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Tuberculosis Health Needs Assessment
Surrey and Sussex 2016/17

Version 5.3 (POST-CONSULTATION)

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Glossary of common terms and abbreviations

- TB – Refers to Tuberculosis infection
- LTBI – Latent Tuberculosis Infection
- S&S area – Refers to geographical area covering both Surrey and Sussex
- S&S TB network – Strategic and operational team comprising of membership of people involved in control, prevention and treatment of TB in Surrey and Sussex.
- PHE – Public Health England
- SoE – South of England refers to geographical patch covering both South East and South West regions.
- TBCB – Tuberculosis Control Board – A strategic group with membership from senior leadership.
- TB CNS – Tuberculosis Clinical Nurse Specialist
- HNA – Health Needs Assessment
- HPT – Health Protection Team
- LA – Local Authority
- CCG – Clinical Commissioning Group
- ETS – Enhanced TB Surveillance – a national database for recording TB notifications
- HP Zone – Health Protection Zone – national database for recording and managing all health protection cases and TB incidents (including single cases, outbreaks, clusters and exposures)
- USP – Under-Served Population (in context of TB, this term refers to people with social risk factors such as being homeless or having a history of homelessness, drug use or imprisonment, or current alcohol misuse homeless, refugees and/or asylum seekers, illegal migrants, trafficked individuals and patients with no recourse to public funds)
- IGRA– Interferon Gamma Release Assay – a type of blood test used to identify TB infection
- DOT – Directly Observed Therapy
- CXR – Chest X Ray
- A&E – Accident and Emergency
- NICE – National Institute of Clinical Excellence
- MDR TB- Multi Drug Resistant TB
- MXU – Mobile X-ray Unit
- VOT – Video Observed Therapy

Executive summary

Over the last ten years, the incidence of tuberculosis (TB) in England has remained relatively high especially when compared to most Western European countries. The prevention, control and treatment of TB is a key public health priority, with two specific indicators included in the Public Health Outcomes Framework[1] - TB treatment outcomes (3.05i) and TB incidence (3.05ii).

In 2015, Public Health England (PHE) and NHS England jointly launched a *'*Collaborative Tuberculosis Strategy for England 2015 to 2020'[2] in order to provide a stronger approach to TB control in England. Since its publication, there has been a drive for a concerted action at national, regional and local level to tackle TB. As per strategy recommendation, seven TB control boards have been established in the country. Surrey and Sussex (S&S) TB network is part of the South of England TB Control Board (SoE TBCB) that is chaired by regional director for PHE (South) and has a dedicated programme manager. It meets quarterly and provides an over-arching support to four local TB networks in the South East and two in the South West of England.

In March 2016, the SoE TBCB agreed its delivery plan for the control of TB in the South with the first key area of work focusing on detailed health needs assessment (HNA) for each TB network.

For S&S TB network, this is the first time an extensive TB-HNA has been carried out. It provides a comprehensive insight on the epidemiology of TB cases, the provision of TB services along with the service users' experience of using these services. During the process, we have tried to capture any unmet needs or gaps for each of the above sections. In addition to covering the gaps and needs in existing arrangements, special efforts have also been made to capture local strengths and areas that are working well.

A table of key recommendations is provided at the end of each section. These recommendations are then matched with those of the national collaborative TB strategy to develop a list of key strategic actions for S&S TB network. Partners and stakeholders from local authority public health teams, TB services, clinical commissioning groups and PHE were consulted on the action plan; and relevant changes were made in light of their suggestions and proposals. Once a year, the S&S TB network will be expected to collectively review the action plan for further updates.

[1] Public Health Outcome Framework 2016 http://www.phoutcomes.info/
[2] Public Health England and NHS England. Collaborative Tuberculosis Strategy for England 2015 to 2020, 2015 Jan. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf

This TB-HNA is jointly owned by all partners and stakeholders and, going forward, we envisage local leads with responsibility for TB to take it to their respective health and wellbeing boards, strategic commissioning boards and other senior forums for their notification and/or endorsement.

We are hopeful that this TB-HNA will provide a fresh perspective to joint working between all partners and will set a strategic direction of travel for the network.

Recommendations leadings to Strategic Action Plan 2016/17

N.B – The following action plan is a snapshot of the full report and contains the suggestions/proposals received from partners during the consultation phase. It will be reviewed annually with all partners for further updates. Please note, a few actions are aspirational (highlighted as proposals in blue).

Due to ongoing national audits around microbiology services any recommendations appropriate for S&S TB network will be added in once these reports are available.

Key themes	Recommendations	Key Actions	Lead Team	Expected timeframe
1. Ensure early diagnosis of TB and improve access to TB services (includes refreshing existing knowledge, better signposting to local services and tackling stigma among population at high risk and who could self-present to health services)	Raise awareness of TB among frontline staff in **primary care** settings (especially in high incident areas).	**1a) -** Primary Care – CCG should promote and encourage local GPs and practice nurses to complete free online CPD programme once a year – RCGP module produced by TB Alert.	CCGs via communication teams	June - 2017
	Raise awareness of TB among frontline staff in **secondary care** services	**1b)** -TB service to organise yearly session for the secondary care staff (including but not limited to) ie mental health & substance misuse services, and accident and emergency services.	TB services	Spring 2017
	Raise awareness of TB among frontline staff from **social care** and **third sector teams.**	**1c)** - Local Authority Public Health (LAPH) team to promote both **signposting** information AND key messages about **signs and symptoms** of TB using posters/leaflets/intranet/email reminders/LA internal staff communication channels etc. Teams benefiting include employment support (Citizens Advice Bureau) housing support, adult and children social care, children and family services, refugee and asylum team etc. LA PH teams can also link this awareness work to their existing public and staff awareness programmes and services, especially for related programmes..	DPH/Public Health Consultant lead for health protection to lead and work in collaboration with TB services and local HealthWatch teams	Spring 2017 and then ongoing
		1d) – PHE to lead a local awareness event for all front line staff from health and social care background.	PHE to work with local network and develop a programme that is promoted by all partners.	Spring 2017

Key themes	Recommendations	Key Actions	Lead Team	Expected timeframe
	Make additional efforts to collect microbiology samples that can help with early diagnosis.	**1d)** - Services to collect and send sputum smears from all pulmonary cases and promote accurate culture samples for non-pulmonary cases	TB services via local pathology services	Ongoing
	Gain better understanding of referral pattern and time delay between the onset of symptoms and the start of treatment.	**1f) –** Use TB Cohort Review and Field Epidemiology Services/Enhanced TB Services data to understand the referral pattern, risk factors and underlying reasons for the delay.	PHE and TBCR chair	Ongoing
2. Tackle TB in under-served population	Raise awareness of TB among **community** in general and **vulnerable groups** in particular.	**2a) –** Similar to 1d - Use National TB Awareness Day (24th March) to promote TB awareness among vulnerable population	PHE, TB services, LAPH	Spring 2017
	Early identification and robust follow up of contacts and cases that have risk factors for non-compliance to treatment.	**2b) – Proposal** – Service should have staff resources or agreed arrangements for community outreach work.	TB services (delivery) CCGs (assurance) as commissioners	October 2017
		2c) – TB service should develop a simple but recognised referral and communication pathway with local substance misuse services for cases with substance misuse and symptoms of TB and vice versa.	TB services and substance misuse sevices	June 2017
		2d) - Proposal – Consider opportunistic screening for active TB and other blood borne viruses at hostels, day centres etc. using mobile X-ray van or other on-going strategies. **2e) – Proposal -** Areas with existing outreach services should do a symptoms/sign check with at risk under-served population groups.	PHE to work with LAPH leads from high incident areas and explore funding options for mobile X-ray services etc.	October 2017
		2f) – Proposal – Options for new technology such as Video Observed Therapy (VOT) should be explored for eligible patients considered at risk (treatment default or lost to follow up).	TB services PHE to support discussions with Find and Treat's VOT team	TBC
	Ensure clear pathways and arrangements are in place to meet the needs of TB patients with **complex social care needs** AND/OR **no recourse to public funds.**	**2g) –**Clarify funding responsibilities between CCG and LA PH team during the management of TB patients with complex social care needs and/or no recourse to public funds**.**	Shared between CCG and LAPH teams PHE to facilitate	October 2017
		2h) – Incorporate, as appropriate, future	PHE	Spring 2017

Key themes	Recommendations	Key Actions	Lead Team	Expected timeframe
		recommendations from national resource for under-served population groups.		
		2i)-Develop TB policy and care pathway which in PPD and IRCs to ensure timely and appropriate TB case management in coordination with local TB service.	PPD / IRC	Spring 2017 and then ongoing
		2j)Provide awareness information for detainees and staff	PPD/IRC	
		2k)Provide TB awareness train the trainer sessions for PPDs and IRCs	PHE	
		2l) Ensure PPDs have appropriate tools on SystmOne to conduct TB screening	NHS England	
		2m)- Proposal – Where possible, local authorities and partner organisations should join NRPF network that provides guidance and support with care needs of individuals with no recourse to public funds (NRPF).	LA social care, housing and refugees teams	
3. Improve treatment and care services, reducing drug resistance and optimising contact tracing	All trusts should have a formal pathway for the management of **MDR-TB and TB/HIV** coinfections.	3a) – Develop a formal pathway for the management of MDR-TB and TB/HIV coinfections.	TB services (delivery) CCGs (assurance) as commissioners	June 2017
	Service users should be given the opportunity to express their views on the TB service following treatment completion.	**3b)-**Ratify and use a service user questionnaire that can be completed during treatment, or at the time of treatment cessation.	TB services in collaboration with PHE	April 2017
	Ensure representation from all key stakeholders in TB network meetings	**3c)-Proposal –** Include patient advocates and relevant HealthWatch lead to TB network	TB network	April 2017
4.Improved delivery of TB Cohort Reviews (TBCR)	Agree a formal process of recording actions from TBCR and review their progress in subsequent cohort reviews and add health protection update.	**4a)-**PHE to develop a template for recording and follow up of actions in TB Cohort Review (TBCR).	PHE and chair of the cohort review	December -16
		4b)-Chair to make sure actions are allocated to the appropriate team during the cohort review with updates to be followed up in subsequent cohort reviews.	PHE and chair of the cohort review	Ongoing
		4c)-PHE to present a brief update on TB situations in each cohort review.		

Key themes	Recommendations	Key Actions	Lead Team	Expected timeframe
		4d) Proposal – Standardise cohort review indicators at board level	TBCB	March - 17
	TBCR to assist with local issues and gaps	**4e)** - See action 1f above		
5.Ensure an appropriate workforce to deliver TB control	CCGs should identify a named person who can work with their local TB services, PHE and lead CCG in developing and agreeing formal service specifications for TB services.	**5a) -** Adopt national or develop local service specifications **AND** use these for the delivery of robust, appropriate and high quality TB services in Surrey and Sussex area.	Local CCGs to work with PHE and lead CCG for the South East	TBC
		5b) - Explore collaborative commissioning of TB services among neighbouring CCGs in Surrey and Sussex area.	Local CCGs to work with PHE and lead CCG for the South East	
	Address the lack of staff in current services	**5c) -** Royal Surrey County Hospital NHS Foundation Trust to recruit a TB CNS to support its local TB service.	Local CCG	Spring 2017
	Every TB service should have appropriate workforce (including a dedicated administrative support) for the size of the service.	**5d) -** Local services to undertake an assessment of their need for an administrative support.	TB services	Spring 20172017
		5e)- Incorporate the future recommendations of national workforce development group (expected to be completed by the end of 2016)	PHE via national delivery board	TBC
	Better management of large scale TB incidents	**5f)-Proposal –** Agree support from all teams to work in collaboration during the management of large scale TB incidents	TB network via task and finish group	June 2017/TBC
6.Clarify roles and responsibilities in exceptional circumstances	Clarify the role and responsibility of each team in managing difficult TB cases and TB situations.	**6a)** Develop and agree a formal plan/memorandum of understanding (MOU) to ensure appropriate resources (**especially funds**) are in place to manage cases requiring accommodation , part2a orders, or in conducting large scale TB screenings in community settings.	A network level task and finish group comprising of CCG, LAPH, acute trust and PHE to explore suitable options such as Local Health Resilience Partnerships.	June 2017

Key themes	Recommendations	Key Actions	Lead Team	Expected timeframe
7.Systematic implementation of latent TB screening in eligible population	Ensure CCGs eligible for national screening programme for LTBI are signed up and delivering the programme.	**7a)** - Crawley CCG to deliver the programme by offering it to all GP surgeries in the area.	Crawley CCG	December -16 and then Ongoing
	Explore opportunities with other CCGs to start LTBI screening among eligible/high risk cohort of patients via primary care settings that are considered as TB hotspots	**7b) –Proposal** PHE to map out local hotspots in areas interested in starting the programme. **7c)- Proposal** CCGs with support from LAPH teams to explore ways (existing service specifications or via securing additional funds) to introduce the programme as pilots in hotspot areas	PHE CCGs & LAPH team	TBC

1. Introduction

1.1 Background

The incidence of tuberculosis (TB) in the UK has decreased substantially throughout most of the 20th century. However, since the late 1980s to 2005, there has been a progressive increase in the incidence of TB in England that has remained at relatively high levels[3]. Despite a recent year-on-year decline in the number of new TB cases since the peak in 2011, the TB incidence in England is still unacceptably high, especially when compared to most Western European countries and the US[4,5,6].

TB is not only a serious disease but it also has major social impacts for those affected. TB is associated with marked inequalities in health; with deprived populations more likely to get TB and suffer worst outcomes[2]. While most cases of TB are currently curable, there are increasing numbers of drug-resistant cases that require more lengthy and complex treatment, and are associated with increased side effects, higher treatment costs and worse outcomes. The Chief Medical Officer highlighted the health inequalities related to TB and antimicrobial resistance, as key priorities for England[7].

TB also has a huge economic impact; costs not only arise from the diagnosis of TB and treatment of drug-sensitive and drug-resistance cases but also from the contact-tracing and wider public health action that is undertaken to prevent transmission[2]. There are also the broader socio-economic effects on families and communities affected by TB. Investing in TB prevention and control to contribute to the eventual elimination of the disease would result in substantial savings to the whole health and social care system.

Due to the health, social and economic burden of TB, it has been identified as a public health priority and there has been a drive to concerted action to tackle this disease. The 'Collaborative Tuberculosis Strategy for England 2015 to 2020'[2] sets out a vision for how high-quality, cost-effective TB control can be achieved. It outlines the need for the establishment of TB control boards to enable co-ordinated action of key partners

[2]Public Health England and NHS England. Collaborative Tuberculosis Strategy for England 2015 to 2020, 2015 Jan. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf

[4] Public Health England. (2015) Tuberculosis in England: 2015 report. Public Health England: London. Available from:https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492431/TB_Annual_Report_v2.6_07012016.pdf.

[5] European Centre for Disease Prevention and Control. Tuberculosis surveillance and monitoring in Europe 2013. Stockholm: European Centre for Disease Prevention and Control; 2013. Available from: http://www.ecdc.europa.eu/en/publications/_layouts/forms/Publication_DispForm.aspx?List= 4f55ad51-4aed-4d32-b960-af70113dbb90&ID=811

[6] Centers for Disease Control and Prevention. Trends in Tuberculosis - United States, 2012. MMWR. 2013 Mar 22;62(11):201–

[7] Annual Report of the Chief Medical Officer. Infections and the rise of antimicrobial resistance. Volume Two, 2011. London: Department of Health; 2013. Available from: http://media.dh.gov.uk/network/357/files/2013/03/CMO-Annual-Report-Volume-2-20111.pdf.

and develop clear lines of accountability. It is expected that TB control boards will work closely with local TB networks, covering a smaller geographical area, who will ultimately deliver the local TB strategy.

1.2 Local context

In the South of England (SoE), one TB control board (TBCB) has been established that covers both the South East (SE) and the South West (SW) of England. In the SE, four TB networks are currently in place. These are:

1. Surrey and Sussex (S&S)
2. Kent
3. Thames Valley and
4. Wessex

The Surrey & Sussex TB HNA covers four local authorities. These are:

1. Brighton and Hove
2. East Sussex
3. West Sussex and
4. Surrey

PHE's office for S&S is located in Horsham. There is an established TB Network (Strategic) for S&S. It is chaired by PHE's Consultant in Communicable Disease Control and has good participation from TB physicians (respiratory, infectious and paediatrics), nurses, microbiologists, public health colleagues from local authorities and commissioners from local clinical commissioning groups. The group meets three times a year and provides a strong platform for discussion on all TB related issues and queries. There is also a well organised cohort review process, where all TB cases are discussed in terms of their management and treatment outcomes.

In addition to this HNA, there are four other detailed HNAs currently underway in the rest of the SE region; while three in the SW region have already been completed.

1.3 Purpose of the report

Although implementation of the 'Collaborative TB Strategy for England 2015 to 2020' is a core aim of the S&S TB network, the group also needs to fully understand:

- the epidemiology of TB for the catchment it serves
- the specific unmet health needs of the affected population including barriers of access to community services
- the strengths of the existing services

The S&S TB HNA brings together all these in one document and makes recommendations with a strategic action plan, which will be shared and collectively

owned by all partners and stakeholders. It will also support the existing work of S&S TB network which includes:

I. Providing leadership to inform the commissioning of TB services for adults and children across the S&S area in line with national guidelines
II. Overseeing implementation of the national 'Collaborative TB Strategy' through the agreed action plan
III. Monitoring performance of the commissioned services and reporting to TBCB

Finally, it will support the network in answering the following questions:

- Which population groups remain at highest risk for TB in the S&S area and what actions are needed to reduce the risks of TB in these groups?
- Are the correct composite of services in place to manage the needs of individuals affected by TB and are there any significant gaps in terms of provision and capacity to deliver?
- Where should commissioners target their resources in order to reduce TB incidence and maximise treatment outcomes?
- What should be the short and long term priority objectives for the TB network in order to reduce TB infection and maximise treatment outcomes?
- What are the strengths of the existing services and how to implement these more widely in other parts of S&S?

1.4 Aim and objectives

Aim

The aim of this project was to produce a comprehensive TB HNA for the S&S area to describe the epidemiology of TB, establish a baseline for current TB services, look at the unmet health needs and gaps in service provision, and make recommendations with an action plan on how to meet the needs and improve treatment and control of TB in S&S.

