

Appendix G7 Service Delivery Expert Papers (EP) 1 to 12

Contents

EP 1 Practice - Emergency departments	3
EP 2 Rurality and Service Delivery	7
EP 3 North West TB Network: Paediatric TB specialism and a Hub & Spoke delivery model	14
EP 4 Practice - the Leicester experience including rapid radiology referral model	19
EP 5 Cancer networks	24
EP 6 Practice - the Birmingham experience	48
EP 7 Contact Tracing – incident investigation process in congregate settings	58
EP 8 Practice – Experience of people who use TB services.....	63
EP 9 Accommodation, Housing and TB.....	68
EP 10 MDR-TB networks/access to specialist advice (National Advisory Service).....	72
EP 11 Policy Update – National TB strategy and TB Control Boards	75
EP 12 TB and HIV collaborative commissioning.....	76

EP 1 Practice - Emergency departments

Section A: CPH to complete	
Name:	Barbara Cleaver
Job title:	Emergency Department (ED) Consultant
Address:	
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Practice - ED experience
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) How does ED link with TB services in your area? Why are they set up this way? In your view, is this usual practice or specific to your area?</p> <p>2) What are the challenges associated with identifying TB in ED in your area, and with getting people with suspected TB into appropriate diagnostic / care pathways?</p> <p>3) What are the opportunities and benefits of the way that ED links with TB services in your area?</p> <p>4) What, in your view, could be changed or improved in how people presenting with TB symptoms in ED are assessed, managed and referred in order to reduce time taken for diagnosis? Is there evidence to support your suggestions?</p> <p>Elements of particular relevance such as: inequalities, demographics, geography, variations due to differences in active TB rates, MDR and LTBI, and accountability arrangements are of great interest especially any evidence or opinion on the following:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches 	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your

testimony in 250 – 1000 words – continue over page if necessary]

Question 1: Referrals to TB services are generally made (9:00 – 17:00) to the TB nurses. If a patient requires admission this is done via the acute medical on-call team. Out of hours an ad hoc TB referral system is in place in some hospitals which might include faxing a copy of the ED notes to the TB team.

Question 2: Challenges include: the need to increase awareness of TB amongst ED physicians, lack of point of care diagnostics, patients who are 'hard to reach' (especially those with drug and alcohol misuse) are often treated without thinking of TB as a potential diagnosis, time constraints within the ED.

Question 3: There is the opportunity to use ambulatory care pathways to give clinicians more time to establish a diagnosis and liaise with TB services.

Question 4: Improved referral pathways, point of care testing and increased awareness of patients in 'hard to reach' groups would help improve the service ED provides.

Additional questions asked by the committee:

- a) A 50% suspicion to diagnosis conversion rate in ED is high. GPs are only around 10% suspicion to diagnosis conversion, so ED is clearly an important setting. How well do you think your colleagues understand the social factors about TB?

The diagnostic accuracy percentage was based on a single audit – it may not be fully representative. I think better education especially for the specialist registrars in Emergency Medicine may improve the understanding of social factors involved with TB.

- b) What do you think about opportunistically screening on the basis of social risk factors in ED?

In hospitals servicing an area with high TB prevalence screening for TB could be beneficial.

- c) In London about a third of TB patients come through ED – how many do you think should have been diagnosed earlier – do you think some would be held onto unnecessarily?

Anecdotally I think many patients could be diagnosed earlier when they present to either the ED or UCC. Once the diagnosis of TB is considered it is routine practise to refer the patient to TB specialists.

- d) Waiting times for consultants to get back to ED staff on specialist issues how do you deal with this

Most abnormal diagnostic test reports are seen by ED consultants and/or ED Specialist Registrars within a 48 hour period and should be acted on according to need. This is a governance issue for each department.

- e) Migrant population might find it difficult to go back, what would you advise?

I would advise setting up ambulatory care pathways so that patients have a clear date and time when they leave ED in order to get further tests. It may be possible to book transport for them to return in some circumstances.

- f) What do you think about incentives to get people to come back

Good idea. Perhaps some of the TB charities could consider funding this initiative

- g) In a migrant population there may be a language problem, what issues do you think this presents and how do you overcome this

The ED frequently sees patient with language barriers, we use in-house interpreters or language line.

- h) You must see quite a few patients with no address, no GP – what do you do?

The safest option in this scenario is to either admit the patient for investigations or use ambulatory care pathways whilst also helping the patient to register with a GP.

Additional costing information supplied to assist with cost impact analysis:

A retrospective cohort analysis identified 154 patients diagnosed with TB over a one year period within the inner London region. All patients attended ED at least once within 6 months prior to diagnosis. This retrospective analysis specifically looked at ED attendance at St-Mary's and Charing Cross hospitals which formed part of the Imperial College NHS Trust.

The following questionnaire was submitted to the ED Consultant responsible for St-Mary's (SMH) and Charing Cross hospital (CXH) and undertaking the analysis. The questionnaire was completed through a telephone interview.

- 1. What is the total number of patients diagnosed with TB over a one year period and seen within one of the EDs at the two sites at least once 6 months before diagnosis?**

154 patients presented to either CXH or SMH over a one year period who were subsequently diagnosed with TB. These patients presented to ED at least once six months' prior to the diagnosis date. This included 75 pulmonary and 79 non-pulmonary cases.

2. What is the diagnosis conversion rate?

Based on Imperial audit data we believe the diagnostic conversion rate is approximately 50%. As far as I'm aware there is no published data on this in the literature for the UK.

3. Based on this can you suggest the total number of suspected cases referred from the EDs to a TB clinic within a year?

In my experience roughly 3 suspected cases are seen over a week at each site. Therefore it is reasonable to assume 308 suspected cases will be referred through the Direct ED Referral Programme to a TB clinic to diagnose 154 TB patients.

4. What proportion of those diagnosed with TB attended ED multiple times prior to diagnosis?

Total = 41 re-attending (27% of diagnosed cases).

20 pulmonary and 21 non-pulmonary patients presented to the ED more than once before being referred to TB services. The average number of re-attendances by these patients was between 2-5 attendances.

5. What is the cost incurred to the emergency department in ensuring direct referral from ED of all suspected cases (308) to a TB clinic after their first visit to ED?

I have spoken with our business manager who agrees the figure of band 6 Administrator salary (if it includes London Weighting). However, it will not take more than 10% (0.1 wte) of their time to ensure direct referral.

Also 15 minutes is an appropriate additional time for a clinician to make a referral to TB services.

6. What is the low, medium and high ED attendance tariff cost and which one is most relevant for an average suspected TB case?

For the 'potential TB patients' the majority will either be Category 3 with 1-3 Tx = £151 or Category 2 with 1-2 Tx = £112.

7. Finally are there any other quantifiable cost savings from diagnosing TB earlier through direct ED referral to TB clinic (other than preventing additional ED visits)

I'm not sure if the data exists. But of the patients with pulmonary TB not picked up in ED - did any of them go on the infect others that were picked up in contact tracing? This would help to think of the cost of onward infection.

References (if applicable):

EP 2 Rurality and Service Delivery

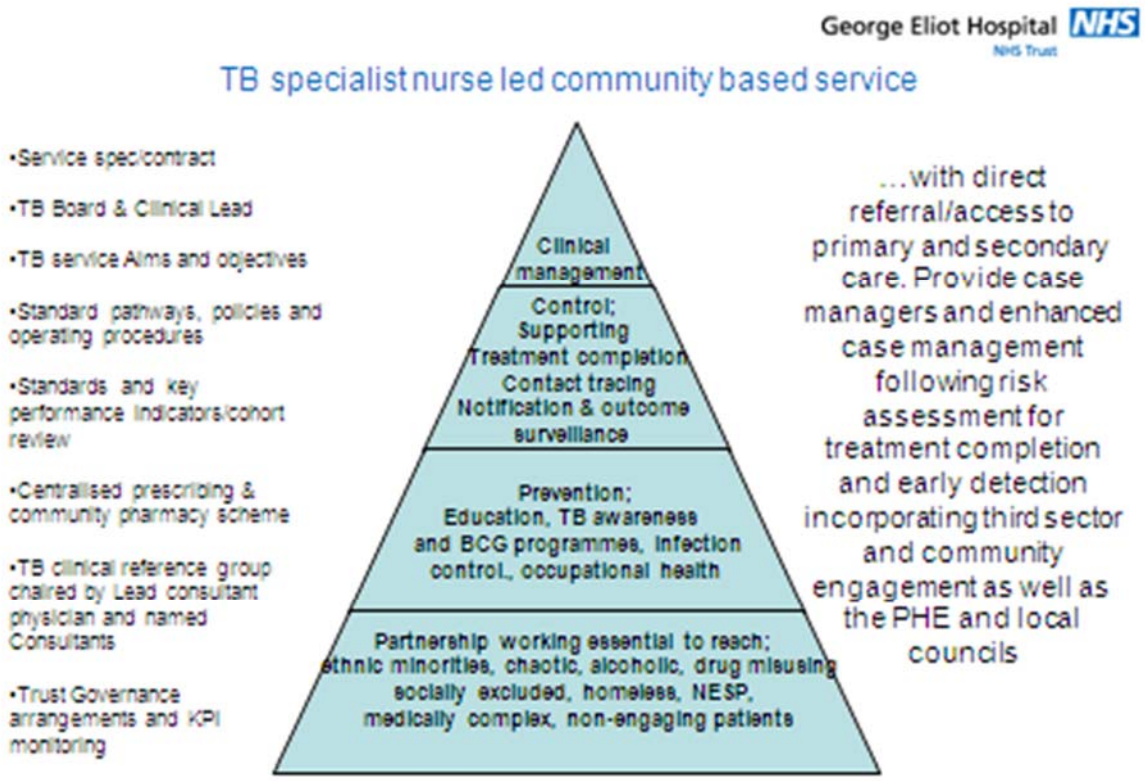
Section A: CPH to complete	
Name:	Debbie Crisp
Job title:	Lead TB Nurse Specialist
Address:	Arden Community TB Service City of Coventry Health Centre 3rd Floor, Room 3021 Stoney Stanton Road Coventry CV1 4FS
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Rurality and Service Delivery
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) In your view, what are the challenges for rural TB services around England?</p> <p>2) How are TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured?</p> <p>3) What are the advantages and challenges of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve (do you have any specific examples)?</p> <p>Elements of particular relevance such as: inequalities, demographics, geography, variations due to differences in active TB rates, MDR and LTBI, and accountability arrangements are of great interest especially any evidence or opinion on the following:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches 	

Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
<p>A mapping exercise of TB service provision in Coventry was undertaken in August 2007 by Lead TB Nurse Specialist in Warwickshire with an option appraisal was undertaken using <i>Stopping TB in England Action Plan</i> (2004) as the gold standard; option three was recommended to provide the full range of services recommended in the Department of Health Commissioning Toolkit to permit effective, quality patient centred care, necessary to manage and the high and increasing rates of TB in Coventry and <i>TB commissioning toolkit</i> (2007) identifies merging low and high TB incidence services together. In 2011 the SHA recommended combining Coventry and Warwickshire TB services based on the <i>Department of health Transforming Community Services; strategy to integrate services (2011)</i> and the Community Service TB service social model was adopted (fig one).</p> <p>The challenges facing rural communities can mirror those in the urban communities but the distances covered (and sometimes the weather) i.e. 60 miles from north to south Warwickshire and 40 miles west to east pose significant resource implications. A TB nurse can claim 300-600 miles a month travelling to see patients across Warwickshire despite careful planning. Crossing the area are main transport routes such as the A5, M6, M40 and M42 where there can be considerable delays. The team will make contact on the phone and try to arrange to speak to wider family members in the home when they make their follow up visits between outpatient appointments. Patients report difficulties accessing TB clinics/expert services as well as phlebotomy and radiology so for example, LFT's may not be repeated and patients being reintroduced to medication may have to be admitted to monitor their bloods daily; yet the TB team would not usually take enough bloods to maintain their competency.</p> <p>Careful risk assessment for staff safety is undertaken prior to home visits and consideration and provision is required for Lone working, identifying safe venues for DOT's, meeting contacts etc. some patients are identified to require a joint visits by a nurse and a support worker and expect to be seen out of work, school etc. so some flexible working is required. Recently we screened 100 night shift workers at 3am ensuring full attendance and screening completion.</p> <p>Challenges around maintaining TB awareness/local pathways in the NHS and wider community take time and sustaining leadership and commitment/continuity to the TB management and control strategy is key. Furthermore, the wider role of the community TB team has to be considered as planning skill mix and patient / nurse ratio's need to include these activities not otherwise undertaken by any other service;</p> <ul style="list-style-type: none"> • Screening out of area referrals <ul style="list-style-type: none"> • Education and awareness for health professionals and communities • Incident management and liaison with PHE (screening on site, teleconferences; reports; liaison with partners) <ul style="list-style-type: none"> • New entrant screening/targeted screening high risk <ul style="list-style-type: none"> • Attend MDT and TB CRG, Strategy groups etc • Safeguarding children and adults referrals and meetings <ul style="list-style-type: none"> • BCG provision, awareness and training • Following up bovine TB contacts – animal contacts (farms & pets) <ul style="list-style-type: none"> • IT skills for reports > KPI's for commissioners <p>Commissioners need to agree a contract (service level agreement) for providers with identified budget lines. Irrespective of how many cases there are, there must be a named lead with expert clinicians providing safe, quality, evidence based, equitable, accessible services within suitable clinical governance framework appropriate to local need, performance managed by quarterly reporting KPI</p>	

back to commissioners.

Success = TRAVEL TO THE PATIENT persistence paid off managing an outbreak across a rural setting in 2005-8 as shown with hard to reach, chaotic patients; you have to go to them, they will not come to you. Clinicians working with partners in the wider community with a centrally co-ordinated approach achieved control.

Figure one



Community based TB service Social Model; Core business

Additional questions asked on the day (Debbie Crisp):

a) Partnerships and relationships appear to be very important... what makes for a successful partnership? Clear service agreements?

We have a TB clinical reference group chaired by a Consultant Physician agreeing pathways at an operational level and report to the Arden TB Board chaired by the Director in Public Health, Local Authority who reports to the Health and well Being Board across Coventry and Warwickshire. These formal groups maintain links with necessary partners across the health and social care domain. TB case managers work with third sector colleagues directly to improve the quality of patients' lives enabling them to adhere to the TB treatment. Considerable effort is required to keep the community engagement agenda progressing and requires partnership work between the TB team, Public health England, the Public Health local Authority and third sector.

b) The service you describe seems like a hub and spoke model but a little different – usually the lead clinician (the hub) is the one who has most cases (so would probably be the one in the city), but your lead clinician is rural - has this made a difference with you being a rural service?

The Lead Clinician was appointed as they are from the same employing Trust as the Community TB team. With the appropriate reporting mechanisms described above and agreed terms of reference the chair simply chairs the meetings and all Clinicians have equal input.

c) Ownership of contact tracing, and governance of this process. Where does it sit? Especially if it crosses geographic boundaries

The Community TB team is hosted by the George Eliot NHS Trust and we follow their Governance arrangements as well as the RCN TB case management & control guide. Our Service Level Agreement determines our boundaries and we are clear about providing a service for residents of both Coventry and Warwickshire. Where residents from other counties work in large factories for example in Coventry or Warwickshire, we liaise with the partner services and usually come to an agreement that we offer patients screening either locally to their work or home and refer across as necessary. Once screened if referral to a TB clinic is required we inform the patient from the outset they will be referred to their clinic nearest to their home.

d) You reported a contact index that is double what we achieve in London – how?

The TB nurses are responsible for screening contacts of their index patients. We work similarly to the RCN guide mentioned above. We persist and go to extra lengths to get individuals screened and are more successful when we have either met the contacts in clinic, at home or in the wider setting (large groups that make up an 'incident' where PHE are involved. Our support workers have a system for reviewing screening results and report to the case manager outstanding reports. We telephone the patient, understand the problem and try a different approach ie. CXR rather than IGRA. We inform the GP and patient of all screening results and ask GP's to discuss the risk with their patients especially if they had been exposed to smear positive pulmonary TB.

Finally, the committee were very interested in your testimony on admin support and we wondered whether you would be able to provide us with some additional information on this aspect of your evidence to help us to work out the potential costs and benefits of this approach, below are a number of questions devised in discussion with our senior costing analyst about this topic:

Costing questions - For admin support (rural service):

- **How many hours of admin support do you think you need and how much do you get (approx. hours per week)?**
- 75 hrs

- **What activities does the administrator do, and what does this free you up to do?**
- The Administrator - provides all the secretarial and admin support to each individual TB nurse, (this includes drafting letters, filing, faxing, emails), maintains electronic diary with clinic rosters, annual leave and study records, prepares staff rota for clinics and DOT's, deals with all phone calls as necessary, acts as the first point of contact with internal and external enquiries uses own initiative, takes messages and redirects queries as necessary.
- Assists the TB lead in undertaking citywide project work as and when, co-ordinate meetings, books hospitality, collates agenda items, attend meetings, take minutes, type and produce finalised minutes and distribute.
- Ensures that filing and resource management for the TB team are undertaken in a timely manner, delegate's tasks to support workers.
- Enters data for sick leave and Annual Leave, attends Building Users Meetings (for base) and feeds back to the team at the weekly team meeting, keeps minutes for meetings and reports monthly data to GEH Trust Board.
- Ordering of all medical stock and stationery supplies
- Organises training for team (ie mask fitting, alcohol training, CPR etc)
- Passes on information on a need to know basis to other members of the team.
- Participates in induction and training of new staff (clerical) in the absence of TB Lead.
- Oversees the smooth running of all the clerical/administrative tasks/projects.
- Oversees the support workers and delegate to them
Makes up the clinics and prepares the clinic letters
Act as receptionist at TB nurse screening clinics for children
Support nurses on projects in and out of the office as required

The TB support Workers

- Attend weekly TB clinics and check vision, check patient details for the TB nurses records
 - Undertakes risk assessment with TB nurse and either visits alone or with the nurse daily, weekly or how ever instructed at patients home or other appropriate venue.
 - Liaises with TB nurses around patient prescriptions and co-ordinates collection and drop off to community pharmacies supplying patient meds.
 - Communicates to patient to collect own meds or delivers in dossett box when undertaking DOTS
 - Looks up screening results for TB nurses and follows their instruction to generate outcome letter to patient & GP.
 - Ensures local database completed and all TB cases are notified on ETS so quarterly reports can be generated with KPI's for Lead nurse
 - Liaises with PHE and supports nurses with data collection TB for cohort review
- **Third Sector** – Citizens Advice team will advise & support TB patients with housing, employment, sickness, financial and benefit needs
 -

- **How has having admin support helped improve patient care?**

-
- o Can you see more patients?
- o Does it help with contact tracing – if so how?
- o What about cohort review work – does it help support this?
- o Overall what has the impact been for you, your patients and the service?

