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Deaths involving tuberculosis reported by coroners in England and Wales: a national observational study

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Research Article

Keywords: Tuberculosis, Deaths, Coroners' Reports, Prevention, United Kingdom

Posted Date: July 23rd, 2026

DOI: https://doi.org/10.21203/rs.3.rs-10277748/v1

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Additional Declarations: Competing interest reported. AM was a medical student at the University of Oxford (2022-2026). HvdW is employed by Oxford University as a postdoctoral researcher and a tutor in global health. GCR is employed by King's College London, through an AI+ Academic Senior Fellowship (2026-2031) and has a contract with the University of Oxford as a Senior Associate Tutor. GCR has had travel expenses reimbursed for attending and presenting at conferences and received fees for speaking at events, teaching, and delivering training. GCR is the director of a limited company and a community interest company (CIC) that funds the Preventable Deaths Tracker's infrastructure, and receives subscriptions to a personal Substack newsletter. AM and HvdW declare no competing interests.

Abstract

Background

Tuberculosis (TB) is the leading cause of death from a single infectious agent worldwide. Although the United Kingdom (UK) is a low-incidence country, it has not met global targets to reduce TB deaths in line with the World Health Organisation (WHO) End TB strategy. This study aimed to determine how many deaths from TB were reported to organisations by coroners in England and Wales to identify lessons from these reports and create a live surveillance tool to measure progress.

Methods

The Preventable Deaths Tracker, a national database of all coroners' Prevention of Future Deaths reports (PFDs), was used. Keywords were used to search 5,036 PFDs and identify deaths involving TB. Descriptive statistics were used to synthesise the data, and thematic analysis to assess concerns reported by coroners and organisational responses to coroners. Finally, we reviewed pertinent UK guidelines and policies to assess whether coroners' concerns were addressed, and developed a live surveillance tool.

Results

Five deaths involving TB were reported by coroners between July 2013 and 19th May 2024, with a median age at death of 28 years, equivalent to 234 years of life lost. 21 concerns were raised by coroners, grouped into five themes, including TB posing an occupational risk, and insufficient guidelines and protocols for prevention and treatment. UK policy implementation addresses coroners' concerns on out-of-hours access to general practitioner records, and UK guidelines highlight biological immunosuppressive treatment as a risk for TB. Significant ambiguity around occupational risks of TB for health workers remained, including guidance for latent TB screening and contact tracing for TB-exposed health workers. A surveillance tool was created to monitor the ongoing publication of PFDs involving TB.

Conclusions

Using thematic analyses and a guideline review, we identified learnings from PFDs, finding that some had not been addressed in the guidelines, including latent TB screening protocols and healthcare workers as an at-risk group for TB in England and Wales. PFDs provide valuable insights for preventing future deaths involving TB, and can help catalyse and monitor action taken in low-TB-burden, high-income countries to achieve the goals set in the WHO End TB plan.

Background

Tuberculosis (TB) is a preventable and treatable airborne disease caused by *Mycobacterium Tuberculosis.* (1, 2) It most commonly affects the lungs (pulmonary TB) but can affect other areas of the body. (3) In 1993, the World Health Organisation (WHO) declared a global emergency as cases of TB reached 8 million new cases a year, and 3 million deaths. (4) The 2024 WHO report estimated that in 2023, there were 10.8 million incident cases of TB, resulting in an estimated 1.25 million deaths from TB, making TB "the world's leading cause of death from a single infectious agent" in 2023. (5) The exact cause of death due to TB varies but can include septic shock, haemoptysis and cachexia. (6, 7)

England and Wales are categorised as low-incidence countries, with 8.5 cases of TB per 100,000 in 2023 in England, and 2.7 cases of TB per 100,000 in 2023 in Wales. (3, 8) Whilst the number of people affected by TB has declined in the United Kingdom (UK) since records began in 1913, there have still been fluctuations in notifications year on year; with an 11% increase in TB notifications in 2023 compared to 2022 in England. (8, 9) There is also significant regional variation; for example, London has a five times higher notification rate than the South West of England. (8) Before the increase in TB notifications in 2023, the rate of decline in notifications had been slowing and was not on track to meet the WHO End TB target to reduce TB deaths by 95% by 2035. (10, 11) In 2023, there were 4939 notifications of individuals diagnosed with TB in England and Wales, and an estimated 272 deaths due to TB in the UK. (3, 8, 12) To reduce TB deaths in line with the WHO End TB plan, this must reach no more than 15 deaths per year in 2035. (8)

A retrospective cohort study from 2001 to 2014 used data from TB surveillance systems in the UK to create a dataset for people affected by TB. (13) They found that 21% of those with TB were diagnosed post-mortem, and 49% of those who died (and for whom information was available) died within two months of starting treatment. (13) Across income and TB incidence settings, posthumously diagnosed TB remains a significant problem. (14–19) Data for England on TB deaths at autopsy, dated to the previous century, showed missed diagnoses. (20, 21) However, an analysis of information from coroners in England and Wales has not yet been conducted to understand concerns raised by coroners.

