Dr Onkar Sahota AM (Chair): That brings us today to the main business of tuberculosis (TB) in London and I welcome our guests: Professor Yvonne Doyle, London Regional Director, Public Health England (PHE); Lynn Altass, National TB Strategy Implementation Manager, National Health Service England (NHSE); Dr Marc Lipman, Consultant Physician at Royal Free Hospital and Jacqui White, Lead Nurse, North Central London TB Service. Thank you, you are very welcome and thank you very much for making the time to come to the Committee.

Let me direct my first question to Yvonne. We are described as the capital of Western Europe, or certainly capital of the developed world, with the highest level of TB. Why do you think we have more TB in London than any other city in the developed capitals?

Professor Yvonne Doyle (London Regional Director, PHE): The simple answer is the nature of our population is different from other European capitals, although we have looked recently in detail at Paris, for instance, which is a global city. New York is another one. Global cities accrue populations with high risk. Many of our TB cases have been living in this country for a while but were born abroad, so we do have accrual of TB from high incidence areas of the world. That has to be balanced against London’s place as a global city. That is one reason, and I think that will continue to be the case because of the sheer flux of people in and out of London.

The other thing is that it is important to keep infectious disease under scrutiny all the time. Obviously we have some excellent people here today who have always made this their life work, but if we lose that collective focus we find the bugs getting the better of us and that happens in all circumstances, including TB.

Dr Onkar Sahota AM (Chair): Yes. Do you think that we hold TB as a disease of yesterday and maybe took the focus off it? I know some cities like Paris took their focus off and they had to refocus on it. Has this happened in London?

Professor Yvonne Doyle (London Regional Director, PHE): I think it has and it waxes and wanes. Fifteen, twenty years ago there was a major effort around TB. I think people felt that it was beaten but actually it is still very prevalent worldwide. Therefore, we needed to get back on the case with it again as a collective city and that is what we are doing.

Dr Onkar Sahota AM (Chair): What is the impact of TB in London currently? What is the impact of this disease?

Professor Yvonne Doyle (London Regional Director, PHE): Much of the TB, and it is an issue that may come up in discussion, is not manifest, it is actually latent TB - it is asleep in people who may be at risk of it, for various social reason or for other reasons, from transmission or contact with cases. It is not that widely known. You will not see it walking around the street. It is kind of a hidden condition. There are between 3,000 and 4,000 cases. Happily the numbers have fallen in the last couple of years, a real fall, and we think that is real. However, there are those cases and once that manifests it makes people unwell. It is mainly respiratory conditions and it is manifested mainly by constant coughing. One of the issues, and clinicians may wish to comment on this, is that we have forgotten that somebody with a persistent cough needs investigation at time. Happily not that many in children, it is mainly a young adult condition.
Kit Malthouse AM MP: I just wanted to ask, to just go back to what you said at the start that there has been a decline, I guess. It strikes me from the day there was a decline back basically to the late 1980s, 1990s and then a general gradual rise right through to the present date over the last 20 years. When you said, “We took our eye off the ball, we lost focus on it because we thought it was beaten”, who is ‘we’?

Professor Yvonne Doyle (London Regional Director, PHE): Collectively in London, everyone. This is not a simple bug, it is linked to people’s social conditions, it is linked sometimes to prisons and it can be linked to other conditions that people suffer from, like human immunodeficiency virus (HIV), so it needs surveillance across the board like people who are homeless, for instance.

Kit Malthouse AM MP: Were there specific decisions taken at that time? For instance, back in 1988, or whenever, were there more TB clinics across London which then decisions were taken to close them down? Were there more clinicians who specialised in TB who decided, “Actually, do you know what? I think I’m going to go off and do something else”? Were there specific decisions taken, rather than just a general, “We’ll concentrate on something else”?

Professor Yvonne Doyle (London Regional Director, PHE): It is an interesting question. I do not know.

Kit Malthouse AM MP: What was the infrastructure like, I guess, back then?

Professor Yvonne Doyle (London Regional Director, PHE): I do not know exactly what was there in 1988, because I was not there in 1988. There has been, and there continues to be, a good infrastructure of TB networks and TB clinics and TB workforce. It is hard to retain the TB workforce, because it is its own cohort. People retire and then you have to retrain and recruit, particularly the nursing groups.