Most certainly as illustrated below the records and information gathered and shared are central to the TB service.

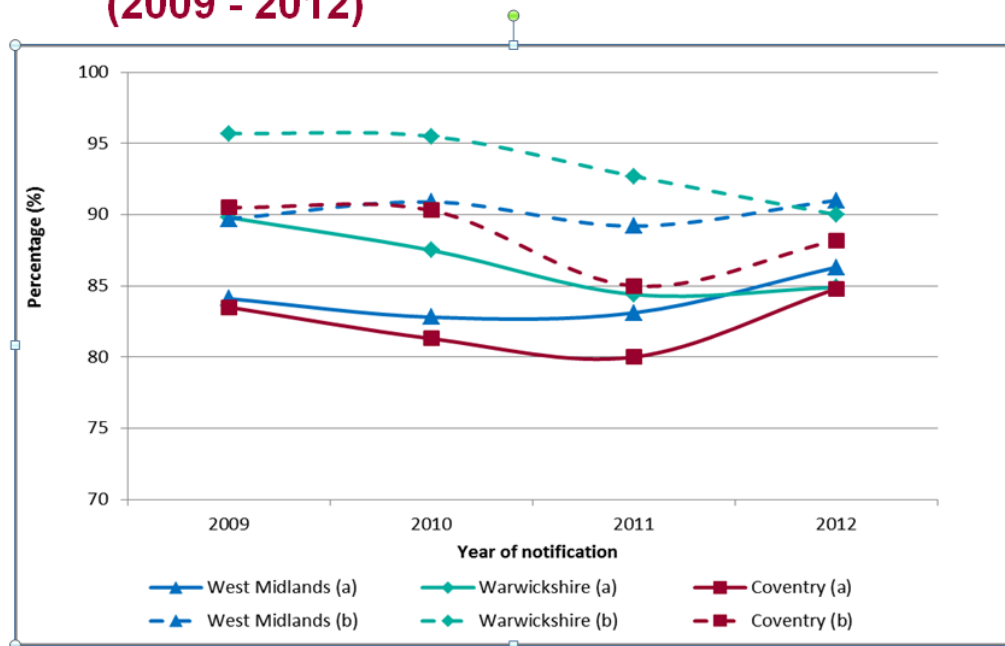
Before the teams merged together the two full time nurses in Warwickshire had no access to clerical support and struggled to ensure the ETS was completed and screening outcome letters were generated in a timely fashion. They had no support from anyone to jointly visit patients and had to write their own minutes and reports.

The BCG programme was and still is, supported by the child health service in Warwickshire who make appointments and record vaccinations to report on the KC50 return. Without this the TB nurses were unable to provide a BCG programme at all.

This significant contribution from the administrators and support workers permit the TB nurse specialists to utilise their expertise in ensuring high rates of patient treatment completion and contact screening completion.



Treatment completion in Coventry, Warwickshire and the West Midlands (2009 - 2012)



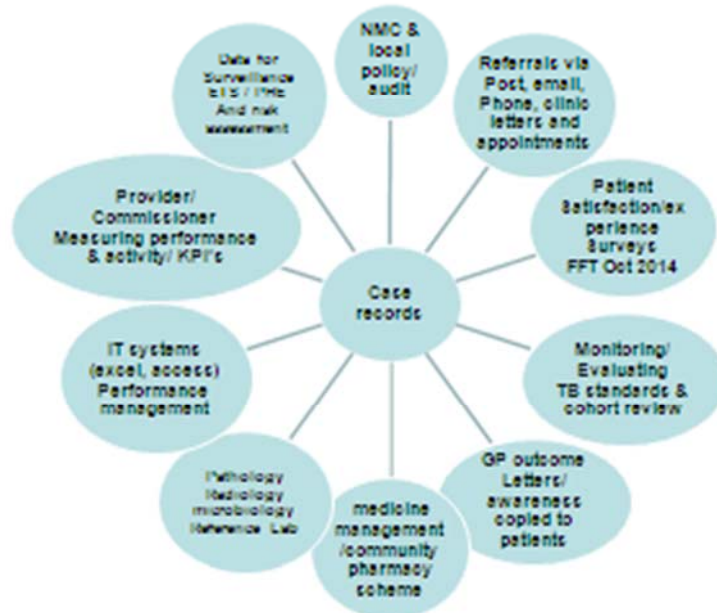
a: % completed treatment of all cases; b: % completed treatment of all cases excluding died and transferred

Data sources: Enhanced Tuberculosis Surveillance (ETS) downloaded on 3rd September 2014.

Prepared by: Field Epidemiology Service (Birmingham), Public Health England

RECORDS/Information for Action

Administrative support essential



References (if applicable):

EP 3 North West TB Network: Paediatric TB specialism and a Hub & Spoke delivery model

Section A: CPH to complete	
Name:	Paddy McMaster and Fran Child
Job title:	Dr Paddy McMaster - Consultant in Paediatric Infectious Diseases Dr Fran Child – Consultant in Paediatric Respiratory Medicine
Address:	Paddy McMaster - Limbert House, North Manchester General Hospital. Fran Child - Royal Manchester Children's Hospital (RMCH), Oxford Road, Manchester, M13 9WL
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Paediatric TB specialism and a Hub & Spoke delivery model
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) How are paediatric TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured?</p> <p>2) What are the advantages and challenges of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve?</p> <p><i>We would be keen for you to have discussions with your network (if possible/practicable) in preparing your response to gain as broad an insight as conceivable regarding your model.</i></p> <p>Elements of particular relevance such as: inequalities, demographics, geography, variations due to differences in active TB rates, MDR and LTBI, and accountability arrangements are sought specifically evidence or opinion on:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches 	

Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
<p>The North West is a large geographical region comprising both low and high incidence TB areas (mean incidence 11.3/100,000; Manchester and Blackburn 40/100,000). It has the 4th highest incidence of TB in the UK with 769 cases per year of whom 60-70 are children < 16 years. Incidence in children tripled from 2003-11 but is now starting to fall again.</p> <p>There are 2 regional centres (AlderHey and Royal Manchester Children’s Hospitals) and 25 District General Hospitals seeing children. The maximum distance between a DGH and a regional centre is 60 miles. The paediatric TB service at RMCH sees 60% of all paediatric TB cases in the area. From January 2009-11 RMCH received 949 referrals of whom 725 were screened and 251 underwent consultant assessment. Of these 77 had latent Tb and 107 had Tb disease. We were also involved in the management of 2-6 Tb incidents involving children / year. With this increasing workload we recognised that standards of care were quite variable around the region with some children experiencing incomplete initial assessment leading to difficulties in their later care. There were delays in both diagnosis and treatment and some children were receiving non-standard treatments. We had 2 paediatric deaths and 5 cases of TB meningitis in 3 years and many children were travelling long distances to receive care.</p> <p>Under the umbrella of the North West TB summit (a group of interested clinicians, Tb nurses, public health and health protection teams) we undertook a detailed review of paediatric TB services in the North West. In most cases care was being delivered by a paediatrician with specific expertise or an adult physician with paediatric input but many of these would only see a paediatric case once every few years. Services were generally poorly resourced, supported by solo clinicians and nurses and had difficulty in providing timely surge capacity.</p> <p>We defined the best model of care to be one with consistently high standards, multidisciplinary expertise, access to specialist investigations and support, rapidly and readily accessible with surge capacity and regular review of performance and outcome. The delivery of such a model was discussed at a stakeholder meeting with Tb nurses, paediatricians, health protection and public health teams and commissioners from around the region. It was agreed that a hub and spoke model would best meet the needs of the children and this was further developed and shared with the district paediatricians for comment.</p> <p>The hub and spoke model comprises 3 levels of care:</p> <p>Level 3 (tertiary centre) – leads the network and leads the care in all children with non-pulmonary, non-lymph node disease.</p> <p>Level 2 (DGH provides the majority of the care) is divided into 2 subgroups</p> <p>Level 2a – DGH leading the care – where there is a critical mass of patient and clinician expertise</p> <p>Level 2b – DGH provides the care – where the DGH is a long way from the centre but there is little clinician expertise and few patients. The regional centre will lead the assessment and treatment and work in close liason with the DGH</p> <p>Level 3 – DGH does not provide care - DGHs where there is little expertise and DGH is close to a regional centre</p> <p>All hospitals work to a common evidence based pathway including quality measures (such as wait times) and an assessment proforma for those with suspected TB disease. There are defined points of integration between primary and secondary care and clear roles and responsibilities for all staff.</p> <p>This model has been piloted at RMCH and 3 DGHs in Greater Manchester over the</p>	

last 12 months. It has generally worked well with feedback from DGH clinicians that they and their patients prefer straightforward cases to be cared for locally but they require more support with atypical, non-pulmonary, complex, young (<2 years), co-infected or MDR cases. They appreciate email and telephone communication and prompt access to advice when needed. They require help with specialist investigation such as bronchoscopy, biopsy or induced sputum and need access to specialist tertiary services such as neurology, spinal teams and PICU. They recognise the importance of TB nurses and cohort review although they struggle to attend due to other service pressures.

We are now in the process of formally commissioning the service for roll out across the region. We need to identify a level 2 spoke in the North of the region and identify methods to ensure effective review of paediatric outcomes across the whole region. This is only partially addressed by cohort review in its current form.

Answers to committee questions:

- a. Paediatric numbers have fallen significantly since 2011 (by 49% across North West, by 36% attending RMCH). This cannot fairly be attributed to the paediatric network as this is reactive rather than proactive. There has been an associated reduction (although less marked) in all Tb cases across the region and the country. The Tb summit has done some work on raising awareness in local communities and with health professionals which may have resulted in earlier diagnosis in adults with consequently less transmission. It is likely that patterns of migration play the biggest role
- b. Although 60% paediatric TB cases are treated at RMCH we do not treat 60% of all latent disease. The latent TB treated at RMCH is from our local catchment area in central Manchester. Most DGHs are happy to treat latent TB without reference to us.
- c. Diagnostic delay is a significant problem. Despite 3rd sector work, a combination of stigma and a lack of awareness of the potential for poor outcomes in children mean that some families present late. More often we see children who have presented repeatedly to primary and secondary care with suggestive symptoms that have not been identified and referred promptly. This is particularly common in children with non-pulmonary forms of TB (including Tb meningitis) but also occurs in children with classical symptoms and signs when paediatricians have simply not considered the diagnosis. We have seen teenagers with classical TB who have been unwell for 9-12 months prior to diagnosis. Diagnostic delay occurs more frequently in low incidence areas far from a regional centre. This may be because of a lack of clinician expertise or awareness or an unwillingness / inability of families to travel a long way to the regional centre.
- d. See c
- e. See c
- f. See c
- g. We agree the process is complex. Tertiary children's services have long been commissioned on a region wide footprint and children's hospitals have systems and staff in place to liaise with commissioners used to developing networks. The SDG may find it helpful to approach such an individual to discuss this further. Nicola Adamson (Associate Director for Strategy at RMCH) Nicola.Adamson@cmft.nhs.uk would be happy to assist with this if necessary.
- h. The demographic footprint in Cheshire is very different to that in Manchester and the TB incidence is much lower. Tb staffing is also significantly better in Cheshire and Merseyside than the rest of the region

- i. Clinical teams are fundamental to the development of high quality clinical services and it is important that those involved in service provision have a full understanding of local services and challenges before developing a service model for paediatric TB. These will clearly vary around the country and it is unlikely one model will fit all. There is a considerable workload associated with this and we have been fortunate to have the TB summit to help us collect data. Perhaps TB control boards will help with this in the future.
- j. Children with MDR are rare and difficult to manage and advice and support should be sought from a centre of expertise. Currently this would be Great Ormond Street Hospital +/- the British Thoracic Society MDR group. These children will also need local paediatric care to manage medication, side effects and treatment. Thorough initial assessment will be very important and should be done in a regional paediatric centre with Tb expertise. In our region we would see and assess the child in the regional centre even if this meant they had to travel 60 miles. We would liaise with GOS and our local adult colleagues and develop a management plan. The ongoing care may then be administered locally by the TB nursing team but we would see the child regularly (at least monthly) and personally review all imaging etc.
- k. We have not submitted a business case or economic data yet. To date we have been piloting a new model and have only rolled this out to 3 DGHS. The next step of formal commissioning will require such data to be collected and we are in the process of collecting 10 year outcome data for all Tb cases at RMCH to facilitate this.
- l. IGRAs in children are possible and we do them in every case. We screened >100 neonates exposed to TB in a neonatal unit and managed to get sufficient samples from all. We do not currently use them instead of mantoux testing as we find subgroups of children who have positive mantoux and negative IGRA and vice versa.
- m. Developing and running a network is time consuming and has impacted on our ability to provide other services. A lot of the development work has been done in our own time. The main time pressures are: development of a regional pathway and assessment proforma, holding stakeholder meetings (probably need about 2-3 ½ day meetings), general organisation, attending cohort review and steering group meetings (3 hours / month) and then running the network and auditing outcomes. Clinical questions from other clinicians can be time consuming (maybe 0.5hrs/week) but are less time consuming than sorting out a sick child who has been suboptimally assessed or managed. Once the network is fully running there will be additional time pressures of reviewing distant radiology / clinic letters etc for children who are no longer needing to travel to RMCH. This will need to be explicitly commissioned. In our region we are looking at commissioning through an operational delivery network. This is a network hosted by a provider (usually the tertiary centre) which is formally monitored in terms of delivery.
- n. I believe Tb control boards will have some funding which could be used for cohort review. I am not sure if this will be sufficient to fund a paediatric network although it might cover some of the administration. Regional commissioning has previously be used effectively to support other paediatric networks in the North West
- o. We are used to commissioning across the North West Region for specialist children's services so this seems a sensible footprint

Costing questions

See 'm' above. Much of the set up was done in our own time. It has probably taken consultant time of 2 hours/week over a period of 12 months to develop / organise our

service to the current level. In addition, we have introduced an extra 9 hours of clinic time/month to manage newly referred patients. Apart from seeing the patients most of the network organisation and planning would be more effectively and efficiently done by a network coordinator. In our region (covering a population of 1 million children) we think it would be reasonable to have 1 coordinator (band 8a) to cover TB / HIV / infectious diseases and allergy. There is an additional requirement for band 4 admin support.

References (if applicable):

EP 4 Practice - the Leicester experience including rapid radiology referral model

Section A: CPH to complete	
Name:	Gerrit Woltmann, MD FRCP, London
Job title:	Consultant Respiratory Physician TB Lead physician
Address:	Department of Respiratory Medicine University Hospitals of Leicester Glenfield Hospital Groby Road Leicester Leicestershire LE3 9QP
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Leicester – service modelled on cancer waiting times
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>The committee are especially interested in service delivery from the perspective of practice using the Leicester model (Inc. how it was modelled on cancer networks/waiting times), configuration and organisation of services in the model, and the accountability arrangements within and between services.</p> <p>Below are a series of questions we would like you to think about when delivering your testimony:</p> <ol style="list-style-type: none"> 1) In your view, what are the challenges for TB services around England? 2) How are TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured? 3) What is the mechanism through which your local TB services are commissioned, how has this been helpful or difficult? How were difficulties overcome? 4) What are the advantages of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve (do you have any examples)? <p>Elements of particular relevance such as: inequalities, demographics, geography, variations due to differences in active TB rates, MDR and LTBI, and accountability arrangements are of great interest especially any evidence or opinion on the following:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches 	

5). What would you consider to be a prompt referral, what is your local target time – in relation to this how have local referral targets impacted on

- referral rate,
- referral time,
- clinic time?

6). Do you allow direct referral from A&E?

- how is this done (sample referral paperwork)?
- how is this managed?,
- who funds this and how was this negotiated?

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
---------------------------	---

1) *What are the challenges for TB services around England?*

The greatest challenge facing TB services in the UK is the provision of matching resources and consistent infrastructure in areas with widely differing TB notification rates. Services must be put in a position where a long-term switch from TB diagnosis and treatment to effective prevention (mainly of LTBI and LTBI progression) becomes a feasible standard. In order of priority TB services will need to focus on rapid TB diagnosis and treatment, systematic and effective contact screening and, in order to see sustained reduction of incidence, migrant screening for LTBI. Whereas the first two priorities are achievable with some additional resource and careful reorganisation, migrant screening will require substantial additional resources for many years, particularly in areas with case rates above national average. There needs to be a revised NICE driven appraisal of the very real health risks associated with previous residence in countries with high incidence levels of transmissible diseases. NHS services will need to address these risk factors more systematically, where the risks are modifiable by early detection and treatment². To maximise cost effectiveness of such screening services a standardised national database infrastructure needs to be employed. To maximise safety and patient acceptance the treatment arm of the migrant LTBI service should remain with existing appropriately skilled TB services.

2) *How are TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured?*

Following the recent NHS wide organisational change the TB services in Leicester, Leicestershire & Rutland (LLR) are hosted and managed by the secondary care provider (UHL) following many years where the services were managed by primary care but hosted by secondary care. In both models the team is providing identical services across organisational boundaries.

The overarching care model has been existence since 2001, in response to a well published TB school outbreak. At that time a TB management board was established, with representation from all key TB stakeholders and generally chaired by a primary care representative with an interest in public health. The board effectively functions as a TB control board and meets quarterly to review local epidemiology, agree policies and public health priorities.

The board was instrumental in establishing the Leicester TB rapid access clinic model and contributed to other policy decisions, including the enhanced contact screening model, nurse led clinics, cohort review, and TB MDT meetings.

Care is delivered by specialists in ID and Respiratory Medicine as well as paediatricians and a team of 8-10 WTE TB nurses. TB nurse numbers are calculated

based on active case numbers (1 nurse per 40 TB cases or 80 LTBI cases on treatment) There is a cultural link worker as well as 3 administrators. Inpatient facilities include access to 13 negative pressure rooms across UHL. The main TB clinics are running in an area of the city, where a large part of the migrant population lives. Nurse led clinics are in operation to deal with follow-up of previously diagnosed cases, management of uncomplicated LTBI as well as migrant screening. TB nurses are trained as nurse prescribers and all medication is dispensed by pharmacies in secondary care.