Coroners in England and Wales have a duty to write Prevention of Future Deaths reports (PFDs) when they deem action should be taken to prevent similar fatalities. (22, 23) Research has analysed PFDs to identify concerns raised by coroners from a range of public health and patient safety concerns, including deaths involving medicines, covid-19 and cardiovascular disease. (24–26) However, deaths involving TB have not yet been explored. This study aimed to explore the number of PFDs written by coroners in England and Wales that involved TB from inception (July 2013) to May 2024 to understand concerns raised by coroners and develop a live surveillance tool to monitor the ongoing publication of PFDs.

Methods

Study design

A national observational study of coroners' PFDs was designed, and the study protocol was preregistered on an open repository. (27)

Data collection

Data were collected using the Preventable Deaths Tracker, which contains all published coroners' PFDs from the Courts and Tribunals Judiciary website from the inception of the publication of PFDs (July 2013), making this information searchable to identify reports. (28) Key words, including "Tuberculosis", "TB", "mycobacterium" and "MTB" were used as informed by a previous study. (19) See Addendum 1.

Data screening and eligibility

Each case identified from the keyword searches was screened by two authors and included if TB was determined to have contributed to or caused death. TB was defined using the International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11) definition as 'tuberculosis attributable to *mycobacterium tuberculosis*'. (2) In this definition, cases caused by both *mycobacterium tuberculosis* or *mycobacterium bovis* were included. (2) Cases where the patient was positive for TB, but TB did not contribute to the death (e.g. latent TB), and cases where deaths were due to infection with non-tuberculous mycobacteria, such as *mycobacterium chimera* or *mycobacterium abscessus*, were excluded. The medical causes of deaths (i.e. Ia Ib, Ic, Id, and II) are used in the Preventable Deaths Tracker (PDT) to categorise PFDs and thus there was a discrepancy in the number of cases included in this study compared with the real-time surveillance tool.

Data extraction

Data, including demographics, circumstances and causes of deaths (see addendum 2) was extracted by one author (AM) and cross-checked by a second author (GR). In most (80%; n = 4) reports, there was missing information; the medical causes of death were missing in three PFDs, one did not report age, and two were missing the coroner's conclusion of the inquest. We emailed the coroner's offices of all four PFDs to request a record of inquest (ROI), which were all received, and any missing responses (if none were published on the Courts and Judiciary website), for which one provided a previously unpublished response, which has now been published online. (29)

Data analysis

Descriptive statistics, including means and interquartile ranges (IQR), were used for continuous variables (e.g. age), and percentages for categorical variables (e.g. sex). We calculated years of life lost (YLL) by using the Office of National Statistics projection of life expectancy tables to sum the expected year of life remaining given each case's age at death and year of death. (30) Using the YLL, we calculated the Value of a Statistical Life using HM Treasury's guidance of £70,000 for every year. (31) We used the medical causes of death to assign each PFD with one or more ICD-11 codes. (32) We reported medical and/or social histories and comorbidities of the deceased if reported by the coroner.

We classified PFDs as completed (if all responses were published), overdue (no responses published), partial (some but not all responses published) or pending (within 56 days, so not yet due for a response under Regulations 29 of the Coroners (Investigations) Regulations 2013). (23) We calculated the rate of response for each recipient and the average response rate for all included PFDs.

Thematic analysis was used to explore coroners' concerns and actions reported in responses or reasons for inaction. We then compared the coroners' concerns with the most up-to-date UK guidance at the time the review was conducted (2024). For concerns regarding drugs, we searched for guidelines from the National Institute for Health and Care Excellence (NICE), the British National Formulary (BNF), Medicines and Healthcare products Regulatory Agency (MHRA) and any professional society involved in treating a condition for which that drug was indicated. For concerns regarding policy implementation, GOV.UK was searched. For concerns regarding TB clinical guidelines, we searched NICE, the Royal College of Nursing (RCN), and GOV.UK. We searched the medicine guidelines for 'tuberculosis' and 'TB', and located the section on contact tracing in TB clinical guidelines. Any relevant information was summarised, noting the date of publication or most recent update of these guidelines.

Software and data sharing

The Open Science Framework (OSF) was used to register the protocol and share study materials. (27, 33) Google Sheets was used for data extraction and statistical analysis. N-Vivo was used for qualitative analysis of the coroners' concerns and responses to PFDs. (34) For visualisation we used Data Wrapper. (35)

Results

There were five PFDs involving TB that were reported by coroners in England and Wales published between July 2013 and May 2024. These deaths occurred between 2012 and 2022 (Table 1). A live reporting dashboard was developed to continue surveillance of PFDs involving TB. (36) Two PFDs were included in the tool but not included in this study as the TB was listed as a secondary cause of death (i.e., II), which resulted from either a road traffic accident or surgical complication that was not relevant to the active TB prior to death.