Undoubtedly the funding for various conditions may have waxed and waned over that period, depending on what was seen as preeminent, so that could have happened. We have looked at this very carefully in recent years. Why has the rate continued to increase? The main reason for that is actually that the prevalence continues to rise. In other words, we are gaining more people with the risk. Once they get to the service they are well treated and completion rates are very good, so this is not a failure of clinical service.

Kit Malthouse AM MP: OK. A stronger driver of the growth over the last 20 years you might say is what you would call the ‘internationalisation of London’.

Professor Yvonne Doyle (London Regional Director, PHE): To some extent that is correct, yes.

Kit Malthouse AM MP: I guess I came to London about that time, so 1990, and certainly the city has changed very significantly during my time in terms of the demographic and the population.

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Kit Malthouse AM MP: That, you would say, would be the stronger driver than necessarily losing a focus that we previously had?

Professor Yvonne Doyle (London Regional Director, PHE): Yes, I think that is the main driver. I am sure clinicians are dying to come in here. That is not to say that we have not had to work hard to get both Commissioners and hospitals and clinics to sustain the TB services. Once the focus goes off, like everything else, it is no different to any other service, sometimes people forget that actually these things come back and they can be very troublesome. It needs constant vigilance to ensure those services remain intact, but they are good.
Kit Malthouse AM MP: It strikes me, given the rate of change of the population in London, that it may be that we have been playing a bit of catch-up, or we have always been behind the curve on TB. There might have been a growing awareness of it, but it has never had quite the awareness and the attention required to keep up with the rate of growth perhaps.

Professor Yvonne Doyle (London Regional Director, PHE): Yes. I absolutely agree with that. The other factor that plays in strongly to TB is social factors, because at least 9% of the cases will have one or two social factors, like homelessness, or having been in and out of a prison system, or drug abuse. Those are very difficult people to keep track of. They will cross across the city and it requires a very co-ordinated service, not focused on institutions but on people’s pathways.

Kit Malthouse AM MP: The final question I just had is I am trying to imagine what the conversation about this looks like in your various decision-making bodies. You go and sit around a table and say, “Do you know what? TB is a growing issue, we need to deal with this, we have not got enough whatever, so we need to get ahead of the curve”. Someone says, “Do you know what actually? We’ll give you a little bit but not enough, because we’ve decided there’s something else more important” or, “This is what we’re interested in”. Is there a parallel conversation amongst clinicians where they say, I do not know, to medical students or registrars, “Do you know what? TB is what you should be doing” and they will say, “Oh do you know what? I’m not really interested in that. I’m going to go off and do cancer instead”? What does the conversation look like? Because much of this stuff is about individual decisions that are taken by various boards, groups, doctors, people in training and all the rest of it. Is it just that TB is not fashionable?

Professor Yvonne Doyle (London Regional Director, PHE): I would defer to Marc [Lipman] and Jacqui [White] on the clinical discussions, but there is another discussion, which is the commissioning and public health discussion. They are actually two separate types of discussions. When Lynn [Altass] and I got together in 2013 we realised that the focus was not as much on TB as it should be for the health problems in London, and we were very keen to engage the Commissioners. We have some excellent Commissioners and some excellent general practitioner (GP) providers doing work in the places that is needed. That had to be rebuilt on the commissioning side, so that is one thing.

Kit Malthouse AM MP: All right, sorry I have used up my time, there are other Members who want to ask about that.

Dr Onkar Sahota AM (Chair): We are very keen to bring the clinicians in and I will do. Just one more question. We have seen international travel to London increase, right? I remember days when there used to be chest X-rays done at the Heathrow Airport and at other airports, and we stopped that service. Do you think that has made an impact on the prevalence going up in the city, that we are no longer screening people coming into London, or into the United Kingdom (UK)?

Professor Yvonne Doyle (London Regional Director, PHE): It is always a question, and you know from Ebola there has been a great pressure to screen it at entry to the country. This was evaluated and found not to be effective in detecting. There is, however, an internationally-linked service that the UK is involved with, which is quite highly effectively - Lynn [Altass] might want to comment on it - which some of our colleagues run, that is about a sort of passport in advance of coming to the UK, which requires screening for TB. That is offered quite effectively in the countries of high prevalence. We feel that is much better value and actually has a much higher detection rate.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is a condition of visa entry. It is a condition of actually getting a visa from a number of countries and we are working with the US, Australia
and New Zealand and I think a number of other countries. Somebody has to have an X-ray to exclude active TB before they get their visa.

