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# Tuberculosis in the East Midlands: Annual review

## Data from 2000 to 2018

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Published September 2019
PHE publications
Gateway number: GW-778

PHE supports the UN Sustainable Development Goals

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# Acknowledgments

## Data in this report

The data presented in this report are correct as at June 2019.

## Acknowledgements

We are grateful to all those who contribute information on tuberculosis patients in the East Midlands, including nurses, physicians, microbiologists, scientists, outreach and social care and administrative staff. We also acknowledge colleagues at the PHE National Mycobacterium Reference Service for information on culture confirmation, drug susceptibility testing and strain typing. Further thanks are due to the PHE National TB Unit for providing the cleaned matched dataset and the PHE East Midlands Health Protection Team for their work supporting Enhanced Tuberculosis Surveillance.

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## Suggested citation

Public Health England. (September 2019) Tuberculosis in the East Midlands: Annual review (2018 data), 2019. Public Health England: (East Midlands)

# Executive summary

This is the East Midlands tuberculosis (TB) annual report for data on patients with TB up to the end of 2018.

New TB notifications in England have decreased substantially from 8,280 patients in 2011 to 4,655 in 2018. In 2018, the TB incidence rate was 8.3 persons per 100,000 population, the lowest rate of TB ever recorded in England. Consequently and since 2017, England continues to be considered a low incidence country under World Health Organisation (WHO) definitions (fewer than 10 people diagnosed with TB per 100,000 of the population) [(1)].

In the East Midlands, 338 TB patients were reported among residents in 2018. This is a slight decrease of 11 patients on the previous year. The incidence rate of 7.0 persons per 100,000 population for the East Midlands remains below the national incidence of 8.3 per 100,000 [(2)]. Although there was a decrease in 2018, the rate of decrease has slowed since the substantial decline between 2012 until 2016 and could suggest a plateau in TB rates in the East Midlands. In comparison, the national rate has continued to decrease. The East Midlands trend will require monitoring if England aims to move towards the WHO End TB Strategy pre-elimination goal by 2035 [(1)].

There continues to be variation in the incidence of TB across the East Midlands with the highest incidence rates reported for residents of Leicester City (40.5 / 100,000 persons). Since the year 2000 the TB incidence in most areas of the East Midlands has decreased, with the most notable decline being in Leicester. However, there were increases in new notifications between 2017 and 2018 in Leicester and Northamptonshire.

There are no upper tier local authorities (UTLAs) in the East Midlands that have a three-year average TB incidence of less than 1.0 per 100,000 – the WHO End TB pre-elimination target rate, although the one-year incidence in Derbyshire for 2018 was 0.9 per 100,000 population.

The incidence rate of TB was 25 times higher in those born outside the UK (44.3 patients per 100,000) compared to the UK-born population (1.8 patients per 100,000). The number of patients and the incidence rate of TB in the non-UK born population have previously seen a year-on-year decline since 2009. However, this increased between 2017 and 2018. In 2018, approximately 37% of TB patients that were not born in the UK, entered the UK 11 or more years previously. The most common country of birth of non-UK born TB patients in 2018 was India (41.7%). However, the incidence of TB in UK-born persons after broadly remaining static, decreased in 2018.

The most common ethnicity for newly diagnosed TB patients in the East Midlands was Indian (43.8%). Although the white ethnic group accounted for 37.4% of all TB patients in 2017, the incidence remains low (3.1 patients per 100,000) in this group.

In 2018, more than half (55.6%) of TB patients had pulmonary disease, of which only 74% were laboratory confirmed by culture which ensures timely identification of drug resistance and whole genome sequencing (WGS) to identify clusters. The proportion of all new patients experiencing a delay of more than 4 months from onset of symptoms to starting treatment was 35% and for pulmonary TB new patients, this was 30%. This was a slight improvement from 2017. The longest delay was found to be between presentation to healthcare and diagnosis with a median of 26 days (pulmonary patients). Further work is required to better understand these delays.

The incidence rate of TB in UK-born children under 15 years of age in the East Midlands has decreased in 2018 (0.9 patients per 100,000) and is an indirect indicator of recent transmission. In December 2016, WGS was introduced in the East Midlands and 96% of culture-confirmed patients in 2018 had a WGS result which could be used to report relatedness.

There was an improvement in rifampicin-sensitive TB patients completing treatment within 12 months, 223 (80.3%), after 4 consecutive annual decreases from a peak of 317 (88.1%) in 2013 (excluding those with CNS, spinal, miliary or cryptic disseminated disease). However this remains lower than the proportion completing treatment for England as a whole (84.7%) [(2)]. Treatment completion for 2017 varied by UTLA ranging from 54.2% (Lincolnshire) to 90.9% (Northamptonshire). The most common reason for not completing treatment at 12 months was death. However, cause of death data quality needs to be improved to better understand if patients are dying as a result of their TB or with their TB.

The proportion of patients with multiple drug resistance (MDR)/rifampicin resistance (RR) in 2018 (2.0%, 4 patients) has decreased from 2017 (3.8%, 8 patients), but is higher than the proportion of MDR/RR TB patients in England (1.6%)[(2)].

There is a clear association in the East Midlands between the incidence rate of TB and deprivation. Social risk factors (histories of alcohol/drug misuse, homelessness, or imprisonment) were noted in 15.3% of TB patients over the age of 15 years, which was a decrease from 19.5% in 2017. These risk factors are more commonly reported in UK-born patients. Those with social risk factors were statistically more likely to have pulmonary disease and require Directly Observed Therapy (DOT). Treatment completion at 12 months was lower in those with social risk factors compared to those with none (74.4% vs 83.6%).

In 2018, 94.8% of TB patients in East Midlands were offered and received an HIV test (292 patients) although there was variation by UTLA, age and place of birth. TB notifications are matched annually with HIV surveillance data and for 2018, it is estimated that 2.7% of TB patients aged 15 years and over in the East Midlands are co-infected with HIV.

Although there was a substantial decline in TB incidence in the East Midlands between 2012 and 2016, the rate of decrease has slowed for 2018 with some areas showing a concerning upward trend. This trend will require monitoring as we near the end of implementation period of the Collaborative TB strategy 2015-2020, which aims for a year-on-year reduction in TB incidences [(3)]. Certain risk groups continue to be more likely to be affected than others within the East Midlands. This underlines the need for services to work collaboratively, across the range of health and social care issues, to extend the downward trend in TB incidence and if we are to move towards the WHO End TB Strategy pre-elimination goal by 2035 [(1)].

## Recommendations

Recommendations for local partners and PHE can be found in full on page 64 in line with the strategy areas for action (AfA). They include:

### Improve access to services and ensure early diagnosis (AfA1):

TB Networks to reduce the delay in TB diagnosis through raising awareness of TB among local communities affected by the disease, other service providers and primary care. This includes utilising the resources available from TB Alert: http://www.thetruthabouttb.org/professionals/professional-education

East Midlands TB Control Board and TB Networks to encourage the use of the RCGP (Royal College of General Practitioners) TB e-learning module: http://elearning.rcgp.org.uk/course/info.php?id=107

### Provide universal access to high-quality diagnostics (AfA2)

TB Networks to increase the proportion of patients that have a diagnostic laboratory result, particularly culture results to ensure prompt identification of drug resistance and allow WGS to identify clusters.

### Improve treatment and care services (AfA3)

TB Networks to continue their supportive case management of complex TB patients, offer DOT where indicated and consider the use of innovative approaches such as Virtually Observed Treatment (VOT) to improve case management.

TB Networks to implement or continue cohort review as a tool to improve local TB control and as a measure of treatment outcomes and contact tracing activity working towards the key performance indicators (KPIs) agreed by the East Midlands TB Control Board.

TB Networks to use the updated 2018 National TB Service Specification and Clinical Policy to commission and monitor local TB services.

TB Networks to ensure information is completed accurately on the PHE Enhanced Tuberculosis Surveillance system, particularly with respect to dates of onset of symptoms, evaluation of treatment completion, TB relationship with death and social risk factors.

## To reduce drug-resistant TB (AfA6)

TB Networks to continue supporting patients to complete treatment, using DOT or VOT where indicated, and to have plans in place to minimise patients being lost to follow-up.

TB Networks to use the British Thoracic Society (BTS) MDR-TB Clinical Advice Service to support MDR-TB case management.

## To tackle TB in under-served populations (AfA7)

East Midlands TB Control Board and TB Networks to encourage the use of the resource ‘Tackling TB in under-served populations (USPs)’ [(4)] to take appropriate local action and better meet the needs of USPs.

TB Networks, to ensure appropriate access to services, treatment and support to enable patients to complete treatment.

TB Networks are encouraged to use ‘Tackling TB - local government's public health role’ [(5)], a joint publication from PHE and the Local Government Association to help support USPs with TB.

## To implement new entrant latent TB screening (AfA8)

Clinical Commissioning Groups (CCGs) to sustain the roll out of the new migrant LTBI (latent TB infection) screening programme within the 4 high-burden CCGs identified within East Midlands.

# TB notifications and incidence

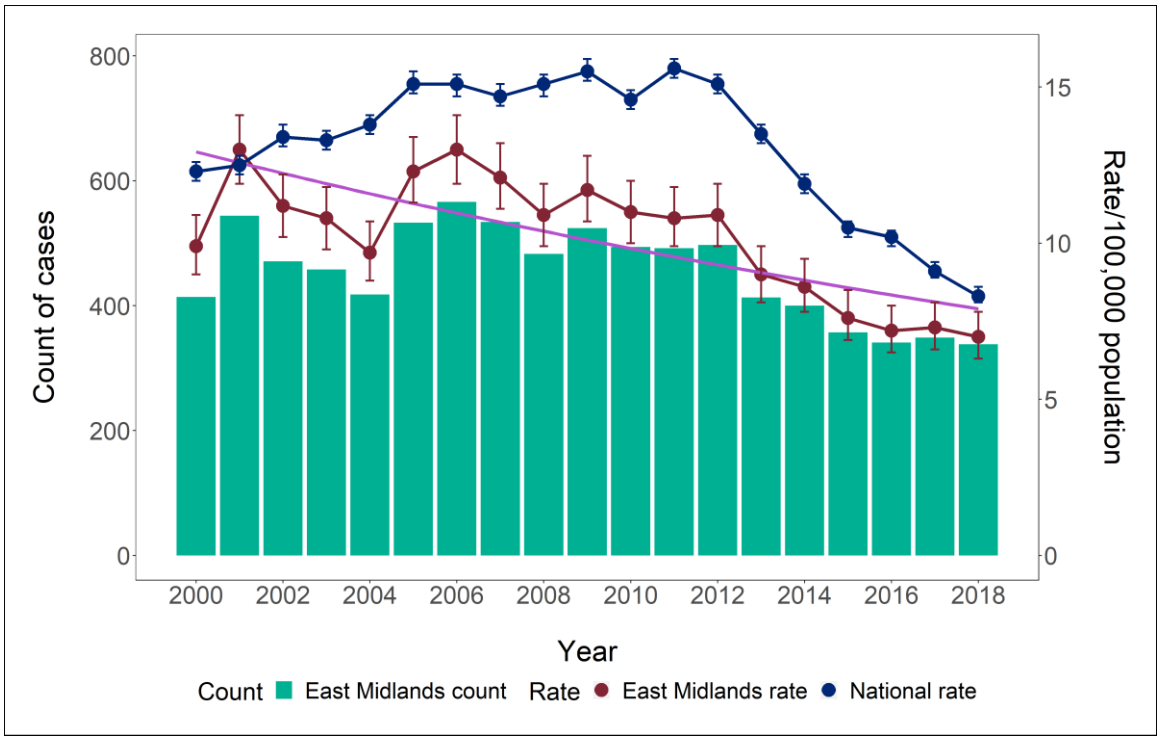
## Overall numbers, rates and geographical distribution

In 2018, 338 TB patients were reported among East Midlands residents, an incidence of 7.0/100,000 population (95% CI 6.3–7.8). This represents a slight (but not statistically significant) decrease of 11 persons from 2017 (Figure 1). Overall, despite a slight increase in 2017, the incidence (count and rates) of TB has declined substantially in the East Midlands, since the early to mid-2000s mirroring the national trend.

The TB incidence of 7.0/100,000 in the East Midlands is statistically significantly lower than the England incidence rate of 8.3 per 100,000 population (95% CI 8.1-8.6). Patients reported in the East Midlands in 2018 accounted for 7.3% of the 4,655 patients reported in England [(2)].

## TB Monitoring Indicator 1: Overall TB incidence per 100,000 population

**Figure 1: TB case reports and rates, for the East Midlands, 2000 to 2018**




As in previous years, the highest incidence rate of TB for East Midlands UTLAs was in Leicester (40.5/100,000). This rate is a further increase from the low point reached in 2015 (36.3/100,000). The increase in Leicester since 2015 is not however significant but could suggest that the long-term downward trend may have now plateaued for Leicester. Therefore, if the goal of TB eradication is to be achieved, then renewed

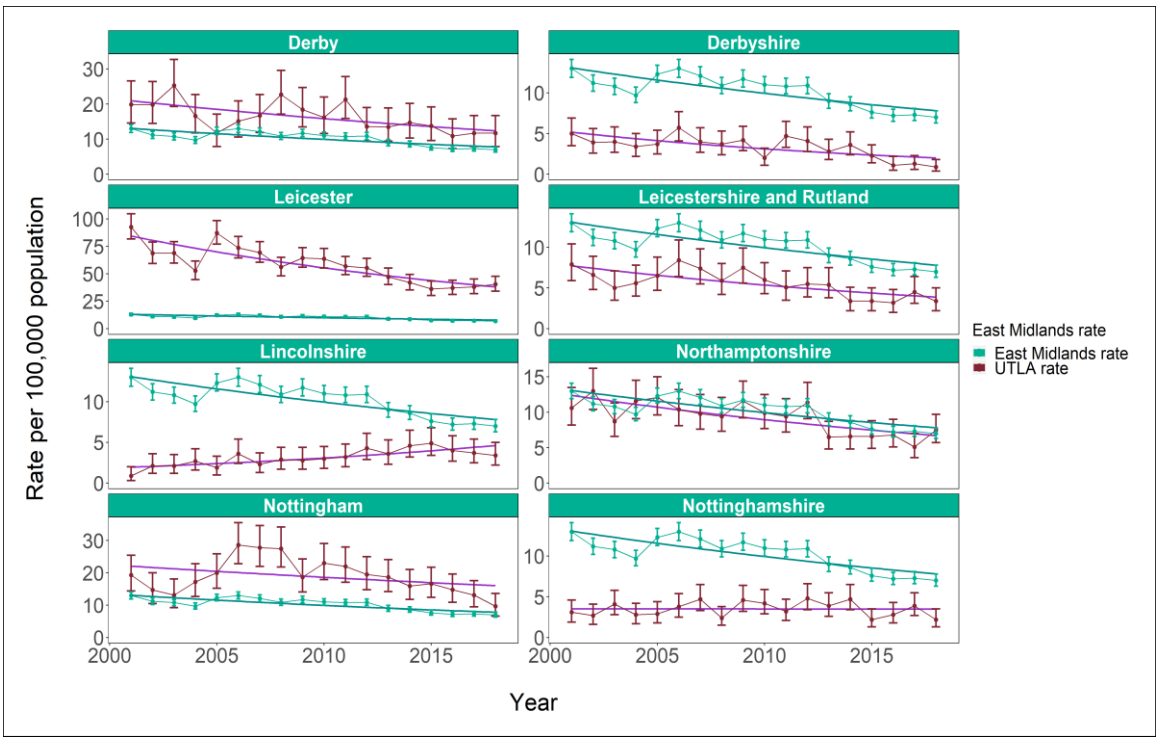
efforts to re-establish the downward trend in Leicester are required. Particular focus may be required in the areas (for example, middle super output areas) with high incidence rates of TB.

The lowest incidence rate of TB new notifications was in Derbyshire (0.9/ 100,000) which was a decrease (but not significant) from 2017 (1.3/100,000).

Overall, Leicestershire and Rutland, Nottingham and Nottinghamshire had further decreases in the number and incidence of new patients with TB reported in 2018 compared with 2017, although none of these reductions were statistically significant. Although there was a decrease in the number of patients in Lincolnshire between 2017 and 2018, the overall trend has been upwards in recent years. There was an increase of 18 patients in Northamptonshire from an incidence rate of 5.1 per 100,000 in 2017 to 7.5 per 100,000 in 2018. The incidence rate remained the same as 2017 in Derby.

The trends of TB incidence (rate) for the UTLA areas in the East Midlands are shown in figure 2 below. These count and rate data for the East Midlands and UTLA areas are tabulated in tables C1a, C1b, C2a, C2b in the appendix.

**Figure 2: TB case rates by sector/UTLA of residence and the East Midlands, 2001 to 2018**

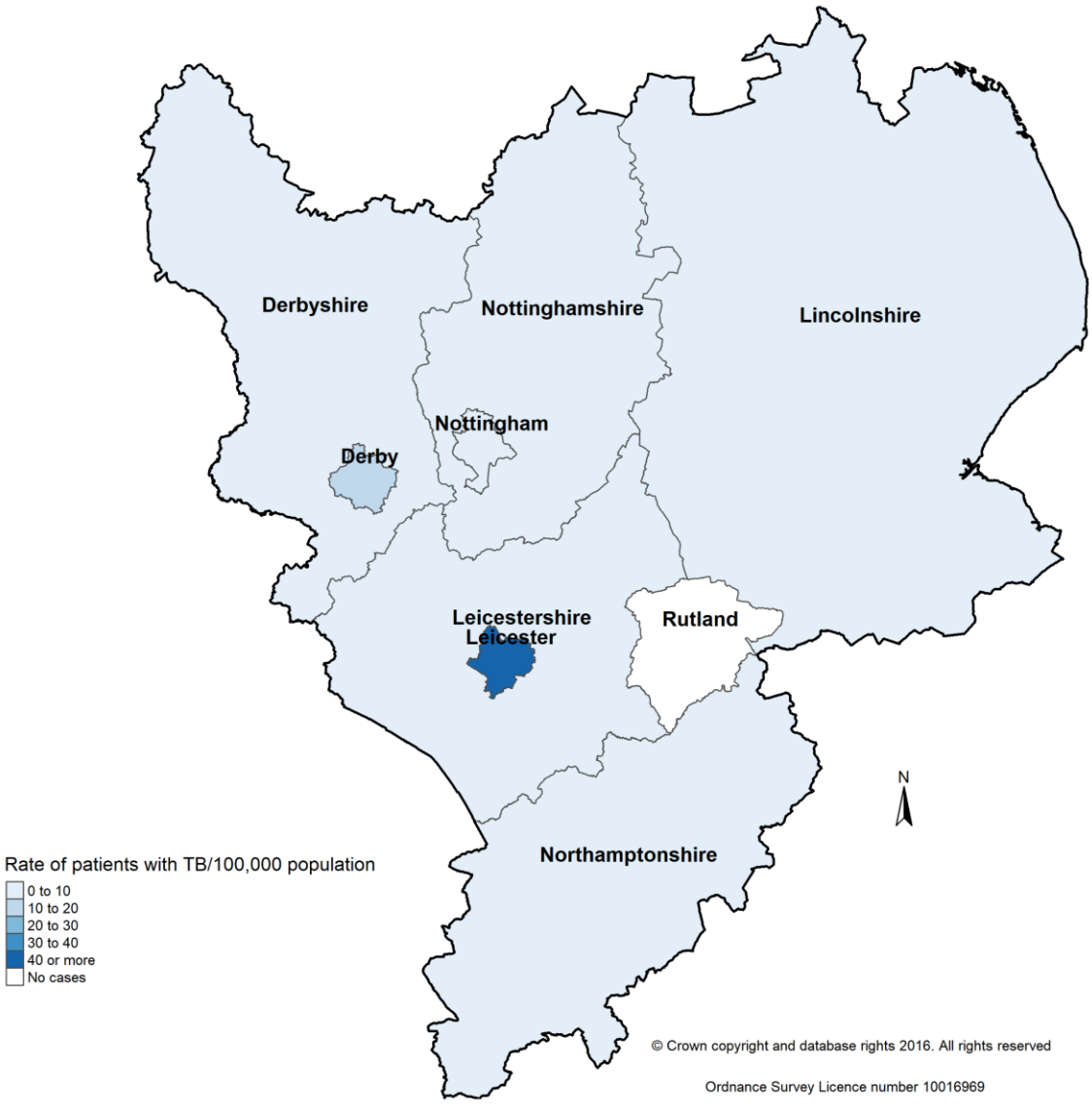



Note: Differing y scale for each UTLA

The mapping figures 3a and 3b below demonstrate that the overall East Midlands incidence rate of TB masks areas with higher incidence. As outlined previously the highest incidence rate of TB occurred within the City of Leicester, with other urban areas also dominating the highest incidence areas.

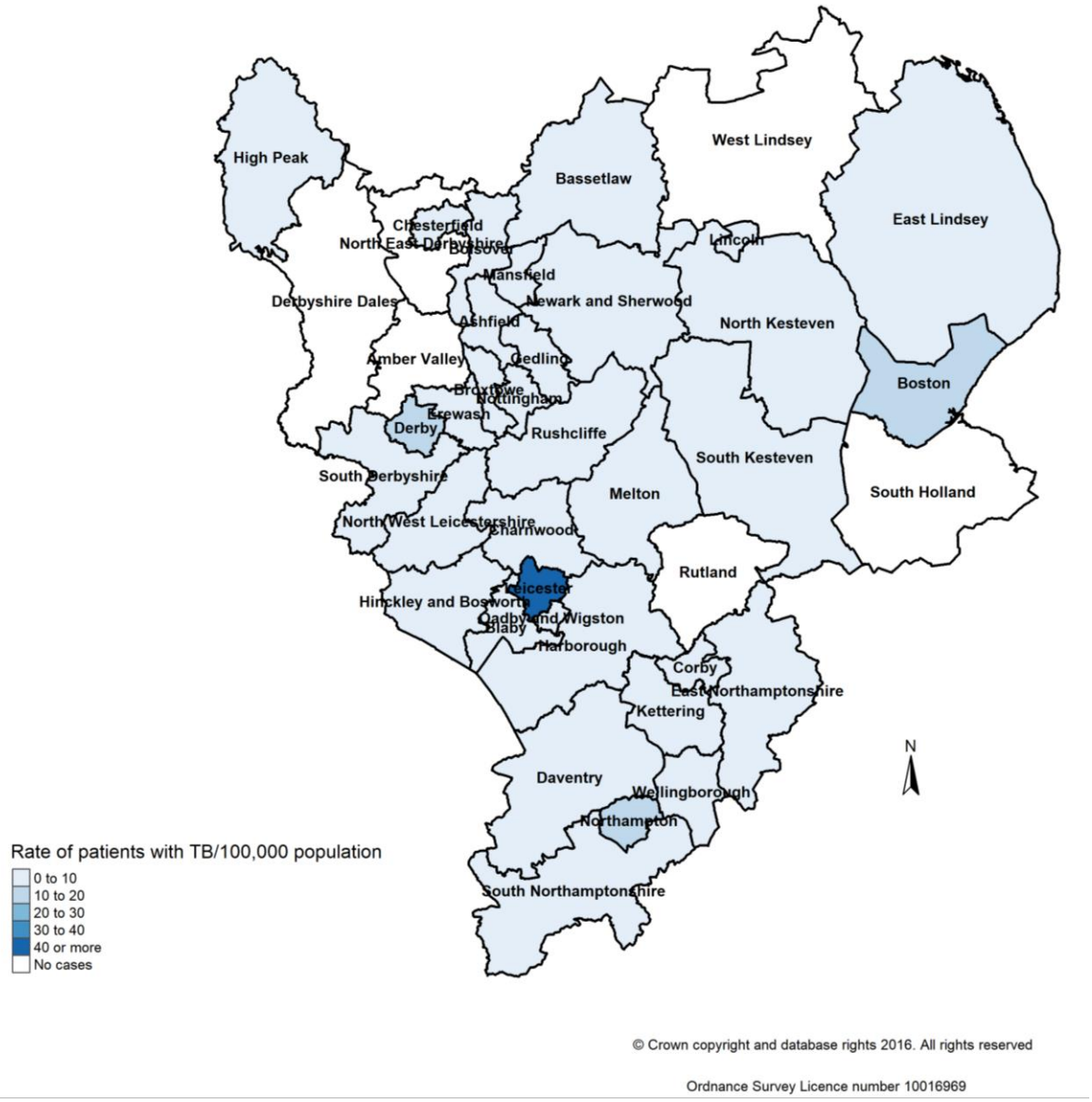
The majority of CCGs in the East Midlands had a three-year average annual incidence rate of fewer than 10 patients per 100,000 population between 2016 and 2018. The exceptions were: NHS Leicester City CCG which had three-year average annual incidence rates of 38.7/ 100,000 and NHS Nottingham City CCG, 12.5 / 100,000). The incidence rates by CCG are shown in the table C3 in the appendix.