Objectives

- to describe the epidemiology of TB in the catchment served by S&S, including differential needs in geographical and ethnic population groups
- to describe the current TB service provision and performance in the S&S area, establish whether existing services are meeting the health needs of the population

affected, and identify areas of unmet needs and gaps in terms of service provision and capacity to deliver
- to describe service user perception of TB services, including their experience and views with regard to service access, timeliness of diagnosis and treatment, health outcomes, and identify opportunities for improvement
- to outline TB policies and strategies, and provide examples of best practice in service delivery based on evidence (local/national/international) and opportunities for service development/redesign
- to bring together the key findings, make recommendations for actions that are in line with the Collaborative Tuberculosis Strategy for England, national clinical guidelines and best practice

Project timescale

Deliverables	March	April	May	June	July	Aug	Sept	Oct
Project plan with identification of key partners (scope)								
Draft service user/service mapping questionnaires								
Test pilot questionnaires and start service mapping								
Epidemiological analysis of S&S								
Review Policies, strategies and guidance								
Develop first draft for consultation								
Consultation timeframe								
Incorporate comments/feedbacks								
Produce final report								
Present findings and final action plan to TBCB								

1.5 Methodology

1.5.1 Quantitative methods

The following applies to the methods used in the 'Epidemiology and Service Performance' sections. The epidemiological component of this TB health needs assessment was carried out as a quantitative analysis of routine TB surveillance data together with population estimates used as denominators to calculate rates.

The main data source used was the Enhanced TB Surveillance (ETS), which contains demographic, occupation and risk factor data as well as clinical, microbiological, treatment and outcome information. The ETS system is through which the statutory notifications for all forms of active TB cases are made[8]. It is a legal requirement for a Registered Medical Practitioner in both the NHS and private sector to notify when they suspect a case of TB. The ETS system is accessible online for timely notification, and for those without online access, paper notification and data collection forms exist.

[8] The statutory notification requirement applies to all new TB cases that are either culture confirmed with M. tuberculosis complex (including M. tuberculosis, M. bovis, M. africanum or M.microti) or are based on clinician's judgement (clinical and/or radiological signs and/or symptoms compatible with tuberculosis) and decision to treat with a full course of anti-TB therapy.

The data on TB cases in ETS from 2010-2014 were used in this report. Where possible, a trend data has been used that covers a period of past five years from 2010-2014. For more up-to-date information, some elements of epidemiology refer to latest data (2014) with the exceptions of treatment outcomes reporting a period between 2009 and 2013, (allowing 12 months for completion from the time of notifying a case); and HIV and TB coinfection (2013).

Similarly, for cohort review data, comparsion has been made pre (2011) and post cohort review (2012-2015 subsequent median) implementation, allowing an indepth review of the progress. Finally for TB situations on HP Zone, the last four years data (2012-2015) has been used to estimate the number, types and characteristics of these situations.

1.5.2 Qualitative methods

A service mapping questionnaire was designed to understand the current provision of TB inpatient and outpatient care in S&S, provision of facilities, local pathways and any gaps in the service delivery. The questionnaire was based on the one used in the 'Public Health Action Support Team (PHAST) London TB Service Review and Health Needs Assessment'[9] and edited for the purpose of the South East HNAs. Local healthcare staff delivering TB care completed the questionnaire and the results were collated and analysed to make relevant recommendations for the action plan. The questionnaire can be found in Appendix I and covered the following areas:

- service and organisation details
- geographical catchment
- access and availability
- staffing and capacity
- pathways, interventions and therapies
- partner TB organisations and working relationship
- gaps in service and suggestions for improvement

Before undertaking the questionnaire, a draft version of the questionnaire was piloted in S&S TB network meeting. During this meeting the purpose of the questionnaire, along with the proposed plan and timeframe for the HNA, were discussed with the group in detail. The suggestions and feedback (relevant to local specifications) were incorporated in the final version of the questionnaire, which was circulated to services via email and also as a paper copy. Colleagues from the services were encouraged to

[9] Public Health Action Support Team. London TB service review and health needs assessment. 2010 Sep. Available from: https://www.brit-thoracic.org.uk/document-library/clinical-information/tuberculosis/london-tb-service-review-and-health-needs-assessment/

complete it jointly with their respiratory consultant, TB/respiratory nurse specialists and microbiology services (as appropriate). Further contacts were made with the services by email and/or by telephone to gain more clarity on areas which had missing information. Questionnaire responses were extracted, collated and summarised. Participants were aware that the findings from the questionnaires would be used in the HNA.

1.5.3 Areas not covered in this report will be added at a later stage

During the development of this work two separate and largescale audits were also taking place in the country. These were:

- a national audit of TB diagnostic service

This audit will capture a detailed analysis of service provision and gaps/needs with recommendations on how to address these. It was decided that the outcomes would be added to this HNA at a later stage.

1.5.4 Limitations

In terms of the quantitative methods, the ETS dataset was the main data source for information. ETS does not contain data on certain variables (eg length of patient's stay in hospital and clinic attendance). Furthermore, the ETS system only records data on notified cases of TB, therefore any cases that were not notified would not be included in the analysis. Patients receiving anti-TB chemoprophylaxis for LTBI are not notifiable and are therefore not included in the ETS dataset.

In relation to the qualitative methods, the questionnaire was used as a pragmatic tool, to gather enough information in a limited timeframe, to provide an overview of inpatient and outpatient TB services in S&S and allow for broad comparison between areas. The findings of the questionnaire are taken to be an accurate reflection of the TB services, particularly for questions with clearly defined answers (eg location of clinic, days and times of clinic). However, it is recognised that for certain questions (eg gaps in service) reflect the the perspective of the person completing the survey.

For the purpose of this HNA, data was only collected from the core members of staff that organise and deliver TB/respiratory outpatient clinics. However, it should be noted that the delivery of the outpatient clinics requires a large number of other staff (eg. receptionists, healthcare assistants, hospital transport teams, porters and cleaners). Furthermore, all of the hospital trusts identified in S&S offered a very similar model of

inpatient TB care, therefore, more detailed information was not collected on inpatient TB services.

1.5.5 Data governance

All data used in this report were anonymised and handled securely. Data extracts were transported in an anonymised form on secure email server and stored on secure password-protected computer drives. Analysis of the epidemiology report was carried out using Stata 13 and Microsoft Excel 2010 and 2013.

2. Epidemiology (key findings)

In 2014:

- there were 168 cases of TB notified among residents of S&S – a rate of 6.0 per 100,000 population. The rate in S&S remains lower than the rate for the South East (7.8) region and England (12.0)
- three cases of TB were diagnosed in children under the age of 16 in 2014, one in a child under the age of five. All were born in the UK, and only one had the BCG vaccination
- the majority of notified TB cases occurred in males (61% n=102/168)
- cases occurred across most age groups above 20 years old, with a median age of 40.5 years old
- in contrast to other parts of the country, number of TB cases among UK-born individuals were the highest (30% n=47). These were followed by those born in India (21% n=33) and Pakistan (8% n=13)
- the most common ethnic group among UK born cases was white, while for those born abroad; the most common ethnic group was Indian
- 56%, (n=94/167) of TB patients had pulmonary disease, similar to that seen for the South East and England (both 53%)
- 71% (n=120/168) of TB cases were culture confirmed in 2014, higher than the proportion for the South East (64%, 431/670) and England (60%).
- the median time between the onsets of symptoms to the start of TB treatment was 85 days – slightly below the South East (88.5 days) but longer than England (74 days).
- 29% of S&S residents with pulmonary TB started treatment within two months of symptom onset and 68% within four months. Delays in this areas were similar to the South East, (31 and 64% respectively), but longer compared with England (40% and 70% respectively)
- between 2010 and 2014, around 11% of S&S TB patients had one or more social risk factor *(*either current or history of homelessness, drug use or imprisonment, or current alcohol misuse). This was above the average for the South East (7.9%)
- TB treatment completion rates have remained consistently lower than South East over the past five years. A high proportion was still on treatment despite not having rifampicin resistant disease (12% in 2013)
- between 2012 and 2015, there were a total of 78 TB situations[10] entered on HP Zone – majority (27% n=23) were in educational settings, followed by exposure in hospital settings (22% n= 17)

[10] **Disclaimer:** Situation data is extracted from a live database which is subject to regular updates. Situation is a collective term used to refer to TB clusters, TB exposures and TB related outbreaks (TB outbreaks are extremely rare due to prolonged incubation period of few weeks to a lifetime). All situations require risk assessment by a trained health protection specialist to assess the level of risk of exposure among close contact

- TB cohort reviews are well established and have played a positive role in managing TB cases – TB treatment completion rate, offer of HIV testing and follow up of close contacts have all improved

of an infectious case of TB. The majority of these situations are straightforward but for some extended contact tracing and screening in close contacts is required to identify and treat those at risk of active and/or latent TB infections. Please note, this is not a direct indicator of health protection workload as in some TB cases, the amount of health protection work required can be many folds that of managing a TB situation. Similarly, clusters of TB are also extremely time consuming where source of infection and epidemiological links are established between different TB cases spread across multiple geographical patches. Since these situations require a collaboration and joint working between PHE, TB services, CCG and LA teams, it is relevant to HNA in terms of identifying any gaps and to make future recommendations for a clear roles and responsibilities, especially those related to resources.

2.1 Overall numbers, rates and geographical distribution (detailed analysis)

Over the years, the incidence and prevalance of TB in S&S have remained relatively low with occasional peaks and troughs. In 2014, there were 168 cases of TB notified among S&S residents at a rate of 6.0 per 100,000 population. After increasing from 3.8 per 100,000 in 2002 to 8.2 per 100,000 in 2011, the TB rate in S&S then decreased to 5.6 in 2013 before increasing slightly in 2014. The rate in S&S remains lower than the rate for the South East of England (7.8), and lower still than the average for England (12.0) (Figure 1).

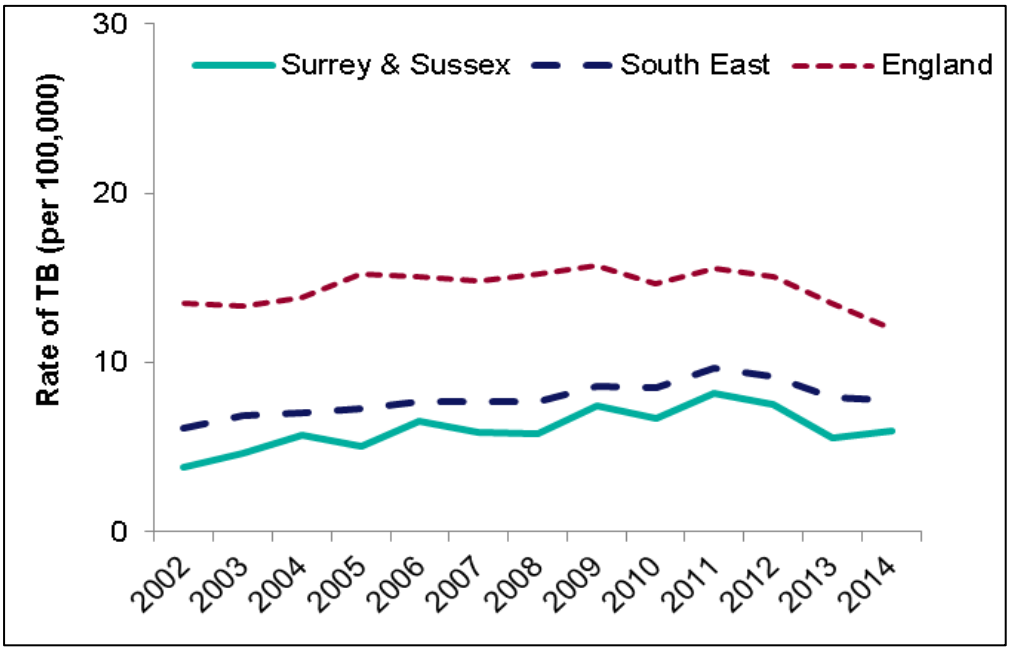


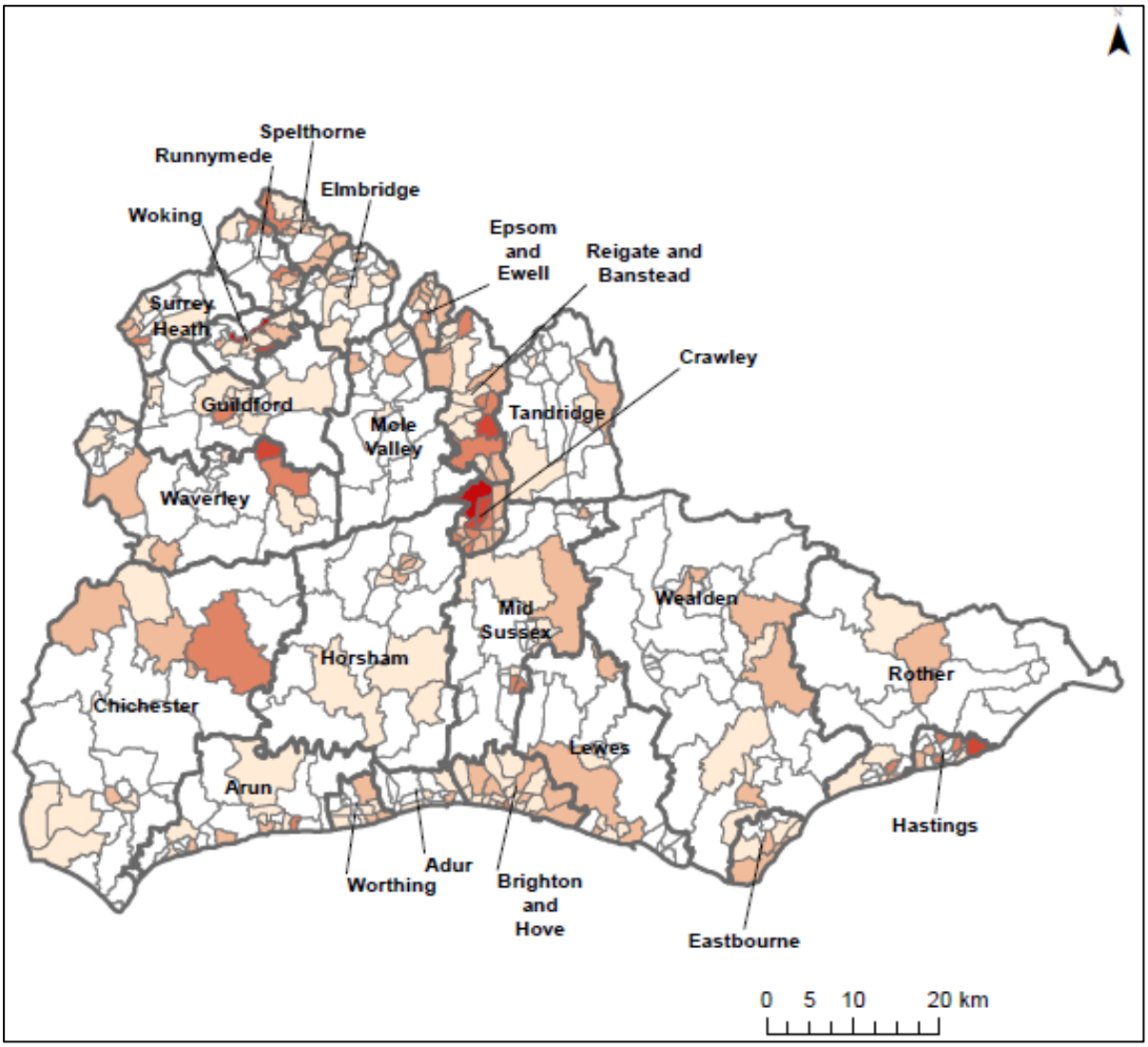
Figure 1: Annual TB incidence rate, 2002 – 2014[11]

2.1.1 By local authority

Most of S&S has very low rates of TB, with a few small areas of higher incidence (see maps and Table 1). In recent years, the lower tier local authorities with the greatest number of cases were Crawley in West Sussex, Reigate and Banstead and Woking in Surrey, Hastings in East Sussex and Brighton and Hove unitary authority.

[11] A trend data by County, Unitary Authority and Clinical Commissioning Group is now available at PHE's TB Strategy Monitoring Indicators http://fingertips.phe.org.uk/profile/tb-monitoring

Map1: Three year avarage TB rates by ward and unitary authority 2012-2014



2.1.2 By clinical commissioning group (CCG)

The CCG with the highest number of TB cases was North West Surrey, followed by Brighton and Hove. The other CCGs with the highest number of cases were NHS Costal West Sussex and NHS Crawley (West Sussex), NHS Surrey Down (Surrey) and NHS Hastings and Rother (East Sussex).

Map 2: Three year avarage TB rates by ward and clinical commissioing group 2012-2014

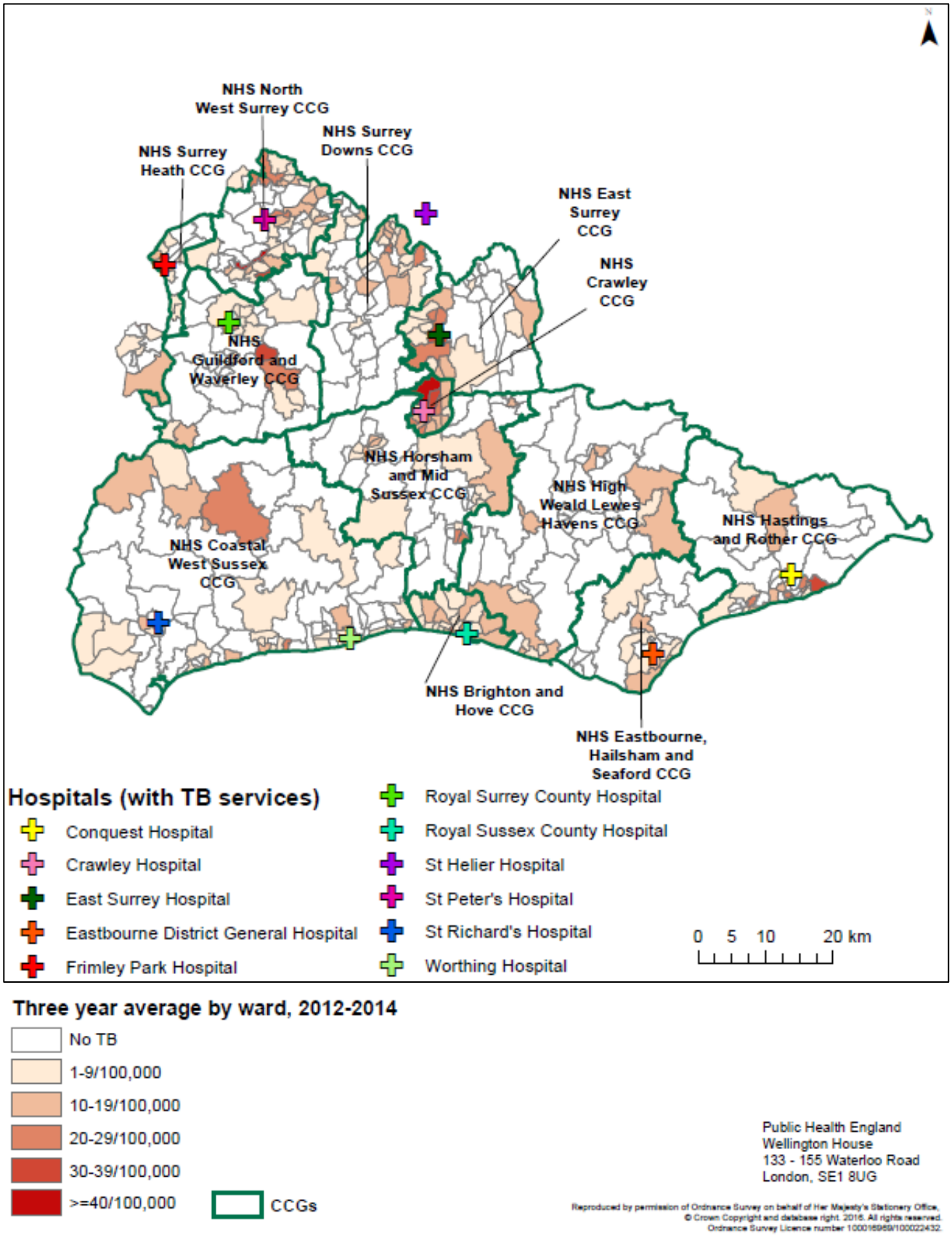


Table 1: TB case numbers by lower tier local authority, Surrey and Sussex, 2010-2014