**Dr Onkar Sahota AM (Chair):** We are having people come into this part of the country, into the UK, who do not require visas, and they are coming because of the European market.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** We are focusing on the countries which have high incidence, Southeast Asia and Sub-Saharan Africa.

**Dr Onkar Sahota AM (Chair):** How about people in East Europe who are coming here?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** Their TB rates, while they are higher than the average in London and England, are actually still not as high as the areas that I have just mentioned, Southeast Asia and Sub-Saharan Africa.

**Kit Malthouse AM MP:** How long has that been a requirement?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** It was piloted probably about four or five years ago I think, and it has now been increased, the number of countries it now serves and they are actually now seeing quite significant -- [TB cases which are treated before they get their visa]

**Dr Marc Lipman (Consultant Physician, Royal Free Hospital):** Thank you. The point that Yvonne [Doyle] and Lynn [Altass] have made is incredibly important about this is an infection. This goes away when you manage infections properly - in other words, infection control. If you take your foot off an infection it comes back. The issue that Yvonne really stressed was this concept of latency. People will be infected, in general, probably as young children or young adults and they will carry the bug with them for maybe 30 years, completely well and then it will reactivate at some point. The tests and investigations that are done to assess latency, or looking for latent TB, they are effective but actually they are not done in the majority of people, or have not been historically. Therefore, people can develop TB at much later stage, will then become infectious to others and so TB is passed on. That is different to something like cancer. In other words, if you have a concerted effort against cancer you can probably reduce a large amount of cancer through early detection systems and so forth. TB is different, just because it will go from person to person. That is probably the explanation for why TB has persisted.

Therefore, to answer your earlier question about whether there was a failure of the system: What happened was that there was a failure of horizon scanning. The idea that if you stopped public health measures for an infection it comes back. We know that. We know that from Baltimore, in the 1950s and 1960s they introduced a very effective TB control programme, so then by the end of the 1970s and early 1980s they had almost no TB. What they then did was divert resource to New York, which saw an explosion of TB, and where did TB come back? Baltimore, because the public health control was lost because the funds were diverted.

What I think we have learnt, and the point I was going to make about Lynn’s [Altass] points about some of the pre-entry screening is these are new approaches that are being taken. In other words, what we are constantly striving for in TB is efficiency and cost-effectiveness. Actually trying to prove that we know we have a responsibility as clinicians working with the NHS to provide the best possible care, so your question about what are we doing about Eastern Europe, you are right, we have to be thinking about that.

The main burden of TB, where the thousands of cases come from is exactly where Lynn is saying, so India, Pakistan, China, Bangladesh. Those are the countries where maybe you would be placing most of your efforts, because that is going to be the maximum yield. It is very much a learning process. One of the things that is
very important for us is to learn from you and to hear the questions you are asking so we can go back and reflect on those and improve our services.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): I would also like to comment that actually 55% of TB in London is non-pulmonary, on average, which means it is not infectious. The actual difficulty of diagnosing non-pulmonary TB – because it can be anywhere in the body, and I will defer to my clinical colleagues here on more details about that – is that it is very hard for GPs. Somebody comes along with a mysterious pain in their spine, it could be back pain. It can be very difficult to diagnose. Those are the people where it can take up to a year or more to diagnose. Pulmonary TB sometimes, while it is transmitting and it is infectious, it is more obvious as it has a cough. If we can get people to send them into the hospital for the appropriate tests a bit earlier we would be a bit better off in terms of transmission.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, I’d like to also comment and with reference to what Yvonne Doyle said, is that we know that TB is linked very strongly to certain communities, as we have mentioned the Sub-Saharan African community, Indian Sub-Continent and Eastern Europe. We know that there is a lot of stigma attached to the disease within these communities, so often these patients will present very late to TB Services with quite advanced disease and may then be poorly compliant with treatment. Similarly, we also know that TB is linked to poverty and health inequalities, so it very much affects patients who have addictions, who are homeless, who are living below the poverty line and, similarly, their immune systems are very low so they will also easily transmit infection and again present very late to services. That has helped to fuel to problem that we have in London.