**Figure 3a: TB case rate by UTLA of residence, East Midlands, 2018**



The incidence rates by middle layer super output area (MSOA), which are geographical areas with a minimum population of 5,000 (national mean is population of 7,200), show that 13 areas in the East Midlands had a three-year average annual rate of more than 40 patients per 100,000 population between 2016 and 2018. Of these, 12 were within Leicester (Leicester 004: E02002830, 005: E02002831, 006: E02002832, 007: E02002833, 010: E02002836, 011: E02002837, 017: E02002843, 018: E02002844, 019: E02002845, 021: E02002847, 022: E02002848 and 023: E02002849 mainly North East/East of City) and 1 in Lincolnshire (Boston 003: E02005419, within Boston town). These high incidence MSOA areas could be good target areas for proactive work on reducing the burden of disease.

**Figure 3b: TB rate per 100,000 population by local authority of residence, East Midlands, 2018**



# Demographic characteristics

## Age and sex

As with previous years, the incidence rate of TB in 2018 for all patients with TB was higher in males; 7.8 patients per 100,000 population (95% CI 6.7 – 9.0) compared to females (6.3 patients per 100,000 population, 95% CI 5.3– 7.4). Males accounted for 54.7% (185) of new TB notifications.

The incidence and rate of TB in the East Midlands was greatest in the age band 20 to 29 years and 40 to 49 years (both 12.1/100,000), with TB in males dominating females in almost all age groups except in the age groups – 50 to 59 years and 60-69 years age bands. This pattern is also demonstrated in the longer-term trends, where the incidence in males dominates the incidence in females in most years and age bands (Figure 5).

**Figure 4: TB case reports and rate by age and sex, for the East Midlands, 2018**

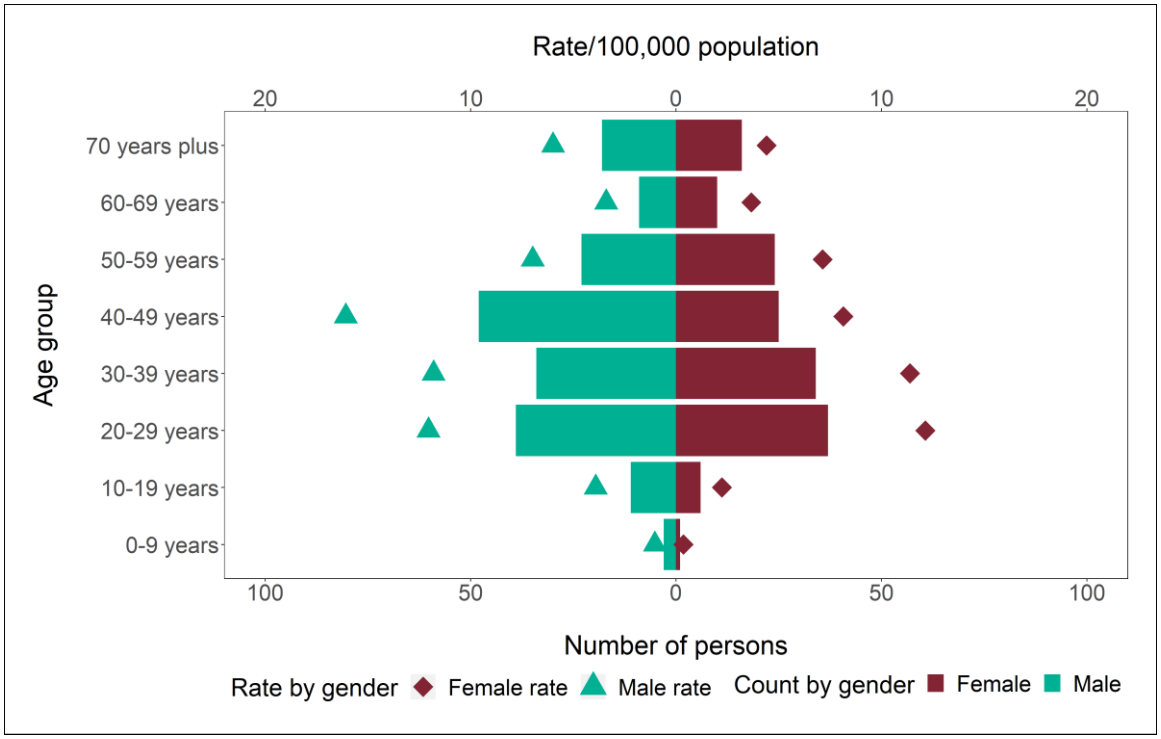
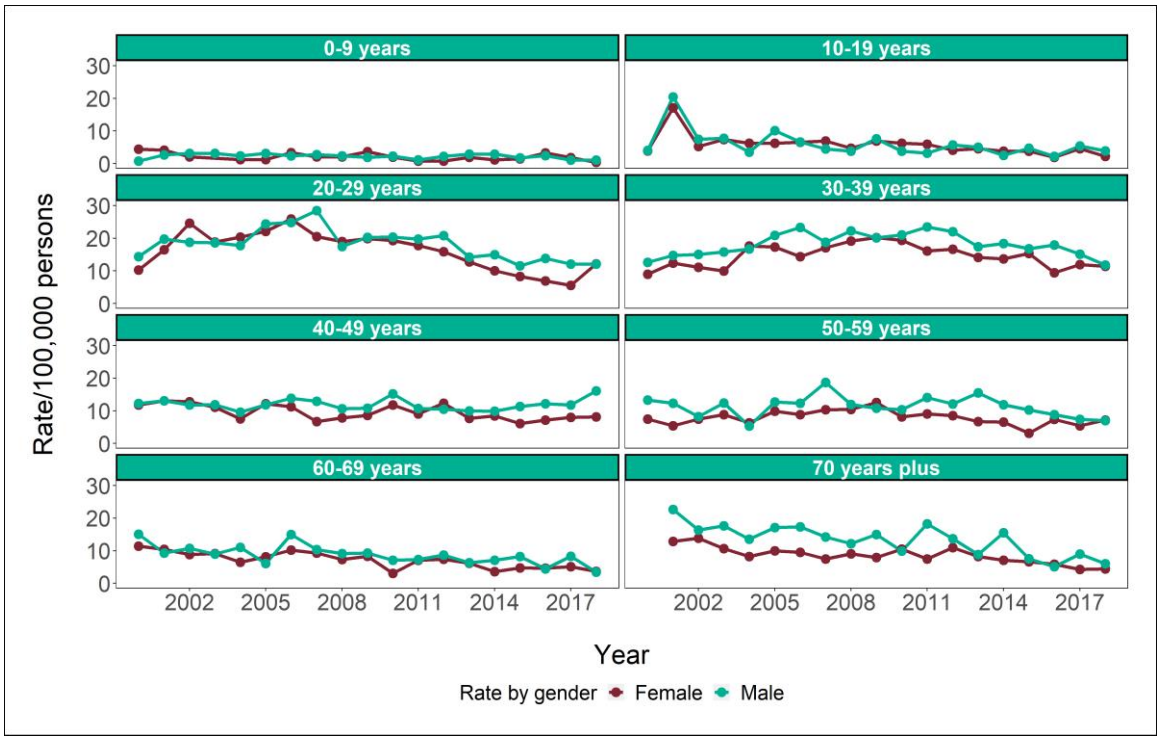


**Figure 5: TB case rates by age group and sex, for the East Midlands, 2000 to 2018**




In 2018, the rate of TB in all children under 15 years of age within the East Midlands was 0.9 per 100,000 population (8 patients), of which 87.5% were born in the UK. This is a decrease from 2.0/100,000 population in 2017 (17 patients – UK and not UK-born). Further information on TB in children for the UK-born population can be found on page 30.

## Place of birth and time since entry

In 2018, country of birth information was recorded for 334 patients (98.8% of all new notifications). Of these, 77.5% of all East Midlands TB patients were born outside the UK (259 new notifications as compared to 225 in 2017).

Using East Midlands residents who were non-UK born as a denominator, there was an incidence rate of 44.3 new notifications per 100,000 population in 2018 which is approximately 25-times higher than the incidence rate in those born in the UK (1.8 per 100,000 population). Although the rates within the non-UK born population have been steadily decreasing since 2005 (99.4/100,000) there has been an increase in 2018 from 37.5 per 100,000 in 2017 (Figure 6). By contrast, the TB incidence within the UK-born population has broadly remained unchanged over previous years but has decreased in 2018 compared to a rate of 2.8 per 100,000 in 2017.

In 2018, information on the time between entry to the UK and TB diagnosis was recorded for 96.5% of non-UK born patients (250 patients). Among those reported in

2018 that were non-UK born and for whom information on time between entry and TB diagnosis was available, 17.2% were notified within 2 years of entering the UK and 45.6% within 6 years. There was a decrease in the proportion of patients notified 11 or more years after entry from the UK from 45.2% (99 patients) in 2017 to 37.2% (93 patients) in 2018. TB within in this group could either represent reactivation or recent exposure in the UK or from travel abroad, (however improved recording of these data may explain some of the increasing trend). It may be appropriate to consider what strategies could help address the TB incidence in this group.

The data on time between entry to the UK and TB diagnosis are displayed in Figure 7 (as a stacked bar chart). Some of the data fluctuations noted may reflect improved coding/recording of data over time.

## TB Monitoring Indicator 2: TB incidence in UK-born and non-UK born populations

**Figure 6: TB case reports and rate by place of birth and year of onset, East Midlands, 2000 to 2018**

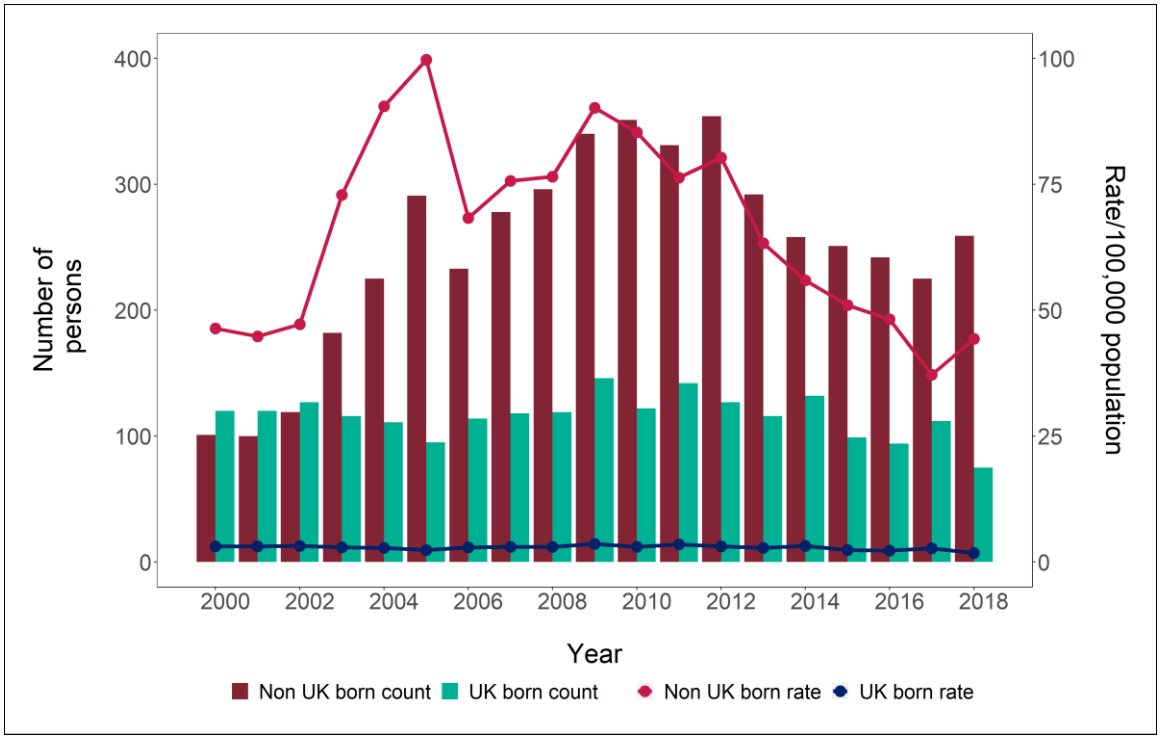
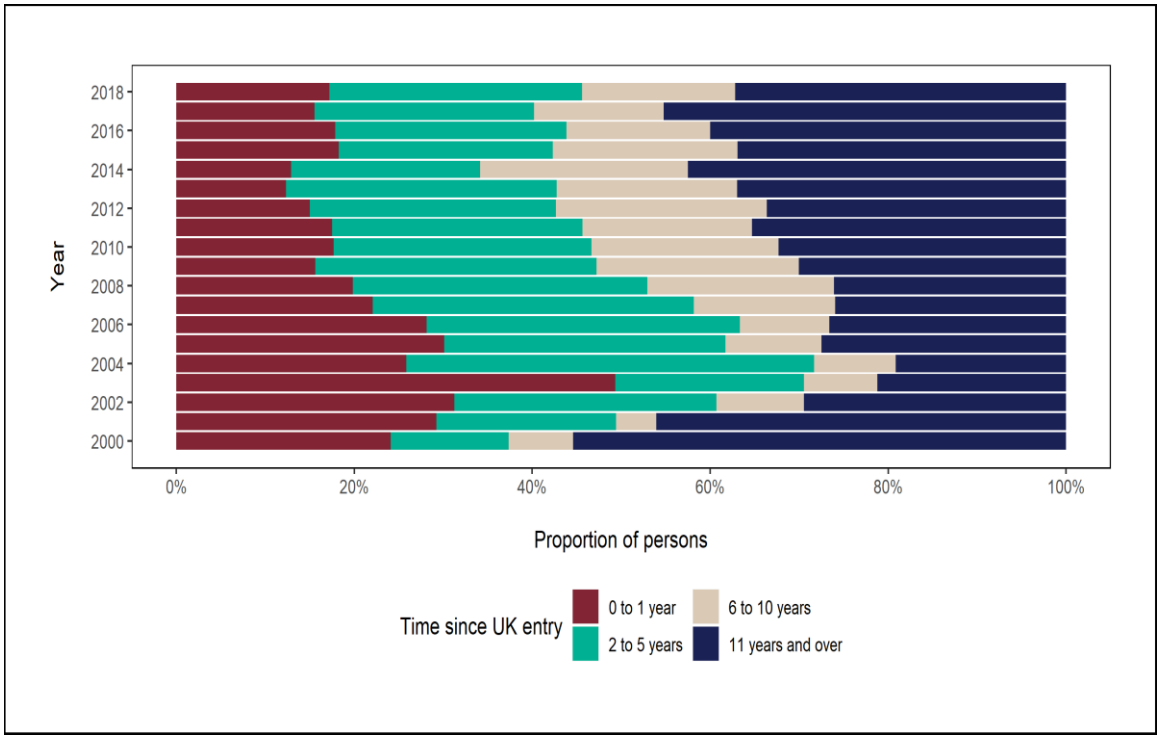


**Figure 7: Time between entry to the UK and TB notification for non-UK born patients by year, East Midlands, 2000 to 2018**



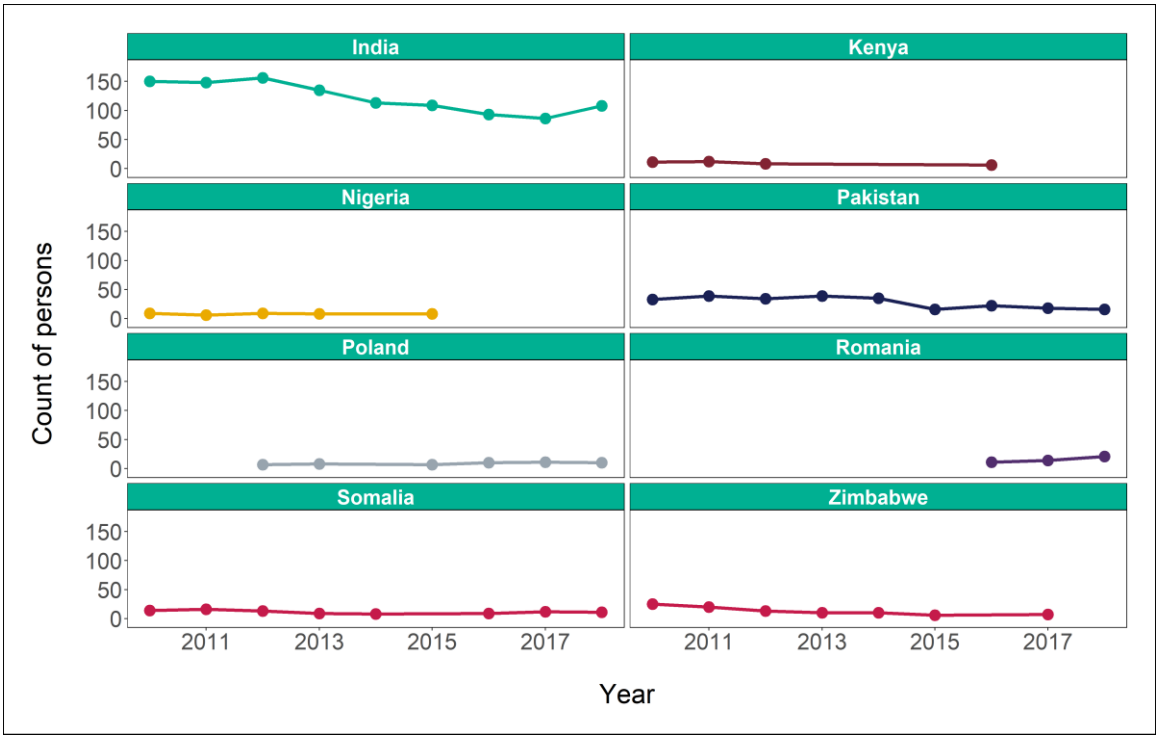

In 2018, the most commonly reported country of birth for non-UK born patients was India (41.7%), (Table 1) followed by Africa Other (11.6%) and Romania (8.1%), which was similar to 2017. There was a non-significant increase in the number of patients from Romania from 14 (6.2%) in 2017 to 21 in 2018. Nationally the numbers born in Romania also saw an increase between 2013 to 2017 but remained stable in 2018 [(2)].

**Table 1: The most common countries of birth of non-UK born TB patients, East Midlands, 2018**

| Country of birth | Number of new TB notifications | % |
|---|---|---|
| India | 108 | 41.7 |
| Africa Other | 30 | 11.6 |
| Romania | 21 | 8.1 |
| Asia Other | 19 | 7.3 |
| Pakistan | 16 | 6.2 |
| Somalia | 11 | 4.2 |
| Lithuania | 10 | 3.9 |
| Poland | 10 | 3.9 |
| Europe Other | 9 | 3.5 |
| Sudan | 8 | 3.1 |
| Bangladesh | 5 | 1.9 |
| Tanzania | 5 | 1.9 |
| Zimbabwe | 5 | 1.9 |
| Other | 1 | 0.4 |

Figure 8 below describes the trend in incidence of TB in patients born outside of the UK, by the most common countries of birth in 2018, from 2010 to 2018.

**Figure 8: Trend in TB case numbers in the 8 most common countries of birth, East Midlands, 2010 to 2018**




* Note: data are only displayed where there are more than 5 persons diagnosed with TB from the relevant country in that year.

## Ethnicity

Ethnicity data was available for 336 patients (99.4% of notifications). The majority of TB patients were of Indian ethnicity, 43.8%, 147 patients, which is a rise from 32.7%, 112 patients in 2017 (Figure 9a). This is now higher than those of white ethnicity, 26.2%, 88 patients – a drop from 37.6%, 129 patients in 2017. In 2018, rates of TB were highest in those of Indian ethnicity (79.5/100,000) followed by Black African ethnicity (51.5/100,000).

For those that were UK born, the trend is slightly downward in recent years (excluding 2017) for white ethnicity but there has been a marked increase for those of South Asian ethnicity in 2018 (Figure 9b). The number of UK-born patients recording Black ethnicity (Black-Caribbean, Black-African and Black-Other combined) has decreased from 2017 and those of Mixed/Other ethnicity have shown a slight increase.

**Figure 9a: TB incidence count and rate per 100,000 population by ethnic group, East Midlands, 2018**

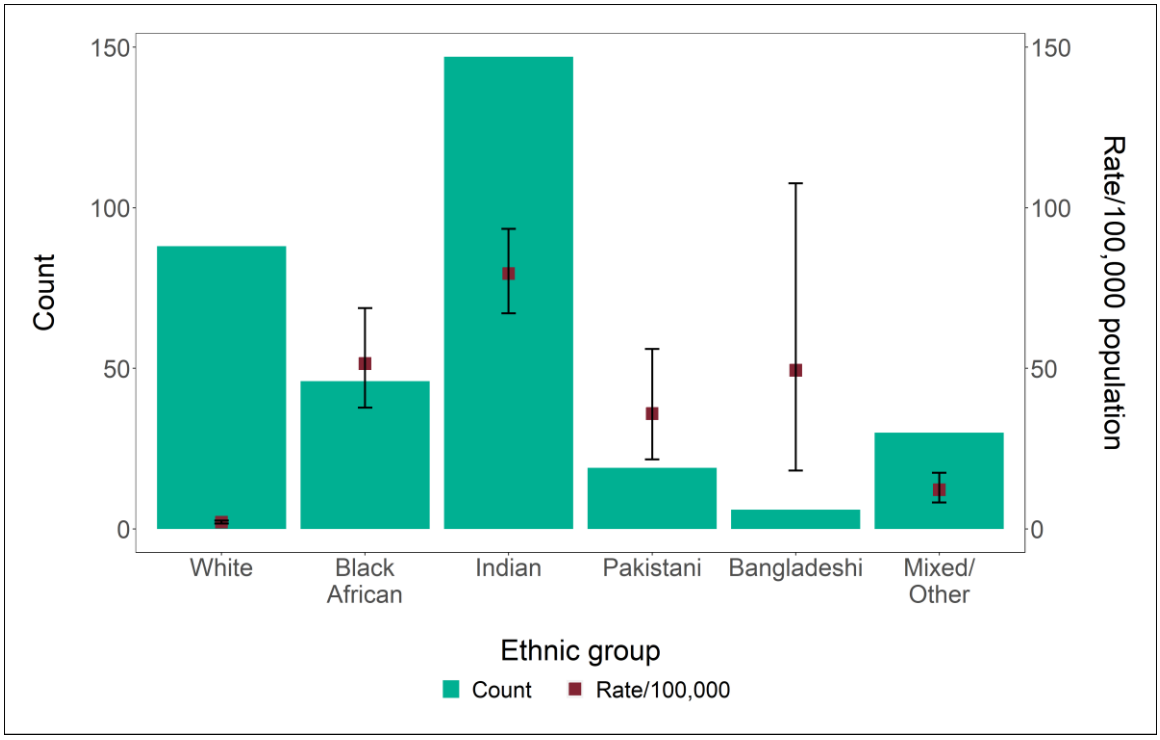
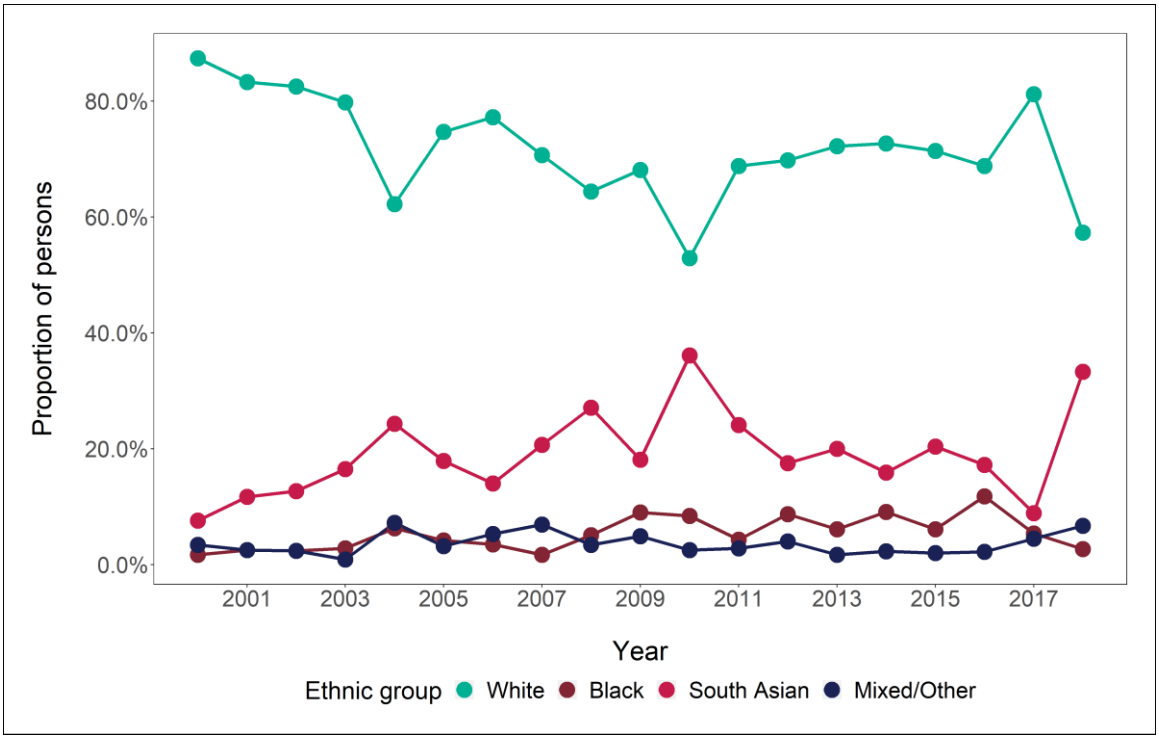



