





Tackling Tuberculosis in Under-Served Populations: A Resource for TB Control Boards and their partners



Version 1.1

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Glossary of acronyms

BBVs	Blood-borne viruses
CYPSE	Children and young people's secure estate
CCGs	Clinical Commissioning Groups
CI	Confidence Intervals
CJS	Criminal justice system
CRCs	Community rehabilitation companies
CXR	Chest X-ray
DOT	Directly Observed Therapy
DsPH	Directors of Public Health
DXR	Digital X-ray Machines
ETS	Enhanced TB Surveillance system
HJIPs	Health and Justice indicators of performance
HJIS	Health and Justice information service
HMIP	Her Majesty's Inspectorate of Prisons
НО	Home Office
HOIE	Home Office Immigration Enforcement
HPT	Health Protection Team
IRC	Immigration removal centre
JSNA	Joint Strategic Needs Assessment
LGA	Local Government Association
LTBI	Latent TB infection
LTBR	London TB Register
MDR-TB	Multi-drug resistant TB
MSM	Men who have sex with men
MoJ	Ministry of Justice
NICE	National Institute for Health and Care Excellence
NOMS	National Offender Management Service
NPA	National Partnership Agreement
OCT	Outbreak Control Team
OST	Opioid Substitution Therapy
PHE	Public Health England
PHEC	Public Health England Centre
PPDs	Prescribed places of detention
PWID	People who inject drugs
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing Substance Misuse Services
SMS	
SRF STI	Social Risk Factor Sexually transmitted infection
TB	Tuberculosis
TBCBs	TB Control Boards
UKCC WHO HIPP	UK Collaborating Centre to the WHO Health in Prisons Programme
USPs	Under-Served Populations
VCSE	Voluntary, Community and Social Enterprise
VOT	Video-observed therapy
WHO	World Health Organisation
YJB	Youth Justice Board
YOI	Young Offenders' Institution

Foreword

Even today and even in England, TB is still a disease associated with social deprivation. In 2015, the rate of TB was 20.5 per 100,000 in the 10% of the population living in the most deprived areas of England compared with only 3.6 per 100,000 in the 10% of the population living in the least deprived areas, with a clear trend of an increasing rate of TB with increasing deprivation (Source: TB in England - 2016 Report, PHE). Tackling TB is therefore as much about addressing health inequalities as it is about health protection.

When considering how people access TB services, we differentiate between passive case finding and active case finding. In passive case finding, we expect people to self-present to healthcare services when they experience non-resolving symptoms. Active case finding, on the other hand, is necessary when people are unlikely to self-present, which is usually the case with Under-Served Populations (USPs). People in this population have previously been described as 'hard-to-reach': this description can imply an active withdrawal of people from services but the lived experience of many is that services simply do not map to their needs in terms of accessibility, acceptability or suitability. 'Under-served' more accurately describes the experience of the population and put the onus on service commissioners and providers to design and deliver services appropriate to the needs of the population. Services have to be pro-active in finding these patients so they can be diagnosed and treated.

USPs represent this country's contribution to the <u>4.3 million</u> [1] people worldwide who develop TB each year but do not get the care they need and as they go untreated continue transmitting infection. These USPs also make up the vast majority of the 1.8 million people a year who die of TB.

TB programmes the world over have historically focused primarily on the bio-clinical aspects of the disease. In recent years, however, they have increasingly recognised TB as a public health issue and looked to improve access to services and to provide integrated clinical and social care. This resource is part of that global progress.

Meeting the needs of USPs is one of the key areas where, as the <u>Collaborative TB</u> <u>Strategy for England</u> [2] stresses, success will depend on bringing together all local agencies, including third sector partners.

Within this multi-agency approach, local authorities have a critical, three-fold role. They are responsible for public health in their local community; they provide social services, which is especially important to ensure USPs receive the integrated care they often need and as the base of the Director of Public Health they have a key coordinating role.

The third sector is also recognised as a key stakeholder. One of the four pillars of the WHO's <u>End TB Strategy</u> [3] is for a strong coalition with third sector/civil society organisations and with communities themselves.

Third sector organisations can work with TB programmes to design and deliver effective and cost-efficient multi-agency policies and programmes for working with USPs. Their delivery roles range from prevention work and case finding, through to providing psycho-social support to patients during treatment.

The purpose of this resource is to improve our understanding of the health needs of USPs in relation to TB, and to support the design and delivery of multi-agency programmes and services to better meet those needs. Produced with multiple partners including PHE, NHS England, NHS Clinical teams, local government and TB Alert, this resource provides TB Control Boards and their partners with a framework around which to build collaborative programmes of work to reduce the burden of TB among USPs in their area. This will not only improve the health of these populations specifically but will protect the health of the wider population and contribute significantly to the wider aims of the <u>Collaborative TB Strategy for England</u> [2].

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Executive summary

This document aims to improve our understanding of the health needs of under-served populations (USPs) with TB, to provide a resource to help tackle TB in this group, and to support the design and delivery of multi-agency programmes and services to better meet the needs of the under-served. Ultimately, this will contribute significantly to control of TB in the wider population in England.

In 2015, 12% of all TB cases in England had at least one social risk factor; this was an increase on 2014 levels. These cases were twice as likely to have infectious TB and twice as likely to die of TB; they had poorer treatment outcomes and were more likely to have drug resistant TB. These findings highlight why this resource is needed.

TB in people with social risk factors can be seen as a barometer of health inequalities and tackling it will play a key role in enabling local authorities, the NHS and PHE to successfully reduce health inequalities. The under-served population is often defined as having multiple, complex needs so the wider determinants of health are important to consider as is the bringing together of many organisations, not only in the health sector but also local government, social care, housing, justice, NHS commissioners, the third sector and voluntary groups.

This resource brings together, in one place, information related to USPs and TB and supports TB Control Boards (TBCBs) and their partners build collaborative programmes of work to reduce the burden of TB among local vulnerable and marginalised people with multiple complex needs. This will not only improve the health of these populations but will reduce health inequalities; in addition to protecting the health of the wider population and contribute significantly to the aims of the <u>Collaborative TB Strategy for</u> <u>England</u> [2].

Chapter 1 defines who under-served populations are, outlines the burden of TB in these populations and maps where they are found in England. For the purpose of this resource the people considered as under-served include:

- some migrants groups, including asylum seekers, refugees and those in immigration detention
- people in contact with the criminal justice system
- people who misuse drugs or alcohol
- people with mental health needs
- people who are homeless

Chapters 2 to 6 take each of the main under-served populations in turn and defines them; describes the burden of TB within these groups; discusses the challenges that need to be overcome; and then makes recommendations on how to meet those challenges. Each chapter includes hyperlinked resources <u>in red text</u> and ends with exemplars of innovation and good practice to stimulate local action.

Chapters 7, 8 and 9 outline the roles of those involved alongside the TB clinical teams in meeting the needs of under-served populations. These chapters cover the roles and responsibilities of local government, TB Control Boards, CCGs and the third sector.

Finally, chapter 10 outlines a selection of 'models of care' that can be used to meet the needs of under-served populations with TB. These should be considered alongside those that appear in chapters 2 - 6.

To make the best use of this resource we recommend you read all chapters. If however you have limited time we suggest you read the chapters relevant to your specialist area as each chapter contains hyperlinked information and exemplars of good practice.

This resource makes many useful recommendations on how collectively we can better meet the needs of the under-served with TB. The detail of these can be found in each of chapters 2 to 6. The overarching recommendations are as follows:

1. Raise awareness of TB in USPs and those who work with them

TB Control Boards, local government, CCGs, primary and secondary care providers to consider how best to reach out to the USPs at risk of TB, and those working with them, to raise awareness of TB to increase early diagnosis and treatment completion. This could include:

- TB awareness raising sessions, run by local TB nurses using the nationally developed TB nurse resource pack, with primary care, community groups working with new migrants, drug and alcohol misusers, the homeless and local authority housing departments
- involve the third sector in reaching out to USPs
- encourage greater use and dissemination of TB awareness raising materials particularly information produced by the National Knowledge Service for drug and alcohol misusers, prisons, the homeless, new migrants and their key workers (see relevant chapters for hyperlinked resources)

2. Work to provide more integrated services for USPs

TBCBs, CCGs and partners to work to develop integrated, patient centred services and pathways with strong links to primary care and existing health and social care services. Consideration to be given to:

• the need for specialised primary care or community based services to support refugees and asylum seekers (see chapter 2)

- the need for 'one-stop shops' and 'outreach services' for people with TB who have mental health, drug or alcohol problems or who are homeless
- improving treatment completion in USPs by developing patient pathways using for example pharmacies or mental health support workers as DOT providers or encouraging concomitant prescribing of opiate substitute therapy and TB medication by TB and substance misuse services

3. Work to address the issue of homelessness and TB

There are a number of ways to address the issue of homelessness and TB, these include:

- TBCBs collaborating with local authorities, housing associations, voluntary and third sector organisations to address issues of homelessness, indebtedness, unemployment and patients with NRPFs (see chapters 6 and 7)
- TBCBs working with local authority housing and social care departments, TB services, CCGs and hostel accommodation providers to develop streamlined accommodation pathways to help house homeless TB patients, including those ineligible for local authority funded accommodation (see chapter 6)
- TBCBs working with CCGs and local authorities to agree the best way to fund temporary housing for homeless TB patients, until treatment is completed (see chapter 6)
- 4. TBCBs and local partners to consider whether the use of an holistic mobile X-ray unit visiting homeless hostels on a periodic basis could help them meet the needs of the homeless with TB (see chapter 6)
- Involve key stakeholders to develop and improve services for USPs with TB. TBCBs to consider inviting key representatives of USP groups to advise or join the TBCB eg PHE Centre Health and Justice leads, migrant health leads, drugs and alcohol leads and local authority housing / homelessness experts
- TBCBs to work with local Directors of Public Health and CCGs to ensure that USPs and their needs are recognised and considered in local JSNAs, Joint Health and Wellbeing Strategies and Sustainability & Transformation Plans (see chapter 7)
- 7. TBCBs, local authorities and PHE Health and Justice leads to encourage the prison estate to prioritise and embed approaches that will lead to early detection and treatment of infectious TB (see chapter 3)
- 8. CCGs, primary and secondary care providers to work to increase the uptake of latent TB (LTBI) testing and treatment among new migrants (see chapter 2)

Chapter 1: Burden of TB in USPs

Key messages

- in 2015, there was an increase in both the number and proportion of TB cases with at least one SRF; overall 12% (579) of TB cases had at least one SRF in 2015 compared with 10% (538) in 2014
- between 2010 and 2015, 10% (3,474) of TB cases had at least one social risk factor (SRF), a third (32%) of whom had more than one SRF
- the proportion of UK born cases with at least one SRF (18%) was nearly three times higher than that of non-UK born cases (7%)
- the proportion of cases with at least one SRF was nearly four times higher in males (14%) compared to females (4%)
- there was considerable geographical variation in the number of TB cases with SRFs by local authority
- a higher proportion of cases with at least one SRF had pulmonary disease (77%) and received directly observed therapy (DOT) (48%) compared to those without a SRF (49% and 6%, respectively)
- a higher proportion of cases with at least one SRF were resistant to isoniazid without MDR-TB (8.3%) compared to those without a SRF (5.3%)
- a higher proportion of cases with at least one SRF had MDR/RR-TB (2.4%) compared to those without a SRF (1.6%)
- outcomes in drug sensitive cases with at least one SRF notified between 2010 and 2014 were worse than those without a SRF; 6.5% died, 8.1% were lost to follow-up and 1.9% had their treatment stopped, compared to 3.9%, 3.9% and 1.0%, respectively, in those without a SRF

1.1 Defining Under-Served Populations (USPs)

The <u>Collaborative Tuberculosis Strategy for England</u> [2] 2015 to 2020 defines USPs (USPs) as individuals whose social circumstances, language, culture or lifestyle (or those of their parents or carers) make it difficult to recognise the clinical onset of TB, access diagnostic and treatment services, self-administer treatment (or, in the case of children and young people, have treatment administered by a parent or carer); or attend regular appointments for clinical follow up.

NHS England, Public Health England and local government all have statutory obligations to address health inequalities. Individuals and defined communities can experience health inequalities due to lack of access to diagnostic or therapeutic services. For some people, this can be a consequence of specific personal

circumstances in their lives, temporary or permanent; for others, barriers to care can exist because of where people live including in institutional settings like prisons and other prescribed places of detention (PPDs).

The scope of people considered within the definition of USPs for the purposes of this resource include:

- some migrants, including some asylum seekers, refugees, undocumented migrants and those in immigration detention
- people in contact with the criminal justice system (CJS) (custodial settings like prisons, immigration removal centres, police custody, children and young people's secure estate etc. as well as those in contact with the CJS in the community)
- people with drug or alcohol misuse including those in contact with drug and/or alcohol treatment services;
- people with mental health needs
- homeless people
- as well as other minority or vulnerable groups who share a common feature of being currently under-served by primary and secondary healthcare services because of a lack of access or other issues

These groups are not mutually exclusive and there are often overlapping health and social care needs exist such as unemployment, homelessness, indebtedness, poverty and lack of recourse to public funds (figure 1.1). This brings into play engagement with other organisations, not only in the health sector but also local government, third sector organisations and charities, social care providers, housing associations and others at national, regional and local level. There is also a need to ensure programmes are informed by the needs of the population they serve - that we listen to the 'patient voice' and the 'lived experience' of service users and their families.

Figure 1.1: Overlapping groups of USPs with multiple complex needs [4]



Homeless people

1.2 Routinely collected data for USPs

Currently, the Enhanced TB Surveillance system (ETS) only collects a limited amount of data relevant to the description included in the definition of USPs.

Data are collected on the presence or absence of four social risk factors (SRF) known to increase the risk of TB:

- current¹ or history² of drug misuse
- current alcohol misuse
- current or history of homelessness
- current or history of imprisonment³

A detailed definition of each SRF can be found in Appendix 1

In addition, data are collected on the following factors:

- unemployment
- TB rates by area level deprivation
- country of birth and year of entry to the UK
- remanded in an immigration removal centre
- asylum seekers

Data in this chapter, with the exception of area level deprivation, are presented for TB cases aged 15 years and older. Data are presented from 2010 (when the social risk factors were included in ETS) until 2015. Additional data tables can be found in <u>Appendix 1</u>.

1.3 Social risk factors in notified TB cases

In England, between 2010 and 2015, 9.7% (3,474/35,816) of all notified TB cases aged 15 years and older had at least one SRF (figure 1.2, <u>Appendix 1</u> table A1.2)

Between 2010 and 2015:

- 3.3% (1,252/38,353) had current or a history of drug misuse
- 3.6% (1,353/37,902) had current alcohol misuse
- 3.2% (1,236/38,561) had current or a history of homelessness
- 3.2% (1,191/37,428) had current or a history of imprisonment

¹ Current for all SRFs refers to when first seen for TB or while in the care of the case manager notifying the patient

² History for all SRFs is collected separately for having that risk factor in the last 5 years or more than 5 years ago

³ For London TB cases a history of imprisonment is only recorded if imprisonment was in the UK, which will lead to an underestimate of the total number of cases with any history of imprisonment.

In 2015, a total of 11.8% (579/4,910) of TB cases had at least one SRF, compared with 9.8%, (538/5,517) in 2014. **Between 2014 and 2015, there was an increase in both the number and proportion of cases with each SRFs**; in 2015 4.3% (221/5,189) had current or a history of drug misuse, 3.9% (205/5,191) had current alcohol misuse, 4.4% (229/5,171) had current or a history of homelessness, and 3.9% (198/5,033) had current or a history of imprisonment (figure 1.2, table A1.2).

Almost one third (31.7%, 1,102/3,474) of cases with at least one SRF between 2010 and 2015 had more than one SRF, with 715 having two SRFs, 318 having three SRFs and 69 having all four SRFs. The proportion of cases with more than one SRF was highest in those with drug misuse (61.1), and lowest in those with alcohol misuse (44.7%) (figure1.3).





*Includes those aged 15 years and older

Figure 1.3 shows the proportion of cases with at least one SRF who had multiple SRFs, with the most common overlapping SRFs being those who had a current or a history drug misuse and imprisonment (6.2%, 215/3,474), those who had current or history of homelessness and current alcohol misuse (4.0%, 140/3,474) and those who had current alcohol misuse and current or a history of drug misuse (3.7%, 130/3,474).

Figure 1.3: Venn diagram showing the number of TB cases with overlapping social risk factors*, England, 2010 - 2015



* Includes those aged 15 years and older.

Please note that the proportion of TB cases with social risk factors is out of the total (N=3,474). The red circle captures those who are currently or have a history of homelessness, green captures those who are currently or have a history of imprisonment, blue captures those who currently have alcohol misuse, and yellow captures those with a current or history of drug misuse. Where timing of risk factor was recorded, 40.5% (313/772) had current drug misuse, 54.0% (445/824) were homeless and 26.8% (282/1,054) were in prison during the course of their treatment.

1.4 Demographic characteristics of USPs with TB and SRFs

The majority of cases notified between 2010 and 2015 with at least one SRF were male (82.5%, 2,864/3,471) and 62.9% (2,186/3, 474) were aged 15 to 44 years. The proportion of cases with at least one SRF was nearly four times higher in males (14.0%, 2,864/20,475) compared with females (4.0% 607/15,299) (table A1.4). The proportion of UK born cases with at least one SRF was 2.6 times higher compared with non-UK born cases (18.2%, 1,523/8,359 versus 6.9%, 1,858/26,882) (figure 1.4, table A1.4). A higher proportion of UK born cases than non-UK born cases had each of the four SRFs. There were more non-UK born cases (802) than UK born cases (404) with current or a history of homelessness (figure 1.4, table A1.4).



Figure 1.4: Number and proportion of TB cases with social risk factors* by place of birth 2010 - 2015

■UK born ■Non-UK born ■Proportion of cases (%)

* Includes those aged 15 years and older

1.5 Geographical distribution of USPs with TB and SRFs

Between 2010 and 2015, there was considerable geographical variation in the number of TB cases with at least one SRF by local authority (figure 1.5, table A1.1).

- in addition, each of the four SRFs had a different geographical distribution. Between 2010 and 2015, the South West (12.4%, 167/1,345) had the highest proportion of TB cases with at least one SRF and the East of England had the lowest proportion (8.1%, 190/2,340)
- in 2015, the South West (13.9%, 32/230) and the North West (13.8%, 59/426) had the highest proportion of TB cases with at least one SRF (table 1.1)

Figure 1.5: Number of TB cases with at least one social risk factor* by local authority, England, 2010 - 2015 (box shows enlarged map of London area)



*Includes those aged 15 years and older

PHE Centre**	Drug misuse		Alcohol misuse		Homeless		Prison		At least 1 SRF		2 or more SRF	
	n	%	n	%	n	%	n	%	n	%	n	%
London	602	3.6	636	4.0	582	3.5	433	2.6	1,563	10.0	477	2.8
West Midlands	171	3.6	147	3.1	112	2.3	182	3.9	425	9.5	141	2.7
South East	87	2.3	112	2.9	129	3.4	117	3.2	307	8.5	91	2.2
North West Yorkshire and	110	3.3	143	4.2	117	3.4	136	4.3	326	10.8	125	3.1
the Humber	85	2.9	87	3.0	84	2.9	104	3.8	247	9.4	84	2.6
East of England	69	2.8	64	2.6	67	2.7	84	3.5	190	8.1	70	2.6
East Midlands	39	1.8	57	2.5	67	3.1	65	3.2	168	8.6	46	1.8
South West	64	4.2	72	4.5	54	3.5	41	3.0	167	12.4	43	2.5
North East	25	3.2	35	4.4	24	3.1	29	3.8	81	10.9	25	3.0

Table 1.1: Number and proportion of TB cases with social risk factors* by PHE Centre, England, 2010 – 2015

* Includes those aged 15 years and older

** Ordered by decreasing total number of TB cases in 2015

Key points from Table 1.1

- between 2010 and 2015, London had a higher proportion of TB cases with drug misuse, alcohol misuse and homelessness compared to the national average, including a high proportion of cases with 2 or more SRFs (table 1.1)
- the West Midlands had a high proportion of TB cases with drug misuse and a history of imprisonment
- the South East had lower proportions of cases with SRFs compared to the national average, other than history of imprisonment which was the same as the national average.
- the South West had the highest proportion of TB cases with at least one SRF, and high proportions in drug misuse, alcohol misuse and homelessness
- the North West had a high overall proportion with at least one SRF, and high proportions of TB cases with alcohol and a prison history
- Yorkshire and Humber had a lower than average proportion of cases with at least one SRF, and low proportions in all risk factors except prison.
- the North East had high proportions of alcohol misuse and prison
- the East of England had the lowest proportion of TB cases with at least one SRF, and low proportions in all risk factors except prison

1.6 Clinical characteristics of USPs with TB and SRFs

Between 2010 and 2015, a higher proportion of cases with at least one SRF had a previous history of TB compared to cases with no known SRFs (9.3%, 342/3,287 versus 6.3%, 2,049/31,866). The majority (76.9%, 2,668/3,471) of cases with at least one SRF had pulmonary TB (figure 1.6, table A1.4). Almost half (48.2%, 1,541/3,200) of cases with at least one SRF received DOT, compared with just 6.1% (1,845/30,264) of those without any SRF.

The proportion of pulmonary cases notified between 2010 and 2015 with at least one SRF that experienced a delay of more than four months from symptom onset to treatment start (28.1%, 573/2,036) was similar to those without a SRF (28.9%, 3,619/12,522) (table A1.4). Sixty one percent (84/137) of TB cases notified after 02/07/2015 (when variable was introduced to ETS) with at least one SRF were current smokers, compared to 13.0% (130/999) of cases without any SRFs.

1.7 Drug resistance among USPs with TB and SRFs

The proportion of TB cases with drug resistance is higher among those with at least one SRF compared to those without a SRF. 8.3% (210/2,533) of TB cases with at least one SRF were resistant to isoniazid without MDR-TB compared to 5.3% (1,005/19,066) of those without a SRF. 2.4% (63/2,594) of TB cases with at least one SRF had initial MDR/RR-TB, compared to cases without any SRFs (1.6%, 315/19,340) (figure 1.6).





^{*}Includes those aged 15 years and older

1.8 TB outcomes among the USPs with TB and SRFs

TB outcomes in cases with at least one SRF are worse than those without a SRF. Between 2010 and 2014, treatment completion was lower for drug sensitive cases with at least one SRF (79.5%, 2,254/2,835) compared to drug sensitive cases without a SRF (89.3%, 24,738/27,717) (figure 1.7, table A1.5). A higher proportion of drug sensitive cases with at least one SRF had died, were lost to follow-up or had treatment stopped at their last recorded outcome compared to cases without SRFs. The proportion of cases that had died at their last recorded outcome was more than two times higher in those with alcohol misuse (10.2%, 115/1,127) compared to those with no alcohol misuse (4.0%, 1,249/31,215) and almost double in those with current or history of homelessness (6.9%, 67/977) than those with no history of homelessness (4.2%, 1,357/32,034).





Figure 1.8: Last recorded TB outcome for drug resistant cohort by two SRF*, 2010 - 2013, England (*includes those aged 15years and older)



For MDR/RR-TB cases notified between 2010 and 2013, 60.0% (30/50) of those with at least one SRF had completed treatment by the last recorded outcome compared with 74.9% (182/243) of those with no SRFs (figure 1.8, table A1.6). The proportion of drug resistance TB cases with at least one SRF who died (10.0%, 5/50) was five times higher than in those with no SRFs (2.1%, 5/243). Almost twenty percent 18%, (9/50) of drug resistant cases with at least one SRF were lost to follow up at the last recorded outcome.

1.9 TB cases that were unemployed, asylum seekers or resident in an immigration removal centre

Between 2010 and 2015, 16.4% (6,141/37,543) of TB cases were recorded as being unemployed at notification. Nearly thirty percent (29.3%, 1,573/5,366) of those unemployed had at least one SRF. Between 2010 and 2015, 263 TB cases were recorded as being asylum seekers; the most frequent countries of birth were Eritrea (59), Afghanistan (26), Pakistan (23), Zimbabwe (21), Sudan (18) and Somalia (16). 58 asylum seekers with TB were notified in 2015. A total of 81 TB cases were recorded as being in an immigration removal centre between 2010 and 2015 (range 7-19 per year), seven of whom were notified in 2015.

1.10 Deprivation

In 2015, the rate of TB was 20.5 per 100,000 in the 10% of the population living in the most deprived areas compared with only 3.6 per 100,000 in the 10% of the population living in the least <u>deprived areas</u> [5], with a clear trend of an increasing rate of TB with increasing deprivation (figure 1.10).





1.11 Data challenges for USP, TBCBs and TB stakeholders

The ETS system is the primary national surveillance system which collects TB notifications and the relevant epidemiological, clinical and microbiological information required to understand the epidemiology of TB in England including USP groups. More detailed data tables are presented in <u>Appendix 1</u> and are published each year in the <u>TB</u> <u>Annual Report 2015</u> [6].

While ETS has many positive attributes there are challenges for those trying to address the needs of USPs. These challenges include:

- The need to import data for London from the London TB Register (LTBR), which collects data on some SRF variables differently (for example in LTBR prison data is only collected for UK prisons, while in ETS data are collected for prisons in the UK and abroad). In contrast, the LTBR collects data on mental health issues whereas ETS does not
- 2. The web page layout and underlying database tables are not ideal for the collection of data on asylum seekers and those detained in IRCs. This information is collected in the occupation section, which is not intuitive and may lead to under-reporting of these factors.
- 3. ETS and LTBR are due to be replaced by one national surveillance system (NTBS) in the next few years. During the development phase of NTBS, there will be an opportunity for a review of the data relating to USPs. This review will include:
 - a. what is collected to ensure it fully captures as many factors as possible to describe TB in USPs (eg ETS currently collects no information on mental health, or other minority groups such as gypsy or traveller populations)
 - how data is defined (eg ETS currently collects data on those in whom alcohol misuse affects their ability to self-administer TB treatment and not all those who misuse or abuse alcohol)
 - c. where in the new system data should be collected (eg should asylum seeker and IRC detainees be captured on the SRF page rather than as a sub-category of occupation)
- 4. Data linkage systems are needed between ETS and other systems that collect data on USPs. These include:
 - a. Prison incidents data (Health and Justice, PHE)
 - b. Find and Treat data
 - c. Data collected on those who are in contact with drug and alcohol treatment services through the PHE <u>National Drug Treatment Monitoring</u> <u>System (NDTMS)</u> [7].

