

Protecting and improving the nation's health

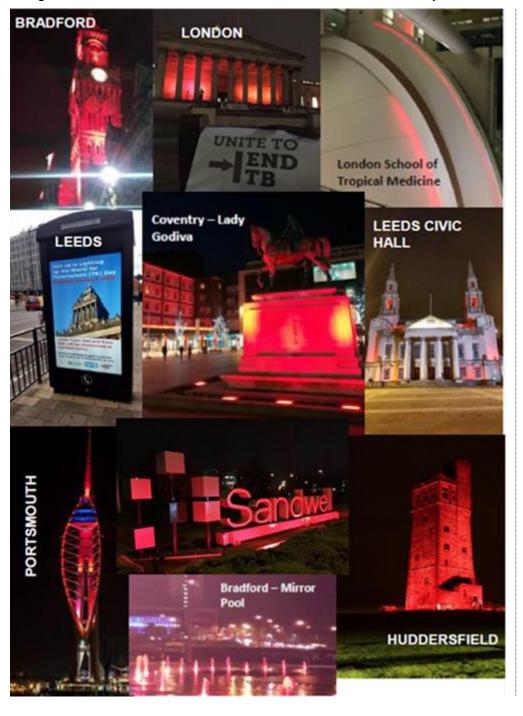
TB Strategy Update

This is a regular update that provides information on the progress of the **Collaborative TB Strategy for England 2015 - 2020.** To subscribe to future updates please **click here**

1 World TB Day - 24 March 2018

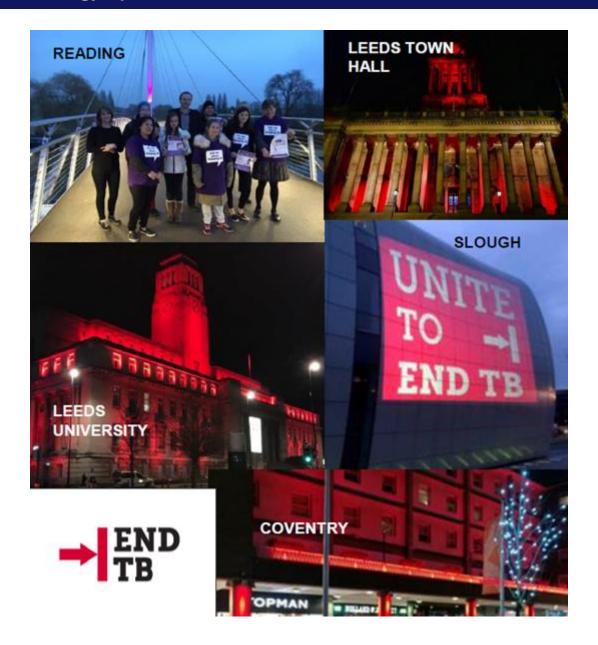
'Light up the World for TB'

Thanks to everyone who made this the best year ever for 'Light up the World for TB' in England - what a variety – from telephone boxes to bridges to iconic landmarks! Let's see what we can do next year.



Contents

- 1 World TB Day 24 March 2018
- 2 2018 National TB Nurse Conference
- 3 TB Control Board TB nurse representatives
- 4 TB on the Parliamentary agenda



England was part of international World TB Day and contributed to lighting up in red for TB across at least 60 landmarks in 49 cities in 24 countries. This can be seen at http://www.stoptb.org/events/world_tb_day/2018/assets/images/LightUpforTB_March2018.gif on the map including some of our photos.

You can upload your photos onto the StopTB website through their social media tab http://www.stoptb.org/events/world_tb_day/2018/multimedia.asp

With a full listing of World TB
Day 2018 world-wide events
and information at
http://www.who.int/tb/world_T
B_day_2018_events/en/



2 2018 National TB Nurse Conference

The third National TB Nurse Conference was held on 22 June 2018 in Birmingham, supported by NHS England and PHE.

Below is a photo of a few of the TB Control Board nurse representatives who attended the conference.



Named in order left to right: Andy Hare, Tracey Langham, Diane Holland, Kath Bintley, Jacqui White, Stacey Farrow, Surinder Tamne (Tammy) and Pat Goodman

Conference feedback

Of those who responded to the post conference survey 98% rated it as good or very good. In addition, being conscious of the distance people have to travel, we asked where would people like the 2019 conference? Two thirds of people who responded said they would prefer to travel to Birmingham – so guess where it will be next year? Birmingham of course!

What did the conference cover this year?

