

UK TB VOICES

The Stories Behind the Statistics



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Foreword



Tuberculosis remains a significant challenge globally and is an important public health issue in the UK. The patient stories in this report give a compelling case for the long-term and sustained action needed to improve prevention, detection and diagnosis of cases and ensure treatment completion.

The prevention of further emergence and spread of drug-resistant Tuberculosis is critical. My concerns about the rising levels of antimicrobial resistance are already well-known and the increasing numbers of patients with Tuberculosis across the world with multidrug resistance is of concern. To date, drug resistant TB is relatively uncommon in the UK, however, there is no room for complacency and we need to remain vigilant.

The patient stories outline the need for action that will deliver best practice on prevention, early detection and treatment is delivered across the country.

A handwritten signature in blue ink that reads "Sally Davies".

Dame Sally Davies

Chief Medical Officer

Why this report and why now?

The story of TB is told in numbers. The deadliest pandemic in human history, TB continues to kill 1.3 million people a year. More than 2 billion people carry the TB bacteria through latent TB infection. Individual treatment costs run into the hundreds of thousands of pounds, drug regimens are measured in months and years, the number of pills in the thousands. The funding shortfalls run into the billions.

At the heart of each of those statistics is an individual: a patient, a husband, a wife, a daughter, a son, someone who has had their life irrevocably changed by TB. Under the flood of numbers and figures, all too often, their tales of treatment and suffering are drowned out.

Yet those are the voices that must not be lost. They are the people who know this disease best, from living with it, from fighting with it, and from working with it. Their stories underpin the global fight against TB, highlighting that the true story of disease is not told in the millions or billions, but in the daily struggle between one person and an implacable, remorseless disease.

This report is designed to cast a light on those daily battles and to highlight that TB is not a disease of a bygone era but a real and present public health threat right here in the UK. Most importantly, this report is designed to support the voices of those who often find themselves forgotten among the numbers.

Following on from the All Party Parliamentary Group on Global Tuberculosis’ report: “Drug-Resistant Tuberculosis: Old Disease – New Threat” in April 2013 and drawing on the first-hand accounts included in this report, we propose the following policy recommendations.

→ IMPLEMENT THE NATIONAL STRATEGY FOR TB

Integrated care: The National Strategy currently being developed by Public Health England and supported by NHS England and the Department of Health must integrate clinical treatment, social care and public health in the prevention, treatment and control of the disease. (Department of Health, PHE)

Inter Departmental Ministerial Group on TB: TB is a disease with a significant local impact and huge international reach. Reducing TB incidence in the UK requires coordinated efforts across government departments, particularly the Department of Health, Home Office, UK Border Agency and the Department for International Development. An Inter Departmental Ministerial Group on TB should be formed, driving best practice and policy coherence across the UK’s TB interventions. The National Strategy should provide the centre-piece of this process.

Latent TB infection: “Reactivation” of latent TB among the non-UK born makes up the majority of UK cases of the disease. Implementation of NICE guidelines on a coordinated programme for latent TB screening and treatment across the UK will lead to a reduction in cases. (Home Office, Department of Health)

Find & Treat: Services like Find & Treat take a non-conventional approach to diagnosing and treating TB that has been proven to be cost-effective. Find & Treat should receive adequate and continued funding and expand to other urban centres to treat TB, and other health conditions prevalent in the homeless population should be supported. (NHS)

Support Community Outreach: Initiatives aimed directly at engaging with specific high-risk communities, raising awareness and encouraging engagement with local health services have been proven to be highly successful and cost-efficient, as well as helping to change the health-seeking behaviour of those communities. Such projects should be expanded and improved wherever possible. (PHE, NHS)

Listen to the Patient Voice: The meaningful engagement of people affected by TB, at both a local and national level, is vital to develop appropriate services that are accessible to all and provide the support needed to enable TB patients to successfully complete their full course of treatment. Local health providers should seek to consult former patients wherever possible. (PHE, NHS)

Engage with Voluntary Sector Organisations: The voluntary sector has a vital role to play increasing awareness of the disease, supporting engagement with the health service in affected communities and providing treatment and social support for people affected by TB. The sector can improve health outcomes at various stages of the patient pathway and commissioners should engage these organisations as service providers. (PHE, NHS)

Promote NHS awareness: Unless primary care providers think that TB is a possibility, they won’t look for it, and this delays diagnosis. Efforts must also be made to improve understanding and clinical recognition of TB across the healthcare profession. (PHE, NHS)

→ STRENGTHEN THE INTERNATIONAL RESPONSE

The only certain way to eliminate TB as a public health threat in the UK is to drastically reduce the number of cases worldwide. This requires financing, but also global leadership. The UK Government has demonstrated that it can galvanise world commitments to tackle enormous challenges in the developing world. The 8.6 million people around the world who contract TB every year need the UK Government to take the lead in addressing the TB epidemic.

TB Position Paper: DFID should develop a specific TB Position Paper examining best practice worldwide for reducing cases of TB and identifying best value for money interventions against the disease. The findings of this position paper should be suitably supported by appropriate financial commitments.

Support Existing Interventions: The Global Fund to Fight HIV/AIDS, TB and Malaria provides 90% of international financing in the fight against TB. For the continued success of existing interventions, it is vital that the Fund is fully funded. The UK government should continue its strong historic backing of the Global Fund. Projects such as TB REACH which actively aim to find people with undiagnosed TB should be supported and augmented to reduce the global epidemic. The UK government should become a donor to TB REACH helping insure its continued scale up and success.

Global Drug Provision: Most TB drugs are no longer covered by patent but remain expensive because of a shortage of producers. This shortage of producers has contributed to stock-outs of key drugs like isoniazid in the UK, US, France and Germany, and a wider range of drugs in a number of developing countries. The UK Government should continue to support key organisations like UNITAID which seeks to shape the market and bring new producers into the market, strengthening the global supply chain and protecting drug supplies in all countries.

→ IMPROVE DRUG, DIAGNOSTIC AND VACCINE DEVELOPMENT

The current drugs against TB are over forty five years old, the vaccine is ineffectual, and one third of all TB patients worldwide are never diagnosed. In the UK the median delay between diagnosis and treatment is 70 days. The UK government must invest in finding appropriate treatment regimens, better diagnostics, and the development of a new vaccine to ensure that healthcare professionals have the necessary tools to fight and beat the disease.

Shorter, easier treatment regimens: The length, complexity and physical effects of the current TB treatment regimens present a major challenge for all patients. Shorter regimens with fewer side effects are desperately needed. This will drive higher completion rates and reduce the incidence of drug resistant TB.

Better diagnostics: Many of the individuals in this report experienced significant delays before their eventual diagnosis with TB. The development of quicker, cheaper diagnostics is a necessity not just for achieving better treatment outcomes, but for reducing the public health threat posed by undiagnosed individuals with active pulmonary TB.

Vaccines: The current TB vaccine, the BCG, has varying efficacy and offers only negligible protection for adults and against pulmonary TB. It is also unsuitable for HIV positive individuals. A new vaccine is necessary to eliminate TB as a public health threat.

WHAT IS TB?