	2010	2011	2012	2013	2014
Brighton and Hove	**22**	**23**	**31**	**15**	**23**
Eastbourne	8	<5	6	<5	6
Hastings	**<5**	**11**	**10**	**<5**	**11**
Lewes	9	<5	8	5	<5
Rother	<5	<5	<5	<5	6
Wealdon	<5	5	8	<5	<5
East Sussex	24	25	34	20	25
Adur	<5	<5	<5	<5	<5
Arun	7	8	5	9	7
Chichester	9	<5	6	<5	8
Crawley	**21**	**29**	**16**	**31**	**16**
Horsham	<5	5	<5	7	<5
Mid Sussex	6	19	<5	8	<5
Worthing	5	10	8	6	<5
West Sussex	51	77	46	63	42
Elmbridge	8	7	6	<5	6
Epsom and Ewell	8	11	10	6	6
Guildford	8	13	8	<5	7
Mole Valley	<5	<5	<5	<5	<5
Reigate and Banstead	**12**	**8**	**22**	**13**	**16**
Runnymede	<5	8	6	<5	10
Spelthorne	10	12	8	6	7
Surrey Heath	8	6	5	<5	6
Tandridge	<5	<5	<5	<5	<5
Waverley	<5	10	11	<5	<5
Woking	**19**	**24**	**17**	**16**	**14**
Surrey	**85**	**101**	**98**	**57**	**78**
Surrey & Sussex total	**182**	**226**	**209**	**155**	**168**

Table 2: TB case numbers by clinical commissioning group*, Surrey & Sussex, 2010-2014

		2010	2011	2012	2013	2014
	NHS Brighton and Hove	22	23	31	15	23
East Sussex	NHS Eastbourne, Hailsham and Seaford	11	10	09	07	8
	NHS Hastings and Rother	<5	13	12	6	17
	NHS High Weald Lewes Havens	9	<5	13	7	<5
West Sussex	NHS Coastal West Sussex	23	26	22	19	18
	NHS Crawley	21	29	16	31	16
	NHS Horsham and Mid Sussex	7	22	7	13	8
Surrey	NHS East Surrey	12	7	19	10	12
	NHS Guildford and Waverley	8	18	16	<5	8
	NHS North East Hampshire and Farnham	<5	<5	<5	<5	<5
	NHS North West Surrey	34	45	35	26	33
	NHS Surrey Downs	20	20	20	14	17
	NHS Surrey Heath	10	7	5	<5	7
	NHS Windsor, Ascot and Maidenhead	<5	<5	<5	<5	<5

2.1.3 By acute trust

In East Sussex, over half of patients were treated at Conquest Hospital in 2014 (Table 3). In West Sussex, a third of patients were treated at Crawley Hospital. In Surrey, 31% of patients were treated at St Peter's Hospital. In Brighton and Hove, almost all patients were treated at Royal Sussex County Hospital.

Table 3: TB case numbers by treating hospital, Surrey and Sussex residents, 2014

		n	%
Brighton and Hove	Royal Sussex County	20	87
	Other hospitals*	3	13
East Sussex	Conquest Hospital	14	56
	Eastbourne District General Hospital	8	32
	Other hospitals*	3	12
West Sussex	Crawley Hospital	14	33
	St Richard's Hospital	9	21
	Royal Sussex County Hospital	5	12
	Worthing Hospital	5	12
	Other hospitals*	9	21
Surrey	St Peter's Hospital	24	31
	St Helier Hospital	12	15
	Royal Surrey Hospital	9	12
	East Surrey Hospital	8	10
	Frimley Park Hospital	7	9
	St George's Hospital	7	9
	Other hospitals*	11	14

*treating less than five residents

2.2. Age and sex

In 2014, 61% of cases occurred in males (102/168). Cases occurred across most age groups above 20 years old, with a median age of 40.5 years old.

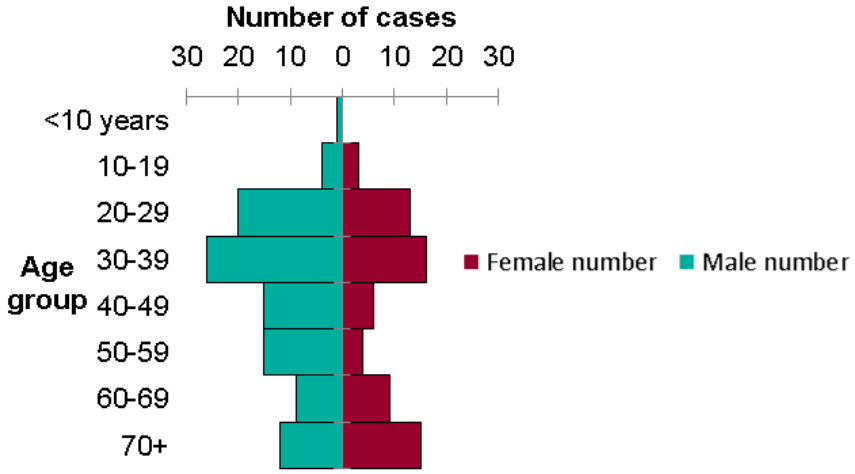


Figure 2: TB notifications by age and sex, Surrey and Sussex, 2014

2.3 Children

Three cases of TB were diagnosed in children under the age of 16 in 2014, one in a child under the age of five. All were born in the UK and only one had the BCG vaccination.

2.4 Place of birth and time since entry

In 2014, the most common countries of birth for those notified in 2014 were the UK and India, followed by Pakistan, the Philippines and Bangladesh (Table 4). The median time since entry for those born in India was five years, seven years for those born in Pakistan, five years for those born in the Philippines and eight years for those born in Bangladesh.

Table 4: TB cases by most common country of birth, Surrey and Sussex, 2014

Country of birth	TB cases		Median time since entry (Years)
	n	%	
UK	47	30	-
India	33	21	5 (1.5-10)
Pakistan	13	8	7 (3-23)
Philippines	11	7	5 (4-11)
Bangladesh	7	5	8 (5-13)
Other countries*	44	28	

*countries with <5 cases in 2014

The proportion of cases among recent arrivals in 2014 (entered the UK less than two years before diagnosis) was 12%, with 19% arriving two to five years earlier (Figure 3). Because of the small numbers involved, year on year fluctuations should be interpreted cautiously. It is worth mentioning that even though the numbers are small, it appears that almost half of non-UK born cases arrived in the UK over five years ago. In other words, the current eligibility criteria of offering latent TB testing to anyone arrived in the last five years would miss these patients.

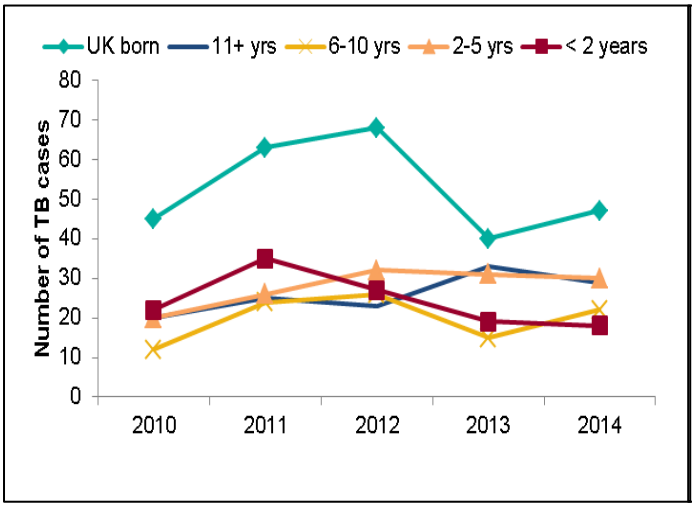


Figure 3: UK born or time since entry to UK (if non-UK born), Surrey and Sussex, 2010-2014

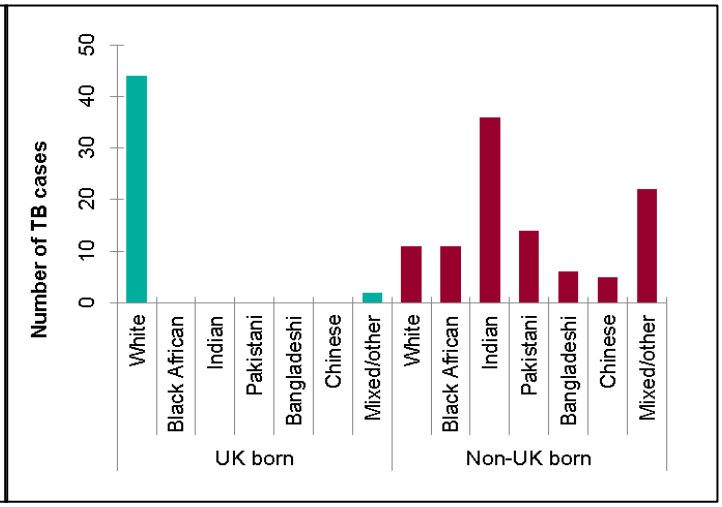


Figure 4: Ethnicity of TB cases, Surrey and Sussex, 2014

In 2014, the most common ethnic group was white (36%, 55/151), 80% of whom were UK born. This was followed by Indian (24%, 36), all of whom were born outside the UK. The next most common ethnicity was mixed/other (16%, 24), almost all of whom were also born outside the UK (nearly half in the Philippines, 42%, 10/24) – (Figure 4).

It is important to highlight that epidemiology of TB in S&S area is unique (ie high number of cases among UK born and white population) and is in contrast to the TB epidemiology in England[12] *(*in 2014, the overall rate of TB in the non-UK born population in England was fifteen times higher than in the UK born population, and 72% of cases were non-UK born). In light of this, it is important to regularly raise awareness about TB among frontline health care and social care professionals in S&S area.

2.5 Site of disease

In 2014, 56%, (94/167) of S&S TB patients had pulmonary disease, similar to that seen for the South East and England (both 53%). The second most common site was extra-thoracic lymph node TB, accounting for 30% (50) of cases.

[12] PHE - Tuberculosis in England 2015 report, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492431/TB_Annual_Report_v2.6_07012016.pdf

Sputum smear status was missing for over half of all pulmonary cases, (52%, 49), higher than the South East (45% missing, 159/350). Where known, 49% were sputum smear positive (22/45), lower than the 55% across the South East. This indicates a need for further efforts to collect and send the sputum for microbiology along with data entry of all results on ETS database.

2.6 Microbiological information

Seventy one per cent (120/168) were culture confirmed in 2014, higher than the proportion for the South East (64%, 431/670) and England (60%). Those with pulmonary disease were more often culture confirmed (81%) than non-pulmonary cases. Of the pulmonary cultures, 97% (116) were *Mycobacterium tuberculosis*, two were *M. bovis* and two were *M. africanum*. Eight cases had first line drug resistance, all of whom were resistant to isoniazid (8/120, 6.7%) and one was multi-drug resistant.

The reasons for the poor collection of non-pulmonary samples are picked up and discussed at TB cohort reviews, however, there is a need to raise further awareness about appropriate collection and reporting of non-pulmonary samples (ie lymph nodes aspirates, biopsies, and tissue specimen). This information plays essential roles in understanding drug resistance and in investigating epidemiological links in a TB cluster.

Table 5: Microbiological information on TB cases, Surrey and Sussex and the South East, 2014

	Surrey & Sussex	South East
Culture confirmed (pulmonary cases)	71% (81%)	64% (81%)
Culture confirmed cases with any first line resistance	6.7%	7.3%
Culture confirmed cases with multi-drug resistance	0.8%	0.7%

Clusters of TB cases with indistinguishable strain types (using a standard method of Mycobacterial Interspersed Repetitive Unit – Variable Number of Tandem Repeat, MIRU-VNTR, 24 loci genotyping) may reflect cases that are part of the same chain of recent transmission, but could also reflect common endemic strains circulating either within England or abroad. Overall 57% of isolates typed with at least 23 loci between 2010 and 2014 were identified as belonging to a national molecular cluster (123/339), and 18% (79) clustered with at least one other case in the South East.

2.7 Reporting delay

Early diagnosis and improved access to services is one of the ten areas of action in the collaborative strategy for TB in England. Ensuring a robust system that addresses this area would play a key role in the prevention, control and timely treatment of TB among all cases. In patients with symptomatic pulmonary TB, a delay of days or weeks can put their health at risk, and can also risk the spread of infection to close contacts. It is improtant to note that delays are of three types:

- a delay between the onset of symptoms and seeking medical help – (can vary from case to case depending on the severity and site of disease, types of symptoms, patient's own perception of health and illness and willingness to seek medical help)
- a delay between the time of seeking medical help to getting the diagnosis – (can vary with the type of symptoms and the availability of a timely appointment to see a clinician)
- a delay between diagnosis and the start of TB treatment – (depends on patients' referral pathways from different services (community/primary care/ hospital services) to TB services)

In order to asertain the underlying reasons for the first two types of delays, a service user questionnaire was undertaken (see appendix II).

Information on the overall delay from symptom onset to treatment start was available for 83% (78/94) of pulmonary TB cases in 2014. The median time between onset of symptoms to start of treatment was 85 days, with an interquartile range (IQR) of 58-140 days. This was slightly below the 88.5 days for the South East, but longer than the median delay in England in 2014 (74 days, IQR 39-139).

In 2014, 29% of Surrey and Sussex residents with pulmonary TB started treatment within two months of symptom onset and 68% within four months. Delays were similar compared to the South East, (31%, 97/316 and 64%, 201 respectively), but longer compared to England overall, where 40% of pulmonary cases started treatment within two months and 70% within four months of symptom onset.

There is a possibility that the above delays for SE in general and S&S in particular could be related to a slightly different risk group where many UK-born individuals from white ethnic background may not be identified as having TB, especially if they presented with non-specific symptoms. However, this is just one possibility and there is a need to understand the underlying reasons for these delays (on a case to case basis) via TB cohort reviews and ETS data.

Table 6: Time between symptom onset and treatment start in pulmonary TB cases*, Surrey and Sussex and the South East, 2014

Year	Surrey and Sussex % (n)	South East % (n)
0-2 months	29% (23)	31% (97)
2-4 months	38% (30)	33% (104)
>4 months	32% (25)	36% (115)
Total	**78**	**316**

***excluding those with missing onset and treatment start dates**

2.8 Social risk factors and under-served population

In the cohort of all TB cases between 2010 and 2014 among S&S residents, an estimated 11% (78/734) had one or more social risk factor (either current or history of homelessness, drug use or imprisonment, or current alcohol misuse) (Table 7). This proportion is above the average for the South East (7.9%) and there is a variation by local authority area: more than 20% of patients in Hastings, Eastbourne, and Reigate and Banstead had one or more social risk factor.

TB patients with social risk factors were mostly males, with a median age of 44.5 years. More than half were UK born and 62% of white ethnicity. In terms of treatment outcomes, 60% with fully sensitive disease completed treatment within a year (which is lower than the South East of 73%). This indicates that as these patients have complex health and social care needs, a strong collaboration between TB services, PHE, LA and social care services is needed to achieve better completion rates.

Unlike elsewhere in the South East, very few of the patients with social risk factors in S&S had multi-drug resistant disease. Patients with social risk factors were more likely to be clustered with other patients in the South East (having the same TB strain type).

In addition to the above social risk factors, there are also patients that are considered as migrants, refugees and/or asylum seekers, trafficked individuals and patients with no recourse to public funds. Collectively these are referred to as the under-served population (USP). Due to difficulty of identifying and recording these individuals on the systems, there is no data available at present, however, a national task and finish group (part of the national TB Delivery Board) undertook a gap analysis with exemplars of good practices (commissioned or adhoc arrangments to support these

individuals during the course of TB treatment) across the country. The group developed a toolkit to support all TBCBs in the country. This work is now available.[13] In S&S, colleagues informed about the following services which are already supporting individuals with compelx health and social care needs. There is a need to further link these teams with local TB services, for both urgent referrals and better support during the course of TB treatment.

- Crawley CCG commissioned a new ' dual diagnosis' case worker at Open House14. This is a CCG-funded pilot project, where by an outreach case worker is attached to an 'Open House' in Crawley and works with clients who have mental health and substance misuse needs
- St John's Ambulance is involved in providing ongoing health advice to homeless people locally in Hastings and work very closely with the TB nurse
- Brighton and Hove CCG has developed a service specification for pharmacists to provide appropriate compliance support to disadvantaged individuals (such as homeless) to receive TB medication in the community
- Brighton and Hove CCG has also set aside a Personal Health Budgets (PHBs) for a member of the traveller community, and are exploring the possibility of small PHBs some for hostel based homeless individuals
- Brighton and Hove and West Sussex local authorities are also participating in a network for "No Recourse to Public Funds" NRPF network15. This is a network of local authorities and partner organisations focusing on the statutory response to migrants with care needs who have no recourse to public funds (NRPF)

A small proportion of TB cases in the South East were estimated as being co-infected with HIV. The latest data from national matching to HIV surveillance estimated that in 2013 3% of South East cases of TB were in individuals who were also HIV positive.

Table 7: Characteristics of patients with social risk factors, Surrey and Sussex and the South East, 2010-2014

	Surrey and Sussex		South East	
	n	%	n	%
One or more social risk factor	**78/734**	**11**	**252/3199**	**7.9**
Median age	44.5 years		41 years	

[13] Public Health England
[14] Crawley Open House provides support and services for those suffering the effects of homelessness, unemployment, loneliness, discrimination, or other forms of social exclusion.
[15] No Recourse to Public Funds (NRPF) Network http://www.nrpfnetwork.org.uk/nrpfconnect/Pages/default.aspx

Male	61	**78%**	222	88
UK-born	41	**55%**	115	46
White	46	**62%**	120	49
Multi-drug resistant	0	0	16	8.0
Clustered in South East	29/78	37	77/200	39
Completed treatment (2010-2013 fully sensitive disease)	34/57	**60%**	148/203	73%

2.9 Treatment outcome

For the purposes of TB outcome reporting, the drug sensitive cohort excludes all TB cases with rifampicin resistant TB (initial or amplified) including MDR-TB (initial or amplified), and non-culture confirmed cases treated as MDR-TB. Treatment outcomes for the drug sensitive cohort are reported separately for the following two groups:

a. For cases with an expected duration of treatment less than 12 months, TB outcomes at 12 months are reported. This group excludes cases with CNS disease, who have an expected duration of treatment of 12 months. In addition, those with spinal, cryptic disseminated or miliary disease are excluded from this group, as CNS involvement cannot be reliably ruled out for the purposes of reporting.