**Figure 9b: Proportional TB case numbers by ethnic group for UK born patients, East Midlands, 2000 to 2018**

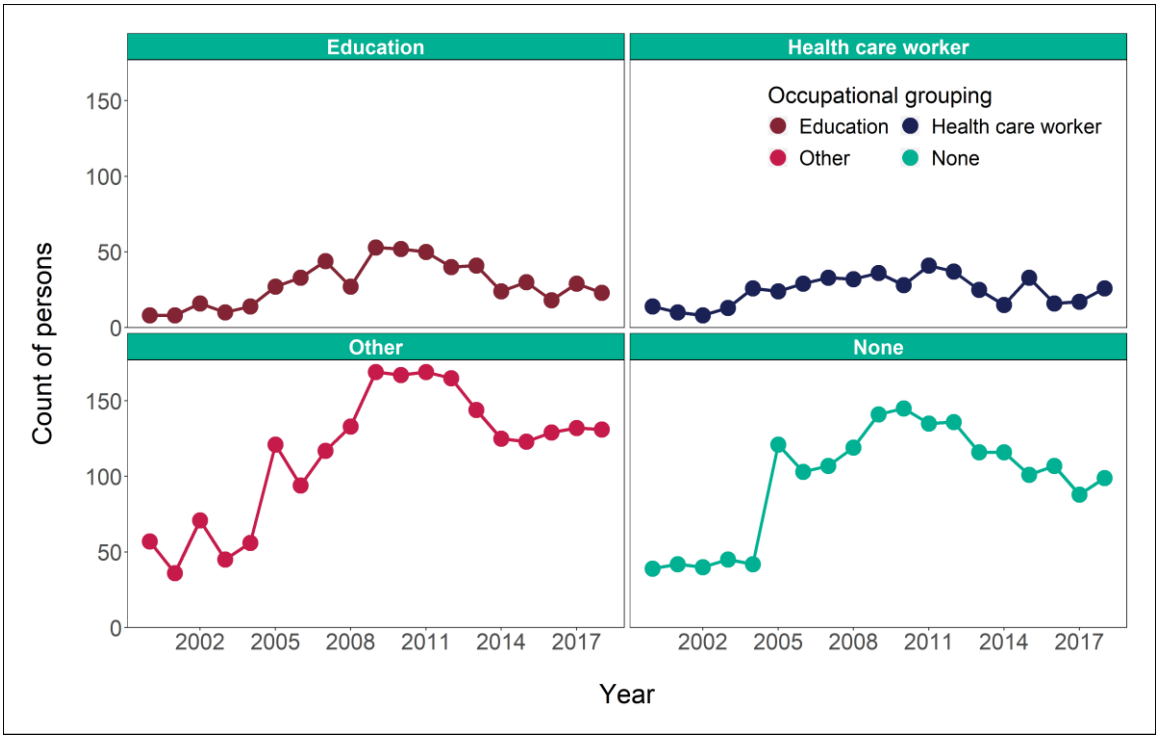



* Patients with Black-Caribbean, Black-African and Black-Other ethnic groups were grouped as 'Black'
** Patients with Indian, Pakistani and Bangladeshi ethnic groups were grouped as 'South Asian'
$ Patients with Mixed/Other and Chinese ethnic groups were grouped as 'Mixed/other'

## Occupation

It is very striking that a substantial proportion (35.5%) of those diagnosed with TB in 2018 (aged ≥ 16 and ≤ 65 years) describe themselves as having no current occupation (figure 10), an increase from 33.1% in 2017. This group includes the retired, unemployed, prisoners, immigration detainees, asylum seekers and home makers. It has previously been recognised that prisoners, for example, have a higher incidence of TB compared to other individuals; however, the data serves as a useful reminder that TB prevention work is critical within subpopulations within the group that describe themselves as having no occupation.

**Figure 10: Trends in occupational category of TB patients aged 16 to 65 years, East Midlands, 2000 to 2018**



## Clinical characteristics

### Site of disease

As in previous years, in 2018, pulmonary disease remained the most common site for tuberculous disease (195 patients, 55.6% of all new infections). Tuberculous lymph nodes (intra/extra thoracic) and pleural sites were the next most common sites with intrathoracic lymph nodes being the second most common site of disease (62 patients, 17.7% of all new infections). All other sites for TB were uncommon in 2018 (Table 2).

**Table 2: Site of disease of TB patients, East Midlands, 2018**

| Disease site | Count of patients | % |
|---|---|---|
| Pulmonary | 195 | 55.6 |
| Miliary | 4 | 1.1 |
| Bone/joint (spine) | 13 | 3.7 |
| Bone/joint (other - not spine) | 9 | 2.6 |
| CNS (meningitis) | 4 | 1.1 |
| CNS (other - not meningitis) | 8 | 2.3 |
| Gastrointestinal/peritoneal | 17 | 4.8 |
| Extrathoracic lymph nodes | 59 | 16.8 |
| Intrathoracic lymph nodes | 62 | 17.7 |
| Pleural | 25 | 7.1 |
| Extrapulmonary-other | 24 | 6.8 |
| Other | 14 | 4.0 |

*patients may have disease at more than 1 site, so the total % will not equal 100%
†CNS: Central nervous system

### Previous history of tuberculosis

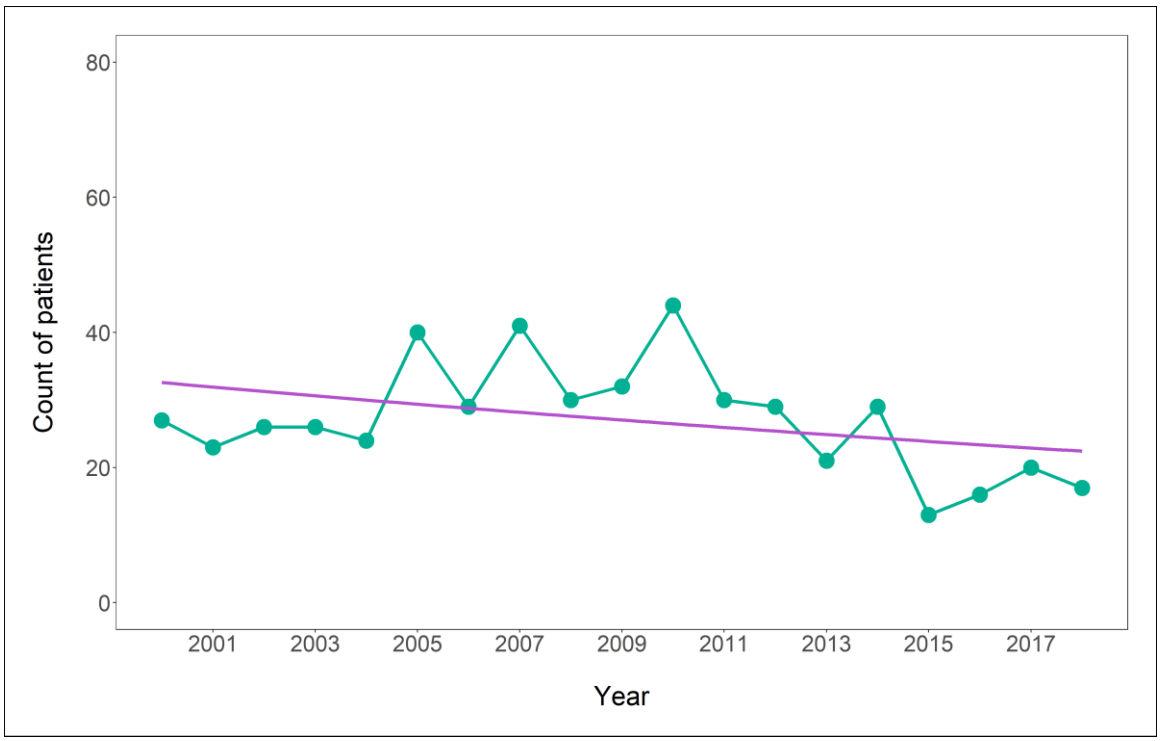
In 2018, information on previous diagnosis (active TB more than 12 months before, either in the UK or abroad) was recorded for 95.6% (323) of patients. Of these, 5.3% of patients were previously diagnosed with TB more than 12 months before their current notification (17 patients). Although the number of patients presenting as new diagnoses each year, who have previously had TB has declined since the year 2000, the proportion of the total new diagnoses has remained broadly flat at around 5-6% since 2011.

In 2018, of those who had a previous TB diagnosis (where their ethnicity was known) 47.1% were of Indian ethnicity, however the proportion varies from year-to-year.

Of those who previously had TB, in 2018 the minority had any social risk factors for TB and 41.2% of these patients were aged 25 to 34 years or older.

Where known, the number of years since the previous diagnosis for all patients in 2018 ranged from 1 to 50 years with a median of 4 years.

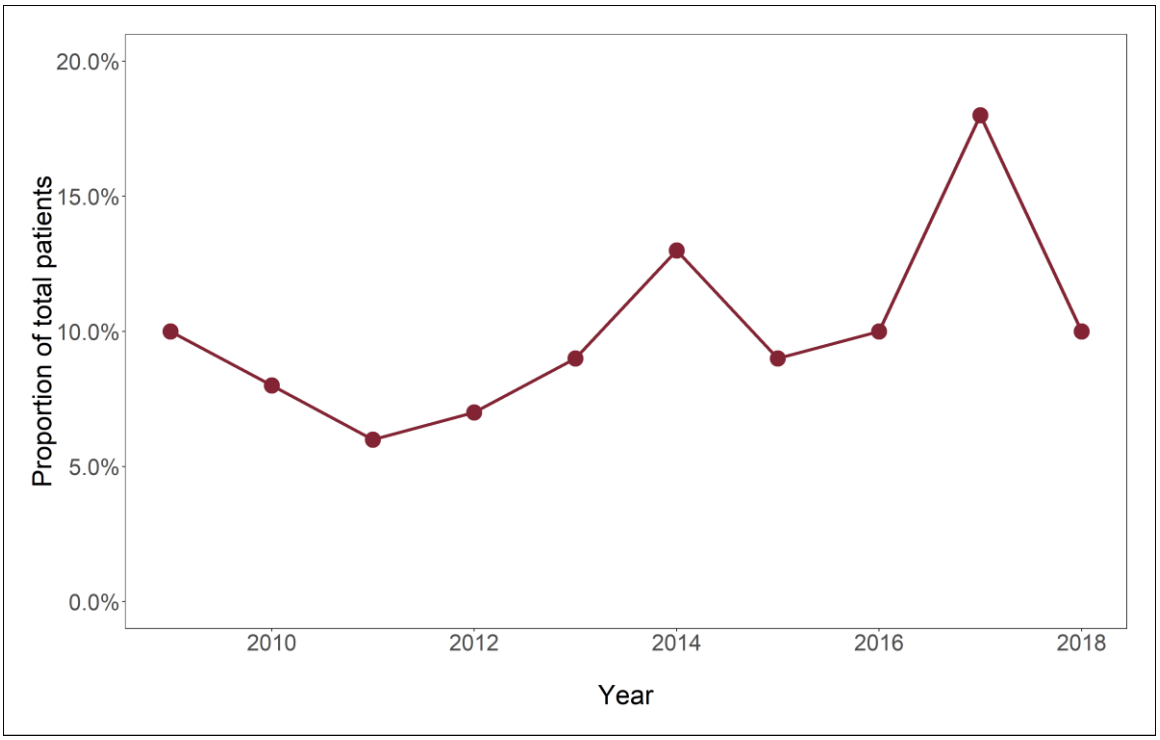
**Figure 11: Trends in the count of total TB patients who have previously had TB, 2000 to 2018, East Midlands**




## Supervised treatments

Since 2009, the number of patients with TB being enrolled into directly observed treatment (DOT) programmes (where the patient is monitored and observed taking their anti-TB treatment to improve compliance with treatment) (Figure 12) had been increasing. However, in 2018 there was a decrease in the proportion of patients receiving DOT to 10% (32 patients) from 18% in 2017 (58 patients).

**Figure 12: Trends in proportion of TB patients that are receiving directly observed treatment, 2009 to 2018, East Midlands**



# Laboratory confirmation of TB

## Laboratory tests data collection

Laboratory data on culture confirmed TB isolates from the National Mycobacterial Reference Service were matched to TB case notifications, and the results were used to report culture confirmation. Results for microscopy, PCR and histology are also collected in ETS.

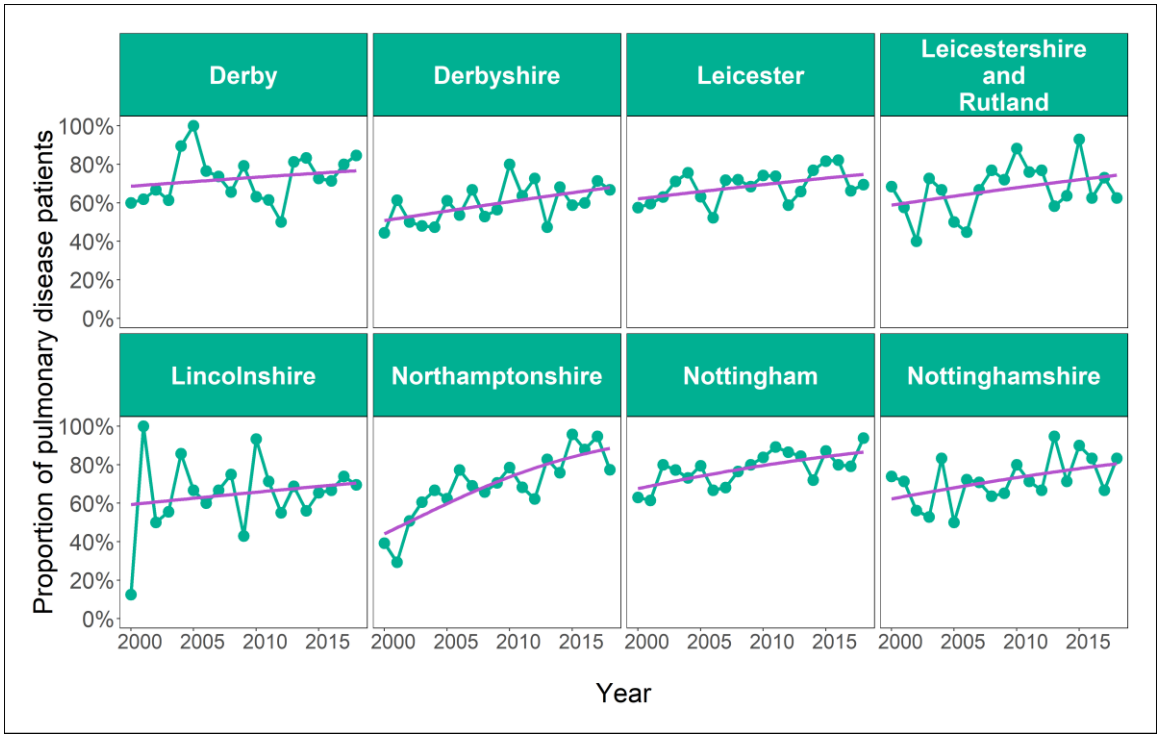
## Culture confirmation and speciation

In 2018, 58.9% (199) of all patients were culture confirmed, this was a similar proportion to that in 2017. This proportion was higher among those with pulmonary TB (74%, 145 patients) compared to patients with extra-pulmonary TB (38.3%, 54 patients).

There was marked variation in the proportion of pulmonary TB patients in the East Midlands confirmed by culture by UTLA area – for example ranging from 62.5% culture confirmed in Leicestershire and Rutland to 93.8% in Nottingham (Figure 13). Of more interest is the longer-term trend in the proportion of patients whose diagnosis was confirmed by culture. Figure 13 demonstrates that in all UTLA areas, confirmation by culture has improved (upward trend) but there is still scope for some areas to also improve.

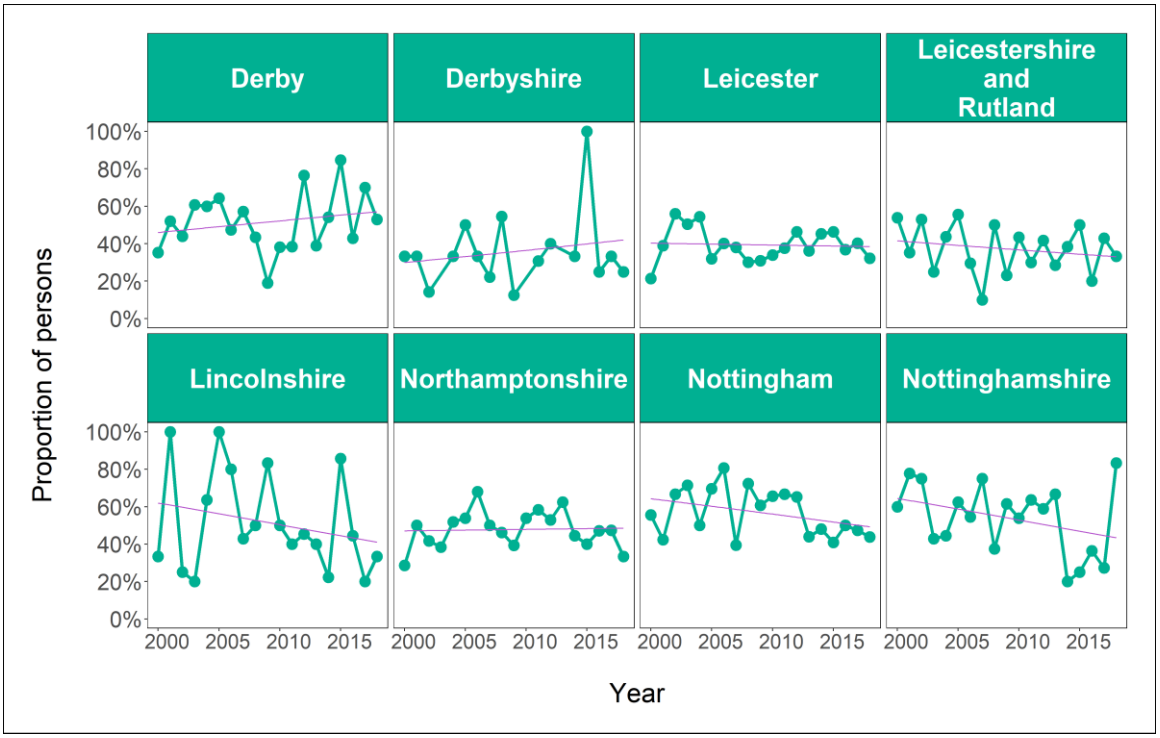
In 2018, 98% of cultured isolates were *Mycobacterium tuberculosis*, the remaining 2% being of other rarer species within the *Mycobacterium tuberculosis complex* (*Mycobacterium africanum* and *Mycobacterium bovis*).

**Figure 13: Proportion of culture confirmed pulmonary TB isolates by UTLA, 2000 to 2018**




Unsurprisingly, the proportion of extra-pulmonary TB confirmed with culture is much lower than for pulmonary TB, reflecting the difficulty in obtaining clinical samples from non-pulmonary sites. However, again there is marked variation with Nottinghamshire achieving 83.3% culture confirmation for this group, whereas for Derbyshire only 25.0% of extra-pulmonary TB patients had their diagnosis confirmed with culture. However, small numbers may skew the results (figure 14). Once again, the trend data (figure 14) is more informative, showing an improved performance for several areas (Derby), but a worsening trend for others, particularly Lincolnshire.

**Figure 14: Proportion of culture confirmed extra pulmonary TB isolates, 2000 to 2018**



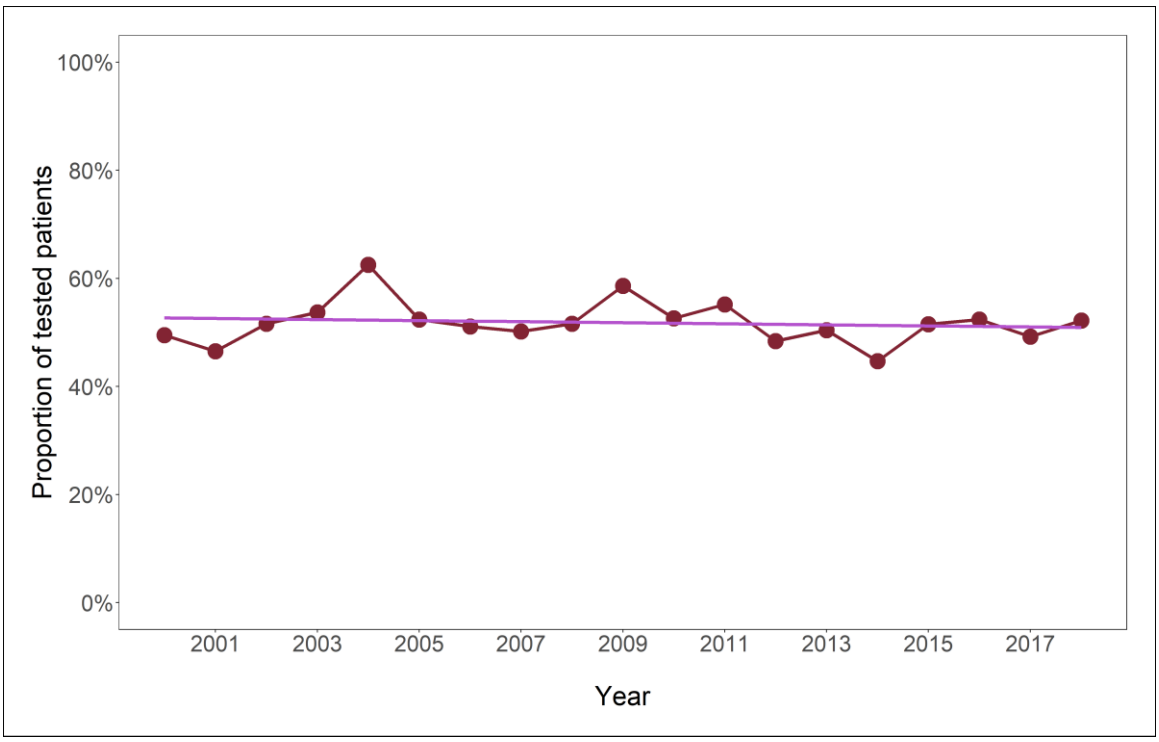

## TB Monitoring Indicator 8: Proportion of pulmonary TB patients that were culture confirmed

### Sputum smear

Sputum smear results are used to assess the infectiousness of pulmonary TB patients with smear-positive patients deemed more infectious than smear-negative results. In 2018, 57.7% (113) of the 196 patients with pulmonary TB had a sputum smear (microscopy) result reported. Of these, 52.2% were sputum smear positive (59). No age group stood out as being more likely to be smear positive, although smear positivity was not reported in children due to the difficulties of obtaining sputum samples from children.

Overall for the East Midlands, the proportion of patients with pulmonary TB who have a sputum smear result reported in ETS has decreased. In 2005, 73.6% of patients had a sputum smear result (positive or negative) reported. This has dropped to only 57.7% reported on ETS in 2018. Of pulmonary TB patients that had a smear test reported, the proportion with a smear positive result have broadly remained the same between 2000 and 2018 (Figure 15).