Other datasets and data collection processes may bring together relevant information which taken together could form a more comprehensive picture of USPs including:

- <u>JSNAs [</u>8]
- Public Health Outcome Framework Indicators [9]
- range of data and intelligence resources available from PHE [10]
- TB cohort review data available at a local level [11]

It is likely that further work on USPs will be required at TBCB level to consider whether or not the entire population of interest are included in their data and if not, how to address this gap.

1.12 Measuring success for TB control among USPs

Important metrics for the National TB team and TBCBs to consider in assessing the success of their strategies to tackle TB in USPs include:

1. **Proportion of USPs completing treatment successfully** (for both drug sensitive and drug resistant TB)

2. Proportion of TB cases among USPs on DOT/VOT

People with multiple complex needs may find adherence to TB treatment more challenging. Supporting treatment through DOT is an important component of a successful treatment programme. VOT (video-observed therapy) may offer a more flexible service if patients have access to appropriate Smartphone technology (personal communication - Andrew Hayward and Alistair Story)

3. Decrease in time from onset of symptoms to treatment start date among USPs

4. The number of new diagnoses of TB made among people defined as USPs A successful strategy aimed at this population should ultimately see a decrease in the number and proportion of TB cases with SRFs year-on-year. If improvements to data collection are made to ensure that all cases with SRFs are recorded as having a SRF, and if improvements are made in diagnosing TB within these populations through active case finding or better access to services, an initial increase in numbers is likely to be observed.

Chapter 2: Under-served migrants in the UK

2.1 Defining under-served migrants in the UK

In 2015, approximately 13% of the UK population were <u>born abroad</u> [12] and 630,000 <u>people migrated</u> [13] to the UK, primarily to work or study. The majority of migrants living in the UK are young and healthy, but some bear a disproportionate burden of ill health. Migrants living in the UK are a diverse population with some migrants particularly vulnerable due to influences such as the conditions in their country of origin, their reason for migration, migration journey, legal status and social determinants of health in the UK. Migrants can become vulnerable for a number of reasons and underserved migrants may include individuals who are undocumented, asylum seekers, refugees, refused asylum seekers, unaccompanied minors, victims of trafficking and those with no recourse to public funds.

A useful description of some key terms used in relation to the migrant population in the UK is provided in table 2.1, alongside an overview of the number of migrants travelling to and living in the UK.

Term	Definition	Population living in the UK
Accompanying another	Those migrating to the UK where the main reason is to join or accompany others. This can include those arriving to marry a UK citizen and family members of other migrants.	In 2015, 73,000 people [13] came to the UK to accompany or join others
Asylum seeker or applicant	An asylum seeker or applicant [14] is a person who has applied for protection as a refugee and is awaiting a decision on their claim	From July 2015 to June 2016 [14] there were 36,465 applications for asylum (main applicants) with the largest number of applications coming from nationals of Iran, Iraq, Pakistan, Eritrea, Afghanistan and Syria
Immigration detainee	Individuals are usually detained in order [14] to: establish a person's identity or basis of claim; effect a person's removal from the UK; or where there is reason to believe that the person will fail to comply with any conditions attached to a grant of temporary admission/release	Between July 2015 and June 2016, 31,596 people entered the immigration detention estate[13]. The majority of detainees leaving the detention estate during this time had been in detention for under two months. At the end of June 2016, 2,878 were residing in the immigration detention estate.
Migrant worker	Those migrating to the UK where the main reason for migration is to work (both those with a definite job and those looking for work)	Approximately 308,000 people came to the UK to work in 2015

Table 2.1: Terminology relation of migrants living in the UK and estimated numbers

Refugee	A refugee [14] is a person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his/her nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country	From July 2015 to June 2016, 3,439 people were resettled [13] through one of the UK resettlement schemes
Refused asylum	An individual whose 'asylum	As of May 2016, 47% of asylum
seeker (also referred	application' [15] has been unsuccessful	applications in 2015 (where the outcome
to as failed asylum seekers)	and who has no other claim for protection awaiting a decision. Some refused asylum seekers voluntarily return home, others are forcibly returned and for some it is not safe or practical for them to return until conditions in their country change	was known) were refused or withdrawn[14] (9,168). Subsistence and accommodation is provided to destitute asylum seekers and their dependents unable to immediately leave the UK (Section 4 support); at the end of June 2016 this was being provided to 3,732 people
Student	Those migrating to the UK where the main reason is to undertake formal study	Approximately 167,000 people came to the UK [13] to study in 2015
Unaccompanied asylum-seeking child (UASC)	A person under 18, or who, in the absence of documentary [14] establishing age, appears to be under that age, is applying for asylum on his or her own right and has no relative or guardian in the United Kingdom	Approximately 3,472 UASC applied for asylum from [14] July 2015 to June 2016
Undocumented/ irregular migrants	'The term 'irregular migrants' [16] typically refers to migrants living in a country who are not entitled to reside there, either because they have never had a legal residence permit or because they have overstayed their time-limited permit	Good quality estimates of the number of undocumented [17] or irregular migrants are lacking, but it is estimated that between 417,000 and 863,000 undocumented migrants are living in the UK
No recourse to public funds (NRPF)	Information is available from homelessness chapter along with TB patient pathway to accommodation and Appendix 3 checklist for accommodation for TB patient NRPF	Section 115 Immigration and Asylum Act 1999 in chapter 5 Health and Justice

2.2 The burden of TB among migrants in England: active TB disease

The rate of TB in the non-UK born population in England has declined over the past decade (figure 2.1), but it still remains 15 times higher than the rate in the UK born population. The non-UK born population therefore bear a disproportionate burden of disease, accounting for 72.5% of all cases reported in <u>England in 2015</u>] (where country of birth was known).



Figure 2.1: TB case notifications and rates by country of birth 2000-2015

The risk of TB among migrants living in England is influenced by a number of factors including the rate of TB in their country of origin, the circumstances of migration (including their journey), their legal status and living conditions in England, as well as other clinical conditions (for example, HIV co-infection).

In 2015, India, Pakistan, Bangladesh and Somalia were the most frequent countries of birth for non-UK born cases notified in England (see table 2.2). This is consistent with previous years, however, there has been a decrease in the number of cases born in these countries in the <u>past three years</u> [6] (see figure 2.2). The decline in the number of cases in the non UK-born population has occurred particularly among new migrants, and 60% of non-UK born TB cases now occur among those who have lived in the UK for more than six years.

Figure 2.2: Trend in TB case notifications for the top five countries of birth of non-UK born cases, England, 2006-2015^{*} (*Five most frequent countries of birth in 2015.)



In 2015, the <u>highest rates of TB</u> [22] in the non-UK born population were in the West Midlands (62.3 per 100,000), Yorkshire and the Humber (59.8 per 100,000), and North East (58.3 per 100,000).

Country of birth	Number of cases	Proportion of cases (%)*	Median time since entry to UK in months (IQR)**
United Kingdom	1,550	27.8	-
India	1,056	19.0	8 (3-18)
Pakistan	638	11.5	10 (4-25)
Bangladesh	210	3.8	10 (5-22)
Somalia	177	3.2	11 (5-16)
Nepal	126	2.3	5 (3-8)
Nigeria	118	2.1	8 (4-13)
Romania	118	2.1	1 (0-5)
Philippines	105	1.9	9 (5-14)
Zimbabwe	102	1.8	13 (11-14)
Eritrea	91	1.6	1 (0-6)
Poland	72	1.3	5 (2-9)
Afghanistan	69	1.2	8 (4-14)
Kenya	60	1.1	18 (10-43)
Sri Lanka	57	1.0	9 (5-16)
Other (each <1%)	1,023	18.4	9 (3-19)
Total*	5,572	100.0	9 (3-16)

Table 2.2: Most frequent countries of birth for TB cases and time between entry to the UK and TB notification, England, 2015

* Where country of birth was known ** Years, IQR refers to interquartile range

2.3 New entrant latent TB infection testing

The majority of active TB cases diagnosed in England are a result of reactivation of LTBI. The incidence of LTBI in immigrants can vary widely but Pareek et al. (2011)[23] reported a point prevalence of 20% (95% CI 18-22%) in a UK based study testing immigrants for LTBI in the UK.

Migrants are a very diverse group and it is currently not known how many of them have substantial barriers to accessing services. Not all migrants register in primary care and recent estimates are as low as 32.5% primary care registration amongst recent migrants [24]. LTBI testing for new entrants from high incidence areas [25] is an effective and cost-effective public health intervention and is recommended by NICE. As part of the <u>Collaborative TB Strategy for England</u> [2] CCGs, prioritised by TB incidence and burden, are rolling out LTBI testing and treatment for new migrants. It is expected to significantly decrease the incidence of TB in England in the longer term. However it may not be able to achieve high uptake rates amongst under-served migrants.

2.4 Challenges for TBCBs working with migrant populations

PHE conducted a survey of TBCBs in 2016 to identify specific challenges associated with tackling TB among USPs including migrant populations (see Appendix 2). The survey highlighted the following as particularly problematic in relation to new migrants:

• referral pathways for accommodation and treatment for those with no recourse to public funds (NRPFs)

Although TB treatment is free in the UK, those with NRPFs (eg undocumented migrants, or refused asylum seekers) will not normally have access to welfare payments, local authority/housing association accommodation or social care services. It was reported in the survey that these issues can influence a person's ability to successfully complete treatment and may also increase the public health risk they pose to others due to prolonged periods of infectivity.

treatment adherence and provision of Directly Observed Therapy (DOT)
 In the UK DOT is recommended for the treatment of patients with MDR-TB, those
 have been treated previously for TB and patients in unfavourable social
 circumstances. DOT is a well-established method to ensure treatment adherence
 [26]. ETS data shows that between 2010 and 2015, 48.2% (1,541/3,200) of TB
 cases with at least one SRF received DOT (See <u>Appendix 1</u>: table A1.4). It was
 reported in the survey that the provision of DOT can be problematic; especially in
 more rural areas with poor transport links, but also in large metropolitan areas
 where it can be a struggle to deliver DOT to all patients who would benefit. It was
 reported that vulnerable migrants are particularly impacted if they have NRPF
 and insecure accommodation.

• treatment - patients who refuse treatment ("refuseniks")

The survey highlighted the issue of a small but significant number of patients with pulmonary TB who refuse to take treatment or who 'stop/start' treatment. These patients often have multiple complex needs, including alcohol and/or drug dependence and/or mental health needs and/or insecure accommodation. It was reported that this issue often goes to the limit of where public health legislation can take management of such individuals, as the law allows for such people to be appropriately detained, but NHS facilities are often not available to accommodate someone for an indefinite period of time who has no intention to commence or adhere to treatment. There is a potential public health risk associated with such individuals both in terms of transmission and emergence of drug resistance (if they stop/start treatment). Management usually requires addressing the substance misuse and/or mental health and social care needs before addressing TB treatment so effective partnership work is required.

• late diagnosis of TB

Late diagnosis of TB can affect the prognosis for the individual and increase the public health risks. It was reported in the survey that late diagnosis can be a problem in relation to the migrant population and that barriers to a timely diagnosis can include stigma, difficulties accessing healthcare and a fear that a positive diagnosis may affect their right to remain in the UK (particularly for undocumented migrants or asylum seekers). For some, TB may also be associated with advanced HIV infection (late diagnosis of HIV infection is a <u>Public Health Outcome Framework Indicator</u> [22]).

• a need for further information about the TB burden among under-served migrant populations

At a local level some migrant communities may not always be visible to services, for example fruit pickers. Country of birth is therefore frequently used as a proxy, but does not reflect whether the individuals diagnosed with TB are migrant workers, students or undocumented migrants for example. There is also a lack of information about comorbidities among migrants, for example HIV, and comorbidities can have implications for detection and treatment. Data on co-morbidities have now been included for collection in ETS.

• language, cultural and information barriers

It was reported that these barriers can prevent effective diagnosis and treatment for vulnerable migrants, due to a lack of knowledge of TB, stigma and a lack of understanding around entitlements to access healthcare (both by the individual and healthcare providers). The understanding of TB is also related to culture and easier access to <u>interpreting services</u> [27] is required. Stigma has been recognised <u>as a barrier</u> [28] and it can impede contact tracing among <u>certain</u> <u>migrant communities</u> [27].

• follow-up and continuity of care

This has been reported to be problematic, between different locations and providers if individuals are moving between IRCs, initial accommodation centres for asylum seekers, 'dispersal' areas and the community.

2.5 Recommendations and resources for TBCBs and their partners working with under-served migrants

1. TBCBs are encouraged to review epidemiological data at local level Review, using the expertise of the PHE Field Epidemiology Service, the profile of local migrant populations and those with TB to decide if focussed work with particular groups is warranted.

2. TBCBs, CCGs, primary and secondary care providers to consider how best to reach out to migrant groups at risk of TB locally and to raise awareness of TB and the services available

Consideration to be given to raising awareness of TB among:

- migrant community groups (see Exemplar 2.4 (E2.4))
- healthcare providers including those in primary care
- other organisations working with the under-served migrants including those seeking asylum (see E2.1)
- local government providers of services to new migrants (see chapter 7)

To support TB awareness raising TBCBs to encourage greater use and dissemination of TB awareness raising materials, slide sets and multi-lingual literature using the:

- TB Alert 'Truth About TB' <u>TB leaflets</u> (see E 2.1)
- TB Alert 'Truth About TB' professional resources and slide sets
- PHEs TB web pages
- Migrant Health Guide
- National Knowledge Service leaflet <u>'TB: Information for staff working with</u>
 <u>people seeking asylum'</u>

Consideration should be given to increasing availability of appropriate interpreting services via "language line" or employing staff with the necessary language skills to improve new migrant access and use of services (see E2.7).

3. Community awareness raising by local TB nurses

Encourage local TB nurses to run TB information sessions with primary care and community groups working with new migrants to raise awareness of TB generally. The sessions could aim to raise awareness of TB in general and to share information on local LTBI testing programmes if appropriate (see E2.6). TBCBs should encourage use of the nationally developed <u>TB Specialist Nurse</u> <u>Resource pack</u>, a set of slides for TB nurses to use and adapt when raising awareness of TB among GPs and migrants.

4. Involve the third sector and community groups to reach out to migrants

Work to improve the understanding and engagement of third sector and community groups with health services and encourage partnership (see chapter 9). This might be through the provision of information, training of key workers to raise awareness about TB generally, but also about the new entrant LTBI testing and treatment programme or support to targeted work with particular groups (see E2.5). Community health workers from the same migrant communities could assist with promoting <u>TB screening and coordinating contact tracing</u> [29] (see E 2.3).

- 5. TBCBs and CCGs to consider the need for specialised primary care or community based services to support refugees and asylum seekers particularly in areas with high numbers of patients and then via these raise awareness of TB. Previous studies and exemplars of good practice (see exemplars 2.1 to 2.4) could be used to inform the planning of services to ensure that refugees, asylum seekers and undocumented migrants complete treatment.
- 6. TBCBs, CCGs, NHS England commissioners and patient representatives to work to improve registration of migrants with primary care (see E2.2 to E2.5). This would facilitate mutual understanding and help address barriers to healthcare access in general but also to TB diagnostic and therapeutic services. This could also involve improving awareness in healthcare staff of a migrant's entitlement to healthcare and other services.
- 7. CCGs, primary and secondary care providers to work to increase the uptake of LTBI testing and treatment among new migrant USPs to increase test uptake. Encourage CCGs and primary and secondary care to use the TB Alert / PHE LTBI toolkit [30] and its recommended resources which provides guidance for providers of new migrant LTBI testing and treatment programmes. The toolkit also provides details on how to maximise the uptake of LTBI testing and treatment and make the programmes patient focussed to ensure maximum retention of patients along the pathway.

8. TBCBs to consider inviting the PHE Centre Migrant Health Leads Group representative to join or advise the TBCB

PHEC all have experts on migrant health who collectively form the PHE Migrant Health Leads Group. TBCBs could use this expertise to support the development of programmes of TB work directed at migrants.

9. Joint Strategic Needs Assessments

TBCBs are encouraged to work with local DsPH and CCGs to ensure that vulnerable migrant populations and their needs are recognised and considered in local JSNAs, Joint Health and Wellbeing Strategies, and Sustainability and Transformation plans (STPs).

10. Consider recommendations in housing chapter on meeting the needs of new migrants who have NRPFs

2.6 Exemplars of good practice on working with vulnerable migrant populations

E 2.1: The Asylum Screening Service - working with asylum seekers in Stoke and Staffordshire to support TB diagnosis and treatment

The Asylum Screening Service is a joint project between primary and secondary care in the West Midlands. The Asylum Service refers patients to an "asylum seeker nurse" who runs community based clinics supporting the health needs of asylum seekers. The asylum seeker nurse assesses the patient for active TB and undertakes an IGRA test for LTBI, among other tests. Language line is used as required. If the patient is either symptomatic for active TB or has a positive IGRA the asylum seeker nurse refers the patient to a "designated asylum seeker TB clinic" run by TB nurses in a community setting where CXRs and a full clinical review are undertaken.

For those individuals with LTBI, routine bloods and a blood-borne virus screen are performed. The TB nurse discusses TB and provides language appropriate written information from TB Alert. Patients then collect three months of treatment and their details are passed back to the "asylum seeker nurse" who will monitor compliance in the community and refer back to the TB service should there be any concerns. The "asylum seeker nurse" advises the TB service on completion of treatment or of non-compliance with treatment, if this arises. For those individuals who are investigated for active disease the TB nurse supports them through this process and if started on active TB treatment those patients remain the responsibility of the TB service. A small incentive is provided to the attending asylum seeker on production of a bus ticket and a valid HC2 certificate and individuals are reimbursed for their travel.

Project Leads: Dr Sven Lehm and Amanda Middleton (TB Nurse) **E-mail:** sven.lehm@uhns.nhs.uk and amanda.middleton@uhnm.nhs.uk

E 2.2 Specialist primary healthcare care service for asylum seekers and refugees

A latent TB testing programme for migrants who arrived in the UK in the last 5 years and live in high incidence areas of Bristol (≥20 per 100,000) is currently being rolled out via primary care. 'The Haven', a specialist primary healthcare service for asylum seekers and refugees, provides IGRA testing and onward referral to TB services. This service has existed for some years and is now linked into the wider LTBI testing and treatment programme being rolled out by Bristol CCG.

Project Lead: Helen Trudgeon, Email: Helen.Trudgeon@phe.gov.uk Website: http://briscomhealth.org.uk/our-services/haven/

E 2.3 LTBI screening in primary care for refugees and asylum seekers

The Meridian Practice is a specialised GP practice for refugees and asylum seekers in Coventry. They register asylum seekers and refused asylum seekers. All patients on registering have a detailed nurse assessment with screening for blood-borne viruses and LTBI using an IGRA test.

Patients with a positive IGRA are seen by the GP, assessed for TB symptoms and sent for a CXR before being referred to the TB Coordinator at University Hospital, Coventry for further assessment and management of either latent TB or active TB. The TB nurse team initiates and manages prophylactic and therapeutic TB treatment. The specialised GP practice team makes a point of supporting patients to get to hospital appointments.

Project Lead: Dr Alison Callaway, GP Clinical Lead Meridian Practice **Email:** alison.callaway2@nhs.net

E2.4 The Doncaster health bus - reaching refugees and asylum seekers

The health bus in Doncaster is managed by Rotherham, Doncaster and South Humber NHS Trust and is used by different health teams. The local TB team started to use the bus in 2015 and visit the 'Conversation Club'. This is a weekly group for refugee and asylum seekers who want to practice their English and get more support.

Doncaster is not a 'high-incidence' TB area so has not attracted funding as part of the national LTBI programme. However, it does have areas of high TB incidence which the TB team are trying to address. The health bus is parked outside the 'Conversation Club' on a bi-monthly basis and the TB team test refugees and asylum seekers who may find accessing health care difficult. The team use IGRA tests to test for LTBI and during April 2015 to March 2016 (6 sessions) tested 104 individuals finding an overall IGRA positivity rate of 27%. Of the 28 positive tests 82% have completed or are currently undergoing treatment.

Challenges encountered included: (i) language barriers and understanding; (ii) not registered with a GP; (iii) limited space on the bus; (iv) transient population; (v) religious beliefs.

Positive lessons learnt: (i) target group already gathering in one place; (ii) face-to-face language help is available; (iii) ability to screen a large group in one session; (iv) people can drop in without an appointment; (v) point of contact for follow-ups; (vi) word of mouth is a powerful tool.

Project Lead: Katie Jenkins, TB nurse, RDaSH Email: Katie.Jenkins@rdash.nhs.uk

E2.5 Latent TB infection case-finding among ESOL students

In 2014 PHE co-ordinated a pilot project on LTBI case finding among Birmingham ESOL (English for Speakers of Other Languages) students. Funding of £30,000 was provided by PHE to support delivery of the project, mainly to cover costs of IGRA testing and third sector involvement.

The project involved awareness-raising and testing for LTBI. Information sessions for college staff were delivered by TB nursing and medical staff from Birmingham Chest Clinic and PHE. The project was introduced to students in March 2014 during the college's annual 'Staying Safe Week'. Two local charities supported the event by providing information on TB, the screening programme and general health messages such as registering with a GP. Teachers, in collaboration with Birmingham Chest Clinic, developed TB teaching resources that included a teaching module for ESOL classes and electronic interactive resources for students available on the college intranet. The charities also delivered more than 30 one-hour long workshops to small groups of students, and one charity recruited and trained local champions (10 health and social care students) to help promote the programme. On the days of testing the charities also helped recruit students for testing.

Over four days in April 2014, LTBI testing using IGRA was done on site at two ESOL colleges. Those tested included ESOL students from high-incidence countries aged 16-35 years who had entered the UK within the previous 5 years. For pragmatic reasons on the days of testing, any ESOL student aged 16-35 years was offered an IGRA test (on the assumption that most would have been recent entrants from high incidence countries). TB nurses and PHE staff administered pre-test health screening questionnaires which included assessment of eligibility. Phlebotomists from a commercial company were on site to collect the blood samples and transport them to the laboratory. Of 588 eligible students, 440 were tested (almost 75% uptake). The median time since migration to the UK was four years and students attended from 105 different countries. 71 (16%) tested positive and were referred to the TB clinic; 53 started LTBI treatment; and 46 (87%) of these completed. Two cases of extra pulmonary TB were identified and one child treated for pulmonary TB. Over 90% of those screened were pro-actively registered with a GP. In addition to screening for TB, BBV testing was offered and of 64 tested, six cases of previously undiagnosed hepatitis B and one case of hepatitis C were detected.

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E 2.6: TB screening in unaccompanied asylum seeking children in Birmingham and Solihull

Birmingham and Solihull TB Services have screened around 60 'Unaccompanied Asylum Seeking Children' (UAASC) over the last 12 months. Referrals were received via Birmingham and Solihull Community Paediatric 'Looked after Children (LAC)' service. This screening does not receive specific funding but is agreed locally.

Future collaboration is planned between the Birmingham and Solihull TB service and Birmingham and Solihull Community Paediatric Services who currently do initial assessments. The LAC service examines children and young people and refers to the TB service for symptom screen and testing. They also arrange screening for HIV, hepatitis B and C where required. The collaboration will look into the processes needed to improve access to health services for the UAASC. They will also assess the feasibility of a single blood test to screen for TB and BBV by the Birmingham and Solihull Community Paediatric Services.

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E 2.7 Cultural link worker in Leicestershire TB service

The post of Cultural Link Worker for the TB service was created in 2010 as part of the TB nursing service development plan in Leicester, Leicestershire and Rutland TB Service. It had long been recognised that in order to provide a culturally competent service there was heavy use of external interpreting and translation services and a business case was submitted to develop a new in-house role. There had already been active recruitment of a specialist team of nurses with diverse language skills, however, it was identified that there remained a need for a peer support role (Band 4) to provide better patient advocacy. The aim was to develop stronger links with communities where TB has the highest impact locally. The role was modelled on a post created by the Children's Diana Team where a Cultural Link Worker developed close working relationships with families to deliver sensitive, appropriate treatment care plans in a collaborative way.

Purpose: The job role was developed to assist patients and families served by the TB Nursing Service by facilitating communication between patients; families; healthcare staff and other allied professionals, helping to overcome potential language or cultural barriers that may be an obstacle to effective use of, or access to, the service.

Role and responsibilities of the link worker: Key elements of this role are: (i) to act as an advocate for patients and families; (ii) to ensure effective dialogue between non English speaking families and providers of health care and other services; (iii) provide education and training for internal staff and staff from other organisations, in relation to cultural and religious awareness; (iv) to be an autonomous practitioner, not always directly supervised during patient visits; (v) to plan own work load within the needs of the service.

On a practical level, the Cultural Link Worker fulfils a highly valued role that is now integrated into the day to day practice of the TB team. Key activities include; (i) accompanying specific patients attending outpatient appointments; (ii) joint home visiting with the specialist TB nurses; (iii) where a need is identified, accompanying patients for investigative/ medical procedures eg bronchoscopy / PEG insertion; (iv) supporting treatment programmes by delivering DOT to specific patients; (v) supporting treatment programmes by helping patients access resources and by signposting to other organisations; (vi) raising TB awareness by linking with community groups and providing information and education about TB; (vii) individual patient advocacy, with employers or other agencies; (viii) facilitating patient experience events and patient feedback activities.

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Chapter 3: People in contact with the criminal justice system

3.1 Defining people in contact with the criminal justice system

The definition of people in contact with the criminal justice system (CJS) includes those not only in custodial settings (like prisons and Young Offenders Institutions (YOI)) but also those in the community under supervision of probation services or in contact with the police (as evidenced by a 'police record' on the Police National Computer system). The range of people included in the definition covers children in the Children and Young People's Secure Estate (CYPSE) and migrants in immigration detention. Of a total population of 57.9 million people [31], the current standing prison population in England and Wales is around 85,000 with about 100,000 unique admissions per year [32]; a further 241,000 people are currently under supervision of probation services in the community [33] and about 1.7 million people per year are on the police national computer system following contact with the police (figure 3.1). This provides a large network of people defined in some way as being in contact with the CJS.

Figure 3.1: Segmentation of population defined as 'people in contact with the criminal justice system' in both community and custodial settings



People in contact with the CJS often have multiple complex needs including physical health, mental health and substance misuse as well as social deprivation such as unemployment, homelessness, indebtedness and lack of education (see figure 3.2). These people are often members of communities and social networks who are disproportionately affected by health inequalities. Therefore, working with people in

contact with the CJS is a way to engage effectively with wider parts of the community often described as 'hard-to-reach', vulnerable, excluded or marginalised.