Table 7: TB treatment completion*, Surrey and Sussex and South East, 2013

Notified year	Surrey and Sussex % (n/N)	South East % (n/N)
2009	70% (123/175)	80% (507/635)
2010	61% (97/159)	80% (509/638)
2011	78% (156/199)	83% (604/726)
2012	74% (142/191)	83% (583/701)
2013	74% (102/138)	86% (523/607)

*within 12 months, excluding those with rifampicin resistance, CNS, spinal, miliary or cryptic disseminated TB

Of those with rifampicin-sensitive non-CNS, spinal, miliary or cryptic disseminated disease in 2013, 74% had completed treatment at 12 months. Outcomes among patients in S&S were consistently worse than that seen for the South East. Of the patients notified in 2013, 12% were still on treatment at 12 months.

Outcomes were best in East Sussex where 80% of patients completed treatment in 2013: whereas this was only 73% in Brighton and Hove, Surrey, and West Sussex.

b. Of the 102 patients notified between 2009 and 2013 with CNS, spinal, miliary or cryptic disseminated TB, 58% (59) completed treatment within 12 months. This was the same as the 58% completion seen across the South East between 2009 and 2013.

2.9 TB situations on HP Zone (Health Protection work)

TB situation is a collective term that refers to either a:

- TB cluster – identified on the basis of having the same genetic strain type in two or more people who may be epidemiologically linked,
- TB exposures to non-household contacts (eg at workplace, educational settings, hospitals and congregations) and
- TB-related outbreaks – TB related outbreaks are rare due to prolonged incubation period of few weeks to a lifetime, but if identified can take years of follow up

All situations require risk assessment by a trained health protection consultant/specialist to assess the level of risk of exposure among close contacts of an infectious case of TB (which may include visit to the actual location of the incident). The majority of these situations are relatively straightforward, but for some, extended contact tracing and screening is required to identify and treat those at risk of active and/or latent TB infections.

Between 2012 and 2015, there were a total of 78 situations on HP Zone for Surrey & Sussex Health Protection team figure 5. Of these, 27% (n=21) were exposures in one of the four educational settings (ie nursery/school/college/university), followed by exposures in hospital settings 22% (n=17) and workplaces 15% (n=12).

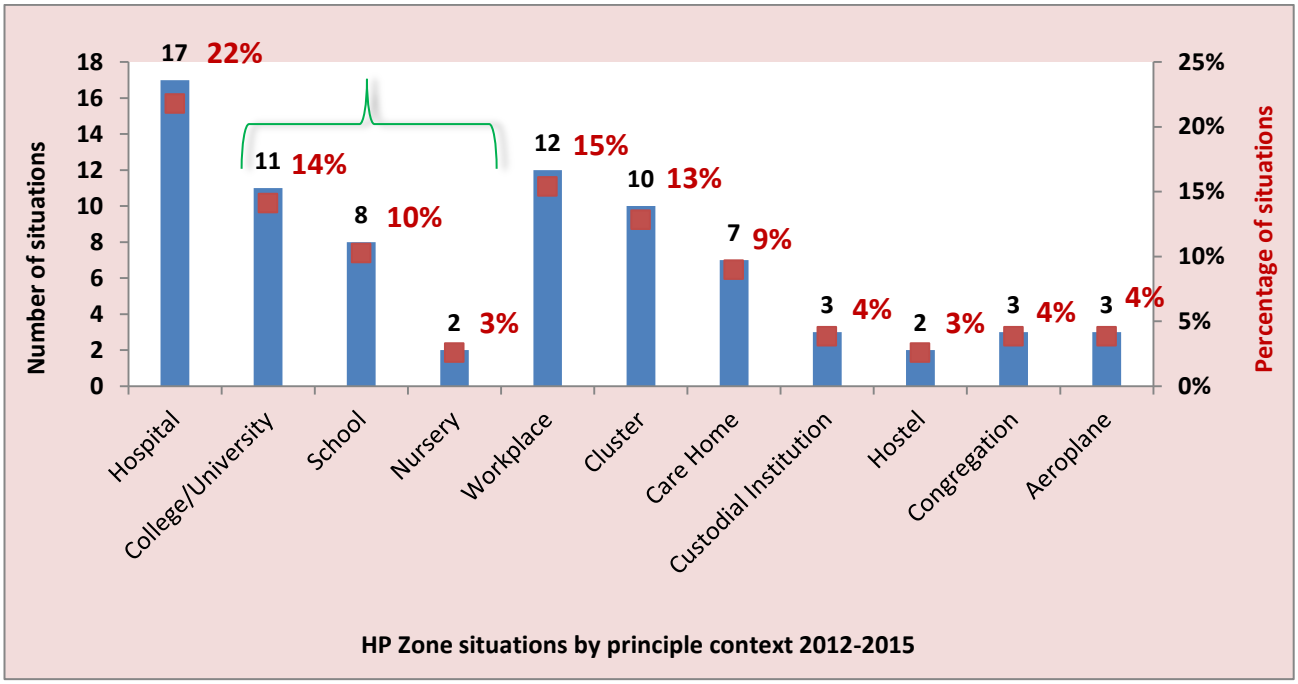


Figure 5: Number and percentage of TB situation on HP Zone for S&S by the location of incident between 2012 and 2015

A TB situation is not a direct indicator of health protection workload as in some single* TB cases, the amount of health protection work required can be many times that of managing a TB situation; however, each TB situation requires a joint working between PHE, TB physicians and nurses, commissioners/CCG and LA public health teams. *In an example of a single TB case, an elderly resident with dementia and pulmonary TB spent four months in a negative pressure facility of a secondary care hospital. The underlying reasons for this prolonged stay were the lack of robust communication between hospital and community teams responsible for patient's continued care at home, carer's poor understanding about TB in general and DOT in particular and unclear service specifications in TB services. PHE's HP team was heavily involved in trying to unpick these issues and proposing the way forward for teams responsible for clinical and commissioning aspects

Reading through some of the situation notes, it is apparent, that there is a lack of clarity from stakeholders over which organisation is responsible for funding which part of the incident response. The National Institute for Health and Clinical Excellence (NICE) guidelines (2016)[16] suggest that: "In an incident situation when large numbers of people may need to be screened, consider a single interferon-gamma release assay for people aged 18–65 years" (NICE 1.2.3.2). Each Interferon Gamma Release Assay (IGRA) test can cost between £20 to £35 (approx.) and in most situations, the agreement on who will bear the cost is organised on an ad-hoc basis with the local commissioners. HPTs from PHE are often expected to negotiate and obtain the best

[16] Nice Guidelines NG33 (Updated in May 2016)
https://www.nice.org.uk/guidance/ng33/chapter/recommendations#/latent-tb

price quotes from multiple providers and then pass it onto the commissioners. All these activities are very resource intensive on the limited capacity of PHE teams.

In addition to the above, TB situations in a prison or immigration removal centre can also add a level of further complexity due to logistics involved (such as identifying close contacts, safety of other population, control of infection in facilities where individuals regularly mix such as indoor gymnasiums and exercise yards and keeping track of a rapidly mobile cohort). A PHE prison guideline has recently been published and a detailed national audit is currently underway to propose improvements to exsiting pathways and systems.

Finally, in rare TB cases/situations, there is a need to obtain a court order (Part 2a Order) as part of the prevention and control of TB infection. These situations also require extensive communication between PH and TB teams, risk assessments of changing situations and follow up of progress/compliance over a period of months. In one example, in excess of 10 Part 2a orders were obtained for one case[17]. Such cases are relatively rare (one or two a year) but due to the complexity of multi-organistional work, an agreed pathway or memorundum of understanding should be developed at a network level. This will help save time by providing clarity on the roles and responsibilities of each team.

2.11 TB cohort reviews in Surrey and Sussex

Since its introduction in S&S in 2012, TB cohort review (TBCR) has played a significant role in improving the management of TB cases. TBCR is held every quarter and provides an opportunity for the retrospective review of TB case management. TBCR includes all TB cases that started TB treatment six to nine months ago. The case manager, usually a TB CNS, presents the case history and management, including relevant clinical and demographic data. All members of the cohort review meeting are given a chance to discuss the case, clarify information and to raise any concerns.

Staff involved in the TBCR include a cohort chair and cohort coordinator, case managers (usually TB CNS), a medical reviewer (usually a TB physician), an epidemiologist (PHE information officer), administrative staff and a data support analyst. In addition to an epidemiological report produced at the end of each TBCR, a separate action list (arising from the issues identified during the review of these cases) is also captured. Both the epidemiology and actions report are circulated,

[17] A short film presented in Faculty of Public Health conference 2016 https://accounts.google.com/ServiceLogin?service=wise&passive=1209600&continue=https://drivegoogle.com/%23&followup=https://drivegoogle.com/&ltmpl=drive&emr=1

among the network, at the end of each cohort review with a lot of focus being given to the epidemiological report.

However, the impact of the TBCR would be increased by a formal process of assigning ownership to the matters arising/actions, and by reviewing the progress in subsequent TBCR. A recent evaluation of the epidemiological impact of TBCR was undertaken by PHE (see appendix 3) which demonstrated a marked improvement in various targets (pre and post cohort review analysis). The three key areas with considerable improvement are as follows:

1.1 Reports on the treatment completion (at 12 months after being notified) among those with fully sensitive strain of TB went up from 42% (pre TBCR in 2011) to 88% (median subsequent 2012-2015)
1.2 Reports on the offer of HIV test to a new case of TB went up from 38% (pre TBCR in 2011) to 87% (median subsequent 2012-2015)
1.3 Identification of one or more contacts of pulmonary TB cases went up from 63% (pre TBCR in 2011) to 98% (median subsequent 2012-2015)

2.3 Key recommendations (epidemiological)

1. Raise awareness among frontline staff from healthcare, social care and third sector organisations about the epidemiology and risk groups for TB in S&S.
2. Encourage collaboration between health, social care and third sector organisations in identifying and collectively managing the needs of those patients considered as USP or from one of the social risk groups. The term 'managing the needs' refers to an agreement on the roles and responsibilties (ie funding, DOT provision and community follow-up) between health (CCG/TB services) and local government teams (public health, housing, social care, substance misuse services).
3. Ensure representation from all key stakeholders (including patients advocates and third sector) in TB network meetings and TB cohort reviews.
4. Agree a formal process of recording actions or issues that are raised during TB cohort review and review the progress on their completion in subsequent TBCRs.
5. Cohort reviews should also explore the reasons for poor culture collection in non-pulmonary cases, poor treatment completion rates, delays in referral and underlying reasons for missing information on sputum smears in pulmonary cases (eg. microbiology pathway or data recording issue).
6. More efforts should be made to collect sputum smears for pulmonary cases. Promote accurate collection of non-pulmonary samples for cultures among key secondary care teams eg ENT & A/E.
7. Clarify and agree funding arrangements with key stakeholders (CCG, LA public health and TB services) in situations requiring large scale screenings in the community.
8. For cases requiring Part 2a orders – finalise a pathway plan (or memorandum of understanding with clear roles and responsibilties for all stakeholders) at a network level.
9. Consider a quarterly review of all TB situations on HP Zone and present a brief update on their management (in network/cohort review meetings), highlighting any issues and risks.

Some strong and positive points also became more apparent which are worth mentioning to ensure their sustainability and further development as appropriate.

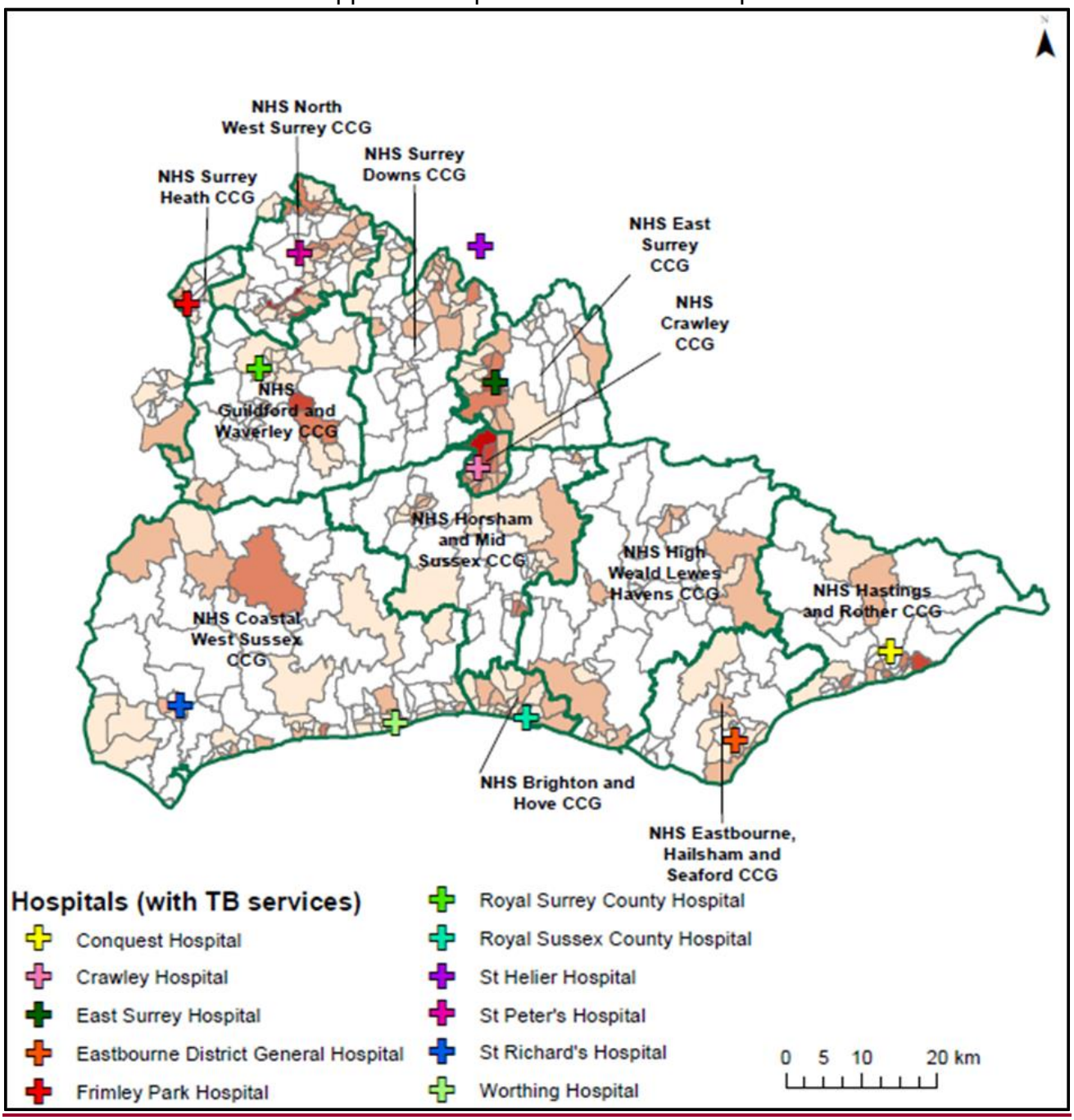
- established TB network with good engagement from all colleagues. The network offers a good platform for sharing expertise and evidence of best practices
- strong representation from all partners in quarterly local cohort reviews. Staff from both TB services and the PHE information team put a lot of effort in preparing the cases and epidemiological reports
- a high rate of culture confirmation among pulmonary TB cases
- some evidence of emerging collaboration between health and social care teams around TB – a good example is the current work on TB related part 2a court order

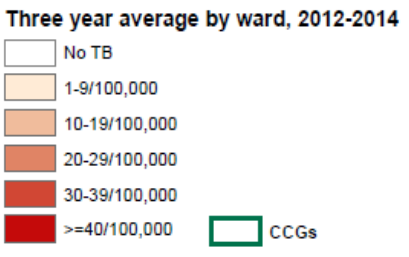
3. Service provision (key findings)

- nine TB services operate from eleven hospital sites in S&S area
- all TB services provide TB screening, diagnosis, treatment and contact tracing
- all services provide either direct inpatient care, or provide specialist advice to non-TB clinical teams caring for inpatients diagnosed with TB
- eight of the nine services (89%) have at least one TB Clinical Nurse Specialist (TB CNS) – the Royal Surrey County Hospital is the only service that does not currently employ a TB CNS
- all nine services (100%) have a dedicated paediatric service or established links to a paediatric team to support the management of children requiring screening or treatment for TB infection
- home visits are made by 7/9 TB services (78%)
- dedicated outreach work was not evident in eight of the nine services (89%) – the exception is Frimley Park Hospital that carries out 'additional outreach' work.
- directly observed therapy (DOT) was available in eight of the nine (89%) – different arrangements for DOT exist at different services
- neonatal BCG immunisations are available to infants meeting the criteria in catchment areas of eight of the nine (89%) TB services
- seven of the nine (77%) TB services assured to have service specifications and commissioning arrangements
- there is evidence of some collaborative/partnership work between TB services and social care and support teams

3.1 Service provision – details

There are a total of nine TB services in S&S area – eight of these are provided via acute hospital trusts while one (East Sussex NHS Healthcare Trust), is a community based service that has the support and input from two acute hospitals.





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3.2 Adult TB services

Eight of nine services (89%) have at least one TB Clinical Nurse Specialist (CNS) who offer nurse led clinics and/or appointments. Royal Surrey County Hospital does not have a TB CNS and the service is led by a respiratory physician. All TB services provide TB screening, diagnosis, treatment and contact tracing. All services provide either direct inpatient care, or provide specialist advice to non-TB clinical teams caring for inpatients diagnosed with TB. Although home visits are provided by more than 50% of the services, only one service based at Frimley Park Hospital is involved in additional outreach work[18] – which includes TB education and awareness raising among voluntary sector staff working with individuals at risk of TB (table 8).

The following hospitals have a respiratory consultant-led TB clinic (outpatient) with follow up support by a TB CNS led clinic;

- Royal Sussex County hospital – additional clinics are held in conjunction with other adult medical specialities (eg HIV medicine, infectious diseases)
- St. Helier hospital
- Frimley Park hospital
- East Surrey hospital
- Crawley hospital
- St Peter's hospital

In hospitals without a dedicated outpatient TB clinic, patients are seen by a respiratory consultant as part of general respiratory outpatient clinics:

- Conquest hospital
- Eastbourne hospital
- Worthing hospital
- St Richard's hospital
- Royal Surrey County hospital

3.3 Paediatric TB service provision

All services (100%) have a dedicated paediatric service or established links to a paediatric team to support the management of children requiring screening or treatment for TB infection. There is a dedicated TB/paediatric infectious disease clinic at:

- Royal Sussex County hospital
- Frimley Park hospital
- Surrey and Sussex Healthcare NHS Trust (Crawley & East Surrey hospitals)

[18] *Outreach is defined as having a dedicated staff such as a nurse or outreach worker who go out in the community for DOT work or carry out home visits for identification of close contacts etc.*

- St Peter's hospital
- St Richard's hospital

Children are/would be managed within the adult TB/general respiratory clinic with paediatric input as required at:

- Royal Surrey County hospital
- Epsom and St Helier hospital
- Worthing hospital
- East Sussex NHS Healthcare

3.4 Number of patients treated as an inpatient in the last year

All services with data available reported that they had had at least one patient treated as in inpatient within the last 12 months. This included patients who were diagnosed as inpatients, and/or patients who were admitted during the course of treatment.