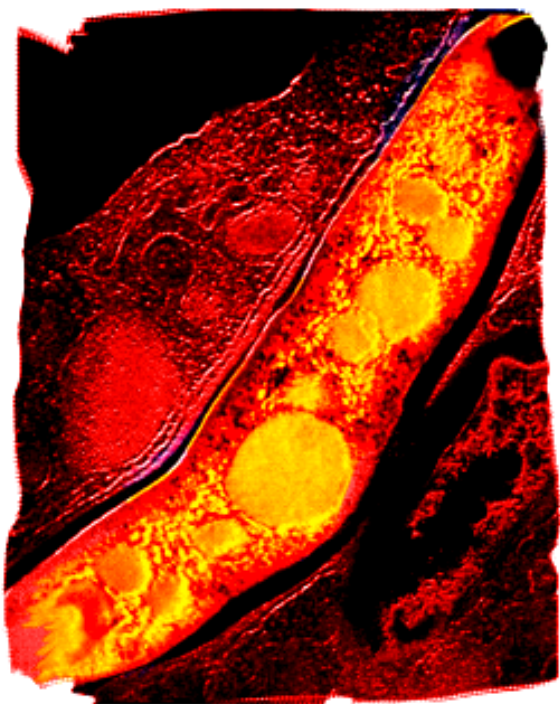
Tuberculosis (TB) is an infectious disease caused by the bacterium mycobacterium tuberculosis. It usually attacks the lungs (pulmonary TB) but can be found in any other part of the body (extra-pulmonary TB).

HOW IS IT TRANSMITTED?

TB is spread by the inhalation of aerosol droplets released when someone with TB of the lungs or throat coughs or sneezes.

The probability of transmission from one person to another depends on a wide range of factors including: the number of infectious droplets exhaled, the quality of ventilation, the duration of exposure, the virulence of the strain of TB, and the level of immunity in the uninfected person.

TB is most frequently transmitted between people who spend a lot of time together, such as family members or people who share accommodation.



HOW MANY PEOPLE ARE AFFECTED?

The World Health Organisation (WHO) estimates that 8.6 million people developed active TB in 2012 and 1.3 million people died from the disease.¹

TB is the leading cause of death for people living with HIV, causing 25 percent of all AIDS-related deaths.² HIV and TB are very closely linked. People living with HIV are between 21 and 34 times more likely to develop active TB than the average person.³

TB most commonly affects people between the ages of 15-44.⁴ It is the third largest killer of women of reproductive age,⁵ and the WHO estimates 10 million children worldwide have been orphaned as a result of a parent dying from TB.⁶

WHAT IS LATENT TB?

When an individual is exposed to TB bacteria, some fall ill immediately but the majority develop what is known as latent TB. For many of us, our immune systems are able to effectively 'wall off' the TB bacteria rendering it temporarily harmless.

Latent TB has no symptoms and is not infectious but remains an underlying health risk. Roughly one-third of the entire world population have latent TB. These people have a 10 percent lifetime chance of developing active TB, which is what most people understand as 'tuberculosis' and can be infectious (if pulmonary) and deadly if left untreated.

For people living with HIV, the risk of developing active TB becomes 10 percent per year rather than per lifetime.⁷ Consequently, many HIV patients are tested for latent TB. Lower immunity as a result of other social risk factors can also increase the likelihood of latent TB becoming active TB.

It is possible to be treated for latent TB. The treatment requires a six month course of a drug called isoniazid, but because of the length of the treatment, and the fact it is by no means certain that latent TB will ever become active TB, few people receive treatment.

DRUG RESISTANT TB

Drug resistance develops because of naturally occurring variations in the genetic makeup of bacteria. When the bacteria are treated with a drug, these variations allow some to survive. As a result, TB treatment regimens incorporate a combination of drugs to ensure that all the TB bacteria are killed.⁸

Lack of treatment completion, sub-standard drugs, incorrect or incomplete prescriptions, and patients being unable to fully absorb the treatment (as a result of vomiting, for example) can help drug-resistant TB (DR-TB) develop.⁹

DR-TB is significantly more difficult and expensive to treat. In the UK, complex DR-TB strains can cost up to £100,000 to treat (compared with £5,000 for a drug sensitive case).¹⁰ DR-TB can be transmitted like any other form of the disease, making the emergence of DR strains a potential disaster for public health systems. **Some experts estimate that more than 2 million people will have active DR-TB by 2015.**¹¹

Some TB strains are resistant to more than one anti-TB drug. Strains have developed that are resistant to two of the most powerful primary drugs used to treat TB, isoniazid and rifampicin. These are called multi-drug resistant TB (MDR-TB). **A small number of cases have even been found that are resistant to virtually all anti-TB drugs and therefore practically impossible to cure.**

SOCIAL RISK FACTORS

Individuals with weakened immune systems are more likely to develop active TB. Health conditions like HIV or diabetes can increase the likelihood of infections and of latent TB developing into active TB.

Social risk factors also play a significant role. These include drug or alcohol abuse, poor housing conditions, imprisonment and homelessness. Smoking, diabetes and poor nutrition have also been linked to TB. Cultural practices like tobacco or Khat chewing also affect infection rates and specially targeted outreach projects have been devised in parts of North London focussing on raising awareness of TB among Khat users.^{12 13}

In 2012, 7.3 percent of TB cases in the UK had at least one social risk factor,¹⁴ but some experts estimate that the rate is far higher. Social risk factors make people more likely to be exposed to TB infection, more likely to develop active TB from latent TB, less likely to complete treatment, and therefore at high risk of developing drug resistance.

The homeless population in particular are at risk of TB; incidence of the disease among the homeless in London is 50 times higher than the national average.¹⁵ Homeless people are also significantly less likely to present to a healthcare professional.¹⁶

The close links between social risk factors and TB reinforce the importance of linking social and clinical care when treating the disease.

¹ http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502_eng.pdf

² <http://www.who.int/mediacentre/factsheets/fs104/en/>

³ http://www.who.int/tb/challenges/hiv/tbhiv_factsheet_2013.pdf

⁴ <http://www.aeras.org/pages/about-tuberculosis>

⁵ <http://www.who.int/mediacentre/factsheets/fs334/en/>

⁶ <http://www.who.int/mediacentre/factsheets/fs104/en/>

⁷ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2953999/>

⁸ <http://www.parliament.uk/briefing-papers/POST-PN-416>

⁹ TB Alert "Multi-drug Resistant Tuberculosis (MDR TB)"

¹⁰ <http://www.appg-tb.org.uk/images/reports/Report%20on%20TB%2011.04.2013%20-MTA.pdf>

¹¹ <http://www.reuters.com/article/2013/08/15/us-tuberculosis-europe-idUSBRE97E0Y120130815>

¹² <http://www.drugs.com/npp/khat.html>

¹³ http://www.haringey.gov.uk/index/social_care_and_health/health/jsna/jsna-adults-and-older-people/jsna-infectious-diseases.htm

¹⁴ http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317139689583

¹⁵ <http://www.parliament.uk/briefing-papers/POST-PN-416>

¹⁶ <http://www.qni.org.uk/docs/Section%20B%20Module%202.pdf>

TB IN THE UK

The incidence of TB in the UK has been steadily increasing since the late 1980s, with a slight drop in notified cases from 8,963 in 2011 to 8,751 in 2012.^{17 18}