Figure 3.2: Multiple complex needs among people in contact with the CJS

3.2 The burden of TB among people in contact with the CJS

Data on TB among people in contact with the CJS is limited primarily to those currently or with a history of imprisonment or immigration detention. People under probation supervision and those in contact with the police who have TB are not currently routinely reported on surveillance systems but there will be a significant overlap in these categories due to movement of people across the CJS from police custody, to court, to imprisonment and then under probation service supervision.

TB in prescribed places of detention in England: Prisons and other prescribed places of detention (PPDs) in England are required to report cases of TB to PHE's <u>National Health & Justice Team</u> [34]. In 2016, PHE's TB Surveillance Unit and the Health and Justice Team undertook improvement of data describing TB cases reported in PPDs for the years 2010 to 2015, inclusive. The data reported to Health and Justice by healthcare teams in prisons, immigration removal centres (IRCs) and other detention facilities including high-security hospitals based in England was matched to notified TB cases in the (ETS).

Data in this chapter is from both sources (Health and Justice surveillance and ETS). Data from Health and Justice surveillance are reported by year of reporting, while data from ETS are reported by year of TB notification. In 2015, 40 cases of TB were reported in PPDs across England including 26 cases of pulmonary TB and 14 cases of extrapulmonary TB (figure 3.1). The majority (30/40) of TB cases reported in 2015 were in prisons with the remainder reported in IRCs (10/40) (figure 3.2).

Figure 3.1: Reports of notified TB cases (single incidents and those linked to outbreaks) among people in PPDs notified to PHE (2015).

30 Outbreak 1 25 3 Outbreak 2 3 Cases 20 Caese reported 20 15 3 10 11 5 0 Pulmonary TB, with or without extra-Extra-pulmonary TB only pulmonary TB

(Source: PHE National Health and Justice Team and ETS, PHE TB Surveillance Unit).

The number of TB cases diagnosed among people in prison has shown a decline since their peak in 2011 - 2012 (see figure 3.2). Two prison outbreaks were reported in 2015 (one with 3 cases and one with 6 cases) (figure 3.1), which is more than has been reported in previous years (1 outbreak in years 2010, 2011 and 2012).





The data presented from this point on refers to data collected through enhanced TB surveillance in ETS. TB cases with a current or a history of incarceration in a prison, and/or remand centre, juvenile institution or young offender's institution. It does not include immigration detention or removal centres.

Between 2010 and 2015, ETS data shows that the proportion of TB cases with current or a history of imprisonment has fluctuated between 2.8% and 3.9%. Where recorded, 26.8%, (282/1,054) of the TB cases reporting imprisonment were currently in prison at the time of diagnosis or during care, 38.3% (404) had been imprisoned in the five years prior to diagnosis (39 known to be abroad) and 39.8% (419) more than five years prior to diagnosis (64 abroad).

Age/sex profile of TB cases with history of imprisonment:

89.3% (1,064/1,191) of TB cases with current or a <u>history of imprisonment</u> [6] between 2010-2015 were male and 64.7% (771/1,191) aged 15 to 44 years.

Place of birth and ethnicity:

53.5% (620/1,159) of TB cases with a history of imprisonment were UK born and 66.2% (406/613) of UK born cases were of White ethnicity.

Delay in treatment initiation among people in prison is common: the highest proportion (31.3%, 237/757)) of cases with a SRF who experienced a delay in treatment initiation from onset of symptoms of more than four months was in those with current or a <u>history of imprisonment</u> [6]. However, restricting this to those who were currently in prison showed

that 26.9% (43/160) had a delay of more than four months. This delay not only increases the risk of transmission of infection to prisoners, prison staff and visitors but also the complexity of contact tracing exercises. In two recent prison TB outbreaks in the West Midlands (see E3.3), over a hundred contacts among current and former prisoners in England, Scotland and Wales had to be traced and tested.

Figure 3.5 Number of TB cases with <u>current or history of imprisonment</u> [6] by local authority, England, 2010-2015



Box shows enlarged map of London area. *Data is available in Table A1.1 Appendix1

3.3 Overlapping risk factors among people in contact with CJS

'In or near prison' populations have long been recognised as being at risk of TB, due to the over-representation of SRF among people passing through the prison estate. ETS data from 2010-2014 shows that 38.6% (385/998) of TB cases with current or history of imprisonment also had drug misuse, 26.5% (264) homelessness and 19.8% (198) alcohol misuse as other social risk factors. A landmark cohort study undertaken of all patients with TB living in London [35] who were or should have been on treatment on 1 July 2003 found evidence of overlapping 'membership' of TB cases in different SRFs groups (see figure 3.6).

Figure 3.6: Overlap between prisoners, problem drug users and homelessness among people diagnosed with TB in London 2003 [35]



3.4 Diagnosis and management of TB in prisons and other PPDs

Diagnosing active TB infection among prisoners and immigration detainees:

All prisons and IRCs have a health screening programme on reception to identify acute health needs including evidence of infectious diseases like TB. PHE has produced a range of resources to support identification <u>and management of TB among people in</u> <u>prisons</u> [36]. <u>NICE TB guidelines</u> [37] updated in 2016 also provide guidance to healthcare teams in_prisons on identifying TB. However, symptom-based guidance is problematic among prisoners (and wider CJS populations) due to overlapping risk

factors for signs classically associated with TB (eg productive cough over 3 weeks as about 80% of prisoners smoke; or weight loss/ night sweats, which can also be associated with drug use and/or poor nutrition and/or homelessness, all of which are common in prisoner populations). To address this, in 2008, the Department of Health funded a programme to install digital x-ray (DXR) machines in prisons. Five London prisons (HMPs Brixton, Belmarsh, Pentonville, Wandsworth and Wormwood Scrubs) and HMPs Birmingham, Manchester and Holme House had machines installed⁴. NICE recommend that prisons with Department of Health funded static digital X-ray facilities should X-ray all new prisoners and detainees (including those being transferred from other establishments) if they have not received a CXR in the last 6 months. This should take place within 48 hours of arrival. PHE Health and Justice have recently reviewed current use of DXR machines in prisons in England and found that only four of the eight machines are currently in use with the rest scheduled to resume service within the year. However, none of the DXR machines are being used in accordance with current NICE guidelines (ie have not implemented universal screening) (table 3.2).

Prison	Currently in use	NICE guidance compliant	
Belmarsh	X	Х	
Brixton	\checkmark	Х	
Pentonville	Х	Х	
Wandsworth	Х	Х	
Wormwood Scrubs	Х	Х	
Holme House	\checkmark	Х	
Manchester	\checkmark	Х	
Birmingham	\checkmark	Х	

Table 3.2 DXR machines currently available in prisons across England

In four of the prisons with a functional DXR, CXR screening is largely restricted to people who are symptomatic. To support the use of the DXR machines in active case-finding, PHE is leading the development of <u>standard TB screening</u> [36] protocol for use at reception.

To contribute to the intelligence around TB identification and management in prisons, PHE has conducted an audit across all London prisons and IRCs [38]. There are plans to replicate this audit across all English prisons to support improved active TB casefinding programmes in prisons. There is also a programme of work currently in development to provide DXR machines to two large London IRCs to support similar active case-finding among detainees.

⁴ HMP Thameside in London, also has a digital x-ray machine which is not funded by the Department of Health

Diagnosing latent TB infection among prisoners and immigration detainees:

In the updated guidance issued by <u>NICE in January 2016</u> [39], it was recommended that in high-incidence areas (and at prisons that receive prisoners from high-incidence areas), prison health services should offer an interferon-gamma release assay test for TB to inmates younger than 65 years who are in regular contact with substance misuse services or other support services. This is provided arrangements have been made for treatment support to continue after release.

Prison health services should incorporate IGRA testing with BBV screening for hepatitis B and C, and HIV testing. They should refer prisoners with positive IGRA to local multidisciplinary TB teams for further clinical investigations. These investigations should be done in the prison if practically possible.

PHE are currently developing a pathfinder programme in a London IRC for LTBI testing among immigration detainees in partnership with NHSE and Home Office Immigration Enforcement as part of the work associated with the National Partnership Agreement between the three organisations to improve active <u>case-finding for TB</u> [40] (see E 3.2).

In August 2016, the <u>Prison Healthcare Board for England</u> [34] commissioned PHE to establish a task and finish group to implement a similar pathfinder programme for LTBI testing in prisons in partnership with the National Offender Management Service (NOMS) and NHS England again as part of a programme of work associated with another <u>National Partnership Agreement [41]</u>.

3.5 Challenges for TBCBs and their partners in working with people in CJS

PHE Health and Justice, informed by engagement with key partners as well as the survey of TBCBs (see Appendix 2), have identified the following challenges which TBCBs and their partners need to consider to be able to understand and meet the needs of people in contact with the CJS:

a lack of a systematic approach to understanding the health needs of this population in both custodial and community settings
 PHE in partnership with NHS England and NOMS have produced guidance on Health Needs Assessments (HNA) for prisons (and police custody suites) [42] which has improved significantly the understanding of health needs and health services for people in these settings. While this has addressed specific understanding of health needs of prison (and IRC) populations, it has not addressed understanding of the needs of people in contact with the CJS in the wider community. An audit of published JSNAs conducted by PHE in 2014 - 15 showed that less than half referenced directly or indirectly populations in contact

with the CJS⁵. Therefore, the needs of this population are not well understood and not being specifically considered by commissioners and service providers. Information resources to support HNA/JSNA development are included in the HNA guidance but further information is available from the <u>National Health and</u> <u>Justice Team</u> at Health&Justice@phe.gov.uk.

• implementation of NICE guidance

Section 3.4 outlined current evidence-based advice to commissioners and service providers in prisons and IRCs to improve active case-finding of both active and LTBI. Evidence from PHE Health and Justice shows that implementation of this guidance is inconsistent and/or incomplete. Consequently, opportunities to diagnose TB (and other co-infections such as HIV) early in detention are being missed. Delayed diagnosis adversely affects the health of the patient, increases costs associated with treatment (including hospitalisation with the need for escorts and bed-watches) and poses a risk of transmission of infection with consequent complex and large scale contact-tracing exercises.

developing and delivering supportive care pathways taking account of • movement within the detention estate and from custody to the community⁶. The majority of prisoners spend only a few months in prison during any period of incarceration and even repeat offenders will in the main spend the vast majority of their lives in the community. Movements around the prison estate are common and include movement into immigration detention for foreign national prisoners. Designing and delivering care-pathways taking into account these challenges is problematic. Within the prison and immigration detention estate, NICE recommend that DOT is implemented for all cases of TB. ETS data for TB cases currently in prison between 2010 and 2015 show that 79.4% (200/252) received DOT. Continuity of care around the prison estate and from prison to detention is supported by the health informatics system SystmOne. But once people leave prison, care becomes more fractured and follow-up and continuity of care may be lost and treatment completion rates decline. ETS data from 2010-2014 shows that among people who are currently in prison with at least one SRF, only 64.4% (154/239) of people with drug-sensitive TB completed treatment by 12 months, which is worse than those who have no SRFs (see Appendix 1: table 1.5). A significant proportion of those who didn't complete treatment were lost to follow up (15.1%), still on treatment (10.5%) or didn't have their treatment outcomes evaluated (8.0%). Between 2010 and 2015, 8.3% (210/2,533) of TB cases with at least one SRF were resistant to isoniazid without MDR-TB compared to 5.3% (1,005/19,066) of those without a SRF. 2.4% (63/2,594) of TB cases with at least one SRF had initial MDR/RR-TB, compared to cases without any SRFs (1.6%,

⁶ Internal PHE communication from National Health and Justice Team- not published.

315/19,340) (<u>see Appendix 1</u>: table A1.4). Further improvements in supporting care pathways are anticipated by the development of a new health informatics system by NHS England (Health and Justice Information Service); especially on transition from custody to community by supporting GP registration but this will not impact until well into 2017-2018.

• homelessness, unemployment, indebtedness and NRPFs

Many people<u>leaving prison return</u> [43] to insecure or temporary accommodation or sleeping on the streets. Low incomes, debt, disrupted access to benefits <u>advice and</u> <u>insufficient income</u> [44] on release from prison all add to the problem. People leaving immigration detention may have<u>no recourse to public funds</u>⁷. All of these issues complicate accessing care and completing TB treatment.

challenges around multiple health needs

ETS data shows that 3.1% of TB cases notified in 2014 were co-infected with HIV a downward trend observed since the peak of 7.8% in 2003; 87% of TB-HIV coinfected between 2010 and 2014 were non-UK born (mainly Africa). People in prison have a high prevalence of infection with BBV, but have traditionally been under-tested. Sentinel surveillance data from PHE show that in 2014 (the most recent year for validated data)⁸, the prevalence of infection among prisoners for HIV, Hepatitis B and Hepatitis C viruses was 0.6% 1.5% and 8.0% respectively compared with the community prevalence for the same viruses of <u>0.2%</u> [45], <u>0.3%</u> [46] and <u>0.3%</u> [47] respectively.

Over 90% of prisoners have mental health problems - 72% of male and 71% of female prisoners had two or more mental health problems (eg personality disorder, psychosis, neurosis, alcohol misuse and drug dependence) and; 20% had 4 or more mental health problems. PHE's National Drug Treatment Monitoring System (NDTMS) reports on treatment delivered on an individual, basis (which may comprise several providers); figures for the financial year 2015/16 show that the largest proportion of those in prison treatment were opiate users (53%) followed by non-opiate and alcohol users (17%), non-opiate users (16%) and alcohol only users (14%). All of these physical, mental health and substance dependence health needs complicate TB treatment for people in prison and offenders in the community.

⁷ Section 115 Immigration and Asylum Act 1999 states that a person will have 'no recourse to public funds' if they are 'subject to immigration control'. A person will be 'subject to immigration control' if they have: a) Leave to enter or remain in the UK with the condition 'no recourse to public funds' eg spouse visa, student visa, limited leave granted under family or private life rules; Leave to enter or remain in the UK that is subject to a maintenance undertaking eg indefinite leave to remain as the adult dependant relative of a person with settled status (five year prohibition on claiming public funds); no leave to enter or remain when the person is required to have this eg visa over stayers, illegal entrants. (NRPF Network)

⁸ Internal PHE communication of unpublished data.

3.6 Recommendations and resources for TBCBs and their partners on working with people in the CJS

PHE Health and Justice recommend that:

1. TBCBs could invite PHE Centre Health and Justice Public Health Leads to work with TBCBs

Each PHE Centre has a health and justice Lead who works together with the National Health and Justice Team to provide public health expertise to commissioners and service providers locally and regionally. This expertise could be used locally to inform the work of TBCBs in understanding and meeting the health needs of local populations in custodial settings and in the community. More information on local <u>Health and Justice Leads</u> [48] is available.

2. Encourage use in prisons of the National Knowledge Service – TB prison resources

These include the following leaflets:

- Tuberculosis (TB): information for discipline and wing staff
- Got TB? Read this!
- Information about TB for those in prisons
- 3. Prison health services and TB clinical teams to be encouraged to work together to achieve DOT for all people in prisons and on return to the community as per <u>NICE Guidance [49]</u>
- 4. TBCBs, local authorities and PHE Health and Justice Lead to encourage the prison estate to prioritise and embed approaches that will lead to early detection and treatment of infectious TB

PHE health and justice leads with support from TBCBs to work with prison services, to use the DXR digital X-ray machine (where they exist) (see E3.3); encourage use at prison reception of a 'standard screening protocol' (once available) and follow NICE Guidance on regular testing of 'at risk' prisoners for LTBI.

5. Prison healthcare teams to work with local TB teams to improve early diagnosis in prisons

A programme of work could be organised by the prison healthcare team and supported by local TB nurses to train prison healthcare staff, prisoners, link workers and prison officers in early symptom recognition and link this to rapid investigation and referral pathways⁹

⁹ Personal Communication from Nic Coetzee - West Midlands

- 6. TBCBs could work collaboratively with NHS England commissioners to improve detection and control of TB in prisons and IRCs in their locality TB control in prisons, IRCs and other parts of the detention estate are an integral part of wider TB control programmes. It would be helpful if TBCBs were updated regularly on activities of health service commissioners and providers to support collaborative work on implementing best practice and addressing complex needs especially in relation to continuity of care (see below).
- 7. TBCBs working with other stakeholders could develop a time limited subgroup / task and finish group to develop supported care pathways across the CJS

Particularly in areas with large numbers of prisons and/or high numbers of offenders under probation service supervision, a collaborative group could be established to scope new ways of working across organisations to enhance service provision especially DOT and possibly linked to other healthcare eg opiate substitute therapy (OST), treatment of HIV or hepatitis C, mental healthcare. This could involve CCGs, NHS Health and Justice Commissioners, PHE Health and Justice Leads, NOMS Regional Representatives, Community Rehabilitation Companies (CRCs), DsPH, drug and alcohol service providers, TB service providers, mental health service providers, Police and Crime Commissioners and voluntary/third sector organisations as well as patient voice representatives (see E3.1). These task and finish groups could consider patient populations and flows across various parts of the CJS, especially transitions from prisons to community.

It could support work by NHS England through the new HJIS programme to register patients leaving prisons with primary care to support ongoing and coordinated treatment on release. It could enable sharing of information held separately by CRCs and health partners to ensure coordination. Specifically, all offenders released from prison are now supervised by CRCs for at least 12 months which provides a regular and mandated point of contact which could be exploited to deliver DOT programmes supplementing services provided through pharmacy and drug/alcohol treatment (alongside opiate substitution therapy) (see chapter 4). It could support JSNA activities to describe populations, identify data sources held locally across organisations to supplement national data, and complement wider work on integrated offender management and healthcare especially for substance misuse and mental health.

8. TBCBs could collaborate with local authorities, housing associations, voluntary and third sector organisations to address issues of homelessness, indebtedness, unemployment and NRPFs Useful advice specifically on issues associated with NRPFs is available from the <u>NRPF Network</u>: a network of local authorities and partner organisations focusing on the statutory duties to migrants with care needs who have no <u>recourse to</u> <u>public funds</u> (<u>see chapter 6</u> for more information).

9. TBCBs could establish a Health and Justice Forum to share good practice While individual TBCB areas will have their own specific circumstances, there will be much in common with regard to designing and delivering a supported care pathway. Programmes which are innovative and effective in one area could be highlighted and shared through a national Health and Justice Forum, linked to the National Health and Justice Team who then bring ideas to the attention of the National TB Delivery Board. This could also serve to improve the evidence-base on what works, as well as link professionals across different TBCB areas, enhancing dissemination of knowledge and supporting health service evaluation.

10.TBCBs and local stakeholders are encouraged to support the PHE Health and Justice leads undertake a baseline audit of the extent to which NICE guidance is implemented in prisons

11. Consider screening for LTBI using IGRA in IRCs

The benefits of undertaking this type of screening are the ease of delivering screening using an IGRA when all potential patients are in one setting and also the fact that many in an IRC fit the criteria listed by the national LTBI testing and treatment programme. An important and challenging step will be ensuring that patients are registered with a GP (see E3.2).

3.7 Exemplars of good practice on working with people in CJS

Exemplars of good practice cited below provide TBCBs with examples of effective partnership work supported by formal partnership agreements and preparing the case for a pathfinder programme for LTBI screening among detainees in IRCs.

E 3.1: National Partnership Agreements between PHE, NHSE and each of NOMS, Home Office Immigration Enforcement and Youth Justice Board

There is a clear mutual interest between health and justice sectors that offending and re-offending behaviour can be associated with drug and alcohol dependence and mental health needs. Addressing health needs in prisons and other PPDS and ensuring continuity of care allows specific public health problems to be addressed efficiently and effectively and can have a wider impact on health of general population including TB control.

In England, formal partnership agreements now exist between PHE, NHS England and each of the following:

- <u>National Offender Management Service (NOMS)</u> (for adult prisons and YOIs)
- Home Office Immigration Enforcement (HOIE) (for immigration detention)
- Youth Justice Board (YJB) for Children and Young People's Secure Estate

The agreements set out the shared strategic intent and joint commitments in cocommissioning, enabling and delivery of healthcare services in adult prisons, IRCs and CYPSE in England. The agreements are binding on all parts of the respective organisations at national, regional and local level. The agreements set out:

- respective roles and objectives of each organisation in commissioning, enabling and delivering healthcare services (including public health and substance misuse services)
- shared principles and objectives
- shared development objectives

Formal governance, performance management and metrics are associated with programmes of work within the agreements. All the agreements have a shared priority around improving the proactive detection, surveillance and management of infectious diseases and improving capability to detect and respond to outbreaks and incidents. This work includes active case-finding programmes for TB as well as agreed ways of working in response to cases or outbreaks of TB in custodial settings. For more information visit https://www.gov.uk/guidance/healthcare-for-offenders Contact: Dr Éamonn O'Moore

Email: ADMINHealth&Justice@phe.gov.uk

E 3.2: Pathfinder project to test and treat for latent TB infection in IRCs

This project aims to pilot LTBI testing and treatment in IRCs. So far it has described the healthcare needs in relation to TB and LTBI amongst residents of Immigration Removal Centres (IRCs) in England, assessed the feasibility, pathway and costs associated with testing and treating for LTBI in IRCs and made recommendations on how to implement the pilot.

The project report found that estimates of incident TB in the UK immigration detention estate were higher than in the general population and that around half of people in immigration detention would remain legally in the UK in addition to those who may remain undocumented.

Based on current estimates, test and treating active and latent TB was found to be feasible and likely to be cost saving if implemented in IRCs. The report recommends implementation of a pathfinder project to help determine the best pathway and service model for this.

Project leads: Dominik Zenner and Shannon Katiyo - Public Health England **E-mail**: Dominik.Zenner@phe.gov.uk

E3.3 Use of Find and Treat Mobile X-ray Unit in a prison TB outbreak in the West Midlands

Over several months in 2014 and 2015 an outbreak of TB occurred in a prison as a result of late detection of a significantly infectious index case. The outbreak resulted in a further 6 linked cases of active TB and was centred on one wing of a prison with capacity for 650 young men.

During the initial phase of the outbreak extensive screening, of potentially exposed staff and prisoners on the 'wing' of the index case, for symptoms and LTBI identified 27 (37%) prisoners with LTBI. Because of rapid transmission on the affected wing and uncertainty regarding transmission to other wings, the multiagency incident control team recommended extending case finding to the entire prisoner population using on site mobile digital chest x-rays.

Funding was agreed by the NHS England team responsible for prison health care commissioning, and mass MXU screening was undertaken by the Find and Treat MXU on site at the prison over a three day period in June 2015.

A total of 550 prisoners accepted screening and X-ray changes were detected in 3 prisoners who were referred to the chest clinic for further investigation, of which two were diagnosed with active pulmonary TB. The MXU detected these two cases early in their disease (sputum smear negative), and both were confirmed as contacts of the index case on the affected wing. The MXU provided an efficient and convenient method of rapidly screening for undetected active TB cases across the prison, and thereby provided assurance that no ongoing (and undetected) transmission was occurring to other wings in the prison.

Project Lead: MXU Co-ordinator, Find and Treat Team: Phil Foley **Email**: <u>Phil.Foley@uclh.nhs.uk</u>.

Chapter 4: People who misuse drugs or alcohol

4.1 Defining people who misuse drugs or alcohol

As described in chapter 1, the enhanced tuberculosis surveillance (ETS) system records information on SRFs for TB including drug misuse and alcohol misuse.

The National Drug Treatment Monitoring System (NDTMS) collects, collates and analyses information from and for those involved in drug and alcohol treatment. NDTMS collects data on an individual's drug and alcohol use and the interventions they are currently receiving or have received in the past. It also includes infectious disease information on hepatitis B and C but does not record TB diagnosis or treatment.

4.2 The burden of TB among people who misuse drugs or alcohol

In 2015, 4.3% (221/5,189) of TB cases had current or a history of drug misuse and 3.9% (205/5,191) had current alcohol misuse.

There has been an increase in the number and proportion of TB cases reporting drug misuse between 2010 and 2015, from 2.9% (188/6,551) in 2010 to 4.3% (221/5,189) in 2015 (figure 1.2, chapter 1 and table 1, <u>Appendix A1.2</u>). There has also been an increase in the number and proportion of TB cases reporting alcohol misuse between 2014 and 2015, from 3.4% (197/5,770) to 3.9% (205/5,191).

There is a significant overlap between cases with drug or alcohol misuse and the other SRFs: the most common overlapping SRFs being those who had a current or history of drug misuse and imprisonment (6.2%, 215/3,474) (figure 1.3, chapter 1).

Where recorded, 40.5% (313/772) of those with drug misuse were current drug users at the time of diagnosis or during care; 45.6% (352) had a history of drug misuse in the five years prior to diagnosis, and 18.0% (139) more than five years prior to diagnosis. Over half (54.3%, 635/1,169) of those with current or a history of drug misuse were on DOT among those with current drug misuse, this was 62.9% (183/291).

Age/sex profile of TB cases with history of drug misuse/alcohol misuse: 71.1% (890/1,252) of TB cases with current or a history of drug misuse notified between 2010 and 2015 were aged 15 to 44 years and 83.7% (1,046/1,250) were male. Nearly half of TB cases with alcohol misuse (48.9% (662/1,353) were aged 15 to 44 years, and 81.4% (1,100/1,352) were male (<u>Appendix 1</u>: table A1.3).

Place of birth/ethnicity: Between 2010 and 2015, the majority of TB cases with drug misuse were UK born (63.7%, 778/1,221) and the most common ethnicities of the UK born were White (68.1%, 525/771) followed by Black-Caribbean (11.0%, 85/771). The proportion of TB cases with drug misuse was higher among the UK born (8.8%, 778/8,843), compared to the non-UK born (1.5%, 443/28,839) and particularly high among the Black Caribbean ethnic group born in the UK (19.2%, 85/442) (<u>Appendix 1,</u> table A1.3). The proportion of TB cases with alcohol misuse was higher among the UK born (7.6%, 669/8,800), compared to the non-UK born (2.3%, 643/28,419), and particularly high among the White ethnic group born in the UK (9.8%, 548/5,612).

4.3 Geographic distribution of people with TB who misuse drugs or alcohol

The geographic distribution of TB by drug misuse and alcohol misuse is shown in **figure 4.1a and figure 4.1b**, **respectively**. To note, these are not mutually exclusive risk factors and both are associated with other factors like homelessness and imprisonment and are clustered around areas of multiple deprivation.