**Figure 15: Proportion of pulmonary TB patients with a sputum smear positive result, 2000 to 2018**




## Other laboratory test results

As with previous years, very few patients had other PCR or histology tests according to the data entered onto ETS. However, these data may not reflect the true situation and so this may be an area to work on in improving the data quality.

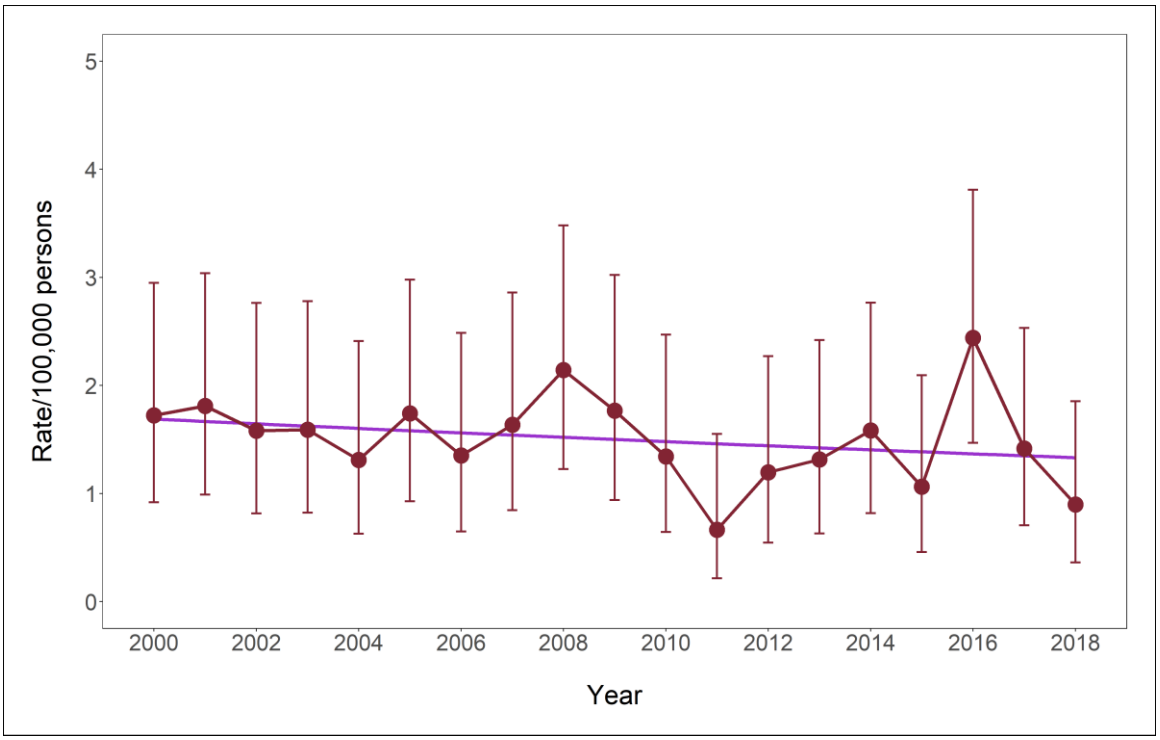
# TB transmission

## Rate of TB in UK-born children

The incidence of tuberculosis in UK-born children is considered a marker of transmission within the locality. On a year-on-year basis the number of UK born children in the East Midlands diagnosed with TB is small relative to the overall total; the trend has slowly declined since the year 2002, although the trend is not statistically significant. Fortunately, the increase in incidence in children in 2016 has returned to the longer-term trend, although the number of new notifications in future years will need monitoring (figure 16).

In 2018, there were 7 new notifications of TB in UK-born children aged 14 years and under within the East Midlands, a rate of 0.9 per 100,000 population, a decrease from 11 children in 2017 (1.4/100,000).

**Figure 16: TB case rates of UK born children aged 0 to 14 years, for the East Midlands, 2000 to 2018**




## TB Monitoring Indicator 5: Incidence of TB in UK born children aged less than 15 years

## Strain typing and clustering

In December 2016, PHE's National Mycobacterial Reference Service replaced MIRU-VNTR strain typing for East Midlands TB isolates with WGS-based single nucleotide polymorphism (SNP) typing. Clusters identified using WGS are defined based on people with TB isolates who are within 12 SNPs of each other. The smaller the number of SNP difference between isolates, the more closely related the isolates are, increasing the potential that they are linked. The higher level of resolution provided by WGS when combined with additional clinical and epidemiological information should improve our understanding of whether patients are likely to be part of the same transmission chain and may also help determine the timing and direction of transmission. Within the Field Service, there is a designated TB cluster investigator whose role is to review and identify clusters within and across PHE Centres. Cluster information is regularly provided to the East Midlands, which are routinely reviewed for epidemiological links and where appropriate prioritised for targeted public health investigation and action.

In 2018, of the patients notified with culture-confirmed TB in the East Midlands, 95.5% (190/199) had a WGS result that could be used to report relatedness (based on sequencing coverage and quality). In 2018, the proportion of people that clustered with at least one other person at a cut-off of 12 SNPs within the East Midlands was 19.5% (37/190) – slightly less to that shown nationally (25%) (Table 3). Of those clustering at 12 SNPs, 14 (37.8%) patients were UK-born and 23 (62.2%) were born outside of the UK.

**Table 3: WGS cluster data 2018**

| SNP cluster threshold | Cluster status | Count | % |
|---|---|---|---|
| 12 SNPs | Clustered | 37 | 19.5 |
| | Not clustered | 153 | 80.5 |

# Delay from onset of symptoms to start of treatment

## Time from symptom onset to treatment start for all patients and those with pulmonary TB

Information on the time from symptom onset to starting treatment was recorded for 95% (321 patients) – all types of TB and for 93.9% (184 patients) for those with pulmonary TB in 2018 (Table 4). The median time between symptom onset to starting treatment for all TB patients was 80 days with an interquartile range (IQR) of 37 to 150 days. The median time between symptom onset to starting treatment for pulmonary TB patients was 73 days with an interquartile range (IQR) of 33 to 130 days which was similar to the median delay to treatment commencement for England (75 days IQR: 37-136) [(2)].

In the East Midlands in 2018, 38.0% of all patients with TB started treatment within 2 months of symptom onset and 65.1% within 4 months. There has been a decrease in the proportion of TB patients starting treatment more than 4 months after symptom onset from 40.4% in 2017 to 34.9% in 2018 although this difference was not statistically significant.

In the East Midlands, 42.4% of pulmonary TB patients started treatment within 2 months of symptom onset and 70.1% within 4 months. There has been a decrease in the proportion of pulmonary TB patients starting treatment more than 4 months after symptom onset from 36.2% in 2017 to 29.9% in 2018 although this difference was not statistically significant.

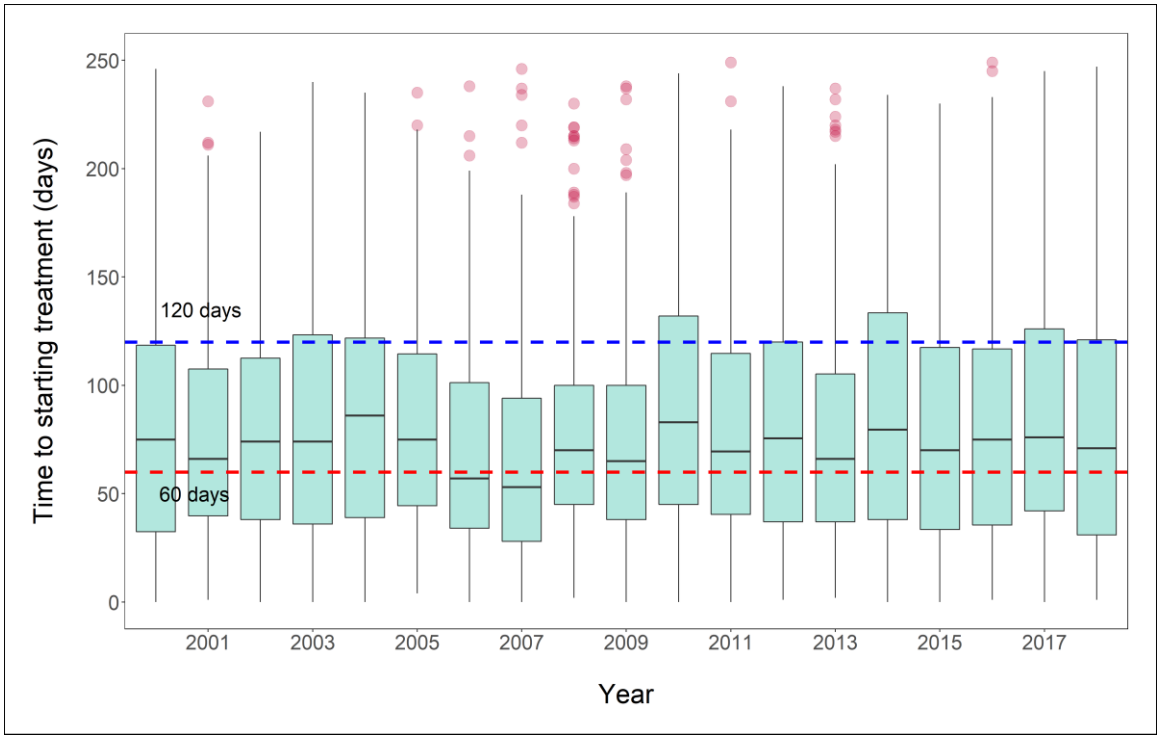
The median time from onset of symptoms (pulmonary TB patients) to starting treatment varies from year-to-year in the East Midlands, however since 2008 has remained approximately around 75 to 90 days (figures 17a and 17b). Although there has been a large decrease from 93 days in 2017 to 73 days in 2018 there is scope to sustain the reduction in the time from development of symptoms to presenting for diagnosis and commencement of treatment as the earlier TB is diagnosed, the less likely it is that transmission to others will occur.

## Table 4: Time between symptom onset and starting treatment for pulmonary TB patients, East Midlands, 2011 to 2018

| Year | 0-2 months Count | 0-2 months % | 2-4 months Count | 2-4 months % | 4+ months Count | 4+ months % | Total |
|---|---|---|---|---|---|---|---|
| 2011 | 75 | 40.3 | 59 | 31.7 | 52 | 28 | 186 |
| 2012 | 70 | 35.2 | 63 | 31.7 | 66 | 33.2 | 199 |
| 2013 | 75 | 41.2 | 63 | 34.6 | 44 | 24.2 | 182 |
| 2014 | 76 | 35.8 | 59 | 27.8 | 77 | 36.3 | 212 |
| 2015 | 81 | 39.9 | 66 | 32.5 | 56 | 27.6 | 203 |
| 2016 | 73 | 39.7 | 58 | 31.5 | 53 | 28.8 | 184 |
| 2017 | 65 | 33.2 | 60 | 30.6 | 71 | 36.2 | 196 |
| 2018 | 78 | 42.4 | 51 | 27.7 | 55 | 29.9 | 184 |

*excluding asymptomatic patients, and those with missing onset dates

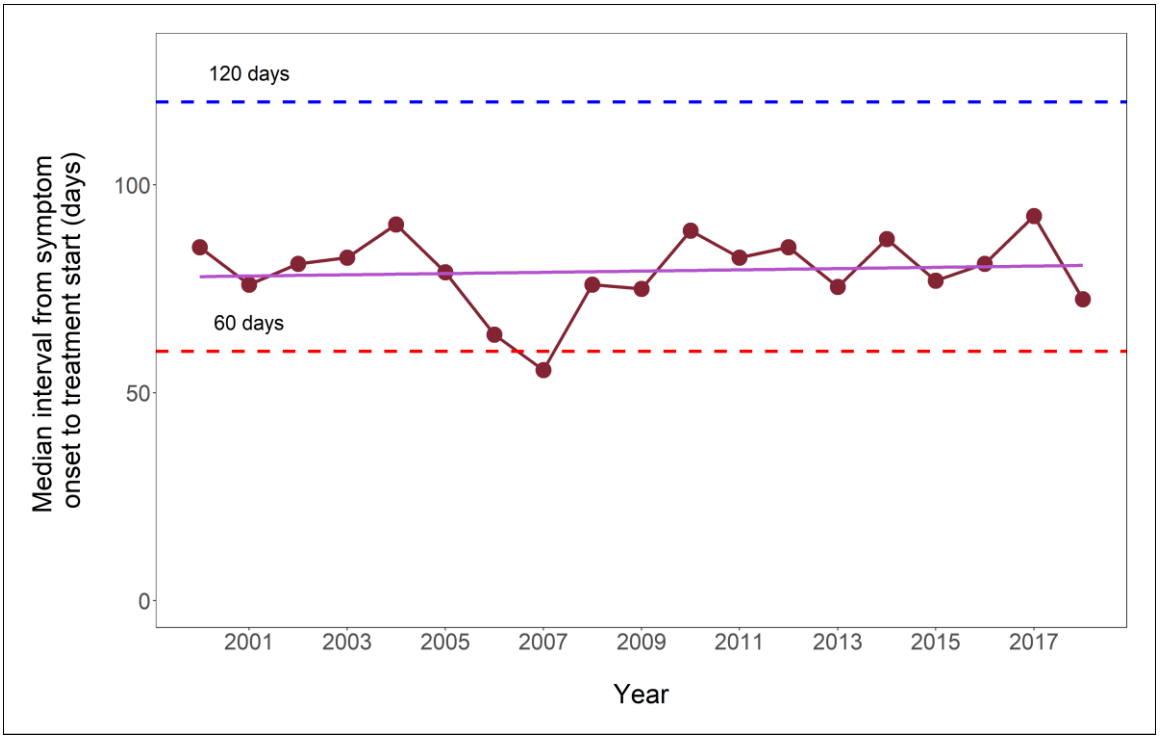
## Figure 17a: Box plot of time between symptom onset for pulmonary disease and treatment start, East Midlands, 2000 to 2018




*excluding asymptomatic patients, those with missing onset dates and those with a symptom to onset delay of more than 250 days (outliers). The red dotted line corresponds to 60 days, and the blue dotted line to 120 days interval.
For an explanation of how to interpret box plots, please see Appendix B: Description of data sources and definitions and other explanations

## TB Monitoring Indicator 6: Proportion of pulmonary TB patients starting treatment within 2 months of symptom onset

**Figure 17b: Median time between symptom onset for pulmonary disease and treatment start, East Midlands, 2000 to 2018**

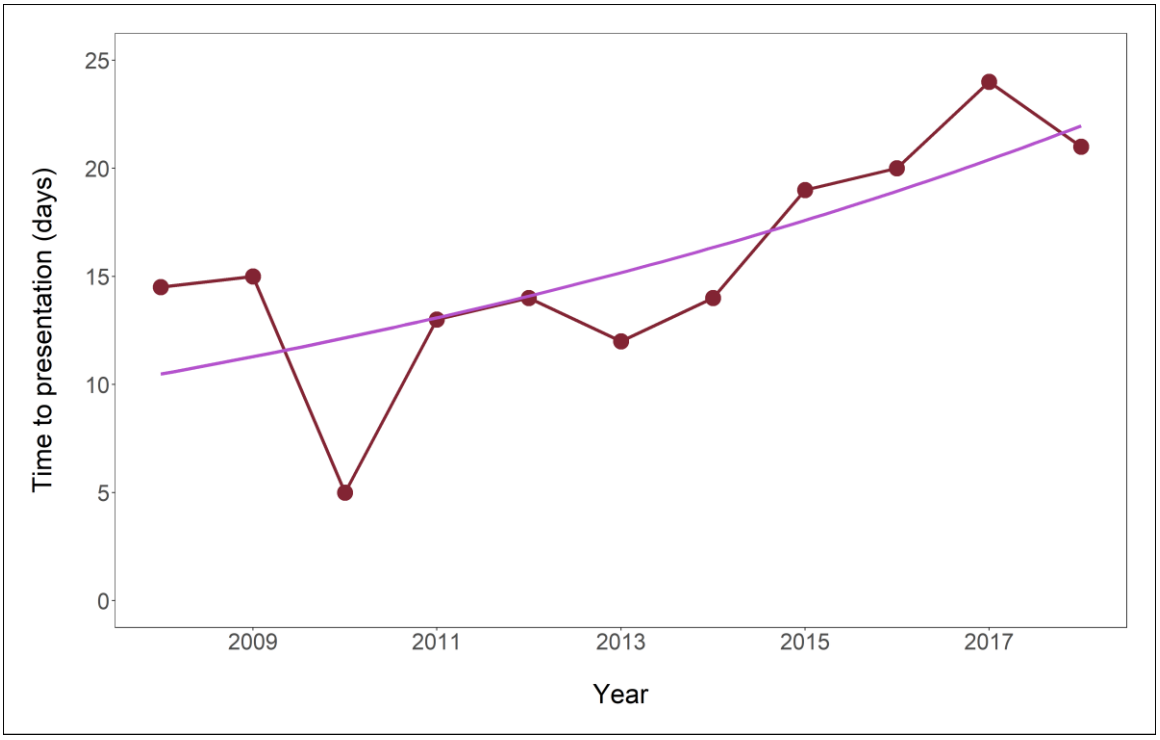



*excluding asymptomatic patients, those with missing onset dates and those with a symptom to onset delay of more than 250 days (outliers). The red dotted line corresponds to 60 days, and the blue dotted line to 120 days interval.

## TB Monitoring Indicator 7: Proportion of pulmonary TB patients starting treatment within 4 months of symptom onset

Delays between the onset of symptoms and commencement of treatment can occur due to patient factors, for example a patient not seeking medical advice in a timely manner and service delays, such as healthcare professionals not recognising the symptoms are due to TB, through to delays in starting treatment even though the diagnosis has been made. Since 2008, the median delay from symptom onset to presentation, such as seeking medical help from any source including a general practice or a hospital, has varied from a low of 6 days to 25 days – although there is considerable variation around the median. The trend is upwards (figure 17c) indicating a continuing need to educate the public about the symptoms of TB and when to seek medical help.

**Figure 17c: Median time between symptom onset and presenting for medical advice, pulmonary TB only, East Midlands, 2008 to 2018**




Delays can also occur between initial presentation and diagnosis/onset of treatment, such as clinicians not recognising that the symptoms and signs were consistent with TB. The median interval from presentation to diagnosis for patients with pulmonary TB in 2018 was 26 days; although there is year-to-year variation, the delay has been in most years around 30-35 days since 2009. Although mostly below 60 days, by time the period from onset of symptoms to presentation is also added, most patients are not starting treatment within 60 days of onset of symptoms. This suggests there is also work to do with healthcare professionals as well as the public to improve the recognition of TB at an earlier stage. However, it should be noted that accurate symptom onset dates can be difficult to ascertain from patients and this should be taken into consideration when interpreting these data.

Once patients are diagnosed (clinically or microbiologically), there is little delay in commencement of treatment – most patients start treatment within a day of diagnosis. However, again this is subject to the data quality of diagnosis and treatment start dates on ETS.

## Characteristics of TB patients with a delay from onset of symptoms to diagnosis/treatment of more than 2 months

Patients (all TB sites) that have a long time interval from onset of symptoms to diagnosis and then commencement of treatment (>60 days) are typically around 40 years of age (median 41 years), which was the same for pulmonary TB patients.

For males, the proportion of TB patients with a delay in starting treatment of more than 2 months (where the delay is known) was 56.6%, 99/175. This proportion was slightly less than for females which was 68.5%, 100/146.

The proportion of pulmonary TB male patients with a delay in starting treatment of more than 2 months (where the delay is known) was 50%, 51/102. This is a lower proportion than for females (67.1%, 55/82).

The proportion of patients with TB (all types) with a delay was highest in those aged 45 to 54, where 42 of the 59 (71.2%) patients in that age group in 2018 experienced a delay in starting treatment of 60 days or more since their symptoms started (where the delay is known). The proportion experiencing the same delay in patients who had pulmonary TB was highest in those aged 25 to 34 years and 55 to 64 years (both 66.7%). Clearly it is important to reduce the time for symptom onset to treatment start (particularly with pulmonary TB), as this is key to reducing transmission. It is therefore concerning that in all age groups (except those aged less than 25 years and 35 to 44 years), for pulmonary TB, that the majority were starting treatment more than 60 days after their symptoms started.

The proportion with a symptom onset to commencement of treatment >60 days within each ethnic group shows that there is no difference between the common ethnic groups with TB (all patients) and delay in commencement of treatment. In 2018, for those identifying of white ethnicity, 70% experienced a delay in commencing treatment of >60 days. For those of mixed/other ethnicity, this was 69.9%, for Indian ethnicity, 59.9%, while Pakistani ethnicity was 66.7%. For other ethnic groups the number of patients is small so not particular pattern can be discerned.

# TB outcomes in drug-sensitive cohort

## Drug-sensitive cohort

For the purposes of TB outcome reporting, the drug-sensitive cohort excludes all patients with rifampicin-resistant TB isolates (initial or amplified) including multidrug-resistant TB (MDR-TB, initial or amplified), and non-culture-confirmed patients treated for MDR-TB [(6)]. Under this definition, all patients whose TB has resistance to isoniazid, ethambutol and/or pyrazinamide but without resistance to rifampicin are included in the drug sensitive cohort. TB outcomes among patients with drug-resistant disease are considered in chapter 6.

Treatment outcomes for the drug sensitive cohort are reported separately for the following groups:

- for patients with an expected duration of treatment less than 12 months, outcomes at 12 months are reported. This group excludes individuals with central nervous system (CNS) disease, who would be treated for at least 12 months. In addition, those with spinal, cryptic disseminated or miliary disease are excluded from this group, as CNS involvement cannot be reliably ruled out for the purposes of reporting
- for patients with CNS, spinal, cryptic disseminated or miliary disease, the overall outcome recorded for treatment outcome is reported. However, for patients notified in 2017, information on the final outcome was collected in 2018 and may only be 1 year after start of treatment for many patients, and treatment may still be ongoing

Due to the length of time of treatment, the most current treatment outcome data is reported for patients whose TB was notified in 2017. In line with national reporting, outcomes are reported for those that started treatment and those who did not, such as diagnosed post-mortem; died without starting treatment; lost to follow up without starting treatment. In 2017, 349 patients with TB were notified, of these 338 (96.8%) were sensitive to rifampicin and are included in the drug sensitive cohort.

## Outcomes for TB patients with expected treatment of less than 12 months

For patients notified in 2017 in the drug sensitive TB cohort, 85.8% (290) had non-CNS, spinal, miliary or cryptic disseminated disease. Of these, 80.3% (233) completed treatment within 12 months (Table 5). This is an increase from previous years where there had been a year on year decline from a high of 88.1% in 2013 (figure 18). However this remains lower than the proportion of patients in England completing treatment at 12 months (84.7%) [(2)].