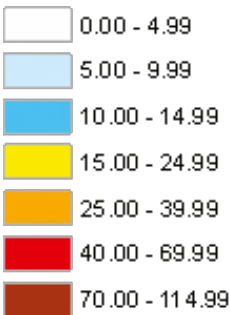
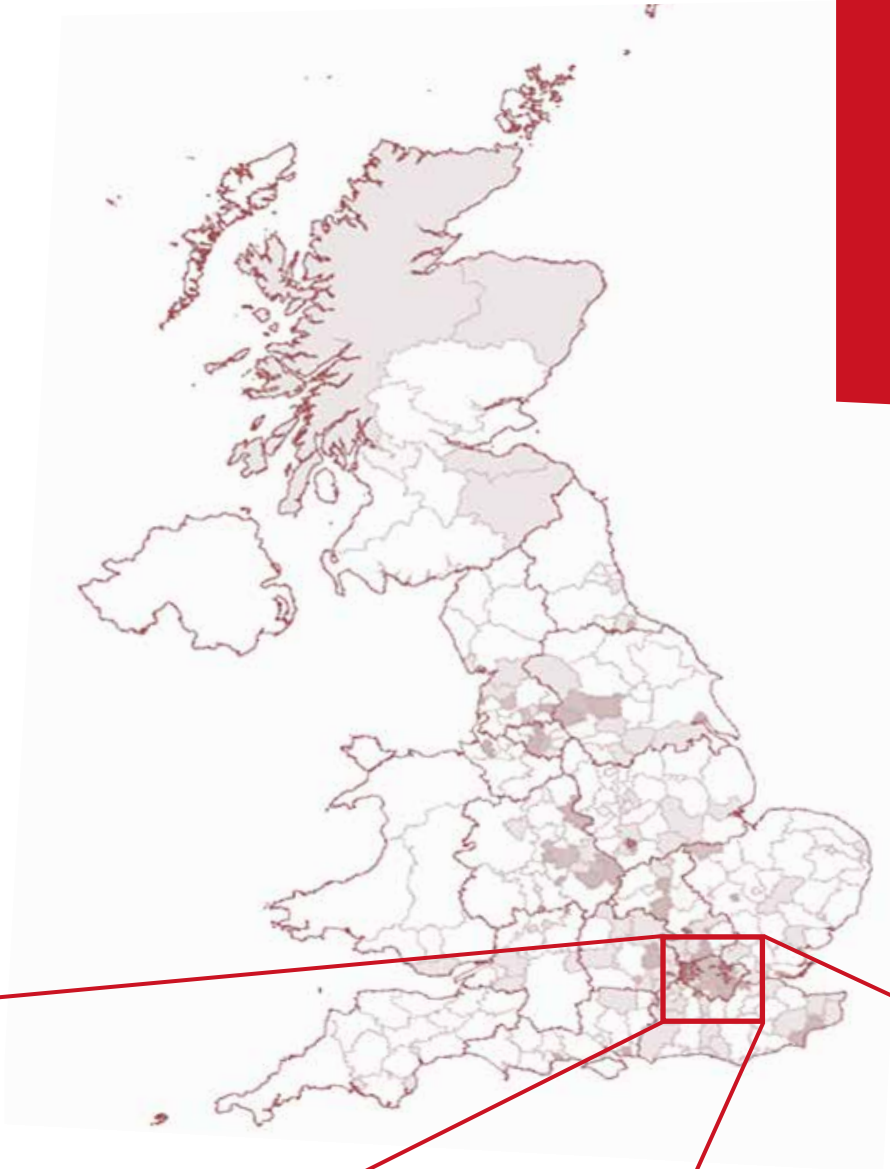
The centre of TB in the UK is London, which has the highest rates of TB of any capital city in Western Europe (42 per 100,000).¹⁹ The disease is particularly prevalent in east and north London, and the east London borough of Newham is the worst affected, with rates of 119 per 100,000, roughly equivalent to rates in Nigeria.^{20 21}

In 2012, over 200 people are known to have died from the disease,²² but as this report highlights, even those who successfully complete treatment often live with the consequences of the disease for the rest of their lives.

The majority of cases in the UK result from latent TB in people born in countries with high rates of TB progressing to active TB. Among the UK's cases, 73 percent were in the non-UK born community, but 70 percent of those developed TB more than two years after arrival in the UK. Most cases are in the UK's urban centres.²³

The average age of TB patients in the UK was 40, with over one quarter of all UK cases occurring in individuals between the ages of 25 and 34.²⁴

Former Public Health Minister Anna Soubry MP has pushed forward the development of a National Strategy for TB. Led by Public Health England, the Strategy will provide a unified framework for TB treatment and prevention in the UK and represents the first time that such a strategy will be implemented. The establishment of the National Strategy and the provision of appropriate funding are critical steps towards reducing rates of TB in the UK and could provide a model for health systems around the world.



MAP OF TB IN LONDON

Reproduced with permission from PHE

Local Authority	Average number of cases 2010 – 2012	Average rate per 100,000 population 2010 – 2012
Newham	346	112.3
Brent	306	98.3
Hounslow	190	74.4
Ealing	234	69.1
Harrow	159	66.1
Leicester	192	57.9
Slough	79	56.3
Redbridge	152	54.1
Tower Hamlets	136	53.5

¹⁷ http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317139689583
¹⁸ http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317134913404
¹⁹ http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317139689583
²⁰ PHE figures
²¹ http://www.who.int/tb/publications/global_report/gtbr12_annex2.pdf
²² http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317139689583
²³ Ibid
²⁴ Ibid

TB ANYWHERE IS TB EVERYWHERE

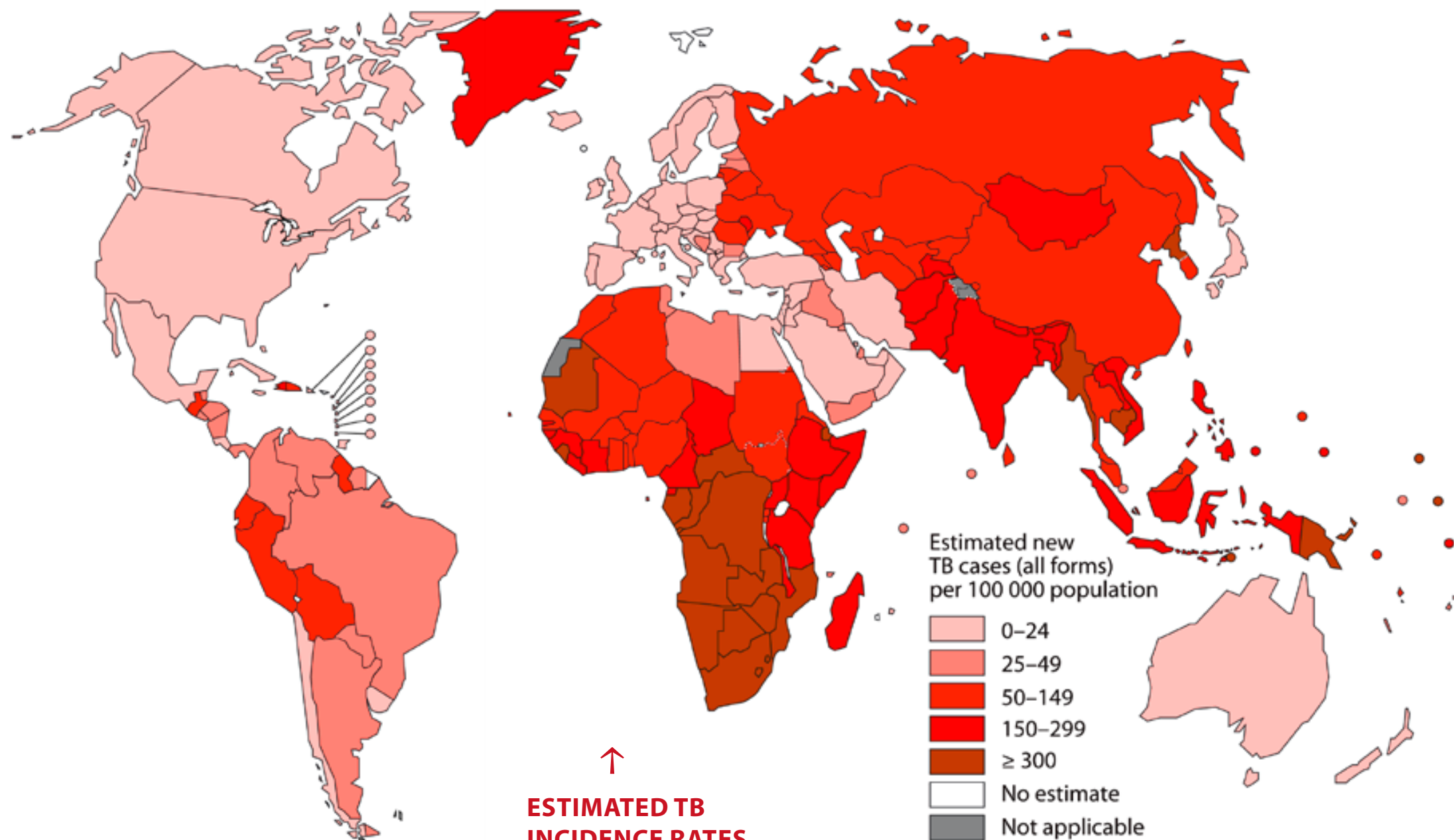
TB is a global disease, it is found in every country in the world and no country has ever completely eliminated it. To fully understand TB in the UK, or any other country, we must explore how the national picture interacts with the global epidemic.