Trust	Hospital Site	Geographical Catchment	Clinic Details	Access
Brighton and Sussex University Hospitals NHS Trust	Royal Sussex County Hospital	Brighton & Hove (TB nurse); some out of area patients (Worthing, Mid-Sussex, Chichester).	**Consultant** - Dedicated TB clinic; joint clinics with HIV and infectious diseases **TB CNS** - Dedicated TB clinic, contact screening **Paediatric patients** - seen by TB nurse and paediatric ID consultant	**Consultant clinic** - Wed 14.00-17.00 **Nurse clinic** – Paediatrics - Mon 09.30-12.00, Adults Wed 1.30- 4.30; TB CNS available to see patients out of usual clinic hours **Home visits** - **No** **Other outreach** - **No**
East Sussex NHS Healthcare Trust (ESHT)	Community based service in conjunction with respiratory physicians at; Conquest and Eastbourne District Hospitals	Hastings and Rother, Eastbourne, Lewes and the Havens	**Consultant** - patients are seen within the general respiratory clinic or as an inpatient **TB CNS** - Patients are usually seen in their home, no specific clinic time **Paediatric patients** – would be referred to the paediatric team for joint management	**2 TB CNS -** 1 WTE Community based service, no fixed clinic times **Home visits** - **Yes** **Other outreach** - **No**
Epsom & St. Helier University Hospitals NHS Trust	St Helier Hospital	Sutton & Merton Epsom & Ewell	**Consultant** - **dedicated TB clinic**; **TB CNS** - dedicated TB clinic, contact screening **Paediatric patients** - seen in general TB clinic and referred to paediatrics if appropriate	**Consultant clinic** - Friday; **Nurse Clinics** - Monday/Thursday/Friday **Home visits** - **Yes** **Other outreach** - **No**
Frimley Park Hospital NHS Foundation Trust	Frimley Park Hospital	Aldershot, Farnborough, Camberley, Farnham, Sandhurst, Bordon. Note only about 3 cases out of 30 last year were from Surrey, majority from the Rushmoor area	**Consultant** - **dedicated TB clinic** **TB CNS** - dedicated TB outpatient clinic **Paediatric patients** - patients are managed by paediatrician with input from TB CNS	**Consultant clinic** - Mon 14.00-16.30 **Nurse clinic**- Mon 920-1530, Tues-Fri 09.00-16.30; **Home visits** - **Yes** **Other outreach** - **Yes**

Surrey & Sussex Healthcare NHS Trust	Crawley Hospital (Outpatient) East Surrey Hospital (Inpatients and outpatients)	East Surrey, Crawley, Horsham, Mid Sussex and East Grinstead	**Consultant - dedicated TB clinic** (although some general resp. also seen) **TB CNS** - dedicated TB nurse clinic **Paediatric patients** - referred to paediatric respiratory CNS	**Consultant Clinic** - Tues PM **Nurse clinic**- Tues PM; However ad-hoc appointments or inpatient reviews can be arranged Mon-Fri 09.00-17.00; **Home visits** - **Yes** **Other outreach** - **No**
Ashford and St Peter's Hospitals	St Peter's Hospital	TB - Woking, Runnymede, Spelthorne, Elmbridge, Feltham, Ashford, Middx, Hounslow. BCG clinics - Waverley, Guildford, Surrey Heath, Woking, Elmbridge, Runnymede and Spelthorne.	**Consultant** - **dedicated TB clinic** **TB CNS** - dedicated TB clinic for screening and treatment follow-up plus BCG vaccination **Paediatric patients** - rapid access paediatric clinic which is attended by TB CNS	**Consultants** -available for input 'all the time' **Nurse clinic**- Alternate Tuesdays 13:30 – 16:30 and every Friday 3 x a month 10:00 – 12:00 and 1 x 14:00 – 16:00 **Home visits** - **Yes** **Other outreach** - **No**
Western Sussex Hospitals NHS Foundation Trust	Worthing Hospital	Coastal West Sussex CCG, Worthing, Adur and Arun	**Consultant** - TB patients are seen within general respiratory clinic **TB CNS**- Specialist TB clinic **Paediatric patients** - close links with paediatric team	**Nurse clinic-** Tues 9-6, Thurs 9-3, Fri 9-3 **Home visits** - **Yes** **Other outreach** - **No**
Western Sussex Hospitals NHS Foundation Trust	St. Richard's Hospital	St Richard's Hospital covers a geographical area Covering Chichester , Bognor Regis, The Witterings, Billingshurst, Emsworth and surrounding areas	**Consultant** - patients seen in general resp. clinic **TB CNS**- Specialist TB nurse clinic **Paediatric patients** - seen in paediatric dept. by TB nurse and paediatrician	**Consultant** - Monday am, Wed AM, Thurs PM **Home visits** - **Yes** **Other outreach** - **No**
Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey Hospital, Guildford	Guildford and Waverley.	**Consultant** - patients seen in general resp. clinic **TB CNS** – **No TB nurse**	**No information available**

Table 8: TB services by hospital, geographical catchment area and acces

3.5 Source of referrals[19]

There is variation in the source of referral to the TB services in S&S as shown in figure 6 below. It should be noted that the source of referral may be difficult to determine. For example if a patient is referred by primary care to a general respiratory clinic where diagnosis is made, the source may have been recorded as either primary care or secondary (ie respiratory) care. Therefore the data should be interpreted with caution. Data was not available for St. Peter's Hospital.

Primary care was the most common source of referral to TB services at East Sussex NHS Healthcare Trust, Frimley Park Hospital, Surrey and Sussex Healthcare NHS Trust and the Royal Surrey County Hospital.

Accident and emergency service was the most common source of referral to the Royal Sussex County Hospital and Worthing Hospital, accounting for 35% of the referrals at the former and 70% at the later. Factors which may contribute to increased presentation via accident and emergency can include the prevalence of social risk factors, lack of opportunities for a timely access to primary care and lack of awareness about TB among frontline healthcare professionals and the community worker.

NB: St Richard's and St Helier hospitals mainly receive referrals from other secondary care specialities.

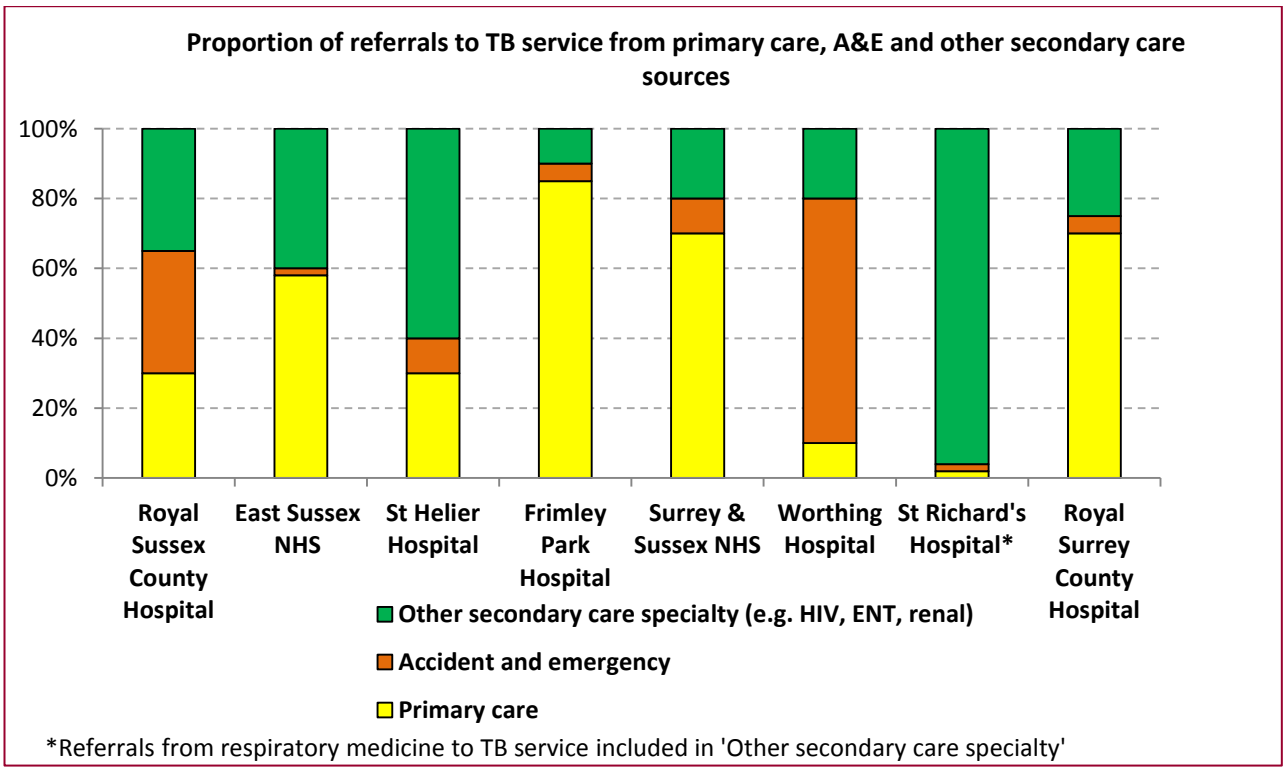


Figure 6: Source of referral to TB service

[19] As reported by the person completing the service mapping questionnaire.

3.6 Staffing and capacity

Nursing staff

Eight of the nine TB services (89%) in S&S employ a TB Clinical Nurse Specialist. Most TB CNSs have dual roles within their trusts, working part-time within TB and part-time in another role.

Recently filled nursing vacancies were reported in Frimley Park and St Peter's Hospital, both of which were short of staff for several months. A post will become vacant/be advertised at Worthing hospital in the coming weeks. Services like Surrey and Sussex Healthcare NHS Trust, St Peter's Hospital and the Royal Sussex Hospital noted that although they do not have specific vacancies, another part-time member of nursing staff would facilitate increased community work (table 9).

One service (11%), Royal Surrey County Hospital, does not currently have a TB CNS within the service. The service is based at the Royal Surrey County Hospital and is managed by a respiratory consultant.

Medical staff

Medical management of patients with TB is provided by respiratory physicians in all nine trusts. An infectious disease consultant also provides medical management of patients at Royal Sussex County Hospital. As previously mentioned, all services also either have a dedicated paediatric service or established links with local paediatric teams.

Administrative staff

Current NICE guidance states "consider providing administration support for TB nurses and case managers so they have capacity for clinical and case management work[20]". In S&S, two services (22%), Epsom and St Helier NHS trust and Surrey and Sussex NHS trust reported having dedicated administrative support within the TB service. Dedicated administrative support was not reported in the other seven TB services.

[20] National Institute for Health and Care Excellence (I.8.7.1) Tuberculosis, NG33, 2016 Jan. http://www.nice.org.uk/guidance/ng33

Crossover arrangements

Formal crossover arrangements, eg for staff cover, were reported between Worthing and St Richard's Hospital. Although formal arrangements were not in place in other areas of Sussex, it was perceived that cover could be arranged on an ad-hoc basis as required.

Commissioning arrangements for TB services

A couple of TB services did not have TB service specification or did not know if these have been developed and agreed for their service. A review of service specifications for all TB services to understand what is commissioned and what is being delivered was outside the scope of this work, however, going forward, this is a high priority area of work. The areas that have information on local commissioning arrangements and service specifications are:

- Epsom & St. Helier NHS Trust (service specification are part of respiratory medicine)
- Frimley Park Hospital (commissioned by Surrey CCG)
- Surrey & Sussex Healthcare NHS Trust covering Crawley & East Surrey hospitals (lead commissioner Crawley CCG)
- St Peter's Hospital, Chertsey, Surrey (commissioned by North West Surrey CCG) – renewal date March 2017
- Western Sussex NHS Foundation Trust (covering St Richards's and Worthing TB hospitals (commissioned by Coastal West Sussex CCG)

Trust	Staffing	Staffing gaps and shortages
Brighton and Sussex University Hospitals NHS Trust	**Nurses:** 1 TB CNS full time, 1 WTE TB CNS; **Doctors:** 2 respiratory consultants (2 p.a. for both), 1 ID consultant (5% of time)+ 2 registrars	No current vacancies No dedicated admin
East Sussex NHS Healthcare Trust (ESHT)	**Nurses**: 2 part-time TB CNS (1 WTE) **Doctors:** 1 consultant TB lead at Conquest; however TB patients can be seen by any of the 8 full time respiratory consultants at Conquest or Eastbourne	No current vacancies No dedicated admin
Epsom & St. Helier University Hospitals NHS Trust	**Nurses**: 1 TB Lead Nurse – Band 7 – part time equivalent (25 hrs); 1 TB Nurse Specialist- Band 7- whole time equivalent (37.5 hrs) **Admin:** 1 TB admin staff-Band 3- part time equivalent (18.5 hrs)	No current vacancies
Frimley Park Hospital NHS Foundation Trust	**Nurses:** Band 7 TB nurse specialist 15hrs per week 0.4WTE; Band 6 Community TB nurse (15hrs per week 0.4WTE (previously band 5) **Doctors:** 1.5 Pas per week	No current vacancies No dedicated admin

Surrey & Sussex Healthcare NHS Trust	**Nurses:** TB Specialist Nurse, Band 7, WTE 0.60; TB Specialist Nurse, Clinical Band 7 WTE 0.88 Paediatric Nurse Band 7 0.5 WTE - No admin for paediatric patients **Admin:** TB Administrator Band 3 WTE 0.42 Doctors: Respiratory consultant Paediatric Consultant but no dedicated time on job plan, all patients seen on adhoc basis.	No current vacancies
Ashford and St Peter's Hospital	**Nurses:** 2 TB Nurses – 1 x 135 hrs per month and 1 x 22.5hrs per week **Doctors:** 1 TB Lead – Part time 1 TB Doctor – Part time	No current vacancies No dedicated admin
Western Sussex Hospitals NHS Foundation Trust, Worthing Hospital	**Nurses** - 1 Specialist Band 7, 0.5WT **Doctors** - 1 Respiratory Consultant	No current vacancies No dedicated admin
Western Sussex Hospitals NHS Foundation Trust, St Richard's Hospital	**Nurses:** TB specialist nurse - 18.75 hrs per week **Doctors:** 2 x FT Resp. consultants	No current vacancies No dedicated admin
Royal Surrey County Hospital NHS Foundation Trust	**Doctors:** TB service provided by consultant physician	**Need a TB Nurse** No dedicated admin

Table 9: Staffing details by each service

3.7 Pathways, facilitates and interventions

3.7.1 Agreed pathways and referral arrangements for Multi-Drug Resistant (MDR-TB)

Although many nurses had experience of managing single-drug resistant TB, multi-drug resistant TB (MDRTB) was reported rarely in S&S. A formal agreement to refer cases of MDRTB to the local tertiary hospital was reported by following hospitals:

- St. Helier hospital
- Frimley Park hospital
- Crawley hospital
- East Surrey hospital
- St Peter's hospital
- St Richard's hospital
- Worthing hospital

Although formal pathways were not in place at Royal Sussex County hospital and East Sussex NHS Healthcare Trust (Conquest hospital and Eastbourne hospitals), it was reported that cases would be discussed in a multi-disciplinary setting on a case-by-case basis and specialist input obtained as required.

3.7.2 Microbiology access and pathways

Good systems were in place to ensure that the laboratory notified the TB team of positive results at:

- Royal Sussex County hospital
- Conquest hospital
- Eastbourne hospital
- St Helier hospital
- Frimley Park hospital
- St Richard's hospital
- Worthing hospital
- Crawley Hospital

Two of nine services (22%), Royal Surrey County hospital and St Peter's hospital, noted that the process of forwarding diagnostic samples to external laboratories can create delays in diagnosis. For example testing externally can increase the turnaround time on microscopic examination/staining. This could increase the time from obtaining the specimen to getting the result by 24-48 hours. With regards to microscopy for acid-fast bacilli, this is likely to be most relevant for acute infectious TB. Culture and sensitivity was carried out at the reference laboratory for all services.

3.7.3 Negative pressure rooms

Six of the nine trusts (67%) had access to negative pressure rooms. Negative pressure rooms were not available at Royal Sussex County hospital or the Royal Surrey County hospital. No negative pressure rooms were available at the Worthing Hospital, although it was noted that these facilities were accessible at another hospital within the trust (St. Richard's) (Table 9).

3.7.4 Directly observed therapy (DOT)

DOT was available in eight of the nine (89%) TB services. Information on DOT was not available for the Royal Surrey County hospital. DOT was delivered by:

A) TB nurses:

- St Helier hospital TB service
- Frimley Park hospital TB service
- St Peter's hospital TB service
- Conquest & Eastbourne hospitals TB service
- Crawley & East Surrey hospitals TB service
- St Richard's hospital TB service

B) Pharmacies and/or care agency staff

- Royal Sussex County hospital
- East Sussex NHS Healthcare Trust (Conquest & Eastbourne hospitals)
- Crawley & East Surrey hospitals TB service
- Worthing hospital TB service (overseen by TB nurses initially while these avenue are being set)

Two services (22%), Worthing and Frimley Park hospitals, had experience of using Video Observed Therapy (VOT). Royal Sussex County hospital has equipment for VOT but has not required this so far.

3.7.5 Contact tracing

Contact tracing was carried out by TB CNS in all services except the Royal Surrey Hospital, where this was carried out by the TB consultant.

3.7.6 Neonatal BCG

Neonatal BCG immunisation was available to infants meeting the criteria in eight of nine (89%) TB services in S&S. Data was not available for Royal Surrey County Hospital. Assessment of eligibility and administration of neonatal BCG vaccine was not managed by the TB services directly, but via the maternity and immunisation

teams. Ashford and St Peter's TB service provide BCG immunisation clinic for one to 16 year olds once a month.

3.7.7 Treatment of patients who are refugees or asylum seekers, or with no recourse to public funds

Three TB services (33%), East Sussex NHS Healthcare Trust, Epsom and St Helier University Hospitals NHS Trust and Surrey & Sussex Healthcare NHS Trust, reported that they had treated patients who were seeking asylum or had been granted refugee status. As these patients require additional support, TB services currently lack formally agreed pathways and support arrangments. In addition, there is no clear evidence on the exact roles and responsibilities of the CCG and the local authority public health team in the management of TB in people with complex social care needs including no recourse to public funds.