All health care professional involved in TB management have access to a network hosted TB database. This allows tracking of active cases as well as contacts related to the index cases. In addition it tracks all microbiological strains, including sensitivities and genotypes. Through the database detailed epidemiology data are made available and audit becomes almost instantaneously. This allows the board to review and optimise policy decisions by auditing the altered outcome at regular intervals.

It is difficult to define the specific impact of any of the stated interventions. However, failures within individual components of the service are identified reliably and can be optimised promptly. The overall impact of all interventions appears to have been a sustained reduction of active TB case notifications by 40 % in a catchment population of 1M over the past 10 years. It is likely that both prevention of LTBI and prevention of progression from LTBI to active TB have contributed to this trend.

3) *What is the mechanism through which your local TB services are commissioned, how has this been helpful or difficult? How were difficulties overcome?*

Ongoing engagement with all stakeholders across organisational boundaries and establishment of a multi-disciplinary control board was a key intervention that allowed the TB service to obtain the required funding and sufficient personnel. By chairing the TB management board meeting primary care is directly involved in key decision making and these decisions are generally carried forward.

4) *What are the advantages of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve (do you have any examples)?*

Diagnostic delay is associated with increased morbidity and mortality and for pulmonary cases with progression to cavitating smear positive status and significantly higher infectivity. Through the rapid access system the time from onset of symptoms to starting ATT is reduced from 90 to 60 days for smear positive pulmonary cases³, thereby reducing the likelihood of transmission to contacts.

The Leicester model has two key aims:

- to prevent LTBI in contacts through early disease detection and prompt treatment of all active cases.
- to prevent progression to active disease by early risk detection and prompt preventative treatment where LTBI is identified in contacts.

Through detailed retrospective review¹ of our policy of delayed contact screening by IGRA testing (2007-2009) we identified an important cohort of early secondary disease occurring soon after diagnosis of the index case. In this group the policy had failed to deliver both prevention of LTBI and progression to active disease. Following policy change contacts of smear positive index cases are tested at the earliest

opportunity and treated preventatively if found to have LTBI (defined as IGRA positivity after contact). Only 10% of IGRA negative contacts convert during the subsequent 3 months and then receive treatment at the later date.

Through the same retrospective review ¹ contacts above age 35 appear to suffer secondary active TB at the same rate as younger individuals. Increasingly the age limit for preventative treatment in this group is relaxed if a recent transmission event is likely.

In the current year the numbers of individuals on preventative treatment for LTBI exceed the number of individuals on active TB treatment (191 vs 140) in LLR. LTBI is screened for in contacts of all TB cases (pulmonary & non-pulmonary), in migrants (not universal screening of migrants yet), in anti-TNF candidates, ESRF patients, HIV clinics and through occupational health.

5. What would you consider to be a prompt referral, what is your local target time – in relation to this how have local referral targets impacted on

There are different triggers for rapid access referrals including suspicious radiology (main trigger), microbiology and histology referrals as well as direct referral from primary or secondary care practitioners.

All x-rays suspicious of active TB should be referred immediately (same day) for rapid triaging and investigation. This is generally done by X-ray coding and immediate fax to the TB service. This will result in an immediate triage process taking into account a detailed symptom questionnaire, risk stratification, x-ray review by a TB physician as well as early laboratory results. Using this system all military cases should be admitted and treated on the day of referral. Smear positive pulmonary cases should be receiving TB treatment within 3 days of referral. Smear negative pulmonary cases should be seen within 7 days and receive treatment within 2 weeks of referral.

A dedicated administrator receives all referrals and maintains a detailed database of all referrals with ultimate outcomes. Faxed referrals are investigated immediately with sampling of sputum and obtaining of symptom / risk questionnaires wherever possible. Admission criteria include patients who are generally very unwell, pulmonary cases with small children in the household and suspected military cases. Patients are seen by TB physicians in dedicated rapid access clinics (weekly or adhoc) depending on room availability. Clinic tariffs are as for other routine OPD clinics. 35 % of referrals are diagnosed with active TB. Referral rates have remained static (300 / year). Not all referrals are seen but often detailed advice is given by letter if other diagnoses appear more likely. Between 60-70 % of treated pulmonary cases are culture positive, suggesting that early detection will not always promote high culture positivity rates.

6. Do you allow direct referral from A&E?

Referrals are accepted from all parts of the secondary care sector and from primary care. In reality most referrals from A&E will be seen by ID physicians or pulmonary physicians on the ward. Telephone referrals from A&E and others can also frequently be investigated as outpatients and channelled into rapid access clinics where applicable. No special tariffs were negotiated for this service or any other part of the rapid access service.

References (if applicable):

1. Thorax. 2013 Mar;68(3):240-6
2. Thorax. 2014 Apr;69(4):354-62
3. Thorax 2011;66:A90 doi:10.1136/thoraxjnl-2011-201054c.54
4. Thorax 2013;68:A33 doi:10.1136/thoraxjnl-2013-204457.68
5. Lancet Infect Dis. 2013 Feb;13(2):137-46
6. Tuberculosis summary needs assessment Leicester Dec 2013

EP 5 Cancer networks

Section A: CPH to complete	
Name:	Kathy Elliott
Job title:	Formerly [National Lead for Prevention, Early Diagnosis and Inequalities National Cancer Action Team]
Address:	
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Cancer services - commissioning and accountability arrangements
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) How have cancer services changed / improved over the last ten years?</p> <p>2) Why have these changes taken place?</p> <p>3) What is the mechanism through which cancer services are commissioned, how has this been helpful or been difficult?</p> <p>4) What are the key outcomes that have been used to measure changes / improvements?</p> <p>5) What evidence has informed these changes?</p> <p>6) How have these changes benefitted patients?</p> <p>7) What were the challenges in implementing these changes? What have been the opportunities or benefits?</p> <p>8) All issues applicable to service delivery are relevant, although anything specific to our core objectives would be particularly welcome they are:</p> <p style="padding-left: 40px;">Gaining an understanding of commissioning models, service models, and service structures that are in place in the UK that have seen a positive shift in cancer outcomes, in particular how services are commissioned, organised and delivered where possible in relation (but not limited) to:</p> <ul style="list-style-type: none"> • Reducing diagnostic delay • Improving treatment completion <p>Elements of particular relevance to the committee are: inequalities demographics, geography, variations due to differences in rates or cancer typology (that may have parity with active TB rates, MDR and LTBI), and accountability arrangements are extremely relevant. Any evidence or data on the following would be particularly</p>	

relevant: <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches. • Implementation issues relevant to different approaches 	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
1. How have cancer services changed / improved over the last ten years?	
1.1 General	
<p>Changes and improvements in cancer services have been initiated and sustained in England through national cancer plans. They have reflected the World Health Organisation view that each nation should have a cancer plan which highlights the burden of cancer, sets policy direction, oversees the allocation of resources for services and helps the workforce plan and deliver policy intentions. The current plan - <i>Improving Outcomes: A Strategy for Cancer</i> was published in 2010. The development of the strategy brought together patients, professionals, charities and government to build on learning from reviews such as the National Audit Office – <i>Delivering the Cancer Reform Strategy</i> – and considered new scientific opportunities, outcomes and service contexts. England has had a national cancer plan which has evolved and been updated since 1995.</p> <p>The Calman-Hine Report (1995) recommended a new structure for the delivery of cancer services, including the establishment of generalist Cancer Units and specialist Cancer Centres, with multi-disciplinary teams for co-ordination of cancer care for individual patients. Also proposed was the establishment of Cancer Networks to provide a framework for planning cancer services across geographical localities.</p> <p>In 2000, the Cancer Plan was published in England. This first national plan covered a range of issues, including the introduction of waiting time targets to promote earlier diagnosis and treatment; extension of cancer screening programmes; the post of National Cancer Director; and plans for significant investment in equipment, staff and specialist palliative care. It also created the National Cancer Research Institute (NCRI) and the Cancer Task Force (later the National Cancer Action Team), to coordinate research and some service delivery from the centre; and highlighted the importance of linked policies, for example on the reduction of smoking, and generic developments such as the importance of good communication skills.</p> <p>The 2007 Cancer Reform Strategy built on the 2000 Cancer Plan by identifying areas in cancer policy that needed concerted action to improve patient outcomes in England. As well as announcing new legislation to further regulate tobacco products, it introduced a co-ordinated programme of work aimed at detecting and diagnosing cancer earlier, including making improvements to the three national screening programmes. It also proposed improvements in the treatment of cancer, through increased radiotherapy capacity, and new processes for assessing cancer drugs. It identified patient information, commissioning and investment as key drivers in achieving the aims of the strategy and highlighted the importance of research and</p>	

survivorship.

Various reviews of the national strategy in the past ten years have highlighted impacts, for example:

- Creating and sustaining a sense of momentum among those working in cancer services
- Improvements in the services, including standardisation and a reduction in the variation in treatment type. Also development of new treatments.
- Increased commitment to the importance of quality standards and investment

Improving Outcomes: A Strategy for Cancer (IOSC) stated that ‘the quality of treatment has already improved significantly, with more widespread and rapid access to the latest forms of surgery, radiotherapy and drugs as well as the establishment of local and specialist multidisciplinary teams (MDTs) across the country. Advances in surgical techniques and the centralisation of complex surgery mean that the quality of cancer surgery has improved with more operations being carried out by specialist surgeons with expertise in particular procedures.’

Increasingly the focus has been on outcomes, the patient perspective and value of investment. Specific recommendations were made for all the parts of the cancer patient pathway (e.g. prevention, early diagnosis, diagnostics, treatment, survivorship and end of life care), as well as key enablers such as information.

Each year government has published an annual report. In 2013 this was a joint publication between the Department of Health, Public Health England and NHS England. The annual report provides updated data, policy and service contexts; progress; and priorities for the coming year. Historically the report has been considered alongside a national conference, Britain against Cancer, with cross party and charity support.

The key challenge set out in *IOSC* was that ‘despite improvements in survival and mortality in recent decades, cancer outcomes in England remain poor when compared with the best outcomes in Europe’. The actions highlighted were to

- Reduce the incidence of cancers which are preventable, by lifestyle changes
- Improve access to screening for all age groups and introduce new screening programmes where there is evidence they will save lives and are recommended by the UK National Screening Committee
- Achieve earlier diagnosis of cancer, to increase the scope for successful treatment – diagnosis of cancer at a later stage is generally agreed to be the single most important reason for the lower survival rates in England; and
- Make sure that all patients have access to the best possible treatment

Other issues highlighted were inequalities, support to patients living with and beyond cancer; and the financial impact of incidence increases, people living longer with cancer and new treatments on the NHS and the wider economy.

Key changes and improvements highlighted in 2013 include

- Significant developments in cancer screening – particularly on the first phase of introducing Bowel Scope Screening (BSS)
- Activity to promote earlier diagnosis of symptomatic cancers, through the *Be Clear on Cancer* campaigns and the associated work with primary and secondary care
- Progress in ensuring better access for all to the best possible treatment, for example through improved access to Intensity Modulated Radiotherapy (IMRT)
- Significant developments in the collection and reporting of new datasets and the

analysis of information, to drive improvements and to inform patients.

Public Health England, NHS England and the Department of Health began to implement their new responsibilities in relation to cancer, including the establishment of Strategic Clinical Networks which replaced Cancer Networks.

The priorities for 14/15 highlighted the importance of the work to save lives (including the rarer cancers) through preventing cancers, screening, early diagnosis of symptomatic cancers, improved access to treatment, and better care for cancer survivors.

- To continue to tackle the 'lifestyle' factors, particularly smoking, which are responsible for over a third of cancers
- To improve uptake of screening amongst disadvantaged groups
- To continue to build on the Be Clear on Cancer campaigns and the growing evidence of effectiveness
- To ensure there is sufficient endoscopy capacity to meet the needs of the bowel screening programme and the needs of symptomatic patients
- To continue to tackle variations in access to treatment, for example to provide comparative data on radiotherapy and chemotherapy to enable those with low levels to consider whether action is needed
- To keep a focus on the treatment older patients receive

It is recognised that improving outcomes is not just about improving survival and mortality, it is about improving all outcomes. Priorities are given for all the relevant domains of the NHS and Public Health Outcomes Frameworks, including patient experience, support for cancer survivors and the enabling strategies.

1.2 Reducing Diagnostic Delay

My national accountability for achieving improved survival through a programme on early diagnosis began in 2008. Although the importance of early diagnosis had been included in the earlier national cancer plan, the review which proceeded the launch of the Cancer Reform Strategy (CRS) highlighted that there needed to be a greater focus and action. As part of the CRS, the National Awareness and Early Diagnosis initiative (NAEDI) was established, chaired by the Department of Health and CRUK. The launch in November 2008 was well attended by national organisations and regional NHS and professional/ clinical representatives. The members of NAEDI provided national leadership, opportunities, funding and support for the development of regional and local awareness and early diagnosis strategies led by 28 Cancer Networks. The initial focus was on 'baseline assessments', accessing, analysing and interpreting local data; recruiting and profiling clinical leadership (public health, general practitioner, and secondary care cancer specialists); establishing governance mechanisms (e.g. in addition to tumour specific groups) and commissioning arrangements; and establishing evidence based programmes of work. Cancer Networks provided system and clinical leadership; expertise and updates on data analysis and research/evaluation; project and programme management; and a system to share experience and provide peer challenge until they were shut down in 2013. This service 'infrastructure' enabled clinical leadership across the person/patient pathway; an efficient mechanism to develop a new programme of work with input from a wide range of organisations and perspectives and access soft monies; and flexibility to evaluate and implement change 'at pace and scale'. Focus and accountability that was locally led and supported nationally.

In 2009 NAEDI supported the publication of a peer reviewed, overview of the research. This underpinned a consensus on the elements of action and services with evidence of effectiveness. It was recognised that, as with many public health/ primary care priorities, we could describe the problem with more certainty than the solutions. There was a commitment to invest in research and evaluate as we implemented. The initial service elements included increasing public knowledge of the early signs and symptoms of cancer; reducing barriers for people to go to their GP when they had these signs and symptoms; support for general practice to be aware, understand the implications for their surgeries and consultations and take action; and access to diagnostics and referral for consultation with specialists/ treatment as needed. For cancer networks and secondary care clinicians this meant thinking about services outside the hospital, which for many was new and challenging. The descriptions of the programmes and services were captured through Cancer Network reports; monitoring returns for short term project funding; DH/ NCAT national reports/ evaluations; and local research. There were tensions and debate about what were one off projects vs the need for sustained programmes of work; the balance between local, regional and national initiatives; prioritisation of investment to increase public knowledge and change behaviour; support for change in general practice; increased access to diagnostics; and overall increases in capacity across the patient pathway.

1.3 Service models

- National public awareness programme – *Be Clear on Cancer* – TV, radio, press. Some alignment to public awareness initiatives by other national organisations (e.g. charities)
- Regional and local public awareness programmes. Past Cancer Network resources to align to national campaigns, including primary care and wider partners.
- Primary care – greater scrutiny of patient experience and outcomes; higher priority to consideration of cancer in consultations for early signs and symptoms; increased referral and access to diagnostics and treatment if needed.

1.4 Potential learning for TB programmes/ services

There is benefit to achieve early diagnosis in both cancer and TB. TB is at a more advanced stage of understanding the epidemiology and targeting of interventions than is possible in cancer. Approaches developed in cancer which may have learning for TB include:

- National plan with excellent engagement processes – national and local. Increasingly this has included primary care and inequalities. (*IOSC annual report and yearly conference*)
 - Monitoring and refreshing a consensus about interventions and change. In cancer there was a lack of realism about the ‘front end of the patient pathway’, including harnessing patient and public involvement; public awareness raising (funding, delivery, evidence, monitoring); access to referral for diagnostics and treatment (for cancer general practice). This has resulted in some shift from an expectation that one off, short term projects will produce results to more realistic development of medium to long term approaches. It also highlighted the lack of
 - alignment of national and local public awareness; and
 - support to GPs – funding; access to diagnostics; feedback on quality; and a general understanding of change in primary care in relation to cancer

- alignment of services/ initiatives that need to happen for the person/ patient in order to achieve both individual and population outcomes
- Medium term
 - Review of outcomes against other countries with similar data, to compare effectiveness of change interventions and generate ideas for action to improve outcomes. (International Benchmarking Project (ICBP))
 - Research funding strategy (NAEDI Research Call(s))

2. Why have these changes taken place?

2.1 General

Cancer is a major cause of mortality and morbidity. More than one in three people will develop cancer during their lifetime, and there are an estimated 1.7 million cancer survivors in England. Cancer touches most people and families, and has been high on media and political agendas.

The 274,000 new cases of cancer registered in England in 2011 (139,000 in males and 135,000 in females) equate to an age-standardised rate of around 423 and 372 per 100,000 population respectively. The number of registrations of new cases has increased by around 500 for males and 1,100 for females when compared to 2010. The four cancer types of breast, lung, colorectal and prostate continue to account for over half of newly diagnosed cases of cancer in England each year. Between 1980-82 and 2009-11, the age-standardised incidence rate in England for all cancers combined increased by 16% in males and 32% in females. In recent years, the increase in cancer rates has been less marked than in earlier years, in particular for females. Between 2002-04 and 2009-11, the age-standardised incidence rates in England increased by 4% in males and 6% in females. Cancer can develop at any age, but is most common in older people. More than three out of five new cancers are diagnosed in people aged 65 or over, and over a third are diagnosed in those aged 75 or over.

ONS mortality statistics show that cancers were the broad disease group which had the largest percentage of deaths registered in 2012, accounting for 29% of all deaths. In 2012, there were around 133,000 deaths at all ages in England where the underlying cause was cancer, 70,000 in males and 63,000 in females. Changes in mortality rates reflect changes in both incidence and survival. The age-standardised cancer mortality rate (ages under 75) was 105.3 deaths per 100,000 population in 2012, a decrease of 16% since 2002. Cancer mortality rates (ages under 75) have decreased in both more and less deprived areas, but there remains a social gradient in cancer mortality, with more deprived areas experiencing higher mortality rates than less deprived areas. In 2010 the cancer mortality rate (ages under 75) for the most deprived fifth of neighbourhoods in England was over one and a half times the rate in the least deprived fifth of neighbourhoods.