Table 1
Summary of deaths involving tuberculosis reported by coroners in Prevention of Future Deaths reports (PFDs) in England and Wales between July 2013 and May 2024.

Preventable Death (hyperlink ref)	Demographics		Dates				Responses to PFDs		
	Age	Sex	Death	Inquest	Report	Circumstances of death	Addressees	Response Date	Status
A(37)	28	M	04/03/2022	30/05/2022-16/05/2023	18/05/2023	The deceased had had a persistent cough for several months and had a chest X-ray performed. The chest X-ray showed a progression in lung consolidation highly suggestive of tuberculosis, but before the X-ray was sent for analysis the deceased began coughing and vomiting blood at home and was unable to be resuscitated by the paramedics.	1. Medica Reporting Limited	1. Received, no date	Completed
B(38)	30	F	27/08/2021	21/07/2022-26/05/2023	21/12/2023	The deceased had been working on a ward with a patient with tuberculosis as a nurse with the Royal air Force (RAF). Neither she nor the RAF were told of the patient's tuberculosis, and when she subsequently became ill with respiratory symptoms, tuberculosis was missed as a diagnosis until the day before she died.	1. NHS England 2. NICE 3. UKSHA	1. 11/03/2024 2. 04/03/2024 3. 01/03/2024	Completed
C(39)	62	M	22/02/2020	04/03/2020-15/09/2020	18/09/2020	The deceased had a history of HIV and TB. He worked as a support worker in a hospital that was not aware of his underlying health conditions, and subsequently developed multi-drug resistant bacterial infections to which he ultimately succumbed.	1. Leeds Teaching Hospitals NHS Trust 2. Reed Nursing Trust	1. 19/11/2020 2. 4/12/2020	Completed
D(29)	25	F	11/05/2013	12/06/2013-17/12/2013	12/02/2014	The deceased had latent TB and many of her family members had open or latent TB. Her progression to active tuberculosis was missed as the out-of-hours GP did not have access to her GP records, and her Rubinstein-Taybi syndrome hindered communication.	1. Care UK	1. 20/03/2014	Completed
E(40)	21	M	12/12/2012	21/12/2012-10/01/2014	14/01/2014	The deceased had been diagnosed with Crohn's disease at 16 and had been	1. Standard Safety Quality Committee	1. NR 2. NR	Overdue

Legend: Summary of the five deaths involving tuberculosis reported by coroners in Prevention of Future Deaths reports (PFDs) in England and Wales between July 2013 and May 2024, ordered by date of death (descending); BNF: British National Formulary; MHRA: Medicines and Healthcare products Regulatory Agency; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RAF: Royal Air Force; UK HSA: United Kingdom Health Security Agency; NR: No reply

Preventable Death (hyperlink ref)	Demographics		Dates				Responses to PFDs		
	Age	Sex	Death	Inquest	Report	Circumstances of death	Addressees	Response Date	Status
						prescribed infliximab, a TNF-alpha inhibitor, which increases the risk of TB disease. He was screened for latent tuberculosis before beginning treatment. When he developed respiratory symptoms, TB was not explored as a possibility until after he developed disseminated TB and TB meningitis, and the diagnosis was not made until after he was pronounced brain dead.	2. British Society of Gastroenterology 3. BNF 4. Vigilance and Risk Management of Medicines, MHRA 5. The Phoenix Partnership 6. Lincolnshire Community Health Services 7. Lincolnshire Hospitals NHS Trust	3. NR 4. NR 5. NR 6. NR 7. NR	

Legend: Summary of the five deaths involving tuberculosis reported by coroners in Prevention of Future Deaths reports (PFDs) in England and Wales between July 2013 and May 2024, ordered by date of death (descending); BNF: British National Formulary; MHRA: Medicines and Healthcare products Regulatory Agency; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RAF: Royal Air Force; UK HSA: United Kingdom Health Security Agency; NR: No reply

Demographics

Two-thirds (n = 3) of the deceased were males. The median age at death was 28 years (IQR: 25–30 years), the youngest being 21 years and the oldest 65 years. A total of 234 years of life were lost, with a median of 52 years for every death (IQR: 50–55). The monetary value of this loss was £16.3 million, with a median of £3.6 million per death (IQR: £3.5-£3.8 million).

Causes of Death

There were a total of 14 medical causes of death reported in the five PFDs (see table in Addendum 3). The most common was pulmonary tuberculosis (n = 3); the other cases of TB were disseminated tuberculosis (n = 1) and one unspecified. One case of TB was multidrug-resistant tuberculosis. In three cases, additional infections were listed as causes, including bacterial infection of an unspecified site, human immunodeficiency virus (HIV) and pneumonia.