- How to integrate the LTBI programme into TB services
- Information governance, quality assurance and practicalities of Video Observed Therapy
- Is Mantoux testing fit for purpose in 2018?
- When to treat pulmonary Non Tuberculous Mycobacteria (NTM) infection
- Managing drug resistant TB British Thoracic Society (BTS) clinical advice service
- Capturing inequalities in people with TB: what are we missing?
- Accuracy of Mantoux and IGRA to identifying LTBI in children
- Contact investigations: a keystone to TB control
- The reality of whole genome sequencing in practice: the successes and the challenges
- Experiences of contact tracing in a large Leicestershire outbreak

Each of the above have been summarised in bite sized portions to give you a taste of what was presented. Please contact the speakers if you want more details about the presentations.

Summaries of the presentations

Opening session - Joanne Bosanquet, PHE Deputy Chief Nurse accompanied by **Jane Cummings**, Chief Nursing Officer for England, NHS England on video.

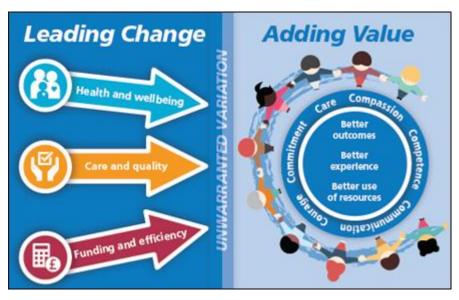
Both Joanne and Jane emphasised how key TB nurses are in England and internationally. Joanne focussed on the role of nurses in advocacy and political

leadership particularly in prevention of avoidable disease, health protection and the promotion of wellbeing and resilience into practice.

Jane spoke about role of TB nurses - their skill, knowledge and expertise and acknowledged the contribution of the wider workforce, including TB outreach workers, TB support workers, DOT workers and administration staff for their work to provide care and support for those affected by TB. Jane talked about the **Five Year Forward View** which considers the futures and choices faced



by the NHS and how using **Leading Change**, **Adding Value** can improve patient care. She praised the development of the TB nurse competency framework and its use across England.



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**Lynn Altass**, National TB Strategy Programme Manager and **Tracy Morrod**, Lead TB Clinical Nurse Specialist, Sandwell and West Birmingham NHS Trust - **How to integrate the LTBI programme into TB services** 

Lynn outlined the new entrant LTBI testing and treatment programme and provided an update on progress. Up to April 2018 32,000 plus people had been tested for LTBI with 18% people testing positive for LTBI. At least 62% of those took up the offer of treatment with 81% completing treatment (Information courtesy of the PHE Screening team).

An **animation video** was launched on World TB Day to raise public awareness of the LTBI test. TB services are key to implementing the LTBI programme and key actions that should be considered by TB services include how to accurately identify and collect

LTBI testing and treatment activity in TB services to support management of workload.

Tracy shared her team's experience of piloting a local nurse led LTBI testing and treatment service and how that had changed with the national led LTBI testing and treatment programme.

Tracy highlighted what works well, what doesn't work so well and offered



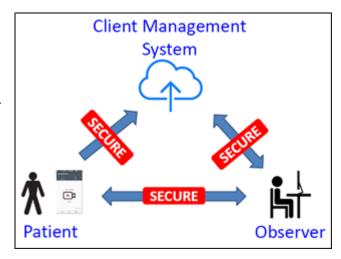
the challenge of why this service should be nurse led. Tracy emphasised the commitment and skill set of the TB nursing team and how they maximise the opportunity to provide a quality service for patients.

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Joe Hall, TB Social Worker, Find and Treat, University College London Hospitals NHS Trust and Michael Nayagam, TB Outreach Worker, St George's University Hospital NHS Foundation Trust, London gave different perspectives on 'Information governance, quality assurance and practicalities of Video Observed Therapy (VOT)'

We all know that Directly Observed Therapy (DOT) is recommended for enhanced case management but the pan London DOT survey showed that only about two thirds of

patients who need DOT get DOT. In addition treatment adherence was poor. The Find and Treat experience of VOT showed that treatment adherence was much improved, cheaper than DOT, more acceptable to patients and can be used 24 hours a day, seven days a week and 365 days a year. Joe outlined the issues around governance, quality assurance and practicalities of VOT comparing the client management system used by the Find and Treat SureAdhere VOT app service versus those of using WhatsApp VOT and issues related to GDPR compliance.



Michael described the experience and process of developing a local TB team in house VOT service using WhatsApp. This service commenced in response to local patient needs and to strengthen local case management and the team worked with the local Information Governance manager to set up the system. This included a secure device to receive the VOT, a recording and reporting system and embedding VOT into the TB service.