Concerns about variation and access to treatment drove the early focus on hospital treatment and care. As confidence grew about the organisation and quality of hospital services, there has been concern about our poor survival outcomes when compared with other countries. Although contested, analysis (EUROCORE5 – Lancet Oncology Dec 2013) continues to support the view that we have a poor relative performance on cancer survival. The results published in the Lancet (2011) showed that relative survival during 1995-2007 improved for breast, colorectal, lung and ovarian cancer patients in all jurisdictions. However, the gap in survival between the best performing countries and the lowest remains largely unchanged, except for breast, where the UK is narrowing the gap. Subsequent studies on survival by cancer stage at diagnosis suggest that the UK's poorer survival could be down to a combination of more advanced cancer stage at diagnosis, unequal access to optimal

treatment, sub-optimal staging of cancers which may influence treatment decisions and the impact of other long term illnesses. An analysis of the comparison of PCT survival outcomes against other countries showed that there was a gap in all areas of the country.

Scrutiny of services, for example through Peer Review, and more robust patient experience feedback have also been drivers for change.

2.2 Reducing Diagnostic Delay

The changes in services took place to respond to poor survival outcomes; research about the patient pathway, including access to primary care and diagnostic services; and evaluation of interventions. In the early stages of NAEDI (2009) a review of research was published - Richards MA and Hiom S (Editors). *Diagnosing Cancer Earlier: Evidence for a National Awareness and Early Diagnosis Initiative*. BJC Vol 101, Supplement 2, 3 Dec 2009.

NAEDI prioritised research, evaluation and monitoring.

Research, evaluation and monitoring have influenced the service / programme delivery, including:

2.2.1 Measurement of public knowledge about signs and symptoms of cancer

National

- A baseline population-based survey using the CRUK Cancer Awareness Measure (CAM) developed by the University College London was undertaken in September and October 2008 and included a general sample of 2,216 members of the public. A separate study focused on ethnic minority communities recruited 1,500 respondents from six ethnic groups.
- The results showed that with the exception of “a lump or swelling”, less than 30% of the public surveyed were able to recall common cancer symptoms. Awareness of cancer symptoms was lower in men, younger people, those from a lower socioeconomic status group and ethnic minorities. On average, people were only able to recall 2 cancer signs or symptoms.
- The CAM was repeated in 2010. In both 2008 and 2010, the CAM was included in the Office for National Statistics (ONS) Opinions Survey (an in home, face-to-face, computer assisted interview). In 2010 the sample size was 2,090. When asked: ‘There are many warning signs and symptoms of cancer. Please name as many as you can think of’ on average, respondents were able to recall just two signs or symptoms of cancer. There was relatively good knowledge that a lump or a swelling could be a sign of cancer, yet recall of other symptoms was low, with less than 32 per cent able to name any other symptom and 9% saying they didn’t not know any. Asking people whether they agreed or disagreed with a list of potential symptoms showed higher knowledge levels. There was still better recognition of a lump than of any other sign or symptom. Added to this, at least a quarter of respondents did not believe that unexplained persistent pain, a persistent cough, or a sore that will not heal could be signs of cancer. Respondents were asked ‘Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor? And shown a list of potential barriers. The biggest barriers were: ‘being worried about what the doctor might find’ (37%), anticipating that it would be difficult to make an appointment at the GP (37%) and not wanting to waste the doctor’s time (26%) (CRUK – Delay Kills. 2012)
- Public knowledge, attitudes and behaviour have been investigated as part of the development of the *Be Clear on Cancer Campaigns*. This has given detailed picture in relation to specific cancers

and symptoms that have been the focus of the campaigns – e.g. lung, bowel, breast, kidney and bladder, ovarian. The impact of the lung cancer campaign has been reported. Public awareness of symptoms increased from 41% to 50%. Urgent referrals for suspected lung cancer increased by 30%, with a breakdown available by stage (early/late) and surgical resection based on LUCADA data.

International

- ICBP researchers developed and used a new research tool, the Awareness and Beliefs about Cancer (ABC) measure, to study people's awareness and beliefs. Nearly 20,000 men and women aged 50 and older were interviewed in Australia, Canada, Denmark, Norway, Sweden and the UK – resulting in the strongest international comparison of awareness and beliefs about cancer in the general population yet.
- The study suggested that international differences in cancer survival, as highlighted in previous ICBP research, are not likely to be explained by differences in awareness and beliefs about cancer and cancer outcomes. The results showed that the public awareness of cancer symptoms and beliefs about cancer outcomes was similar internationally. All of the countries reported that around eight out of eleven cancer symptoms were recognised by members of the public. In all of the countries, people had positive beliefs about cancer with around nine out of ten people agreeing that 'cancer can often be cured' and seven out of ten disagreeing that 'a diagnosis of cancer is a death sentence'.
- More people in the UK than in other countries said that there were specific reasons they wouldn't go to their GP, even with a symptom that worried them. People in the UK mentioned that embarrassment and not wanting to waste the doctor's time would put them off seeing their doctor. Across all countries, the knowledge that the risk of cancer increases with age was low, particularly in the UK. Low one year cancer survival in the UK and Denmark does not seem to be explained by poor awareness and negative beliefs about cancer.

Local

- The CRS made a commitment to measuring local as well as national public awareness. The results of the local studies were used to inform local strategies. NCAT encouraged Cancer Networks to lodge results in a national data archive. <http://www.data-archive.ac.uk/home>
- A national analysis of the local surveys is in progress. Some areas have repeated the survey to measure change and commission/ delivery further initiatives/ services.

Be Clear on Cancer

- *Be Clear on Cancer* – national communications, which highlight the symptoms of a range of cancers and encourage people with the relevant symptoms to visit their GP. A process of testing locally and regionally is conducted to ensure that the campaign messages are balanced and do not cause anxiety, and to assess the impact on NHS services. If appropriate, campaigns are then run nationally across England. The campaigns are evaluated and decisions on which to run next are based on the analysis of the evaluations. Evaluation includes monitoring a wide range of indicators – knowledge, attitudes and behaviour, with increasing linkage to NHS indicators. The national lung cancer campaign which ran from May-June 2012 led to an estimated 700 additional cancers being diagnosed when compared to the same period in the previous year. Approximately 400 more people had their cancers diagnosed at an early stage and around 300 additional patients had surgery as a first treatment of diagnosed lung cancer. Methods used are being applied to breathlessness and hypertension.

2.3 Greater understanding of the primary care part of the diagnostic pathway. Key projects/ outputs were

- *National Audit of Cancer Diagnosis in Primary Care (RCGP 2011)*. For the first time GPs/ primary

care teams had information about their patients from a primary care perspective. This challenged the view, widespread in the media and amongst charities, that GP referral was the only issue. Over two thirds of all patients were referred to a specialist within a month of their first consultation. Of those patients who consulted a GP, three quarters were referred after only one or two attendances. People who were housebound, had communication difficulties or who presented as an emergency tended to have more advanced cancer at diagnosis. Better access to diagnostics, particularly for specific cancers, would change the GP's management of some cases. With continuing support by Cancer Networks (now shut down), as at March 2013, a quarter of all practices in England had done either the generic or significant event cancer audit.

- *NAEDI/ Cancer Networks – supporting primary care programme.* (University of Durham). Between 2010 and 2013 NAEDI and Cancer Networks supported change in primary care, including GP leadership. This included the use of clinical audit, clinical decision support tools, consultation techniques such as safety-netting, the provision of practice level cancer intelligence and practice improvement plans. Bridging funding was made available from the charities for the year of transition from Cancer Networks to Strategic Clinical Networks. An independent evaluation of the GP leadership and primary care support through Cancer Networks was commissioned nationally. The final report (2013) measured participation of 74% of general practices (n=4380) in any NAEDI initiative. Measurement of participation was spread across 20 Cancer Networks (70%). Participation and impact of four initiatives, with the strongest evidence base (clinical audit; significant event analysis; risk assessment tools; practice plans) was measured. There was significantly greater increase in 2ww referrals for practices engaging in practice plans, risk assessment tools, clinical audit, and significant event analysis. Practices that produced practice cancer plans (alone or in combination with other activities) showed the greatest change. The amount of variation in referral practice was less for intervention practices. A key element of the intervention was clinical leadership and local determination of interventions. A framework to describe the interventions was developed and used for the analysis. At the end of March 2013, there were approximately 120 GPs and 15 Public Health Consultants providing clinical leadership on a sessional basis. GPs were working with other GP cancer expertise and being supported by Cancer Networks to work across the cancer patient pathway. An overview of the work and research was presented to International Forum on Quality and Safety in Healthcare (Paris 2014). The conclusion about the reasons for the positive impact of the programme were
 - Shared purpose – understanding and harnessing the different perspectives
 - Clinical leadership – GP, hospital, public health
 - 'open approaches' – sharing ideas and data – generating energy
 - Relationships and networks 'with reach', building bridges and sharing knowledge for action
 - Patient and public focus – and outcomes
 - Sustaining a focus and improvement over time

The mechanisms to facilitate change were

- Continued education for GPs
- Improvement of accuracy and use of 2 week wait referrals, including the use of risk assessment tools
- Face to face engagement with practices. New work investigating intensity, capacity and impact of practice context and motivation was commissioned by a cancer charity.
- Links to generic quality incentives
- Shared purpose and vision
- Use of tools to improve quality
- Shift from projects to absorbing into mainstream practice

The challenges documented were

- Short-termism – funding, fixed term contracts, organisational change, relationships between GPs and organisation of cancer services
- Clarity about roles – realism of job objectives, individual's roles and responsibilities
- Skills – relationships between GPs and new (and changing) health care and public health organisations
- Using theory and evidence – dissemination; accessibility; easy to read and understand format for GPs
- Engaging clinicians and developing clinical leaders – work with individual GPs 'patchy'; clinical leadership in every practice
- Change takes time – changing 'hearts and minds' as well as altering processes. Primary care a complex environment – isn't a 'one size fits all' solution to implementing change
- *CRUK – Facilitator Initiative - the evaluation of this initiative which has provided increased support to practices is in progress, building on the previous local evaluation.*

- 6th annual meeting of the Cancer and Primary Care Research International (Ca-PRi) network (April 2013) held in England, with an opportunity to update on longer term research such as the DISCOVERY Programme (NIHR funded research collaboration – better pathways to cancer diagnosis)
- Editorials and papers in the General Practice peer read journals. Increased confidence in the model of patient pathways to treatment – Walter et al. J Health Serv Res and Policy 2012.
- ICBP primary care module (to be published shortly)
- *Understanding GP Referral Styles* – Macmillan

2.4 Evaluation of early implementer local initiatives

Descriptions and evaluation of local initiatives was profiled and shared nationally. Small sample sizes and limited implantation times limited the learning. Examples include -

- Lyon D, Knowles J et al. Improving the early presentation of cancer symptoms in disadvantaged communities: putting local people in control. BJC Vol 101, Supp 2, Dec 2009, S49-54
- Athey VL, Suckling RJ, Tod AM, et al. Early diagnosis of lung cancer: evaluation of a community –based social marketing intervention. Thorax published online Nov 2, 2011.

2.5 Service models and structures

- Research and 'logic models' reinforced the need for public awareness; consideration of access to primary care/ general practice, including inequalities and patient views; and the need to understand and support change in service delivery in general practice to respond to population needs and access/ referral to diagnostics
- NHS and public health changes highlighted the lack of consensus and funding for local public awareness raising (e.g. populations which were at risk but not reached through national media or on whom national media was unlikely to change behaviour); and for public health/ general practice clinical leadership to support the review of research and prioritisation of service delivery changes.
- Cancer Networks (shut down in 2013) enabled sharing practice, data collection and evaluation, and alignment of service changes.

2.6 Potential learning for TB programmes/ services

- A consensus about the drivers and interventions that will needed to achieve earlier diagnosis.
- A funded programme of work to implement action, with data to monitor progress within year. For cancer this meant understanding the impact of public awareness and change in access to primary care and referral to diagnostics to align to commissioning/budget setting.
- Ways to generate hypothesis about effective interventions. In cancer this is being driven by international comparisons and evaluation alongside implementation.

3. What is the mechanism through which cancer services are commissioned, how has this been helpful or been difficult?

3.1 General

Commissioning for cancer treatment is particularly complex. There are many different types of cancer, each requiring different interventions, with a different care pathway. The other important element of complexity is the co-ordination of services

across the treatment and care pathway for the patient. For each cancer this involves health and social care teams in general practice, in the community, in acute general hospitals and in specialist centres. Where diagnosis and treatment of cancer are rare, they require specialised commissioning, which are not appropriate for GP consortia. The areas of cancer commissioning which are currently covered by national or regional specialised commissioning will continue to be subject to consultation and changes.

It has taken time, both nationally and locally, to ensure that early diagnosis, is included in commissioning decisions. The focus on cancer treatment funding means that the relatively small investment in the primary care part of the pathway is either not considered or given little priority. The move of public health to Local Government has meant that the alignment of public awareness, outreach, access to primary care, and more effective diagnosis and treatment has been more difficult.

Expenditure on cancer has increased from £3.19 billion in 2003/4 to £5.50 billion in 2011/12. This increase is broadly in line with the overall increase in NHS expenditure. The share of total expenditure was 6.5% in 2004/5 and 6.6% in 2011/12. This share of total expenditure peaked in 2009/10 at 6.8%. There is a large variation in expenditure levels between commissioners. The highest spending primary care organisation spends more than twice as much per person than the lowest spending organisation. It is unclear how much this variation can be explained by variation in the incidence and prevalence of patients with cancer and other factors. I am not aware of expenditure information by CCG or Local Authority related to early diagnosis of cancer. The NAO report highlighted efficiency savings to commissioners.

3.2 Reducing Diagnostic Delay

Systematic and 'scaled up' cancer awareness and early diagnosis programmes and services were not in place ten years ago. Between 2008 and 2013 there was national commissioning and support for the development of local programmes and services. Nationally NAEDI brought together DH, professional organisations and charities to align investment and programme opportunities. Cancer Networks and clinical leads worked with PCTs/CCGs to support local decisions about improving cancer outcomes and value for money.

In 2013, with the implementation of the new health and care structures, this situation changed with the establishment of new organisations with specific accountabilities for achieving improved outcomes; interpreting need and evidence for interventions/services; and implementing and reviewing policy and resources.

Public Health England has responsibility for improving the general health of the public, and its responsibilities are set out in Framework Agreement between DH and PHE, which was published in November 2013. Each year, DH and PHE will agree plans and deliverables to promote public health. PHE has taken responsibility for certain parts of the national cancer programme from April 2013. These include: national coordination and quality assurance of cancer screening programmes; elements of the programme to promote early diagnosis of symptomatic cancer; cancer registration/ and the National Cancer Intelligence Network (NCIN). PHE also has responsibility for piloting and roll out of new screening programmes and extensions to existing programmes. In addition, it has wide-ranging operational responsibilities for tackling smoking, alcohol misuse, obesity and physical inactivity, which are major contributors to cancer incidence. Local delivery of public health

services is through local government. It is unclear whether previous work done by Cancer Networks has been carried forward by public health consultants working now in local government. This included ensuring cancer data was considered in the production of the Annual Report of the Director of Public Health and the Joint Strategic Needs Assessment; alignment of public awareness initiatives including commissioning the integration of public messages in outreach and digital communications to maximize population reach and reduction of inequalities; and public health advice to CCGs and support for change in primary care.

NHS England directly commissions routine cancer screening programmes through an agreement with DH, based on evidence based specifications prepared by PHE. These specifications are part of an agreement on NHS public health functions. They cover; the scope of the cancer screening programmes; delivery of the programmes; operational requirements and quality assurance; and teaching and research activities. For 2014/15 the priority is moving forward in tackling areas with low levels of screening coverage.

Locally the role of Strategic Commissioning Networks (SCN) (12) is to support CCGs, Health and Wellbeing Boards (HWBs) and NHS England to make the best decisions about healthcare for the populations they serve by providing advice and leadership at a strategic level. Cancer is one of the four SCN groupings. One of their roles is working with the NHS locally to support the *Be Clear on Cancer* campaigns. CCGs and LA's are accountable for commissioning local services and interventions.

The new arrangements have been implemented at a time when we had gained experience in implementing early diagnosis services – public health, primary care, diagnostics and treatment – and understanding public and patient perspectives. New accountabilities provided opportunities to embed more sustainable approaches. The organisational changes also created challenges – loss of organisations, their memory and staff; new teams being established without the capacity, expertise or funding to embed early diagnosis programmes and services; and a 'stop – start' approach to addressing this population outcome which needs joined up work between many national and local organisations. There was no clear accountability for 'joining up the actions' to ensure effective local services for the public and patients. It is unclear at this stage whether the new organisations have improved their contributions and found ways to ensure they align.

It is still early days for the implementation of the public health and NHS structural changes, and reviews of progress are only now beginning to emerge.

Living Well for Longer – National support for local action to reduce premature avoidable mortality (DH – 2014) has included early diagnosis as one of three themes, alongside prevention and treatment and care. It also reinforces the ambition in the Mandate to make England among the best in Europe in relation to cutting avoidable deaths from the five major causes, including cancer. The focus to achieve earlier diagnosis is through greater symptom awareness amongst professionals and the public, and by having access to the highest quality treatment and care. The Longer Lives website (PHE) provides three areas relevant to early diagnosis: needs assessment (CQC assessments); commissioning (GP profiles); delivery and practices (improved access). National actions for earlier diagnosis include improving primary care's ability to identify diseases; NHS Health Check; public awareness campaigns; screening programmes; and aspects of treatment – acute diagnostic tests; and access to hospital or community based treatment. Specific deliverables are outlined in relation to screening; and related to symptomatic diagnosis of cancer – e.g.

- increase the percentage of CCGs with confirmed access to scientific and diagnostic commissioning information to 75% to enable effective monitoring of

rates of early diagnosis in a wider range of CCGs

- evaluation of Primary Minister Challenge Fund pilots that provide evidence on how to improve access to general practice services and develop more innovative and sustainable models of primary care, in order to develop a set of common evidence-based principles for improving access to primary care.

Primary care's role is highlighted:

- Risk awareness and symptom recognition – significant event audits to help GPs see where diagnosis could have been improved; training for GPs to better recognise symptoms; IT systems to produce 'pop ups' when combinations of symptoms are recorded.
- Data – by driving professional pride to make improvements in clinical practice; so that members of the public are aware of the quality, care and accessibility of GP practices in their area; by using GP registers as a source of epidemiological data to support needs assessment and service planning
- Inspection – by defining what good care looks like; by supporting improvement and, where needed, taking enforcement action; by conducting thematic reviews of particular conditions
- Access – by extending access to improve convenience and continuity of care including extending access times, and greater use of telephone, email and video consultations.