I have worked in TB Services for a number of years, as probably many of us have, and I think we very much concentrated previously on it being a TB treatment programme, rather than being a TB control programme. In the last decade we have really learnt a lot about we have realised that we need to concentrate and develop a TB control programme. If you look at cities like New York they adopted a similar model many years ago now, which was implemented very successfully. We have learnt an awful lot and we realise now that we need to be much more proactive about actually controlling TB, rather than just treating it in the clinics.

Dr Onkar Sahota AM (Chair): In New York they have a very centralised system across the city, co-ordinated a programme of huge investment, someone taking leadership from the New York Public Health Department. Who is taking the leadership here in London?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Probably my colleagues would like to answer that one.

Professor Yvonne Doyle (London Regional Director, PHE): We met our opposite numbers about this in New York to see how they had done it, but it is a very different system and they have a law. They can use the law. We have infectious disease laws but they can use the law in all sorts of permissive ways to help public health, which we do not have in London. How we do it here, therefore, is we have a TB Control Board, which I chair. It does need someone in charge and it needs leadership at each level, at the clinical level, at the commissioning level, at the voluntary sector level, so we have representatives. In fact, we have political representatives on the board as well and local government. We set that up two years ago this month in order to co-ordinate everyone’s efforts on this, because it is a complicated disease where there is very strong clinical input and public health. We use the best of what we can do work that forward.

We started off by saying, “What is the problem we are trying to solve here at the moment?” This was a very important realisation at the beginning. We know from our yearly surveillance, and there are very good reports produced every year on TB by the health protection side of our work with the clinicians, that the clinical services are very good. They are high quality and there are high completion rates. Therefore, we began to
realise that the issue for us in London was getting under the control what we call the ‘prevalence’: the amount of cases out there; where they are coming in from; and how you actually deal with it. That is where we put our focus, first and foremost, on securing the commissioning of good quality services, including anything on the preventive side that should be secured. We had good support from the London NHS Clinical Commissioning Groups (CCGs) on that right at the beginning. We then began to make sure that we tied up the loose ends on just making sure as many people as could be followed up were followed up. The contract tracing was a good as it could be and that is not easy for stretched services. Also, we made sure, and this is really good practice, that there was good buy-in to the reviews of the complicated cases - for instance the multi-drug resistant cases. I have sat in on that and it is very good and it gets a lot of clinical input. That was the first step.

The next thing was “What are we going to do to actually reduce the prevalence?” We set ourselves a very ambitious target of reducing the prevalence by 50%. There was a lot of controversy about that. People were worried that this would expose everyone and we would not do it, but my view was we have to do this because otherwise people will have no ambition about this, so let us try. We set that out and everything we do at that board answers that question: how will this get us to a reduction of 50% or more?

The next thing we know we have to do is try to find that secret TB out there that is actually waiting to light up. Clearly identifying TB cases earlier than late would be great, but the really big issue is the latent TB, the TB that is waiting to light up. Because when it does, that can transmit. The person themselves may not know that it is doing so or that it is harming them. It may be, as Lynn [Altass] says, obscure in their bodies. That is our major endeavour now in our second, going into our third year.

Dr Onkar Sahota AM (Chair): I know some of my colleagues will explore the work of the TB Board in more detail. We will come back to it. Just one more thing just before bringing Kit [Malthouse AM] in is that I understand that people form the Sub-Saharan countries are adding to the pool of TB in this country. Nevertheless, no one is exempt from it and there is latent TB around, so when you get poor housing, poor nutrition levels, reliance upon soup kitchens, these sort of people become much more vulnerable, to TB, and that is the time when the latent TB manifests itself. Have you seen any increase in this in the last few years?

Professor Yvonne Doyle (London Regional Director, PHE): We have seen an increase in homelessness and we have seen an increase in the number of social risk factors that might lead to increased TB. Because of the really sterling work, including getting at the prevalence, we are actually beginning to see a drop in some of the highest prevalence areas of London. We have to watch this very carefully, because it could simply be that we are not getting as many students as we had before or something has changed in policy and it is nothing to do with us at all, so we are to really watch this one. We are actually seeing an improvement and we think at least some of that is the work that is being done in these areas by GPs doing latent screening, by the very good cohort reviews in contact tracing and by getting and trying to identify and treat the multi-drug resistant cases. It is helping but it is a struggle, because the other factors are working against us as well, so it is very hard work.