Some of the world's fastest growing economies are also those with the heaviest burdens of TB. Three of the top five fastest growing countries by air freight volume in 2014 are designated by the WHO as high burden countries.²⁵ All five of the BRICS countries (Brazil, Russia, India, China and South Africa), for example, are considered high TB burden countries by the WHO and between them account for around 45 percent of global annual TB cases.²⁶

In a world where migration and international travel are increasingly common, it is inevitable that TB and other airborne infectious diseases will spread widely. There are also a number of factors as to why migrants from high TB burden countries experience higher rates in their destination country than the general population.

One of these is that migrants from high burden countries have a higher rate of latent TB than the non-migrant population, as a consequence a there is likely to be a greater number of individuals who develop active TB. Another is that migrants are more likely to visit a high burden TB country and thus have a greater chance of being exposed to active TB when returning to their country of origin to see friends or family.

Another important factor is the healthcare seeking behaviour of migrant populations. Some new migrants don't immediately register or engage with the health system and therefore may not seek treatment when they start experiencing symptoms. Other factors may have a role to play, including the perception that they will be charged for treatment, find themselves unable to work or face deportation. There may even be a cultural norm within their community not to seek healthcare.²⁷



ESTIMATED TB INCIDENCE RATES, 2011

Reproduced with permission from WHO Global TB Programme

These barriers to seeking healthcare must be overcome. A person with active pulmonary TB who does not get appropriate treatment will spread the disease to between 10-15 people a year.²⁸ This furthers the epidemic and increases the cost of dealing with the disease.

Implementing policies that seek to overcome all these barriers is critical to reducing the number of cases in the UK but represents just one part of the necessary policy response. The only sure way to eliminate TB as a public health threat in the UK is to actively step up attempts to diagnose and treat TB all over the world, particularly in the countries where it is most prevalent.

Current policy: The UK Border Agency requires all prospective new entrants from high burden countries who wish to stay in the UK for more than six months to have an X-Ray screening for active pulmonary TB.

By the start of next year, this will have been extended to 82 countries, every country deemed to have rates of TB greater than 40 per 100,000.

²⁵ All figures <http://www.iata.org/pressroom/pr/pages/2011-02-14-02.aspx>

²⁶ http://www.who.int/tb/publications/global_report/gtbr12_annex2.pdf

²⁷ <http://www.hpa.org.uk/MigrantHealthGuide/AssessingMigrantPatients/CulturalCompetenceAndUnderstanding/>

²⁸ <http://www.who.int/mediacentre/factsheets/fs104/en/>

TB TREATMENTS

Treatment regimens for TB are long, even for standard, drug-sensitive cases. Basic treatment requires a patient to take a cocktail of four antibiotics: Isoniazid, Rifampicin, Ethambutol and Pyrazinamide every day for six to nine months.

All of these drugs are over 45 years old and have potentially severe side effects, some of which will be explored in this report.

The length of the basic treatment regimen, the sheer quantity of pills, and their side effects are major contributing factors to patients not completing treatment, particularly within hard to reach communities. In addition to driving drug resistance, the toxic nature of the drugs can cause life-long health problems such as hearing problems, visual impairment and reduced liver or kidney function.

Treatment for DR-TB is much longer and more arduous than for standard cases of TB. **It can take up to 24 months and generally requires up to 8 months of daily intravenous injections.** These second-line drugs are less effective against the TB bacteria and are associated with much more severe side effects.

Around 40 percent of TB patients experience side effects, though for most the majority of side effects are mild. Nonetheless, in combination with the length of treatment, even comparatively mild side effects can be a major obstacle to patients completing their treatment and ultimately recovering.

• Isoniazid:

First introduced in 1952, additional side-effects can include weight-gain, reduced liver toxicity and neuropathy (nerve damage) and others.

• Rifampicin:

First introduced in 1967, additional side-effects can include: breathing problems, liver toxicity, reduced white blood cell count, anaemia and others.

• Pyrazinamide:

Discovered in 1952, additional side-effects can include: anaemia, liver toxicity, joint-pain and others.








• Ethambutol:

Discovered in 1961, additional side-effects can include: loss of appetite, vomiting, blurred vision, changes in visual acuity and others.

• **Voractiv** is a combination of the four main TB drugs in one tablet.

• **Rifater** is a combination of Rifampicin, Isoniazid and Pyrazinamide in one tablet.

• **Rifinah** is a combination of Rifampicin and Isoniazid in one tablet.

	Rifampicin	Isoniazid	Pyrazinamide	Ethambutol 400mg 100mg	Voractiv	Rifater	Rifinah 150mg 300mg
							
Best absorbed if the stomach is empty – take at least one hour before you eat food or two hour afterwards	✓	✓			✓	✓	✓
Can be taken with or without food			✓	✓			
MOST COMMONLY EXPERIENCED SIDE EFFECTS							
Stomach upset such as nausea (feeling sick), vomiting and diarrhoea	✓	✓	✓	✓	✓	✓	✓
Flu-like symptoms such as chills, fever, dizziness and joint pain	✓		✓		✓	✓	✓
Skin rashes and itchiness	✓	✓	✓	✓	✓	✓	✓
Menstrual disturbances	✓				✓	✓	✓
Pins and needles in the fingers or toes		✓		✓	✓	✓	✓
Body secretions (urine, saliva, semen, vaginal fluids) may turn orangey red	✓				✓	✓	✓

The BCG, Bacille Calmette Guerin is the most widely distributed vaccine in the world and is an anti-TB vaccine. It was developed more than 90 years ago and provides protection against the more severe forms of the disease, but has negligible impact against pulmonary TB (by far the most common type of the disease) and is only effective for a period of around 15 years.



Personal Stories of TB

Amy



I don't remember when the cough started.

Over the course of several months my GP diagnosed me with a series of chest infections. The antibiotics made no difference. As my cough worsened my appetite faded away. After nearly nine months I got an appointment at the chest clinic and by that point, I only weighed five and a half stone.

The cough had developed into an awful pain in my left lung. I took to my bed and stayed there for weeks. The doctors couldn't seem to diagnose me and I was scared that I might never recover.

It felt like my body was giving up on me, I was incredibly weak, I couldn't eat, even my favourite food made me feel nauseous. TB is a wasting disease; it consumes you from the inside. I'd been ill for over nine months, I couldn't remember the last time I'd had a proper meal.

Finally, the diagnosis arrived. I had active pulmonary TB.