Mandate for NHS England by 2014/15 – an objective for NHS England, working with CCGs, is to develop their contribution to the new system-wide ambition of avoiding an additional 30,000 premature deaths per year by 2020. Tackling premature deaths from cancer will be a key part of this. ...including, where possible, comparing our services and outcomes with the best in the world. Of particular relevance to cancer is an objective to prevent ill-health, and provide better early diagnosis and treatment of conditions such as cancer and heart disease. The Mandate continues to provide a national ambition for earlier diagnosis of cancer and achieving improved population outcomes.

3.3 Potential learning for TB programmes/ services

Nationally PHE, DH and NHSE have developed processes to review and fund public communications programmes for early diagnosis and cancer. These have included understanding how the alignment of national and local communications can best reach all population groups – giving value for money and greater effectiveness.

Some work has been done between NHSE, DH and the cancer charities (CRUK and Macmillan) to sustain GP clinical leadership and increase the involvement of all GPs and practices in taking action to improve cancer outcomes.

Making it easier for patient to see their primary care team should help improve early diagnosis rates. What are the issues for TB high risk groups in having access to primary care? How can access be increased?

4. What are the key outcomes that have been used to measure changes / improvements?

4.1 General

Priority over many years has been given to valuing, improving and using cancer information.

The NCRS and the dataset that it collects is now the largest, most detailed and timely

cancer data collection system anywhere in the world. Major changes have taken place in the past years.

The new unified registration service is part of Public Health England and collects data on all 350,000 new tumours diagnosed each year from the entire 52 million population of England. The NCRS now receives data directly from more than 500 local data systems, 12 national data feeds and includes cases from more than 1400 weekly multi-disciplinary team meetings. Data comes from all 162 acute trusts and a range of private providers..... 200,000 records each month and span pathology reports, patient administrative data, imaging, and MDT meeting information. Details of treatments including radiotherapy, surgery and chemotherapy are also collected and there are links to all three cancer screening programmes. Outcome data now includes the responses from Patient Reported Outcome Surveys.

Improving data quality is a priority. The Cancer Outcomes and Services Dataset (COSD) was designed to support consistency in data recording, data submission and outcomes analysis across NHS cancer services in England. COSD Information Standard mandated submission of the generic core dataset and site specific cancer stage data for all NHS providers from January 2013. A third phase from January 2014 will see the required submission of site specific pathology items.

New datasets have been developed and collected to address specific treatment and commissioning concerns and investments. Examples include the Systematic Anti-Cancer Therapy (SACT) Dataset and the Radiotherapy Datasets (RTDS).

The ambition to improve survival rates has driven improvements in the collection and use of survival data, including international comparisons. Key developments have been the collection of staging information, agreement about proxy indicators to assess progress, and the International Benchmarking Project. The focus on the early part of the cancer pathway has led to new information and data collection tools, for example public knowledge of early signs and symptoms of cancer and symptom epidemiology. Of particular interest has been:

- Diagnostic Imaging Dataset (DID) – a monthly data collection covering data on diagnostic imaging tests on NHS patients in England. It includes estimates of GP usage of direct access to key diagnostics tests for cancer. Low use and delays in the delivery of diagnostic tests can cause problems for delivering earlier diagnosis and so these data are important for supporting further consideration about how diagnostic services can be more effective and to reduce variations.

- Routes to Diagnosis - In May 2013, NCIN produced a data briefing looking in more detail at the proportion of patients presenting by the different emergency routes. The routes to diagnosis study showed that in 2006 to 2008, 24% of newly diagnosed cancers first presented into secondary care as an emergency presentation. The emergency presentation route comprises different emergency pathways into secondary care, including accident and emergency attendance, emergency GP referrals and emergency admissions to inpatients or outpatients. Stage at diagnosis, age at diagnosis and the presence of co-morbidities were associated with a worse prognosis in the first year after diagnosis. Even adjusting for these factors, emergency presentation was associated with a worse prognosis in the first year after diagnosis. Proxy measures for emergency presentations have been developed and are available.

The cancer pathway is complex and the collection and analysis of cancer information is highly specialised. Effort has been made to ensure information is available to a range of audiences in formats and timescales to increase its use. For example GP

and Service Cancer Profiles have been produced. NCIN, now part of Public Health England, provides web access to the information, along with publications such as 'What cancer statistics are available and where can I find them?'

Other information of importance is

- Inequality and equalities information, e.g. Incidence of and mortality from cancer in relation to socio-economic deprivation within England.
- National Cancer Audits – lung, colorectal, head and neck cancer patients which have been collecting data for between 8 and 9 years. Also gastro-intestinal cancers – in third year of data collection, and a new prostate cancer audit commences in 2014. A new national breast cancer audit is being commissioned.
- Peer Review
- Patient feedback information

The NHS and Public Health Outcomes Framework indicators and the Clinical Commissioning Group Outcomes Indicator Set are starting to enable us to assess progress, at national and local level.

NHS Outcomes Framework (NHS OF) encourages improvements in quality of care through a focus on improving health outcomes for all. It is structured around five domains. Those particularly targeted on cancer are the survival and mortality indicators within Domain 1 (the 2012 data for cancer under 75 mortality indicator was added on 5th Dec 2013). The Health and Social Care Information Centre (HSCIC) indicator portal provides data on the indicators both at national and local level, enabling comparisons between different areas of the country, highlighting variations. The survival data by CCG and Area Team was made available in June 2014.

- One-year survival for all cancers
- Five-year survival for all cancers
- One-year survival for breast, lung and bowel cancer together
- Five-year survival for breast, lung and bowel cancer together
- Five-year survival for all cancers in children

These indicators are being developed by London School of Hygiene and Tropical Medicine (LSHTM) in collaboration with the Office of National Statistics (ONS) and are composite indicators building on the work previously published on cancer survival rates for individual primary care trusts.

The Public Health Outcomes Framework (PHOF) and the NHS Outcomes Framework (NHS OF) share the 'under 75 mortality rate from cancer' indicator, recognising the critical contributions that both the NHS and the public health services can make to reducing 'preventable mortality'.

CCG Outcomes Indicator Set – all match England level indicators in the NHS Outcomes Framework – under 75 mortality from cancer; one and five year survival from cancer; and one and five year survival from breast, lung and colorectal cancers combined.

4.2 Reducing Diagnostic Delay

Population outcomes to assess progress on reducing diagnostic delay have been included in the outcome frameworks. Quality of data is improving and information is being made more accessible, although the timeliness and format of information to decision makers continues to be raised. International comparisons, which underpin the Mandate priority, are not, at this stage included in the information. Analysis done on PCT outcomes, reported in the CRS 2nd Annual Report (2009), showed that every PCT had a poor position in relation to the average and best in Europe, and therefore the limitations of national benchmarking. For Cancer, EURO CARE and the

International Benchmarking Initiative provide opportunities to review the national position with high quality and improving data. It is unclear how this will be replicated and placed alongside data across many conditions to respond to the Mandate. Until this is done, many areas will not prioritise achieving improved outcomes.

4.3 Inequalities

Understanding and reducing inequalities is a priority in the cancer plan(s). IOSC continued to support a national initiative introduced as part of the CRS – the National Cancer Equalities Initiative. Recent outputs from the information work stream include a publication by NCIN and CRUK in 2014 - Cancer by Deprivation in England 1996 – 2011. Change in incidence and mortality with socio-economic deprivation is examined (standardised for population age) for each cancer type, over time, and for males and females separately and combined. Key messages include: It is shown that if the more deprived groups had the same rates as the least deprived, there would have been around 15,300 fewer cases and 19,200 fewer deaths per year across all cancers combined in the most recent 5-year periods.

Outputs available on incidence figures for 1996-2010 and mortality for 1997-2011 are:

Cancer by deprivation in England 1996 - 2011: This report contains statistics and summary analysis for each cancer type, by sex and period of time.

Incidence and mortality for all cancers combined (excluding non-melanoma skin cancer) were higher in the more deprived quintiles than the least deprived; if rates for the more deprived groups had been the same as the least deprived, around 15,300 fewer cancers would have been diagnosed per year, in the most recent period examined (2006-2010). Similarly, there was a yearly excess of around 19,200 deaths from cancer in the period 2007-2011.

In general, differences in cancer incidence and mortality by deprivation have not improved over time. For incidence, the deprivation gap reduced in males in two cancer sites over 15 years (cancer of unknown primary and stomach), but increased for five sites (female oropharynx, male and female kidney, male oesophagus, male non-Hodgkin lymphoma and vulva). For melanoma the gap became increasingly negative in males: rates began higher in the least deprived and the difference increased. For mortality there were no statistically significant changes over time. In the most recent period, 2006-2010, the incidence of female breast cancer was highest in the least deprived quintile. However, the more deprived had a statistically significantly higher mortality, with an estimated 350 yearly excess deaths in the period 2007-2011.

Lung cancer had by far the largest number of excess cases (11,700 persons per year) and deaths (9,900 persons per year), in the most recent periods. Other smoking related sites, such as larynx and oral cavity, also had strong associations between deprivation and incidence or mortality.

For all cancers combined, in the latest period examined, the deprivation gap was not statistically significantly different between males and females. However, for the cancer sites where the deprivation gap was significantly different between males and females it was larger in males. This occurred for seven sites (colorectal, oesophagus, larynx, bladder, liver, oral cavity and oropharynx), both for incidence and mortality, and in stomach cancer for incidence and chronic myeloid leukaemia (albeit with a low overall magnitude) for mortality alone.

Lung cancer stood out with the majority of the excess cases and approximately half the excess deaths. However, the influence of breast, prostate and melanoma (which have substantial negative excess cases) served to reduce the total excess cases in the all cancers combined figure. If those cancer sites with negative excess cases had been excluded then lung cancer would have accounted for approximately half the total excess cases and half the total excess deaths.

For breast cancer, while the excess cases were negative, the excess mortality figure was positive, meaning that, while the more deprived were less likely to get diagnosed with breast cancer, they were statistically significantly more likely to die from breast cancer. Only for melanoma was the burden of excess deaths negative, as persons in the least socio-economically deprived quintile had the highest age-standardised mortality rate.

An earlier report - Evidence to March 2010 on cancer inequalities in England – provided an analysis of additional inequalities dimensions; gender, age, ethnicity, sexuality, disability, religion. Key messages included:

Gender

Adjusting for women's longer life expectancy, men are diagnosed with more cancers and have a higher mortality from cancer. As a result, there are more women than men living with or beyond a diagnosis of cancer. Men's one-year survival is generally similar to or slightly better than women's for individual cancer types. Despite this, the different mix of cancers in women means that their overall one-year survival is significantly better.

The National Cancer Patient Survey of 2004 showed that, for those cancers which affect both sexes, men generally report more favourably on their care than women. However, this and an earlier survey showed poor patient experience for men with prostate cancer.

Men have a lower awareness of the signs and symptoms of cancer and a lower uptake of screening. Although it has been assumed that men delay seeking help, there is no evidence that this is the case.

More men than women die at home. This may be explained by men, on average, dying at a younger age than women and therefore being more likely to have a care giver, often a spouse.

Age

Older people- For the vast majority of cancers, incidence increases with age. Just over half of all cases of cancer diagnosed in 2003-5 in England occurred in people over 70 years and over a fifth in people over 80 years. Despite this, older people may not be aware of their increased risk and may have lower awareness of cancer symptoms than younger age groups. Significant reductions in cancer mortality have been achieved among the under 75s over the past decade. However, the improvement has been much less marked for the over 75s. Cancer survival decreases with age and there is evidence that older people's cancers are investigated and treated less intensively.

Younger people - Cancers in children aged less than 15 years old are rare, with an age standardised incidence rate of 139 per million children each year in the period 1991-2000. For teenagers and young adults (aged 13 to 24), the overall incidence rate of cancer was 224 cases per million persons each year in the period 1999-2003. Overall five-year survival from childhood cancers was 76% for children diagnosed between 1996 and 2000 and has increased significantly over the last forty years. Despite this, cancer remains a significant cause of death among children, teenagers

and young adults (but not infants aged less than 1), exceeded only by transport accidents. The low incidence of cancers in these age groups presents challenges to GPs in terms of identifying potential signs and symptoms of cancer and referring appropriately. There is some evidence that teenagers and young adults are not always referred to the appropriate specialist services³².

Ethnicity

There are variations in cancer incidence between ethnic groups, which are likely to be the result of a mixture of lifestyle and genetic factors. White men and women have a higher incidence of many cancers than those from other ethnic groups. Women from Black and Minority Ethnic (BME) groups are more likely to present with more advanced breast cancers and have poorer survival than White women.

Awareness of cancer is generally lower in BME groups than amongst White men and women and screening uptake is generally lower in minority ethnic groups than in the population as a whole. Although there may be some cultural factors involved in this, it is also likely to be related to deprivation.

There is a need for access to culturally relevant information about cancer and its signs and symptoms; existing cancer information rarely reflects multi-ethnicity in terms of images and language.

The report highlights the dominance of the contribution of lung cancer to the excess cases and deaths in the more socio-economically deprived. We also see that differences in overall cancer incidence and mortality by deprivation have not improved over time, with some individual sites even showing a widening of the deprivation gap. The enduring impact of socio-economic inequality is substantial: for all cancers combined, excluding non-melanoma skin cancer, if all socio-economic groups had the rates of the least deprived, around 19,200 deaths from cancer could be prevented each year in England (based on figures from 2007-2011).

Geographic Patterns of Cancer Survival in England, Patients Followed up to 2012 (ONS – 2014)

This bulletin presents age-standardised one- and five-year net survival estimates for men and women diagnosed with one of eight cancers in England during 2005–2007 and followed up to 2012. It includes data on cancers of the oesophagus, stomach, colon, lung, breast (women), cervix, prostate and bladder (Background notes 1, 2 and 3). Annual trends in unstandardized net survival during 2003–2007 are also presented (Background note 4). Results are presented for England as a whole and for three geographic levels of organisation of the NHS in England – NHS Region, Clinical Senate and Area Team (Background Note 5).

Key findings

- One-year and five-year net survival increased for eight common cancers in England for adults (15-99 years) diagnosed during the period 2005-2007.
- For men, the largest increase was 1.3 per cent per year in one-year survival for cancer of the oesophagus, and 1.3 per cent per year in five-year survival for cancer of the colon.
- For women, the largest increase was 1.2 per cent per year in one-year survival for cancer of the oesophagus, and 1.7 per cent per year in five-year survival for cancer of the cervix.
- The geographic disparities in net survival between NHS Regions, Clinical Senates and Area Teams in England are wide. Detailed information is available on the ONS website and could be compared to TB geographic information.

<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77->

354609

5. What evidence has informed these changes?

5.1 General

An overview of new evidence supporting IOSC was included in Annex B of the updated strategy: International Cancer Benchmarking Partnership (ICBP); International comparison of drug usage; Routes to Diagnosis; Review of quality of cancer registration; Clinical trials of screening; Measurement of service quality through peer review; Patient experience survey; National audit office study of cancer services

There has been a yearly reporting and update on incidence, mortality and survival, with highlighting key information about trends for example the pace of increase in incidence of cancer. For example the IOSC 3rd Annual Report highlighted that

- Five-year survival estimates for patients diagnosed with 21 common cancers have generally improved slightly or stayed the same during 2007-2011 compared to 2006-2010. Five-year survival in 2007-2011 was over 80% for cancers of the breast (women), prostate, testis, Hodgkin lymphoma and melanoma of skin, but less than 21% in cancers of the brain, lung, oesophagus, pancreas and stomach in both sexes. Survival from pancreatic cancer remains the lowest in both sexes (4.7% for men, 5.4% for women). . . . net survival is often considerably lower among the elderly, even after adjusting for death from other causes.
- Screening data – uptake in screening a priority for the coming year
 - Slight reduction in coverage for cervical screening
 - Need for improved uptake and coverage of bowel cancer screening
 - Promote informed choice on breast screening to more disadvantaged groups
 - IOSC (38). Cancer screening remains an important way to detect cancer early, and in some cases, such as cervical screening, prevents cancers. Over 5% of all cancers are currently diagnosed via screening, but this is set to rise as the extensions to the breast and bowel screening programmes progress. Around a third of breast cancers are now diagnosed through screening, but we recognise that some groups and communities are not accessing these services.
- Proportion of patients diagnosed with cancer at stage 1 and 2 – a useful proxy indicator for survival improvements. Based on East of England 2011 data –
 - 20,564 out of the 22,548 cases covered by the indicator (91%). Of these 12,074 (59%) were stage 1 or 2.
 - There were large differences between cancer sites, and between different groups in the community. Older patients were less likely to be diagnosed at an early stage than younger patients, and men were more likely to be diagnosed at a later stage than women. The type of cancer people are diagnosed with played an important part in these differences.
 - Using these East of England baseline data, we have modelled how many lives could be saved if there was an increase in the proportion of cancers diagnosed at stages 1 and 2. There are many assumptions made in doing this modelling, but it is interesting to note that for every increase of 1% in the proportion of cancers diagnosed at stages 1 or

2, an additional 800 patients are alive one year after diagnosis and an additional 1200 patients are alive 5 years after diagnosis.

- Whilst the general direction is a positive one, we recognise that there is a long way to go to match the best countries in the world. The recent EUROCARE5 publication in the Lancet Oncology in December 2013, which shows our poor relative performance on cancer survival, looks at cancers diagnosed in the period up until 2007, but closing the gap remains a major challenge.

6. How have these changes benefitted patients?

*I*OSC set out how the policy aimed to benefit patients. The changes linked to early diagnosis are highlighted.

The public's wishes are likely to include:

- Information and advice on how to reduce their risk of cancer
- Access to services (e.g. stop smoking services) which can help them reduce the risk of cancer
- **Information on the symptoms and signs of cancer, so that they can seek help early if problems arise and thereby improve their chances of cure;**
- **Balanced information on screening programmes so that they can make informed choices;**
- **Access to high quality screening programmes which can prevent cancer or catch it early before it causes symptoms; and**
- **The reassurance that if they or their relatives do develop cancer they will have rapid access to high quality services which deliver outcomes which are the best in the world**

Cancer patients and their carers are likely to want:

- **Good access to assessment and diagnostic services which can either exclude cancer or make the diagnosis without delay;**
- Access to reliable and balanced information about their condition, possible treatments and side effects, so that they can make choices which are appropriate for them;
- Easy access to comprehensive information about the services available to them and the outcomes achieved by these services;
- To be empowered to make choices where these are clinically appropriate and to be supported in decision making to the extent that they wish
- To know that the best treatments will be available to them. If the NHS cannot provide treatments because they do not offer value for money they will be told about this and will be able to pay for such treatments themselves without losing their right to NHS care
- To know that they will receive the support they need (physical, emotional, social and financial) through their treatment
- To be treated as a whole person, not just a 'set of symptoms'
- To know that everyone involved in their care has the necessary training and expertise
- To be reassured that everyone involved in their care will work effectively together, so that their care will feel seamless even when delivered in different locations;
- To be told about relevant clinical trials when considering treatment
- To know that at the end of the treatment they will be
 - Supported to regain as normal a life as possible
 - Given advice about how to minimise their risk of developing further cancer-related problems

- Given advice about possible signs of recurrence or long-term effects of treatment; and
- Able to re-access specialist services without delay should they need to do so;
- To know that if they do develop progressive or advanced cancer they will be supported through this and have access to the best treatments; and
- To know that if they are approaching the end of life their preferences for care will be discussed with them and every effort will be made to meet their needs and their preferences for care.