It was agreed that further work around information governance and VOT service delivery was required which the PHE based National TB Office would support.

Dominik Zenner, Head of TB Screening Unit, Public Health England - Is Mantoux testing fit for purpose in 2018?



Lithograph 1934: Tuberculosis Test for Children. Elizabeth Olds

Dominik went through how Mantoux (TST) and IGRA works including the differences, comparison of the two types of tests and what that means, the evidence for test efficacy and cost effectiveness using systematic reviews of Mantoux and IGRA and also summarised NICE guidance. The presentation concluded that:

- both tests are valid but imperfect
- the significant changes to the NICE guidance favour TST driven by cost effectiveness which tilted the choice to overtreatment rather than under-treatment
- decisions, based on risk and benefits, differ depending on situation and circumstances including availability of test product and workforce training
- we need a better test and we need to get better at using the tests monitoring and evaluation is crucial.

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Martin Dedicoat, Infectious Diseases Consultant, Heartlands Hospital - When to treat non Tuberculous Mycobacteria (NTM) Infection

Did you know that over 120 species of NTMs have been identified? They are not usually transmitted between humans or animals to humans and are found in soil and water which makes them different to the TB we are used to. They can be found in sputum as:

- contaminants
- colonising organisms
- disease causing organisms



Martin summarised NTMs causing respiratory disease, their diagnosis, laboratory testing and treatment. NTMs are important because they aren't notified i.e. hidden workload for TB and respiratory services – nurses and doctors. Martin highlighted some patient examples for the more common NTMs showing the difficulties of treatment and case management issues and the role of surgery. There was a census from TB nurses that managing NTM patients added considerably to their workload and welcomed the concept of these cases being notified to better capture workload activity.

The British Thoracic Society has published guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) guidance published in Thorax by Haworth et al in 2017.

Martin Dedicoat, Infectious Diseases Consultant, Heartlands Hospital - Managing drug resistant TB - British Thoracic Society (BTS) clinical advice service

Martin described how to, and who could use the service:

 any TB nurse or physician looking after a patient with MDR-TB or XDR-TB or other drug resistant TB or complex TB (clinical or social) who needs advice can post a case

- register on https://mdrtb.britthoracic.org.uk/WebPages/Lo gin/frmLogin.aspx
- the clinical service advisers are contacted and comment on the case. The clinical service advisers include TB physicians (ID and respiratory), paediatricians, TB nurses, public health, pharmacists, microbiologists and thoracic surgeons



- cases are included in a monthly MDT where the discussion includes the person who posted the case and a summary of the discussion is uploaded – patients are anonymised. Example cases can be looked at on the website
- any change in the case can be posted for further comment by the clinical service advisers and a further MDT discussion can be requested

The aim of the service is to support and provide practical advice. It does not judge or criticise previous care and the advice is not compulsory. To date over 50 cases have been posted to the BTS MDR-TB clinical advice service of which nearly 70% are MDR-TB, suspected MDR-TB or XDR-TB.

Currently there are only two experienced TB nurse specialists who are clinical service advisers and the BTS would welcome applications from experienced TB nurse specialists to participate in the MDTs as clinical service advisers. Clinical service advisers are not expected to participate in every monthly MDT. Please contact the BTS via their website <a href="https://www.brit-thoracic.org.uk/standards-of-care/lung-disease-registries/mdr-tb/">https://www.brit-thoracic.org.uk/standards-of-care/lung-disease-registries/mdr-tb/</a>

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Al Story, Clinical Lead and Manager, Find and Treat, University College Hospitals NHSE Foundation Trust - **Contact investigations: a keystone to TB control**

The take home message from Al Story was that not enough contacts are being identified and that services need to use more 'shoe leather' and outreach workers. Key was the increasing use of WGS and social network analysis to ensure the right contacts are identified and followed up. He also highlighted the need to do things differently questioning traditional approaches to contact tracing.

Anjana Roy, Senior Scientist, Programme Manager for USPs, Public Health England - Capturing inequalities in people with TB: what are we missing?

Anjana led an energised scoping session on capturing inequalities among TB patients. The purpose of this session was to identify gaps on the changing profile of TB patients, which are not currently being recorded and encourage discussion among those in the frontline services. Results of the session will inform:

- improving the patient journey with added focus on patient issues such as legal and economic status, access to social care benefits, accommodation, mental health and social risk factors
- gathering evidence to inform policy through improved national data collection
- updating a study to determine remaining or newly relevant gaps in knowledge regarding the under-served groups. The study plan / protocol is currently under consultation.