TB drugs are daunting; I knew about the potential side-effects and they scared me, drugs are supposed to make you better, not make you ill. So I didn't take them. A week passed then two, then three. I knew I should have taken them but I didn't. Finally, I spoke to a TB nurse. She seemed to understand straight away, and said that she'd help me through any side-effects. So, a month after finally getting my diagnosis, I started taking the pills.

Although, at the time, that seemed like a huge first step, it was barely the start. **By the time I swallowed the first set of pills my left lung had collapsed. I found out a couple of weeks later and was devastated. A vital part of me had literally died.**

I was lucky that I didn't experience the worst side-effects from the drugs, but that didn't mean I got off lightly. I had searing joint pain. I used to wake up in the middle of the night with the feeling that my joints were on fire. My hair was falling out and I was put on pain medication and steroids. I couldn't even guess how many pills I took during that first phase of treatment.

After battling on with the treatment, I was finally given the all clear at the end of that year. I was looking forward to putting the TB behind me and catching up on lost time at university.

But at the start of February the following year, just three months after getting the all clear, I relapsed. My Easter was spent in hospital, in my own room, alone. **Everyone who entered had to wear a mask because the hospital was worried I might infect other people. TB is often a very lonely disease, and I have never felt so lonely as I did that Easter.**

The first round of my TB treatment had not been successful at all. My collapsed lung had provided the perfect place for the bacteria to hide and when I'd stopped taking the drugs, it came back fast.

The doctors said that my left lung had become a "reservoir of infection" and was attracting other bugs that were making me ill. It was, according to the specialist, irreparably damaged and the only option was to remove it.

But before I could get to have the operation, there was another complication. I had a shadow on my right lung. I'd stopped treatment a couple of months before the operation, and the TB had bounced back again.

I can't describe the shock. I was horrified. TB had already claimed one lung and was infecting the other. It was using my own body against me to make me ill. It was stealing away my quality of life.

The hospital didn't have a plan for me. Nobody seemed sure what to do next. I was sick, my education was on hold and I didn't know if I'd be able to finish my degree. As an intermittent student, I was ineligible for benefits but TB drugs hadn't yet been made free for patients so I had to pay for them. I plunged into debt.

They added second line drugs into my treatment. May came around; the doctors decided it was the right time to have the operation.



And all of a sudden, things got easier. I started putting on weight, I was getting fewer infections, I was still on treatment but I was finally getting better and my life was back on track. But it wasn't quite that easy.

Two years after completing the last round of TB treatment, I was diagnosed with depression and anxiety. Academically I was struggling, I'd got support with my financial problems but it was still difficult. Although my health was under control, my life was not.

My GP said my depression was due to the "severity and prolonged nature of the illness", but I think it was because I blamed myself for what happened. A doctor had once told a whole ward that it was my own fault that I was in hospital. It was a throw-away comment, but it stuck in my head and I felt so guilty.

Still, I managed to graduate, sorted out my finances and saw a counsellor. Now I do whatever I can to let people know about this disease and the effects it can have.

Nine years ago TB turned my life upside down and I'm still putting it back together. I'll be carrying the consequences for the rest of my life and I'm one of the lucky ones, I survived. Whatever we can do to stop this disease, we have to do it. No one should have to go through what I went through.

The long delay that Amy experienced between the onset of symptoms and her eventual diagnosis are quite common. The median delay between patients experiencing symptoms and diagnosis with TB was 74 days in 2012, and 43% were diagnosed more than 90 days after the onset of symptoms. People who have active pulmonary TB and are left untreated remain infectious. Reducing the diagnostic delay is vital to reducing the number of cases of the disease.

Natalie



Natalie had two children whilst she had undiagnosed TB.

Both her boys were screened for TB and thankfully had no trace of the disease.

I was in pain for six years before they diagnosed me with TB.

I was 16 when I first realised something was wrong. I'd been suffering from kidney pain for weeks. Eventually, it became so bad I was admitted to hospital.

They tested me for everything but couldn't make a diagnosis. After a week they decided it was a viral thing, and that it would get better with painkillers and rest.

But it didn't get better. The pain was always there. Sometimes it got a little easier, sometimes a little worse but always there. When I was 19 and pregnant with my first child, it became almost unbearable. I was rushed to hospital with an enlarged kidney. Over the next few years the problems continued. My GP kept prescribing antibiotics but nothing helped.

My second pregnancy was much harder, the pain was more intense, and by the end I could barely walk. Thankfully my son was born healthy, but when we went home from the hospital, the pain was still there.

Eventually, I saw a nurse practitioner and insisted that something was seriously wrong; I refused to take any more antibiotics. She tested my urine, took blood samples, tested for STDs, even tested for cervical cancer but everything came back clear. Finally **she said that I might have TB, but she wasn't sure because she thought you could only get it in your lungs.**

I sent a series of urine samples and finally the diagnosis came back. I had TB of the kidneys.

It was a relief to finally find out; to have it confirmed in the end. The nurse practitioner didn't know what to do next. She called the hospital and spoke to a TB specialist. He'd never encountered TB in the kidneys before so he spoke to a consultant urologist. I was admitted to hospital.

I didn't have drug-resistant TB so I had the normal six month supply of four drugs. The side-effects hit me hard and I was completely unprepared for them. In fact, I felt much worse on the medication than I had done before. I was vomiting a lot. I developed rashes all over my body. They added strong painkillers, anti-nausea tablets and anti-heartburn pills to my medication.

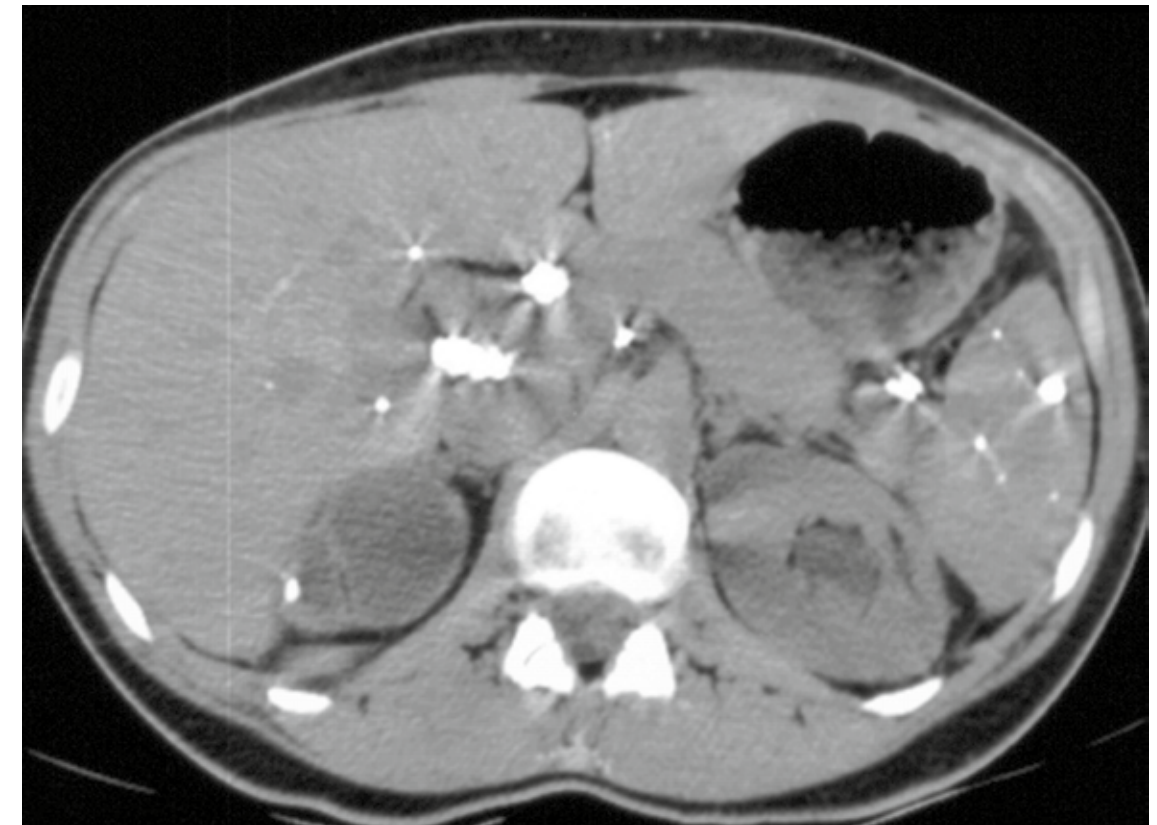
In total, I took over 2,500 pills in six months.