. It is important to understand and respond to how other expectations may influence a person's decision to seek advice if they have an early sign or symptom related to cancer. For example if cancer is seen as a 'death sentence' or that 'treatment is worse than the cure' people will be less likely to access services.

7. What were the challenges in implementing these changes? What have been the opportunities or benefits?

7.1 Reducing Diagnostic Delay

The challenges have been

- Establishing a new service and programme of work during a time of financial restraint
- Breaking up a newly developed, integrated programme/ services (nationally, regionally and locally) to fit with the new organisations
- Gaining credibility and establishing mechanisms to sustain 'joined up clinical leadership' across secondary care (cancer specialists and diagnostics); general practice; and public health, particularly when cancer hospital services and palliative care have been historically seen as most important.
- Sustaining research and development, investment, action, and evaluation in all the components of the service/ programme. For example is investment in supporting primary care more or less important than improving public knowledge or development of new diagnostic tests. What is a balanced programme when progress is needed on all parts of the pathway? How is different commissioning and funding aligned?
- Cancer seen as an NHS responsibility, without taking into account the contribution of organisations and actions that change public knowledge and behaviours.

It is unclear whether joint outcomes are sufficient to drive the alignment of commissioning and services/programmes.

The opportunities have been

- To move from a new 'silo' priority to integration into broad based services. Moving from one off projects to sustained, effective services and service improvement. For example local initiatives to address population needs causing inequalities could incorporate improving knowledge, confidence and access to primary care. CCG cancer commissioning plans could support GPs role in diagnosis and referral.
- The contribution of public health in local government to addressing the determinants of health, inequalities and equalities.
- A greater focus on public/ patient perspectives
- A greater focus on clinical leadership

8. All issues applicable to service delivery are relevant, although anything specific to

our core objectives would be particularly welcome they are:

Gaining an understanding of commissioning models, service models, and service structures that are in place in the UK that have seen a positive shift in cancer outcomes, in particular how services are commissioned, organised and delivered where possible in relation (but not limited) to:

- Reducing diagnostic delay
- Improving treatment completion

Elements of particular relevance to the committee are: inequalities demographics, geography, variations due to differences in rates or cancer typology (that may have parity with active TB rates, MDR and LTBI), and accountability arrangements are extremely relevant. Any evidence or data on the following would be particularly relevant:

- The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this
- The cost and/or cost effectiveness of different approaches.
- Implementation issues relevant to different approaches

References (if applicable):

Included in text above.

Additional questions asked on the day (Kathy):

- a) Fascinating the survival changes – but these are the major cancers where there is big publicity. TB is like a rare cancer – so getting buy in is more challenging. Firstly have you made improvements in the rarer one, and secondly how have you done this?

The evidence from cancer has indicated that it is more than ‘the big publicity’ that has resulted in changes in survival. Although there are similarities between the population affected for TB and some rarer cancers, there are also opportunities to segment and target interventions on TB which are not possible with rarer cancers.

Data is being collected on survival and rarer cancers, so, in time we will know if there has also been an impact on rarer cancers. Because population sizes are smaller, it will take time to have sufficient data to know if any changes have been significant. There will also need to be evaluation that measures the impact of all interventions, and not only mass media campaigns.

DH worked closely with charities representing the rarer cancers and published a summary document and recommendations.

- b) We have one in 30,000 people, not one in 3. You had tools, logic models, plans for people at the coal face, investment in collecting impact data, and you had leadership. But you also had a central model and political commitment, and also a vertical model. We won't get that – the best we get will be local networks. Could you do this with just local networks?...

I would argue that we achieved these outcomes working with a devolved model through networks. The tools, local plans, leadership and quality/ use of data were led locally, with support from NCAT. This applied to assessing the local need; appointing and supporting clinical leadership (secondary care, general practice, public health); developing governance, programme, project and funding arrangements; implementing NHS service changes (primary and secondary care); local involvement of partners; and outreach to community or high risk groups. The only exception was the national media campaigns.

In my view the local leadership, ownership and implementation was critical for success – and that NCAT's model of working with national partners to support local decision making was the right model. This was supported through national public health leadership; learning sets; regular communications (blog, website); responding effectively to local requests; and a working relationship that supported mutual challenge.

This working style has been documented, with papers on the NCAT archived website.

- c) and how do you resource this?

Funding was provided locally and nationally. With experience it was clear that some investments should be done once nationally (e.g. analysis of survival data) to ensure excellent quality, benchmarking and value for money. Where local investment was not available charities contributed funding (e.g. new primary care models and leadership). National, NHS funding, was appropriate in relation to increased diagnostic testing and for national media campaigns. The approach to funding evolved pragmatically, respecting local investment, and ensuring national levers were in place to enable local action.

- d) Being negative – conversion rate and the money – worse than other European countries for the same money, why do you think that's so?

We were on a journey ensuring the data was comparable, which resulted in the International Benchmarking initiative. This has, and will continue to provide valuable insight. For example the module on public awareness showed that our knowledge levels are not so different, but we are more inclined to not want to waste the GP's time. Future modules will be exploring the differences in primary care systems.

GP cancer leads and primary care multidisciplinary teams have gained an enormous amount of insight into referral, conversion and commissioning decisions which needs to be understood and action taken. Ensuring that 'the right' patients see their GP 'at the right stage'; GPs are supported in 'making tough and high quality referral decisions'; and that peer led review processes are in place to improve the quality of referrals, and therefore conversion rate and money will all be important. In our experience respect for the GP clinical and patient perspective were critical elements, as well as a programme of research to unpack the international comparisons.

- e) If we take the 2 week standard in cancer - is there some kind of learning from this for TB?

I'm sure there is. Underpinning this will be an understanding of the TB patient pathway. Where are the delays? Why do they occur? In what proportion of patients would having a 2 week standard have made a difference?

- f) What do you think are the important messages from large scale change methodology for cancer and how might they transfer to TB?

Key approaches include:

- Shared purpose – understanding and harnessing the different perspectives
- Clinical leadership – GP, hospital, public health
- 'open approaches' – sharing ideas and data, energy-generating
- Relationships and networks with 'reach', building bridges and sharing knowledge for action
- Patient and public focus - and outcomes
- Sustaining a focus and improvement over time

The large scale change methodologies are available from NHSIQ - <http://www.nhsiq.nhs.uk/resource-search/publications/nhs-inst-leading-large-scale-change.aspx>

NHSIQ has recently reviewed improvement methodology building on the learning from large scale change and other evidence –

<http://www.nhsiq.nhs.uk/resource-search/publications/white-paper.aspx>

EP 6 Practice - the Birmingham experience

Section A: CPH to complete	
Name:	Sue Ibbotson and Grace Smith
Job title:	PHE Regional Centre Director-West Midlands Director of the Regional Mycobacteriology Laboratory (West Midlands)
Address:	6th Floor 5 St Philip's Place Birmingham B3 2PW
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Practice - Regional case study - Birmingham
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) In your view, what are the challenges for TB services around England?</p> <p>2) How are TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured?</p> <p>3) What are the advantages and challenges of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve (do you have any examples)?</p> <p>Elements of particular relevance such as: inequalities, demographics, geography, variations due to differences in active TB rates, MDR and LTBI, and accountability arrangements are of great interest especially any evidence or opinion on the following:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches 	

Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
<p>1) In your view, what are the challenges for TB services around England?</p> <p><i>Summary points:</i></p> <ul style="list-style-type: none"> - Challenges for TB services and TB control relate to the epidemiology of TB, the biology of the disease, its diagnosis and treatment, behavioural factors, the commissioning and configuration of services, and the extent of political and patient advocacy. - These challenges compound with the result that TB control represents a “wicked problem” requiring a multi-layered and systematic approach. - Control therefore translates into a complex and diverse set of implementation tasks requiring common vision and purpose, great clinical and public health leadership, wide engagement and good partnership, and a long term focus on strategy, implementation, evaluation and continuous quality improvement. - This in turn requires dedicated, long term resourcing. Securing such resources for TB is difficult as it is often, even in high prevalence areas, not seen to be a highest-order priority in comparison with other demands on scarce resources. More so, when the responsibility for control is carried by multiple commissioners and providers. As a result services have been often fragmented with many clinical settings involved with relatively small numbers of TB cases. - Relatively few of the professionals involved have dedicated time within their role to control TB – all too often, responsibility for TB control is but a small part of the “day job” for busy professionals and this is part of the reality that, even in high prevalence areas, the incidence of TB is comparatively low. <p><i>Epidemiology:</i></p> <ul style="list-style-type: none"> - The population affected by TB is heterogeneous as are the determinants of their disease, and their need for approaches to control - - Whilst having a focus on “find and treat” is crucial, there is also a need to consider the underlying social determinants of disease – poverty, overcrowding and homelessness – both in prevention and treatment. It often proves difficult for example for TB services to provide the required and sometimes quite bespoke package to ensure adherence to treatment of individuals with TB who lead chaotic lifestyles; and the persistence in some areas and for some population groups of conditions that support the activation and transmission of TB provides a preventive challenge. The new public health responsibilities of local authorities present a real 	

opportunity to address these issues both strategically and in clinical practice. This requires political commitment and advocacy.

Characteristics of the infection, diagnostic, treatment and behavioural factors:

- The long and unpredictable latent period, the stigma associated with having TB in some cultures, and the multiple modes of presentation of TB infection contribute to delayed diagnosis which in turn hampers control and increases the risk of transmission in institutional or social settings. We can think of TB as having the worst characteristics of infectious disease and cancer when it comes to the challenges of diagnosis, treatment and control.
- It is not easy to pick up active TB “coincidentally” in routine clinical practice – there is no simple and cheap blood test that can be just tacked on to a battery of others, a chest x ray will not inevitably pick up TB disease, and nor will TB be tested for routinely when sputum is sent to the lab.
- Clinicians need therefore to “think TB” in the clinical consultation and deliberately set out to prove or disprove the diagnosis. And whilst classical symptoms of pulmonary TB are well known, 50% of disease is non pulmonary and may present in a myriad of ways. In primary care or general hospital practice, clinicians may rarely come across a case of TB, even in higher prevalence areas – all of which conspires to make the diagnosis of TB challenging
- The long treatment period leads to a significant risk of failure to adhere which again hampers control of disease.
- In areas where the requirement for DOTS and the occurrence of cases in institutional and social settings is high, there is an inevitable tendency, given limited TB service resources, to focus on a reactive approach to service delivery. Given this demand there has often been much less ability to “get ahead of the curve” within available resources, although there are honourable examples, in the work in Birmingham and elsewhere to develop and use TB genotyping, in the leadership and systematic approach to latent TB screening in high risk groups in Leicester, in the development of innovative approaches to community engagement, case finding, and support for treatment. These , however, often grow from small scale or pilot initiatives often supported by non-recurrent funding rather than being part of an agreed strategy, and therefore take a long time to become an established part of the approach to control.

Commissioning challenges and the configuration of services

- TB control has, understandably, not been a high priority for CCGs who are responsible for the commissioning of both the public health (contact tracing) and treatment services for TB. These are “slim” organisations with a broad and

increasing responsibility for service commissioning for the population they serve. Their public health support is provided through a “core offer” from local government public health departments which, similarly have variable capacity to devote to that element of their function. Accordingly, the expansion of services in the face of increasing TB incidence is challenging.

- Roles and responsibilities were not sufficiently clear through the NHS and PH transition of 2013, requiring much local work to re-establish all components of the prevention and commissioning pathways. (for example, it was not clear who should fund the use of IGRA testing in the management of TB incidents, and this was a complex question to resolve requiring both national and local level work)
- The distribution of public health and health care resources to control TB owes much to historical precedent, and has often been driven not by what is required to control TB but by other considerations – such as the demands on a respiratory service of which the TB service is but a part, or by the interests of individual clinicians, public health physicians, managers and political leaders
- Given that TB treatment services have by and large developed as part of generic respiratory services provision there is no well-embedded way of “taking the services to” the 30% of the TB population who are under-served by mainstream services – those who are either “hard-to-find” and/or “hard-to-treat”
- The architecture of public health and health care services means that many different organisations have important responsibilities and roles to play in TB control. The NHS (primary care, CCGs, and provider Trusts), local government (departments of public health, social care, housing, Health and Wellbeing Boards; Overview and Scrutiny committees; individual Members and portfolio holders), Public Health England (specialist health protection services), and the voluntary sector (patient advocacy). In common with many other health and care issues there is no single organisation charged with the overall responsibility for controlling TB, and no single organisation that has all the necessary levers to do so.
- This situation demands the development of a strategic coalition involving a significant number of players – at local level commissioners, clinicians, local government, Public Health England and the Third Sector - and a ruthless focus on the development and implementation of a multilayered strategy for control.
- In turn, this requires great system leadership from those involved, as well as leadership for the public health, clinical and other aspects of control.
- Whilst we by and large know “what” we need to do to control TB, the evidence base for “how” to do it in a way that is relevant and sensitive to the particular needs of different populations and the opportunities and barriers in the health care system is much weaker and we do not enough about “why” approaches either work or don’t work in particular places and with particular populations, so that we can replicate

them elsewhere. We have not been systematic enough in identifying and disseminating learning from other places, both in the UK and internationally, not just about what works but why it works.

- In a climate of significant financial constraints, the anticipated “return on investment” of different approaches to control and improvement (for TB as for other services) is a significant consideration. It is not enough to know that an intervention is effective and cost effective. We need to know in addition which of the possible control strategies yield the greatest value and the highest return, particularly expressed in terms of reducing public sector costs eg cost to the health and social care system. In TB control, this debate is particularly relevant as we consider how much resource and energy should be devoted to case finding and treatment in high prevalence areas, as opposed to the resources that should be committed to finding and managing latent TB cases.
- Ruthless attention to both developing strategy and to “the implementation task” is therefore imperative, and requires a focus on the coordination of translational research, evaluation and the development of new sort of “evidence” to complement the impressive and growing evidence we have about the disease, its epidemiology and its treatment.

Political and patient advocacy

- Ensuring that rare diseases are prioritised within the research and health service sectors often relies on good and sustained advocacy, not only from clinicians, but from politicians and patient groups. TB is an “old” and “unglamorous” disease often affecting groups in the population whose voices may not be heard. Although charitable groups such as TB Alert do great work, there is otherwise little patient advocacy and there has been to date little political advocacy to drive improvements in control strategies and service provision. Public Health England’s adoption therefore of TB control as a “Big Ambition” over the next few years, and NHS England and PHE’s joint approach to the National TB Strategy is to be welcomed.
- Political advocacy initially via Birmingham City Council’s Overview and Scrutiny Committee was one of a number of key drivers, along with a high profile and tragic death from TB of a school girl in the city which came together with the efforts of clinical and public health leaders to galvanise the now-established and crucial whole system approach to TB control we are pursuing in the West Midlands conurbation.

2) How are TB services set up and managed in your area? Why are they set up in this way? Is there evidence to support the way that they are configured?

- There are multiple TB services across the West Midlands conurbation, and their

pattern is largely historic, driven by the commissioning decisions of the individual PCTs, the demand for services and the interest of clinicians.

There is a single integrated TB nursing service which serves the populations of Birmingham and Solihull, and the service is based at the Birmingham Chest Clinic in Birmingham City Centre but delivered in patient's homes and secondary care clinics. The secondary care medical services are provided by the Heart of England NHS Foundation Trust, University Hospital Birmingham, City Hospital Birmingham and the Birmingham Children's Hospital

The more recent development and implementation of a *well-owned and coordinated multiagency strategy for TB control* across Birmingham and Solihull, clear public health leadership, the identification of a single clinical commissioner for this area representing the Birmingham CCGs, and a mandated and funded lead clinician for Adults and for children will, we anticipate will drive improved outcomes for patients, but these changes are too recent to provide evidence at this point.

- Public Health England DsPH in the other higher prevalence local authority areas are now facilitating a similarly coordinated and strategic approach across the wider West Midlands conurbation.
- Key drivers for the development of control strategy in Birmingham and the West Midlands:
 - o The *epidemiology of TB in West Midlands*, and our performance against the targets set in the CMO's 2004 TB Action Plan
 - o

Key features of the epidemiology of TB in West Midlands are :

- Provisional data show that a total of 989 TB cases were reported in the West Midlands in 2013, a rate of 17.5 per 100,000 population. This was lower than the previous two years but not significantly different, and similar to rates seen in the last five years.
- The West Midlands has a significant high burden of disease; second to London. Highest rates are in urban areas and higher than other Western European cities
- 75% of West Midlands cases from 5 LA areas. Rates are consistently high in these areas and show increasing trends
- The highest Upper Tier Local Authority (UTLA) rate in 2013 was reported in Sandwell (39.5 per 100,000) followed by Birmingham, Wolverhampton and Coventry LAs, all of which had rates statistically significantly above the West Midlands average.
- Provisional rates showed there were no Local Authorities (LAs) in the West Midlands with rates higher than 40 per 100,000 in 2013, the level at which universal neonatal BCG should be considered.
- Rates were highest in those of black African ethnicity, followed by Indian and Pakistani groups. 65.0% of TB cases reported in the West Midlands in 2013 were in people born outside the UK. Although over half of UK-born cases were in white people, rates in black people born abroad were nearly 40 times that in UK-born whites. Rates in non-UK born and UK-born South Asians were about 50 and 10 times that in UK-born whites respectively.
- There are two distinctive themes within our epidemiology: cases of TB amongst non-UK born/immigrants from high incidence countries) and amongst those who are socially at risk – homeless, drug/alcohol misuse, prison history
- 53.6% of cases in 2013 where site of disease was known had pulmonary tuberculosis (including military TB; with or without extra-pulmonary disease) and so were potentially infectious.