Figure 4.1a Number of TB cases with drug misuse by local authority, England, 2010 - 2015



Figure 4.1b Number of TB cases with alcohol misuse by local authority, England, 2010 - 2015



4.4 The challenges for TBCBs and other stakeholders working with TB patients who misuse drugs or alcohol

Using information from the survey of TBCBs (see <u>Appendix 2</u>) and engagement with stakeholders, PHE has identified the following challenges for TBCBs and relevant healthcare services for people who misuse drugs or alcohol:

• provision of DOT and treatment outcomes

NICE guidelines [39] recommend DOT for vulnerable people with complex needs as part of enhanced case management. This includes people with a history of drug or alcohol misuse. ETS shows that less than half (48.2%, 1,541/3,200) of cases with at least one SRF received DOT between 2010 and 2015. The highest proportion of cases receiving DOT was among those with current alcohol misuse (60.7%, 756/1,245); followed by those with current or a history of drug misuse (54.3%, 635/1,169), homelessness (58.1%, 666/1,147) and imprisonment (51.7%, 572/1,106). Challenges to DOT and wider continuity of care include homelessness/insecure accommodation, mental health needs, barriers due to cultural or language issues and stigma. How and where medications are dispensed is also important.

Seventy four percent 73.7% (671/911) of drug sensitive TB cases with drug misuse notified between 2010 and 2014 (with expected treatment duration of less than 12 months) completed treatment within 12 months.

Seventy two percent 72.3% (749/1,036) of drug sensitive TB cases with alcohol misuse notified between 2010 and 2014 (with expected treatment duration of less than 12 months) completed treatment within 12 months.10.0% (104/1,036) died within 12 months (double the proportion compared to those with no SRF or those with drug misuse).

• opioid substitution therapy (OST) and associated use of TB medications

If OST and TB medications are not available at the same point of access it increases the risk that TB medication will not be collected or TB treatment refused entirely. Furthermore, the interactions between OST and some TB medications could mean that OST doses need to be reassessed and adjusted. It is vital therefore that TB treatment and OST treatment are co-ordinated. Local authorities commission drug and alcohol services while CCGs commission TB testing and treatment services and a co-ordinated service plan is needed to provide optimum care across primary care, substance misuse services and pharmacy services (see chapter 9).

• co-infection with BBVs among injecting drug users with TB

People who use drugs are at risk of co-infection of TB with <u>HCV, HBV and HIV</u>
[50]. In people infected with HIV, TB is an indicator disease of advanced immunosuppression, <u>NICE guidance</u> [51] and the <u>British HIV Association</u>
(BHIVA)[52] recommend that people diagnosed with TB should be tested for HIV. In 2014, 3.2% (197/6,209) of TB notified cases and un-notified isolates were co-infected with HIV, a continuation of the downward trend observed since the peak of 8% in 2004.

• challenges around homelessness, unemployment, indebtedness and no recourse to public funds (NRPFs)

As with other risk groups NRPFs are a key concern and solutions are needed for those who misuse drugs or alcohol (<u>see chapter 6</u>).

• access to primary care services

People who misuse drugs or alcohol may find accessing primary care services difficult. This can then have an impact on access to prescribed medication and adherence to TB treatment.

4.5 Recommendations and resources for TBCBs and their partners working with people who misuse drugs or alcohol

Elements of a TB service which better meets the needs of people who misuse drugs or alcohol could include:

1. Partnership working and aligning care pathways

CCGs and local authorities to consider designing, delivering and commissioning more aligned pathways to support improved access to DOT and primary care services (E4.1). A "one-stop shop" encapsulating current health and social care services could offer huge dividends. Drug treatment services could work in partnership with nurse led TB clinics and pharmacy adherence clinics. This is a model very successfully implemented in HIV services. Specialised GP practices for vulnerable people could also offer TB nurse-led clinics. Social care and peer support models could be integrated to address wider issues including homelessness, legal advice and NRPFs.

A referral pathway for suspected TB in people who misuse drugs or alcohol that can be adapted for local use is shown in figure 4.2.

Figure 4.2: Referral pathway for suspected TB in a client of the drugs and alcohol services



2. TBCBs, PHE drugs and alcohol leads / or health and wellbeing teams to work with DsPH and CCGs to raise awareness of TB

TBCBs, PHE, drugs and alcohol leads and local authorities to raise awareness of TB for keyworkers through dissemination of the information leaflet for<u>those</u> <u>affected</u>, their <u>keyworkers</u> and <u>families</u> developed by PHE's National Knowledge Service for TB.

3. TBCBs to work with DsPH to encourage greater use by TB clinical services and substance misuse services of concomitant prescribing of opioid substitution therapy (OST) and TB medication

Encourage mental health support workers to act as DOT providers or encourage concomitant prescribing of opiate substitution therapy and TB medication by TB and substance misuse services. See E4.2 and chapter 10 - Models of Care.

4. Linking TBCBs to local services

TBCBs are encouraged to develop formal links with local PHE drugs and alcohol leads as well as representatives from local front line services to develop joint-working to tackle TB in people who misuse drugs or alcohol.

5. CCGs and local authorities to consider developing, if appropriate, specific outreach services to support USPs who misuse drugs or alcohol

It may be appropriate in some areas to develop outreach services like <u>Find and</u> <u>Treat</u> (see chapter 10, Models of Care). Outreach work can improve active casefinding and provide ongoing support for treatment and care. Ideally, such services should be aligned with established services in primary and secondary care to enable people to move into more structured TB care over time. For some USPs with chaotic lifestyles, or those without recourse to public funds, these 'bespoke' services may provide the most accessible and consistent model of care.

6. CCGs and local authorities to consider commissioning substance misuse services to test for LTBI and BBVs

Where a local need has been identified, services for people who misuse drugs or alcohol should be commissioned to provide testing for LTBI as well as BBVs. <u>NICE guidelines</u> recommend that substance misuse services in areas with high TB incidence, and with access to IGRA should provide testing for people under 65 who access their services. Substance misuse services could then refer people with positive IGRAs to local TB teams for further clinical investigation.

7. Local authorities to plan and support comprehensive interventions for TB

Local authority commissioners should be encouraged via the TBCB or local DPH to plan comprehensive interventions relating to TB in people who misuse drugs or alcohol as part of their JSNA and JHWS processes.

<u>PHE's JSNA support packs</u> for alcohol, drugs and tobacco provide data and advice to help local areas develop strategies to effectively address public health issues relating to alcohol, drug and tobacco use. The drug prevention, treatment and recovery support pack for adults includes two good practice prompts for planning comprehensive interventions which relate to TB:

- are confidential tests for HIV and hepatitis B and C, and screening for TB promoted in accordance with national guidance and quality standards?
- have drug and health commissioners agreed pathways that ensure ready access to treatment and support for hepatitis, TB and other respiratory diseases? Is there specific pathway support for people who use or have used drugs?

The Bradford and Airedale integrated plan is an example of where TB and substance misuse services have been aligned (E4.1).

4.6 Exemplars of good practice on working with people who misuse drugs or alcohol

E4.1: Bradford and Airedale integrated care plan

In order to ensure that treatment interventions for TB and substance misuse are fully aligned in Bradford and Airedale the TB service in 2015 developed an integrated care plan for TB positive substance misuse service users. Service providers use their formal and informal networks to create and agree a single integrated care plan with consent to share data established with the service user.

At the start of the project the TB service agreed a template "Integrated care plan for TB and substance misuse patients" which is adapted to meet the needs of each TB patient. For more details see chapter 10 - Models of Care

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E4.2: Reaching out to drug and alcohol users in Leicester

Inclusion Healthcare, a social enterprise that offers primary care services to vulnerable groups, and local TB services have combined forces in Leicester to screen street drug and alcohol users for TB.

A dedicated clinical service has been commissioned by the CCG to provide screening, assessment and follow-up for cases of latent and active TB. Screening clinics and DOT are provided by a team of specialist TB nurses and substance misuse nurses. The clinics are run from the inner city homeless shelter and Inclusion Healthcare's inner city GP surgery. Nurses work with a multi-agency task force to identify and trace those who should be offered screening.

Using the homeless centre and other healthcare services which are familiar to the clients increases their willingness to be screened and referred for treatment.

Regular follow up and completion of treatment is a challenge in this client group and, the chances are improved because of the multiagency approach and the co-location of essential parts of the screen and treat service.

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Chapter 5: People living with a mental health problem

5.1 Defining people living with or recovering from a mental health problem

ETS does not specifically define people living with, or recovering from, a mental health problem as a distinct group (see chapter 1). Research shows that people with a mental health problem are over-represented among people who misuse drugs or alcohol [54] who are <u>homeless or in prison</u> [55].

Information on TB patients with mental health issues is available via the PHE London TB Register (LTBR)¹⁰. This information is collected by TB nurses as part of their TB case manager's assessment. Data from the LTBR from 2009 – 2015 showed that a third of TB patients who reported mental health problems had at least one additional SRF (266/807). Twenty per cent also had alcohol misuse (177/885), 18% drug misuse (171/925), 16% experienced homelessness (149/942), and 11% had been in prison (103/915).

Data presented in this chapter are taken from the LTBR database unless otherwise specified.

Definitions of mental health problems: In order to characterise people with mental health needs in relation to TB, it is important to recognise that mental health problems comprise a very broad range of psychiatric signs, symptoms and diagnoses. The <u>nature of the problems</u> [56] depends on the needs of patients and the settings where care is delivered.

<u>Mental health problems</u> [57] vary in severity and duration. These can be divided into two main areas: firstly, common mental health problems including anxiety and depression that <u>25% of adults</u> [58] experience and secondly severe mental illness (SMI) such as schizophrenia and bipolar disorder that often require treatment by specialist services. Approximately 1% of the adult population experience severe mental illness. People living with <u>long term complex mental illness</u> [57] experience the highest levels of physical ill-health.

¹⁰ An online London TB surveillance and notification system that collates information from TB clinics on TB patients treated in London

5.2 The burden of TB among people living with or recovering from mental health problems

In 2015, the LTBR showed that 2351 cases of TB were notified in London, and 5.4% reported a mental health problem. Overall numbers of people with TB have decreased in recent years, but numbers reporting mental health problems have remained roughly stable, meaning the proportion who report mental health problems has increased (figure 5.1).

Figure 5.1: Number of TB patients treated in London with reported mental health problems, LTBR, 2009 - 2015.



Age/sex profile: Mental health problems were reported in similar proportions of male (5.0%, 600/11950) and female (4.4%, 386/8685) patients. Patients with TB who reported mental health problems tended to be older (median age of 42 years versus 34 years among patients who did not report mental health problems).

Place of birth and ethnicity: In London, TB is more common among <u>individuals born</u> <u>outside the UK</u> [6] but the proportion of TB patients with reported mental health problems were twice as common among UK-born patients (table 5.1). Reported mental health problems were also more common among White (11%, 249/2276) and Black Caribbean patients (11%, 71/653).

Table 5.1: Reported mental health problems among patients with TB by place of birth, LTBR, 2009 - 2015

Place of birth	Mental health problems reported		Total
	Number	%	
UK born	286	8.4	3400
Non-UK born	689	4.0	17047
Total	975	4.8	20447

Data from the LTBR shows that:

- patients with mental health problems were more likely to have pulmonary disease (59% versus 46% of patients with no mental health problem, 2009-15). These were also more often sputum smear positive (49% versus 36% of patients with pulmonary disease and no mental health problem in 2014-2015) which suggests that patients with mental health problems are more likely to be infectious than TB patients who do not report mental health problems
- delays of more than four months were also more common among patients with mental health problems: 32% among pulmonary patients in 2014 - 2015 had a delay of more than four months between symptom onset and treatment start compared to 26% of pulmonary patients without reported mental health problems
- patients with mental health problems were more likely to first attend A&E services in relation to their TB illness (35% versus 24% among those without mental health problems in 2014-15) and less likely to attend a GP (28% versus. 44%)
- during treatment, patients with mental health problems were more likely to spend time as a hospital inpatient (49% versus 30%)
- just 76% completed treatment within 12 months compared to 86% of those without reported mental health problems; they were also more likely to have died (6.4% died versus 2.3%)

5.3 Challenges for TBCBs and others working with people with mental illness

The following challenges were identified from the TBCB survey (<u>see Appendix 2</u>) and advice from national experts in mental health:

recognising the needs of people with a mental health problem
 Mental health problems are often less visible than other risk factors for TB
 patients. Systematic consideration of mental health in TBCB plans provides an
 opportunity to help address psychosocial and emotional problems related to TB
 and its management including issues related to stigma.

- multiple complex needs among people with a mental health problem As mentioned above in Section 5.1, people with mental health problems often also have other SRFs which challenge access to diagnostic and treatment services eg homelessness, drug or alcohol misuse or contact with the CJS.
- **no recourse to public funds (NRPF)** Patients who have NRPF are increasingly vulnerable when they have TB compounded by a mental health problem.
- homelessness / insecure accommodation / houses of multiple occupancy People with mental health problems are over-represented among homeless people (See chapter 6 on Homelessness and TB). Homelessness and living in overcrowded conditions exacerbate mental health problems eg having no private space to self-administer TB treatment and/or to rest and recuperate can compound mental health issues.
- late presentation of illness and poor treatment adherence

Treating TB successfully requires timely diagnosis and adherence to treatment. Data on patients with mental health issues in London shows that they present later reflecting a range of issues including stigma, lack of knowledge, poor access to services and segmented care being focussed primarily on mental health needs but not on physical health. Further challenges, reported among people with mental health problems, include patients who refuse treatment including 'stop-start' patients (LTBR). This leads to poorer outcomes for patients but also increases the risk to public health due to the risk of disease transmission as well as the emergence of drug resistance.

5.4 Recommendations and resources for TBCB and their partners working with people with mental illness

Responding to the challenges above and considering the evidence presented to the USPs task and finish group, the following recommendations are made:

- Clinical and mental health services to consider patient-centred care plans that consider the totality of need for patients with TB and mental health problems. Mental health care providers and TB services are encouraged to share information and coordinate care as much as possible. This is especially important in relation to supporting adherence, but also in supporting TB patients to access mental health support.
- 2. TBCBs to encourage primary care as well as mental health service providers to promote physical health checks for people living with, or recovering from, a mental health problem, and use any appropriate

opportunities to increase awareness of TB. There is evidence that a considerable proportion of people with mental health problems are not offered physical health checks. Offering physical health checks to those with mental health problems has the potential to pick up other healthcare problems such as TB.

3. TBCBs to encourage clinical services and primary care to improve access to smoking cessation support for people living with or recovering from a mental health problem

Smoking prevalence is much higher in patients with a mental health problem, with rates increasing with the severity of the condition. Smoking increases the risk of TB [59]. TBCBs could consider active engagement with public health, primary care and mental health service providers to increase promotion and availability of smoking cessation support for people with a mental health problem and TB. In addition to the impact on risk and recovery from TB, such coordinated action has the potential to significantly reduce the disproportionate level of preventable deaths (caused by smoking) amongst people with a mental health problem.

4. TB clinical teams to consider greater use of mental health services as DOT compliance support workers.

Encourage mental health support workers as DOT providers or encouraging concomitant prescribing of opiate substitute therapy and TB medication by TB and substance misuse services. See E4.2 and <u>chapter 10 - Models of Care.</u>

5. TBCBs are encouraged to explicitly recognise the needs of people with mental health problems in their work plans

Given the significant overlap of SRFs and mental health problems among people with TB and the negative influence of poor mental health on diagnosis, access to services, treatment adherence and outcomes, it is important that TBCBs specifically consider the needs of this population and work with local authorities and clinical services to meet these needs. This would also contribute to addressing issues of health <u>inequalities and 'parity of esteem'</u> [60] where mental health is <u>valued equally</u> [61] as physical health.

6. National TB Surveillance team to include information on the mental health of patients with TB in the new national TB surveillance system. This should improve information available at TBCB level on TB patients with mental health problems and ensure questions asked by TB services about a person's mental health are consistent with mental health questions asked in <u>national surveys</u> [62].

Chapter 6: Homelessness and TB

6.1 Defining homelessness

Health and social care, homelessness and criminal justice systems adopt different definitions of homelessness in practice. These different definitions present a challenge to understanding the scale and nature of populations at risk of, or experiencing homelessness, including those who have TB, and a challenge to agreement over who is responsible for funding accommodation to meet housing and related support needs.

The <u>legal definition</u> [63] of homelessness is that a household has <u>no home in the UK</u> or anywhere else in the world available and reasonable to occupy¹¹.

Not all legally homeless [63] households are entitled to assistance with accommodation. Homeless households who are entitled to assistance – 'statutory homeless households' or 'households owed the main homelessness duty' - have passed additional tests described below. To be owed the main duty the household must first make a homelessness application to a <u>local housing authority</u>, and their information will be checked, and further evidence sought, to ensure that the household also:

- is legally homeless
- has the right to live in the UK and is eligible for assistance
- can be classed as in 'priority need' of help
- is homeless through no fault of their own ie. is unintentionally homeless

If the household is found to satisfy these four tests, they are eligible for assistance with settled accommodation. Legislation defines 'priority need' and this can include someone vulnerable as a result of 'other special reason': practice suggests that, with appropriate evidence eg of treatment, this <u>can be applicable to people with TB.</u>

Although not all homeless households are 'owed a duty', local housing authorities are required, by the <u>Homelessness Act 2002</u> [64] in their homeless prevention strategies, to consider and plan for the needs of <u>all</u> households who may be at risk of, or experiencing, homelessness – this should include people at risk of, or with, TB. For the purpose of effective homeless and TB prevention and response <u>FEANTSA's</u> broader and evidence-based <u>categorisation of homelessness</u> [65] is more appropriate to local commissioning, one that recognises the following living situations as homelessness:

¹¹ The legal definition is set out in Part VII of the Housing Act 1996 (specifically clause 175, as clarified by clauses 176 – available for occupation, and 177 – reasonable to continue to occupy), and is used as the starting point for determining whether a local authority has a legal duty to assist a household to secure accommodation. This seeks to understand if any person is homeless.

- rooflessness (without a shelter of any kind, sleeping rough)
- houselessness (with a place to sleep but temporary in institutions or shelter)
- living in insecure housing (threatened with severe exclusion due to insecure tenancies, eviction, domestic violence)
- living in inadequate housing (in caravans on illegal campsites, in unfit housing, in extreme overcrowding)

For people with TB <u>NICE guidance</u> [65] has adopted 'a broad and inclusive definition of homelessness' which includes people with TB in under-served groups and are people :

- who share an enclosed air space with people at high risk of undetected active pulmonary TB (that is, people with a history of rough sleeping, hostel residence or substance misuse)
- without the means to securely store prescribed medication
- without private space in which to self-administer TB treatment
- without secure accommodation in which to rest and recuperate in safety and dignity for the full duration of planned treatment

ETS records if a patient is currently homeless or if they have ever been homeless in the last five years. In practice 'homelessness' is not defined as widely as the NICE definition, which in turn is more limited than FEANTSA's definition.

It is common within the drug treatment and criminal justice systems to define homelessness as 'rough sleeping' or 'No Fixed Abode'.

6.2 The burden of TB among homeless people

Unstable housing and homelessness can make it more difficult for patients to complete the lengthy TB treatment regimens required for cure, thereby increasing the risk of transmission and poor treatment outcomes. Non-completion of treatment can contribute to drug resistance, relapse and onward transmission of the disease. TB cases can also occur in individuals who also face particular challenges in accessing affordable, suitable and stable homes, such as people with close links to high incidence countries who may be ineligible for social security; people with a history of imprisonment; people who misuse drugs and alcohol: ETS data between 2010-2014 (see figure 1.3, chapter 1).

ETS data shows that between 2010 and 2015 the proportion of TB cases with a current or history of homelessness increased from 3.0% to 4.4% (<u>Appendix 1</u>, table 1).

66.7% (824/1,236) of cases notified between 2010 and 2015 with current or history of homelessness had known information about the timing of their homelessness. Where recorded, over half (54.0%, 445/824) of the TB cases reporting homelessness were currently homeless at the time of diagnosis or during care, 35.4% (291) had a history of

homelessness in the five years prior to diagnosis and 14.4% (119) more than five years prior to diagnosis.

Age/sex profile of TB cases: 81.5% (1,007/1,235) of those with current or a history of homelessness between 2010 and 2015 were male, and the majority were aged 15 to 44 years (66.7%, 824/1,236).

Place of birth and ethnicity: ETS data shows that 66.5% of TB cases with current or a history of homelessness were non-UK born; but a higher proportion of UK born cases had current or history of homelessness (4.5%, 404/8,948) compared to non-UK born cases (2.8%, 802/28,889) (see Appendix 1, table A1.3). A higher proportion of UK born cases with Black Caribbean ethnicity were homeless or had a history of homelessness (8.5%, 38/445) compared with other ethnic groups born in the UK. The countries of birth with the highest proportions of cases with current or a history of homelessness were from Poland (17.3%, 56), Eritrea (16.6%, 71) and Lithuania (19.8%, 39), but numbers were small (see Appendix 1, table A1.3).

Figure 6.1: Number of TB cases with current or history of homelessness by local authority, England, 2010 - 2015



6.3 Challenges for TBCBs and their partners working with homeless people

Homelessness is complex to understand. Causes are typically described as either structural or individual, and can be inter-related ie one may arise as a consequence of the other. They vary across the life course. Structural factors include poverty, inequality, housing supply and affordability, unemployment or insecure employment, access to social security. Individual factors include poor physical health, mental health problems, addiction to drugs or alcohol, bereavement or relationship breakdown, violence and abuse, experience of care or prison. There is a danger that simply dealing with each in turn may not enable the most effective solution: addressing both structural and individual factors is necessary to prevent and move people on from homelessness.

Housing Sector Perspective

There are structural challenges to meeting the housing needs of people with TB. In England, homelessness has risen in recent years, particularly as experienced by people with more complex needs. In 2015/16 local authorities [66] reported responding to the threat of, or actual, homelessness for 28% more households compared to 2009/10. Rough-sleeping has increased by 102% [67] since 2010. In the housing sector there is concern that homelessness will continue to rise as additional welfare reforms are implemented.

The challenges perceived by the housing sector to meet the housing needs of people with TB are:

- **insufficient affordable housing**: there is not enough housing to meet the general population's needs, and the planned supply of new homes is not addressing this. High demand for housing across the country presents a challenge to providing temporary accommodation for people who are homeless, and to moving people on into more permanent solutions. This can mean that homeless people with TB who are eligible for assistance may still not be placed in the right home for the duration of their treatment.
- high cost and poor quality housing in the private rented sector and overcrowding: The unregulated private rented sector is growing in size, and the prevalence of poor housing conditions is highest compared to other tenures. In 2011, 1.1million households were reported to be overcrowded, primarily in the rented sectors, and in London this represents one in ten households (2011 Census Analysis - <u>Overcrowding and Under-occupation in England and</u> <u>Wales</u>)[68].
- **complex statutory framework for homelessness:** The statutory framework is complex and continues to evolve through case law. It is a specialist area of law

and requires regular workforce development to ensure that the right decisions are made.

- exclusion of those who have no recourse to public funds: Homeless people who have no NRPF are excluded from homelessness assistance and social security [69] which presents a significant challenge to meeting housing needs (see Appendix 3).
- a diverse homelessness sector: The 'homelessness sector' is diverse and different to other areas, comprising a multitude of information, advice, support, homeless response and housing services, delivered by public, private, voluntary, community and charitable bodies. It can be resource intensive to navigate.

TB Control Board Perspective

The main challenges as identified by TBCBs in their survey and by the PHE Housing and Health lead are:

- **accommodation:** Access to accommodation was identified as a major issue among all the TBCBs for all USPs. These include those people who misuse drugs or alcohol, migrants (both legal and illegal), those released from prison or remand settings, those with mental health issues and those with MDR-TB.
- **no recourse to public funds:** Accommodation has been described as a major problem for those patients with no access to public funds.
- funding accommodation for homeless TB patients: The 2016 NICE guidance recommends that the cost of housing for TB patients with NRPF should be met from "health and public health resources". See NICE guidance 1.8.11 [70] where it states:

"Local government and clinical commissioning groups should fund accommodation for homeless people diagnosed with active TB who are otherwise ineligible for state-funded accommodation. Use health and public health resources, in line with the Care Act 2014."

Providing accommodation for TB patients who are homeless helps promote treatment adherence and treatment completion (so reducing the risk of disease transmission to the wider public), helps reduce the risk of patients being lost to follow-up and reduces the risk of developing drug resistant TB. It also prevents unnecessary bed blocking, escalating hospital costs and frees up clinicians and others from protracted housing negotiations [69].
Providing accommodation in the community for homeless TB patients at a cost of \pounds 40-50 per day for bed and breakfast is substantially cost saving compared to the minimum cost of a hospital in-patient stay varying from £187 - £243 per day (based on the respiratory tariff, 2015-16, HRG DZ51Z 'complex tuberculosis').

Different mechanisms to fund accommodation for homeless TB patients exist, or are being sought, around the country. Exemplar 6.6 describes a service level agreement (SLA) in Hackney; other possibilities include: a risk / cost share across a number of CCGs (E6.12) or an STP footprint; or an agreement between the local commissioners (the CCG) who fund the local authority or other social housing provider to provide accommodation for the duration of treatment for homeless TB patients. In the longer term this is cost saving for the CCG.

- provision of directly observed treatment: 68.0% (664/977) of homeless TB cases notified between 2010 and 2014 with drug sensitive TB completed treatment by 12 months, with 8.9% (87/977) of cases being lost to follow up, and 6.8% (66/977) having died. A significant proportion of cases were still on treatment at 12 months (11%, 107/977). Lost to follow-up and incomplete treatment is high in the homeless and this in turn increases the risk of transmission and development of MDR-TB. NICE guidance recommends DOT for all homeless cases. However only 58.1% (666/1,147) of cases notified between 2010 and 2015 received DOT. Further consideration therefore needs to be given to how to support TB services offer more DOT to the homeless.
- "treatment refusniks" (patients who refuse treatment) including stop-start patients occurs more commonly in the homeless group and <u>treatment completion</u>
 [6] is a major issue.
- access to primary care services can be a major issue. In addition, language and cultural differences have been identified as barriers to access.