I've always hated taking drugs, even paracetamol, and TB drugs are much bigger. Every morning I lined them all up, made some toast, and ate a bit of toast after every tablet to make sure I kept it down. It would take over an hour to take all my tablets.

I had a great TB nurse who came to see me every day and was such a fantastic support. At the end of the six months I was given the all-clear.

I might have been given the all-clear, but the impact of the disease will always be with me. I have permanent scarring on my kidneys and experience frequent bouts of awful back pain. My kidneys are weak and prone to infections.

At the time Natalie was being treated, there was only one TB nurse in her region. She wrote to her MP every day whilst she was being treated, campaigning for more support for TB patients and better awareness about the disease. Eventually, her MP acted and led a successful campaign to increase the number of TB nurses in Natalie's area.



There's such a lack of awareness about TB, even among the health profession. One day during my treatment course I went into my local hospital because I was really struggling. I told the nurse I had TB in my kidneys and she told me that I was being stupid because you can't get TB outside of the lungs.

We have to raise awareness of this disease; we have to make sure that people think that TB is always a possible diagnosis. I hadn't been travelling, I'm not a 'high risk' person, I just worked in a care home and maybe one of my patients had a bad cough...and that was that. It never occurred to my GP that I might have TB, but since my diagnosis they've diagnosed other TB patients because they're more aware of the disease.

We also desperately need better treatments; **I ate more drugs than food during my six month course. Shorter treatment courses, and easier drugs, would make TB so much easier to handle.**

Finally, I would say we should be positive. We can cure and treat this disease, we can beat it and we really must do everything we can to eliminate it.

Viren



It started as a dull ache in my side; a little discomfort in my lung but nothing unbearable.

I thought I was just tired or a little run down. We had a holiday planned and I thought it would disappear after a week or so of resting. As the holiday got nearer, the discomfort turned into a pain that flared every time I took a deep breath.

It didn't get better when we were away, in fact, it got worse and I started to lose my appetite. I started to get some swelling on my face. My wife, Sharda, noticed something strange under my right shoulder blade.

When we got back to Birmingham my voice was disappearing fast. I was breathless and extremely tired. When I went to see the GP

the next morning, he immediately referred me to the hospital.

At the chest clinic they said I had fluid on the right side of my lung. The consultant thought it was pneumonia and gave me some more antibiotics.

Less than a week after my voice had disappeared to a whisper. I went back to the hospital and they ran a series of tests. I stayed in the hospital for a week whilst they tried to get to grips with what they thought was pneumonia.

For three months I continued to have regular check-ups at the respiratory clinic. Nothing they gave me seemed to make me better. Finally, the consultant decided to test for TB.

They took me into a side room and sat me down. When the doctor told me I had TB I was stunned. **I was born in Tanzania but we've lived in Birmingham for 35 years, I had no idea where I could have caught TB.** In other ways, though, I was relieved. I'd feared I might have cancer.

I took my tablets first thing in the morning the next day. The doctor had warned me about side-effects but I didn't think they'd happen so quickly. My skin became unbearably itchy, I lost weight and my appetite disappeared. I was referred to the Queen Elizabeth Hospital to monitor my liver and kidney as a precaution due to the toxicity of the drugs.

Sharda was a huge support, with so many tablets to take for so long it can be difficult to stick on the treatment. She was brilliant, making sure I was comfortable and ate as well as possible. With her help I managed to complete the treatment and was given the all clear at the end of the course of drugs.

The physical effects of treatment were difficult, but in some ways I found other aspects of the treatment worse. **I was off work for a year. I'd never been off sick and hadn't expected to miss the daily contact with people as much as I did.** I also didn't know anything about TB, or have anywhere to ask questions. My only real support was my Sharda.

The worst thing was keeping it secret from my family and friends. TB has a real stigma attached to it. I wasn't contagious so I didn't tell anyone, but I knew if I had mentioned it my friends and family would have stopped talking to me.

But, we got through the treatment, and I thought life would return to normal and for a while, it did. The kidney check-ups continued, first they were ok, but then my kidney function started to deteriorate.

By 2010 my kidney function had fallen to just 30%, I was starting to get tired and dizzy, my ankles and face were swollen. One evening at work I vomited after the evening meal, my manager drove me home.

My condition got worse. I had a blood test and was immediately called into hospital with a severe kidney infection. I think that was the longest night of my life. My blood pressure was checked every ten minutes, then they moved me to an intensive care ward.

Eventually they managed to stabilised my blood pressure. The next morning they hooked me up to a dialysis machine.



Dialysis is hard. It's difficult not being able to move for long periods. I couldn't eat a normal diet and I had very little energy. Again, Sharda was a huge support; she was there every step of the way.

A blood specialist came and did some tests. A week later, the results came back revealing an abscess on my liver which was dragging down my kidney function.

The treatment took six weeks. At first I hoped my kidneys might start working again, but even as my liver responded they didn't get any better.

I was on dialysis for 18 months. Then one morning I got an unexpected call from the hospital.

When they told me they had a donor match I didn't have time to think. We rushed into hospital and before I knew it, I was on an operating table.

So, once again, I find myself taking TB tablets, but this time, I'm glad to do so. To make sure that the body doesn't reject the kidney, I have to take tablets which reduce my immune response, putting me at high risk of getting infections like TB. I'll have to take these for another year, but, if all goes well, for the first time in years I should be free from TB, free from dialysis and back to full health.

Stigma associated with TB is a challenge faced by many patients. Fear is the principal driver of stigma around the disease, largely caused by a lack of understanding. The consequences of this stigma can be severe, it causes diagnostic delays and treatment non-compliance, which can endanger others and drive the development of drug resistance. It also isolates people who have TB, as in the case of Viren who felt he couldn't tell his family and friends. This, in turn, makes the disease much harder to manage.

Steve



My TB story starts with a job offer.

I had been given the opportunity to start a new job in Australia. To get a visa I had to be given the all-clear for a number of conditions, one of which was TB.

I hadn't been well at the time but I'd been given a course of antibiotics and none of the tests came up positive. I was given the all-clear to start my new life down under.

Almost as soon as I arrived, my health started to deteriorate. I felt increasingly tired and weak and found myself in and out of hospital. As is often the case with TB, I was diagnosed with a host of different problems, and the solution was always more antibiotics. Of course, nothing worked.

Before long, my partner and I made the decision to return to the UK.

The journey back from Australia takes 24 hours, and I don't remember very much about it. By the time we landed at Heathrow I was so weak that I was taken immediately to A&E. I spent a fortnight in the intensive care unit.

Eventually, I was diagnosed with TB in the lymph nodes in my neck. I was in my local hospital, and they didn't have a lot of experience with TB. I was given the standard treatment of four TB drugs: isoniazid, rifampicin, ethambutol, and pyrazinamide. At no point was I warned about the side-effects, so although there were a lot of pills to take, I wasn't too worried by the length of the treatment.