Medical and social histories

In two PFDs (40%), there was a reported history of TB (Preventable Death C, Preventable Death D), with one of these deceased also reporting a history of HIV (Preventable Death C). One of the deceased (Preventable Death B) was believed to have contracted TB after being exposed to a smear-positive patient whilst working as a Royal Air Force (RAF) nurse. For the other two Preventable Death, it was either not reported how the deceased had contracted TB (Preventable Death A), or this could not be determined (Preventable Death E). One case reported a history of Crohn's disease, with the treatment predisposing to TB (Preventable Death E), and another reported Rubinstein Taybi syndrome (Preventable Death D). No medical or social histories were reported by the coroner in one case (Preventable Death A).

Geographical Variation

Two PFDs involving TB were written in the East Midlands and London (Fig. 1). Most (80%, n = 4) deaths occurred in hospital, with one death occurring in the deceased's home.

Key findings from thematic analysis

Coroners raised 21 individual concerns across the five PFDs, which were categorised into four major themes. One further theme, regarding missed or late diagnosis, was identified in the circumstances of death section of the PFD

Theme 1: TB as occupational risk to health workers

One case highlighted that health workers were not always informed of their risk of TB due to contact with infectious patients (for example only the 'named nurse' would know). One case also demonstrated that agency staff may also have underlying health conditions that would make them more vulnerable to contracting TB, which was not disclosed during their shifts. Training of agency staff in personal protective equipment (PPE) was also raised as an issue.

Theme 2: Lack of awareness and training regarding TB risk factors among UK health professionals

Coroners were concerned about insufficient education of UK health professionals regarding TB signs and symptoms. One coroner also felt that a potential new diagnosis requires a greater sense of urgency in initiating treatment. Another concern was about the awareness of health professionals of the increased risk of TB with Infliximab treatment, and the subsequent education of patients about this risk; Infliximab is a biological treatment used to treat autoimmune diseases. There was also a concern that contacts of smear-positive TB patients will require more extensive contact tracing due to increased infectivity.

Theme 3: Insufficient guidelines and protocols to screen for and communicate about TB

The coroners identified guidelines on contact tracing and TB screening as lacking. The concerns regarded how contact tracing was adapted for health care professionals caring for people who pose a high risk of infection, especially as health workers are not identified as a group at increased risk of TB, and potentially inadequate protocols for TB screening when placing someone on a drug that increases their TB risk.

Theme 4: TB communication system failures

There were concerns regarding gaps in communication systems which harmed those at risk of TB. This included the lack of an alert on a computer system to highlight new, significant changes suggestive of TB to the referring clinician, and the inability of out-of-hours general practitioners (GPs) to access GP records and view important TB information, both of which delayed diagnosis of TB in patients. The challenge of communicating TB exposure and risk to agency health workers was acknowledged by two coroners.

Theme 5: Missed or late diagnosis of TB

Four of the deceased (80%) experienced missed or late diagnosis. In Preventable Death A, the deceased had received a chest X-ray which revealed significant and unexpected changes suggestive of TB, but he died at home before a diagnosis was made. In Preventable Death B, the deceased was diagnosed with TB and began treatment only one day before her death, after several missed opportunities for diagnosis over several primary care and hospital visits. In Preventable Death D, the deceased's diagnosis of latent TB was not accessible to an out-of-hours general practitioner (GP), and so her progression to active TB was missed. In Preventable Death E, the deceased was diagnosed with TB after he was pronounced brain dead.

Responses to PFDs

The five reports were sent to 14 addressees, who were categorised by type of organisation (Table 3). Most (80%, n = 4) of the PFDs were complete, with all responses published, and one was overdue, with no responses from seven organisations published at the time of writing (October 2025). Government bodies and healthcare providers were the organisations sent the most PFDs (n = 5).

Table 3
Organisations sent the five Prevention of Future Death reports involving tuberculosis between July 2013 and May 2024.

Addressee	Number of PFDs	Number of responses	Response rate (%)
Government arm's length bodies	**5**	**3**	**60**
BNF	1	0	0
MHRA	1	0	0
NHS England	1	1	100
NICE	1	1	100
UK HSA	1	1	100
Professional membership organisations	**2**	**0**	**0**
Intensive Care Society	1	0	0
British Society of Gastroenterology	1	0	0
Healthcare providers	**5**	**3**	**60**
NHS Trusts (Leeds Teaching Hospitalst; Lincolnshire Hospitals; Lincolnshire Community Health Services)	3	1	33
Private healthcare providers (Reed Nursing Trust; Care UK)	2	2	100
Technology companies	**2**	**1**	**50**
Medica reporting Limited	1	1	100
The Phoenix Partnership (TPP)	1	0	0

Legend: Recipients of Prevention of Future Death reports (PFDs) describing deaths involving tuberculosis in England and Wales between July 2013 and 19 May 2024 and their response rates; BNF: British National Formulary; MHRA: Medicines and Healthcare products Regulatory Agency; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; UK HSA: United Kingdom Health Security Agency

There was one response from an organisation, Employment Agency Standards, who was not a listed addressee, but who was contacted by another recipient of a PFD, Reed Specialist Recruiting. Of these eight replies, only two (25%) contained descriptions of tangible changes in response to the PFD.