Dr Onkar Sahota AM (Chair): You said the GPs are screening for latent TB. Is this happening?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): There is a National TB Strategy, which was launched in January this year, and a lot of the previous work in London contributed to that. The NHSE and PHE are jointly funding it. It is a collaborative strategy and part of the funding for it includes primary care-based latent TB screening.

Dr Onkar Sahota AM (Chair): Is it happening somewhere?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is starting.
Dr Onkar Sahota AM (Chair): Because I am a GP and I have not been aware of the scheme around.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Where are you based?

Dr Onkar Sahota AM (Chair): Ealing.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): We are about to start it.

Dr Onkar Sahota AM (Chair): I see.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): We are working with Ealing and Brent, Harrow --

Dr Onkar Sahota AM (Chair): These are the boroughs with the highest incidence of TB?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Newham, for instance, has been running it for a year. They actually were ahead of the game on this. The CCG put their own funding into this, rather than waiting for the NHSE funding, and they have screened about 3,500 cases so far and they are finding 26% of those patients that have the test are positive for latent TB and they are then offered the treatment.

Andrew Boff AM (Deputy Chair): 26% of those --

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Tested for latent TB. It is a targeted programme.

Dr Onkar Sahota AM (Chair): It is a targeted programme.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is a targeted programme, so they have to come from a country that has a TB rate of 150 per 100,000 or more.

Andrew Boff AM (Deputy Chair): Right.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Then, as I said, that is the figure so far, about 26%.

Andrew Boff AM (Deputy Chair): It sounds quite an effective programme, if you are picking up 26%.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It will be effective. We will not necessarily see the results until perhaps starting in two years’ time, because we know when people enter the country, unless they have active TB already, they do not seem to develop TB until they have been here two years or more.

Professor Yvonne Doyle (London Regional Director, PHE): Two to five years is when we find the highest switch around is, when it lights up. We do not know why that is. It could be a whole load of factors. To answer Dr Sahota’s questions, you will not necessarily hear about latent screening everywhere in London because we have gone for a rolling programme, starting with the areas of the highest problems, and Newham is the highest in the country. To the credit of the CCG they decided to start that. They are now also helping other areas like Brent. The CCG in Newham have offered to give their help to show how to do it in Brent, and
then we will roll on. What we intend to do is ask CCG areas who would be interested in going with this and we will try to support them to do it as part of the strategy.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): On a sector-wide basis, and there are five sectors for TB in London, we have been running programmes. Yesterday we ran one for North East London and we had all the CCGs there, we had nurses, public health. We also had one last week in North West London, to which Ealing came and were working very closely with the people there. We have had one in South West London and we are about to have one in North, Central and South East London. We are working very actively. As I said, Ealing are working with Hounslow and Harrow and Brent together. We are trying to get them to group together because it makes more sense in terms of the services, because they often refer. You have North West London Health Care, for instance, in your patch, so you have consultants in Ealing, who are part of that, and we are trying to get a more streamlined approach generally to how patients are cared for anyway.

Dr Onkar Sahota AM (Chair): Thank you.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): You are right, Ealing is in the top 10 for the country. Twenty-five of the CCGs in London are in the top 59 CCGs for England.

Dr Onkar Sahota AM (Chair): Yes. Thank you.

Kit Malthouse AM MP: Just a short follow-up on the visa thing, we never quite finished it. Are you are saying that has just started?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It has been running for two years but it was being piloted for a short period before that as well.

Kit Malthouse AM MP: Right.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): A condition of the visa is that they have had a chest X-ray.

Kit Malthouse AM MP: There are now some countries where it is 100% of people who come have to have this X-ray?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): I think it is if they are going to be here for a certain period of time.

Kit Malthouse AM MP: Right.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is three months or six months.

Kit Malthouse AM MP: Right, but it is too early, presumably, to tell whether that is being effective. Is that right?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): We have had some outputs from it in terms of information data and they have been picking up active cases, which then have treatment before they can have their visa to come to this country.