Rifampicin can wipe out your white blood cells and can cause anaemia, at one stage I was given thirty bottles of haemoglobin. Isoniazid can cause neuropathy or nerve damage. I very quickly began to lose feeling in my legs and hands. I was told that when the course of medication was over my nerves would recover. I completed treatment years ago, but I don't think I'll ever recover full sensation in legs and hands.

My hospital didn't know how to handle my side-effects and I was referred to the Royal London Hospital. I was terribly ill for a long time, so at first I didn't notice, but eventually I realised that my vision was deteriorating.

The consultant at the Royal London Hospital immediately sent me to see one of the country's leading optic surgeons. **It turned out that one of the drugs, ethambutol, was attacking my optic nerve. I was immediately taken off the drug, but my optic nerve was damaged beyond repair.** I am now registered blind.

I was then put onto a course of second line drugs. One of them, streptomycin, has to be intravenously injected every day and is known to be extremely toxic. It's commonly associated with hearing loss. Thankfully, I didn't suffer any problems with my hearing, but as a consequence of having to have treatment with second-line drugs, my treatment dragged on for two and a half years.

TB and HIV are inextricably linked. TB is the leading cause of death for people who are HIV+, and people living with HIV are between 21 and 34 times more likely to develop active TB than people who without the disease. TB and HIV services are very closely linked in most UK hospitals, and most people who are diagnosed with HIV are tested for TB and vice-versa.

I didn't have a TB nurse. I didn't feel like I had anyone to ask about what I was going through, my partner had no one to help him care for me. For most of my treatment I was a zombie on the floor. The whole thing was just a shambolic mess. I'm HIV positive, which may have complicated my treatment. I had two consultants who argued it out, one felt that the TB medication was solely responsible for the problem; the other said that my side-effects were a consequence of my reduced immune response.

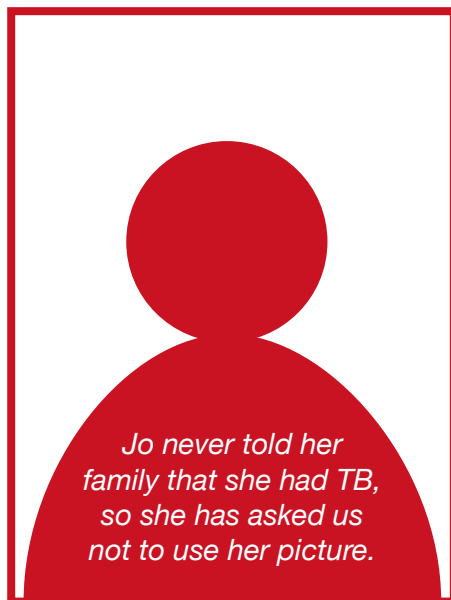
I have no idea how I was infected with TB. I worked in London, one person on a tube or a train, it could have been anything. There's a lot of talk about migrants carrying TB, but it's so difficult to test for. **I was a migrant going to Australia and one of the best health systems in the world tested me specifically for TB and didn't find anything, even though I was already ill with it!**



Everybody thinks TB disappeared in the 1950s and they don't know that TB can be found in any part of your body, and they don't realise how easy it is to catch. They think it's all gone. Raising awareness is vital.

Ultimately, though, it's almost impossible to stop TB spreading, the only solution is to actively go looking for the disease all over the world and eradicate it, that's the only way to stop it.

Jo



From my early teens I was the black sheep of the family.

I spent a lot of time with an older crowd. By my late teens I was into drugs and alcohol. By my twenties I was a heavy drinker, a street drinker, staying in crack houses. I lived in cramped, overcrowded places with many people coming and going. My life had become a whirlwind of alcohol and drugs and my family more or less disowned me.

Living on the street takes a toll, I didn't eat well, I weighed hardly anything. There's always some pain or problem, I was in and out of hospital a lot.

On one occasion a nurse was putting me on a drip and said to me: "It's people like you that waste our resources." I remember thinking that as soon as I got my feet under me I'd never go back into a hospital.

My words came back to haunt me.

A couple of months later I collapsed in the street, still clutching my cans of cider. They took me to hospital kicking and screaming. I was diagnosed with pneumonia, but because I wouldn't stay in the hospital they gave me antibiotics and I left.

Two days later I was back in the same hospital, I'd collapsed again and was diagnosed with fluid on my lungs. Draining the fluid proved impossible. I was transferred to another hospital where I had a lobectomy – a piece of my lung removed. As I was leaving they took a sputum sample in case I had TB and gave me a bag of medication. They weren't sure whether I had TB or not, but because of my lifestyle, I guess they thought they might not be able to find me again and it was better to be sure.

I don't know whether I could have been diagnosed sooner. I'd had what I now know to be classic symptoms of TB, but the doctors always thought they were because of the drink and I did too. Maybe if I'd been diagnosed sooner I wouldn't have had the operation. I guess I'll never know.

I'd been in hospital for two weeks and they detoxed me whilst I was recovering from the operation. When I was discharged I was in such a lot of pain that I didn't go straight back to the street and start drinking.

Two weeks later I got a call from a TB nurse called Jacqui. She'd been trying to track me down for a little while. I went up to the hospital and saw her. We sat for two hours and she talked me through everything. She told me about TB, about pulmonary TB and about the medication. She explained that TB drugs can be very hard on the liver and kidneys and that if I started drinking again I could suffer permanent damage.

She asked me about my close contacts, who I might have got TB from or who I might have given it to. The only people I'd spent time with were other street drinkers, and they're difficult to track down and if you do, it's hard to make sure they take their tablets. One day, years later, I saw one of the people I used to drink with. She told me that she'd been diagnosed with TB but had never taken the drugs. I might have given her TB, she might have given it to me, I just don't know.

If it wasn't for Jacqui I might not have taken the drugs either. She was so supportive, she was always understanding. Before I knew it my six months of treatment were drawing to an end and I'd started going to AA meetings. After how bad my life had been on the street, treatment wasn't too bad and I was lucky not to have any side effects.



When they tested me towards the end of my six month course, I discovered that my TB was isoniazid resistant. That meant another six months on the drugs, but Jacqui was fantastic and we became firm friends. Thanks to her I got through it and finally, after twelve months, they gave me the all clear. Throughout the whole process I never told my family. Even now they still don't know I had TB.

When my treatment was over, Jacqui once again offered me a lifeline. She'd contacted NHS Find & Treat and asked if I wanted to go along to see their work. I didn't want to hear any mention of TB again, but I thought I'd go along because she'd been so good to me.

They offered me a few shifts as a volunteer, and then a few training courses, and then asked me to speak about my experiences a couple of times. Little by little they built my confidence and skills. I filled the rest of my time working with local charities and eventually starting volunteering at a North London hospital. I'm now full-time at the hospital and I've got my life back together.

We need to raise awareness of the disease, but we also need to support the people who have it. TB treatment is long, people need help and support to stay on treatment, especially people like me who were on the street.

For me, TB was a blessing in disguise. It's such a negative, terrible disease, but it was the catalyst for meeting Jacqui, for working for Find & Treat and for turning my life around.

NHS Find & Treat is a pan-London service that seeks out marginalised and vulnerable populations and screens them for active pulmonary TB. It is run by a multi-disciplinary team that takes a holistic approach to care for TB patients with a strong focus on social support. Many past-patients are offered the opportunity to volunteer with the van as Jo did, helping them grow their skills and confidence and ensuring that patients have support from people who truly understand their situation.

Dr Marc Lipman



TB has fascinated me since I qualified as a doctor.

The thing about this disease is not just that treatment can be extremely complex, nor that it has such inextricable connections to conditions like HIV, but the fact that you just can't separate the social care from the medical care, and if you do, you're just not going to deal with the infection properly.