- Outcome reporting and treatment completion has improved in recent years in the West Midlands. Outcome data are currently being collected for cases notified in 2012, as of the 20th March 2014, 99.7% (1,081/1,084) of cases have an outcome reported. Of all cases, 85.7% (929/1,084) completed treatment.
- The national CMO Action Plan target of a progressive decline in rates of tuberculosis in the UK-born was not achieved based on provisional data. Provisional calculations show that rates remained at 6.6 per 100,000 in 2013 which was the same as in 2004.
- The national CMO Action Plan target of a reduction in incidence of tuberculosis in people who entered the UK less than 5 years before diagnosis was achieved. Provisional data shows that the proportion decreased from 47.7% in 2004 to 31.7% in 2013.

- *Political advocacy* – interest expressed by Birmingham Overview and Scrutiny Committee, and subsequently by a number of Councillors who are both important advocates and provide leadership for community engagement in high incidence wards; and the death of a school girl followed by both a Child Death Panel review and the issue of a Coroner’s Section 43 report.
- *Clinical leadership* – provision of dedicated (funded), effective and mandated clinical leadership for TB control across the city; the development of comprehensive genotyping services.
- *Public health leadership* – the HPA and later the new DPH for Birmingham provided leadership for the development of a coordinated and strategic approach to control. The appointment by the HPA/PHE in the West Midlands of a full time senior coordinator for the Strategic Coordinating Group is seen by partners as being instrumental to success. The expert review of services undertaken by the HPA also provided helpful impetus and support for action.
- *Increased investment* – resulting in increased resources for TB incident management and case management

3) What are the advantages of the way that your service is configured? Is there evidence on whether your model can help to reduce diagnostic delay, improve contact tracing or improve treatment completion in the community that you serve (do you have any examples)?

- Our earlier model was disparate at different levels and our current model helps bring everyone together with common objectives priorities and crucially a manager who is able to provide full time leadership for the endeavour.
- We are on a journey. We have secured the multiagency engagement that we previously lacked, and the leadership and coordination that we believe is essential.

Many of the evidence-based processes are much better aligned and these are beginning to impact on diagnostic delay and improved treatment.

- The major achievement is that we now have a well-owned strategic approach across Birmingham focussed on:
 - o *Leadership*
 - o *Commissioning*
 - o *Case detection and investigation* (Rapid referral suspected cases; improving % culture confirmed pulmonary cases; Contact tracing – best possible; High risk groups – targeted screening & treatment/ CXR; New entrant LTBI screening and treatment);
 - o *Case holding* (Treatment adherence - improvement needed from <85% in 2011; DOT for high risk groups; Link workers for those who are socially marginalised – to address issues of housing/immigration/benefits; Low threshold, accessible, well staffed clinics)
 - o *Monitoring and evaluation*

- The progress we have achieved through our current programme of joint work has been recognised as good (ref HPA/PHE review of progress), including:
 - o The promulgation of NICE guidance for case management and the treatment of MDR TB
 - o The development of named case workers
 - o A focus on consistent, high quality TB incident response (including the use of innovative social networking and genotyping approaches in epidemiological investigation)
 - o The roll out of cohort review
 - o Strain type cluster investigation
 - o The establishment of a world-leading laboratory service in Birmingham
 - o Awareness raising work in general practice and with communities
 - o A focus on useful epidemiological reports, surveillance data (ETS), treatment outcome data
 - o The establishment of TB control Boards – Birmingham etc

- But, we have not yet seen our rates of TB reducing, and it is too soon for us to set targets for that reduction until we have better information about the total burden of disease.

The TB Board are currently consulting widely on potential Quality Improvement targets, as listed in the Annexe, drawing on experience from visits to successful services in Rotterdam and Manchester

Annexe

Quality Improvement Targets for Birmingham and Solihull –Draft In Consultation

These are suggestions for discussion locally. If accepted they would be put forward as clinical standards for primary and secondary care

1 Treating known pulmonary disease well

Aim is to have 95% with completed treatment within 9 months. All outside this to be subject to cohort review

2 anticipating disease in medically compromised patients

Aim is to ensure that 100% of patients having systemic chemotherapy, radiation affecting more than one body site or the trunk or immunomodulation (systemic steroids for more than one month or anti TNF therapy) are adequately assessed for active and inactive pulmonary TB. Any breaches should be a quality contract breach

3 no pulmonary disease in recent contacts of pulmonary TB

Aim is to ensure that there is no case of active TB in any person who was a contact of known pulmonary TB in the previous 12 months. Any exception is a SUI

4 rapid referral of pulmonary TB to a respiratory specialist with an interest in TB

Aim is to ensure that all known cases of pulmonary TB are referred within two weeks of presumptive, radiological, immunological or bacteriological diagnosis to a specialist with an explicit interest in TB. Any outside this timeframe should be a contract quality breach

5 all patients with a cough lasting for more than 3 weeks or haemoptysis have chest X-ray or and sputum analysis

Aim is to ensure that those at high risk of pulmonary TB are investigated as soon as possible. Failure to refer for investigation is see as a serious case event

6 all cases of complex TB (eg MDR TB, comorbidities) are assessed by MDT

Aim is to ensure that all difficult cases are jointly assessed and reviewed by a Multi professional team

7 All cases of active TB in children under 10 are reviewed in a peer review environment

Aim-to review transmission in Birmingham-as most cases will have been acquired here

Grace Smith and Sue Ibbotson 9th September 2014

References (if applicable):

^a From Public Health England, Field Epidemiology Services (West Midlands).
“Spotlight on Tuberculosis in the West Midlands. World TB Day 2014” and summary
presentation Coetzee N. “West Midlands – TB priorities”. May 2014.

4)

EP 7 Contact Tracing – incident investigation process in congregate settings

Section A: CPH to complete	
Name:	Dr Sudy Anaraki
Job title:	Consultant in Communicable Disease Control
Address:	North East and North Central London Health Protection Team Public Health England Ground Floor, South Wing Fleetbank House 2-6 Salisbury Square London EC4Y 8JX
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service Delivery Group of the Guideline Development Group for Tuberculosis
Subject of expert testimony:	Contact Tracing model for a big metropolitan area
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1. How is contact tracing delivered in your area?</p> <ol style="list-style-type: none"> a. Why is it set-up in this way b. Is there evidence to support the way this is configured or the approach you have taken c. Who delivers which elements, and what training or other support mechanisms are in place d. Who is ultimately responsible and what governance processes are in place <p>2. What are the advantages and challenges of the way that contact tracing is configured and/or delivered in your area?</p> <ol style="list-style-type: none"> a. Is there any data about the impact of this model on diagnostic delay, improvements in contact tracing or improved treatment completion? <p>3. What is the mechanism through which delivery is monitored and evaluated, and what accountability arrangements are in place for the service?</p> <p>4. Are there any associated outcomes or evaluation data available on the work outside of the areas suggested in <u>Q.2a</u> above, or any other elements you would like to inform the committee of in terms of opportunities and benefits for improved patient or service outcomes?</p>	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]

How is contact tracing delivered in your area?

London TB Extended contact tracing (LTBEx) pilot project works with local HPTs in order to enhance the coordination, and timely and complete follow up of contact investigation for TB incidents in congregate settings, by improving collaboration with clinical, non-clinical and diagnostic services for contacts of TB cases and supporting mass screening exercises, where possible.

The LTBEx team receives referrals of (potential) TB incidents from the four London HPTs, carries out a risk assessment (with or without the HPT – by prior agreement), plans the incident contact screening (in conjunction with the local TB service), provides on-site screening, and follow up the results of screening. Screening outcomes are then reviewed, and decisions are made as to whether further screening is then required.

Why is it set-up in this way

Prior to the LTBEx project, TB incidents were managed by the 4 HPTs and approximately 30 TB clinics in London. There were some shortcomings and gaps including:

- Variations in risk assessment and contact screening: The execution of the contact tracing and screening process is subject to wide variation, depending on the interpretation of national guidance, personal judgements and availability of resources.
- Geographical boundaries: Local TB services are restricted by geographical boundaries, and are only able to provide contact screening for the areas that they cover. However contacts of the same case may often live across a wider area, and would generally need to be referred to different TB clinics in the areas where they live. This has resulted in contacts being assessed and screened differently, depending on their area of residence and follow up of screening outcomes becoming more difficult and time consuming.
- Difficulties in arranging on-site screening: Due to considerable pressure to manage their case loads, it had not always been possible for clinics to offer on-site screening, or screening has not been arranged in a timely manner. Where on-site screening was not possible, contacts would have been referred to their local clinics.
- Poor uptake of screening: contacts referred to TB clinics are less likely to attend compared to those who are offered on-site screening.
- Poor data collection: Previous TB incident audits across London HPTs suggested a need for improvement in data collection, communication and follow up of results.

Is there evidence to support the way this is configured or the approach you have taken

- Since January 2013, LTBEx has responded to 106 TB incidents across London, in a variety of settings, including workplaces, schools, colleges and hostels. To date, screening has been completed for 71, screening is planned for 8 incidents, and results are pending for 7 incidents. Three potential incidents are not yet confirmed (awaiting further information about onset dates and degree of possible exposure), and 17 did not require screening.
- Previously TB incidents were managed by the TB clinic covering the borough where the incident occurred. However, of the 3181 of contacts identified by LTBEx, only 40.9% were resident in the same borough as the incident location, while 44.0% lived in another London borough, 6.9% lived outside London or overseas, and 8.3 % did not have a (recognisable) postcode.
- Screening exercises carried out by LTBEx have been able to overcome cross-boundary issues, remove

the necessity for complicated and time-consuming referrals between London clinics, and thereby improve the efficiency of screening pathways and overall screening uptake rates.

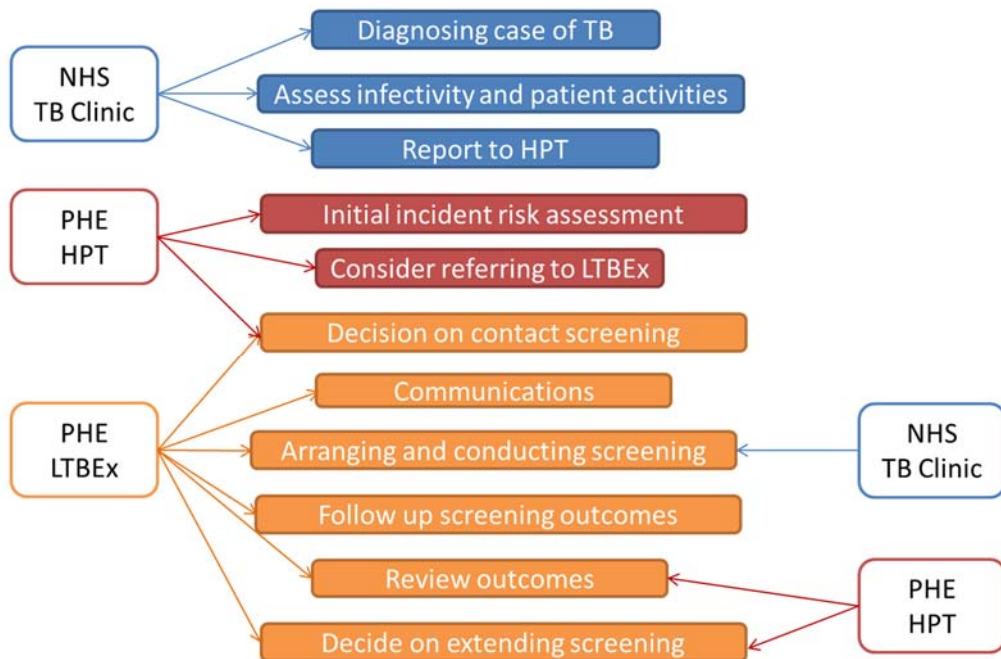
- On-site screening has been offered in 32/71 incidents, with an overall screening uptake of 76.4% (or 81.5%, if excluding an unusual incident at a tertiary healthcare setting, where significant numbers of previous inpatients were recalled for screening), compared to uptake of 64.1% for incidents where on-site screening was not possible/practical.
- Incidents where LTBEEx have provided contact screening had a yield of 15% for LTBI and 1% for active disease.

Who delivers which elements, and what training or other support mechanisms are in place

NHS-TB clinics: diagnosing cases of active TB; assessing infectivity; reporting cases of infectious TB in congregational settings to the HPT; and supporting timely contact screening

PHE-HPT: the initial risk assessment; discussing with, and referring to LTBEEx (as appropriate); arranging for joint risk assessment with LTBEEx, or delegating management of the incident to LTBEEx

LTBEEx team: joint risk assessment with HPT, or on behalf of the HPT; visiting the venue and undertaking an environmental assessment; communications with contacts; planning screening; conducting screening onsite, when appropriate; reporting results back to HPT; referring those with evidence of infection, active or latent TB, to their local TB clinics for further clinical assessment; and providing regular reports to the PHE London Region and Centre, HPTs and NHS stakeholders. LTBEEx team members are Consultant in Health Protection, Senior Health Protection Specialist, TB Public Health Nurse Specialist, TB Public Health Nurses, Information Analyst and Administrator



Who is ultimately responsible and what governance processes are in place

The team leader (Consultant in Health Protection) is ultimately responsible for the LTBEEx team and is accountable to the PHE London Regional Director and Deputy Director for Health Protection.

What are the advantages and challenges of the way that contact tracing is configured and/or delivered in your area?

Advantages:

As a dedicated contact tracing team, LTBEEx provides an integrated approach to incident management and screening. It provides consistency across London and overcome cross-boundary issues. The project provides additional capacity to TB clinics, and enhances partnership working amongst all stakeholders. It also collects systematic data on cases, incident settings and contacts, which will provide further evidence on effective TB incident management and contact investigation.

Challenges:

LTBEEx is currently not able to provide screening independently from local TB clinics, therefore cannot completely avoid delays in screening and overcome local variations in service provision as still have to follow local clinic protocols to some extent.

Is there any data about the impact of this model on diagnostic delay, improvements in contact tracing or improved treatment completion?

Data from a joint audit by two London HPTs in 2014 indicates that in the absence of LTBEEx, the uptake of screening is only as high as 50%, compared to uptake rates of over 75% where LTBEEx has provided onsite screening.

Screening yield for is 15% for LTBI and 1% for Active TB. These contacts were referred quickly to their local TB services for appropriate clinical follow-up and treatment. A yield of more than 10% for latent TB infection is considered to be cost effective.

What is the mechanism through which delivery is monitored and evaluated, and what accountability arrangements are in place for the service?

The project is accountable to the PHE London Regional Director, and the Deputy Director for Health Protection.

The LTBEEx project is currently being independently evaluated by a team of health economists and epidemiologists at University College London. The outcomes of the evaluation, and any subsequent recommendations will determine the future of the project.

Are there any associated outcomes or evaluation data available on the work outside of the areas suggested in Q.2a above, or any other elements you would like to inform the committee of in terms of opportunities and benefits for improved patient or service outcomes?

Provisional project data indicate that it is a cost effective and acceptable approach, and as a pan-London service, LTBEEx is uniquely placed to develop and implement agreed standards for TB risk assessment and evidence-based incident management, which can also be applied elsewhere.

References (if applicable):

EP 8 Practice – Experience of people who use TB services

Subject of expert testimony:	The experience of using TB services by an individual affected by TB
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>Please give equal weight/time to providing information on all the questions below:</p> <ol style="list-style-type: none"> 1) What was your experience of TB services: At the point at which you were diagnosed with TB, through your treatment for TB, at the point at which your treatment finished? 2) Did the services or staff you encountered as you completed treatment for TB focus on TB alone, or did they link you with other services or people who could help with any other issues relevant to your situation or treatment? 3) Do you think your experience is typical of people in your situation? Why / why not? 4) What was good about your experience of TB services? 5) What could have been better? 6) Do you think people are treated equally and fairly in TB services? Why / why not? 7) In your view, how could TB services change / improve in order to reduce the time that it takes to diagnose TB in people, increase contact tracing and improve treatment completion? 8) Is there anything else you would like to tell us about your experience of TB services? 	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
<ol style="list-style-type: none"> 1) What was your experience of TB services: At the point at which you were diagnosed with TB, through your treatment for TB, at the point at which your treatment finished? <p>The service user found that once she accessed the service and started treatment the support she received from her TB nurse was excellent. The TB nurse was seen as crucial in supporting the service user to understand the treatment, deal with side-effects and also provided much broader support and friendship which was invaluable.</p> <p>However, the service user described that prior to entering the TB service her care</p>	

was much less satisfactory. She presented approximately 20 times in the emergency department. On her final visit to ED she presented with fluid in the lungs and was finally diagnosed several weeks later with TB. She received little support until entering the TB service and meeting with her TB nurse.

- 2) Did the services or staff you encountered as you completed treatment for TB focus on TB alone, or did they link you with other services or people who could help with any other issues relevant to your situation or treatment?

The service user described that the TB service helped provide her with broader support to help her overcome alcohol addiction. She was also crucially given an opportunity to volunteer with the Find and Treat service which she found very rewarding and which helped her move forwards with her life and led her onto TB Alert.

- 3) Do you think your experience is typical of people in your situation? Why / why not?

The service user commented that she thinks every case will be different. However, she feels her situation may be typical of people with a chaotic lifestyle.

- 4) What was good about your experience of TB services?

The service user felt that the TB nurse was the crucial factor in helping her successfully complete her TB treatment and also support her to overcome alcohol addiction problems.

- 5) What could have been better?

The service user described that when she was first diagnosed, prior to meeting with her TB nurse, she was simply given 'a big bag of tablets to take' without any clear discussion and support.

- 6) Do you think people are treated equally and fairly in TB services? Why / why not?

The service user described that the TB service itself treats people fairly and equally, but that in a general hospital setting, such as emergency department, some of the staff can be less supportive and understanding.

- 7) In your view, how could TB services change / improve in order to reduce the time that it takes to diagnose TB in people, increase contact tracing and improve treatment completion?

The service user described the length of time it took her to be diagnosed with TB and

how staff in the emergency department did not have a high suspicion of TB even though she was clearly symptomatic. She believed this was due to her not clearly fitting the profile for what ED staff think of as a 'TB patient'. Better staff awareness in an ED setting that TB can affect anyone could have helped reduce the time to diagnosis.

8) Is there anything else you would like to tell us about your experience of TB services?

The service user commented that, 'From being in touch with my nurse and having her there for me is what made the difference for me, not only did something so awful at the time become manageable, in my case catching TB actually turned my life around for the better and probably even saved it.'

References (if applicable):

Subject of expert testimony:	The experience of using TB services by an individual affected by TB
-------------------------------------	---

Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
--	--

Please give equal weight/time to providing information on all the questions below:

9) What was your experience of TB services: At the point at which you were diagnosed with TB, through your treatment for TB, at the point at which your treatment finished?

