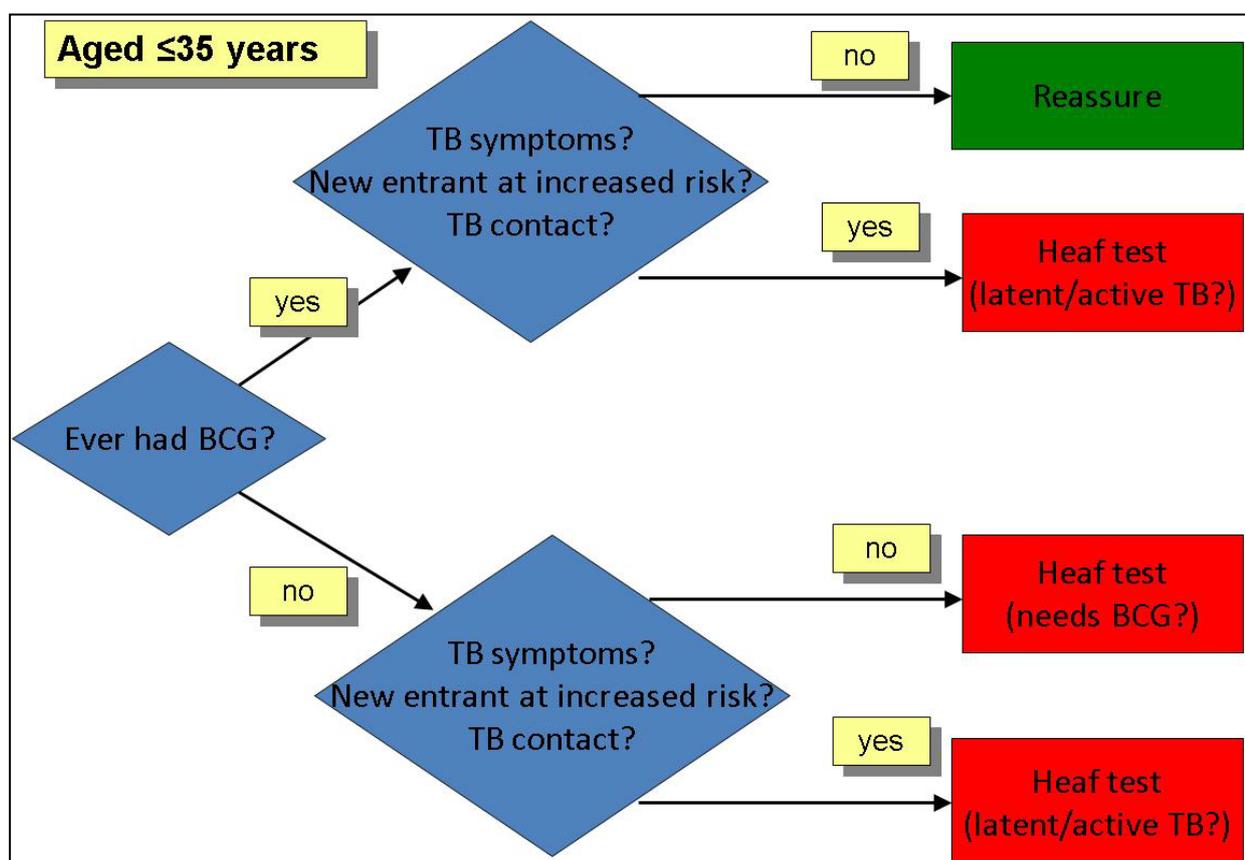


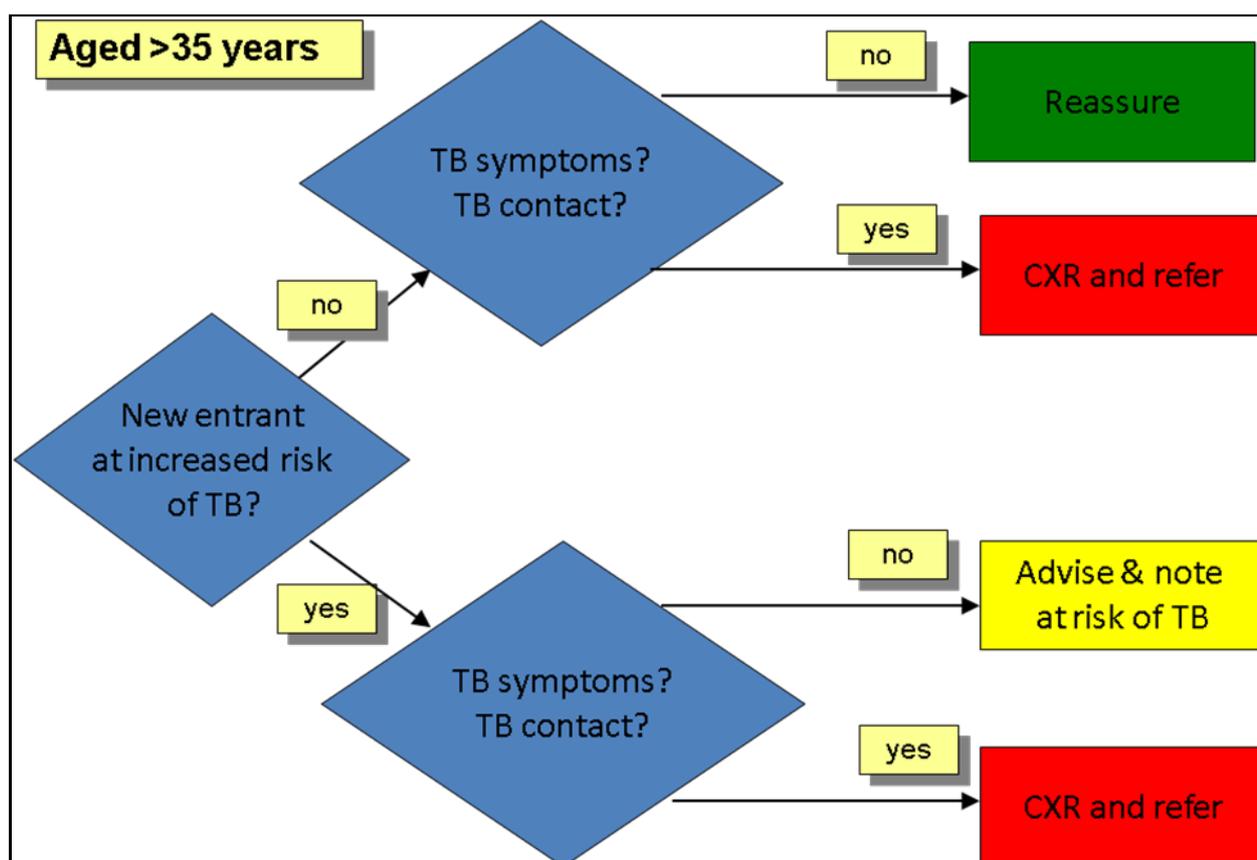
Can education to promote screening in primary care increase identification of TB?



Educational intervention

- Two lunchtime practice visits
 - To raise awareness and promote screening and opportunistic case finding
 - Theory based education
- Local guidelines
- Prompts to screen embedded in medical record
- Feedback
- Financial incentive for tuberculin tests done





Who is reached?

	Interven	Control
• Patients registering	121,291	116,780
• % white patients	51.6%	50.0%
• % black patients	31.6%	30.9%
• % S Asian patients	7.6%	9.1%
• immigrants/practice	248	272

Impact of education to promote screening for TB in primary care

- 17% increase in % cases of active TB identified in general practice
- 12% increase in % cases of latent TB identified in general practice
- 10-fold increase in BCG immunisation
- Non-significant reduction in diagnostic delay for pulmonary TB: 61 vs 28 days ($p < 0.1$)