The social aspect of care is critical. TB drugs are far from perfect; and treatment is long and often arduous. Sometimes the best thing one can do as a health professional is simply be there for somebody. Sometimes we need to work harder to put ourselves in the patient's shoes.

We try to make sure that the social care starts from day one. Roughly 40% of all TB patients will experience side-effects, and a proportion of these will be severe. Even patients with relatively mild side-effects

can need a lot of support to get them through treatment.

It's challenging because **there's no such thing as a 'typical' TB patient, every case is different. TB is often linked to social risk factors such as homelessness or alcohol excess but the list of potential complications is enormous.** We've introduced a social care team into our TB services to try to make sure that everyone has the support they need.

Understanding the individual is the first step, it underpins everything else. The second step is to understand the disease, to do that we've introduced something called 'cohort review'. This is vital to managing the disease in a standardised fashion. For each patient we go through a sort of "check-list" covering things issues that relate to both individual care and public health matters. We are interested in understanding their social and medical needs. And knowing answers to questions such as: Is their disease drug sensitive? What's their HIV status? What about their family? What are the wider implications? Where did they get the disease? It's an almost never-ending list.

This system helps us standardise our treatment and follow-up. When a patient is signed-off we need to make sure that they don't just disappear but are given advice to come back if they experience symptoms that concern them that might be due to TB. It also enables us to provide some information and education about TB and general health maintenance.

The third important aspect of managing TB is improving our understanding of the communities that it affects. **If populations with high rates of TB are not aware of the disease and how to access healthcare then we're not doing our job correctly. We do recognise, though, that some communities can initially be reluctant to engage with the NHS.**

This may be for a number of reasons. Sometimes because there's an expectation of a medical review costing money, also it may relate to visa and immigration issues, simply because it's just not what is done, and also inevitably due to the stigma related to TB. We have to work hard to ensure that this is minimised and at the very least no one avoids treatment because of stigma. Until we really understand what is the healthcare seeking behaviour of specific populations we can't devise an appropriate strategy to combat TB among them.

One thing we can try to do, however, is make it clear that it's a good thing to detect TB as early as possible for the individual, the family and for the community at large. We have to try to foster an attitude around TB that is preventative and proactive, a lot of that is about clear messaging targeted at high risk populations.

A national TB Oversight Group was formed in April 2013 to develop and oversee a national strategy to strengthen TB control and reduce the incidence of TB in England. Alongside this, a London TB Board has been established with the aim of halving TB rates in the capital in 5 years. The success of these initiatives will require a 'whole system' approach that looks at all stages of the prevention, care and control of TB and involves clinicians, public health experts and social care stakeholders.

At the centre of it all, though, has to remain the patient. **Political rhetoric that demonises certain populations does not help, if anything it drives them away from accessing treatment and consequently getting better.** In my experience people who travel, who migrate, who move thousands of miles from their country of origin are generally ambitious. Sometimes there are other reasons but migrants are usually people with drive. They do not want to get ill and they do want to have a job, and earn money in this country.



One of the reasons why there is such a strong link between domestic and international TB is because we've done so well at attracting the brightest and the best to the UK, that's how UK PLC will continue to develop and thrive. With that, of course, come the associated health issues, and we have to come up with the strategies to try to provide good health-care and so avoid people getting sick with TB.

I remember one patient who perfectly demonstrates my point. He was a young Somali man with MDR TB all along his spinal column. He was bright and wanted to be a vet. He'd come to the UK to finish his studies, get into vet school, and get a job.

When we saw him he'd already lost 25 kilos, there was hardly anything left of him, he weighed about 45 kilos. Over time, his condition improved but he had a hard time with some of the drugs, and he said to me over and over "I can deal with the side-effects, I simply have to get better. If I were still in Somalia I would be dead by now."

He made it clear that he was fully aware that even though he had transported himself solely for the veterinary training, as a result of being here he was encountering a healthcare system that was literally saving his life. Now, thankfully, he's through treatment and has got a job.

But the thing to remember about TB is that whilst you might be cured with treatment lasting months, the consequences can last forever. This young man came back into the clinic recently with problems with his hearing as a consequence of one of his TB drugs. He's been cleared of MDR-TB, but the effect of his curative treatment will be with him for the rest of his life and he'll never forget having TB.

Conclusion



Tuberculosis (TB) is one of the world's leading causes of death and an enormous burden on public health services around the world. 1.3 million people lost their lives to TB last year, and many millions more had their lives and livelihoods disrupted or wrecked by the disease. Given that TB is both treatable and curable this pattern is all the more unacceptable.

TB treatment is long and arduous, even in the UK. Treatment regimens can take years and patients can expect to take thousands of pills, many of which are associated with severe and debilitating side-effects. No patient should have to take drugs that may leave them with permanent disabilities. We must do more to find shorter and more effective regimens with fewer side-effects.

More manageable anti-TB drugs, however, is just one part of the jigsaw. Clinical care must be accompanied by social care and health systems need to be patient-centred. More must be done to crack earlier diagnose, to heighten public awareness, drive down rates of the disease in the UK, and to demonstrate our leadership in the global fight against TB.

I'm aware that when we talk about diseases like TB in the debating chambers of places like Westminster, it is all too easy to talk in general terms, concepts and unfathomable statistics and forget that at the heart of each individual case is the story of one person and their struggle with the disease. The stories found in this report are examples of remarkable courage and determination but they are also examples of the daily reality of fighting the disease, played out a million times every day across the planet. It is the daily reality for too many people, and that's why my colleagues and I in the Westminster parliament are determined to keep up the pressure for positive change.

Andrew George MP

Co-Chair of All-Party Parliamentary Group on Global TB



RESULTS UK

RESULTS works to create the public and political will to end global poverty. We engage and educate people - both members of the public and decision-makers - to become effective agents for change by building their understanding of key issues and their confidence to raise these issues within their communities, the media and the Government. By conducting strategic grassroots and high-level advocacy, RESULTS aims to achieve policy change (money spent more effectively) and resource mobilisation (more money spent) to tackle the root causes of poverty.



TB ACTION GROUP

The TB Action Group (TBAG) is the only network for people affected by tuberculosis (TB) in the UK and has been at the forefront of the civil society response to the illness. TBAG is facilitated by TB Alert and was formed in 2008 to provide a voice to people who have been personally affected by TB, either through their own illness or the illness of a loved one. Network members therefore have a crucial insight into how services should be designed and delivered, and can provide valuable peer support for people during treatment for TB. By using their own personal experiences and insights, they are able to raise awareness of the illness among communities and health professionals and to advocate for improved services.



TB ALERT

TB Alert is the only charity that focuses on TB both in the UK and overseas. We have projects on the ground in India, Zambia, Zimbabwe and Malawi. This gives us a unique perspective in order to address issues around TB that are common both to low incidence countries like the UK and high incidence regions such as Africa and Asia. We advocate for the policies and resources to be put in place to fight TB as a global issue. TB Alert aims to be a standard bearer for best practice in TB care and control.



ALL-PARTY PARLIAMENTARY GROUP ON GLOBAL TUBERCULOSIS

The APPG TB is an interest group that sits in and is recognised by the UK Parliament. It is comprised solely of parliamentarians and has members from all major political parties. The group works with parliamentarians to promote innovative and effective ways to tackle the devastating impact of TB within the UK and globally.

The APPG provides a valuable forum for parliamentarians, civil society organisations and governmental departments - focusing on political context in the battle to control TB. It also offers parliamentarians the opportunity to strategise, stimulate debate and commission research into key themes to strengthen the fight against TB - often resulting in increased resources and policy change.

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