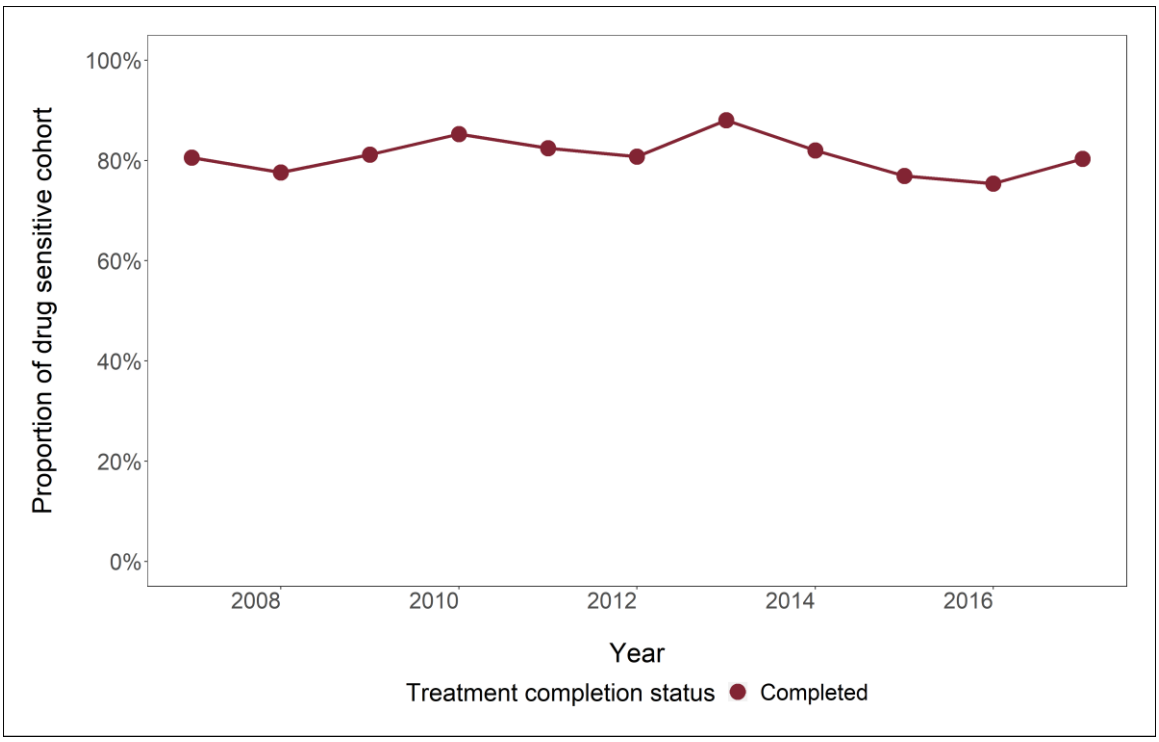
**Table 5: Number and proportion completing treatment at 12 months, East Midlands, 2007 to 2017**

| Year | Count | % | Total |
|---|---|---|---|
| 2007 | 382 | 80.6 | 474 |
| 2008 | 333 | 77.6 | 429 |
| 2009 | 392 | 81.2 | 483 |
| 2010 | 371 | 85.3 | 435 |
| 2011 | 362 | 82.5 | 439 |
| 2012 | 353 | 80.8 | 437 |
| 2013 | 317 | 88.1 | 360 |
| 2014 | 278 | 82.0 | 339 |
| 2015 | 233 | 76.9 | 303 |
| 2016 | 230 | 75.4 | 305 |
| 2017 | 233 | 80.3 | 290 |

*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

## TB Monitoring Indicator 10: Proportion of drug sensitive TB patients who had completed a full course of treatment by 12 months

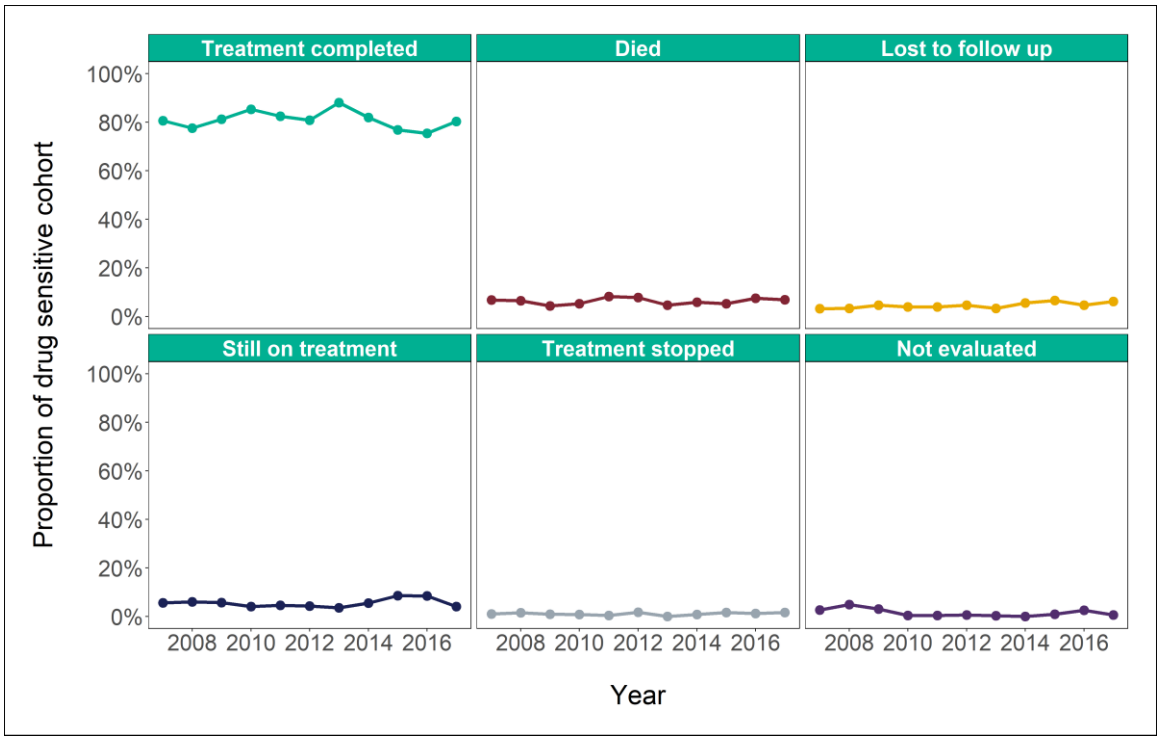
**Figure 18: Proportion of drug sensitive cohort patients completing treatment at 12 months, East Midlands, 2007 to 2017**




*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

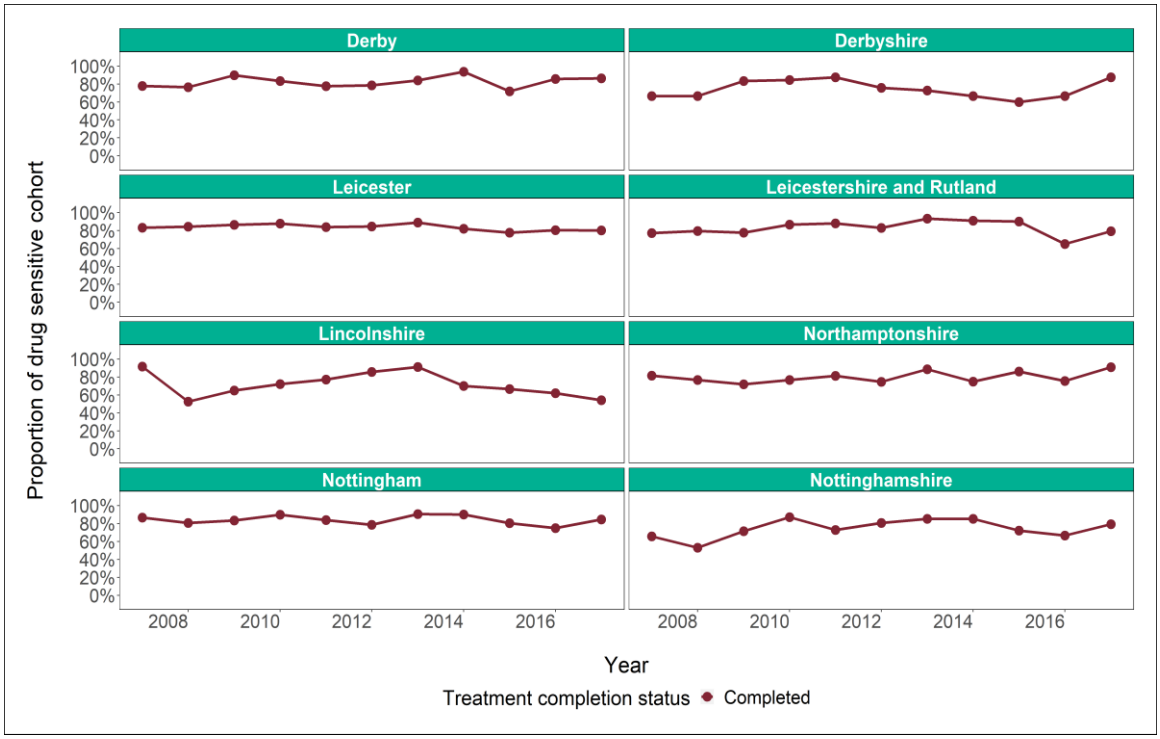
In this cohort 6.9% died, 6.2% were lost to follow up, 4.1% were still on treatment at the end of 12 months, a small proportion (1.7%) had their treatment stopped and 0.7% had not had their treatment outcome evaluated – figure 19* and table 7 below.

## Figure 19: Outcomes of treatment for the drug sensitive cohort at 12 months after treatment commencement, East Midlands, 2007 to 2017




*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

## Figure 20: Outcomes of treatment for the drug sensitive cohort at 12 months after treatment commencement by UTLA, 2007 to 2017




*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

Treatment completion proportions in 2017 varied by UTLA area, ranging from 54.2% (Lincolnshire) to 90.9% (Northamptonshire). The trends in treatment completion by UTLA are displayed in figure 20 and tabulated in table 6 below. Although most areas have shown an upward trend in treatment completion, the trend has been down ward for Lincolnshire in recent years.

**Table 6: Proportions completing treatment for the drug sensitive cohort at 12 months after treatment commencement by UTLA, 2007 to 2017**

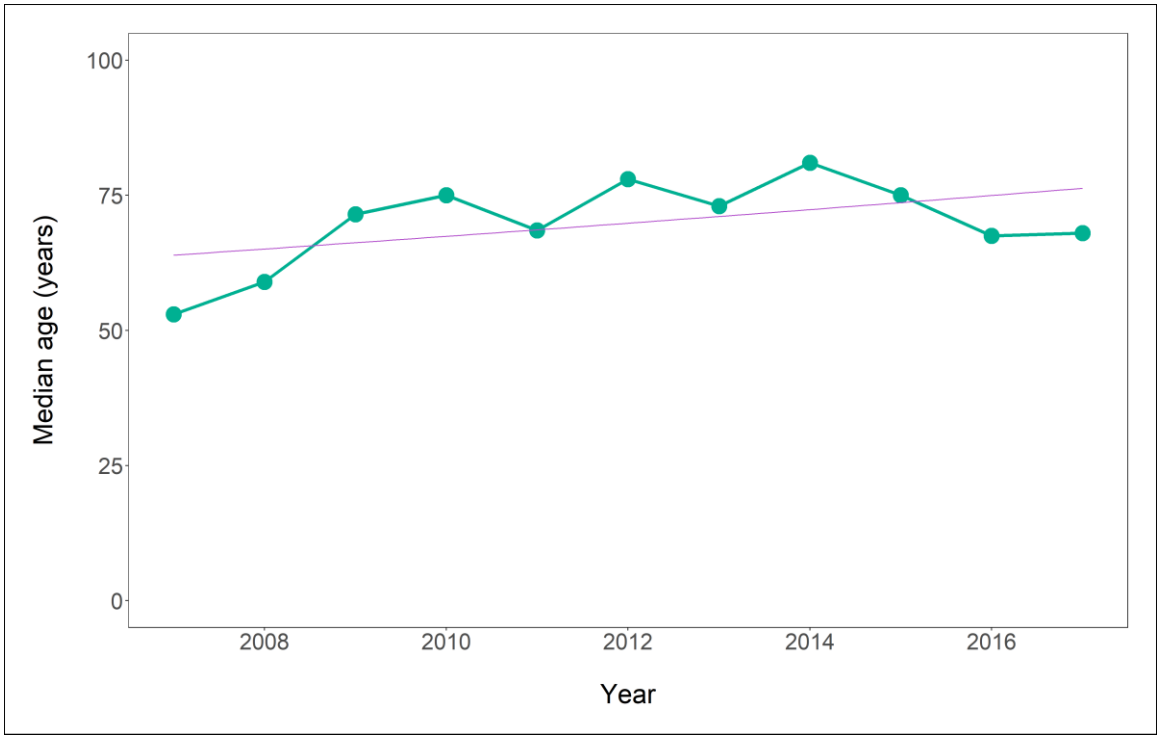
| UTLA | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | % | | | | | | | | | | |
| Derby | 77.8 | 76.5 | 89.7 | 83.3 | 77.6 | 78.6 | 84.0 | 93.8 | 71.9 | 85.7 | 86.4 |
| Derbyshire | 66.7 | 66.7 | 83.3 | 84.6 | 87.5 | 75.9 | 72.7 | 66.7 | 60.0 | 66.7 | 87.5 |
| Leicester | 83.2 | 84.3 | 86.4 | 87.8 | 83.8 | 84.5 | 89.0 | 82.1 | 77.7 | 80.4 | 80.2 |
| Leicestershire and Rutland | 77.1 | 79.4 | 77.6 | 86.5 | 87.9 | 82.9 | 93.3 | 90.9 | 90.0 | 65.0 | 79.3 |
| Lincolnshire | 91.7 | 52.6 | 65.0 | 72.2 | 77.3 | 85.7 | 91.3 | 70.0 | 66.7 | 62.1 | 54.2 |
| Northamptonshire | 81.7 | 76.8 | 71.8 | 76.7 | 81.4 | 74.7 | 88.6 | 75.0 | 86.1 | 75.6 | 90.9 |
| Nottingham | 86.7 | 80.6 | 83.3 | 89.8 | 83.9 | 78.6 | 90.6 | 90.0 | 80.4 | 75.0 | 84.6 |
| Nottinghamshire | 65.6 | 52.9 | 71.4 | 87.1 | 72.7 | 80.6 | 85.2 | 85.3 | 72.2 | 66.7 | 79.3 |

*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

The most common reason for not completing treatment at 12 months (those notified in 2017, excluding those with CNS, spinal, miliary or cryptic disseminated disease) was death with 20 patients who died (6.9%). For most of these it was unknown if TB contributed to the death or not (50% of those that died). However, in 7 (35% of those that died) patients, TB either caused or contributed to the patient's death. Deaths from or contributed to by TB, should be avoidable, so it is particularly important to know if TB caused or contributed to death. Cause of death data quality therefore needs improving to help provide insights into how to prevent this outcome.

Since 2007, the trend in the median age of patients (drug sensitive cohort) that have died is towards older age, with the median age in 2017 being 68 years, although there is fluctuation from year-to-year (Figure 21).

**Figure 21: Age trend of patients who have died where TB caused or contributed to the death for the drug sensitive cohort, 2007 to 2017**




*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

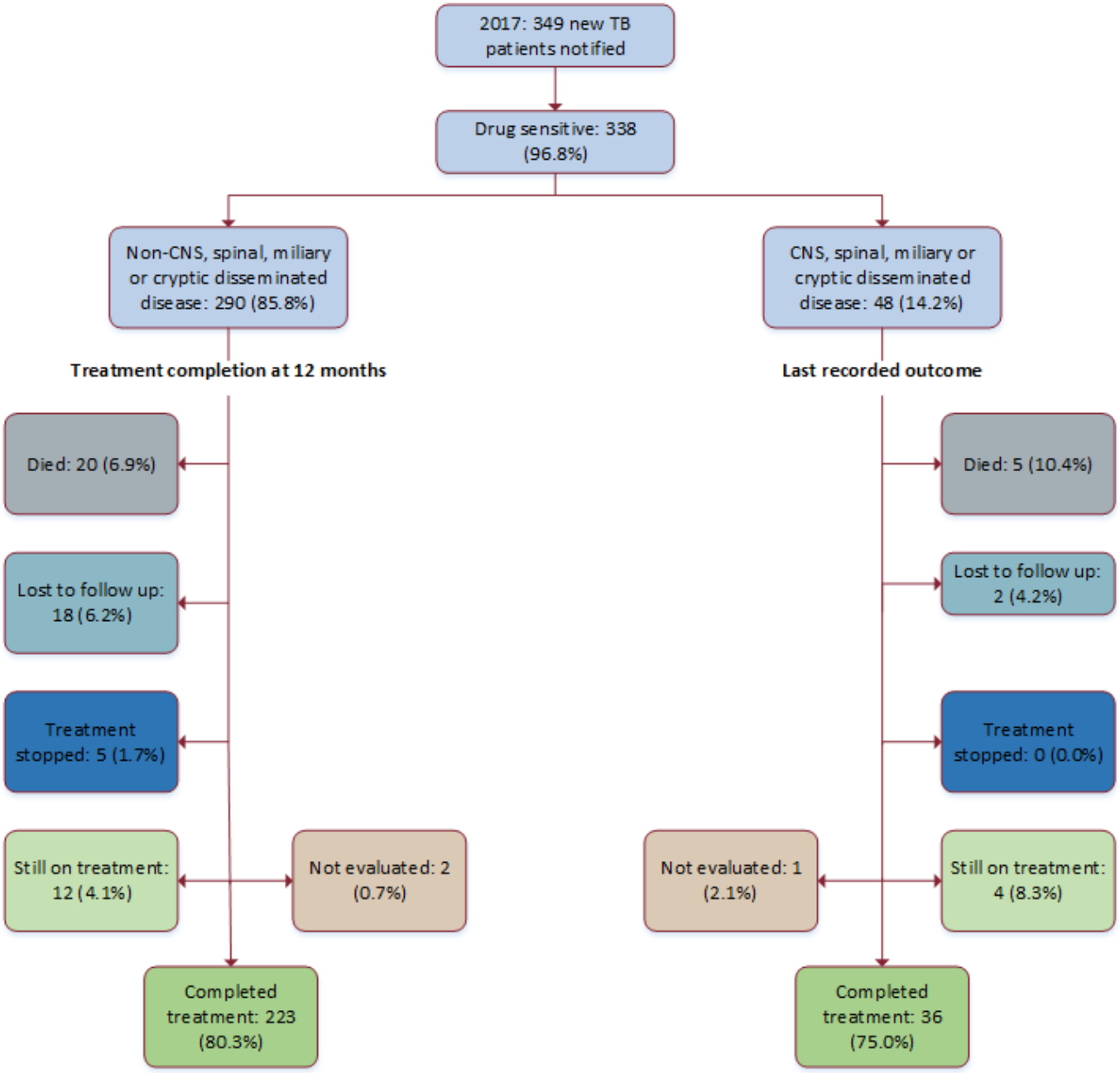
Eighteen patients notified in 2017 were lost to follow up (6.2%). Where the reason for loss of follow up was known, 9 of these patients had left the UK (50%). Where ethnicity was known in the drug sensitive cohort, in those identifying as Indian ethnicity 4.7% were lost to follow up, whereas for those of White ethnicity the proportion lost to follow up was 8.7%.

**Table 7: TB outcome at 12 months, East Midlands, patients diagnosed in 2017**

| Treatment outcome | Count | % |
|---|---|---|
| Treatment completed | 233 | 80.3 |
| Still on treatment | 12 | 4.1 |
| Treatment stopped | 5 | 1.7 |
| Died | 20 | 6.9 |
| Lost to follow up | 18 | 6.2 |
| Not evaluated | 2 | 0.7 |
| Total | 290 | 99.9 |

*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

**Figure 22: Flow chart showing TB outcome for drug sensitive cohort, East Midlands, patients diagnosed in 2017**




*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

In 2017, 48.3% of patients (140) completed treatment between 6 and 8 months of treatment commencement (Table 8). There were 7 patients (2.4%) for whom treatment took longer than 12 months to complete and for 18.6% there was another outcome (including death, loss to follow up, treatment having been stopped and treatment outcome not having been evaluated).

**Table 8: Time to treatment completion for drug sensitive patients with expected treatment duration of less than 12months, East Midlands, 2017**

| Time to complete treatment | Count | % |
|---|---|---|
| <6 months (168 days) | 30 | 10.3 |
| 6-8 months | 140 | 48.3 |
| 8-10 months | 40 | 13.8 |
| 10-12 months | 19 | 6.6 |
| >12 months | 7 | 2.4 |
| Other outcome (death, lost to follow up, treatment stopped, not evaluated | 54 | 18.6 |
| Total | 290 | 100.0 |

* Excludes patients in the DR cohort and those with CNS, spinal, miliary or cryptic disseminated TB. Treatment completed at last recorded outcome

## Outcomes for drug sensitive cohort of patients with CNS, spinal, miliary or cryptic disseminated TB

Of the 48 patients with CNS, spinal, miliary or cryptic disease notified in 2017, 36, (75.0%) had completed their treatment, 4, (8.3%) were still on treatment and 5 (10.4%) had died and 2 (4.2%) were lost to follow up at the last recorded outcome (Table 9). The median treatment time for those that completed treatment was 358 days (IQR 251 – 376) (approximately one year).

**Table 9: Overall outcome for patients with rifampicin sensitive, CNS, spinal, miliary or cryptic disseminated disease, East Midlands, patients notified in 2017**

| Treatment outcome | Count | % |
|---|---|---|
| Treatment completed | 36 | 75.0 |
| Still on treatment | 4 | 8.3 |
| Treatment stopped | 0 | 0.0 |
| Died | 5 | 10.4 |
| Lost to follow up | 2 | 4.2 |
| Not evaluated | 1 | 2.1 |
| Total | 48 | 100.0 |

*Excludes rifampicin resistant, multidrug resistant TB, and patients with CNS, spinal, miliary or cryptic disseminated disease

## Deaths and lost to follow up in the drug sensitive cohort (all patients including those with CNS, miliary and cryptic disseminated disease)

Overall, 7.4% (25) of drug-sensitive patients notified in 2017 had died at the last recorded outcome with 88% recorded as having pulmonary TB (22 patients).

The proportion of all drug-sensitive patients notified in 2017 and lost to follow up at the last recorded outcome was 5.9% (20 patients), of these 10 (50%) had left the UK and the remainder were recorded as ‘other or unknown reason’.

# Drug resistant TB (including outcomes in the drug resistant cohort)

## Drug resistance

## TB Monitoring Indicator 9: Proportion of culture confirmed TB patients with drug susceptibility testing reported for the 4 first-line agents

## TB Monitoring Indicator 18: Proportion of culture confirmed TB patients with any first-line drug resistance

## TB Monitoring Indicator 19: Proportion of culture confirmed TB patients with multi-drug resistant TB

### Overall initial drug resistance

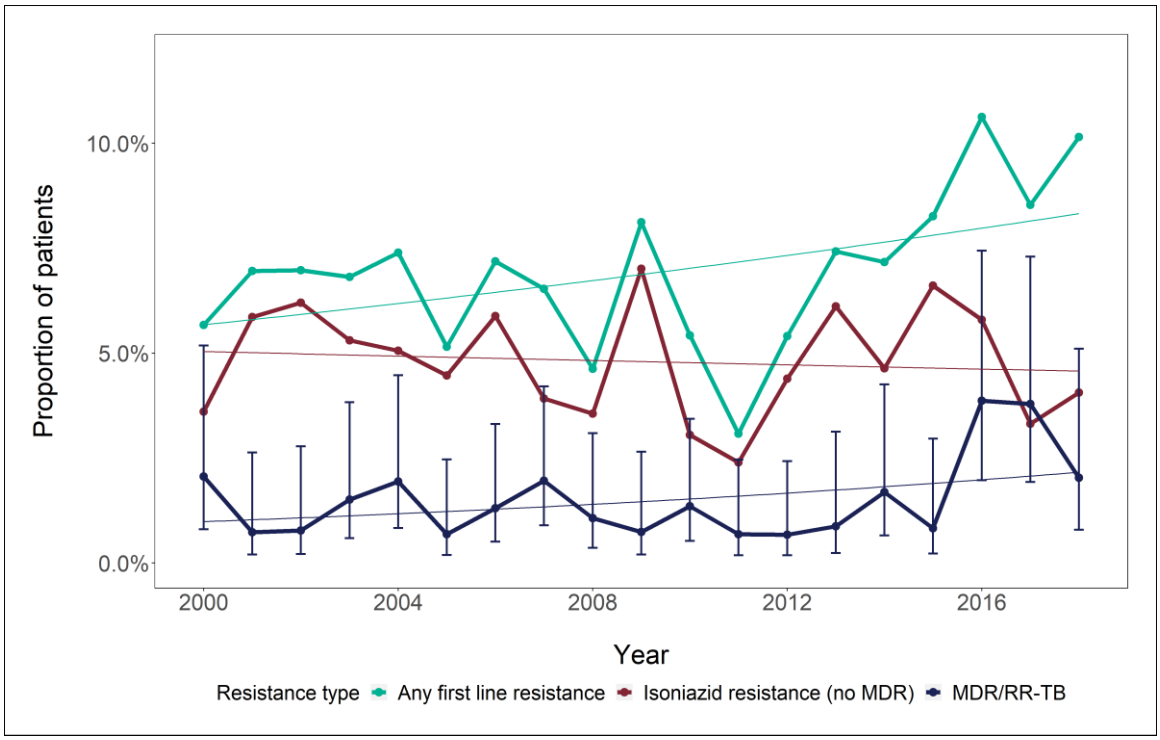
There are a wide range of anti-TB antibiotic drugs; resistance may occur to one or more of these antibiotics and may occur in complex combinations. A distinction is made between first, second and third line TB antibiotic drugs depending upon their clinical effectiveness. First-line drugs are isoniazid, rifampicin, pyrazinamide and ethambutol. Second-line drugs at the time of the data being generated were injectable agents, such as amikacin, capreomycin and kanamycin; fluoroquinolones, for example, moxifloxacin, ofloxacin, ciprofloxacin, and other oral bacteriostatic agents. MDR-TB patients have initial resistance to at least isoniazid and rifampicin. Extensively, drug-resistant TB patients (XDR-TB) have initial MDR and resistance to at least 1 injectable agent and at least one fluoroquinolone[(6)].