Lancet 2007



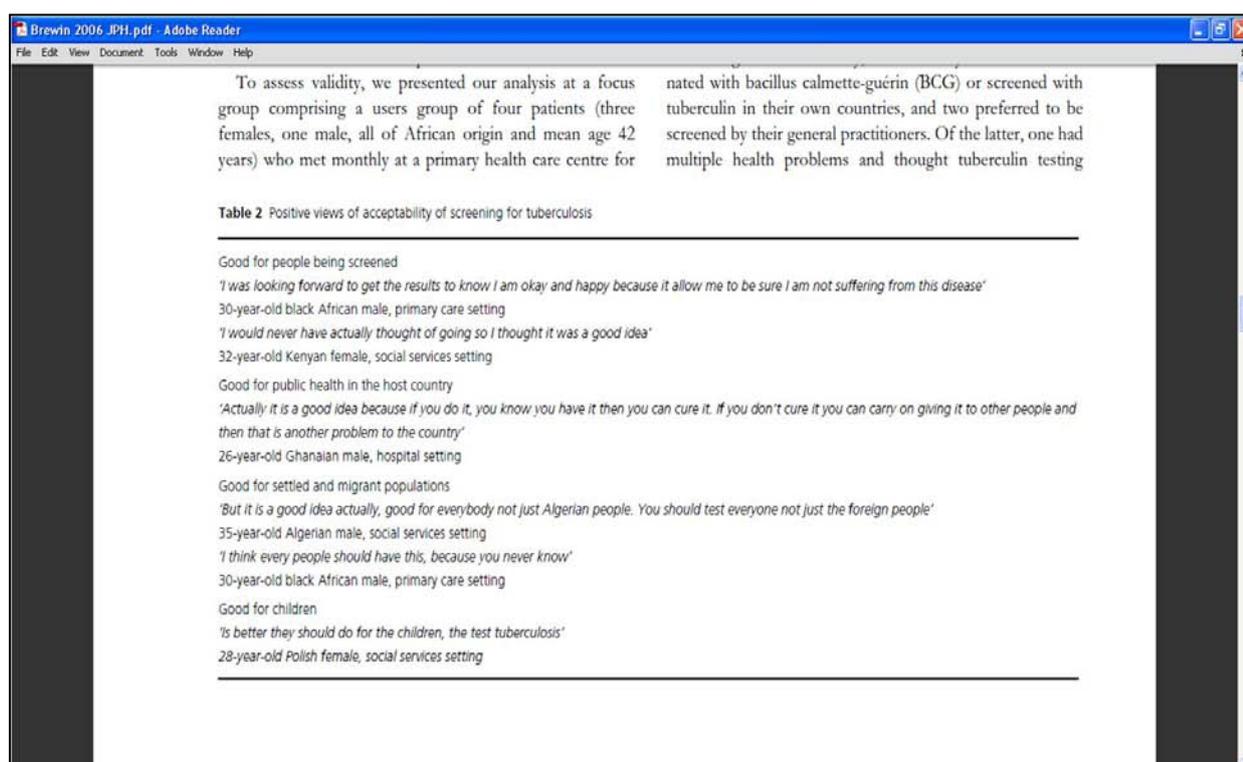
'Screening is a good thing'

'It is very good to come, to have that privilege'

43 yr old Ghanaian female, hospital setting

'I really like for the screening or testing'

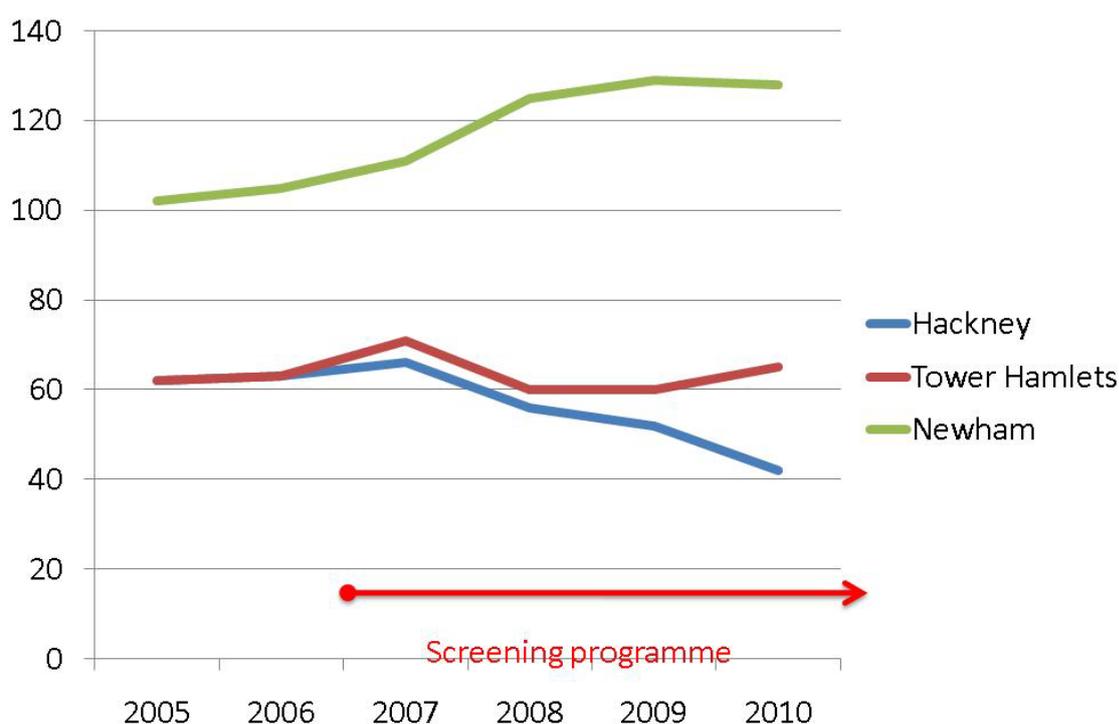
49 yr old Tamil male, Social services setting