6.4 Recommendations and resources for TBCBs and other stakeholders working with the homeless

A measure of success of the <u>Collaborative Tuberculosis Strategy for England 2015</u> – 2020 [2] would be the development and implementation of 'systematic, joined-up care between health services, health and social care, public health and housing that specifically reaches under-served or vulnerable groups'. The following recommendations are intended to support this:

- 1. TBCBs are encouraged to invite a representative with housing and homelessness expertise to become a member of the board or to have a role advising the board on housing issues.
- 2. TBCBs working with local authority DsPHs are encouraged to look for opportunities to influence wider strategic partners who commission housing related support services

Ensure that the TBCB is working through its DPH member, is familiar with the housing market in their locality, particularly the availability of genuinely affordable rented housing and is informed by and able to influence strategic partnerships and partners who are able to commission housing and housing related support services including local housing authorities and social landlords (see exemplars E6.1, E6.2).

3. TBCBs, working with their partners, are encouraged to develop streamlined accommodation pathways to help support TB services find solutions for homeless patients, particularly those who have NRPFs

To support this recommendation there are a number of exemplars to assist TB patients who have NRPFs into accommodation, these include the London NRPF check list (see <u>Appendix 3</u>), the Bristol NRPF pathway, the City and Hackney local authority SLA and the London Commissioning guidance for the homeless (see exemplars E6.2, E6.3, E6.6, E6.8, E6.11, E6.12).

4. TBCBs to work with partners to agree a process to fund accommodation for homeless patients with TB

TBCBs to work with CCGs and local authorities to agree the best way to fund temporary housing for homeless TB patients linked to treatment completion (see exemplars E6.2, E6.7, E6.9 and <u>Appendix 3</u>). In particular, with respect to patients with NRPF, agree a process on how to fund accommodation as per NICE Guidance 1.8.11.3 [70].

5. Consider contingency funds to fund accommodation

TBCBs to work with local CCGs or across Sustainability and Transformation Plan (STP) areas to consider risk / cost share (through local contingency funds or cost share across CCGs) to help fund accommodation for NRPF patients (see E6.6 E6.9 E6.12).

6. TBCBs to encourage, via their DPH lead, local authority JSNAs to include local strategic assessments of health and housing needs for TB patients and consider the relationship between TB, housing circumstances and homelessness, making use of the <u>homeless health needs audit tool [72]</u> and where there is unmet need, ensure local commissioning plans address this.

- 7. TBCBs are encouraged to raise awareness of TB as an issue for homeless people among non-health groups such as housing departments in local authorities and other housing providers. By increasing awareness that secure housing reduces TB transmission and improves treatment completion greater emphasis may be placed on finding housing solutions for the homeless with TB. A number of areas are supporting the housing workforce to identify and respond to TB and homelessness. To support awareness raising the following resources may be useful:
 - TB and homelessness: information for homelessness service managers
 - TB and homelessness: information for homelessness sector staff
 - TB and homelessness information from TB Alert
- 8. TBCBs to encourage hospital trusts to consider existing local strategies / processes eg 'delayed transfer of care' strategies to find solutions to accommodating homeless TB patients.
- 9. TBCBs to encourage TB services to identify housing needs at an early stage during a patients 'episode of care' and involve local authority and other housing specialists in early case conferences. See <u>Appendix 3</u> for the roles of key players in accommodating TB patients who have NRPFs.
- **10.TBCBs and local partners** to consider whether the use of a mobile X-ray unit visiting homeless hostels on a periodic basis could help them meet the needs of the homeless (see E6.10).
- **11.Encourage use of a common definition of homelessness by using** the definition adopted by FEANTSA and/or NICE and locally agree a definition of suitable housing for TB treatment (see E6.4).
- 12. Local authorities to update service information systems to prompt frontline workers to ask questions to identify homelessness and TB, record the nature of the homelessness and enable data sharing to help manage cases more effectively and to inform commissioning.

6.5 The TB patient's pathway to accommodation

A patient's pathway to accommodation illustrates a process for identifying and providing accommodation for homeless people diagnosed with active pulmonary TB (see figure 6.2). Multidisciplinary TB teams, commissioners, local authority housing lead officers and other social landlords, providers of hostel accommodation, hospital discharge teams and PHE should ensure that a patient's accommodation needs are met for the duration of their TB treatment.





† Developed by PHE London

E6.1 Exemplars of good practice for TBCBs working with homeless people

Buckinghamshire TB team recently identified a need to better provide for their 2 - 3 homeless TB cases per year. They are developing a protocol with the social services team and Buckinghamshire County Council (BCC) to identify link social worker(s).

The aim is to provide fast-track access to appropriate accommodation for the length of TB treatment for those who are homeless by working closely with the local authority and social services. This protocol will ensure patients on treatment are never discharged into homelessness.

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E 6.2: London checklist to help accommodate TB patients with NRPFs

A checklist (see Appendix 3) has been developed in London with a view to reduce some of the delays in finding accommodation for patients who have NRPF by identifying the main steps of the process and with whom each responsibility lies.

The checklist establishes from the outset who takes overall responsibility for coordinating the process of accommodating TB patients with NRPFs up until a case conference is held. This checklist has been developed in collaboration with the NRPF network; Find and Treat, TB Reach, Imperial College Healthcare Trust TB services and Discharge team, the Whittington Hospital TB Social Care team and Islington NRPF Team (see Appendix 3).

Project Leads: Anita Roche or Sara Atkins or Samar Pankanti Email: Anita.Roche@phe.gov.uk or Samar.pankanti@nhs.net or Sara.Atkin@phe.gov.uk





Project Leads: Samar Pankanti and Sara Atkins Email: Samar.pankanti@nhs.net and Sara.Atkin@phe.gov.uk

E 6.4: Homeless Healthcare Team - Southampton

The Homeless Healthcare Team in Southampton seeks to provide equity of provision for homeless people whilst recognising that a separate service is needed because many people are unable or unwilling to access mainstream provision despite having extremely complex needs.

The service is provided to homeless people across the city of Southampton. The description "homeless" encompasses people living in: (i) hostels or night shelters; (ii) bed and breakfast; (iii) supported accommodation for those with mental health or substance misuse problems; (iv) refuge houses for women fleeing domestic violence,; (v) approved premises for offenders; (vi) bedsits or private rented accommodation without security of tenure; (vii) mobile homes, caravans or cars (viii) people with no accommodation who are residing on the streets; (ix) asylum seekers and / or migrants who find themselves without any kind of financial or housing support.

The Homeless Healthcare Team in Southampton seeks to uncover and meet new areas of need within Southampton in a bid to address health inequalities. This team has been important in helping address the needs of homeless TB patients. More service level information is available from Solent NHS Trust.

Website: http://www.solent.nhs.uk/service-info.asp?id=40&utype=1

E 6.5: Specialist GP clinics for destitute and homeless refugees and asylum seekers

In Brixton London, a specialist GP clinic sees destitute and homeless refugees and asylum seekers. The patients' are at particularly high risk of TB as many come from countries with a high incidence of TB and are destitute and homeless.

Since 2014 the clinic has offered IGRA testing to these patients. Of 92 patients screened between November 2014 and November 2015 33% were positive for latent TB. Patients with a positive IGRA were referred to the local chest clinic for further follow-up.

Project Leads: Dr Shazia Munir and Dr Judith Eling. Health Inclusion Team, Guy's and St Thomas' Trust **Email address**: shazia.munir@nhsnet and juditheling@nhs.net

E 6.6: Bristol patient pathway for patients with NRPF

Bristol CCG, local authority Public Health and PHE Health Protection have drafted a patient pathway for those exceptional circumstances where homeless TB patients have no permanent secure accommodation and NRPFs.

Individuals with TB who are homeless in Bristol undergo housing, social care and asylum assessments as necessary. If it is deemed that they are not eligible for support from these assessments a case conference is held to discuss the patient pathway and public health implications of their situation. Under the pathway, attendees at the case conference include the treating TB consultant, TB nurses, local authority Housing Options team, local authority Public Health (Health Protection) representatives, PHE Health Protection and the TB service commissioner from the local CCG. The local authority Social Care, Asylum team and others may also be invited to attend as required.

This patient pathway is working to agree with the CCG, local authority Public Health and PHE Health Protection team how to fund prompt housing for the patient in question for the duration of their TB treatment.

While housed and on treatment, the City Council Tenant Support Services and Asylum services (if appropriate) will work with the individual to facilitate longer term support.

Project Contact: Helen Trudgeon - Health Protection Practitioner, **Email:** Helen.Trudgeon@phe.gov.uk

E 6.7 Olallo House, a residential unit for destitute TB patients in London

Olallo House includes a five-bed residential unit for destitute Eastern European TB patients in London. Available to all TB services in London, the unit has a dedicated support worker and each resident has an individual care plan. The dedicated support worker seeks to enable residents to regularise their residency, access benefits and/or employment in order for them to move on into independent, self-supported, accommodation and to support the resident to complete TB treatment.

The unit is part of a larger complex served by the charity The Saint John of God Hospital Services. The TB patients are usually funded via contributions from CCGs (see chapter 11 Models of Care).

Contacts: Miguel Neves / Pawel Zabielski **Email:** Miguelneves@sjog.org.uk / pawelzabielski@sjog.org.uk

E 6.8: The housing of TB patients with NRPFs in City and Hackney

In 2008 the Homerton Hospital TB team reviewed their lost to follow up patients; a common factor for all was lack of housing, and the lack of eligibility for local authority benefits. This needed to be addressed in order to reduce the 'lost to follow up' and non-completion of treatment.

The TB team audited TB patients who had either bed-blocked and/or been lost to follow up over the previous 3 years (2005-2008) and the financial impact these had upon services. A series of meetings was held with London Borough of Hackney's Homeless Persons Unit and a Service Level Agreement (SLA) to accommodate homeless patients with NRPF was developed. Homeless TB patients with NRPF are housed in temporary accommodation for the duration of their TB treatment; they are provided with daily DOT and non-adherence results in eviction. They are provided with a monthly bus pass to support attendance for clinic-based DOT.

Since 2008, every patient housed via the SLA has completed treatment. City and Hackney have not had a lost to follow up patient since 2008. Thirty five patients from 21 different countries have been housed, 45% of whom had smear positive pulmonary TB. Housing these patients creates a vital opportunity for them to complete treatment, gain social and psychological support from the TB case worker, and prevent onward transmission of the disease.

Project Lead: Dr Susan Collinson, Homerton Hospital, TB Team **Email:** sue.collinson@homerton.nhs.uk

E 6.9 Use of personal health budgets for traveller community by Brighton and Hove CCGs

Brighton and Hove CCGs have developed the PHB (Personal Health Budget) for a member of the traveller community and are exploring the use of small PHBs, for hostel based homeless individuals. Though not specifically for TB patients PHBs could be applied to TB patients as well. This came out of work with the NHSE PHB Equalities network

Project Contact: Wazi Khan Email: Wazi.Khan@phe.gov.uk

E 6.10 The Find and Treat Service, London

Find and Treat are a specialist outreach team that work alongside over 200 NHS and third sector front-line services to tackle TB and blood borne viruses (BBV) among homeless people, high risk drug or alcohol users, vulnerable migrants and people in contact with the criminal justice system.

Find and Treat outreach, a platform of point of care (POC) diagnostics on a Mobile Health Unit (MHU) to almost 10,000 people across London annually and support referral and onward care to ensure access to and engagement with TB treatment services. Additionally the service provides training, advice and practical assistance to frontline TB services and allied health and social care services. The outreach team includes clinical nurse specialists, social and workers, substance misuse professionals, radiographers, expert technicians and former patients who work as peer advocates. Peers are recruited from the client group and work both on the MHU and directly supporting patients in the community. The service operates in every London Borough and regularly supports PHE and local providers to respond to incidents and outbreaks nationally. UCLH host the service on behalf of London CCGs and are working with PHE and local partners in the West Midlands to create a national outreach service as recommended by NICE and the National Collaborative TB Strategy.

Find and Treat aim to take TB control into the community, find active TB cases early and support patients complete a full course of treatment. See chapter 11, 'Models of Care' for further details.

Project Lead: Dr Alistair Story – Clinical Lead – Find and Treat Email address: al.story@nhs.net

E 6.11 London Commissioning Guidance for the homeless

<u>Commissioning guidance for London on health and care for people who are homeless</u> was published by the London Homeless Health Programme in 2016.

The London Homeless Health Programme was established in response to the 'Better Health for London' report which suggested Health and Care commissioners should develop a pan-London, multi-agency approach to healthcare for the homeless and rough sleepers. It outlines 10 commitments for improving health outcomes for people who are homeless in London. Commissioners can use this document to find guiding principles in their work to improve health services for people who are homeless in their localities. Each commitment includes ideas and practical tips on how to commission high quality, timely and co-ordinated healthcare for people who are experiencing homelessness. The work builds on the peer-led consultation and evaluation report More than a statistic. The Commissioning Guidance outlines how commissioners can respond to the lived experience of people who are homeless and their views about their health and the health services they access.

The London Homeless Health Programme has also partnered with Groundswell to produce a card that reminds GP receptionists and other practice staff of the national patient registration guidance, which confirms that people do not need a fixed address or identification to register or access treatment at a GP practice.

Point of contact: https://www.uhanabeautrica.com

E 6.12 A CCG risk share arrangement to fund accommodation for TB patients with NRPFs in London

To date in London the funding of accommodation for TB patients who are homeless and have no recourse to public funds (NRPFs) has predominantly been managed in an ad hoc manner. This has required a business case to be developed each time accommodation is needed, along with evidence of the Public Health rational for providing accommodation.

The London Clinical Leadership Group (a subgroup of the London TB Control Board) advocated for a more efficient and equitable way to manage these cases. The London TBCB engaged with the TBCB Lead CCG and the Chair of the Office of CCGs in London to progress this. A business case for a risk share arrangement between all London CCGs to fund accommodation for TB patients who are homeless and have NRPFs was developed and tabled for discussion with the Chief Officers from London's 32 CCGs. The business case was accepted and an operational policy and governance structure has been developed.

All patients will require a full assessment of their eligibility for housing and other benefits in the first instance, and only those who have NRPFs, are on treatment for TB and currently homeless, will be referred to this pathway. Accommodation will be linked to treatment compliance and is only for the duration of treatment.

Fundamental to the development of this business case was gathering data to quantify the scale of the problem. This demonstrated that although the numbers of patients with TB and NRPFs were small each year, it was unpredictable; with almost all CCG areas affected over three years, not just high incidence areas. Additionally, the advice and support of the commissioning representatives on the TBCB was vital to progress the business case through the appropriate channels.

Please contact the project leads if you would like to see examples of documentation to support this approach to providing accommodation for patients with NRPFs.

Project Contact: Johan van Wijgerden – London TB Programme Manager, Anita Roche – TB lead PHE London

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Chapter 7: Local government and its role in tackling TB in USPs

People in USPs with TB typically have multiple complex problems that require an integrated health and social care approach. Local authorities are well placed to ensure a joined up approach to holistic TB care and support including social care, housing support, crisis loans and benefits, substance misuse services, and voluntary sector assistance. By tackling TB in USPs, local authorities, in partnership with the NHS, can help reduce health inequalities in communities.

The structural reforms initiated by the <u>Health and Social Care Act (HSCA12)</u> [73] have had a profound impact on the way public health is organised, commissioned and delivered. Local authorities are now responsible for improving the health of their local population and for commissioning public health services in their areas which include specialist substance misuse services, sexual health and family planning, children's 0-19 public health nursing, NHS health checks and healthy lifestyles services such as stop smoking and weight management.

Given the role of DsPH in reducing health inequalities in their boroughs, tackling TB amongst USPs is a key priority. TBCBs and other TB stakeholders need to engage meaningfully with local authorities to address the holistic medical and social care needs of people with complex lives who have TB.

In the new health and social care structures, post April 2013, local authorities have a statutory duty to establish Health and Wellbeing Boards (HWB). The HWB is a formal subcommittee of the local authority which includes a range of stakeholders such as the NHS, CCGs and local authority. The HWB has a duty to show leadership around integrated working between the NHS, social care and Public Health. It is a statutory duty of Health and Wellbeing Boards to publish an up to date Joint Strategic Needs Assessment (JSNA) to identify public health needs, gaps and priorities. Another statutory duty of the HWB is to produce and publish a Joint Health and Wellbeing Strategy (JHWS) detailing how public health and health issues can be addressed, based on the priority areas [74] of the JSNA [75].

7.1 The generic role of local authorities in supporting USPs with TB:

Local authorities have a democratic mandate as councillors are elected by the people. In relation to USPs their key roles are:

• Strategic roles:

- I. establishing Health and Wellbeing Boards (HWB) where the issues of health inequalities and the under-served maybe tackled
- II. producing a JSNA and JHWS.
- III. incorporating the TB agenda within the local authority health protection or other relevant forums

• Direct / frontline roles:

- I. Providing housing for vulnerable clients (working with the NHS in a joined up way under CCG funded housing agreements where relevant). Along with their public health responsibilities local authorities have a duty to provide social care services such as residential accommodation for those who are in need of care due to their age, illness or disability. Being diagnosed with active TB can mean that patients on a case by case basis, based on certain vulnerability factors, may be eligible for accommodation. Local authority housing departments make decisions on homeless applications based on statutory right to housing based on criteria set out in the Housing Act 1996 [63] and the homelessness code of guidance for local authorities [76]. However, DsPH, housing and social care colleagues should work together to ensure that patients with non-infectious TB and social issues, especially those with or no recourse to public funds can access appropriate housing.
- II. Social workers proactively engaging with clients with chaotic lives Local authority social work departments (via their statutory social services function) have social workers specialising in different areas including mental health social work and substance misuse social work. These professionals work with clients with social risk factors who may experience even more difficulties as a result of their TB. Local authorities can also assist vulnerable persons with crisis grants and hardship loans.
- III. Using all the assistance tools at the local authorities' disposal eg crisis grants and loans and applying Part 2A orders as required. Local authority heads of environmental health may be asked to activate a Part 2A Order as outlined in the Health Protection Act [77] for people who are infectious and not complying with medical treatment or isolation. The Regulations of the Public Health Act include legal powers, available to enforce actions to protect public health. They are available to local authorities and involve an application to a magistrate. Local authorities would typically

use these powers in consultation with other organisations, such as PHE, the NHS or the emergency services.

7.2 The role of the local authority Director of Public Health in supporting USPs with TB

Directors of Public Health (DsPH) work with their CCG colleagues to ensure the quality of acute services including TB services; they influence offender health by providing strategic direction as board members of Strategic Community Safety Partnerships (which also impact on persons leaving prison services), are members of Prison Health Partnership Boards which ensure the quality of prison healthcare. DsPH also work with CCGs on primary care initiatives including GP registration of vulnerable or marginalised people; commission substance misuse services (important as substance misuse is a recognised risk factor for TB) and commission HIV prevention programmes at a regional and borough level (HIV being another key risk for TB). In addition, DsPH often have advisory roles around homelessness, benefits, chaotic persons and similar issues.

7.3 What can local authorities do for USPs with TB?

- promote local leadership of TB and USPs at all levels such as local leadership through elected members, strategic leadership through the HWB and health leadership via CCGs, wider NHS partners and public health teams
- include TB in the local authority's JSNA and the JHWS and ensure TB is on the agenda of the HWB and in the STPs
- encourage multi-agency working on TB via the HWBs. These boards have a role in oversight and challenge of NHS commissioners to ensure that they achieve and sustain effective TB control. This could include identifying if indicators such as treatment completion rates or key performance indicators (KPIs) determined by the local TBCB, are being met
- in areas of high incidence, consideration should be given to appointing a senior TB coordinator role, perhaps from the local authority public health team
- encourage local health service commissioners to prioritise the delivery of appropriate clinical and public health services for TB, especially in areas where TB rates are highest, and drive improvements in early diagnosis and appropriate treatment, both key to reducing TB rates in England
- ensure a joined-up, multi-agency approach to holistic TB patient care and support by fully involving council departments, such as social care, housing, and benefits and other statutory agencies such as the NHS. Assist with supporting an individual's social needs where possible which can improve treatment completion rates
- encourage the NHS to work with local authority housing departments, encourage the formation of multidisciplinary TB teams and encourage NHS commissioners, local authorities and hostel accommodation providers to agree

a process for providing accommodation to those who are vulnerable or otherwise ineligible for funded accommodation (<u>see chapter 6 - Housing chapter</u>)

- consider how third sector organisations can help improve access to services and patient support and encourage and empower the voice of people affected by TB. These groups are important sources of support and role models for others, as well as their participation in commissioning decisions and the design of health programmes
- help with awareness raising in Children's Services, Adult Services, Housing and Benefits, Citizen's Advice; as the support to TB patients benefits from the use of the "whole family" approach ie that if an adult has TB that the impact on any children is considered or if a child has TB the impact on education etc <u>Tackling</u> <u>Tuberculosis - Local government's public health role</u> [78] could usefully support this recommendation
- facilitate appropriate access to information and advice on TB, its symptoms, diagnosis and treatment for USPs such as the homeless
- work, via the DPH, with CCGs and NHSE to ensure that screening, immunisation and treatment services reach out to diverse populations and are accessible to deprived or marginalised sections of the population
- consider undertaking a Scrutiny Committee review of TB in areas of high incidence

7.4 Is there a role for Council Scrutiny of TB?

Some councils have carried out Scrutiny Reviews focusing on services available for people with TB. Whilst access to services and quality are important topics, prevalence of TB within different communities (for example, migrant and transient communities), and strategies to prevent the spread of disease are other ways to tackle this issue. Council scrutiny can play an important role bringing together public agencies and civil society organisations to establish the extent to which TB issues are prevalent in local areas and to ask questions about planning for better outcomes from services.

7.5 Recommendations for TB Control Boards:

- 1. TBCBs to ensure that a DsPH is on the TBCB to represent the views of the local authority on TB.
- 2. TBCBs are encouraged to work with DsPH in areas of high TB incidence to ensure that TB and the needs of the under-served with TB are included on the agendas of the Health and Wellbeing Board and local Health Protection Board (where they exist) and are included in the local JSNA and Joint Health, Wellbeing Strategy and STPs.

- 3. TBCBs to give due consideration to the "roles" of the local authority (as outlined above) and support and use these where appropriate to take forward work to tackle TB in their USPs.
- 4. TBCBs to encourage local authorities, in areas of high incidence, to appoint a Councillor as a "TB Champion" – someone who can put political weight behind the issue and support the local authority public health department and NHS to enable their voices to be heard.
- 5. TBCBs to ensure that DsPH and local authority "TB Champions" (as outlined above) are aware of specific local work to tackle TB such as the new migrant LTBI testing and treatment programmes where they are in place.
- 6. TBCBs to encourage joined up working across agencies and the inclusion of TB and USPs in needs assessments that take full account of the work that the local authorities undertake.
- 7. TBCBs to work with local authority housing and social care departments, NHS TB services, NHS commissioners, and hostel accommodation providers to agree a process for providing accommodation to those who are vulnerable and have TB, including those ineligible for state funded accommodation (see chapter 6 for more information).

Chapter 8: TB Control Boards, Clinical Commissioning Groups and USPs – roles and responsibilities

8.1 TB Control Boards

Tackling TB requires the coordinated action of many partners, working together across local authority, CCG and NHS boundaries. In 2015, PHE and NHS England launched the Collaborative TB Strategy for England [2]. Seven TB Control Boards (TBCBs) to support the local delivery of the strategy were established. The TBCBs each cover a defined geographical footprint and provide strong local leadership bringing together many stakeholders and supporting them to collectively improve local TB control.

Figure 8.1: TB case notification numbers by TB Control Board, England, 2015



TB burden

8.2 Responsibilities of TB Control Boards

The generic responsibilities of the TBCB, as laid out in the <u>Collaborative TB Strategy for</u> <u>England</u> [2], include:

- to plan, oversee, support and monitor all aspects of local TB control, including clinical and public health services and workforce planning
- to work closely with local clinical and TB networks and engage with other key
- stakeholders such as local government and the third sector
- to include representation from PHE, NHS England, CCGs, local authority directors of public health and social care, the NHS (primary and secondary care, adult and pediatric TB specialists and front line nursing representation), patient advocates and the third sector
- to develop a local TB control plan based on the national strategy, local services, local need and evidence-based models
- to agree and ensure the appropriate commissioning of TB services, and through collaborative working and the use of existing accountability arrangements, hold providers and commissioners of clinical care and public services to account
- to ensure TB cohort review is undertaken regularly (every 3–4 months) and fed back to the TBCB, commissioners, TB service provider management and local directors of public health; and that appropriate action is taken as a result of the outputs of cohort review
- to ensure full and consistent use of current national guidelines in particular those of the National Institute for Health and Care Excellence (NICE)
- to ensure an appropriate workforce strategy is developed and implemented
- to ensure the needs of USPs are addressed and health inequalities are reduced
- to involve USPs in designing and shaping services to ensure they are responsive to the specific needs of these groups
- to ensure the delivery of quality-assured local programmes of new entrant latent TB screening focused on areas of high TB incidence
- to consider commissioning a team to undertake extended community contact
- tracing of incidents and outbreaks
- to ensure appropriate TB awareness-raising in collaboration with the third sector, local authorities and other organisations who provide this

With respect to USPs the TBCBs role is very much that of working to understand and meet the needs of the USPs as part of wider strategies to prevent and control TB at a local level. TBCBs have a strategic leadership role: creating the environment for, and supporting collaboration across and between partner organisations, enabling these partners to work more synergistically; encouraging the sharing of best practice and signposting partners to existing resources that will further support them in their work. Additionally, the TBCB has an advocacy role, ensuring that the needs of vulnerable and marginalised groups are understood, not only to prevent TB but also to address health

inequalities. TBCBs do not commission or provide services directly but work through other agencies to achieve shared goals and deliver improved TBCBs.

Given the complex social, as well as healthcare needs, of many people within USP populations, delivering effective TB control at a local level requires work across health and social care partners (commissioners and providers), voluntary and third sector organisations, patient advocates and representatives, local government officials and elected members, as well as the wider community. TBCBs should reflect the needs and priorities of their local communities but also take advice and support from national bodies in identifying and disseminating good evidence-based practice. Work at TBCB level may also provide examples of evidence based practice and should be shared with others to improve health, and support delivery of effective care.

Along with these overarching TBCB roles, there are many specific actions that TBCBs can undertake to support the work to reach out to USPs and these are detailed in the individual chapters within this USP resource.

8.3 Responsibilities of Clinical Commissioning Groups (CCGs)

CCGs are responsible for funding diagnosis and treatment of TB in primary care and secondary care. This includes multi drug resistant TB (MDR-TB) except for the prescribing and cost of two drugs (Delamanid and Bedaquiniline) which are the responsibility of NHSE specialised commissioning.