10) Did the services or staff you encountered as you completed treatment for TB focus on TB alone, or did they link you with other services or people who could help with any other issues relevant to your situation or treatment?

11) Do you think your experience is typical of people in your situation? Why / why not?

12) What was good about your experience of TB services?

13) What could have been better?

14) Do you think people are treated equally and fairly in TB services? Why / why not?

15) In your view, how could TB services change / improve in order to reduce the time that it takes to diagnose TB in people, increase contact tracing and improve treatment completion?

16) Is there anything else you would like to tell us about your experience of TB services?

Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
From diagnosis to end of treatment – My experience of TB services	
<p>Prior to diagnosis:</p> <ul style="list-style-type: none"> • Understanding the context; diagnosis is a process that begins before arriving at an actual diagnosis. • Presented to GP (primary care) 10-15 times over a nine month period (system delay) <p>Diagnosis and treatment process:</p> <ul style="list-style-type: none"> • Limited information about side effects of treatment, and no reassurance and support: <i>'Provide more information about the effects of medicine to reduce the risk of patients not completing treatment when experiencing treatment side effects'</i> • Absence of health information: <i>'Provide more information about the disease and treatment to patients and communities'</i> • Lack of financial support and assistance: <i>'Address structural and personal factors, for example, compensating the high cost of treatment and income loss'</i> <p>TB services and links with other service providers</p> <ul style="list-style-type: none"> • No referral to other services (internal/external) or signposting elsewhere for social and financial support • Lack of integration with social care and voluntary/third sector involvement <p>The patient experience</p> <ul style="list-style-type: none"> • Patient support needs are not reflected in service design and delivery • Low levels of awareness amongst medical professionals, leading to delayed diagnosis and complications • Lack of peer support groups and patient involvement <p>What was good about my experience of TB services?</p> <ul style="list-style-type: none"> • Empathy and care • Person-centred approach • Non-judgmental attitude <p>What could have been better about my experience of TB services?</p> <ul style="list-style-type: none"> • NHS awareness • Basic patient support package • Integrated services for patients <p>Are people treated equally and fairly in TB services?</p> <ul style="list-style-type: none"> • Rights: <ul style="list-style-type: none"> – Access to free treatment – Housing, benefits and other welfare assistance – Non-discrimination 	

How could TB services change/improve?

- Reduce diagnostic delay:
 - Ensure education and training amongst primary and secondary care staff
 - Provide rapid diagnostic clinics for patient access
 - Follow NICE guidance. i.e. two week referral time frame
- Increase contact tracing:
 - Ensure that correct protocols are followed
- Improve treatment completion:
 - Increase access to patient support initiatives

References (if applicable):

International Standards for Tuberculosis Care (ISTC 3rd Edition) Accessed via http://www.who.int/tb/publications/ISTC_3rdEd.pdf

EP 9 Accommodation, Housing and TB

Section A: CPH to complete	
Name:	Gill Leng
Job title:	Housing and Health Lead
Address:	Health Equity and Place Division Public Health England London
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Housing
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) The needs of commissioners/CCG's/LA's in relation to TB and housing. In particular:</p> <ul style="list-style-type: none"> • barriers to implementing the current guidance, • other needs i.e. networking/ wider commissioning footprints and • understanding the issues surrounding the statutory responsibilities for housing 'groups at need' <p>2) All issues applicable to service delivery in the above context are relevant, although anything specific to our core objectives would be particularly welcome such as: Information on commissioning models, service models, and service structures/networks that are in place (or could be developed) for housing specialists to support TB treatment and control.</p> <p>In particular how services are commissioned, organised and delivered where possible in relation (but not limited) to managing:</p> <ul style="list-style-type: none"> •improving TB contract tracing •Improving TB treatment completion <p>If you have any evidence or data describing: inequalities demographics, geography, variations in housing provision due to differences in active TB rates, MDR and LTBI, along with information on accountability arrangements it would be extremely useful especially if they cover:</p> <ul style="list-style-type: none"> •the effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this •the cost and/or cost effectiveness of different approaches •implementation issues relevant to different approaches <p>3) What can housing associations do to support TB treatment completion and housing those in need during treatment?</p> <p>4) Can you give examples of where providing housing for TB treatment is working successfully and tell us</p> <ol style="list-style-type: none"> a. how they do this? b. who makes the decisions and how – to house someone? (any criteria used?); and c. who pays for this, and what local agreements are needed to be in place to manage? 	

this successfully?	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]
<p>1. The needs of commissioners in relation to TB and housing</p> <ul style="list-style-type: none"> • Data collected likely to be insufficient to commission accommodation (little evidence of analysis – typically at very local level, instigated by healthcare workforce eg, TB nurses and not as part of regular commissioning) • Practical issues <ul style="list-style-type: none"> ○ Local authority (legal) definition of ‘homelessness’ is much narrower than NICE guideline – not required to consider NICE guideline ○ Inconsistent approach to what is recorded, and when: not able to get the full picture ○ Missed opportunities eg, DOT • Populations within ‘homeless’ <ul style="list-style-type: none"> ○ Additional needs eg, offenders, substance misuse, mental health ○ Eligibility for housing ○ Eligibility for funding • Suspect that number ‘homeless’ is much greater than reported currently (NICE definition) • <u>Recommend that to address the needs of commissioners:</u> • Everybody’s business (matter of reducing inequalities): <ul style="list-style-type: none"> ○ Not just a matter for health protection and clinical services ○ Importance of housing (and employment) as wider determinants • Establish pathways, recognising that there are different pathways with different commissioners eg, prison leaver • Makes sense commission across local authority boundaries (London particularly) • Should be role for local governance eg, Health & Wellbeing Board (in addition to TB control boards), so that commissioning across wider determinants possible • Should be absolute clarity about commissioning & service LA statutory duties, and rights of the individual <ul style="list-style-type: none"> ○ Social care & housing ○ Who will pay? • Develop shared definitions/terminology eg, <ul style="list-style-type: none"> ○ Homelessness; overcrowding; sub-standard etc, ○ ‘Housing department’ ○ ‘Housing’ – not an official allied health professional but workforce operates in similar way ○ ‘Link to other’ – in housing terms? Be more specific <p>2. Commissioning and service models</p> <ul style="list-style-type: none"> • No knowledge of single effective model for outcome • Elements of a model: <ul style="list-style-type: none"> ○ Temporary accommodation <ul style="list-style-type: none"> ▪ Homerton Hospital SLA with LB Hackney Council (NRPF) ▪ Spot purchasing of hostels: Westminster ○ Find and Treat <ul style="list-style-type: none"> ▪ Housing knowledge of TB outreach workforce ○ Multi-disciplinary teams (not TB specific) eg, 	

- TB team in Three Boroughs Homeless Team
- NRPF teams eg, Islington
- Cost savings:
 - Time in hospital
 - Professional time in resolving accommodation problem
- Funding? Inconsistent and ad hoc
- 'At risk', contact tracing & lost to follow up
 - Many missed opportunities
 - Housing workforce of 250k working in most deprived areas

3. Social landlord role

- C. 4.7 m homes (housing association, local authority etc.)
 - Temporary and supported housing
 - Social and market rent
 - Managing agents of private rent
 - Various ownership models
- Support services: alcohol, drug use, mental health, unemployment
- Housing expertise to MDTB teams
- Regular contact with households/communication channels
 - Could advise of change in circumstances/prevent lost follow up
- Opportunities to harness
 - Strategic partnership (don't have to access through LA)
 - Understanding of risk and how to manage this
 - Training/awareness raising amongst workforce
- Housing sector much bigger than social landlords eg, environmental health, LA teams

4. Examples of successful housing for TB treatment

- Specific and targeted provision
 - Olallo House (London)
 - BRICSS (Bradford)
 - East London: spot purchase supported housing (Westminster)
- Common features
 - Clearly identified need
 - Part of a pathway
 - Support meets wider needs eg, substance misuse, employment, and enables move on
 - Community model within schemes eg, peer support
- Differ
 - Olallo: CCG individual cases; spot purchased; charitable £
 - BRICSS procured jointly by CCG/public health (pilot) – not TB specific
- Potential for existing provision to be used more effectively eg, supported housing
 - But, supported housing at risk from reducing local authority expenditure

Conclusions

- Challenges: housing system is complex
 - Majority of policy decisions devolved to local housing authority
 - Social landlords also free to choose their own policy re: who they let their homes to (this could also be an opportunity)
 - Private rented sector unregulated – poor quality, high cost, unstable

Appendix G7 Service Delivery Expert Papers (EP 1 to 12)

- Local authority commissioning role under-developed
- Opportunities
 - Health and Wellbeing Board to provide direction
 - Care Act 2014: whole population & prevention
 - Fewer resources: joint commissioning
 - Housing associations developing new markets
 - Housing workforce role in health and wellbeing

References (if applicable):

EP 10 MDR-TB networks/access to specialist advice (National Advisory Service)

Section A: CPH to complete	
Name:	Professor Onn Min Kon
Job title:	Consultant Respiratory Physician
Address:	Chest and Allergy Clinic, St Mary's Hospital Imperial College Healthcare NHS Trust Praed Street London W2 1NY Adjunct Professor and Reader in Respiratory Medicine, Imperial College London
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service Delivery Group of the Guideline Development Group for Tuberculosis
Subject of expert testimony:	MDR-TB networks/access to specialist advise
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>5. How is the MDR-TB network set up and managed?</p> <p style="margin-left: 20px;">a. Why is it set-up in this way</p> <p style="margin-left: 20px;">b. Is there evidence to support the way the network is configured</p> <p>6. What are the advantages and challenges of the way that the network is configured?</p> <p style="margin-left: 20px;">a. Is there any data about the impact of this model on diagnostic delay, improve contact tracing or improved treatment completion?</p> <p>7. What is the mechanism through which advice can be sought and provided and what accountability arrangements are in place for the service?</p> <p>8. Are there any associated outcomes or evaluation data available on the work outside of the areas suggested in <u>Q.2a</u> above, or any other elements you would like to inform the committee of in terms of opportunities and benefits for improved patient or service outcomes?</p>	
Section B: Expert to complete	
Summary testimony:	[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]

The background to the development of the service was the recognition that numbers of MDR TB have doubled in last 20 years. Although there are approximately 80 cases in the UK per year, the absolute number being looked after per clinician is small. Historically advice was therefore via ad hoc calls to an 'expert' and possible referral regionally for negative pressure facilities. Sporadic cases would also occur not only in higher incidence areas but increasingly in lower incidence areas and therefore cases are also geographically dispersed.

The BTS Joint TB Committee advocated a centralised, coordinated advisory service and hence the MDR advisory service was established 2008 with a non-restricted educational grant from Genus pharmaceuticals. This was overseen by a Lead Physician – Prof Peter Davies for 2 hours per week. This also secured funding for an administrator for 3 days per week. The service is accessed by a secure website.

All MDR cases identified by the HPA reference laboratory are sent to inform the originating clinician of the service. Cases are reviewed by a virtual electronic panel. Of all cases notified by the HPA, 71 of 111 were discussed. The number of clinicians accessing the service were 27 in 2008 and 33 in 2009.

The current situation is that the advisory service is now BTS managed and funded since 2011 and accessed via the BTS website with oversight provided by the TB Specialist Advisory Group. A Lead Clinician is elected every 3 years by the Executive with no remuneration. There is a Coordinator/Administrator who is funded for 1 session per week. All cases are anonymised and cases reviewed by a non-remunerated multidisciplinary panel. The service acts as an 'Advisory' Service and does not therefore take clinical responsibility.

The panel consists of :

- Microbiologist/Lab Directors
- Respiratory Physicians
- ID Physicians
- HIV Physicians
- Paediatricians
- Public Health Physicians
- Specialist Pharmacist
- TB Specialist nurse
- Thoracic Surgeon
- Clinicians in training
- Patient

After an on line registration is approved by the forum administrator users are prompted to provide anonymised case details according to a pre-set questionnaire template. This includes a free text box and an opportunity to post X-ray and CT images.

The utility of this service is demonstrated by:

- User numbers: between Jul 2011-Nov 2013 – there were 134 queries from 91 different health professionals - this elicited 1086 discussion posts from the Expert Group.
- Positive feedback provided by users (shared during session)
- Advocated by TB Net MDR TB consensus – ERJ 2014
- BTS MDR TB service quoted as exemplar by the ERS consilium

The advantages of this service and model are

- Expert panel – voluntary – adjunct to local MDT
- MDT with wide membership
- High and low incidence settings covered in UK
- Rapid response
- Professional Body/ Clinician led
- Web based with upload of data possible
- Training and educational aspects

The disadvantages of this service model are:

- Different opinions are offered for clinicians
- Criteria for panel selection unclear
- Ensuring confidentiality continues to need review
- Variable data quality by clinician submitting case
- There is no liability for advice given
- Sustained funding uncertain

Developments associated with this group are:

- TB Drug Monograph – comprehensive drug information monograph
- MDR drugs - Patient information leaflet with TB Alert

There is a need to consider making this service an integral part of new drug specialist commissioning ratification and to act as a MDR register.

References (if applicable):

Jordan TS, Cullen D, Davies PD. A centralised electronic Multidrug-Resistant Tuberculosis Advisory Service: the first 2 years. *Int J Tuberc Lung Dis* 2012; 16: 950–954.

Blasi F, Dara M, van der Werf MJ, et al. Supporting TB clinicians managing difficult cases: the ERS/WHO Consilium. *Eur Respir J* 2013; 41: 491–494.

MDR TB Service 2014 survey

Lange C et al. Management of patients with multidrug-resistant/extensively drug-resistant tuberculosis in Europe: a TBNET consensus statement. *Eur Respir J*. 2014 Jul;44(1):23-63.

EP 11 Policy Update – National TB strategy and TB Control Boards

Please see

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf

and

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/396265/TB_infographic_16_jan_2015.pdf

EP 12 TB and HIV collaborative commissioning

Name:	Anton Pozniak
Job title:	TB Service Lead /HIV Service Director
Address:	Chelsea and Westminster Hospital 369 Fulham Road London SW10 9NH
Guidance title:	NICE Guideline Tuberculosis (update) service delivery
Committee:	Service delivery Group of the Guideline development Group for Tuberculosis.
Subject of expert testimony:	Program collaboration and Service Integration – HIV&TB
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]
<p>1) How have HIV services changed / improved over the last ten years, can any changes or improvements be attributed to TB-HIV programme collaboration and service integration?</p> <p>2) Why have these changes taken place, especially from the perspective of TB-HIV program collaboration?</p> <p>3) What is the mechanism through which HIV and/or HIV-TB collaborative services are commissioned, how has this been helpful or difficult? How were any difficulties overcome?</p> <p>4) What are the key outcomes that have been used to measure changes / improvements in relation to HIV-TB service collaboration and preventative commissioning approaches?</p> <p>5) What evidence has informed these changes?</p> <p>6) How have these changes benefitted patients?</p> <p>7) What were the challenges in implementing these changes? What have been the opportunities or benefits?</p> <p>8) All issues applicable to service delivery are relevant, although anything specific to our core objectives would be particularly welcome they are: Commissioning models, service models, and service structures that are in place with and without TB-HIV collaboration especially where there is evidence of changes in TB incidence and prevalence or improved diagnosis. In particular how services are or could be commissioned, organised and delivered where possible in relation (but not limited) to:</p> <ul style="list-style-type: none"> • Reducing diagnostic delay for TB • Improving TB contact tracing • Improving TB treatment completion <p>Any evidence or data describing: inequalities, demographics, geography, variations due to differences in HIV rates and active TB rates, MDR and LTBI, and accountability arrangements in relation to areas that do/ do not have collaborative programs are of</p>	

<p>great interest especially any evidence or opinion on the following:</p> <ul style="list-style-type: none"> • The effectiveness of different service models (in relation to the outcomes above), and where possible the factors that contribute to this • The cost and/or cost effectiveness of different approaches • Implementation issues relevant to different approaches <p>9) How are specialist commissioning set up for HIV services?</p> <p>10) How have HIV services dealt with governance issues of involving the third sector?</p> <p>11) What impact has self-referral had on numbers entering the service for diagnostic testing?</p>
--

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250 – 1000 words – continue over page if necessary]

HIV services have become more OPD focused over the last 10 years with the widespread success of HIV treatments in preventing immune suppression and its associated complications. BHIVA has been active in audit and guidelines on HIV/TB and these have informed HIV and other physicians about the management of individuals.

In most units HIV/TB OPD and in patient services have been set up and to include specialists from both disciplines but onward referral for complex cases is often informal and units with low caseloads of HIV/TB can continue managing cases that might be better referred and a Cancer model might be more appropriate in this regard. HIV inpatient services are not formally organised and consequently patients can be admitted with TB/HIV to units where this condition is rarely seen and managed.

Until regionalisation by networking of HIV services is better organised this situation will remain.

There needs to be more concrete proposals regarding funding and commissioning and integration of TB and HIV services.

Commissioning of HIV and TB services are not aligned and the funding streams for IP and OPD can be different even for a trust. For example HIV/TB could be seen in a TB clinic and be under PbR or in an HIV clinic where payment is by a block type contract based on SOPHID-soon to be HARS data. Differential commissioning may also lead to disjointed priorities and even a different focus on the priorities within the New National Strategy. A major challenge to change is the commissioning process and structure. If management and treatment for both were in the Infection CRG and prevention and surveillance for both were in PHE then this would potentially simplify the matter.

The number of persons coming from high prevalence TB countries with HIV has diminished partly due to migration patterns but there are a substantial number of patients recently arrived the UK with LTBI which need assessment for chemopreventative therapy. The BHIVA guidance set out the methodology for detecting and treating LTBI in HIV but few centres follow this policy in part related to cost and also the HIV clinics are not integrated with the TB clinics at the LTBI screening level. They work best together when an HIV patient has active TB. Funding for this screening has not been set aside by either TB or HIV services.

Issues regarding contact tracing are similar for all hard to reach groups including alcohol and drug misuse homelessness and psychiatric disorders etc. The other issue for HIV is disclosure and stigma which can be a barrier to completing contact tracing and where more integration between HIV and TB services can be useful.

References (if applicable):

HIV commissioning Guidance

<http://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-serv.pdf>

British HIV Association: Treatment guidelines for Tuberculosis in HIV positive individuals (2011).

<http://www.bhiva.org/PublishedandApproved.aspx>

Standards of Care for People Living with HIV in 2013

<http://www.bhiva.org/standards-of-care-2013.aspx>