3.7.8 Community outreach

Community outreach[21] work is an essential part of early diagnosis and prevention of TB. The 'Collaborative Tuberculosis Strategy for England 2015 to 2020' recommends for the provision of community outreach especially for active case-finding among vulnerable populations.

In S&S, only one service Frimley Park reported having community outreach work that incorporates home visits, DOT, follow-up of patients and/or contacts who miss their appointments and close working relationship with partners and community organisations to support additional social needs of patients, eg housing (table 10).

3.7.9 Home visits

With regard to visiting a patient at his/her home (to access patient's environment and to complete the list of contacts) the RCN case management guidance[22] proposes that a home visit should be made within one week after the diagnosis and start of treatment. In S&S, 78% (n=7/9) of the TB services have indicated in the questionnaires that they make home visits to the patients (please note, our questionnaire did not specify the timing of these visits – at the start of diagnosis ot during the treatment).
These are:

- Conquest & Eastbourne District hospitals TB service

[21] Community outreach work incorporates a dedicated staff such as a nurse or outreach worker who goes out in the community for DOT work or carry out home visits for identification of close contacts.
[22] Royal College of Nursing – Tuberculosis case management and cohort review (2012) https://www2.rcn.org.uk/__data/assets/pdf_file/0010/439129/004204.pdf

- Crawley & East Surrey hospitals TB service
- St Helier hospital TB service
- St Peter's hospital TB service
- Frimley Park hospital TB service
- St Richard's hospital TB service
- Worthing hospital TB service

For the remaining 2 TB services, at Royal Sussex County hospital and Royal Surrey Hospital, this information was either marked 'no home visits' or could not be ascertained.

Pathways, facilitates and interventions

Trust	Referral pathways for laboratories and diagnostics	Are negative pressure rooms available?	Directly observed treatment (DOT)		
			Given by TB nurses	Given by outreach worker	Other
Brighton and Sussex University Hospitals NHS Trust	Yes	No∆	No	No	Pharmacy; Care agency
East Sussex NHS Healthcare Trust (ESHT)	No*	Yes	Yes	No	Care agency
Epsom & St. Helier University Hospitals NHS Trust	Yes	Yes	Yes	No	No
Frimley Park Hospital NHS Foundation Trust	Yes	Yes	Yes	No	No
Surrey & Sussex Healthcare NHS Trust	Yes	Yes	Yes	No	Pharmacy, IRC Nurses, Home Carers
Ashford and St Peter's Hospital	Yes	Yes	Yes	No	No
Western Sussex Hospitals NHS Foundation Trust – Worthing Hospital	Yes	No∆	Yes	No	Pharmacy; Care agency
Western Sussex Hospitals NHS Foundation Trust – St Richard's Hospital	Yes	Yes	Yes	Yes	No
Royal Surrey County Hospital NHS Foundation Trust	Yes	No	Unknown	Unknown	Unknown

*ad-hoc arrangements exist

∆Negative pressure room are not available on site but services have access to negative pressure room in another hospital

Table 10: Summary of local pathways, facilities and interventions

Links with partner agencies

There was some variation in reported links with partnership agencies, some of which is likely to reflect local need and geography.

	Primary Care services	Local Authority Public Health team	Immigration and removal services (if applicable)	Adults and social care	Homeless Team	Asylum seekers and refuges team	Children and families team	Substance misuse services	Mental health services	HIV team	Local voluntary sector teams	Other
Brighton and Sussex NHS Foundation Trust	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	
East Sussex NHS Healthcare Trust (ESHT)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	
Epsom & St. Helier NHS Trust	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
Frimley Park hospital NHS Foundation Trust	Yes	Yes	Unknown	Yes	Yes	Unknown	Unknown	Yes	Unknown	Yes	Yes	Ghurkha welfare trust
Surrey & Sussex Healthcare NHS Trust	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	
Ashford and St Peter's Hospital, Chertsey, Surrey	Yes	Yes	No	No	No	No	Yes	No	No	Yes	No	
Western Sussex hospital NHS Foundation Trust - Worthing Hospital	Yes	Yes	No	Yes	No	Yes	Yes	No	No	Yes	No	
St Richard's Hospital	Yes	Yes	Unknown	Yes	No	No	No	No	No	Yes	No	
Royal Surrey Hospital NHS Foundation Trust	Data unavailable											

Table 11- Evidence of links with partner agencies

3.8 Links with partner agencies

TB, like many other illnesses, requires hollistic and joint working relationships/links between multiple partners. Only by using this collaboration, can a service successfully diagnose the disease at an earlier stage and also offer support during the course of patient's treatment journey. Some of these partners include (but are not limited to) primary care services, community health centres, substance misuse services, mental health services, local authority's public health team, social care teams, housing departments, asylum seekers and refugees team, children and family services and offender management services. Each team has a different level of involvement depending on the specific needs of the patient.

TB services in S&S appear to have good working relationship with some local health and social care services.

Where information was provided (table 11) 89% (n=8/9) of the TB services reported having links with primary care and with the local HIV team. Links with adult and social care teams were also reported frequently.

Only two services (22%) reported having established links with community or voluntary sector organisations. Similarly two services reported links with mental health teams (table 11).

Frimley Park Hospital, has established links with community groups supporting individuals at risk of TB. They were involved in annual education and awareness raising of staff and volunteers working with homeless charities and organisations such as the Citizen's Advice Bureau. Royal Sussex County Hospital had been contacted by and agreed to accept direct referrals from Doctors of the World for patients with suspected active TB, however, no referrals have been made by the organisation as yet.

Additionally, ad-hoc working relationships have been formed to support specific screening and treatment interventions. For example East Sussex NHS Foundation Trust worked closely with local homeless charities to carry out large scale screening of contacts of a homeless man who had been diagnosed with TB.

St Richard's Hospital has are plans to develop links with community groups working with high-risk populations andhomeless charities. .

There are currently no specified links or pathways between Surrey and Sussex Healthcare NHS Trust, Worthing Hospital and Royal Surrey County Hospital and community or voluntary sector organisations supporting under-served populations.

3.9 Services capturing users' experience

It is important to collect data on service users' views of the service to gain a better understanding on the quality of the service and also to identify areas that need further improvement. There are many examples where making small changes have significantly improved patients' experience.

In S&S, there is a need to incorporate this work for all TB services as, at present, only two TB services, Brighton and Sussex University Hospital and Frimley Park Hospital, routinely collect data on service user experience.

3.10 Respondents views on gaps in the current services

All those completing the questionnaires were asked about gaps or areas for development within their services. Several key themes emerged.

3.10.1 Staffing

Although specific vacancies were not reported, understaffing was identified in several services including both nursing staff and administrative staff. Where there was not an explicit provision for staff to assess patients in the community this limited the ability of staff to undertake this, which can impact on access for underserved or 'hard-to-reach' populations.

3.10.2 Clinical pathways

Pathways are needed to support both routine and complex management of patients with TB. Specific pathways were identified for different services, eg the need for an MDRTB pathway at Royal Sussex County Hospital.

3.10.3 LTBI screening

Currently LTBI screening is not happening routinely within the S&S TB services. The potential role for the TB services in LTBI screening was highlighted by several services.

3.10.4 Education

TB specialists working in Surrey and Sussex recognise that there are specific challenges to working in this field in a low prevalence area, including the need for increased awareness among other health professionals. This is also relevant for organisation working with people at increased risk of TB, eg homeless charities or drug

and alcohol services. Additionally, increasing TB literacy at the community level could improve awareness and reduce stigma of TB.

3.10.5 Links with partners

The need for clear funding pathways between CCGs and TB services was highlighted. This is particularly relevant for the management of patients with complex social circumstances – eg homeless patients.

3.11 New entrant screening

From May 2012, the system of active TB case-finding at ports of entry was replaced with 'pre-entry TB screening' prior to migrants applying for a visa to enter the UK[23]. This means that everyone who applies for a UK visa for more than six months and who is resident in a country with a TB incidence of >40 per 100,000, will be screened for pulmonary TB at one of the UK approved TB screening centres. The preferred screening tool is a chest x-ray (CXR) and other tests for active or latent TB are not acceptable alternatives. Visas will only be granted if the applicant has been issued with a certificate of clearance to show they're free from active pulmonary TB.

Pre-entry TB screening can only detect active TB of the lungs, however, the majority of active TB cases diagnosed in England are a result of reactivation of LTBI. Therefore, systematic screening and treatment of LTBI in new entrants should significantly reduce the incidence of TB. This one of the key interventions supported in the 'Collaborative Tuberculosis Strategy for England[24] and has been established as a cost-effective intervention by the National Institute for Health and Care Excellence (NICE).

In January 2015 funding was identified to establish new migrant LTBI testing and treatment services in areas with high incidence (>20 per 100,000). Only one area in S&S (Crawley CCG) met the TB incidence threshold set by the national team. In November 2015, Crawley CCG's funding bid was approved and at the time of writing this report, one large practice has started delivering the service. In July 2016, a coordinator was successfully recruited by the CCG to roll out this programme to other GP surgeries in the Crawley area. This work is currently underway and there is an expectation that by the end of 2016, all interested GP surgeries would be able to participate in this programme.

[23] Public Health England. Tuberculosis screening [online]. 2015 Jul. Available from: https://www.gov.uk/guidance/tuberculosis-screening

[24] Public Health England and NHS England. Collaborative Tuberculosis Strategy for England 2015 to 2020, 2015 Jan. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf

Ongoing work that links with this HNA

It should be noted that there are two TB related audits underway - healthcare in prison services in the South East and a national diagnostics services audit. In addition a national review of TB workforce is currently ongoing. These are expected to be completed Spring 2017. A national toolkit for diagnosing and supporting TB management among USP groups was recenly publshed is now availbale[25].

3.12 Key recommendations (service mapping)

1. CCG should aim to adopt/incorporate national TB service specifications for their local TB services.
2. Explore collaborative ways of commissioning to ensure that appropriate, high quality TB services can be offered to all patients in S&S area regardless of geography.
3. There is an urgent need to further scope and address the gaps identified at Royal Surrey County Hospital.
4. Use cohort review to explore and address the underlying reasons for high levels of A&E referrals.
5. Develop a well-defined, ongoing programme of TB awareness raising and education programmes for local health and social care professionals, particularly those who work with under-served population (such as GP, social care, housing, substance misuse services, refugee and asylum teams etc).
6. Ensure TB services include community outreach work for a comprehensive contact tracing and follow up of cases - especially in local hot-spot areas where under-served and vulnerable population congregate or for those with complex social needs.
7. Ensure clear pathways and arrangements (especially) funding are in place to manage TB in patients with complex social care needs and/or no recourse to public funds.
8. Develop a systematic approach to TB screening and active case finding among other migrants and vulnerable population groups who are at greater risk including those in prisons and IRCs
9. Systematically implement the latent TB screening programme for new migrants from high incident countries using local hot-spots.
10. TB services lacking dedicated administration support should be provided with adequate admin resources to manage case work and data entry on ETS/cohort review forms.
11. Incorporate the future recommendations diagnostic services, TB workforce

[25] Public Health England (2017) Tackling TB in Under-Served Populations: A Resource for TB Control Boards and their partners. Public Health England: London. https://www.gov.uk/government/publications/tackling-tuberculosis-in-under-served-populations

development group and toolkit for USP groups (national work is expected to complete on all these by the end of 2016) and the local users' survey.

Aspire to:

- establish a team that is able to undertake extended community screening and follow-up of cases, across traditional boundaries, in response to large-scale incidents or outbreaks
- participate in London MDR-TB cohort review
- explore the use of mobile x-ray units (MXUs) for early diagnosis of active TB among vulnerable population in venues like hostels, day centres, pubs and crack houses

Some strong and positive points have become more apparent, which are worth mentioning to ensure their sustainability and further development as appropriate.
A few of these are:

- majority (89% n=8/9) of the TB services have at least one TB CNS, established, links with paediatric services, arrangements for DOT provision, neonatal BCG vaccination programme and good representation on TB networks and cohort reviews
- majority also have either the availability or access to negative pressure rooms/facilities

4. Service user survey 2016

A questionnaire was devised, piloted and finalised in collaboration with the TB services. Contact was then made with all nine TB services in Surrey & Sussex seeking users that would be suitable to interview. Initial methods included face-to-face and/or telephonic interview along with an online link to the questionnaire. In order to achieve the best uptake rate, we swiftly added the postal method as well.

A copy of the survey, together with a covering letter was sent out to 64 patients identified from the TB register. The letters gave users the options of completing the questionnaire on paper, by telephone or online. Although most of the letters were sent from the PHE Horsham office, some were sent directly by the TB nurses since they felt that they would achieve a better response that way. In September 2016, 39 more letters were sent out. The aim of this second wave was to target services with low uptake.

4.1 Summary of key findings

- 28 responses were received from all of the nine TB services. The ethnicity and sex breakdown of respondents was representative of the Surrey Sussex population
- The majority of respondents (76% n=23/28) were referred into their TB service via their GP surgeries
- Overall 86% respondents rated their care as good or excellent
- Approximately half of the patients (43% n=12/28) did not feel that they had a delay from the time they became unwell to the time they were referred to the TB team for treatment. For those that did experience a delay, it was a result of waiting a long time for referral appointment, being seen by a GP several times before being referred and uncertainty over the diagnosis
- Over half of the respondents waited more than two weeks to see a clinician after becoming unwell. The main reason given for this was the gradual onset of symptoms
- All but two respondents reported that they had details of a clinical person that they could contact for a medical situation
- A number of respondents noted that they hadn’t realised the side effects of treatment would be so severe; and some felt that they needed more support than was provided
- High travel costs and parking facilities were a cause of concern for a number of respondents

4.2 Demographics of respondents

Of the 28 patients who responded, 15 (54%) were males and 12 (43%) were females. One remaining patient did not complete the demographic information one (3%). The ethnic breakdown of respondents coincided with the TB epidemiology in S&S area. 10 patients (38%) were of White British origin and 10 patients (38%) were of Asian British, Indian or Pakistani origins. Of the remaining seven patients, four identified their ethnic group as Other, two as British African and African and one as White other. GP surgeries were the main source (76%) of the referrals to TB services (Table 12).

TB Clinic/Hospital service	Gender	Age range	Ethnicity	Initial Referral Route to TB service
Ashford & St Peters	M	26-35yrs	Pakistani	GP
	F	>65yrs	Pakistani	X ray
	F	36-45yrs.	Indian	GP
Epsom & St. Helier	M	26-35yrs.	White British	GP
	F	26-35yrs.	African	GP
	F	26-35yrs.	Indian	GP
Worthing (WSH)	M	46-55yrs.	Indian	Consultant
	F	>65yrs.	White British	GP
St Richards (WSH)	M	56-65yrs.	White Polish	GP
	M	>65yrs.	White British	GP
Frimley Park Hospital	F	46-55yrs.	Other Ethnic Group	GP
	F	26-35yrs.	Other Ethnic Group	GP
	M	36-45yrs.	Other Ethnic Group	GP
East Sussex Hospitals Trust (ESHT)	M	16-25yrs.	White British	GP
	F	36-45yrs.	Asian / Asian British	GP
	M	26-35yrs.	White British	GP
	M	46-55yrs.	White British	Walk in centre
	M	26-35yrs.	Black African	GP
	M	36-45yrs.	Thai British	GP
Brighton and Sussex University Hospitals Trust (BSUH)	F	26-35yrs.	White British	GP
	M	46-55yrs.	Asian / Asian British	GP
Surrey and Sussex Hospitals (SASH)	M	>65yrs.	White British	GP
	M	16-25yrs.	White British	GP
	F	>65yrs.	Indian	GP
	NK	NK	NK	A&E
	F	46-55yrs.	White British	GP
	F	16-25yrs.	Pakistani	Walk in centre

Royal Surrey Hospital	M	56-65yrs.	Other Ethnic Group	GP

Table 12: Demographic summary results

4.3 Reasons for overall delay (from onset of symptoms to starting TB treatment)

Just over half of the respondents (15/28) reported a delay between becoming unwell to being seen by a TB team for treatment. The three most commonly given reasons for this were: “I had to wait a long time for a referral appointment”/“I had to see my GP several times before they referred me” and “Symptoms unclear/uncertainty over diagnosis.”

Key reasons for overall delay	% of Respondents (n=15)
I had to wait a long time for a referral appointment	**33%(5)**
I had to see my GP several times before they referred me	**27%(4)**
Symptoms unclear / uncertainty over diagnosis	**33%(5)**
Don’t know	20%(3)
Not registered with GP and had to go to walk in centre	7%(1)
I did not seek medical attention sooner	0%(0)
Total number of respondents	**15**

Table 13: List of key reasons for overall delay (NB respondents could choose more than one option)

4.3.1 Reasons for delay in seeking medical help

Further analysis of the above overall delay shows the reasons at different stages of patient’s journey. In the first instant, over half of the respondents who became unwell (13/22) waited more than two weeks to visit a clinician. A variety of reasons were given for this, but the most common was: “There was a slow build-up of my symptoms.”

Reason for delay in seeing a clinician	% of respondents (n=13)
There was a slow build-up of my symptoms	**38% (5)**
I thought I would get better without seeing a doctor	23%(3)
I was too busy with work or education	23%(3)
I did not know about the early symptoms of TB	23%(3)
I was not registered with a doctor	8%(1)
I was registered with a doctor but could not get an earlier appointment	15%(2)
Went to Pharmacy and didn’t want to bother GP	8%(1)
No specific reason	15%(2)
Total number of respondents	**13**

Table 14: List of key reasons for delay in seeking medical help (NB respondents could choose more than one option)

4.3.2 Reasons for delay in confirming the diagnosis and providing treatment with TB service

After the first contact with a clinician, some patients were referred by their physicians to local hospital teams for diagnosis (ie radiology, ENT or TB clinic). Once referred 28% (n=5/18) were seen within 2 weeks by a hospital team while 33% (n=6/18) were seen between 2 weeks and 1 month and 22% (n=4/18) were seen between 1 and 2 months (Table 15).

Time in weeks/months	Wait to be seen by hospital ward / clinic to confirm TB diagnosis (18 respondents)
Less than 2 weeks	**28% (5)**
Between 2 weeks and 1 month	**33% (6)**
Between 1 and 2 months	**22% (4)**
Between 3 and 4 months	5% (1)
4 months or longer	10% (2)
No response given	**10**

Table 15: Wait from referral to confirmation of diagnosis

Once diagnosed with TB, patients were referred to TB clinic for treatment. 77% (n=20/26) were seen by TB clinic within 2 weeks of referral (Table 16).

Time in weeks/months	Wait to be seen by TB service once diagnosed (26 respondents)
Less than 2 weeks	**77% (20)**
Between 2 weeks and 1 month	12% (3)
Between 1 and 2 months	12% (3)
Between 3 and 4 months	0% (0)
4 months or longer	0% (0)
No response given	**2**

Table 16: Wait from confirmation of diagnosis to start of treatment at TB clinic.