Responses documented in the scoping session are being collated and a summary will be sent to the attendees of the session.

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**Steve Welch**, Consultant Paediatrician TB lead, Heart of England NHS Foundation Trust - **Accuracy of Mantoux and IGRA to identifying LTBI in children** 

Steve looked at the science behind both tests and used a range of real life scenarios and case studies to highlight the issues of using IGRA and Mantoux in children which are:

- what is latent tuberculosis?
- risk of progression to active TB?
- higher risk in children
- how reliable are these tests in children?
- · effect of BCG?
- what is the question?
- what is the population?
- be pragmatic

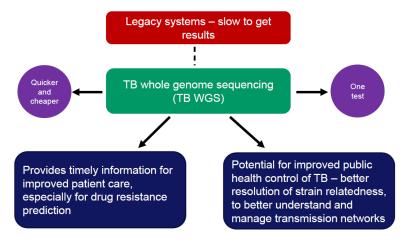
Steve outlined the NICE 2016 guidance on TST and Mantoux for children and the immunocompromised and the outcomes in two different studies which showed:

- IGRA is more specific than TST
- IGRA and TST are least sensitive where most needed in the under 2 years, immune compromised
- treat exposure aggressively in high-risk groups
- consider degree of exposure
- select TST or IGRA pragmatically

Steve finished by representing the case studies and asking the audience what they would test would they use and / or what treatment would they give? The audience was very positive on the practicalities of this presentation.

Cassie Gregory, Health Protection Nurse Specialist, Public Health England - The reality of whole genome sequencing (WGS) in practice: the successes and the challenges

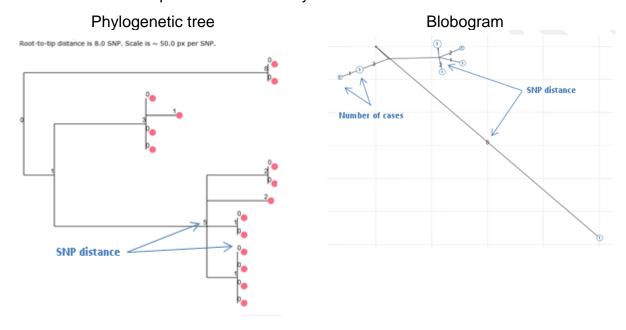
Cassie summarised the use of WGS for TB:



And outlined the benefits of WGS for TB control:

- faster diagnostics
- earlier indication of resistance patterns patients can be started on appropriate treatments in a timely manner
- drug sensitivity prediction reliable sensitive and specific
- identifies when cases are genetically linked (clustered) together represented by single nucleotide polymorphs (SNP) differences
- relatedness results are timely and useful for real-time public health action

WGS results can be represented in two ways shown below:



Cassie described the advantages and disadvantages of WGS and described some examples where WGS has been used in the West Midlands. These highlighted a number of practical issues including an initial lack of formal process, ad hoc receipt of WGS results by clinic teams, lack of preparation for meetings and some TB services had cluster meetings, others didn't.

Cassie explained what actions were taken to improve the local process. These included:

- a short term, part time appointment to embed WGS TB cluster investigations in the West Midlands
- checking the process from the sample arriving in the lab to availability of the result
- visiting TB teams, existing cluster meetings and other PHE centres
- attended national and local meetings and conferences on WGS in TB
- local Task and Finish Group set up to agree documentation and workflow

#### Which has led to:

- Flowchart for WGS TB cluster investigations and a Flowchart for TB teams regarding cluster investigations
- Handbook on WGS TB cluster investigations for the West Midlands
- WGS workshop event with PHE, TB services and Local Authority Public Health
- TB WGS cluster meetings taking place in all high incidence areas and on an adhoc basis in low incidence areas
- all newly clustered cases are sent to TB services by nhs.net email monthly
- plans to add on the bottom of WGS result that the case is part of a cluster
- commencing use of a Cluster Investigation Tool (developed in the North West)
   for all new cluster cases to aid future investigations and identify linked contacts
- use of Cluster Reports with interactive functions for clusters

#### And for the future:

- need to trial using the Cluster Investigation Tool routinely in clinical practice
- Field Services producing cluster context reports
- need to collate cluster information at an earlier stage
- need to work more collaboratively with other stakeholders on cluster investigations
- need to ensure data capture methods can catch up with new technology iPads, online platform which links to lab data, new ETS system