It is recommended that CCGs, should work with their TBCB and NHS England on implementation of the Strategy and its impact on care of people with TB from USPs.

To improve access to TB services among USPs, and deliver on their responsibilities to reduce inequalities, **CCGs are encouraged to:**

- commission and support targeted TB case finding and prevention activities, which focus on high-risk groups including those from USPs
- commission appropriate access to TB services, treatment and support to enable USP patients to complete treatment
- with particular reference to the homeless, CCGs are encouraged to consider and utilise a new publication from London's Homeless Health Partnership, "Homelessness Health Commissioning for London"
- support TB awareness raising among healthcare workers by utilising the TB resources from <u>TB Alert</u>
- raise awareness of the RCGP TB e-learning module in primary care
- continue the roll-out of latent TB programmes in priority CCGs, targeting all communities including USPs, to encourage those at risk of developing TB to have an LTBI test

- support healthcare staff to use the <u>latent TB toolkit</u> [79] to enhance the delivery of latent TB programmes
- develop appropriate arrangements with partner organisations ie local authorities, third sector organisations on appropriate access to services, treatment and support to enable USP patients to complete treatment
- work with local partner organisations on actions agreed by local TBCB to support of the wider implementation of care for TB patients from USPs which may include appropriate outreach arrangements

Chapter 9: Community, Voluntary Sector and Programmes of Work

The Voluntary, Community and Social Enterprise Sector and TB Control Boards

The Voluntary, Community and Social Enterprise (VCSE) sector – or third sector – is crucial to the sustainable delivery of health and wellbeing. VCSE organisations are an integral part of the wider health and care system, and they operate extensively within it. Many specialise in working with USPs, either directly or indirectly, and are a key partner for TBCBs and statutory services to assist them in engaging with these client groups and meeting their duties to identify and reduce the health inequalities.

The VCSE sector is not a homogeneous grouping. It is recognised and valued for its diversity and flexibility, and for the added social value and impact it brings. England's third sector organisations, ranging from small community-based groups to established household name charities, have many comparative advantages. First, they have a deep understanding of different populations. They might be staffed by people from the demographic they assist, such as refugee and migrant organisations, or by people who have been through a similar life experience, such as homelessness. Second, they have built trust among the people they support, having provided help consistently and over a long period. And third, as they are often embedded within the communities they serve, they have better access than most statutory agencies.

Just under a quarter of England's VCSE are involved in the provision of adult health and/or social care and support service with the statutory sector spending £3.39 billion on health services provided by voluntary and community organisations. Other's may specialise in working with particular groups, for example, refugees, homeless people or Black, Asian or minority ethnic communities. The VCSE sector can help statutory services to engage more effectively with people from USPs; for example, a voluntary organisation providing mentoring support to a person being released from prison can assist in ensuring continuity of care, support that person to access health services in the community, and accompany them to appointments to reduce the likelihood of nonattendance while they build trust in the health service.

In some areas you will also find community interest companies (CICs), some of which previously had their roots as delivery arms of primary care trusts. While generally, less embedded in local communities than other voluntary sector organisations, these will have extensive experience as commissioned providers and are a key part of the mix of local stakeholders. There are different types of CICs besides the type described here which have floated off from the NHS. Many CICs are small organisations, often started by ex-service users to meet a particular need or work in a specific local area.

The VCSE sector has a strong reputation because of the relationship it has with communities and client groups and the often innovative way it delivers services. Its understanding of, and access to, specific population's means it can support TBCBs and statutory services in a number of ways including:

- providing information on USPs and understanding their needs including those from communities with protected characteristics eg race, age, disability, religion and belief derived from the <u>Equality Act 2010</u> [79]
- engaging, developing relationships with, and building trust with USPs to design appropriate services
- understanding 'what works' through a person-centred approach
- delivering outcomes that the public sector finds it hard to deliver, either working independently or on partnership programmes
- acting as an advocate and facilitator for USPs to ensure that their voice is heard

In England there is less history of partnering and commissioning the third sector in TB than in HIV or sexual health. <u>TB Alert</u>, the UK's national TB charity, has been addressing this by training a wide range of third sector organisations to understand TB, how it affects the people they support and how they can contribute to improved health outcomes; and facilitating partnership building between the statutory and third sectors. This is complemented by a range of resources under The <u>Truth About TB</u> campaign which supports national and local TB awareness raising, training and case finding work.

The VCSE sector has a key role to play in reaching USPs. The <u>Collaborative TB</u> <u>Strategy for England</u> [2] stresses the critical importance of bringing together all local agencies including third sector partners in order for the strategy to succeed. The third and voluntary sectors form one of the four pillars of the WHO's End TB Strategy for a strong coalition with third sector/civil society organisations and with communities themselves.

These organisations can work with statutory TB programmes in many ways. Some might simply distribute leaflets or display awareness posters. But at the more involved end they can work as key commissioned partners in case finding or providing clinical support, working alongside public health, social care or outreach teams. This usually involves well-established organisations staffed by professional teams who have experience of being commissioned across varying health issues.

Additionally, a number of VCSE organisations work with PHE, Department of Health, and NHSE in the Health and Care Strategic Partners Programme. This brings together 22 VCSE organisations and consortia as a source of expertise that allows policy makers to improve health and care services. For further information on the partnership working on prison issues please contact Hazel Alcraft - <u>Hazel.Alcraft@clinks.org</u>

Resources

For further information on national, regional and local VCSE organisations please contact:

- Regional Voices http://www.regionalvoices.org/
- NAVCA https://www.navca.org.uk/
- Volunteering Matters https://volunteeringmatters.org.uk/
- National Voices http://www.nationalvoices.org.uk/

For specific work with offenders and people in contact with the criminal and youth justice systems contact:

Nacro - https://www.nacro.org.uk/ Clinks - http://www.clinks.org/

For specific work with families contact: Family Lives - http://www.familylives.org.uk/

TB Alert provides information for the public and a range of resources for professionals including health promotion, professional education, patient support, and guidance documents. www.thetruthabouttb.org/

9.3 Exemplars of good practice of working with the Voluntary, Community and Social Enterprise Sector

E 9.1: LTBI and BBV health checks in Wolverhampton with the Roma community

Wolverhampton recently started a pilot scheme looking at enhanced health checks for the Roma community in a GP surgery with the aim to register and engage with primary care. As part of this enhanced health check LTBI and BBV checks are being conducted.

Project Lead: Steve Barlow – Health Protection Lead Practitioner Contact details – steve.barlow@wolverhampton.gov.uk

E 9.2 TB Awareness raising sessions for those working with USPs in Shrewsbury and Telford

<u>For VCSEs</u>: In 2013, a gap in knowledge around TB was noted in agencies that engage with USPs such as people with a history of drug or alcohol misuse or the homelessness. To improve the lack of knowledge the local TB team proactively approached the agencies offering TB awareness sessions. A number of awareness sessions for agencies in Shrewsbury and Telford have now been delivered through the Telford and Wrekin homelessness partnership, housing trusts and similar relevant organisations eg <u>Telford After Care Team</u> (TACT).

The aim of the sessions was to both inform and supply information on TB the disease and on how the TB team can be accessed directly for any enquiries, direct referrals including self-referral.

<u>For General Practitioners</u>: In 2013, the TB team initiated an awareness raising campaign among GPs about TB and under-served groups as well as new entrants from high incidence countries. Initially they tried to infiltrate the Certificate of Personal Effectiveness (CoPE) training days in the county but this did not prove successful. However, provision via a general GP newsletter of TB information has been well received. This enabled the team to update the GPs about the services available and contact details. Since 2015 the team have targeted GP practices where large numbers of immigrant population are registered.

<u>For Practice Nurses/ local Community Nurses and Prisons</u>: The TB team have been actively involved via the education facilitator with the practice nurse forum and community infection control nurses on raising awareness of TB. These teaching sessions have been well received and improved direct referral of patients. They have also enabled the TB team to build a good working relationship, especially successful with the local prison service.

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Similar work is also being carried out by the Birmingham and Solihull TB services.

E 9.3 Greater Manchester Public Health Network policy round table

Addressing TB Stigma in Greater Manchester

Purpose of the round table: TB is commonly associated with stigma: discrimination can mean people with symptoms of TB delay seeking help, therefore increasing their risk of becoming seriously unwell and infecting others.

In 2015, Greater Manchester (GM) Public Health Network hosted a policy round table which aimed to bring together expert practitioners and policy makers including VCSEs to identify potential GM actions required to address TB stigma to decrease TB incidence, reduce health inequalities, and ultimately eliminate TB as a public health problem in GM.

A number of recommendations were proposed to address TB stigma in GM:

1. Collaboration between GM local authorities, third sector, NHSE and PHE to deliver targeted outreach interventions and one-to-one support within identified communities in order to raise awareness

2. Consideration to be given to the development of <u>an effective GM communications</u> <u>strategy</u> that targets the public and the wider workforce in order to stimulate and develop a social movement to change people's perceptions of TB and address TB stigma without increasing levels of anxiety or polarisation.

3. <u>Training and development</u> to be delivered to <u>the wider health and social care</u> <u>workforce</u> in order to raise awareness of TB and to address TB stigma. Staff should have the necessary skills to address socioeconomic needs of the targeted communities in order to facilitate access to local services in culturally-competent ways.

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Similar work is also being carried out by the Joint Yorkshire and Humber and North East TBCB

Chapter 10: Models of Care for USPs

TB affects marginalised populations, who may or may not have access to social support, such as the migrant and homeless populations as well as those dependent on alcohol and substance misuse and those with mental health issues. A few coordinated approaches are currently in use which include clinical as well as community / social support through the duration of treatment such as the London Find and Treat Service, Olallo House to provide integrated care for those with TB and substance / alcohol misuse. Other examples of models of care that meet the needs of the USPs include the use of pharmacies to support DOT in the community to ensure treatment completion; Video (or virtually) observed therapy, an innovative approach currently being piloted which bridges the gap between the care-giver and patient and limits the time and financial cost for DOT; specialised clinical services to support contact tracing in varied USP settings such as developed by the London TB Extended contact tracing (LTBEx) team and low cost solutions to support treatment adherence.

This chapter draws together different models of care for USPs, providing more detail for each, so that those working with USPs, can review how they might locally meet the needs of this group and can then consider appropriate use of these models locally.

10.1 Diagnosis, treatment and social care integration: Find and Treat Service

Find and Treat are a specialist, London-based outreach team that works alongside over 200 NHS and third sector front-line services to tackle TB among homeless people, those who misuse drugs or alcohol, vulnerable migrants and people who have been in prison. TB is a disease of poverty and inequality and these groups have the highest rates of TB and the greatest risk of onward transmission. The Find and Treat team is multidisciplinary and includes: former TB patients who work as Peer advocates, TB nurse specialists, social and outreach workers, radiographers and expert technicians. Their job is to take TB control into the community, find cases of active TB early and support patients to complete a full course of treatment.

The service spans the TB pathway from detection, to diagnosis and onward care. To 'Find' TB cases Find and Treat raise awareness among service users and frontline professionals and screen almost 10,000 high risk people each year using a Mobile Health Unit, a holistic one-stop-shop that offers digital radiology, Genexpert to rapidly detect pulmonary TB, a range of immunisations, point-of-care tests and other health opportunities. The screening service covers every London Borough and supports PHE to manage outbreaks of TB nationally.

In addition, TB clinics and frontline third sector partners across London and nationally refer around 300 complex and socially vulnerable patients a year to the outreach team asking Find and Treat to help locate TB patients who have stopped treatment and are no longer attending their local TB service, or patients who require community DOT or that need practical assistance and advice on accommodation.

In partnership with <u>Groundswell</u> Find and Treat recruit, train and support former TB patients who have experienced homelessness to work as Peer advocates in their multidisciplinary team. The Peers provide an authentic voice to other service users and professionals and can increase screening uptake, support people to get cured, improve awareness and tackle stigma.

The Find and Treat service has been independently evaluated by NICE and the Health Protection Agency (HPA now PHE) who both demonstrated that it is highly cost effective and potentially cost saving. The work of Find and Treat is vital to addressing health inequalities in London. As evidence of its impact and support to patients the Find and Treat service has managed to locate and re-engage on treatment 75% of patients 'lost to follow up' by local TB services and assisted 84% of TB cases diagnosed on the Mobile Health Unit to complete treatment as compared with 83% of all cases nationally, whether homeless or not.

Find and Treat service is recognised by the WHO, ECDC and NICE as an exemplar of best practice for 21st century TB control and has been independently evaluated as highly cost effective. The integration of POC diagnostics for BBV, provision of essential vaccinations, targeted IGRA testing for a one-stop-shop LTBI service and support to register with primary care providers has made the service cost effective and potentially cost saving [80].

Find and Treat works with leading academics internationally to innovate and evaluate health interventions designed to improve care and strengthen disease control among vulnerable and underserved populations. Successful translational research innovations include establishing a Peer support service with the charity Groundswell, a residential holistic TB care facility in London with the charity St John of God Hospitalier (Olallo House) and a Video Observed Treatment service across London and nationally in partnership with UCLH and the University of San Diego. Find and Treat are now funded by the EU Horizon 2020 programme to replicate the service model in Romania and Bulgaria and are working in close partnership with the Dublin SafetyNet service to establish the model in Ireland.

The Collaborative TB Strategy recommends consideration is given to "expansion of an outreach service, similar to the 'Find and Treat' service in London, to the rest of England" with the idea being that this will go some way towards meeting the needs of USPs. A TB pilot was set up in Birmingham to screen USPs on two separate occasions

in 2014 and 2015 see E 10.1. A national TB outreach programme could offer: integrated detection and management of TB and other major public health infections; improved health of homeless, vulnerable and excluded people and could provide an increase capacity to manage incidents and outbreaks nationally.

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Box E10.1: Ad-hoc screening of USPs in Birmingham, Sandwell and Dudley using the mobile x-ray unit and Find and Treat

The project was jointly funded by Sandwell and West Birmingham Hospitals Charitable Trustees, Dudley Metropolitan Borough Council Public Health and PHE West Midlands (2014 and 2015). TB screening using the Find and Treat mobile x-ray unit took place at hostels, soup kitchens and homeless centres in Birmingham, Sandwell and Dudley over 6 days in 2014 and again in 2015. Pre-screening meetings were held with organisations and clinical staff to talk about the programme and the Find and Treat Team worked closely with Mango Hoto a local African Community Leader. Find and Treat agreed a joint care pathway with the Birmingham TB Service.

The Find and Treat team collected data on patients, screened them with a chest X-ray and undertook BBV testing and gave flu vaccines. TB service staff (medical and nursing) and PHE staff provided onsite support and awareness raising information.

- in July 2014: Over 6 days a total of 651 people were screened and 13 referrals for further assessment were made
- in July 2015: Over 6 days a total of 697 persons were screened and 20 referrals for further assessment were made including 2 hospital admissions

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10.2 A 'One Stop' service - Olallo House offering accommodation and social support to improve TB treatment completion

The Olallo House is an accommodation and support service in Euston, central London which caters for homeless individuals and couples; it offers 5 rooms for the care of people with TB. Olallo House clients include migrants, non UK nationals who were/are street homeless with NRPF. They also accommodate UK nationals at risk of becoming homeless and affected by substance misuse, dual diagnosis, mental and/or physical health needs (TB, HIV and Hep C). Olallo House enables an individual patient centred holistic plan to support those with TB to complete their TB treatment while addressing other social needs leading to recovery (eg ESOL, employment, social relationship and addiction management).

Patient assessment for eligibility can be initiated while a patient is in hospital. The appropriateness of the placement and funding negotiations are undertaken collaboratively by the Olallo House TB Coordinator, Find and Treat and with funders (usually CCGs). Once in Olallo House patients participate in a specifically designed protocol for DOT.

Olallo House is run by a highly skilled and multi-lingual team of professionals. They include members who can speak and communicate in a variety of languages including English, Irish, Polish, Russian, Portuguese, Lithuanian, Spanish, French, Italian, German, Slovakian, Ukrainian and Romanian. The professionals supporting the patients are trained and cater to individual patient needs including DOT, health and well-being, specialist one-to-one key worker, group and individual support plans, employment, resettlement, coaching, chaos management and reconnection support.

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10.3 The Housing First Model

The Housing First model is a means of meeting the needs of people with complex and multiple needs eg, people with drug or alcohol problems and experience of the CJS by housing them first and then supporting USPs with complex needs from a stable and secure environment. Accommodation is provided alongside wrap-around support; it is not a pre-requisite to complete treatment or overcome other 'hurdles' before accessing accommodation. This model is one way in which Birmingham and Coventry seek to meet the needs of people with TB who are homeless, and has also had success in London. The target client groups for Housing First is predominantly rough sleepers (71%) and those with multiple and complex needs.

10.4 Integrated care plans for TB services and substance misuse services

In order to ensure that treatment interventions for TB and substance misuse are fully aligned in Bradford and Airedale the TB service in October 2015 developed an integrated care plan for TB positive substance misuse service users.

In practical terms this translates into service providers engaging with the Fresh Start Recovery Hub (Drug Treatment Service), women's services, hostel services, substance misuse services and community drug and alcohol services including mental health. Using their wider formal and informal networks a single integrated care plan is created with consent to share information established with the service user.

At the start the substance misuse service and TB Service agreed a template "Integrated care plan for TB and Substance Misuse "and this is then adapted to meet the needs of each individual TB patient.



The integrated care plan

The integrated care plan protocol:

- is documented with the relevant service records
- is reviewed at 6-weekly intervals (or more frequently)
- includes a TB treatment plan and key contact details
- includes a substance misuse treatment plan and key contact details with specific reference to:
 - retention in treatment
 - treatment stability
 - accommodation stability

- frequency of appointments
- the wider support networks and key contact details (formal and informal)
- how access and retention for TB treatment and medication compliance will be supported and by whom
- the agreed contingency planning for and response to non-attendance with any provider with specific reference to an agreed list of supportive contacts and addresses that can be contacted/method of contact in all situations of non-attendance
- integration of pharmacy medication protocols where relevant
- pharmacy integration (where service user is on opiate substitute therapy)



Care pathway

SMS: Substance Misuse Service

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10.4 Pharmacies providing DOT

Currently, there are 11,500 pharmacies in England, located on the high street, in supermarkets and in every shopping centre. They are easily accessible, with long opening hours, with trusted professionals and staff that reflect the social and ethnic backgrounds of the communities they serve. 95% of people are within a 20 minute walk of a pharmacy and access is greatest in the most deprived areas.

TB patients, especially those with complex issues such as those in USPs, do not always take their medicines as intended or complete the whole course, with the associated worse outcomes, potential to develop drug resistant TB and become infectious to other people. Treatment completion was lower for drug sensitive cases notified between 2010 and 2014 with at least one SRF (75.6%, 399/528), compared to cases without a SRF (87.0% 4,287/4,928) at the last recorded outcome (see Appendix 1: table A1.5).

One way to improve the taking and completion of TB treatment would be for pharmacists to be commissioned to provide a supervised TB drug administration scheme or DOT. Many pharmacists and or pharmacy technicians across the country are commissioned to provide a supervised administration scheme for methadone and buprenorphine, and similar scheme for TB treatment could potentially be set up as demonstrated in Birmingham (E10.2). This service would have to be commissioned locally by CCGs, who would develop a service level agreement, which would set out the requirements of the service and the associated funding. Pharmacists are already familiar with providing such a service to people who are addicted to, eg diamorphine, little to no additional training would be required for the provision of the service for TB patients. If the commissioner recommends, the pharmacist could be commissioned to provide the service in people's homes. This would of course require additional governance arrangements, eg safeguarding and robust governance. In addition, pharmacy teams could provide advice on how to take TB medicines to improve adherence and monitor side effects referring as necessary back to the TB service team if concerned.

Evidence exists to show that people who access community pharmacies may not always access other conventional NHS services. Community pharmacies could be specifically targeted to reach out to USPs in the community including, for example, asylum seekers, people from ethnic backgrounds homeless, people who misuse drugs or alcohol and travellers. Trained pharmacy teams working alongside other primary or secondary care professionals could also help support TB patients to take their medicines as intended having being involved in the treatment decisions.

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E10.2 Directly Observed Therapy (DOT) via the pharmacy route in Birmingham: Nishkam Pharmacy and Birmingham and Solihull TB Service

On occasion TB patients seen at the Birmingham Chest Clinic need more intensive treatment monitoring due to risk factors for patient non-compliance. This is delivered through DOT.

DOT is the observation of a person taking his / her prescribed medication for the treatment of TB disease or TB infection. This requires a person who has received training to observe the patient take their TB medication. DOT is provided by health care workers, but where adequate training and supervision has been provided, DOT may be provided by non-health care workers who work in a variety of settings including pharmacies, homeless centres, hostels and drug and alcohol centres etc. In Birmingham DOT for some patients is offered by the Nishkam Pharmacy.

Where DOT is provided by someone other than the patient's specialist TB nurse or Case Manager, the TB case manager remains responsible for the total management of the patient and must support the provider of DOT and oversee the service provided by other organisations.

With respect to DOT at Nishkam Pharmacy, if a patient with TB needs DOT and lives near the Nishkam Pharmacy, they are risk assessed by their case manager / specialist TB nurse and if appropriate offered pharmacy DOT. The dispensing pharmacist is contacted and trained in how to provide DOT and the paperwork to be completed. DOT is prescribed on an FP10. The dispensing pharmacist and TB nurse jointly meet the patient at the pharmacy and discuss the patient plan and agree dispensing days. The nurse stays in weekly phone contact with both the patient and pharmacy and if the patient fails to attend on any one day the pharmacist informs the TB Service. On a monthly basis the TB nurse collects the DOT charts from the pharmacy. An SLA is in place between the pharmacy and the TB Service and DOT provision is monitored by local key performance indicators (for further information please contact Hanna Kaur).

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10.5 Video (or virtually) Observed Therapy

Innovative approaches are currently being piloted which bridge the gap between the care-giver and patient and limit the time and financial cost of frequent travel to healthcare services for DOT and in so doing increase adherence to treatment. Telephone and video communication enables health professionals to watch their patients take their medication [81], address patient concerns and provide advice and support [82]. Video (or virtually) observed therapy (VOT) has been successfully used with TB patients in London since 2007. Findings from a trial in London of VOT against traditional DOT has shown huge potential to improve adherence [83].

The London based outreach team of Find and Treat was established to find cases of TB among vulnerable groups. To ensure patients take the full course of TB treatment they offer DOT and in some cases VOT.

Patients selected for VOT first receive face-to-face instructions from the person who will monitor the videos and do the follow-up. Thereafter, the patient films themselves taking their medication and submits the videos; at the same time they can also report side-effects and ask questions in the videos. The Find and Treat staff monitoring the videos screen them to verify whether the treatment protocol is followed, send reminders, answer queries and provide support when needed.

As internet access is crucial to the success of this intervention, most patients are provided with a smartphone and/or data package. This functions as an incentive and also facilitates the communication between the patients and healthcare services, for example to set-up appointments and to send reminders.

Main advantages of the VOT alternative compared to DOT:

For the patient: more flexibility on when/where to take medication, saves time, improves confidentiality, improves adherence and gives a more active role in own treatment. For healthcare services: saves money, increases productivity (more patients can be covered in less time), and reduces exposure of healthcare workers to TB.

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10.6 London TB Extended contact tracing (LTBEx) model

TB contact tracing is an important element of TB control and NICE recommends those who have had close and prolonged contact with cases of infectious TB should be offered screening. Where significant TB exposure has occurred outside of the household, for example at schools, workplaces, hostels and detention centres, it is called a TB incident.

London TB Extended contact tracing (LTBEx) was a pilot project that ran between January 2013 and March 2016. It worked with local Health Protection Teams (HPTs) to enhance the coordination and timely management of mass contact investigations for TB incidents in congregate settings, including schools, colleges, workplaces, prisons and hostels. The project was an innovative pan-London initiative combining both clinical and public health aspects of TB prevention and control. It provided a consistent approach to TB incident risk assessment, overcame cross-boundary issues and improved screening uptake and its efficiency. The team received referrals from HPTs and offered an end-toend service that could perform a risk assessment on behalf of the HPTs, provide effective communication with members of the public, service users and stakeholders; perform on-site TB screening at schools, colleges, hostels and other congregate settings; follow up the screening results, refer patients with positive results for further investigations; and collate the data on all TB contacts in a centralised database. Prior to the launch of LTBEx project in January 2013, TB incidents were managed by the four London HPTs and approximately 30 TB clinics in London. There were some shortcomings and gaps include variations in risk assessment and contact screening, geographical boundary issues, difficulties in arranging on-site screening, poor uptake of screening and poor data collection.

The LTBEx pilot data showed a significant increase in the uptake of screening of at least 25%, possibly due to the convenience of screening for service users in a familiar environment. Offering on-site TB screening, for example, at hostels and detention centres, made the service more accessible for the London USPs and allowed for the screening to be offered in a timelier manner. The screening yield was approximately 14% for latent and active TB (less than 1% for active TB). The data collected on contacts provides a unique dataset which will influence evidence based TB contact tracing. In addition LTBEx was well received by TB services and stakeholders' feedback from HPTs and TB clinics and service users has been very positive.

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10.7 Low cost solutions to support treatment adherence

Patients who struggle to take or complete their treatment often face barriers which can be overcome at very low cost relative to the resources and public health consequences associated with patients disengaging from treatment. Such barriers include having insufficient food to tolerate medication, lacking money for transport fares to attend appointment, or needing phone credit to stay in contact with clinicians. TB Alert's Patient Support Fund has helped fill this gap by making small grants, averaging around £200, in response to applications made by TB nurses or case workers. The positive impact of these grants is evidenced by an audit carried out in 2013 of grants to 50 patients. 22 of the patients had completed treatment, 21 were still on treatment, five were lost to follow up and two could not be evaluated. Excluding the patients still on treatment, 22 out of 29, or 76%, had completed treatment; this figure reaches 81% the patients who could not be evaluated are also excluded. This is a considerable achievement when considering the vulnerability and status of these patients, many of whom had no recourse to public funds, were homeless or destitute, had drug or alcohol dependency issues, were undocumented migrants or refused asylum seekers.