Actions reported in responses to PFDs

Of these eight replies, only two (25%) contained descriptions of tangible changes in response to the PFD. The reply to Preventable Death A from Medica Reporting Limited (Other), a provider of radiology and pathology diagnostic services, said that the organisation "*have edited the Medica Alerts policy to include a potential new diagnosis of TB as a reason to raise an urgent notification to referrers*." (37) They also stated that they had "*highlighted the findings of the inquest to all reporters*." This addressed one of the concerns in the theme 'Insufficient guidelines, protocols and systems to screen for and communicate about TB'.

The reply to Preventable Death C from Leeds Hospital Trust (Healthcare) described the addition of 'fit tested' (in reference to PPE) as a skill on a computer system that is now viewable by members of Leeds Hospital Trust. (39) They also stated that some wards are adding 'bank notes' to shifts, stipulating that agency or bank staff must have been fit tested before working a shift, and they have advised all bank and agency staff who are assessed as high risk to check the status of a ward and bring copies of their risk assessment to shifts. This addressed one of the concerns in the theme 'TB as occupational risk to health workers'.

Reasons for inaction

In two responses, the risk of TB in healthcare workers in the UK was not acknowledged as a substantive problem, and further action was not advised. Several organisations also advised that they were not responsible or capable of further action to prevent similar deaths. These organisations fell into all three categories which provided responses: government arm's length bodies, healthcare providers and technology companies.

Guideline and policy review

From the coroners' concerns, we identified four key focus areas which we believed could be addressed by adaptation of implementation of new and/or improved guidelines and policies. These four focus areas were: Insufficient pre-infliximab screening protocols; Insufficient awareness of the risks of developing active TB for patients on infliximab; Lack of access to GP records for out-of-hours GPs can hinder clinical diagnoses; Healthcare workers as heightened risk group for occupational TB exposure, and communication post TB exposure.

Seventeen guidelines and policy documents were identified to explore these four focus areas (Table 5). For concerns regarding drugs, we searched for guidelines from NICE, BNF, MHRA, and any professional society involved in treating a condition for which that drug was indicated. For concerns regarding policy implementation, GOV.UK was searched. For concerns regarding TB clinical guidelines, we searched NICE, RCN, and GOV.UK. We searched the medicine guidelines for 'tuberculosis' and 'TB', and located the section on contact tracing in TB clinical guidelines.

Table 5
Guideline review for four key findings

Key finding	Organisation which published guidelines	Summary of these guidelines
Pre infliximab screening protocol is insufficient	NICE, 2015 (41)	"Before treatment [with infliximab] is started, people must be screened for active and inactive tuberculosis." The way in which they should be screened is not specified
	NICE, 2016 (42)	Screening for active pulmonary tuberculosis should begin with a chest X-ray. Screening for latent tuberculosis usually involves using a Mantoux test, although sometimes an interferon-gamma release assay (IGRA) is advised.
	BNF (43)	"Manufacturer advises to evaluate patients for active and latent tuberculosis before treatment." The screening suggested is a tuberculin skin test (TST).
	MHRA, 2024 (44)	Before starting treatment patients must be evaluated for active and latent tuberculosis. This evaluation should include a medical history. Various screening tests (e.g. TST, chest X-ray, and/or IGRA) are advised. The risk of false negative tuberculin skin test results is mentioned.
	British Association of Dermatologists, 2017 (45)	Latent tuberculosis should be screened for with an IGRA. A chest x-ray should be used to rule out any lung abnormalities at baseline.
	British Society of Gastroenterology, 2019 (46)	Screening for active or latent tuberculosis is required before starting anti-TNF therapy. A chest x-ray and an IGRA (as a TST is likely to have false-negative results due to immunosuppressive therapy) should be used.
	British Society of Rheumatology, 2018 under review (47)	Pre-screening for tuberculosis is required. This should include taking a history, a chest X-ray, and either a TST or IGRA or both as appropriate, but it is noted that IGRAs have a lower-false positive and false-negative rate.
There is insufficient awareness for healthcare professionals about the risks of tuberculosis inherent to infliximab	NICE, 2015 (41)	"Patients should be advised to seek medical attention if symptoms suggestive of tuberculosis develop (e.g. persistent cough, weight loss and fever)."
	BNF (43)	"Patients should be advised to seek medical attention if symptoms suggestive of tuberculosis develop (e.g. persistent cough, weight loss and fever)."
	MHRA, 2024 (44)	"Patients must be monitored closely for tuberculosis during and after treatment with infliximab, and those with signs/symptoms suggestive of TB should seek medical advice. It is noted that tuberculosis while on this medicine is often extrapulmonary.
	British Association of Dermatologists, 2017(45)	Any symptoms or signs suggestive of TB should prompt further clinical assessment and investigation. It is noted that active TB on anti-TNF therapy is often disseminated and extrapulmonary.
	British Society of Gastroenterology, 2019 (46)	"Primary infection with TB on anti-TNF agents is therefore a significant risk, particularly in higher incidence areas, irrespective of baseline screening."
	British Society of Rheumatology, 2018 under revision (47)	Patients should be closely monitored for TB while on treatment, and any patient who develops symptoms consistent with TB should be investigated for active TB.
The lack of access to GP records for out-of-hours GPs	UK Government: NHS England (48)	Since this PFD was published, Summary Care Records have been more widely implemented across the country. Out-of-hours GPs are one of the care settings permitted to view summary care records.
The identification of healthcare workers as a group at increased risk of tuberculosis exposure and the effect this has on warning healthcare workers of tuberculosis contact	NICE, 2016 (42)	The guidelines for warning contacts of tuberculosis cases do not advise on contact tracing of healthcare workers, as they are not mentioned as a specific group at risk in this section.
	Royal College of Nursing, 2023 (49)	The guidelines do make note of an increased risk of tuberculosis cases which are smear positive, but they do not identify healthcare workers as a group at increased risk of tuberculosis infection.
	UK Government: UK Health Security Agency (50)	The tuberculosis action plan for England, 2021–2026 identifies healthcare workers as a group at higher risk. There are no specific details given on contact tracing for healthcare workers.