Hackney PCT Local Enhanced Service for TB

- Introduced in 2006/7, 80% of practices (39/50)
- Steady increase in coverage since
- £210 paid per case active TB, £8 per Mantoux
- Costs between £30-39K/year to run
- Increases in number of cases active TB identified in primary care, from 51 up to 123 in 2009/10

TB Notification rates East London Source: HPA 2011



Trial of HIV Screening in Primary Care (RHIVA 2)

General Practice Training and Information Session



Prost 2009 STI.pdf - Adobe Reader
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Downloaded from sti.bmj.com on 11 August 2009



Feasibility and acceptability of offering rapid HIV tests to patients registering with primary care in London (UK): a pilot study

Audrey Prost, Chris Griffiths, Jane Anderson, Daniel Wight and Graham Hart

Sex Transm Inf published online 31 May 2009;
doi:10.1136/sti.2008.033233

Updated information and services can be found at:
<http://sti.bmj.com/cgi/content/abstract/sti.2008.033233v1>

These include:

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Characteristics of participants offered HIV screening

	Health check attendees (N=111)	Accepted a rapid HIV test (N=38)	Refused a rapid HIV test (N=45)
Age			
Mean \pm SD	33.4 \pm 12.9	32 \pm 8.58	34 \pm 14.7
Sex (%)			
Female	55.9 (62)	42.1 (16)	63.8 (30)
Ethnicity (%)			
Black African & Black Caribbean	18.9 (21)	31.6 (12)	19.1 (8)
White UK	30.6 (34)	28.9 (11)	38.3 (18)
White Other	32.4 (36)	28.9 (11)	27.7 (13)
Other	18 (20)	10.5 (4)	17 (8)
Ever tested for HIV			
Yes	38.7 (43)	42.1 (16)	53.2 (25)

Advantages

Reducing the wait for results

I think that what I remember about HIV tests was the wait. [...] I don't think that much can take away the stress of possibly testing positive for HIV, but I think that if you can close the gap between giving the initial sample and getting the result, it certainly would alleviate a lot of anxiety.

(Female participant, Canada, 35)

Primary care more accessible than sexual health clinics

You know, sometimes to go to some AIDS clinic, once you go there, people just know what you're [there] for. They know you most probably have some sexual disease going down there. [...] With a GP nobody knows, so you could be sick for anything. [...] So I think it's good if the GP has it. Nobody ever, ever offered me an HIV test. [...] They will only find out in the hospital when I'm sick [...] Before they find out, probably five, ten people, they've got it through me, but with a GP, you can easily find out [...]

(Male participant, Nigeria, 28)

Summary

- Screening for TB effective and acceptable in primary care
- Opportunistic and systematic screening means reaches some hard to reach groups
- Can be rolled out in routine practice – cheaply
- Complements other strategies such as Find and Treat
- Similar findings for HIV screening.....?



EP22: The Truth About tuberculosis awareness and advocacy programme

Paper presented to NICE Programme Development Group (PDG) on Identifying and managing tuberculosis among hard-to-reach groups

by Elias Phiri (TB Alert, Brighton)

Manchester, 22 March 2011

TB Alert has developed *The Truth About TB* awareness programme as the Department of Health's lead partner in delivering the TB awareness raising objectives set out in the TB Action Plan (2004) and TB Commissioning Toolkit (2007). *The Truth About TB* is a programme of work that brings together Primary Care Trusts (PCTs), Local Authorities (LAs) and the voluntary/third sector to raise awareness about TB among communities vulnerable to TB.