In 2018, 96.5% (192) of culture-confirmed patients had drug susceptibility test (DST) results (either phenotypic of WGS) for all 4 first-line drugs (isoniazid, rifampicin, ethambutol and pyrazinamide) and 99% (197) had results recorded for at least isoniazid and rifampicin. Of those with DST results for at least isoniazid and rifampicin, the proportion of patients with TB resistant to one or more first-line drugs was 10.2% (20 patients). This was non-significant increase from 2017 (8.5 %, 18 patients) although slightly lower than the proportion reported in England (11.4%) [(2)]. The proportion of patients with isoniazid-resistant TB without MDR increased (non-significant) from 3.3% (7 patients) in 2017 to 4.1% (8 patients) in 2018 (Figure 23).

In 2018, out of the culture-confirmed patients with DST results for at least isoniazid and rifampicin, there was a higher proportion of TB resistance to one or more first-line drugs in females (13.1%, 11/84) compared to males (8.0%, 9/113), however this difference

was not significant. There was a similar proportion of resistant TB among those born outside of the UK (10.1%, 15/149) than UK born (8.9%, 4/45). Although the overall numbers are small, it is concerning that the number of patients with any first line resistance is increasing.

**Figure 23: Trend in the proportion of patients with TB isolates which have resistance to first-line drugs, 2000 to 2018**




## Drug-resistant cohort

The drug resistant (DR) cohort includes culture confirmed patients with initial and acquired MDR/ Rifampicin resistant (RR)-TB, as well as those treated with a second-line regimen for MDR/RR-TB without resistant phenotypic DST results. TB patients may be treated with a second-line regimen in the absence of phenotypic DSTs if they were diagnosed abroad, were diagnosed with genotypic methods without culture confirmation, were a contact of an MDR/RR-TB patient or for other clinical reasons.

The numbers in the DR cohort (including those without a culture result) has decreased from 11 patients in 2017 to 4 patients in 2018, however there is a lot of year-to-year variability and the numbers are small in any one year, so no particular trend can be established. The 2018 MDR/RR-TB and XDR patients are explained below in more detail.

## Multi-drug resistant/rifampicin resistant TB (MDR/RR) patients

The proportion of MDR/RR TB patients (culture confirmed with DST results for at least isoniazid and rifampicin) was 2.0% (4 patients) in 2018, a decrease from 3.8% (8 patients) in 2017; although this is higher than the proportion of MDR TB patients in England (1.6%), the number of patients in any one year varies widely from year to year, so no particular inference should be derived from this difference.

## Extensively Drug Resistant (XDR) patients

XDR patients are reported as a subset of MDR patients and have resistance to isoniazid and rifampicin, plus any fluoroquinolone and to at least one of the 3 injectable second-line drugs. These patients are rare in the East Midlands.

## TB outcome at 24 months for patients with rifampicin resistant disease

Due to the length of time of treatment for patients with drug resistant TB, the most current treatment outcome data is reported for patients notified in 2016. In 2016, there were 10 patients with DR TB, 3 (30%) had completed treatment at 24 months, 5 were still on treatment and for 2 the treatment status was unknown.

## TB Monitoring Indicator 13: Proportion of drug resistant TB patients who had completed treatment at 24 months

# TB in under-served populations

## Social risk factors

Patients with TB in the East Midlands with recognised, reported risk factors form a relatively small part of the overall number of people with TB for the region. Nonetheless although the numbers are small the trends are increasing, for example in homelessness, imprisonment and alcohol misuse. In 2018, information on social risk factors was completed for 287 (87%) patients aged 15 years and above; 44 (15.3%) patients had one or more social risk factors (Table 10). This was a decrease from 19.5% in 2017. A social risk factor for the acquisition of TB is defined as current/history of homelessness, current/history of drug use, current/history of imprisonment or current alcohol misuse. Homelessness was the most common social risk factor (7.3%) followed by imprisonment (4.9%), alcohol misuse (4.5%) and drug use (3.2%) (Table 11). These risk factors are not mutually exclusive as 4.2% of patients (12) had multiple risk factors recorded. Very few patients with TB over the years have a recorded history of being an immigration centre detainee, with none having been recorded as such in 2018 (however the data quality for this variable is poor). Data quality for risk factor recording has improved from 2017 but could still be improved further with 13% of patients with TB having no risk factor data recorded in 2018.

**Table 10: Number and proportion of patients with TB who had any risk factor social risk factor recorded, East Midlands, 2018**

| Year | Count | % | Total |
|---|---|---|---|
| 2010 | 25 | 6.5 | 384 |
| 2011 | 29 | 8.0 | 363 |
| 2012 | 24 | 6.6 | 362 |
| 2013 | 29 | 9.5 | 305 |
| 2014 | 34 | 12.4 | 275 |
| 2015 | 30 | 11.0 | 273 |
| 2016 | 30 | 11.3 | 265 |
| 2017 | 50 | 19.5 | 257 |
| 2018 | 44 | 15.3 | 287 |

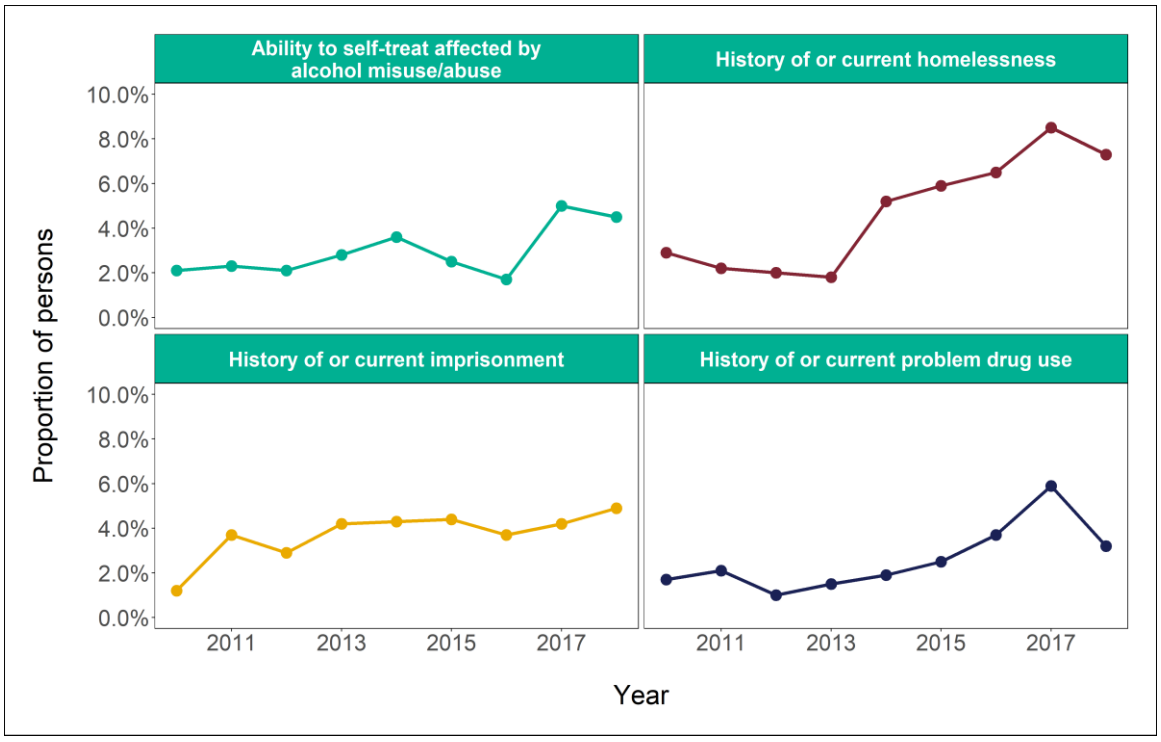
* For patients 15 years and over. Total number of patients for the year with risk factor data recorded

There was a statistically significantly higher proportion of TB patients with recorded social risk factors in males (over the age of 15 years), of 25.5%, 39/153 as compared to females, 3.7%, 5/134) p<0.001. The proportion of TB patients with social risk factors was also higher in UK born patients (23.3%, 14/60) compared to non-UK born patients (13.2%, 30/227), although this difference was not statistically significant (p=0.053).

Individuals with social risk factors were statistically significantly more likely to be a pulmonary TB patient than those without social risk factors. Of the 44 patients with risk factors recorded, 81.8%, (36/44) had pulmonary disease, compared to those without risk factors where 53.9% (131/243) had pulmonary disease, p=0.001.

There was a statistically significantly higher proportion of patients receiving DOT within those that reported having one or more social risk factors (42.5%, 17/40) compared to those without any social risk factors recorded (3.8%, 9/237) p<0.0001.

**Figure 24: Trend in key social risk factors among TB patients, East Midlands, 2009 to 2018**




Treatment completion at 12 months for drug-sensitive TB patients notified in 2017 with at least one social risk factor was lower than for patients with no social risk factors (74.4% vs 83.6%), although this was not statistically significant. Treatment completion in those patients with at least one social risk factor in the East Midlands was similar for England as a whole (74.9%)[2]. There were too few patients with risk factors to meaningfully compare the other outcomes (death, lost to follow up, still on treatment or

treatment stopped) with those with no risk factors and whether DOT made a significant difference to those with social risk factors completing treatment.

**Table 11: TB outcome at 12 months, East Midlands, drug-sensitive patients diagnosed in 2017 with at least 1 social risk factor**

| Outcome at 12 months | No known risk factors Count | No known risk factors % | At least one risk factor Count | At least one risk factor % | Total |
|---|---|---|---|---|---|
| Treatment completed | 158 | 83.6 | 32 | 74.4 | 190 |
| Died | 10 | 5.3 | 4 | 9.3 | 14 |
| Lost to follow up | 10 | 5.3 | 2 | 4.7 | 12 |
| Still on treatment | 6 | 3.2 | 3 | 7.0 | 9 |
| Treatment stopped | 4 | 2.1 | 1 | 2.3 | 5 |
| Not evaluated | 1 | 0.5 | 1 | 2.3 | 2 |
| Total | 189 | 100.0 | 43 | 100.0 | 232 |

* For patients 15 years and older. Excludes rifampicin resistant TB and patients with CNS, spinal, miliary or cryptic disseminated disease

## TB Monitoring Indicator 17: Proportion of patients with drug sensitive TB with at least 1 social risk factor who completed treatment within 12 months

## Deprivation

TB has always been a disease associated with social deprivation and continues to be so. In any one year, approximately 40% of patients with TB are from the most deprived quintile and 70% from the bottom 2 quintiles for deprivation; 2018 was no exception with 47% of patients being from the most deprived quintile and 24% from the second most deprived quintile (Figure 26). For 2018, the rate of TB in the most deprived quintile was approximately five-times higher than that in the least deprived quintile (16.6/100,000 vs 3.1/100,000) (Figure 27). Further strategies to address the ‘health-need’ gap for this group of patients are needed as the gap would appear to be static rather than improving.

**Figure 25: TB case proportion by deprivation, East Midlands, 2010 to 2018**

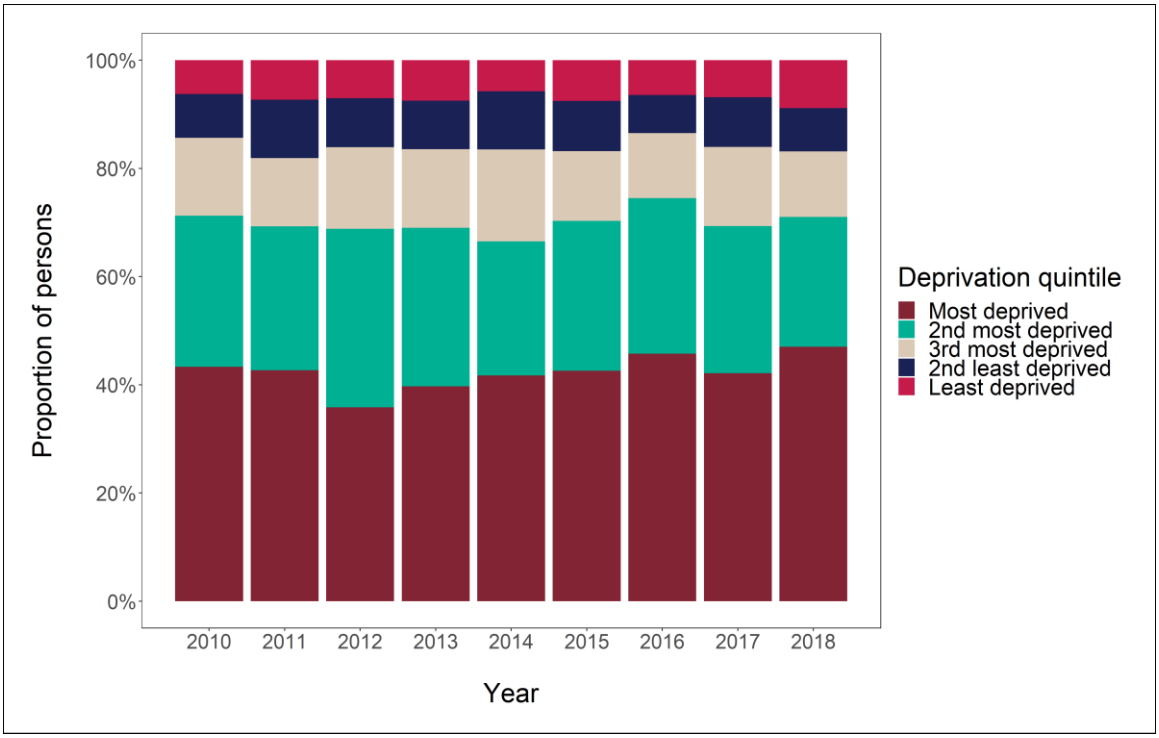
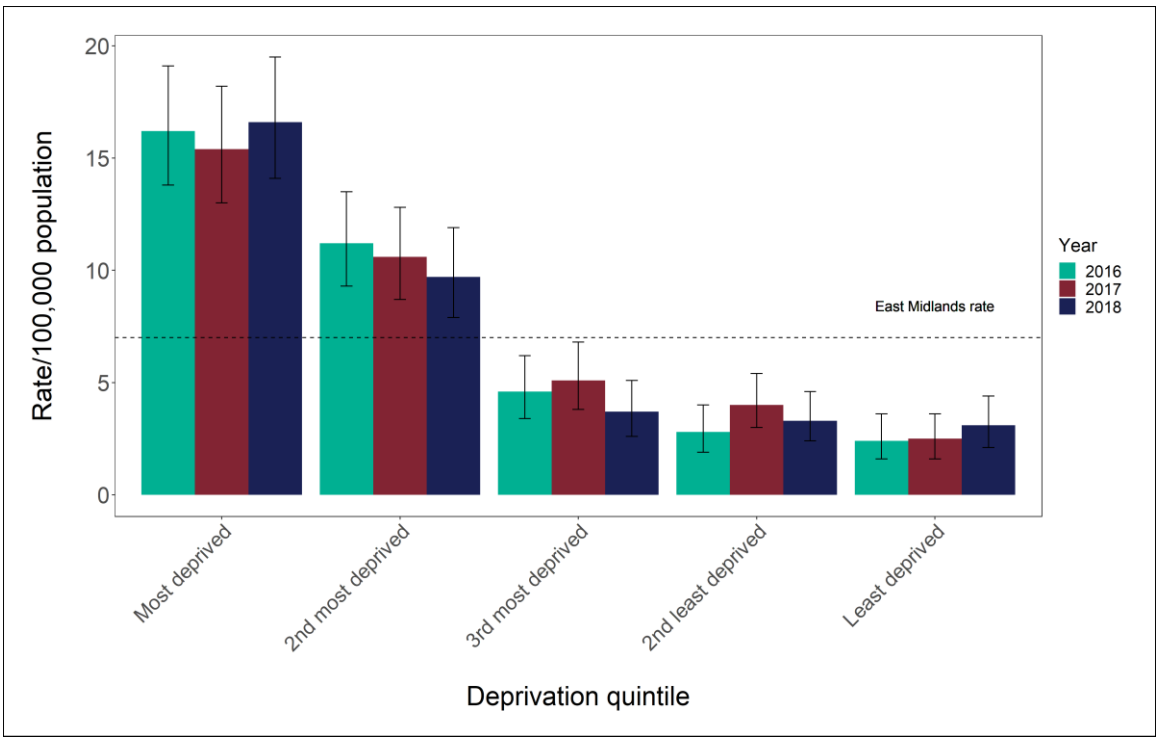



**Figure 26: TB rate per 100,000 population by deprivation quintile with East Midlands overall rate, East Midlands, 2015 to 2018**



## Prisoners

One of the recognised social risk factors for having TB is a history of imprisonment. In the East Midlands since 2011, the number of people with TB who are or have a history of imprisonment recorded in ETS is low, ranging from 10 to 14 per year, or 2.9 – 4.9% of the total number of people with risk factors recorded. This compares with a population prevalence of imprisonment of 0.13% for the UK, therefore although small compared to the total numbers, prisoners are over-represented in the East Midlands population with TB [7].

# TB-HIV co-infection and HIV testing of TB patients

## HIV testing

TB complicating HIV infection is a well-recognised and particularly lethal clinical state, but can be successfully treated with a combination of highly active antiretroviral therapy (HAART) and appropriate TB antibiotic treatment[6]. For this reason, it is essential that all patients with TB should undergo HIV testing so that if they are diagnosed as having TB-HIV co-infection they can start curative TB treatment and HAART as soon as possible, and in so doing extend their life expectancy and reduce the risk of TB and HIV transmission to others.

Although the enhanced TB surveillance system does not collate data on HIV positivity in TB patients, it does collate data on whether patients were offered HIV testing as part of their care.

In 2018, data on HIV testing was recorded for 308 patients with previously unknown HIV status (excluding those diagnosed with TB at post-mortem). Of these 94.8% (292) were offered and received an HIV test – the same figure as those offered and receiving testing in England overall (94.8%)[2]. There was, however, variation by UTLA of residence with the proportion being offered and receiving testing ranging from 83.3% in Derbyshire to 100% in Leicestershire and Rutland (Figure 28). HIV testing was not offered for 14 patients (4.5%) in 2018.

Only 28.6% of children were offered and received HIV testing (where their HIV status was not already known and they hadn't died), as compared to 96.3% of adults. While there may be good clinical reasons why children are not being offered HIV testing, this difference may represent an inequality which needs addressing, particularly as children in previous years are also less likely to be offered a test than adults. Patients were more likely to be offered and receive HIV testing if they were not born in the UK – 97.5% (231) were tested in 2018 as compared to 87.0% (60) of those that were UK-born. HIV testing is not therefore universal for patients presenting with TB (where their status is not already known).

Figures 28 and 29 below show the proportion of patients with TB who have been offered HIV testing in 2018 by UTLA and the trend since 2000, respectively. Although the overall coverage of HIV testing is good, there are some UTLA areas within the East Midlands where approx. 8% of patients were not offered HIV testing in 2018. This is an important area to understand why such variation exists and implement improvements where appropriate.

**Figure 27: HIV test status by UTLA area, East Midlands, 2018**

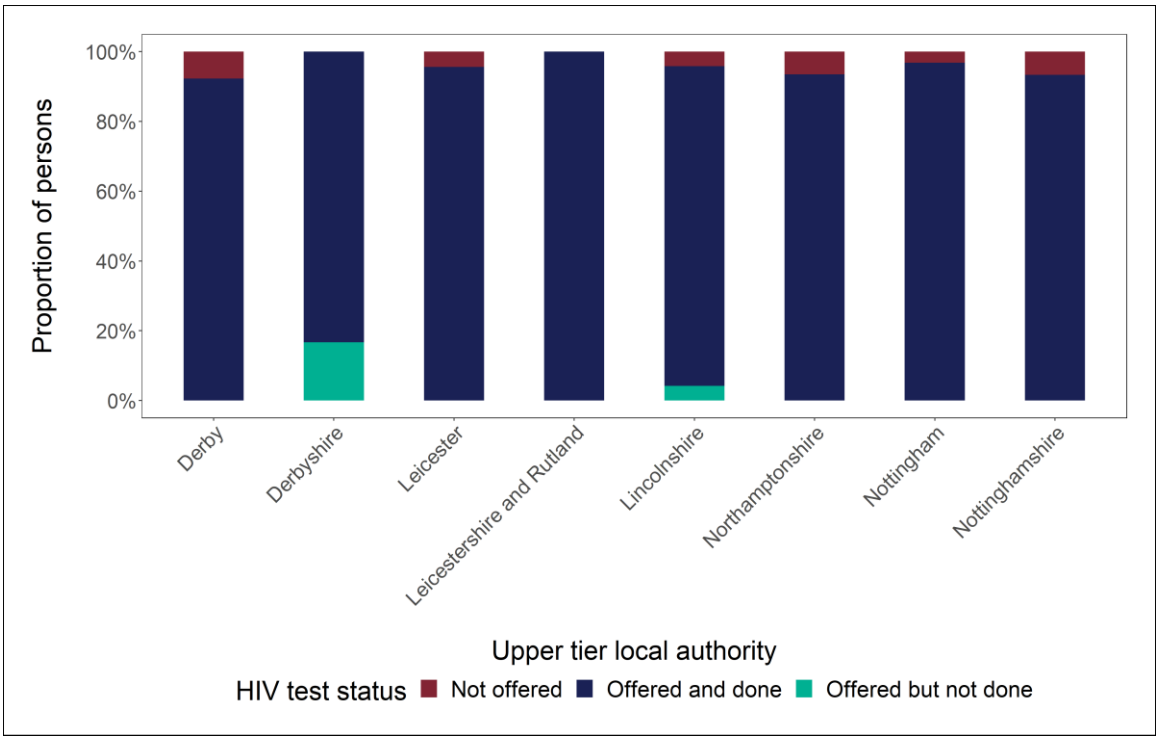
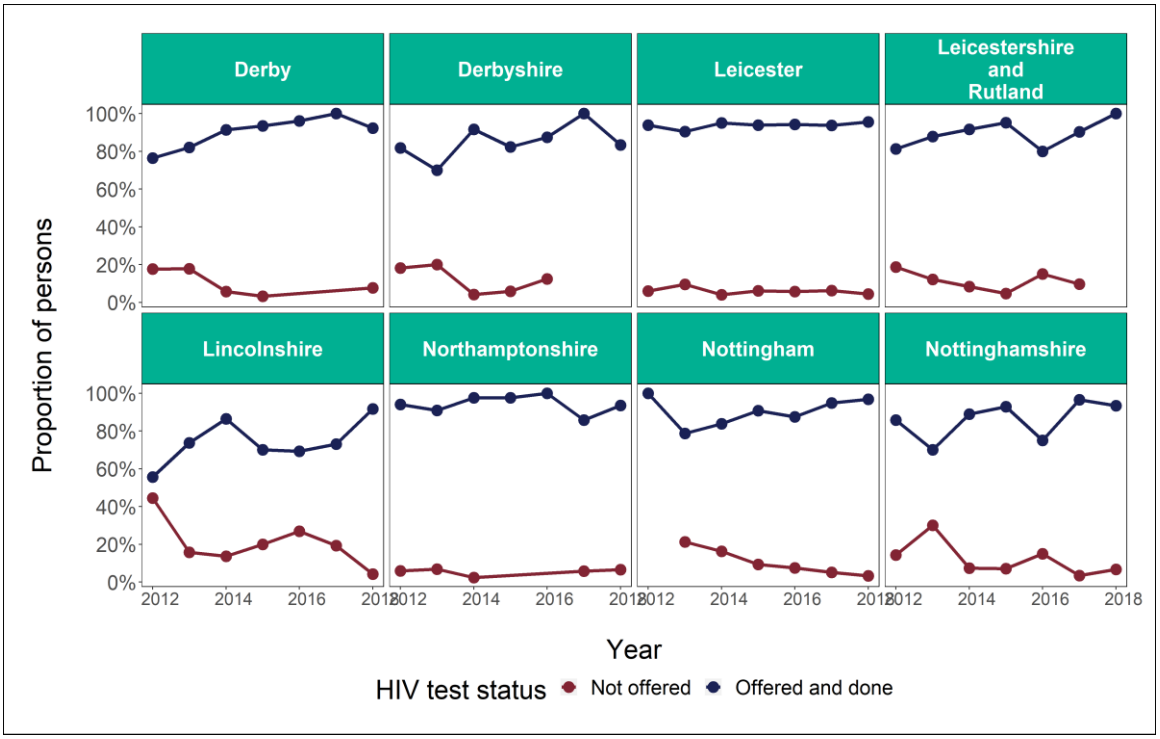



**Figure 28: HIV test status by UTLA area, East Midlands, 2012 to 2018**




Note: excludes patients where TB was diagnosed post-mortem and also those where their HIV status is already known.