4.4 Patients' experience of TB services during their treatment and follow-up

Journey to the clinic

Eighteen of the 27 respondents found it easy to travel to the TB clinic. Three respondents reported it wasn't easy to attend the clinic due to a long journey and five found it difficult due to travel costs. One responded stated: "My daughter takes me as I couldn't get there on my own" and another: "Public transport routes locally are very unreliable."

Appointment timing

The majority of respondents (23/27) felt that the appointments were offered at a convenient time to them. Two respondents stated that they would prefer an appointment time between 9am and 12noon, and one respondent stated that they would prefer an appointment time after 5pm.

Waiting to be seen

Approximately half of the patients (16/27) did not feel that they waited long to see a member of the team in clinic. Only three responses were given for the reasons for a delay. Two respondents felt that there was a backlog of people to be seen and one respondent reported that their appointment was forgotten.

Appointment duration

All respondents felt that they had enough time with their doctor or nurse during the TB appointment – although a few (four) respondents felt that this was not always true. All respondents felt they were given enough notice of the dates and times of the appointments or tests.

Provision of information and clinical tests

During treatment users were most commonly provided with information in the form of a leaflet. However, websites, DVDs, verbal information were all given as well. One respondent reported receiving a “TB pack” from his service. The majority of respondents were happy with the information provided, although three respondents were not happy and two respondents were not sure.
All but one respondent reported that they had details of a clinical person that they could contact for a medical situation (such as drug side effects). All respondents were satisfied with the information given before and after tests taken, and understood the nurses’ answers to their questions. All respondents but one said the test results and diagnosis had been explained to them by a member of staff.

	Yes always	Yes sometimes	No
Nurse’s answers to questions by user are understood (n=27)	85%(23)	15%(4)	0
Given enough information before any tests are carried out (n=26)	77%(20)	23%(6)	0
Member of staff explains test results and diagnosis (n=28)	82%(23)	14%(4)	4%(1)

Table 3.6 Provision of information

Treatment

The majority of respondents felt that clinic staff explained how to take TB medication properly, and that they were informed about side-effects of the TB medication. However, a number of responses indicated that users hadn't realised how severe the side-effects of treatment could be:

"Needs more information on how ill the tablets make you"

"I had many side-effects, some of which were not communicated to me and I became very stressed due to this"

"Didn't realise how ill they would make my dad, three months was terrible"

Some respondents felt that they needed more support than was provided during the treatment period:

"I needed a lot of emotional support which was not available to me"

"More telephone contact to see if all was ok".

"it would have been helpful to have more support apart from the consultant"

	Yes fully	Yes to some extent	No
Clinic staff explain how to take TB medication properly (n=27)	81%(22)	11%(3)	7%(2)
Clinic staff inform user about side effects of the TB medication (n=28)	64%(18)	29%(8)	7%(2)

Table 3.6: Advice on medication and side effects

4.5 Service users' views on what works well in the current TB services

Overall 86% respondents rated their care as good or excellent. Responses gave a very clear message of appreciation with the nursing service that was provided. There were also positive comments about the TB service as a whole. Some of the positive responses are given below:

- the entire team have been friendly, professional, helpful and sympathetic
- nurse XXX was lovely, very supportive and flexible due to phone appointments sometimes being needed
- doctors and nurses have been brilliant
- nurse XXX was a huge positive. Always checking in to see how things were and always on hand to answer questions
- XXXX Is honestly the most professional and nicest nurse I have ever dealt with, she made me feel comfortable, reassured and made my recovery very easy
- our TB nurse XXXX was really helpful and was always available to us when needed. She was keeping good track of the medication
- since being referred to the TB clinic, my experience has been pleasant due to the support received by the nurse. She is approachable, available, and flexible
- my consultant was excellent and very overworked

4.6 Service users' views on areas for improvement in current TB services

Primary care

Most users felt there needed to be an improvement in the referral time for GP to TB team. In addition, one respondent sought better ongoing TB care in primary care once they were under treatment:
"My GP's, they never had to treat TB before me and they were not familiar with the medication and the side effects"

Another respondent was also concerned about the communication flow from clinic back to the GP:
"Communication between department and GP - GP does not seem to receive information from clinic"

Car Parking

Car parking was another area where users sought improvement. Four respondents reported concerns around parking, in particular that it was expensive and there was a lack of disabled bays.

Miscellaneous

A couple of respondents felt that they would have liked to have more support available to them during treatment (see above). Another respondent expressed concerns about the time taken for close contacts that were children to be screened, and how this made them very anxious. Some of the other comments and suggestions are listed below:

- quicker appointment to see hospital clinician for a quicker diagnosis
- shorten OPD waiting times. Never met the consultant in the outpatient. Results were partially discussed in the outpatient
- sometimes not enough meds in pharmacy we had to come back again 1wk later to pick up
- aftercare - how do I know it's gone? How did I catch it?
- remember my appointment and more knowledge when liver complication

4.7 Key recommendations (service users')

1. In order to maintain and further improve high quality of care, all TB service should routinely administer a local level questionnaire for their patients. This will allow the services to understand patients' needs and help them tailor their services to match patients' expectations.

2. TB services should regular engage with their counterparts from accident and emergency, substance misuse, mental health services and other hospital teams ie ENT, gastroenterology, hepatology and microbiology to expedite patients' referral for robust referrals an earlier diagnosis.

3. All TB services should continue to participate in TB cohort reviews which provide a good platform for sharing skills and learnings to improve patients' experience.

Aspire to;
TB service should engage with community services and where possible hold local level awareness/signposting campaigns so that frontline teams from housing, social care, children and family services etc. can refer their clients, with symptoms suggestive of TB, directly to TB service avoiding delays and hence improving earlier diagnosis.

Some strong and positive points have become more apparent, which are worth mentioning to ensure their sustainability and further development as appropriate. A few of these are:

- an overwhelming manjority of the resoponses were positive and 86% of those who participated in the survey ranked their services as good or excellent
- similarly, majority of the respondents were happy with the information received from their TB services about next steps in their treatment pathway. Both of these points indicate a high level of patient care and follow up

5. TB policy, strategy and guidance

The following section provides a brief overview of current UK and international policy, strategy and guidance relating to TB. It does not provide a detailed review of the guidance but the key points from each publication and any further information relevant to TB care in S&S area are outlined in the following section. Key UK and international policy, strategy and guidance relating to TB were identified and include the following publications:

Collaborative Tuberculosis Strategy for England 2015 to 2020, Public Health England (PHE) and NHS England, January 2015[26]

Tuberculosis, National Institute for Healthcare and Excellence (NICE) guidance [NG33], NICE, January 2016[27]

Defining a model for a Gold Standard for a TB MDT group and associated networks, British Thoracic Society (BTS), March 2014[28]

Management of tuberculosis in prisons: guidance for prison healthcare teams, PHE, May 2013[29]

Guidance for PHE Centre Health Protection Teams on responding to TB incidents and outbreaks in prisons and other places of detention, PHE, July 2014[30]

TB Alert Strategic Plan, April 2012 – March 2017, June 2012[31]

The End TB Strategy, World Health Organisation (WHO), March 2015[32]

[26] Public Health England and NHS England. Collaborative Tuberculosis Strategy for England 2015 to 2020, 2015 Jan. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf

[27] National Institute for Health and Care Excellence (I.8.7.1) Tuberculosis, NG33, 2016 Jan. http://www.nice.org.uk/guidance/ng33

[28] British Thoracic Society. Defining a model for a Gold Standard for a TB MDT group and associated networks. British Thoracic Society; 2014 Mar https://www.brit-thoracic.org.uk/document-library/clinical-information/tuberculosis/defining-a-model-for-a-gold-standards-for-a-tb-mdt-group-and-associated-networks/

[29] Public Health England. Management of tuberculosis in prisons: guidance for prison healthcare teams, 2013 May.https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323325/TB_guidance_for_prison_healthcare.pdf

[29] Public Health England. Guidance for PHE Centre Health Protection Teams on responding to TB incidents and outbreaks in prisons and other places of detention, 2014 Jul. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/328660/TB_guidance_for_HPTs_July_2014.pdf

[31] TB Alert. TB Alert Strategic Plan, April 2012 – March 2017, 2012 Jun. Available from: http://www.tbalert.org/wp-content/uploads/2015/10/TB-Alert-strategic-plan-2012-17.pdf

[32] World Health Organisation. The End TB Strategy, 2015 Mar. Available from: http://www.who.int/tb/post2015_TBstrategy.pdf

Collaborative Tuberculosis Strategy for England 2015 to 2020, PHE and NHS England

The 'Collaborative Tuberculosis Strategy for England 2015 to 2020' was jointly launched by PHE and NHS England in 2015. It sets out a vision for high-quality TB control in England and outlines the ways TB services should be organised and resourced to tackle TB in an effective way. The strategy also outlines how TB services can be strengthened to ensure there is clear oversight and coordination of TB control through the establishment of formal TB control boards, TB networks and cohort reviews.

TB control boards are responsible for planning, overseeing and monitoring all aspects of TB control. TB networks, that cover a smaller geographical area, focus on local strategic issues, including commissioning, quality assurance (adherence to NICE guidelines etc,) and incident and outbreak control. TB control boards are expected to work closely with TB networks to ensure that national support is provided for delivering local TB action plans. Cohort reviews should also be undertaken regularly and findings reported back to the TB control board, as well as commissioners, management of TB service providers and local directors of public health.

Ten evidence-based areas are identified, which can be used as a framework for commissioners and providers of TB services to develop specific services that meet TB control needs. Each area contains a more detailed set of actions on how improvements can be achieved, key actions relevant to the BGSW HNA have been summarised below.

1. Improve access to services and ensure early diagnosis

- awareness raising of TB among populations at high risk and also health and social care professionals
- improving the accessibility of clinic venues and times
- local government has a key role in tackling social and economic risk factors associated with TB

2. Provide universal access to high quality diagnostics

- ensuring high-quality diagnostic services and microbiology advice, including timely notification to clinical teams, is available to all clinicians and patients with suspected TB
- ensure TB microbiology services are audited annually

3. Improve treatment and care services

- ensure appropriate levels and mix of staffing
- involve service users in service design
- ensure paediatric cases are managed by a paediatric TB specialist or with advice from a paediatric TB specialist
- ensure TB/HIV co-infected cases are managed jointly with an HIV specialist or by a clinician with a joint TB/HIV expertise

4. Ensure comprehensive contact tracing

- undertake comprehensive contact tracing, particularly for under-served populations
- improve arrangements for contact tracing through community outreach workers
- commission TB services with a specific plan for the delivery in the event of an incident to include contact tracing, investigation and follow-up of TB cases including those beyond the immediate household

5. Improve BCG vaccination uptake

- in low incidence areas, ensure that robust processes are in place so that all eligible babies are identified
- improve monitoring systems for BCG uptake

6. Reduce drug-resistant TB

- ensure patient compliance with TB treatment by providing DOT when required
- ensure all cases of complex and MDR-TB are discussed within the TB network
- ensure all clinicians who treat a case of MDR-TB have access to specialist advisory services

7. Tackle TB in under-served populations

- provide outreach interventions, including active case-finding among these populations and use of MXUs with incentives for people to have CXRs
- ensure NICE guidance on TB in under-served groups is followed

8. Systematically implement new entrant latent TB screening

- establish systematic LTBI screening for new entrants from countries with a high incidence of TB (estimated incidence greater than 150 per 100,000) and who arrived in the UK within the last five years. This is a cost-effective intervention recommended by NICE
- work with local authorities, communities and third sector organisation to raise awareness of LTBI screening

9. Strengthen surveillance and monitoring

- PHE to develop a single National TB Surveillance System to replace ETS and the London Tuberculosis Registrar (LTBR), which should be responsive to local needs
- PHE to provide an annual suite of indicators to enable local TB control boards to monitor performance

10. Ensure an appropriate workforce to deliver TB control

- key stakeholders should work with providers to ensure the TB workforce has a career framework, continued professional development and opportunities to influence TB policy

TB, the National Institute for Health and Clinical Excellence (NICE) guidelines

TB NICE guidelines were published in January 2016, updating the previous guidance from March 2011. The current guidance provides detailed recommendations for preventing TB, diagnosing and managing latent and active TB, drug-resistant TB, infection control, case finding, treatment adherence, follow-up and the organisation of services. For each main area of the guidance key new/updated recommendations and any salient points to the S&S TB HNA have been outlined in the following section.

I. Preventing TB, including in under-served groups

It is recommended that multi-disciplinary TB teams (in partnership with primary care, the voluntary sector, PHE and Health Education England (HEE)) should maintain a TB education programme for local health and social care professionals who work with the general public and at‑risk groups. Educational programmes should raise awareness about high-risk groups for TB but they also should also highlight that TB occurs in people without risk factors.

II. Diagnosing and managing latent TB, including recommendations specifically for children and young people

A key new recommendation for the 2016 guidance is the increase in the upper age‑limit for offering treatment for LTBI and, in line with this, the increase in the upper age‑limit for offering testing for LTBI; this was previously 35 years, but has been increased to 65 years. This has been implemented based on evidence considering of benefits, risks and costs of diagnosing and treating LTBI.

The guidance now recommends that in an incident situation involving screening large numbers of people, the offer of a single interferon-gamma release assay to people aged 18-65 years (previously aged five years and older) should be considered. This was because of considerable resource implications in offering this test to large numbers of people, especially for children in which care would have to be provided in paediatric hospitals (recommendations for testing for TB in children have been updated in the new guidance but the details are not specified here).

Further new 2016 recommendations include testing for hepatitis B and C and HIV before starting treatment for latent TB.

III. Case finding and adherence, treatment completion and follow-up, including in under-served groups

Another revised 2016 recommendation is to offer screening to the close contacts of any person with pulmonary or laryngeal TB, the recommendation previously referred to all people with active TB, this is to limit testing to contacts of people with potentially infectious TB.

In terms of case finding, new entrants from high-incidence countries should be offered testing for latent TB and offered treatment (if aged 65 years or younger, in whom active TB has been excluded, but who have a positive Mantoux test or a positive interferon‑gamma release assay for latent TB infection). People born in high-incidence countries (>150 per 100,000 per year) should be made a priority for latent TB testing when they arrive in the UK.

DOT should be offered to people who: Do not adhere to treatment (or have not in the past), have been treated previously for TB; have a history of homelessness, drug or alcohol misuse; are currently in prison or have been in the past five years; have a major psychiatric, memory or cognitive disorder; are in denial of the TB diagnosis; have multidrug‑resistant TB; request directly observed therapy after discussion with the clinical team or are too ill to administer the treatment themselves.

IV. Service organisation

The NICE guidance echoes the ‘Collaborative Tuberculosis Strategy for England’ regarding TB service organisation, focusing on the responsibilities of TB control boards and the purpose of cohort reviews. A new 2016 recommendation is that TB control boards should ensure there is adequate capacity to manage a sudden increase in demand, such as in incidents or large scale active case‑finding initiatives in congregate settings, especially those involving under‑served groups, and outbreaks in settings where transmission risk may be high (eg schools, workplaces, hostels and prisons).

Multiple new 2016 recommendations relate to the commissioning of TB services. It is advised that regular attendance at any multi-disciplinary team and cohort review meetings is included as a programmed activity for all TB staff as part of their work planning. Commissioners should take into consideration differing needs across current geographical and organisational boundaries and put agreements in place so that TB staff can traverse these boundaries, covering the whole service or TB control board area if appropriate. Commissioners in low-incidence areas should work with their respective TB control boards to devise collaborative approaches to deliver and manage TB services.

The NICE guidance also recommends providing administrative support for TB nurses and case managers to increase their capacity for clinical and case management work.

In terms of other non-clinical staff, it is recommended that consideration should be taken to employing trained, non‑clinically qualified professionals to work in conjunction with clinical teams. For instance, such professionals may contribute to awareness raising, supporting people to attend appointments, collecting samples and contact tracing.

Another new 2016 recommendation is that PHE working with the Local Government Association (LGA), should ensure that people with TB are considered a priority for housing. This may be achieved by working in collaboration with national housing organisations such as the Chartered Institute of Housing, Homeless Link, Sitra and the National Housing Federation. The training of housing commissioners and frontline staff on the importance of stable housing for successful TB treatment is also recommended.

V. Under-served groups

The updated guidance also incorporates ‘Tuberculosis: identification and management in under-served groups’ published in March 2012. In terms of prevention, the guidance states that education programmes should increase other professionals' awareness of local epidemiology, highlighting under-served and other high-risk groups.

In relation to active case finding, investigations should be coordinated around places where the person with TB spends significant amounts of time (eg pubs, crack houses, parks and community centres). Collaboration with voluntary, community and statutory organisations should occur to aid outreach contact investigations. Consideration should be given to the use of digital mobile X‑rays in settings where under‑served people at risk congregate.

Defining a model for a Gold Standard for a TB MDT group and associated networks, BTS

This guidance was produced by the BTS to provide advice to PHE, NHS England and other national stakeholders involved in TB control on how to strengthen TB control in the UK. The document mainly focuses on the development and commissioning of local and regional multi-disciplinary networks but also provides guidance on the provision and commissioning of local TB services.

In terms of commissioning, the BTS put forward that CCGs should plan TB services by focusing on all elements of TB control (eg. diagnosis, treatment, contact tracing, case management, DOT, active and latent case finding, treatment of LTBI and BCG vaccination), to prevent fragmented commissioning. Another key recommendation is that each CCG or lead CCG, even in low-incidence areas, identifies a TB lead. The TB lead could be part of the role of a CCG respiratory lead or could involve partnership across CCGs, as necessary. Where there are low numbers of TB cases within a CCG,

then it is suggested that collaborative commissioning of TB services is more likely to provide high-quality care.

In relation to staffing considerations, the BTS recommendations also reflect the NICE guidance. It is recommended that activities pertaining to TB network (including cohort reviews) should be incorporated into job plans and calculations should take into account preparation and travel time. Administrative support should also be accounted for when planning TB services to enable good clinical and nursing practice and enhance communication between stakeholders.

As per the 'Collaborative Tuberculosis Strategy for England' the BTS recommends a systematic new entrant screening programme to be implemented in primary care practice. As well as new entrant screening for LTBI, services are also urged to optimise active case finding for TB. Another key recommendation that was also covered in the national strategy is the formation of TB networks. The guidance discusses the development of TB networks for cities and high incidence areas but also focuses on the need for and development of TB networks for low incidence areas.

The guidance highlights that a hub and spoke model of TB care is the preferred service delivery model. This should enable all TB services to provide local standard case management and for those that need a higher level of care to allow referral to specialists to provide enhanced case management.

In line with the most recent NICE guidance, BTS recommend the provision of regular educational opportunities for primary care staff and other local professionals, that is delivered locally to ensure it is readily accessible.

Management of tuberculosis in prisons: guidance for prison healthcare teams

An audit on prisons and detention centres in the South of East is was recently completed (see appendix IV for full report-draft) Key recommendations from that piece of work have been included in this assessment.