Kit Malthouse AM MP: Right, OK.
Murad Qureshi AM: Just on the back of what Kit said, because the issue about when people come into the country has been brought up twice now. Are there issues with frequent travellers? I have just recently been to Eastern Europe. I have been going in and out. I am going to South Asia in a few months’ time. I do not require any visas. I am not going to be picked up at all really, am I, with the visa application, because I do not have to put them in. How do you deal with frequent travellers and that movement of people across national boundaries?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is a level of risk. You do not stay in those countries for long periods of time, so your exposure to the local community, in terms of TB, and my clinical colleagues can perhaps say this better than I, is relatively low.

Murad Qureshi AM: It depends on the amount of time you are out there and the type of trips you are taking. Is that what you are saying?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Yes.

Murad Qureshi AM: OK.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Just to be clear, if you are travelling abroad, so say if you are going to India, if you are coming back with a UK passport you will not get screening. It will be people coming from India with an Indian passport seeking a visa to the UK, so it is somewhat different.

Kit Malthouse AM MP: You would still present the same risk.

Murad Qureshi AM: OK true. However, I do, for example, share the same air with passengers on the plane. That is one of the worst places to be sitting to pick up things from other people, is it not? Let us face it.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Not TB. Viruses maybe, but not TB.

Murad Qureshi AM: Not TB, OK.

Professor Yvonne Doyle (London Regional Director, PHE): It is a good question though. It is a much lesser problem than the issue of latent TB lighting up and so on, or people with social factors, but we do actually get cases in people who have travelled, particularly in areas of very high prevalence. Sometimes they are not quite sure how it happened, but they can pick up TB and that is part of the regular infection service. People are understanding what the risks are before they go to a place and what they need to know if they come back. There is very good information about, you know, if you are feeling unwell, if you have night sweats, if you are coughing consistently you must see your doctor and you may need a chest X-ray. That would be part of a normal infection service. It is not a latent problem, you will either get it or you will not. It is not that easy to get just by breathing the air.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): No. To reassure you, if you are a healthy individual you actually need a lot of exposed contact to someone who has active disease. In healthy individuals, usually, in most contacts that we trace, we do not find evidence of active disease and occasionally find latent disease. Your risk would be low, and I think that is the point.

Murad Qureshi AM: Hence why doctors do not come down with TB the whole time, right?
Andrew Boff AM (Deputy Chair): Incidentally, you know this is a really good interesting scrutiny session because we could almost abandon our list of questions, which we are very close to doing because it is so interesting this subject, so forgive us if we dance around a little. Back in 2005 the Department of Health issued the guidance that for children over the age of 12 months living in, or moving into an area of the UK where the incidence of TB is over 40 per 100,000 population, or greater, is not on its own an indication for vaccination. Is that advice still current?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): According to the TB Green Book, and in fact London has decided that because our TB rates were for a long time above 40 per 100,000, that even though we have 32 CCGs, we asked that we be treated as a single geographic area and the London Immunisation Board agreed to that a couple of years ago. Therefore, we have recommended to CCGs that they offer the BCG (anti-TB) vaccine to neonates, anybody who is born in London, and it is now part of the maternity tariff, so it should actually be offered at birth. It is obviously getting the mechanisms in place to actually make it happen.

Kit Malthouse AM MP: Yes, my kids were born at University College Hospital three years ago and they had it straightaway at birth.

Andrew Boff AM (Deputy Chair): But for young people who are mixing, as they do in London, with people who have come from countries, or visited countries with high TB rates, they are not automatically being tested.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Children are an interesting issue, because actually only about 5% of our TB population are children. I have forgotten what the population is, it is about 20% of the population of children in London. It is disproportionately less and my clinical colleagues here will perhaps say more than I about that. We do see children but it is the babies and that is why we give the BCG because it is the babies that get the more severe forms of the disease like meningeal TB and miliary TB and that is more important. As children get older they could perhaps get different manifestations.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): It comes down to your expectation of BCG. If you were to say to me, “Well, I had a BCG 50 years ago, am I protected?” the answer is probably not. Protection is actually avoiding infection, we are acquiring it. If we were both six weeks old and we had both been immunised six weeks earlier and you said to me, “What’s my protection being offered by BCG?”, I’d say huge. Exactly what Lynn is saying is that severe, so TB meningitis, some dramatic event that is going to kill a small child, BCG would be very effective if given at birth. Sometimes there is a misunderstanding about perhaps what the purpose of BCG is, or its effect.