## TB Monitoring Indicator 16: Proportion of TB patients offered an HIV test

## TB-HIV co-infection rates

To estimate co-infection nationally, TB notifications are matched annually by anonymously linking reports in ETS with the SOPHID and HANDD HIV datasets[i] for patients aged 15 years and older (see Tuberculosis in England: 2018 for methods[2]). TB and HIV co-infection in the East Midlands is uncommon. In 2018, 3% of TB patients aged 15 years and above in the East Midlands were co-infected with HIV, a similar proportion to those identified nationally (2.7%). In the East Midlands, this is down from a peak of 8.6% in 2005[2].

[i] SOPHID: Survey of Prevalent HIV Infections Diagnosed. HANDD: HIV and AIDS New Diagnoses Database

# BCG vaccination

## BCG vaccine coverage

The BCG immunisation programme is a risk-based programme. The vaccine is recommended for individuals at higher risk of exposure to TB, particularly to protect against serious forms of the disease in infants. Detailed information on the BCG programme can be found in the 'Green Book'[8].

In the East Midlands none of the UTLA areas previously met the criteria (TB incidence ≥40 per 100,000 population) for a universal neonatal BCG vaccination programme and therefore the BCG programme is selective. However, it is important to note that some localised areas (middle super output areas) in the region do have rates greater than 40/100,000. It may be appropriate to consider whether BCG vaccine is indicated in these limited areas.

From April 2015, neonatal BCG has been included as part of the Cover of Vaccination Evaluated Rapidly (COVER) programme and so data from the universal programme are publicly available[9]. For the selective programme it is not possible to gain denominator figures and provide meaningful coverage figures.

## BCG vaccination status of TB patients

Historically, BCG vaccination was widely provided in adolescence in the UK and variably internationally to protect against the development of TB infections. BCG vaccination is not 100% protective against TB and is most effective at preventing TB meningitis in early childhood. Where BCG vaccination has been recorded, between 70% and 80% of patients with TB since 2010 had previously been vaccinated with BCG (Figure 30). However, for a lot of patients, the data on BCG vaccination status is not recorded. Where prior BCG vaccination has been recorded, the median interval between vaccination and diagnosis of TB is around 30 to 40 years (Figure 31).

**Figure 29: Trend in prior BCG vaccination in TB patients, 2010 to 2018**

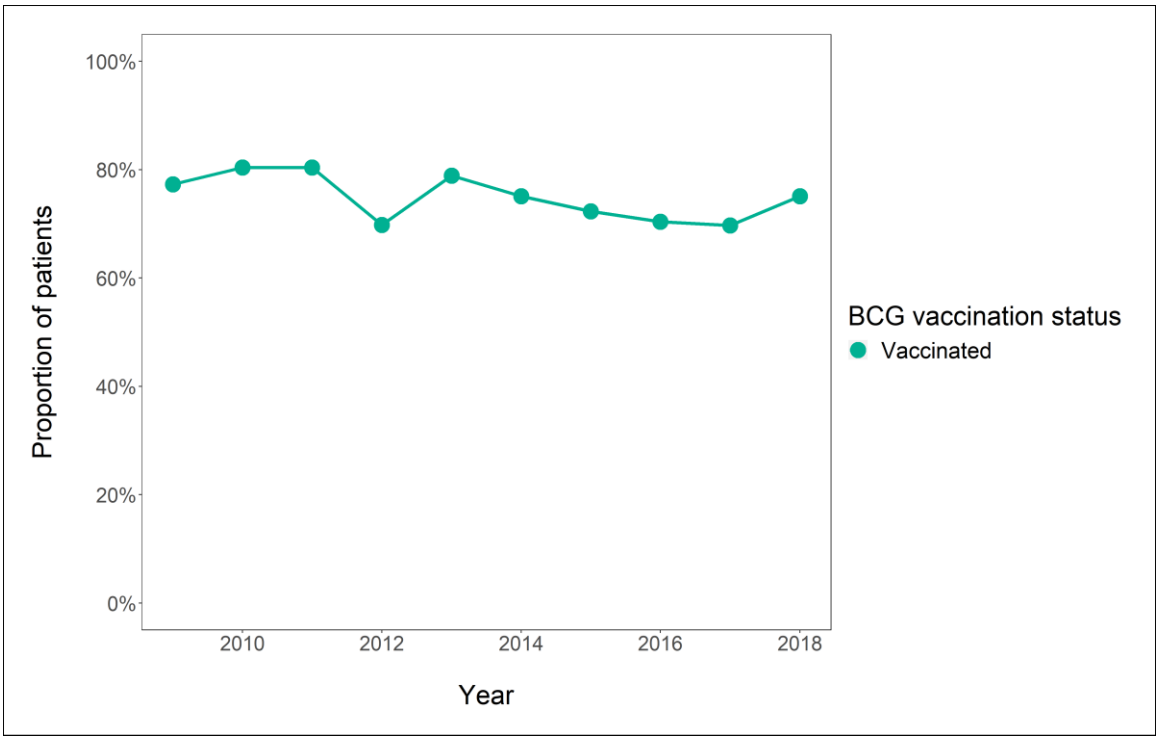
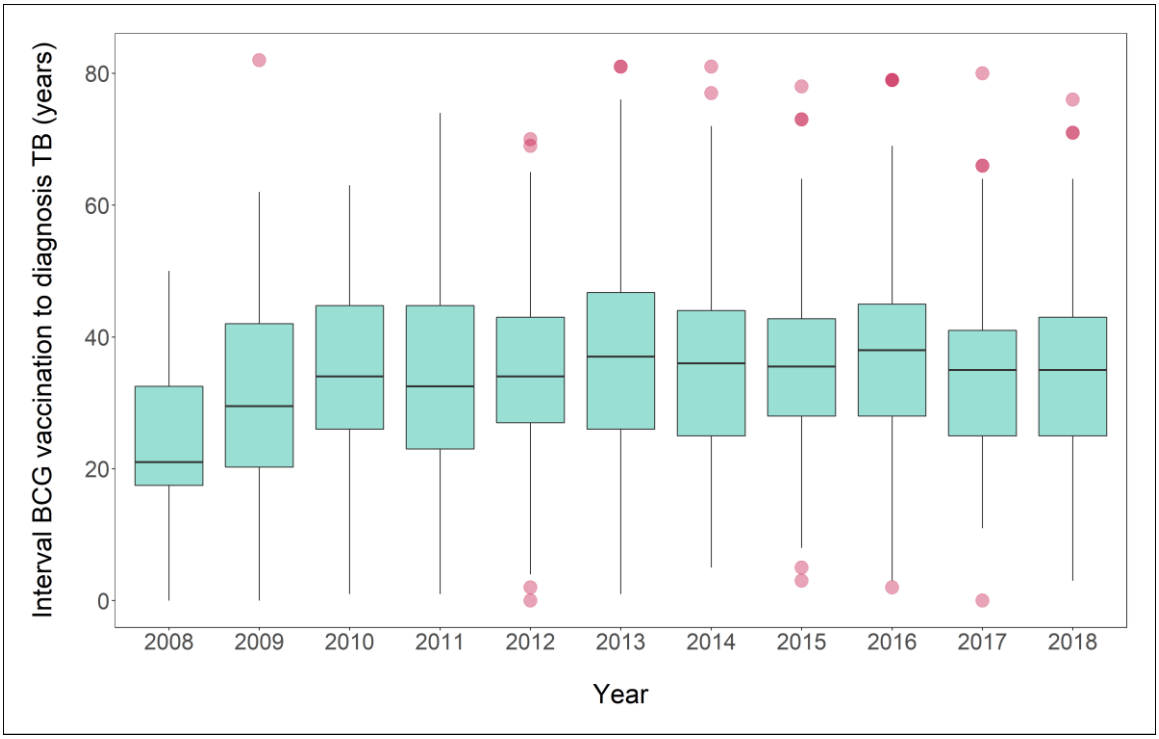



**Figure 30: Trend in interval between BCG vaccination and diagnosis of TB, where BCG vaccination is recorded, 2008 to 2018**



# Latent TB infection testing and treatment

This report, derived from the ETS surveillance system, which is a national case register and management system for patients of active TB, does not record latent TB infection data (LTBI). A new development has been the establishment of a national programme for the screening and treatment of LTBI for new migrants introduced by the Department of Health and Social Care and PHE, which began in April 2015. Data from this programme is currently collected separately to the ETS[3].

Individuals are eligible for the national LTBI testing programme if they are aged 16-35 years and entered the UK from a high incidence country (≥150 patients per 100,000 or sub-Saharan Africa) within the last 5 years, and had been living in that high incidence country for 6 months or longer. Eligible individuals are primarily identified prospectively by GP practices during the new patient registration process; however, some CCGs also search retrospectively through GP clinical systems or use community or secondary care services for identification.

Laboratory testing providers were selected for high TB incidence and burden CCGs[ii] following a national NHS procurement process and establishing a laboratory provider framework[10]. As per national programme clinical guidelines, individuals who receive a positive diagnostic result (IGRA) are referred to secondary care to rule out active TB and initiate LTBI treatment[11].

Four CCGs in the East Midlands have latent TB testing and treatment programmes that commenced in 2016: NHS Leicester City, NHS Nottingham City, NHS Southern Derbyshire CCGs and NHS Nene CCG, however data for the latter are not available as screening has not yet commenced. Details of the numbers of patients eligible for inclusion and their positivity are tabulated below.

[ii] High incidence is here defined as >20.0 cases per 100,000; high burden is defined as ≥0.5% of the TB case burden in England.

**Table 12: Number of LTBI tests by CCG and year, 2016 - 2018**

| Clinical Commissioning Group | 2016 | 2017 | 2018 |
|---|---|---|---|
| NHS Leicester City CCG | 426 | 1,671 | 970 |
| NHS Nottingham City CCG | 218 | 204 | 139 |
| NHS Southern Derbyshire CCG | 33 | 13 | 72 |

**Table 13: Proportion of people that tested positive for LTBI by CCG, 2016 - 2018**

| Clinical Commissioning Group | Number positive | Total tests with results | Proportion positive |
|---|---|---|---|
| NHS Leicester City CCG | 523 | 3063 | 17.1 |
| NHS Nottingham City CCG | 65 | 560 | 11.6 |
| NHS Southern Derbyshire CCG | 30 | 118 | 25.4 |
| **National Total** | **6651** | **39639** | **16.8** |

# Outbreaks and incidents

The PHE East Midlands Health Protection Team was involved in investigating 35 TB incidents or outbreaks during 2018 (Table 15) – a decrease from 40 in 2017. The most common incidents reported involved patients of TB in workplace settings (40%, 14/35). Leicester City reported the highest number of TB incidents in the East Midlands in 2018.

**Table 15: Number of TB incidents reported to East Midlands HPT by setting and UTLA, East Midlands, 2018***

| UTLA | Incident setting | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Care Home | Community | School | Workplace | Homeless | Hospital/ Healthcare setting | College/ University | Total |
| Derby City | | | | | | 1 | 1 | **2** |
| Derbyshire | | | | 2 | | | | **2** |
| Leicester City | | | 5 | 3 | 1 | 3 | 1 | **13** |
| Leicestershire County and Rutland | | | | 2 | | 1 | 1 | **4** |
| Lincolnshire | | 1 | | 1 | 1 | 1 | | **4** |
| Northamptonshire | 1 | | 1 | 4 | | 1 | | **7** |
| Nottingham City | | | | | | | | **0** |
| Nottinghamshire | | | 1 | 2 | | | | **3** |
| **Total** | **1** | **1** | **7** | **14** | **2** | **7** | **3** | **35** |

* Data source: HPZone

# Discussion

This report of TB in the East Midlands includes data up until end of 2018 and provides the latest epidemiological picture of TB in the area.

Although there was a decrease in the rate of TB in the East Midlands in 2018 the rate of decrease has slowed since the substantial decline between 2012 until 2016 and could suggest a plateau in TB rates in the East Midlands. This is of concern as we near the end of the implementation period of the Collaborative TB strategy 2015-2020, which aims for a year-on-year reduction in TB incidence and health inequalities[3]. This trend will require monitoring and renewed efforts are required if England aims to move towards the WHO End TB Strategy pre-elimination goal by 2035 [1].

Although the East Midlands figures remain below the TB rate for England as a whole[2] there remains variation in TB across the East Midlands. The highest rates of TB continue to be concentrated in the large urban areas of Leicester City, Nottingham City, Derby City and Northampton town where the latent TB screening programme is targeted. The UTLAs Leicester City and Northamptonshire both experienced increases in TB incidence from 2017 to 2018.

Although the rates within the non-UK born population have been steadily decreasing an increase was noted in the East Midlands for 2018 with the TB rate in the non-UK born population now 25-times higher than the UK-born population. India was the most common country of birth for the non-UK-born population. Nearly half of the non-UK-born patients in the East Midlands were within those that had been in the UK for more than 6 years (46%).

In contrast, the number and incidence rate of TB in the UK-born population remains low and has decreased from 2017 to 2018. Although the rate in UK-born persons is substantially lower than those non-UK born, numerically they still contribute substantial numbers of new notifications each year (75 in 2018). Therefore, a focus on addressing TB rates in this group is important to reduce TB in the East Midlands.

The time between symptom onset and starting treatment for pulmonary TB patients is of concern and has broadly remained unchanged over the last 5 years. The proportion of pulmonary TB patients starting treatment more than 4 months after onset did decrease slightly in 2018, accounting for approximately 30% of patients and is similar to national figures. This delay in treatment increases the opportunity for TB transmission to others and the risk of adverse outcomes for the patient. Based on the median delays of approx. 10 weeks from symptom onset to commencing treatment for pulmonary patients, the longest delay was found to be between presentation to healthcare and diagnosis (nearly 4 weeks for those with pulmonary disease) highlighting the need for

further education and awareness surrounding TB amongst healthcare professionals. In 2018 patients typically presented to a healthcare setting, 3 weeks (median) after onset of symptoms.

TB outcomes for drug sensitive patients within the East Midlands has improved for the first time since 2013 with those completing treatment increasing to 80.3% in 2017 although it remains below the England overall figure 84.7%. Geographical variation was noted across the East Midlands in treatment completion.

The number of MDR/RR TB patients in the East Midlands decreased in 2018 (2.0%). The associated workload of DR patients should not be underestimated, with half of DR patients in the East Midlands from 2016 taking over 24 months to complete treatment. Culture confirmation, particularly for pulmonary patients, is important to ensure DR patients can be identified and effective treatment regimens put in place.

In 2018, there was a decrease in the proportion of TB patients with one or more social risk factors. Although it is difficult to ascertain the population level burden of social risk factors, anecdotally this is reported to be increasing. In the East Midlands there is a clear trend between the acquisition and development of TB and deprivation. Reducing TB in underserved populations is one of the priority areas outlined in the TB strategy. Those with social risk factors were statistically more likely to have pulmonary disease and require DOTs. In addition, treatment completion rates at 12 months were lower in those with at least one social risk factor compared to those without. This probably reflects the complex clinical and social needs of these patients although it was interesting to note that patients receiving DOT has decreased. This underlines the need for good management of such patients, as described in the NICE guidance for vulnerable patients[12] and a need to tackle ongoing social and economic factors outlined in the resource ‘Tackling tuberculosis in under-served populations’[4].

Although the offer and uptake of HIV testing was high, the offering and uptake of tests was not universal across all groups and geographies. UK guidance states all TB patients should be offered a test, regardless of age or ethnicity[13].

For the LTBI screening programme, the number of tests carried out in the East Midlands in 2018 decreased compared to 2017. Where data were available it showed positivity to be between 11.6% and 25.4% of those tested in East Midlands CCGs.

# Conclusion and recommendations

Although there was a substantial decline in TB incidence in the East Midlands between 2012 and 2016, the rate of decrease has slowed for 2018 with some areas showing a concerning upward trend. This trend will require monitoring as we near the end of implementation period of the Collaborative TB strategy 2015-2020, which aims for a year-on-year reduction in TB incidences [(3)]. Certain risk groups continue to be more likely to be affected than others within the East Midlands. This underlines the need for services to work collaboratively, across the range of health and social care issues, to extend the downward trend in TB incidence and if we are to move towards the WHO End TB Strategy pre-elimination goal by 2035 [(1)].

Work nationally is now focusing on preparing a five-year TB Action Plan (2020 to 2025) to move England towards TB elimination. This TB Action Plan will build on the work carried out during the current Strategy period, and will refocus this to deliver any outstanding areas-for-action, consider new ideas, technologies and research and build on co-ordinated, multi-stakeholder working to deliver improved TB control across England [(2)].

Recommendations for the NHS and PHE East Midlands derived from the data presented in this report are included below in line with the strategy areas for action (AfA):

## Improve access to services and ensure early diagnosis (AfA1)

TB Networks to explore reasons behind the delay in diagnosis in order to identify areas for improvement and intervention.

TB Networks to reduce the delay in TB diagnosis through raising awareness of TB among local communities affected by TB, other service providers and primary care. This includes utilising the resources available from TB Alert: http://www.thetruthabouttb.org/professionals/professional-education/

East Midlands TB Control Board and TB Networks to encourage the use of the RCGP TB e-learning module. http://elearning.rcgp.org.uk/course/info.php?id=107

## Provide universal access to high quality diagnostics (AfA2)

TB Networks to increase the proportion of patients that have a diagnostic laboratory result, particularly culture results to ensure prompt identification of drug resistance and allow WGS to identify clusters.

## Improve treatment and care services (AfA3)

TB Networks to continue their supportive case management of complex TB patients, offer DOT where indicated and consider the use of innovative approaches such as VOT to improve case management.

TB Networks to implement or continue cohort review as a tool to improve local TB control and as a measure of treatment outcomes and contact tracing activity working towards the KPIs agreed by the East Midlands TB Control Board.

TB Networks to use the updated 2018 National TB Service Specification and Clinical Policy to commission and monitor local TB services.

TB Networks to encourage universal HIV testing for all those diagnosed with tuberculosis and ensure where possible, tests are carried out[13].

TB Networks to ensure information is completed accurately on the PHE ETS system, particularly with respect to dates of onset of symptoms, evaluation of treatment completion, TB relationship with death and social risk factors.

## To reduce drug-resistant TB (AfA6)

TB Networks to use the British Thoracic Society (BTS) MDR-TB Clinical Advice Service to support MDR-TB case management.

TB Networks to continue supporting patients to complete treatment, using DOT or VOT where indicated, and to have plans in place to minimise patients being lost to follow-up.

## To tackle TB in under-served populations (AfA7)

East Midlands TB Control Board and TB Networks to encourage the use of the resource ‘Tackling TB in Under-Served Populations’[4] to take appropriate local action and better meet the needs of USPs.

TB Networks, to ensure appropriate access to services, treatment and support to enable patients to complete treatment.

TB Networks are encouraged to use ‘Tackling TB - local government's public health role’[5], a joint publication from PHE and the Local Government Association to help support USPs with TB.

## To implement new entrant latent TB screening (AfA8)

CCGs to sustain the roll out of the new migrant LTBI screening programme within the 4 high-burden CCGs identified within East Midlands.

# Appendix A: Notes on the report

## About the Field Service

The Field Service (FS) supports Public Health England (PHE) centres and partner organisations through the application of epidemiological methods and public health microbiology to inform public health action. It does this in 2 main ways, firstly by providing a flexible expert resource, available, as and when needed, to undertake epidemiological investigations for key health protection work and secondly through the expert analysis, interpretation and dissemination of surveillance information to PHE Centres, local health partners, service providers and commissioners of services. Within the FS network, excellence and innovation is encouraged, we foster academic collaborations and take active part and lead in research, development and training.

## Intended audience

This report is for use by healthcare professionals who diagnose and/or care for people with TB, commissioners involved in planning and financing TB services, public health professionals working to improve TB control and the health of at-risk populations, researchers with an interest in TB, and government and non-governmental organisations working in the field of TB. In particular this report is for the use of the East Midlands TB Control Board.

## Aim of report

This report describes the recent epidemiology of TB in East Midlands. It includes local trends, which areas and population groups have a high burden of disease, and detail on the care of patients.

## Further TB information

The national report of TB in England is available at: https://www.gov.uk/government/publications/tuberculosis-in-england-annual-report. Additional data on TB notifications in the UK to the end of 2018, and breakdowns by country, can be found in the Official Statistic for TB, ‘Reports of patients of tuberculosis to ETS systems: United Kingdom, 2000 to 2018’. This is available at: https://www.gov.uk/government/collections/tuberculosis-and-other-mycobacterial-diseases-diagnosis-screening-management-and-data.

As part of the Collaborative TB Strategy for England 2015-2020, TB Strategy Monitoring Indicators are available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf). Where data for these indicators are presented in this report, the indicator name is shown.

A number of TB indicators at UTLA and Clinical Commissioning Group level can be found at: http://fingertips.phe.org.uk/profile/tb-monitoring.

Note: data presented for TB monitoring indicators at East Midlands level DO NOT need to suppress small numbers due to the large size of the underlying population and the fact that these are not accompanied by any identifiable information.

# Appendix B: Description of data sources and definitions and other explanations

## Data sources

This report is based on TB case notifications made to the PHE ETS system in England to the end of 2018. The information is updated annually to take into account denotifications (where the patient was found not to have TB), late notifications and other updates. The data presented in this report supersedes data in previous reports.

Diagnostic laboratories serving acute hospitals are the first place in which TB infection-related samples are received and processed within the pathway of clinical diagnosis and management of suspected TB patients. Results for microscopy, polymerase chain reaction (PCR), histology and culture are collected in ETS. Appropriate referral of positive cultures to the PHE National Mycobacterial Reference Service is an important part of the routine work of the diagnostic laboratories in the investigation and management of TB patients.

The National Mycobacterial Reference Service (NMRS) culture positive samples and undertakes molecular diagnostic methods to define species of *Mycobacterium*, TB antibiotic (drug) susceptibility and organism relatedness. Historically, organism relatedness has been determined by Mycobacterial Interspersed Repetitive Unit-Variable Number Tandem Repeats (MIRU-VNTR) typing, however this has been superseded in recent years by WGS.

Screening of people exposed to a patient with active TB is a key strategy to find and treat active and latent TB, and prevent further transmission. The outcomes of contact tracing activities are discussed by cohort reviews undertaken in most areas of East Midlands (for more information on the purpose of cohort reviews, please see the Collaborative Tuberculosis Strategy for England, 2015 to 2020: https://www.gov.uk/government/publications/collaborative-tuberculosis-strategy-for-england [(3)].

## Definitions

| | |
|---|---|
| BCG | Bacillus Calmette-Guérin vaccination |
| CI | Confidence interval |
| CCG | Clinical Commissioning Group |
| Cluster | 2 or more patients notified within the time period of analysis with TB cause by strains with ≤12 SNP differences |
| CNS | Central nervous system |
| Cohort review | The systematic review of all TB patients notified by a TB service in a 3-4 month period, looking at standard outcomes in terms of patient care and number of contacts screened |
| Cryptic disseminated TB | Systemic illness without localising features |
| DOT | Directly observed treatment |
| Drug | In the context of TB control, a drug is an anti-TB antibiotic |
| Drug resistant cohort | The drug resistant cohort includes any patients with rifampicin resistant TB (initial or acquired), including MDR-TB (initial or acquired), as well as those without culture confirmation treated with an MDR-TB regimen |
| Drug-sensitive cohort | The drug sensitive cohort excludes all TB patients with rifampicin resistant TB (initial or acquired) including MDR-TB (initial or acquired), and non-culture confirmed patients treated with an MDR-TB regimen |
| DST | Drug sensitivity testing, based on phenotypic analysis of cultured TB isolates or WGS predictions. |
| ETS | Enhanced TB surveillance system |
| First-line drug resistance | First-line anti-TB antibiotic drug resistance is defined as resistance to at least 1 of the first-line antibiotics – such as isoniazid, rifampicin, ethambutol, pyrazinamide |
| HAART | Highly active antiretroviral therapy |
| IGRA | Interferon-gamma release assay – blood test for TB infection which does not differentiate between active disease and LTBI |
| IMD 2015 | The Index of Multiple Deprivation 2010 rank for each LSOA, based on deprivation score assigned, relative to other LSOAs in the PHE East of England area |
| IQR | Interquartile range |
| LSOA | Lower super output area (geographic definition) |
| LTBI | Latent TB infection |
| MDR | Multidrug resistance: patients initially resistant to at least isoniazid and rifampicin |

| | |
|---|---|
| Miliary TB | TB infection spread via the bloodstream to all parts of the body |
| MIRU-VNTR | Mycobacterial Interspersed Repetitive Unit-Variable Number Tandem Repeats |
| PCR | Polymerase chain reaction |
| Post-mortem diagnosis | A patient diagnosed at post-mortem is defined as where TB was not suspected before death, but a TB diagnosis was made at post-mortem, with pathological and/or microbiological findings consistent with active TB that would have warranted anti-TB treatment if discovered before death |
| Pulmonary tuberculosis | A pulmonary patient is defined as a patient with TB involving the lungs and/or tracheobronchial tree, with or without extra-pulmonary TB diagnosis. In this report, in line with the WHO's recommendation and international reporting definitions, miliary TB is classified as pulmonary TB due to the presence of lesions in the lungs |
| Second-line drugs | Second-line drugs include injectable agents, including amikacin, capreomycin and kanamycin; fluoroquinolones, such as moxifloxacin, ofloxacin, ciprofloxacin) and other oral bacteriostatic agents |
| SNP | Single nucleotide polymorphism – mutation of 1 base pair in the genome of an *M. tuberculosis complex* isolate |
| TB | Tuberculosis |
| UTLA | Upper tier local authority (geographic definition) |
| VOT | Video observed therapy |
| WGS | Whole genome sequencing |
| XDR | Extensive drug resistance: patients initially MDR and resistant to at least 1 injectable agent (amikacin, capreomycin or kanamycin) and at least 1 fluoroquinolone (moxifloxacin, ofloxacin or ciprofloxacin) |

## Treatment outcome

Information on outcomes were reported for all patients reported in the previous year, excluding those with known rifampicin resistant disease: outcomes for these were reported at 24 months. Definitions for outcome are based on World Health Organization (WHO) and European definitions but adapted to the UK context. In this report, all data was obtained from the ETS matched dataset provided in June 2019.