The *Management of tuberculosis in prisons: guidance for prison healthcare teams* guidance is mainly directed at prison healthcare staff, but PHE Health Protection Teams (HPTs) and local TB services are other key audiences. The purpose of the guidance is to reduce the risk of transmission of tuberculosis within prisons. The guidance proposes that:

- all new prisoners should be risk assessed for TB using symptom screening and, if equipment is available in the prison for this, via digital chest x-ray (CXR)
- prisoners with symptoms suggestive of TB should be referred to the prison doctor/GP. Suspected or confirmed cases of TB should be reported as soon as

possible to the local HPT and the local TB service. Sputum samples should be obtained as per NICE guidance
- for those with TB or who are suspected of having TB, there are a number of criteria for which isolation in a single cell is indicated. Isolation is usually required until two weeks of treatment has been completed but 'step down' from isolation needs to be agreed with the local TB service and local HPT
- all prisoners should receive DOT if they require treatment for TB. The local TB service should attempt to visit the prisoner within one week of commencing therapy. Prisoners should be placed on 'medical hold' until s/he is no longer deemed infectious to others and is fit enough to attend court
- when prisoners are discharged or transferred to a different prison there should close liaison with the local TB service (and receiving prison if a transfer). At least one week's medication should accompany the prisoner if s/he has to leave the prison for any reason

Guidance for PHE Centre health protection teams on responding to TB incidents and outbreaks in prisons and other places of detention, PHE

The Guidance for PHE Centre Health Protection Teams on responding to TB incidents and outbreaks in prisons and other places of detention is to ensure that HPTs to deliver a consistent approach to the public health leadership of TB incidents and outbreaks in such settings.

In terms of planning and preparing for incidents and outbreaks, HPTs are expected to maintain regular formal contact communication with other key organisations and stakeholders and should ensure that robust mechanisms are in place to ensure the notification of prison/detention centre TB cases to HPTs. HPTs should in turn inform the PHE Health Protection Director, the PHiPs Team, and PHE based Field Epidemiology Service (FES).

In responding to an incident or outbreak, HPTs are expected to lead the response, provide expert advice on TB control and ensure that timely investigation and management occurs. The document refers to three distinct phases in the response to an incident or outbreak; 1) Assessment phase 2) Control phase 3) Evaluation phase. The guidance can be referred to for the necessary steps pertaining to each phase.

TB Alert Strategic Plan, April 2012 – March 2017

In 2012 TB Alert, the UKs National TB charity published it's five-year strategic plan that focuses on awareness raising about TB, providing support to TB patients, working with key partners to develop policy related to the prevention, management and control of TB and advocating for TB patients and staff to mobilise resources and improve TB-related policy.

The strategic plan contains five main strategic objectives that are applicable to the charity's work in the UK and internationally. Key initiatives are described that will go towards delivering each objective. TB Alert's five strategic objectives for 2012-2017 are to:

1. Meet the needs of individuals and communities affected by TB for information and support and raise awareness of TB among health practitioners

2. Strengthen collaboration between health and social care systems and civil society, for the care of patients and the prevention and control of TB

3. Influence resource mobilisation and policy for the care of patients and the prevention and control of TB.

4. Measure and demonstrate the impact and cost-efficiency of TB Alert's work

5. Secure committed, skilled and effective staff and trustees and a diversified funding base

The End TB Strategy, World Health Organization

In May 2014, the 67th World Health Assembly adopted the WHO's 'Global strategy and targets for tuberculosis prevention, care and control after 2015'. Labelled 'The End TB Strategy' the goal is to end the global TB epidemic and set a number of targets to reduce by 95% the number of TB deaths in 2035 compared with 2015, reduce by 90% TB incidence rate in 2035 compared with 2015 and by 2035 have zero TB-affected families facing catastrophic costs.

The strategy outlines three strategic pillars, which are outlined below. Each strategic pillar is achieved through key components of which the detail can be referred to in the strategy:

1. Integrated, patient-centred care and prevention: Aims to ensure equal, unhindered access to affordable TB services and promote engagement in care. Also, focuses on early detection, treatment and prevention for all TB patients

2. Bold policies and supportive systems: aims to strengthen health and social sector policies and systems to address the social determinants of TB and tackle TB among vulnerable groups, such as migrants

3. Intensified research and innovation: aims to boost research into the development of new TB tools and interventions in the diagnosis and treatment of TB

The three strategic pillars are underpinned by four key principles:

1. Government stewardship and accountability, with monitoring and evaluation
2. Strong coalition with civil society organizations and communities
3. Protection and promotion of human rights, ethics and equity
4. Adaptation of the strategy and targets at country level, with global collaboration.

Appendix I. Service provision questionnaire

SERVICE MAPPING QUESTIONNAIRE WK

Appendix II - Service User's questionnaire

SERVICE USER QUESTIONNAIRE -Po

Appendix 3 Surrey and Sussex TB Cohort Review

Evaluation - Summary of Findings

The Tuberculosis Cohort Review (TBCR) was introduced in S&S in April 2012 to improve the management of TB locally. Its introduction seems to have significantly improved the important outcome of treatment completion for both TB cases and for contacts with Latent TB infection (LTBI). The numbers offered HIV testing has also dramatically improved. Other outcomes, such as identifying at least one contact, were already very successful and had little room for improvement. Identifying five or more contacts remains a poorly achieved outcome and loss to follow up has shown no consistent improvement. The reporting of DOT was unreliable and so outcomes for this are hard to interpret. Caveats:

- Often inconsistent data reporting with errors identified
- Two reports not included as unreliable data
- Limited comparison data – using single point of reference for “pre-TBCR”
  Unclear impact of confounding factors such as introduction of pre-entry TB screening (also in 2012)

Target met or exceeded

Less than 75% of target met

Less than 50% of target met

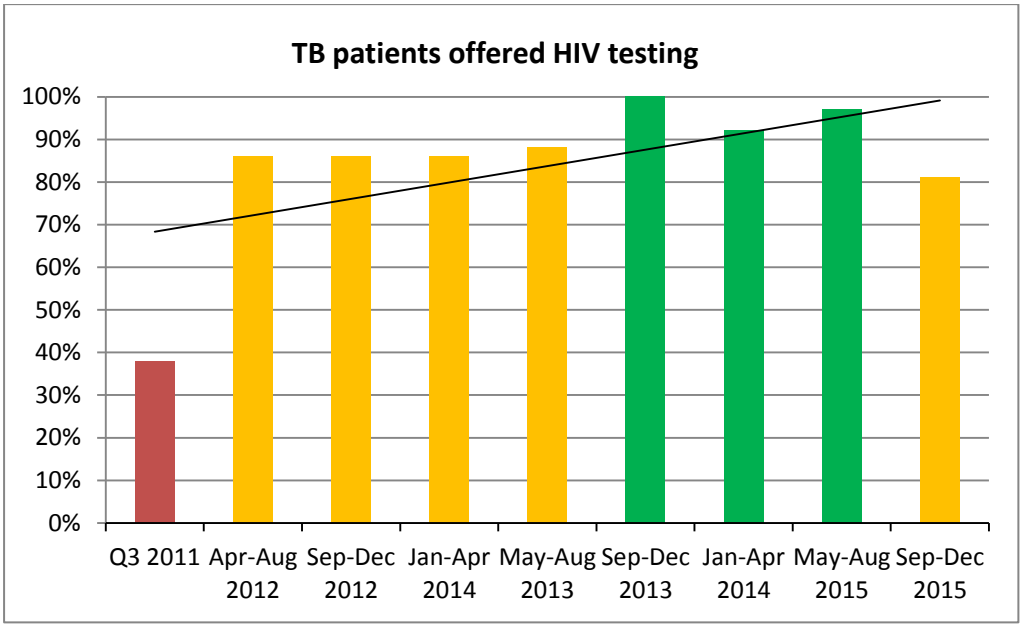
Target outcome	Initial score (2011)	Subsequent median (2012-15)
100% of TB patients assessed as requiring DOT will be offered DOT	100%	80% ↓
>90% of TB patients will be offered HIV testing	38%	87% ↑
At least 85% of TB cases will successfully complete, or expect to complete, a recommended treatment regimen within 365 days.	42%	88% ↑
Less than 1% of TB cases will be lost to follow-up at time of cohort review	5%	3% ↓
Among all pulmonary cases, at least 95% will have one or more contacts identified	63%	98% ↑
Among all pulmonary cases, at least 80% will have five or more contacts identified	28%	34% ↑
Among all pulmonary sputum smear positive cases, at least 95% will have one or more contacts identified	100%	100% ↔
Among all pulmonary sputum smear positive cases, at least 80% will have five or more contacts identified	70%	56% ↓
At least 90% of contacts of smear positive cases will receive clinical evaluation	90%	94%↑

At least 85% of contacts with LTBI who are started on treatment will successfully complete, or will be expected to complete	40%	100%↑

Improvement in outcome measures

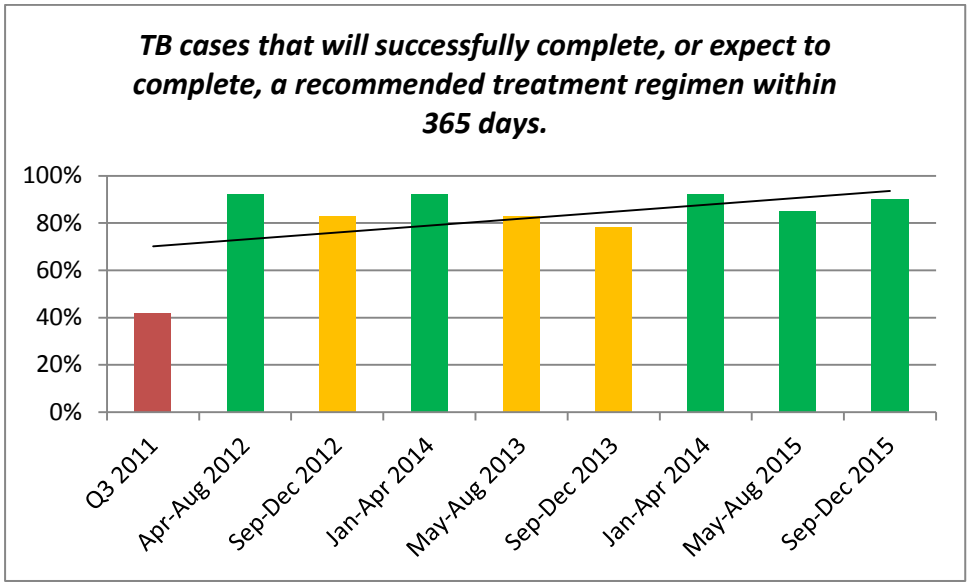
TB patients offered HIV testing

Initially HIV testing appeared poor at 38%. This improved dramatically up to a median value of 87% over the subsequent 8 reviews. The median fell below the target of 90% though this target was met in three out of the subsequent eight reviews.



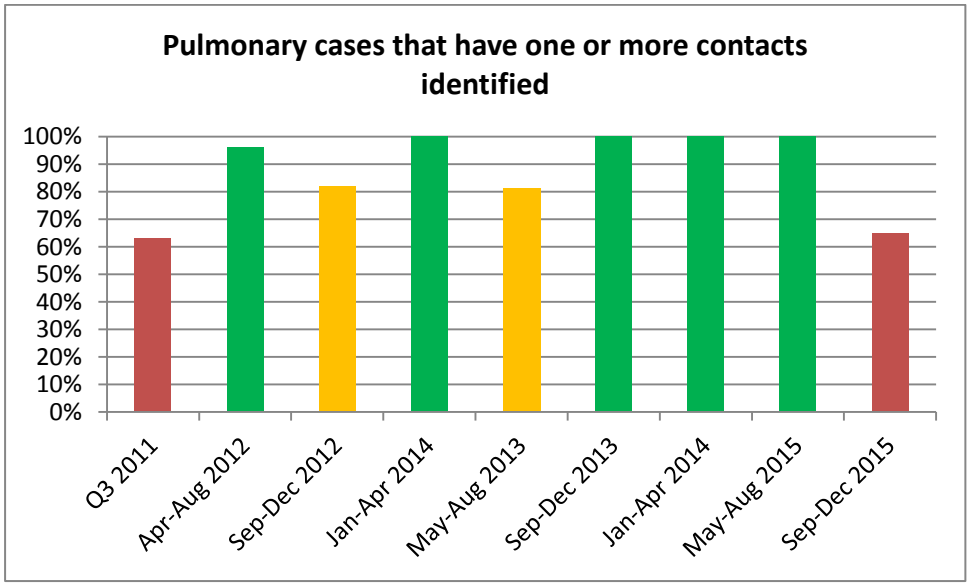
TB cases that successfully complete, or are expected to complete, a recommended treatment regimen within 365 days

Initially treatment success was low at 42%. This improved dramatically up to a median value of 88% over the subsequent 8 reviews. The target of 85% was met in five out of the subsequent eight reviews.



Pulmonary cases will have one or more contacts identified

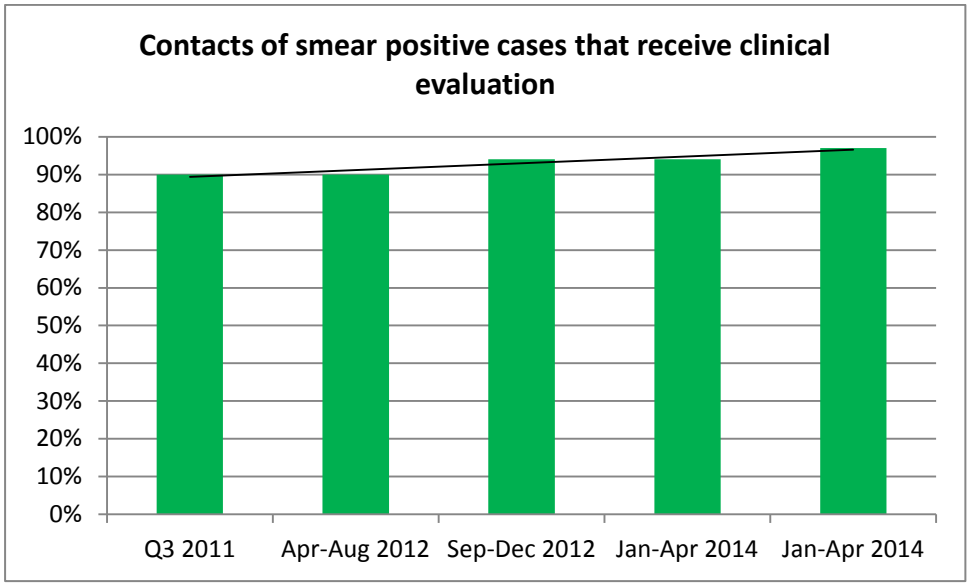
Contacts identified from pulmonary cases rose from 63% to a median of 98% over the subsequent 8 reviews. The target of 95% was met in five out of the subsequent eight reviews.



Contacts of smear positive cases that receive clinical evaluation

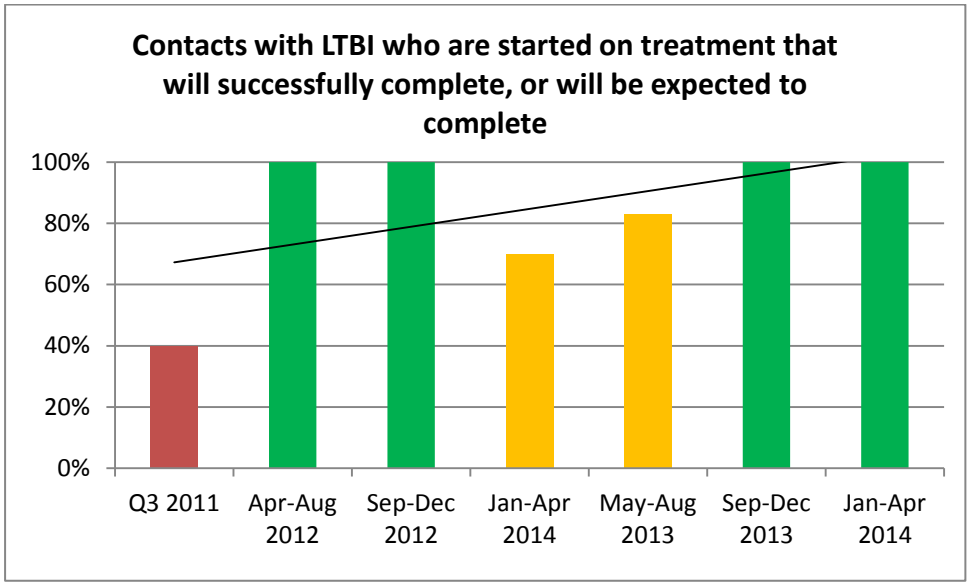
Data was absent for a number of the reports[33]. This remained a successful outcome, initially with 90% of contacts being evaluated, which rose to a median of 94% over the subsequent 4 reviews.

[33] Data was incomplete for this outcome measure. It was reported up until the review held on 3rd Sep 2014 and then once more on the 23rd April 2015, giving only 5 of the possible 9 values.



Contacts with LTBI who are started on treatment that will successfully complete, or will be expected to complete

There appears to be a significant improvement in treatment outcomes for those with LTBI, with figures rising from an initial 40% to a median of 100%. The target of 85% was met in four out of the subsequent six[34] reviews.



[34] One of the reports, for the review held on 15th September 2015, did not have data for this outcome and the report from 15th February 2016 was not applicable as there were no contacts with LTBI. These two have therefore been omitted from the analysis.

No clear improvement in outcome measures

Performing well:

Pulmonary sputum smear positive cases that have one or more contacts identified

Data was incomplete for this outcome measure.[35] However, the outcomes were consistently high only once dropping below 100% to a low of 92%. The target of 95% was mostly met.

Performing poorly:

TB patients assessed as requiring DOT that are offered DOT

DOT outcomes were not well reported and last appeared in the "epi reports" on 30th April 2014. The outcome started at 100% and fell to a low of 33%, well below the target of 100%.

TB cases lost to follow-up at time of cohort review

There seems to be no obvious improvements in losing patients to follow up. On two occasions the target of less than 1% was met. The highest loss to follow up was 6%. The mean average over all cohort reviews was 3%.

Pulmonary cases that have five or more contacts identified

There was little evidence of sustained progress with the higher numbers of contacts identified. At no point was the target of 80% of cases having five or more contacts identified met. The percentages rose from an initial 28% to a median of 34%.

Pulmonary sputum smear positive cases that have five or more contacts identified

Data was incomplete for this outcome measure.[3] There seemed to be no obvious sustained improvement in identifying five or more contacts, and only once was the target of 80% met, though these figures are better than for the pulmonary cases.

Author of TB cohort review evaluation; James Sidebotham, on attachment to East Sussex Public Health Department, ESCC.

[35] Data was incomplete for this outcome measure. It was reported up until the review held on 3rd Sep 2014 and then once more on the 23rd April 2015, giving only 5 of the possible 9 values.

Appendix IV – Audit of prisons and IRCs in the South East

SE TB audit report Feb 14.docx