Figure 1 – Truth about TB logo



TB has been rising steadily in England for 20 years and is associated with health inequalities. The government recognises the role of third sector organisations (TSOs) in helping to reduce health inequalities. Such a role is set out in the TB Action Plan (2004), which strongly recommends the involvement of TSOs to support PCTs to: *Maintain awareness...and develop initiatives to support local awareness raising among high risk groups*. Many TSOs already work closely with the groups known to be at most risk from TB – substance mis-users, homeless people and BME communities – and are well placed to reach out to people who may have poor access to health services, and to understand and help dispel the stigma and myths that make some communities reluctant to come forward for treatment. Third sector involvement can thus increase awareness among the highest

risk communities, aimed at resulting in earlier presentation that lessens impact on patients' health and welfare and reduces levels of onward transmission.

Since 2008, TB Alert has been working with PCTs to encourage and support the development of relationships with the third sector, and local government, and to incorporate the social model of health – which goes beyond the clinical model to consider the wider socio-economic influences on health – into TB programmes. In 2010, TB Alert began to build the capacity of third sector organisations to become stakeholders in TB care and control programmes. We aim to develop a body of evidence to demonstrate to TB commissioners the effectiveness of a local partnership approach to address TB to meet calls in the TB Commissioning Toolkit for commissioners to develop: *sophisticated working relationships with partners in the local authority, the not for profit sector and voluntary organisations.*

To begin to engage the third sector in TB awareness, TB Alert launched 12 x TB awareness seminars for TSOs, which were organised in partnership with local PCTs, HPUs and appropriate TSOs. The half-day seminars provided a “high level” introduction to directors and programme managers of third sector organisations. Delegates learnt about the impact of TB on the communities and individuals their organisations serve, and the resources and support available to them through *The Truth About TB* programme. Local TB clinicians, local PCT managers and former TB patients gave presentation at seminars, alongside TB Alert staff, to provide a wide-ranging but locally specific overview of the issues including: DH national TB framework; a clinical overview of TB; local TB demographics issues; an overview of the TB pathway and services; and a service user perspective. The TB awareness seminars were delivered in Bradford, Leeds, Manchester, Birmingham, Blackburn, Bristol and the five TB sector areas in London. Over 400 delegates attended and the feedback from the seminar was very positive.

The second phase of building TB capacity in TSOs is the delivery of TB training workshops and development of TB resource packs. In June/July 2011, TB Alert will deliver TB training workshops to provide more in-depth knowledge and guidance for delivery staff of organisations that wish to participate in *The Truth About TB* programme. The sessions will include information on how organisations can integrate TB programmes into their own programmes and raise TB awareness within the communities in which they work. The workshops will also provide TSO staff with the awareness and skills they need to develop and deliver their own independent TB awareness raising programmes, whilst working with their own communities and to participate with confidence in TB networks. Participants will receive a resource pack including ideas for developing local TB awareness programmes, speaking notes, presentations, national and local statistics, and tips for generating local news coverage.

TB Alert has also developed two core TB awareness materials that are supporting *The Truth About TB* programme: “*The Real Story*” DVD and the www.thetruthabouttb.org website. *The Real Story* is story of five ex-TB patients’ journeys through TB, from their experience of early symptoms to their diagnosis and treatment that put them on the road to recovery. The DVD is in English and dubbed into eleven other languages common among communities vulnerable to TB in England. The website contains key information in easy to read English.

A monitoring framework has been developed to monitor and evaluate the role of TSOs with a view to them being local commissioned to deliver awareness programmes to communities at risk to TB. TSOs participating in *The Truth About TB* programme are fully briefed by TB Alert on monitoring their programmes.

Patient involvement and support is a key element of the TB Alert’s work. A Patient Support Fund helps especially vulnerable patients through TB treatment by, eg, provision of a bus pass to enable travel to the clinic for DOT. TB Alert also supports the TB Action Group (TBAG), a network of people who are or have been affected by tuberculosis. This provides a voice to people in the UK who have valuable insight into TB services. Four main areas of TBAG’s activities are: advising NHS on service design and delivery; raising awareness of TB; peer support; lobbying.

World TB Day (24th March) is an important opportunity to raise TB awareness amongst communities at risk to TB and the general population. In the past TB Alert has focused on supporting TB nurses and other statutory organisations with TB awareness resources. This year, TB Alert is working with TSOs and TB nurses to hold joint World TB Day events. This is also an opportunity for TSOs to start integrating TB programmes in their programmes of work.