## Proportions

All proportions in this report are calculated among patients with known information or a known result, except where otherwise stated.

## Confidence intervals

A 95% confidence interval for incidence was obtained using the relevant procedure in R.

## Population denominator

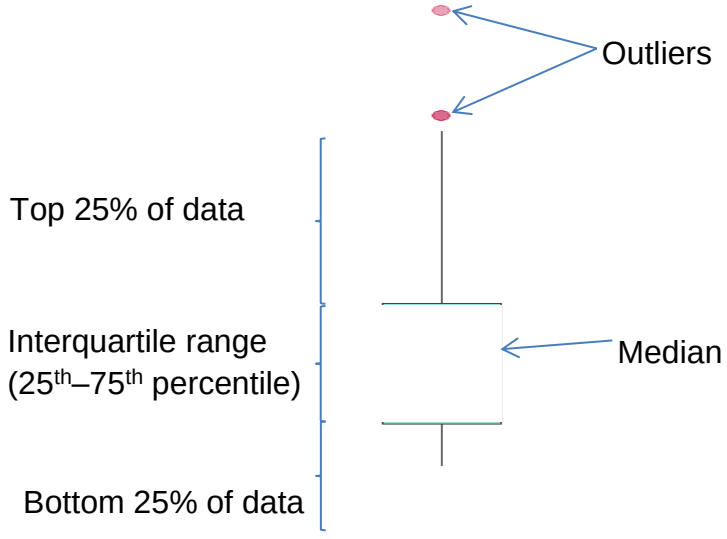
Tuberculosis rates by geographical area (Centre, local authority, MSOA and LSOA), age, sex and place of birth were calculated using ONS mid-year population estimates. Tuberculosis rates by ethnic group were calculated using population estimates from the Labour Force Survey (LFS) (http://www.esds.ac.uk/findingData/qlfs.asp). The LFS is based on a population sample, so estimates are liable to sampling errors, particularly for small population subgroups, and should be interpreted with caution.

## Cluster definitions

Analysis of clustering in the East Midlands was carried out on patients that clustered in the East Midlands and notified in 2018.

Strain typing was performed by the National Mycobacterial Reference Service using WGS. Analysis was undertaken on strain type clusters as defined above. Analysis of clustering in East Midlands was carried out on patients that clustered in East Midlands in 2018.

## Interpretation of box plots



# Appendix C: TB among East Midlands residents

**Table C1a: TB new notifications numbers East Midlands Public Health England Centre, 2000 to 2018**

| Patients with TB | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Persons | 414 | 544 | 471 | 458 | 418 | 533 | 566 | 534 | 483 | 524 | 494 | 492 | 497 | 413 | 400 | 357 | 341 | 349 | 338 |

**Table C1b: TB new notifications incidence rate East Midlands Public Health England Centre, 2000 to 2018**

| Patients with TB | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Rate | 9.9 | 13 | 11.2 | 10.8 | 9.7 | 12.3 | 13 | 12.1 | 10.9 | 11.7 | 11 | 10.8 | 10.9 | 9 | 8.6 | 7.6 | 7.2 | 7.3 | 7 |
| Lower confidence limit | 9 | 11.9 | 10.2 | 9.8 | 8.8 | 11.3 | 11.9 | 11.1 | 9.9 | 10.7 | 10 | 9.9 | 9.9 | 8.1 | 7.8 | 6.9 | 6.5 | 6.6 | 6.3 |
| Upper confidence limit | 10.9 | 14.1 | 12.2 | 11.8 | 10.7 | 13.4 | 14.1 | 13.2 | 11.9 | 12.8 | 12 | 11.8 | 11.9 | 9.9 | 9.5 | 8.5 | 8 | 8.1 | 7.8 |

## Table C2a: TB patient numbers by UTLA of residence, East Midlands, 2000 to 2018

| UTLA | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Derby | 46 | 46 | 59 | 39 | 28 | 36 | 40 | 55 | 45 | 40 | 53 | 34 | 34 | 37 | 35 | 28 | 30 | 30 |
| Derbyshire | 37 | 29 | 30 | 25 | 28 | 43 | 30 | 28 | 32 | 15 | 36 | 32 | 22 | 28 | 18 | 9 | 10 | 7 |
| Leicester | 262 | 196 | 199 | 155 | 263 | 226 | 216 | 177 | 206 | 207 | 188 | 184 | 158 | 142 | 125 | 130 | 135 | 144 |
| Leicestershire and Rutland | 51 | 43 | 33 | 37 | 43 | 56 | 50 | 40 | 51 | 41 | 35 | 38 | 38 | 24 | 24 | 23 | 33 | 25 |
| Lincolnshire | 6 | 14 | 14 | 18 | 13 | 25 | 16 | 20 | 20 | 21 | 23 | 31 | 26 | 34 | 36 | 30 | 28 | 26 |
| Northamptonshire | 67 | 83 | 56 | 75 | 79 | 69 | 66 | 64 | 79 | 68 | 65 | 80 | 46 | 47 | 48 | 50 | 38 | 56 |
| Nottingham | 52 | 40 | 36 | 48 | 57 | 82 | 80 | 80 | 55 | 69 | 67 | 60 | 58 | 50 | 53 | 48 | 43 | 32 |
| Nottinghamshire | 23 | 20 | 31 | 21 | 22 | 29 | 36 | 19 | 36 | 33 | 25 | 38 | 31 | 38 | 18 | 23 | 32 | 18 |

## Table C2b: TB rate per 100,000 by UTLA of residence, East Midlands, 2000 to 2018

| UTLA | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Derby | 19.9 | 19.8 | 25.3 | 16.6 | 11.8 | 15.1 | 16.7 | 22.7 | 18.4 | 16.2 | 21.3 | 13.6 | 13.5 | 14.7 | 13.8 | 10.9 | 11.7 | 11.7 |
| Derbyshire | 5 | 3.9 | 4 | 3.4 | 3.7 | 5.7 | 4 | 3.7 | 4.2 | 2 | 4.7 | 4.1 | 2.8 | 3.6 | 2.3 | 1.1 | 1.3 | 0.9 |
| Leicester | 92.7 | 68.7 | 68.9 | 52.7 | 87.2 | 73.7 | 69.4 | 56.1 | 64.4 | 63.7 | 57 | 55.4 | 47.2 | 42 | 36.3 | 37.2 | 38.2 | 40.5 |
| Leicestershire and Rutland | 7.9 | 6.6 | 5 | 5.6 | 6.5 | 8.4 | 7.4 | 5.9 | 7.5 | 6 | 5.1 | 5.5 | 5.4 | 3.4 | 3.4 | 3.2 | 4.5 | 3.4 |
| Lincolnshire | 0.9 | 2.1 | 2.1 | 2.7 | 1.9 | 3.6 | 2.3 | 2.9 | 2.8 | 3 | 3.2 | 4.3 | 3.6 | 4.6 | 4.9 | 4 | 3.7 | 3.4 |
| Northamptonshire | 10.6 | 13 | 8.7 | 11.6 | 12.1 | 10.4 | 9.8 | 9.4 | 11.6 | 9.9 | 9.4 | 11.4 | 6.5 | 6.6 | 6.6 | 6.8 | 5.1 | 7.5 |
| Nottingham | 19.3 | 14.7 | 13.1 | 17.2 | 20 | 28.6 | 27.8 | 27.5 | 18.7 | 23 | 22 | 19.5 | 18.7 | 15.9 | 16.6 | 14.8 | 13.1 | 9.7 |
| Nottinghamshire | 3.1 | 2.7 | 4.1 | 2.8 | 2.9 | 3.8 | 4.7 | 2.4 | 4.6 | 4.2 | 3.2 | 4.8 | 3.9 | 4.7 | 2.2 | 2.8 | 3.9 | 2.2 |

Rates calculated using ONS mid-year population estimates

**Table C3: Average TB number and rate per 100,000 population by Clinical Commissioning Group of residence, East Midlands, 2016 to 2018**

| CCG | Average count per year 2016-2018 | Average rate / 100,000 population per year 2016-2018 |
|---|---|---|
| NHS Bassetlaw CCG | 1 | 0.9 |
| NHS Corby CCG | 4 | 6.3 |
| NHS East Leicestershire and Rutland CCG | 12 | 3.7 |
| NHS Leicester City CCG | 136 | 38.7 |
| NHS Lincolnshire East CCG | 14 | 6.0 |
| NHS Lincolnshire West CCG | 7 | 2.8 |
| NHS Mansfield and Ashfield CCG | 5 | 2.7 |
| NHS Nene CCG | 43 | 6.6 |
| NHS Newark and Sherwood CCG | 4 | 3.3 |
| NHS Nottingham City CCG | 41 | 12.5 |
| NHS Nottingham North and East CCG | 6 | 4.2 |
| NHS Nottingham West CCG | 3 | 2.4 |
| NHS Rushcliffe CCG | 5 | 4.3 |
| NHS South Lincolnshire CCG | 4 | 2.7 |
| NHS South West Lincolnshire CCG | 3 | 2.6 |
| NHS West Leicestershire CCG | 15 | 3.7 |
| NHS Derby and Derbyshire CCG | 38 | 3.7 |

Rates calculated using ONS mid-year population estimates

## Table C4: TB patient numbers, East Midlands, 2000 to 2018

| Age group | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 0-9 years | 13 | 17 | 13 | 8 | 9 | 11 | 14 | 12 | 11 | 14 | 11 | 5 | 8 | 13 | 11 | 9 | 16 | 8 | 4 |
| 10-19 years | 21 | 102 | 35 | 42 | 27 | 46 | 37 | 32 | 25 | 41 | 28 | 25 | 27 | 26 | 17 | 23 | 11 | 27 | 17 |
| 20-29 years | 63 | 92 | 109 | 94 | 98 | 123 | 139 | 138 | 105 | 116 | 115 | 112 | 109 | 81 | 76 | 61 | 65 | 56 | 76 |
| 30-39 years | 69 | 87 | 84 | 82 | 109 | 118 | 114 | 107 | 122 | 118 | 114 | 111 | 106 | 86 | 88 | 89 | 77 | 78 | 68 |
| 40-49 years | 67 | 74 | 72 | 68 | 52 | 75 | 81 | 65 | 61 | 65 | 92 | 67 | 77 | 59 | 60 | 56 | 61 | 61 | 73 |
| 50-59 years | 56 | 49 | 44 | 60 | 33 | 64 | 60 | 81 | 63 | 66 | 53 | 67 | 60 | 66 | 56 | 42 | 52 | 42 | 47 |
| 60-69 years | 52 | 39 | 39 | 37 | 37 | 31 | 56 | 46 | 41 | 44 | 26 | 39 | 43 | 34 | 29 | 35 | 25 | 36 | 19 |
| 70 years plus | 73 | 83 | 74 | 67 | 52 | 65 | 65 | 53 | 54 | 60 | 55 | 66 | 67 | 48 | 63 | 42 | 34 | 41 | 34 |

## Table C5: TB patient rate by age, East Midlands, 2000 to 2018

| Age group | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 0-9 years | 2.5 | 3.4 | 2.6 | 1.6 | 1.8 | 2.2 | 2.8 | 2.4 | 2.2 | 2.8 | 2.1 | 1 | 1.5 | 2.4 | 2 | 1.6 | 2.8 | 1.4 | 0.7 |
| 10-19 years | 3.9 | 18.8 | 6.4 | 7.6 | 4.8 | 8.2 | 6.6 | 5.7 | 4.4 | 7.3 | 5 | 4.5 | 4.9 | 4.8 | 3.2 | 4.3 | 2 | 5 | 3.1 |
| 20-29 years | 12.3 | 18.3 | 21.9 | 18.7 | 19.1 | 23.2 | 25.5 | 24.7 | 18.4 | 20.2 | 19.8 | 19.1 | 18.4 | 13.5 | 12.5 | 9.9 | 10.5 | 8.9 | 12.1 |
| 30-39 years | 10.8 | 13.5 | 13.1 | 12.8 | 17.3 | 19.1 | 18.8 | 18.1 | 21.1 | 20.7 | 20.2 | 19.9 | 19.3 | 15.7 | 16 | 16 | 13.6 | 13.5 | 11.6 |
| 40-49 years | 12 | 13.1 | 12.4 | 11.5 | 8.6 | 12 | 12.7 | 10 | 9.2 | 9.7 | 13.6 | 9.9 | 11.4 | 8.8 | 9.1 | 8.7 | 9.6 | 9.8 | 12.1 |
| 50-59 years | 10.4 | 8.9 | 7.8 | 10.6 | 5.8 | 11.3 | 10.6 | 14.5 | 11.4 | 11.9 | 9.4 | 11.7 | 10.3 | 11.1 | 9.2 | 6.7 | 8.1 | 6.4 | 7.1 |
| 60-69 years | 13.2 | 9.9 | 9.8 | 9 | 8.8 | 7.1 | 12.6 | 9.8 | 8.4 | 8.8 | 5 | 7.4 | 8 | 6.3 | 5.3 | 6.4 | 4.6 | 6.7 | 3.5 |
| 70 years plus | NA | 17.1 | 15.1 | 13.5 | 10.4 | 12.9 | 12.8 | 10.3 | 10.4 | 11.3 | 10.2 | 12.2 | 12.1 | 8.5 | 10.8 | 7 | 5.5 | 6.4 | 5.1 |

Rates calculated using ONS mid-year population estimates

**Table C6: Number of TB patients by place of birth, UK and non-UK born, East Midlands, 2000 to 2018**

| UK/non-UK born | | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| UK born | n | 120 | 120 | 127 | 116 | 111 | 95 | 114 | 118 | 119 | 146 | 122 | 142 | 127 | 116 | 132 | 99 | 94 | 112 | 75 |
| UK born | Rate | 3.1 | 3.1 | 3.2 | 2.9 | 2.8 | 2.4 | 2.9 | 3 | 3 | 3.6 | 3 | 3.5 | 3.1 | 2.8 | 3.2 | 2.4 | 2.3 | 2.8 | 1.8 |
| UK born | LCL | 2.6 | 2.5 | 2.7 | 2.4 | 2.3 | 1.9 | 2.4 | 2.5 | 2.5 | 3.1 | 2.5 | 3 | 2.6 | 2.4 | 2.7 | 2 | 1.8 | 2.3 | 1.4 |
| UK born | UCL | 3.7 | 3.7 | 3.9 | 3.5 | 3.4 | 2.9 | 3.5 | 3.6 | 3.6 | 4.3 | 3.6 | 4.1 | 3.7 | 3.4 | 3.8 | 2.9 | 2.8 | 3.3 | 2.3 |
| Non-UK born | n | 101 | 100 | 119 | 182 | 225 | 291 | 233 | 278 | 296 | 340 | 351 | 331 | 354 | 292 | 258 | 251 | 242 | 225 | 259 |
| Not UK born | Rate | 46.4 | 44.7 | 47.2 | 72.9 | 90.4 | 99.4 | 68.3 | 75.7 | 76.5 | 89.8 | 85.3 | 76.1 | 80.3 | 63.3 | 55.8 | 50.9 | 48.2 | 37.5 | 44.3 |
| Not UK born | LCL | 37.8 | 36.4 | 39.1 | 62.7 | 78.9 | 88.3 | 59.8 | 67.1 | 68 | 80.5 | 76.6 | 68.1 | 72.1 | 56.2 | 49.2 | 44.8 | 42.3 | 32.7 | 39.1 |
| Not UK born | UCL | 56.4 | 54.4 | 56.5 | 84.3 | 103. | 111.5 | 77.6 | 85.2 | 85.7 | 99.8 | 94.8 | 84.8 | 89.1 | 71 | 63.0 | 57.6 | 54.7 | 42.7 | 50 |

**Table C7: First-line drug resistance among TB patients with culture confirmed disease*, East Midlands, 2000 to 2018**

| First line resistance | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| No. of isolates | 11 | 19 | 18 | 18 | 19 | 15 | 22 | 20 | 13 | 22 | 16 | 9 | 16 | 17 | 17 | 20 | 22 | 18 | 20 |
| Proportion of isolates % | 5.7 | 7 | 7 | 6.8 | 7.4 | 5.2 | 7.2 | 6.5 | 4.6 | 8.1 | 5.4 | 3.1 | 5.4 | 7.4 | 7.2 | 8.3 | 10.6 | 8.5 | 10.2 |

*culture confirmed patients with drug susceptibility testing results for at least isoniazid and rifampicin

**Table C8: Time between symptom onset and starting treatment for all TB patients*, East Midlands, 2011 to 2018**

| Year | 0-2 months Count | 0-2 months % | 2-4 months Count | 2-4 months % | 4+ months Count | 4+ months % | Total |
|---|---|---|---|---|---|---|---|
| 2011 | 131 | 39.5 | 95 | 28.6 | 106 | 31.9 | 332 |
| 2012 | 109 | 30 | 105 | 28.9 | 149 | 41 | 363 |
| 2013 | 116 | 38 | 93 | 30.5 | 96 | 31.5 | 305 |
| 2014 | 124 | 32.9 | 103 | 27.3 | 150 | 39.8 | 377 |
| 2015 | 120 | 35.2 | 104 | 30.5 | 117 | 34.3 | 341 |
| 2016 | 112 | 34.6 | 100 | 30.9 | 112 | 34.6 | 324 |
| 2017 | 102 | 30.5 | 97 | 29 | 135 | 40.4 | 334 |
| 2018 | 122 | 38 | 87 | 27.1 | 112 | 34.9 | 321 |

*Excluding asymptomatic patients, and those with missing onset dates

**Table C9: Social risk factors among TB patients*, East Midlands, 2018**

| Risk factor | Count of patients | Proportion of patients |
|---|---|---|
| Ability to self-treat affected by alcohol misuse/abuse | 14 | 4.5 |
| History of or current problem drug use | 10 | 3.2 |
| History of or current homelessness | 22 | 7.3 |
| History of or current imprisonment | 14 | 4.9 |

* For patients 15 years and over. Total number of patients for the year with risk factor data recorded

# Appendix D: Surveillance data quality

### Table E1: Percentage completeness of key data fields in ETS for 2018 with percentage change from 2017, East Midlands

| East Midlands | Demographic | | | | Clinical | | | | Social risk factor | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | NHS Number* | | Ethnic group | UK/non-UK born | HIV Testing# | Previous TB diagnosis | | Previous TB treatment^ | Drug misuse | | Alcohol misuse | | Homelessness | | Prison | |
| | ETS | Lab | Known | Known | Known | Known | Reported$ | Reported | Known | Reported | Known | Reported | Known | Reported | Known | Reported |
| Percentage complete 2018 | 97 | 89 | 99 | 99 | 94 | 96 | 99 | 71 | 94 | 100 | 93 | 98 | 91 | 98 | 87 | 98 |
| Percentage change from 2017 | 0 | +10 | +1 | +2 | -1 | +3 | +2 | +1 | +2 | +2 | +2 | +1 | +2 | 0 | +7 | +1 |

### Table E2: Percentage completeness of diagnosis, death and treatment data fields in ETS for 2018 with percentage change from 2017, East Midlands

| East Midlands | Diagnosis | | | | | Death | | Treatment | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Sputum smear status** | Site of disease | Symptom onset date^ | Date first presented | Date diagnosed^ | Date of death† | Relationship between TB and death§ | Start of Treatment date^ | Date treatment completed@ | Treatment Outcome reported at 12 months§ | | Treatment Outcome reported at 24 months¥ | |
| | Known# | Known | Known | Known | Known | Known | Known | Known | Known | Known | Reported‡ | Known | Reported |
| Percentage complete 2018 | 58 | 100 | 98 | 95 | 99 | 96 | 55 | 98 | 99 | 98 | 99 | 95 | 98 |
| Percentage change 2017 to 2018 | +1 | - | 0 | +4 | +3 | +3 | +7 | +1 | 0 | +1 | 0 | -5 | -2 |

**Pulmonary patients only. †Patients notified in 2015 that have treatment outcome died only. ‡Data are reported but may be reported as unknown. # Data are reported and has a known value. ^Excludes patients diagnosed post-mortem. ¥ For patients notified in 2017 and still on treatment at 12 months. @Patients notified in 2017 that have completed treatment only. §For patients notified in 2017

Key: 99- 100% complete | 95 - 98% complete | <95% complete | % increase | No change | % decrease | 100% reached

# Appendix E: Local authority TB epidemiological summaries

Local authority TB epidemiological summaries will provide further information about TB patients among residents of East Midlands upper tier local authorities with an average of at least 50 TB patients per year over the previous 3 years. These will be available from your local FS team.

# References

1. World Health Organisation. Towards tuberculosis elimination: an action framework for low-incidence countries. Geneva: World Health Organisation; 2014.

2. Public Health England. Tuberculosis in England: 2018 2019 [Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/821334/Tuberculosis_in_England-annual_report_2019.pdf.

3. Public Health England, NHS England. Collaborative Tuberculosis Strategy for England, 2015 to 2020 2015 [Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/403231/Collaborative_TB_Strategy_for_England_2015_2020_.pdf.

4. Public Health England. Tackling tuberculosis in under-served populations 2017 [Available from: https://www.gov.uk/government/publications/tackling-tuberculosis-in-underserved-populations.

5. Local Government Association. Tacking tuberculosis: local government's public health role 2018 [Available from: https://www.local.gov.uk/tackling-tuberculosis-local-governments-public-health-role.

6. World Health Organisation. Definitions and reporting framework for tuberculosis - 2013 revision. . Geneva, Switzerland: World Health Organisation; 2013.

7. Prison population figures: 2018. Ministry of Justice, HM Prison Service, HM Prison and Probation Service; 2018 05/01/2019.

8. Joint Committee on Vaccination and Immunisation. Tuberculosis: the green book chapter 32 2011 [Available from: https://www.gov.uk/government/publications/tuberculosis-the-green-book-chapter-32.

9. Public Health England. Cover of vaccination evaluated rapidly (COVER) programme 2018 to 2019: quarterly data 2018 [Available from: https://www.gov.uk/government/statistics/cover-of-vaccination-evaluated-rapidly-cover-programme-2018-to-2019-quarterly-data.

10. NHS England. Latent TB Testing Laboratory Analysis Services: appointment of providers 2015 [Available from: https://www.england.nhs.uk/tb-strategy/providers/.

11. Public Health England, NHS England. Latent TB Testing and Treatment for Migrants. A practical guide for commissioners and practitioners 2015 [Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/442192/030615_LTBI_testing_and_treatment_for_migrants_1.pdf.

12. National Institute of Health and Clinical Excellence. Tuberculosis in vulnerable groups. 2013 [Available from: https://www.nice.org.uk/advice/lgb11/resources/tuberculosis-in-vulnerable-groups-60521141388229.

13. British HIV Association. UK National Guidelines for HIV Testing 2008 [Available from: http://www.bhiva.org/documents/guidelines/testing/glineshivtest08.pdf.