The provision of such forms of integrated clinical/social care should be a local responsibility. NICE (NG33) recommends that multidisciplinary TB teams improve adherence to treatment among the USPs using a flexible approach, as funds could be used to provide transport to clinics. However, the increase in demand for Patient Support Fund grants, coupled with the difficulty in raising funds from trusts and foundations, meant the programme had to be scaled back in 2014. Today only occasional grants are made.

A small number of localities including Birmingham have established such local funds. This should become the norm for all TB services. Local advocacy and decision-making should recognise the significant impact this low cost intervention can have to support treatment completion among USPs.

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Appendix 1: Additional Data Resources on TB in USPs

Epidemiological data, definitions and tables

Drug misuse is defined as problem drug use of illicit injecting drug use or long duration/regular use of illicit opiates, cocaine, and/or amphetamines, and/or daily/almost daily use of cannabis (or synthetic cannabinoids).

Alcohol misuse is defined as the patient's ability to self-administer the prescribed tuberculosis treatment regimen, in the absence of directly observed therapy, is affected by alcohol misuse or abuse (based on the clinical judgement of the case manager).

Homelessness and insecure housing tenure are defined as not having a permanent or secure accommodation of your own. This includes people who are sleeping rough, living in temporary accommodation such as bed and breakfast, hostels, hotels and squats and people who are involuntarily dependent on friends for accommodation.

Imprisonment includes incarceration in a prison and/or remand centre, juvenile institution or young offender's institution. It does not include migration detention or removal centres.

Local authority district	one	east social factor	Drug misuse		Alcohol misuse		Homel	essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
London											
Barking and Dagenham	16	4.5	5	1.4	4	1.1	4	1.1	9	2.5	359
Barnet	35	6.7	8	1.5	12	2.3	16	3.0	7	1.3	526
Bexley	11	7.5	6	4.1	4	2.7	1	0.7	4	2.7	147
Brent	115	7.7	30	2.0	65	4.4	36	2.4	14	0.9	1,490
Bromley	14	8.4	7	4.2	7	4.2	1	0.6	0	0.0	167
Camden	50	16.2	21	6.8	16	5.2	29	9.4	15	4.9	309
City of London	1	16.7	0	0.0	0	0.0	1	16.7	0	0.0	6
Croydon	43	7.0	13	2.1	13	2.1	19	3.1	9	1.5	610
Ealing	79	6.6	33	2.7	30	2.5	28	2.3	12	1.0	1,206
Enfield	56	12.7	24	5.4	18	4.1	24	5.4	22	5.0	442
Greenwich	51	8.2	16	2.6	21	3.4	12	1.9	21	3.4	623
Hackney	91	19.8	46	10.0	41	8.9	46	10.0	30	6.5	459
Hammersmith and Fulham	53	19.3	22	8.0	23	8.4	22	8.0	21	7.6	275
Haringey	73	13.7	35	6.6	23	4.3	25	4.7	21	3.9	534
Harrow	38	4.8	10	1.3	23	2.9	6	0.8	5	0.6	789
Havering	14	10.9	8	6.2	6	4.7	4	3.1	2	1.6	129
Hillingdon	55	8.0	23	3.4	22	3.2	17	2.5	12	1.8	684
Hounslow	46	4.7	15	1.5	18	1.8	10	1.0	11	1.1	973
Islington	80	21.7	35	9.5	30	8.1	38	10.3	39	10.6	369
Kensington and Chelsea	40	19.8	20	9.9	14	6.9	17	8.4	11	5.4	202
Kingston upon Thames	8	5.0	4	2.5	3	1.9	3	1.9	1	0.6	160
Lambeth	61	12.6	13	2.7	27	5.6	19	3.9	31	6.4	483
Lewisham	41	9.8	10	2.4	21	5.0	15	3.6	13	3.1	418
Merton	16	4.7	3	0.9	6	1.8	6	1.8	4	1.2	341
Newham	118	6.4	34	1.9	68	3.7	27	1.5	9	0.5	1,835
Redbridge	51	6.2	18	2.2	25	3.0	10	1.2	12	1.5	822
Richmond upon Thames	4	5.1	3	3.8	0	0.0	1	1.3	0	0.0	78
Southwark	46	8.5	11	2.0	19	3.5	17	3.1	9	1.7	543
Sutton	13	8.2	5	3.1	6	3.8	5	3.1	3	1.9	159
Tower Hamlets	68	10.2	42	6.3	25	3.7	34	5.1	23	3.4	668
Waltham Forest	64	10.0	32	5.0	15	2.4	29	4.5	19	3.0	638
Wandsworth	44	10.2	16	3.7	12	2.8	15	3.5	27	6.2	433
Westminster	68	21.6	34	10.8	19	6.0	45	14.3	17	5.4	315
West Midlands											
Birmingham	157	7.7	72	3.5	51	2.5	33	1.6	68	3.3	2,050
Bromsgrove	2	22.2	1	11.1	0	0.0	0	0.0	1	11.1	9
Cannock Chase	1	16.7	0	0.0	1	16.7	0	0.0	0	0.0	6
Coventry	46	7.7	22	3.7	19	3.2	11	1.8	18	3.0	599
Dudley	13	7.1	4	2.2	10	5.5	1	0.5	1	0.5	183

Table A1.1: Number and proportion of TB case notifications with social risk factors by local authority, England, 2010-2015

Local authority district	one	least social factor		Drug misuse		Alcohol misuse		essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
East Staffordshire	2	2.7	0	0.0	0	0.0	2	2.7	1	1.3	75
Herefordshire, County of	1	3.7	1	3.7	1	3.7	0	0.0	0	0.0	27
Lichfield	8	42.1	5	26.3	1	5.3	0	0.0	7	36.8	19
Malvern Hills	1	9.1	0	0.0	1	9.1	0	0.0	0	0.0	11
Newcastle-under-Lyme	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	30
North Warwickshire	1	5.3	1	5.3	0	0.0	0	0.0	0	0.0	19
Nuneaton and Bedworth	5	6.0	1	1.2	2	2.4	0	0.0	2	2.4	84
Redditch	1	2.0	1	2.0	0	0.0	1	2.0	0	0.0	51
Rugby	1	1.6	0	0.0	0	0.0	0	0.0	1	1.6	61
Sandwell	50	8.5	15	2.5	16	2.7	21	3.6	19	3.2	589
Shropshire	13	22.0	6	10.2	7	11.9	3	5.1	8	13.6	59
Solihull	4	4.3	3	3.3	0	0.0	1	1.1	3	3.3	92
South Staffordshire	4	23.5	1	5.9	0	0.0	1	5.9	4	23.5	17
Stafford	7	15.9	2	4.5	1	2.3	2	4.5	4	9.1	44
Staffordshire Moorlands	1	7.1	0	0.0	0	0.0	1	7.1	1	7.1	14
Stoke-on-Trent	24	11.8	6	3.0	14	6.9	7	3.4	6	3.0	203
Stratford-on-Avon	1	4.2	0	0.0	1	4.2	1	4.2	0	0.0	24
Tamworth	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Telford and Wrekin	1	1.8	0	0.0	1	1.8	0	0.0	0	0.0	56
Walsall	20	7.5	10	3.8	8	3.0	7	2.6	10	3.8	265
Warwick	7	9.2	3	3.9	4	5.3	3	3.9	1	1.3	76
Wolverhampton	50	11.4	13	3.0	9	2.0	17	3.9	27	6.1	440
Worcester	4	11.1	4	11.1	0	0.0	0	0.0	0	0.0	36
Wychavon	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	28
Wyre Forest	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	9
South East											
Adur	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Arun	6	15.4	2	5.1	2	5.1	3	7.7	1	2.6	39
Ashford	8	13.3	2	3.3	3	5.0	2	3.3	2	3.3	60
Aylesbury Vale	6	7.5	0	0.0	1	1.3	0	0.0	5	6.3	80
Basingstoke and Deane	1	1.5	0	0.0	0	0.0	1	1.5	0	0.0	66
Bracknell Forest	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	56
Brighton and Hove	15	10.9	5	3.6	5	3.6	6	4.4	3	2.2	137
Canterbury	13	21.0	3	4.8	1	1.6	8	12.9	9	14.5	62
Cherwell	16	17.4	5	5.4	0	0.0	9	9.8	10	10.9	92
Chichester	4	13.3	0	0.0	3	10.0	1	3.3	0	0.0	30
Chiltern	2	6.3	2	6.3	2	6.3	1	3.1	2	6.3	32
Crawley	9	7.1	4	3.2	4	3.2	6	4.8	1	0.8	126
Dartford	4	6.5	2	3.2	4	6.5	0	0.0	0	0.0	62
Dover	5	16.1	2	6.5	2	6.5	1	3.2	1	3.2	31
East Hampshire	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	15
Eastbourne	6	16.2	1	2.7	2	5.4	4	10.8	3	8.1	37

Local authority district	one	least social factor	Drug misuse			Alcohol misuse		essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
Eastleigh	1	3.7	0	0.0	0	0.0	0	0.0	1	3.7	27
Elmbridge	3	8.3	3	8.3	1	2.8	1	2.8	0	0.0	36
Epsom and Ewell	1	2.1	1	2.1	0	0.0	0	0.0	0	0.0	48
Fareham	1	4.2	0	0.0	1	4.2	0	0.0	1	4.2	24
Gosport	2	11.1	1	5.6	0	0.0	1	5.6	0	0.0	18
Gravesham	8	7.3	0	0.0	6	5.5	2	1.8	0	0.0	109
Guildford	5	10.6	3	6.4	3	6.4	0	0.0	0	0.0	47
Hart	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	12
Hastings	11	26.2	7	16.7	4	9.5	3	7.1	3	7.1	42
Havant	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	13
Horsham	3	13.6	1	4.5	2	9.1	0	0.0	2	9.1	22
Isle of Wight	6	30.0	3	15.0	3	15.0	2	10.0	5	25.0	20
Lewes	4	14.3	1	3.6	3	10.7	0	0.0	1	3.6	28
Maidstone	5	9.1	2	3.6	2	3.6	3	5.5	0	0.0	55
Medway	8	7.3	0	0.0	2	1.8	3	2.8	6	5.5	109
Mid Sussex	4	9.1	0	0.0	2	4.5	1	2.3	1	2.3	44
Mole Valley	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
New Forest	1	5.9	0	0.0	1	5.9	0	0.0	0	0.0	17
Oxford	27	13.6	5	2.5	5	2.5	19	9.5	7	3.5	199
Portsmouth	8	7.5	2	1.9	3	2.8	4	3.8	3	2.8	106
Reading	10	3.3	3	1.0	5	1.6	8	2.6	4	1.3	305
Reigate and Banstead	13	17.1	5	6.6	4	5.3	6	7.9	9	11.8	76
Rother	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	15
Runnymede	1	3.1	0	0.0	0	0.0	0	0.0	1	3.1	32
Rushmoor	4	3.1	2	1.5	1	0.8	1	0.8	1	0.8	131
Sevenoaks	1	3.0	0	0.0	0	0.0	1	3.0	0	0.0	33
Shepway	2	3.8	0	0.0	0	0.0	1	1.9	1	1.9	53
Slough	13	3.0	3	0.7	3	0.7	4	0.9	10	2.3	429
South Bucks	2	5.3	0	0.0	0	0.0	1	2.6	1	2.6	38
South Oxfordshire	3	12.0	1	4.0	2	8.0	2	8.0	3	12.0	25
Southampton	9	4.6	2	1.0	4	2.0	4	2.0	2	1.0	197
Spelthorne	1	1.9	0	0.0	0	0.0	0	0.0	1	1.9	52
Surrey Heath	2	5.6	0	0.0	1	2.8	0	0.0	1	2.8	36
Swale	3	10.7	1	3.6	0	0.0	0	0.0	2	7.1	28
Tandridge	1	8.3	0	0.0	1	8.3	0	0.0	0	0.0	12
Test Valley	1	5.3	0	0.0	0	0.0	1	5.3	0	0.0	19
Thanet	15	30.0	6	12.0	8	16.0	6	12.0	7	14.0	50
Tonbridge and Malling	2	7.1	1	3.6	0	0.0	0	0.0	1	3.6	28
Tunbridge Wells	2	5.7	0	0.0	0	0.0	1	2.9	1	2.9	35
Vale of White Horse	4	11.8	1	2.9	1	2.9	2	5.9	0	0.0	34
Waverley	1	3.3	0	0.0	0	0.0	1	3.3	0	0.0	30
Wealden	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	25

Local authority district	one	least social factor	Drug misuse			Alcohol misuse		essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
West Berkshire	2	4.4	0	0.0	1	2.2	1	2.2	0	0.0	45
West Oxfordshire	2	8.0	0	0.0	0	0.0	1	4.0	1	4.0	25
Winchester	2	10.5	1	5.3	1	5.3	0	0.0	0	0.0	19
Windsor and Maidenhead	3	4.4	2	2.9	2	2.9	0	0.0	1	1.5	68
Woking	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	93
Wokingham	3	3.7	0	0.0	2	2.4	0	0.0	1	1.2	82
Worthing	3	8.8	0	0.0	3	8.8	0	0.0	0	0.0	34
Wycombe	9	7.1	2	1.6	6	4.8	7	5.6	2	1.6	126
North West											
Allerdale	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Barrow-in-Furness	2	11.8	1	5.9	0	0.0	0	0.0	2	11.8	17
Blackburn with Darwen	5	1.8	3	1.1	2	0.7	0	0.0	3	1.1	285
Blackpool	26	31.3	17	20.5	11	13.3	11	13.3	8	9.6	83
Bolton	16	5.1	3	1.0	4	1.3	7	2.2	6	1.9	312
Burnley	3	6.3	2	4.2	3	6.3	0	0.0	0	0.0	48
Bury	6	5.3	1	0.9	5	4.4	1	0.9	1	0.9	113
Carlisle	1	4.8	0	0.0	0	0.0	0	0.0	1	4.8	21
Cheshire East	10	12.5	4	5.0	6	7.5	2	2.5	5	6.3	80
Cheshire West and Chester	2	3.4	2	3.4	1	1.7	2	3.4	1	1.7	58
Chorley	6	23.1	1	3.8	1	3.8	1	3.8	4	15.4	26
Copeland	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	7
Eden	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3
Fylde	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Halton	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Hyndburn	1	2.0	0	0.0	1	2.0	0	0.0	0	0.0	50
Knowsley	4	20.0	0	0.0	3	15.0	1	5.0	0	0.0	20
Lancaster	5	14.7	2	5.9	1	2.9	0	0.0	2	5.9	34
Liverpool	45	17.2	15	5.7	18	6.9	23	8.8	28	10.7	261
Manchester	49	5.2	16	1.7	27	2.8	29	3.1	12	1.3	950
Oldham	30	10.6	7	2.5	13	4.6	6	2.1	17	6.0	283
Pendle	3	2.8	2	1.9	3	2.8	1	0.9	1	0.9	106
Preston	19	11.0	6	3.5	4	2.3	7	4.0	9	5.2	173
Ribble Valley	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	5
Rochdale	12	6.3	4	2.1	5	2.6	1	0.5	5	2.6	191
Rossendale	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	19
Salford	16	10.1	2	1.3	3	1.9	10	6.3	7	4.4	159
Sefton	6	11.3	-	1.9	4	7.5	2	3.8	2	3.8	53
South Lakeland	3	11.1	1	3.7	3	11.1	0	0.0	-	3.7	27
South Ribble	1	3.7	0	0.0	0	0.0	0	0.0	1	3.7	27
St. Helens	1	4.2	0	0.0	1	4.2	0	0.0	0	0.0	24
Stockport	2	2.1	1	1.1	1	1.1	1	1.1	0	0.0	94
Tameside	20	13.0	5	3.2	14	9.1	3	1.9	6	3.9	154

Local authority district	one	least social factor		rug suse		ohol suse	Homel	essness	Pris	son	Total
	n	%	n	%	n	%	n	%	n	%	n
Trafford	4	2.6	3	1.9	3	1.9	1	0.6	1	0.6	154
Warrington	7	12.1	2	3.4	1	1.7	1	1.7	5	8.6	58
West Lancashire	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	13
Wigan	9	13.0	4	5.8	1	1.4	4	5.8	4	5.8	69
Wirral	9	14.5	4	6.5	2	3.2	3	4.8	4	6.5	62
Wyre	3	12.5	1	4.2	2	8.3	0	0.0	0	0.0	24
Yorkshire and the Humber											
Barnsley	3	7.1	2	4.8	3	7.1	1	2.4	1	2.4	42
Bradford	60	7.6	31	3.9	15	1.9	22	2.8	33	4.2	790
Calderdale	7	6.1	2	1.7	2	1.7	2	1.7	3	2.6	115
Craven	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	14
Doncaster	12	10.2	2	1.7	3	2.5	2	1.7	7	5.9	118
East Riding of Yorkshire	6	15.4	1	2.6	2	5.1	1	2.6	3	7.7	39
Hambleton	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	6
Harrogate	1	3.6	1	3.6	1	3.6	0	0.0	0	0.0	28
Kingston upon Hull, City of	9	7.8	6	5.2	3	2.6	4	3.5	3	2.6	115
Kirklees	20	4.0	5	1.0	7	1.4	6	1.2	5	1.0	496
Leeds	54	9.2	11	1.9	17	2.9	19	3.2	31	5.3	585
North East Lincolnshire	9	31.0	3	10.3	7	24.1	1	3.4	1	3.4	29
North Lincolnshire	5	7.9	2	3.2	0	0.0	1	1.6	3	4.8	63
Richmondshire	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	10
Rotherham	9	8.6	2	1.9	4	3.8	3	2.9	4	3.8	105
Ryedale	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	6
Scarborough	2	11.1	2	11.1	1	5.6	1	5.6	0	0.0	18
Selby	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	7
Sheffield	34	7.5	10	2.2	15	3.3	17	3.7	4	0.9	454
Wakefield	16	15.5	5	4.9	7	6.8	4	3.9	6	5.8	103
York	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	30
East of England											
Babergh	1	9.1	0	0.0	1	9.1	0	0.0	0	0.0	11
Basildon	8	11.4	1	1.4	3	4.3	4	5.7	0	0.0	70
Bedford	11	7.7	7	4.9	3	2.1	3	2.1	5	3.5	142
Braintree	2	7.7	1	3.8	1	3.8	1	3.8	1	3.8	26
Breckland	1	5.0	1	5.0	0	0.0	0	0.0	1	5.0	20
Brentwood	3	11.5	0	0.0	2	7.7	1	3.8	0	0.0	26
Broadland	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	13
Broxbourne	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	31
Cambridge	6	7.4	4	4.9	2	2.5	5	6.2	4	4.9	81
Castle Point	1	6.3	0	0.0	0	0.0	1	6.3	0	0.0	16
Central Bedfordshire	5	9.4	1	1.9	1	1.9	2	3.8	2	3.8	53
Chelmsford	1	3.0	0	0.0	0	0.0	0	0.0	1	3.0	33
Colchester	2	4.2	0	0.0	1	2.1	1	2.1	0	0.0	48

Local authority district	one	least social factor	Drug misuse		Alcohol misuse		Homel	essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
Dacorum	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	50
East Cambridgeshire	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	13
East Hertfordshire	1	3.8	1	3.8	0	0.0	0	0.0	0	0.0	26
Epping Forest	2	3.9	1	2.0	0	0.0	1	2.0	2	3.9	51
Fenland	4	11.4	4	11.4	1	2.9	0	0.0	3	8.6	35
Forest Heath	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	14
Great Yarmouth	11	21.2	5	9.6	2	3.8	1	1.9	6	11.5	52
Harlow	1	1.6	0	0.0	0	0.0	0	0.0	1	1.6	64
Hertsmere	3	4.8	1	1.6	2	3.2	1	1.6	0	0.0	62
Huntingdonshire	4	9.1	1	2.3	1	2.3	2	4.5	3	6.8	44
Ipswich	5	9.6	1	1.9	4	7.7	0	0.0	1	1.9	52
King's Lynn and West Norfolk	5	18.5	2	7.4	1	3.7	1	3.7	3	11.1	27
Luton	22	4.8	7	1.5	11	2.4	9	2.0	5	1.1	457
Maldon	1	14.3	0	0.0	1	14.3	0	0.0	1	14.3	7
Mid Suffolk	1	8.3	0	0.0	1	8.3	0	0.0	0	0.0	12
Milton Keynes	3	1.7	1	0.6	1	0.6	2	1.1	0	0.0	175
North Hertfordshire	3	7.0	2	4.7	1	2.3	1	2.3	0	0.0	43
North Norfolk	1	7.1	0	0.0	0	0.0	0	0.0	1	7.1	14
Norwich	3	4.3	0	0.0	1	1.4	1	1.4	3	4.3	70
Peterborough	26	9.7	10	3.7	3	1.1	10	3.7	17	6.3	269
Rochford	1	16.7	0	0.0	0	0.0	0	0.0	1	16.7	6
South Cambridgeshire	2	5.0	1	2.5	1	2.5	0	0.0	0	0.0	40
South Norfolk	2	16.7	1	8.3	0	0.0	1	8.3	1	8.3	12
Southend-on-Sea	6	6.1	4	4.1	2	2.0	4	4.1	3	3.1	98
St Albans	5	9.8	2	3.9	1	2.0	3	5.9	4	7.8	51
St Edmundsbury	9	25.7	1	2.9	4	11.4	3	8.6	5	14.3	35
Stevenage	4	7.7	1	1.9	3	5.8	1	1.9	0	0.0	52
Suffolk Coastal	2	7.7	0	0.0	2	7.7	0	0.0	0	0.0	26
Tendring	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	18
Three Rivers	1	2.9	0	0.0	1	2.9	0	0.0	0	0.0	35
Thurrock	6	9.4	3	4.7	2	3.1	0	0.0	5	7.8	64
Uttlesford	2	16.7	0	0.0	1	8.3	1	8.3	0	0.0	12
Watford	5	5.4	1	1.1	0	0.0	4	4.3	3	3.2	93
Waveney	5	19.2	3	11.5	2	7.7	1	3.8	2	7.7	26
Welwyn Hatfield	3	4.8	1	1.6	1	1.6	2	3.2	0	0.0	62
East Midlands											
Amber Valley	3	12.0	2	8.0	0	0.0	1	4.0	1	4.0	25
Ashfield	1	3.7	0	0.0	0	0.0	1	3.7	0	0.0	27
Bassetlaw	2	11.1	2	11.1	0	0.0	0	0.0	0	0.0	18
Blaby	1	3.1	0	0.0	1	3.1	0	0.0	0	0.0	32
Bolsover	1	8.3	1	8.3	0	0.0	0	0.0	0	0.0	12
Boston	8	22.9	1	2.9	3	8.6	5	14.3	3	8.6	35

Local authority district	one	least social factor	Drug misuse		Alcohol misuse		Homel	essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
Broxtowe	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	34
Charnwood	6	9.8	5	8.2	2	3.3	1	1.6	4	6.6	61
Chesterfield	5	16.7	1	3.3	5	16.7	3	10.0	3	10.0	30
Corby	1	3.7	0	0.0	1	3.7	1	3.7	0	0.0	27
Daventry	1	5.9	0	0.0	0	0.0	0	0.0	1	5.9	17
Derby	15	6.6	3	1.3	1	0.4	8	3.5	5	2.2	229
Derbyshire Dales	2	22.2	0	0.0	1	11.1	1	11.1	0	0.0	9
East Lindsey	1	4.5	1	4.5	1	4.5	1	4.5	1	4.5	22
East Northamptonshire	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	18
Erewash	1	3.8	0	0.0	1	3.8	1	3.8	0	0.0	26
Gedling	2	6.3	2	6.3	2	6.3	0	0.0	1	3.1	32
Harborough	3	16.7	0	0.0	1	5.6	0	0.0	2	11.1	18
High Peak	1	5.6	0	0.0	1	5.6	0	0.0	0	0.0	18
Hinckley and Bosworth	1	6.3	0	0.0	1	6.3	0	0.0	0	0.0	16
Kettering	1	3.0	0	0.0	1	3.0	0	0.0	0	0.0	33
Leicester	35	3.6	8	0.8	13	1.3	15	1.5	8	0.8	974
Lincoln	2	8.3	1	4.2	1	4.2	1	4.2	2	8.3	24
Mansfield	2	7.7	0	0.0	1	3.8	0	0.0	1	3.8	26
Melton	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	3
Newark and Sherwood	5	38.5	0	0.0	1	7.7	0	0.0	5	38.5	13
North East Derbyshire	1	14.3	0	0.0	0	0.0	1	14.3	0	0.0	7
North Kesteven	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	12
North West Leicestershire	2	11.1	0	0.0	2	11.1	0	0.0	0	0.0	18
Northampton	16	8.6	1	0.5	2	1.1	7	3.7	8	4.3	187
Nottingham	29	8.7	6	1.8	6	1.8	16	4.8	8	2.4	333
Oadby and Wigston	1	2.9	0	0.0	1	2.9	1	2.9	0	0.0	35
Rushcliffe	1	3.8	0	0.0	0	0.0	0	0.0	1	3.8	26
Rutland	4	33.3	1	8.3	0	0.0	0	0.0	4	33.3	12
South Derbyshire	3	14.3	2	9.5	2	9.5	2	9.5	2	9.5	21
South Holland	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	15
South Kesteven	4	9.1	1	2.3	2	4.5	1	2.3	1	2.3	44
South Northamptonshire	3	20.0	1	6.7	2	13.3	0	0.0	2	13.3	15
Wellingborough	3	6.7	0	0.0	2	4.4	0	0.0	1	2.2	45
West Lindsey	1	7.1	0	0.0	0	0.0	0	0.0	1	7.1	14
South West											
Bath and North East Somerset	5	7.7	2	3.1	2	3.1	2	3.1	0	0.0	65
Bournemouth	9	9.5	6	6.3	4	4.2	3	3.2	2	2.1	95
Bristol, City of	45	9.1	15	3.0	22	4.5	18	3.7	10	2.0	493
Cheltenham	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	40
Christchurch	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	6
Cornwall	10	11.4	5	5.7	2	2.3	5	5.7	5	5.7	88
Cotswold	.0	8.3	č	8.3	0	0.0	0	5.7	Ŭ		

Tackling Tuberculosis in Under-Served Populations: A Resource for TB Control Boards and their partners