Legend: A review of guidelines relating to concerns raised by coroners in Prevention of Future Death reports describing deaths involving tuberculosis in England and Wales between July 2013 and 19 May 2024; BNF: British National Formulary; MHRA: Medicines and Healthcare products Regulatory Agency; NICE: National Institute for Health and Care Excellence

Focus area 1: Insufficient pre-infliximab screening protocols

Infliximab is used as an immunosuppressive therapy for various autoimmune conditions, including Crohn's disease. The screening protocol for TB varies for people starting on infliximab, and sometimes the screening method is not specified. (41) In Preventable Death E, the deceased did not receive a screening test for latent TB prior to starting infliximab, although this was advised at the time. (40, 51) According to existing guidelines, screening may involve a chest X-

ray, tuberculin skin test (TST), and/or an interferon gamma release assay (IGRA). (43–48) Disagreement between guidelines is in regards to whether to use an IGRA or a TST. Three guidelines note the high false-negative rate of TST, especially in those who have had the Bacillus Calmette–Guérin (BCG) vaccine. (44, 46, 47) However, the NICE guideline (2024), in most instances, recommends the less accurate TST over IGRA when screening for latent TB. (42)

In summary, several society guidelines provide sufficient and detailed guidance on screening for latent TB for patients on infliximab, while the NICE recommendation could be updated to recommend IGRA as latent TB test..

Focus area 2: Insufficient awareness of the risks of developing active TB for patients on infliximab

The 2005 British Thoracic Society guidelines states that "In patients receiving anti-TNF-α [e.g. infliximab] treatment there is an increased risk of clinical tuberculosis (TB) developing." (52) All six guidelines assessed contained warnings for healthcare professionals about the risks of active TB for someone on infliximab. (41, 43, 44, 46, 47, 53) Five of the guidelines recommend advising patients to seek help if symptoms suggestive of TB develop, and recommend initiating clinical investigation for symptoms. (41, 43–45, 47) Two guidelines also note that TB, which develops in patients treated with infliximab, may present as disseminated. (44, 45)

In summary, we found sufficient communication about the risks of TB in the guidelines.

Focus area 3: Lack of access to GP records for out-of-hours GPs can hinder clinical diagnoses

In Preventable Death D (29), an out-of-hours GP did not realise that the deceased had latent TB infection due to the inability to access their GP record. A broader policy response to this problem, Summary Care records, is a system which allows care settings, including out-of-hours GPs, to access a summary of information about vulnerable patients. It has been widely implemented since the publication of the PFD which recommended them.(48)

In summary, this coroner's concerns have been adequately addressed through this implementation strategy.

Focus area 4: Healthcare workers as heightened risk group for occupational TB exposure, and communication post TB exposure

Whilst the green book and tuberculosis plan for England identify healthcare workers as a group at increased risk of TB infection, neither NICE nor RCN identify them as a group at increased risk of TB in the sections on contact tracing. (31, 42, 49, 50) Smear-positive TB is noted in both the NICE and RCN guidelines to increase risk of transmission, but there are no clear guidelines as to the effect this has on contact tracing of exposed health workers. TB is a prescribed illness according to the Industrial Injuries Disablement Benefits scheme, which entitles health workers to compensation should they develop TB infection occupationally. (54) In response to the coroner's concerns, NHS England cited a paper by Public Health England that did not show an increased risk of TB disease for health workers when stratifying for country of birth, suggesting that the significant burden of TB in health workers in the UK was due to reactivation of latent TB. (55)

In summary, the guidelines we reviewed did not consistently identify health workers as an at-risk population, limiting communication and awareness about occupational risk and exposure.