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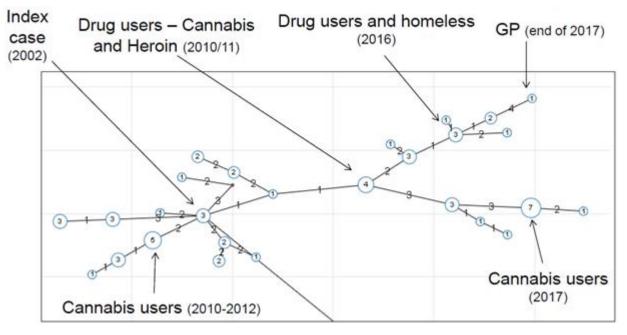
Roz Kennedy, Specialist TB Nurse and Helen Thuraisingam, Lead Nurse - Clinical Nurse Manager, University Hospitals of Leicester NHS Trust - Experiences of contact tracing in a large Leicestershire outbreak

This was a fascinating reflection on the work that was required to investigate and follow up a cluster and how WGS, geography, time and life style impacted on the TB team workload and approach.

In summary there were eight active TB cases, 124 contacts identified with 39 latent TB cases across 28 households!

Not only did the TB team use the WGS blobogram (see next page), they also used geographical maps, time lines and social network diagrams to understand follow the outbreak.

The team also collected information on the active cases and contacts to better understand the cluster demographics. TB patients in the cluster required treatment for 9 months, extensive household screening and investigation of contacts and DOT for all the active TB and LTBI cases.



This cluster identified a number of challenges:

- the speed, size and impact of the unravelling outbreak
- logistics and magnitude of screening
- logistics of DOT and TB nurse team
- complex interwoven family and social networks
- ensuring interagency collaboration controlled and strategic

The approach taken by the team was to:

- develop and build relationships
- ensure consistency
- raising awareness
- candour dealing with the 'elephant in the room'
- identify nuggets of information being intuitive and tenacious
- being visible and available
- working closely with other clinicians and PHE not underestimating the value of historical experience and skills that other people bring
- community, working and engaging with patients to support social networking



# 3 TB Control Board TB nurse representatives

The TB nurse representatives represent, and are the voice of specialist TB nurses and TB services on the TB Control Boards. The table below details who the TB nurse representatives for each TB Control Board:

| TB Control Board                     | TB nurse representative                                                                                             | TB nurse representative                                                                 |
|--------------------------------------|---------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|
| East Midlands                        | Diane Holland                                                                                                       |                                                                                         |
|                                      | Lead Nurse Infection Prevention and Control, TB<br>Service, Chesterfield Royal Hospital Foundation<br>Trust         |                                                                                         |
| East of England                      | Andy Hare                                                                                                           |                                                                                         |
|                                      | TB Clinical Nurse Specialist, Essex Partnership University Trust                                                    |                                                                                         |
| London                               | Kath Bintley                                                                                                        | Jacqui White                                                                            |
|                                      | TB Nurse Specialist, St Helier Hospital                                                                             | Clinical Team Lead, North Central London TB<br>Service                                  |
| North West                           | Stacey Farrow                                                                                                       |                                                                                         |
|                                      | TB Nurse Specialist, The Pennine Acute Hospitals NHS Trust, Rochdale Infirmary                                      |                                                                                         |
| South of England                     | Alison Blake                                                                                                        | Pat Goodman                                                                             |
|                                      | Lead Nurse for Community TB Service, Cornwall Partnership NHS Foundation Trust, Camborne Redruth Community Hospital | TB Specialist Nurse, Arthur Blackman Clinic, St.<br>Leonards on Sea                     |
|                                      | Tracey Langham                                                                                                      | Nuala Whitehead                                                                         |
|                                      | Respiratory and TB Team Leader, Royal Berkshire NHS Foundation Trust                                                | Senior Nurse Respiratory Medicine, Lead<br>Nurse/Service Manager, Portsmouth TB Service |
|                                      | Vacant                                                                                                              |                                                                                         |
| West Midlands                        |                                                                                                                     |                                                                                         |
| Yorkshire & Humber<br>and North East | Cathy Mullarkey (Yorkshire and Humber)                                                                              | Carole Maclean (North East)                                                             |
|                                      | Senior Specialist Health Visitor TB Liaison, The Reginald Centre, Leeds                                             | Specialist Health Visitor TB and Migrant Health, Low Fell Clinic, Gateshead             |
|                                      | Meg Goodrick (Yorkshire and Humber)                                                                                 |                                                                                         |
|                                      | TB Liasion Nurse, Integrated Community Services, City Health Care Partnership CIC, Hull                             |                                                                                         |
| National Office                      | Surinder K Tamne (Tammy)                                                                                            |                                                                                         |
|                                      | TB Unit, National Infection Service, Public Health England                                                          |                                                                                         |