Local authority district	one	least social factor		rug suse		ohol suse	Homel	essness	Pri	son	Total
	n	%	n	%	n	%	n	%	n	%	n
East Devon	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	13
East Dorset	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	11
Exeter	4	10.8	1	2.7	3	8.1	2	5.4	0	0.0	37
Forest of Dean	1	20.0	1	20.0	0	0.0	0	0.0	0	0.0	5
Gloucester	11	15.7	4	5.7	6	8.6	4	5.7	1	1.4	70
Mendip	3	13.6	3	13.6	1	4.5	1	4.5	1	4.5	22
Mid Devon	1	7.7	1	7.7	0	0.0	0	0.0	0	0.0	13
North Devon	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	11
North Dorset	1	7.7	0	0.0	0	0.0	0	0.0	1	7.7	13
North Somerset	3	6.0	0	0.0	1	2.0	2	4.0	1	2.0	50
Plymouth	8	9.0	0	0.0	2	2.2	2	2.2	4	4.5	89
Poole	1	4.3	1	4.3	1	4.3	0	0.0	0	0.0	23
Purbeck	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	9
Sedgemoor	7	35.0	3	15.0	4	20.0	0	0.0	0	0.0	20
South Gloucestershire	11	11.5	4	4.2	3	3.1	3	3.1	6	6.3	96
South Hams	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	18
South Somerset	2	7.7	0	0.0	1	3.8	1	3.8	0	0.0	26
Stroud	5	19.2	4	15.4	3	11.5	1	3.8	1	3.8	26
Swindon	3	2.3	0	0.0	1	0.8	1	0.8	1	0.8	131
Taunton Deane	1	5.6	0	0.0	1	5.6	0	0.0	0	0.0	18
Teignbridge	9	21.4	4	9.5	3	7.1	4	9.5	3	7.1	42
Tewkesbury	2	10.5	1	5.3	0	0.0	0	0.0	1	5.3	19
Torbay	12	24.0	4	8.0	8	16.0	1	2.0	0	0.0	50
Torridge	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	4
West Devon	1	5.9	0	0.0	0	0.0	0	0.0	1	5.9	17
West Dorset	3	27.3	2	18.2	1	9.1	1	9.1	1	9.1	11
West Somerset	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	2
Weymouth and Portland	1	9.1	0	0.0	0	0.0	0	0.0	1	9.1	11
Wiltshire	7	7.9	2	2.2	3	3.4	3	3.4	1	1.1	89
North East											
County Durham	12	19.0	3	4.8	3	4.8	0	0.0	9	14.3	63
Darlington	2	6.9	0	0.0	2	6.9	0	0.0	0	0.0	29
Gateshead	7	11.5	2	3.3	1	1.6	2	3.3	3	4.9	61
Hartlepool	5	20.0	3	12.0	3	12.0	1	4.0	1	4.0	25
Middlesbrough	15	15.6	4	4.2	6	6.3	6	6.3	6	6.3	96
Newcastle upon Tyne	17	6.7	4	1.6	7	2.8	8	3.2	5	2.0	253
North Tyneside	6	12.2	4	8.2	3	6.1	2	4.1	2	4.1	49
Northumberland	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	47
Redcar and Cleveland	1	4.2	0	0.0	1	4.2	0	0.0	0	0.0	24
South Tyneside	4	10.3	1	2.6	3	7.7	1	2.6	1	2.6	39
Stockton-on-Tees	6	10.2	3	5.1	2	3.4	2	3.4	2	3.4	59
Sunderland	6	5.9	1	1.0	4	3.9	2	2.0	0	0.0	102

	Year	Drug r	nisuse	Alco misu		Homeles	ssness	Pris	on		ast 1 RF	2 or r SR	
		Ν	%	n	%	n	%	n	%	Ν	%	n	%
	2010	188	2.9	257	4.0	200	3.0	177	2.8	584	9.9	164	2.2
	2011	204	2.8	236	3.3	195	2.7	213	3.0	592	8.9	188	2.4
All cases	2012	220	3.1	219	3.1	185	2.6	225	3.2	593	8.9	184	2.4
All Cases	2013	217	3.3	239	3.7	217	3.3	192	3.0	588	9.5	195	2.8
	2014	202	3.5	197	3.4	210	3.6	186	3.3	538	9.8	175	2.8
	2015	221	4.3	205	3.9	229	4.4	198	3.9	579	11.8	196	3.5
	Total	1,252	3.3	1,353	3.6	1,236	3.2	1,191	3.2	3,474	9.7	1,102	2.7
	2010	114	8.1	113	8.2	70	4.9	83	6.2	235	18.4	100	6.3
	2011	134	8.6	121	7.8	61	3.9	127	8.5	271	18.6	125	7.3
UK born	2012	129	8.0	98	6.1	54	3.3	106	6.8	253	16.7	94	5.4
	2013	133	8.6	130	8.5	70	4.5	99	6.6	259	17.6	115	7.0
	2014	124	8.5	98	6.8	74	5.1	94	6.7	236	17.0	101	6.4
	2015	144	11.2	109	8.4	75	5.8	111	8.9	269	21.7	111	8.0
	Total	778	8.8	669	7.6	404	4.5	620	7.3	1,523	18.2	646	6.7
	2010	68	1.4	134	2.8	123	2.5	83	1.7	328	7.4	58	1.1
	2011	63	1.1	106	2.0	128	2.3	78	1.5	301	6.0	58	1.0
Non-UK	2012	86	1.6	111	2.1	124	2.3	112	2.1	316	6.2	86	1.5
born	2013	81	1.6	104	2.1	145	2.9	92	1.9	321	6.9	77	1.5
	2014	75	1.7	96	2.2	132	3.1	90	2.1	293	7.2	71	1.6
	2015	70	1.8	92	2.4	150	3.9	84	2.3	299	8.3	79	2.0
	Total	443	1.5	643	2.3	802	2.8	539	1.9	1,858	6.9	429	1.4

 Table A1.2: Number and proportion of TB cases with social risk factors* by place of birth, England, 2010-2015

* Includes those aged 15 years and older

Demographic Characteristic	Drug n	nisuse	Alcohol	misuse	Homele	ssness	Pris	son	At leas	t 1 SRF	2 or mo	ore SRF
Demographic Characteristic	n	%	n	%	n	%	n	%	n	%	n	%
Sex												
Female	204	1.2	252	1.6	228	1.4	127	0.8	607	4.0	139	0.8
Male	1,046	4.8	1,100	5.0	1,007	4.5	1,064	5.0	2,864	14.0	962	4.0
Age group (years)												
15-44	890	3.7	662	2.8	824	3.4	771	3.2	2,186	9.6	682	2.6
45-64	342	3.9	576	6.8	382	4.4	370	4.4	1,107	13.7	392	4.1
65+	20	0.4	115	2.1	30	0.6	50	1.0	181	3.7	28	0.5
Place of birth												
UK Born	778	8.8	669	7.6	404	4.5	620	7.2	1,523	18.2	646	6.7
Non-UK Born	443	1.5	643	2.3	802	2.8	539	1.9	1,858	6.9	429	1.4
Ethnicity (UK born)												
White	525	9.3	548	9.8	329	5.8	406	7.6	1,083	20.6	488	7.8
Black Caribbean	85	19.2	31	7.1	38	8.5	80	18.4	140	33.0	63	13.1
Black-African	14	4.1	11	3.3	8	2.3	23	6.6	40	12.1	11	3.0
Indian, Pakistani, Bangladeshi	97	5.0	48	2.5	10	0.5	65	3.3	161	8.7	46	2.2
Other	50	12.6	26	6.5	17	4.2	39	9.7	84	21.6	33	7.8
Country of birth (Non-UK born)												
India	22	0.3	164	2.0	64	0.8	42	0.5	252	3.2	36	0.4
Somalia	56	3.2	46	2.7	84	4.8	67	3.9	191	11.9	44	2.4
Pakistan	27	0.5	38	0.8	39	0.8	36	0.7	115	2.5	21	0.4
Poland	22	6.9	50	15.9	56	17.3	24	7.8	99	32.2	44	11.9
Eritrea	5	1.2	4	0.9	71	16.6	28	6.7	90	22.6	15	3.2
Romania	13	3.3	14	3.5	36	9.3	20	5.2	66	17.8	13	3.0
Lithuania	20	10.2	26	13.6	39	19.8	31	16.3	64	33.7	38	17.6
Nigeria	8	1.0	14	1.7	27	3.2	19	2.3	59	7.6	7	0.8
Bangladesh	23	1.7	15	1.1	13	0.9	15	1.1	54	4.2	9	0.6
Ireland	21	11.5	34	18.8	14	7.7	13	7.5	49	28.2	22	11.2

Table A1.3: Characteristics of TB cases with social risk factors*, England, 2010-2015

* Includes those aged 15 years and older ** the top ten countries of birth by the number of cases with at least 1 SRF were included

Clinical Characteristics	Drug misuse		Alcohol misuse		Homeless		Pri	son	At lea SF			more RF	No S	RF
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Previous TB diagnosis	112	9.3	157	12.3	124	10.8	107	9.4	342	10.4	108	10.3	2,049	6.3
Pulmonary, with or without EP	1,025	81.9	1,098	81.3	981	79.4	941	79.0	2,668	76.9	965	87.6	15,689	48.6
On DOT	635	54.3	756	60.7	666	58.1	572	51.7	1,541	48.2	720	69.4	1,845	6.1
Time from symptom onset to treatment start**														
0-2 months	314	39.5	349	44.2	332	43.3	284	37.5	846	41.6	296	40.3	5,138	41.0
2-4 months	250	31.4	223	28.3	231	31.1	236	31.2	617	30.3	231	31.4	3,765	30.1
>4 months	231	29.1	217	27.5	190	25.6	237	31.3	573	28.1	208	28.3	3,619	28.9
Drug resistance														
INH-R without MDR-TB	104	11.1	82	8.2	79	8.7	93	10.6	210	8.3	101	12.0	1,005	5.3
MDR/RR-TB	24	2.5	20	2.0	35	3.7	32	3.5	63	2.4	33	3.8	315	1.6

Table A1.4: Clinical characteristics of TB cases with at least one social risk factor*, England, 2010-2015

* Includes those aged 15 years and older **For pulmonary cases excluding those diagnosed post-mortem and those who did not start treatment

EP - extra-pulmonary

TB outcome	At leas	st 1 SRF	No S	SRF	Total ^{**}
TB outcome	n	%	n	%	N
Treatment completed	2,254	79.5	24,738	89.3	26,992
Died	184	6.5	1,070	3.9	1,254
Lost to follow up	229	8.1	1,081	3.9	1,310
Still on treatment	53	1.9	302	1.1	355
Treatment stopped	55	1.9	264	1.0	319
Not evaluated [#]	60	2.1	262	1.0	322
Total	2,835	100.0	27,717	100	30,552

Table A1.5: Last recorded TB outcome for the entire drug sensitive cohort by social risk factor*, England, 2010-2014

* Includes those aged 15 years and older but excludes cases in drug resistant cohort

** Total cases with reported information on at least 1 SRF reported

[#] not evaluated includes missing, unknown and transferred out

Table A1.6: Last recorded TB outcome for the drug resistant cohort by social risk factor*, England, 2010-2013

TB outcome	At least 1 SRF		No SRF		Total ^{**}
	n	%	n	%	N
Treatment completed	30	60.0	182	74.9	212
Died	5	10.0	5	2.1	10
Lost to follow up	9	18.0	35	14.4	44
Still on treatment	3	6.0	8	3.3	11
Treatment stopped	3	6.0	13	5.4	16
Total	50	100.0	243	100	293

* Includes those aged 15 years and older, and those with initial and acquired MDR/RR-TB cases, and cases treated with an MDR-TB regimen only

** Total cases with reported information on at least 1 SRF reported

Appendix 2: Findings from a survey of TBCBs to assess the needs of USPs

A survey of TB Control Boards (TBCBs) was undertaken in early 2016 to gauge their understanding of their local USPs and health needs; asking them to highlight key challenges as well as share exemplars of good practice to guide further action nationally. Responses from the survey have been used to develop this resource with the overarching aim of supporting TBCBs and their partners meet the needs of their USP. This is informed by the evidence and supported by intelligence (including epidemiology) and exemplars of good practice written by national experts and key stakeholders and includes models of care.

A survey tool was developed by a working group of the USP task and finish group. This was sent to the TBCB managers for completion suggesting it be done so by coordinating input from key local TB stakeholders, according to need, including TB Nurses, Respiratory/ID physicians, CsCDC/CHPs, DsPH or other key experts within their professional network. A high level of engagement across all TBCBs was received.

The survey tool included 4 sections:

- 1. Background information
- 2. Key challenges for TBCBs regarding USP
- 3. What do the TBCBs needs
- 4. Exemplars of good practice

1. Background Information

All seven TBCBs across England completed the survey tool within the specified timeframe. The majority of the TBCBs consulted their CCDC/CHP/Health Protection Practitioner, PHE Centre HPT, PHE Centre Director/Deputy Director for Health Protection, TB nurse(s), NHS Acute Trust Respiratory Medicine/Infectious Disease Physician, Local Government Director(s) of Public Health, local authority and Social Care, CCG representative(s) NHS England Commissioner(s) and third sector/charity organisations.

2. Key Challenges for TBCBs re: USP

2.1 Inclusion of TB in PHE Centre Business Plans: Five of the seven TBCBs reported that specific activities relating to 'Area 7 of the Collaborative Strategy: Tackling TB in USPs' was included in their PHE Centre Business Plans.

- 2.2 Recourse/access to public funds (including benefit payments) and access to primary care for USPs with TB were identified as the primary concern among all the TBCBs. The TBCBs specifically highlighted the homeless and migrant groups. Lack of referral pathways and consideration are required for those on very low income and no sick pay, were also reported. Barriers included language and cultural variation among the USP with TB was raised by all the TBCBs.
- 2.3 Accommodation and housing was a major concern for all the TBCBs. Specific issues about living in inadequate accommodation were over-crowding, issues with private rental, undocumented migrants, alcohol and substance misuse TB patients, those on low income and MDR-TB patients.
- 2.4 Access to secondary care services (including TB clinics).TBCBs reported that once the patients reached secondary care (TB services) they were well cared for. Lack of resources form the service perspective and pressure on the respiratory / infectious diseases departments in areas of low prevalence was noted.
- 2.5 **Community and Social care.** All TBCBs reported lack of continuity of care in the community. In most settings there is no provision for social care specifically for TB patients. Hand-over to a community provider / service is usually lacking. Few areas have community based TB services available, however knowledge and experience of TB in the community is low. Offensive, aggressive and violent behaviour towards community staff not trained to deal with USPs, along with care for elderly patients with TB, is a cause for concern as it can take a long time to organise social care.
- 2.6 DOT/treatment adherence: Resources and referral pathways are not always available to ensure completion of treatment among the USPs specifically among the homeless, those with substance misuse and migrants. Other comments include overall chaotic lifestyle makes DOT difficult and is not available everywhere. In places where DOT/VOT are available, resources are not always sufficient in terms of capacity or experience of staff to ensure the same completion rate compared to non-USPs.
- 2.7 **Contact tracing** complex cases may not be adequately investigated when needed, as contact tracing may be less of a priority as the amount of investigative work a TB nurse time and resources is limited. Contact tracing across settings specifically prison and community were raised.
- 2.8 Treatment 'refusniks' (patients who refuse treatment) including 'stop-start' patient. Applicable to all patients with SRF and especially those with no fixed address. Typical refusniks include Individuals with chaotic life styles, MDR-TB cases who require complex treatments, and individuals experiencing adverse drugs reaction who require extra support. Also within this category are migrants diagnosed

at their first port of entry and subsequently move elsewhere after treatment has started.

- 2.9 Late presentation of TB: Illegal immigrants and asylum seekers fearing a TB diagnosis will affect their asylum claim, those working very long hours on poor pay, individuals not registered with a GP are at risk of delay in diagnosis. Many of these patients present with little or no means to support themselves and getting them to stay in treatment a serious challenge for the TBCBs.
- 2.10 **Other Issues:** These included: (i) Screening for USP in low incidence areas, in particular rural areas with large migrant populations; (ii) Access to a specific social worker with TB responsibilities is lacking; (iii) Access to funds to facilitate outpatient attendance and DOT from patient perspective; (iv) Finances for food and phone for those on very low income; (v) Areas where TB nursing service is part of respiratory or infectious diseases in areas of low incidence, TB services are stretched; (vi) TB services working with complex patients who require DOT or outreach support have restricted resources; (vii) insufficient TB detection in prisons.
- 3. Recommendations: What do the TBCBs need?
- 3.1 Specific guidance/clarification on issues relating to patients with no recourse to public funds including entitlements, roles/responsibilities of different agencies. Guidance to outline specifically the responsibilities of CCGs, local authorities, NHS England for specific groups (homeless, no recourse to public funds).
- 3.2 Specific guidance/clarification on issues relating to access to secure accommodation / housing including entitlements relating to TB with reference to existing guidance. National document providing clarity about roles and responsibilities is required outlining the joint responsibilities for both (or either) CCGs and local authorities and include legal guidance (if available) for TB patients.
- 3.3 Clarification on roles/responsibilities of NHS / CCG commissioners:

Commissioning guidance for CCGs and the NHS including laws / guidance ranging from access of benefits, housing, transportation costs for both TB services for DOT, travel expenses for patients to visit clinics. Clarity around commissioning responsibilities for all organisations responsible for delivery of services.

3.4 Clarification on roles/responsibilities of Local Government / DsPH: Specifically joint working between social care, drugs and alcohol specialists, offender management, housing, refugees and asylum seekers. Identify 'social care champions 'from the LGA.

- 3.5 **Further advice/discussion on ratio of TB nurses**: TB services and management to take account of complex populations/settings.
- 3.6 Guidance required for managing those who refuse treatment. Further advice/support on use of legal powers to manage treatment 'refusniks'. To include population health protection, individual treatment choices, impact on population vs impact and MDR-TB and XDR-TB patients
- 3.7 National/regional/local health improvement/awareness campaign aimed at specific populations/settings. All TBCBs agreed that awareness is important for specific high risk groups. In addition, the need to consider adapting the awareness campaigns locally and consider joined up, development of awareness materials in different languages and co-ordinate awareness campaigns with related diseases.
- 3.8 Other recommendations: National commissioning of Mobile Health Screening for USP groups that struggle to access mainstream health services. Further advice/guidance on diagnosis of active and/or LTBI in specific populations/setting required.

3. Exemplars of good practice

Key interventions to improve detection of latent and active TB infection and the support required to ensure successful completion of treatment were received in response to the survey tool. Examples of projects reaching out to USPs from around the country have been included in the relevant sections under "Exemplars of good practice" (E).

4. Conclusions

TBCBs across England have identified specific sub-populations among USPs requiring particular attention reflecting local demography and epidemiology. Common issues across all groups included access to health and social care; recourse to public funds; housing and homelessness; 'fractured' care and treatment pathways (including 'stop/start' treatment issues and access to DOT); complex contact tracing exercises; and complex issues around public health law. This information has fed in to the development of the resource for TBCBs and their partners to help tackle TB in USPs.

Appendix 3: Checklist to help accommodate TB patients with no recourse to public funds

This checklist aims to reduce some of the delays in finding accommodation for patients who have no recourse to public funds (NRPF) by loosely identifying the main steps of the process and with whom each responsibility lays. It is very important to establish from the outset who is taking overall responsibility for co-ordinating this process up until a case conference is held.

This document has been developed in 2016 by the London TB Control Board in collaboration with the NRPF network, Find and Treat, TB Reach, Imperial College Healthcare Trust TB services and discharge team, the Whittington Hospital TB Social Care team and Islington NRPF Team.

discharge team, the Whittington Hospital TB Social Care team and Islington NRPF Team.				
Process	Responsible team:			
Identify which agencies (including. street outreach teams, drop- in centres, night shelters, citizens advice, solicitors etc) have they been to for housing before or the patient is already known to. They may have already established that the case is NRPF. If the case is not known to any of the above agencies, look on CHAIN (street homeless database) or refer to Find and Treat who can look on CHAIN.	TB case manager			
Establish eligibility for state funding:	Hospital homeless/discharge team			
 What is the immigration status of the patient (in order to confirm that they are NRPF and do not have access to mainstream housing/benefits)? <u>Click here</u> for link to practice guidance 				
Identify patients' local connections, including but not limited to:	TB case manager			
Last known address				
 Whether they are registered with any GP 				
Where any family are located				
Street where the patient was habitually rough sleeping				
Inform HPT of information gathered so far				
 Review immigration status: Does the patient require immigration advice eg they have no current immigration permission – signpost/make referral if possible. 	Hospital overseas officer/agent - referral to them is via the hospital discharge team To find an immigration/asylum adviser see: Law Centres Network; OISC; Law Society and legal aid agency.			
Conduct a needs assessment:	Local authority Health And Social Care			
 Does the patient meet the criteria for LA housing under the Care Act 2014 (s.18 if eligible care needs; s.19 discretionary power if not eligible); If the patient meets the criteria for support under the Care Act, are they caught by Schedule 3 of the Nationality, Immigration and Asylum Act 2002, 	team (sometimes called NRPF Team)			
 restricting access to such support? The local authority must undertake a human rights assessment to establish whether the patient can return to their country of origin. For information about affected groups see <u>NRPF</u> 				

Network practice guidance.	
Conduct mental health assessment:	TB case manager
 Does the patient have further additional support 	hospital Mental Health team
requirements other than housing?	
If at this point the patient is eligible for housing under the Care Act (subject to the Schedule 3 exclusions and human rights assessment if required) accommodation should be provided and funded by the LA (see above).	Local authority Health And Social Care team (sometimes called NRPF Team)
 Assisted voluntary return should be explored even if patient has immigration permission: Cases can often be repatriated through local charities. <u>https://www.gov.uk/return-home-voluntarily/who-canget-help</u> 	Local authority if assessed as having eligible care needs; OR hospital team if the person does not have eligible care needs. This would be done in collaboration with local charities, eg <u>Refugee Action, Routes Home,</u> <u>Thames Reach</u>
 Accommodation and Funding If the patient is NRPF and not eligible for housing: Identify local CCG contact Arrange a <u>case conference</u> with all relevant stakeholders (including but not limited to HPT, TB team, LA housing and social care team, hospital homeless/discharge team, CCG, LA public health, Find and Treat and other agencies identified in the process Funding must come from CCG or local authority when the person has eligible care needs (see above) If the patient has a GP, then the local CCG should be responsible for funding accommodation costs. 	TB case manager but may be HPT
 Accommodation - referral to Olallo or other eg B&B: If the patient has additional needs for social support, a referral to Olallo may be appropriate If private sector accommodation (incl. some housing associations) is been provided, and case is not an EEA national, establish whether any of the exemptions apply and if not, what the patient's 'right to rent' status is. For more information see: https://www.gov.uk/government/publications/right-to-rent-landlords-code-of-practice 	TB case manager/hospital discharge team, in collaboration with Find and Treat

Other resources:

NRPF network <u>http://www.nrpfnetwork.org.uk/nrpfconnect/Pages/default.aspx</u> Find and Treat <u>https://www.uclh.nhs.uk/ourservices/servicea-z/htd/pages/mxu.aspx</u> TB Reach <u>http://www.stoptb.org/global/awards/tbreach/</u> Combined Homelessness and Information Network (CHAIN) <u>http://www.mungos.org/about</u>

Appendix 4: Members of the Task and Finish Group in the USPs (USPs)

- Eamonn O'Moore (Chair) Director, Health and Justice
- Alan Gibson, Assistant Director Home Office (in charge of immigration reval).
- Alex Bunn, General Practitioner, BMA rep for prisons
- Alistair Story, Head of Find and Treat Service
- Anita Roche, CCDC and TB Lead London, PHE
- Ann Norman, RCN Professional lead- Criminal Justice Nursing/ Learning Disability Nursing
- Anjana Roy, (Programme Manager), Senior Scientist, PHE Colindale
- Bernadette Purcell, Consultant in Communicable Disease Control Surrey and Sussex Health Protection Team
- Caroline Twitchett, Children's Lead, H&J/NHSE London
- Cathie Railton, TB Control Board role Yorkshire & Humber
- Charlotte Anderson, Senior Epi Scientist, London
- Christine Kelly, NHS England Commissioner, Health and Justice
- Claire Laurent, Health Equity and Mental Health Division
- Dave Spurgeon, Research and Development Manager, Nacro
- Dominik Zenner, TB Screening Lead, PHE Colindale
- Eliza Alexander, Consultant Microbiologist and Interim Clinical Lead for NMRL Specialist Microbiology Services, NIS PHE
- Gemma Smith, Scientist, Travel and Migrant Health, PHE Colindale
- Gill Leng, Housing and Health Lead, PHE Health and Equity
- Gul Root, Lead Pharmacist, Health and Wellbeing Directorate, Programme
 Improvement and Delivery
- Gurmit Kular, PH commissioning manager, NHSE/Quarry House
- Hanna Kaur, Lead TB Nurse. NHS Birmingham and Solihull TB Service
- Helen Trudgeon, Health Protection Practitioner: Avon, Gloucestershire and Wiltshire Health Protection Team

- Ian Palmer, Health and Wellbeing Manager; Midlands and East Of England; Drugs and Alcohol Team Anglia and Essex
- Jane Rossini, PHE Centre Manchester centres to be represented PHE North
 West Deputy Centre Director; Centre Management Team Cumbria and Lancashire
- Kate Davies, National Head of Public Health, Armed Forces and their Families and Health and Justice for NHS England
- Lily Makurah, HWB : HW Health Equity and Mental Health Division
- Lynn Altass, National TB Strategy Programme Manager, NHS England/PHE
- Maciej Czachorowski, Scientist: Health and Justice, PHE
- Magdalene Mbanefo, Health and Justice Public Health Lead, PHE London
- Maeve Lalor, Principal Scientist, TB section, PHE Colindale
- Mike Wade, South of England TB Control Board, South West TB Lead
- Muhammad Abid, CCDC, Lead Thames Valley
- Nic Coetzee, CCDC, West Midlands
- Nicola Hathway, Health Protection Nurse, Cardiff
- Poonam Dave (Minutes), PHE Colindale
- Robert Wolstenholme, Programme Officer, PHE Alcohol, Drugs and Tobacco
- Shannon Katiyo, Public Health Registrar, PHE Colindale
- Shazia Munir, General Practitioner in Inclusion Health/Clinical Lead for Refugee
 Clinic
- Sarah Anderson, Head of National TB Office, PHE Colindale
- Seamus Watson, National Programme Manager Mental Health; HW Health Equity and Mental Health Division
- Stephanie Perrett, Public Health Wales lead and TB Strategy Lead
- Susanne Howes, Health and Justice Lead, East Midlands
- Wazi Khan, South of England TB Control Board TB Programme Manager