Discussion

This national observational study is the first to explore concerns raised by coroners following deaths from TB in England and Wales and created a live surveillance tool to monitor ongoing reports. (36) The TB deaths reported by coroners occurred in younger people, with a median age of 28 years at death. Most (80%) of the deaths included in this study involved a missed or late diagnosis of TB. The themes identified in the coroners' concerns were occupational health risks for agency health workers being underappreciated; lack of awareness of TB symptoms and risks; and insufficient guidelines, protocols and systems to screen for and communicate about TB. In our guideline and policy review, we identified a gap in identifying health workers as a group at increased risk of TB, particularly for contact tracing. We also found a disagreement between the recommended latent TB screening in the guidelines from three societies (the British Association of Dermatologists, the British Society of Gastroenterology, and the British Society of Rheumatology) and the 2024 NICE guidelines.

TB in health workers, particularly agency staff, was seen as an underappreciated risk by coroners. However, we found disagreement in the guidelines on whether health workers should be viewed as a priority group and in the responses to the coroners' concerns. Two responses to the PFDs referenced a study by Public Health England (PHE) from 2016, which found no increased risk of TB in healthcare workers in the UK after stratifying for country of birth. (55) The PHE paper suggests that, at the time, TB in health workers in the UK was predominantly caused by the reactivation of latent TB, after exposure did not happen in the UK. Importantly, this paper views healthcare workers as having a substantive TB burden. (55) The two PFDs of health workers who died due to TB had details that suggested they were exposed during the course of their work in the UK. Since the TB burden in the UK has increased since 2013, it would be important to update the analysis by PHE to investigate whether there have been broader trends in where transmission occurs. Future work should also study the risks associated with healthcare workers who have more precarious employment such as agency staff or carers, and who may have additional social risk factors. Greater awareness about the existing legal classification of TB as an occupational disease in health workers, termed a 'prescribed disease', is important. (54)

Strengths and limitations of this study

This study builds on prior research that uses reproducible methods to analyse PFDs. (24–26, 56, 57) PFDs were screened in duplicate and verified by a medical doctor (HMVDW). Our study also included a thematic analysis of the content of responses to PFDs and a policy review to understand what had been

addressed and where there may be gaps for action to prevent future deaths.

It must be acknowledged that this study can not represent all deaths involving TB in England and Wales as the decision to write a PFD is made by coroners, who are independent judicial officers, and PFDs represent only around 0.15% of all inquests in England and Wales. Most (93%) coroner areas did not report deaths involving TB in PFDs. There is established inter-area and inter-coroner variation in writing PFDs, and coroners' concerns are subjective. (58) In this study information was missing in 80% of the PFDs: three medical causes of death, one age, and two coroner's conclusion of the inquest. However, we were able to fill in the missing information from ROIs. As of January 2026, there is no clear guidance for how to write PFDs, which has implications for research that compares PFDs and their responses..

Implications for practice, policy and future research

This study identified multiple concerns that should be used to guide/improve practice, including educating staff about TB symptoms, the increased risks of developing active TB when taking infliximab, and the increased risk of infectivity of smear-positive TB. Whilst all of the guidelines that were reviewed about infliximab mentioned the increased risks of TB, further research into the awareness of prescribers could inform whether further education is required.

Our review of ten UK guidelines found that healthcare workers are not identified as an at risk group of TB in NICE or RCN guidelines, and are not mentioned in the contact tracing section, which should be reviewed. While the choice of initial TB diagnostic test was not identified by coroners as an area of concern in the deaths we reviewed, there is an urgent need to revisit NICE guidelines on TB diagnosis, to reflect updated WHO guidance for molecular diagnostic tests, which give information about drug-resistance, and advise against smear microscopy as an initial diagnostic test. (59) While there is a renewed focus on preventing TB in the United Kingdom, with the current TB action plan, and the 2026–2030 government action plan currently in development, these areas are not current focus points. (50, 60)

Conclusions

We found that by thematically analysing concerns raised by coroners, responses to PFDs, and existing policies, we identified lessons from PFDs that can inform practice and policy for TB prevention. To support this, we created a live surveillance tool to monitor the publication of new reports. Overall, we found that PFDs identified health workers, particularly agency staff, as an at-risk group for TB, but UK guidelines do not consistently identify them as such. Advice on contact tracing for health workers after exposure to a TB patient needs further clarification. Further work is required to raise awareness among health workers about treatments that increase the risk of TB, such as infliximab. PFDs provide valuable insights for preventing future deaths involving TB, and can help catalyse action in low TB burden, high-income countries to achieve the goals set in the WHO End TB plan.