# Key aspects of this role include:

- providing expert advice and clinical representation
- developing, supporting and strengthening local and regional TB nursing networks
- supporting nurse representation at the national TB Delivery Board and national TB Programme Board
- supporting the annual national TB nurses' conference
- supporting local implementation of the TB strategy
- championing the role of nurses and wider workforce in TB care and control
- supporting continuous personal and professional development
- sharing good practice and leadership



## And farewell to one of the TB control board nurse representatives

Debbie Crisp, circled below, the TB nurse representative on the West Midlands TB Control Board and Lead TB nurse for Coventry and Warwickshire has retired in a blaze of glory when she, and the TB team, recently won the Team of the Year award at the George Eliot Hospital!!



What has Debbie got to say about her time working in the NHS and TB?

'I worked for 38 years in the NHS as a midwife, school nurse and most recently as a specialist TB nurse. I managed the combined Coventry and Warwickshire TB service for eight years and worked as a TB specialist nurse for 18 years. I was appointed in 2001 to develop a TB service and the rest is history.

I completed two modules in TB management and Control at the Birmingham University of Central England in 2001 and then attended Dr John Innes TB workshop and was invited back annually to present a session on TB nursing models. I chaired the Central England TB nurse group for 17 years until January 2017. I have written articles and until recently led the neonatal BCG programme in Warwickshire which has now successfully transferred to local maternity services.

Until the TB Action Plan (2004) and Commissioning Toolkit (2007) I had only the BTS Code of Practice (2000) on which to base my practice. Then NICE guidance kicked off and with the **RCN case management and cohort review** guidance (2012) I had an operational framework. Underpinning all of the TB nurses work now is the Collaborative TB Strategy, 2015 - 2020 which has led to wider recognition and ownership of TB services and control of TB.

I have really enjoyed my work and feel that TB nurses really do make a positive difference to patients. But it's hard work and dependent on the commitment of teams. I am optimistic about the future of TB nursing and am privileged to have worked with colleagues across the country in producing the TB nurse competency framework (2017) which will be central in shaping the future workforce.'

Have a great retirement Debbie.

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Using the TB nurse competency framework

Congratulations to Ingrid Madzikanda, lead TB Specialist Nurse at Bradford Teaching Hospitals NHS Foundation Trust. Ingrid successfully used the **TB nurse competency framework** to review and upgrade the team's band 5 posts to band 6 to better reflect, and acknowledge the level the TB nurses were actually working at.

4 TB on the Parliamentary agenda

On 7 June 2018 MPs in Parliament dedicated a parliamentary debate to TB for the first time in 65 years.

The motion being debated was:

"That this House recognises that Tuberculosis (TB) remains the world's deadliest infectious disease, killing 1.7 million people a year; notes that, at the current rate of progress, the world will not reach the Sustainable Development Goal target of ending TB by 2030 for another 160 years; believes that, without a major change of pace, 28 million people will die needlessly before 2030 at a global economic cost of £700 billion; welcomes the forthcoming UN high-level meeting on TB in New York on 26 September as an unprecedented opportunity to turn the tide against this terrible disease; further notes that the UN General Assembly Resolution encourages all member states to participate in the high-level meeting at the highest possible level, preferably at the level of heads of state and government; and calls on the Government to renew its efforts in the global fight against TB, boost research into new drugs, diagnostics and a vaccine, and give its fullest possible support to the high-level meeting".

If you are interested please see:

https://www.parliamentlive.tv/Event/Index/b01468ce-e264-431d-851f-b0197f96b619?agenda=True to hear and see the debate. If you click on the INDEX tab toward the right of the screen, it lists the motions being debated and the MPs speaking, then scroll down to 13.30 and you will see Nick Herbert MP open the TB debate. The debate lasts about 90 minutes and at about 14.55 Minister Baldwin sums up.

During the debate it was really good to hear Nick Herbert, other MPs and Minister Baldwin praise the collaborative work of UK TB stakeholders to bring TB rates down and sheer hard work of those on the clinical frontline.

Thank you, to everyone involved with TB and working to improve TB control. Together we are making a difference and this is being noted by politicians.

To subscribe to future updates please click here