Abbreviations

TB
Tuberculosis
UK
United Kingdom
PFDs
Prevention of future death reports
WHO
World Health Organisation
OSF
Open Science Framework
ICD-11
International Statistical Classification of Diseases and Related Health Problems 11th Revision
ROI
record of inquest
YLL
years of life lost
NICE
National Institute for Health and Care Excellence
BNF
British National Formulary
MHRA
Medicines and Healthcare products Regulatory Agency
RCN
Royal College of Nursing
NHS
National Health Service
TNF
tumour necrosis factor
HIV

human immunodeficiency virus
general practitioner
PPE
personal protective equipment
TST
tuberculin skin test
IGRA
interferon gamma release assay
BCG
Bacillus Calmette–Guérin

Declarations

Ethics approval and consent to participate

This study uses publicly available information, and the data is collected from deceased individuals where the UK's General Data Protection Regulation (GDPR) and Data Protection Act 2018 do not apply. The Preventable Deaths Tracker has also obtained ethical clearance from the King's College Research Ethics Committee.

Consent for publication

Not applicable, as this study used publicly available data.

Competing Interests

AM was a medical student at the University of Oxford (2022-2026). HvdW is employed by Oxford University as a postdoctoral researcher and a tutor in global health. GCR is employed by King's College London, through an AI+ Academic Senior Fellowship (2026-2031) and has a contract with the University of Oxford as a Senior Associate Tutor. GCR has had travel expenses reimbursed for attending and presenting at conferences and received fees for speaking at events, teaching, and delivering training. GCR is the director of a limited company and a community interest company (CIC) that funds the Preventable Deaths Tracker's infrastructure, and receives subscriptions to a personal Substack newsletter. AM and HvdW declare no competing interests.

Funding

No funding was obtained for this study.

Author Contribution

AM updated the study protocol, carried out screening of PFDs, extracted remaining data, contacted coroners' offices, conducted all analyses, produced all figures and tables, designed and performed the guideline and policy review, and wrote the first draft of the manuscript. GCR conceptualized, designed, and initiated the study, conducted keyword searches in the Preventable Deaths Tracker, cross-checked data extracted, provided supervisory support and guidance, and edited the first draft of the manuscript. HW screened the PFDs, provided supervisory support, and edited drafts of the manuscript. AM is the guarantor. The corresponding author (AM) attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Acknowledgement

AM thanks Professor Kerry Walker for her valuable advice regarding the writing of the manuscript.

Data Availability

Study materials are openly available via an online repository (https://osf.io/m3kt5/overview), including the study protocol (https://osf.io/2g4px/overview). Individual Prevention of Future Deaths reports are available on the Courts and Tribunals Judiciary website (https://www.judiciary.uk/?s=&pfd_report_type=&post_type=pfd&order=relevance).

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Figures

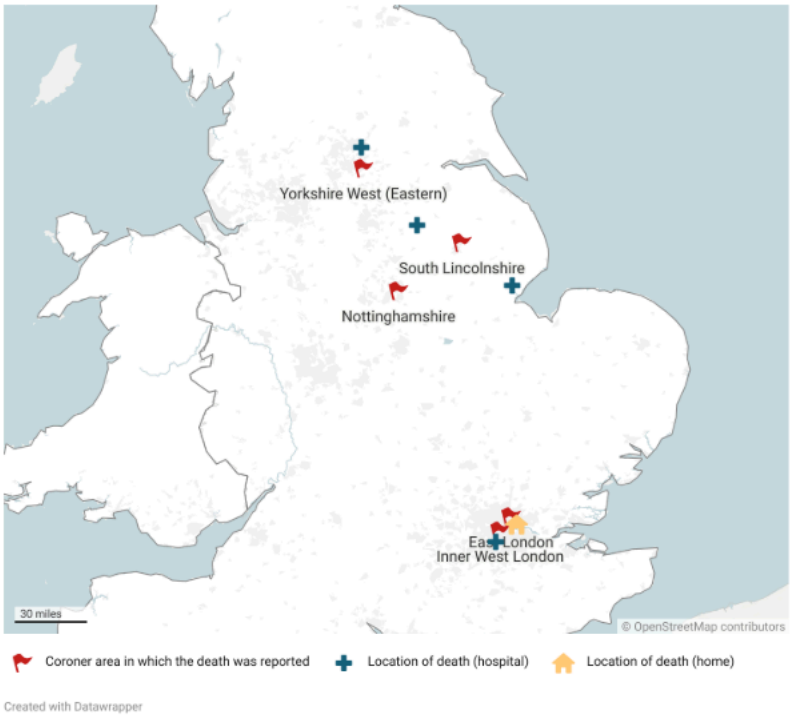


Figure 1

Map of the location of Prevention of Future Deaths reports involving tuberculosis issued by coroners in England and Wales between July 2013 and 19 May 2024

Supplementary Files

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- Addendum1.docx