Andrew Boff AM (Deputy Chair): If I was an expert we would not have you guys here.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Sure.

Andrew Boff AM (Deputy Chair): The risks for children, over the age of 12, so not babies, mixing with other children who may be a high infection risk, that is not a risk to all children?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): The interesting thing here is it is about length of time, like Jacqui [White] mentioned just now. It is about how long you spend with people who have infectious TB.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): I think it is also important to say that children are very rarely infectious. Very rarely infectious. The do not cough up the bacteria. It is very
It is incredibly difficult to get kids to cough up spit. You cannot get sputum from them at all.

The reason why it has changed is that now the risk is felt to be of death in the first year of life and BCG will definitely cover that off. It is an interesting debate as to when the best time to give vaccinations are. Given the number of cases we see in the one to 16 year age group, BCG is probably not worth their effort and the cost of the thing, but it is to protect the lives of those babies.

Kit Malthouse AM MP: For newborns, right.

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Dr Onkar Sahota AM (Chair): Let me just come back this way. You said London is looked at as one big CCG, right? Or one big area. Are all the 32 CCGs giving that vaccination to newborns in London?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Not all of them are at the moment.

Dr Onkar Sahota AM (Chair): Why not? If it is a London-wide policy why is it not happening?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It was only instituted last year, in 2014, and it is increasing.

Dr Onkar Sahota AM (Chair): How many boroughs are giving it?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): You have got me, let me think. 75% of them, because I had to do a report about a month ago. 75% of them are trying to do universal BCG, or offering it.

Dr Onkar Sahota AM (Chair): There is a huge variation out there --

Lynn Altass (National TB Strategy Implementation Manager, NHSE): The ones that are tending not to give it are the ones in South London, particularly South West London, which have very low rates of TB anyway, and they are doing it on an at-risk basis so the babies of the mothers who are at risk are offered BCG.

Dr Onkar Sahota AM (Chair): Despite having taken this decision that everyone in London should be treated equally, right, that all boroughs should be doing it, we still have not got there. What is holding it up?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): There are issues around training. BCG requires special training in how to give it. If you give it wrong it can leave the skin with a very bad scar.
Kit Malthouse AM MP: That is quite true. Both my sisters have horrific scars on their arms.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Yes. You have to balance. The boroughs that are giving it are the ones that should be giving it and we are working with the ones that are not, but it is a risk assessment.

Dr Onkar Sahota AM (Chair): In my part of London, there are some hospitals giving it and some hospitals are not, right?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): You will have a local catch-up mechanism that is provided by your community services for those babies that do not get it. Some parents do not want it to be given to their baby at birth and they then have a second thought and say, “Yes I do” and babies have it, but by that time they have left the care of the maternity services.

Dr Onkar Sahota AM (Chair): All I am trying to say is it is very patchy out there on the ground.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Also we see that coming through from patients. It has previously been a confusing and quite contentious policy, the whole selective BCG policy, because you will have situations where you will have a family across one side of the street who will get the BCG vaccination and Mum says, “Well, my friends have got it across the road but we’re not having it”. Obviously it has changed now and it is great that it has changed, but that is difficult for people to understand. Actually it is not that logical because TB bacteria will travel across the street. The universal policy is definitely the way forward. London does have a high incidence of disease.

Andrew Boff AM (Deputy Chair): The universal BCG was ended in 2005. Has it actually had an effect, do you think, on the infection rates as a result of that?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It was abandoned for the older children but it was then concentrated on the babies under a year, who actually have more disabling disease.

Professor Yvonne Doyle (London Regional Director, PHE): The short answer is no, it has not actually made a huge difference to the numbers and certainly not to the deaths. We will be watching and every one of those would be picked up with the cohort reviews, so it is under surveillance. What is a problem, as Jacqui [White] has said is that it can be quite confusing to know whether you are getting it or whether you are not and if you do not get it where else could you get it. Therefore, we decided that the children who are most at risk are the babies and London universally should go down this route of offering it. It has not yet done that, because it is quite recent, and we need to make sure it does.

Andrew Boff AM (Deputy Chair): Yes, to everyone in London. There is a logic, is there not in saying in boroughs where there is a high incidence you just offer it to everybody?

Professor Yvonne Doyle (London Regional Director, PHE): That is exactly what is being done.

Andrew Boff AM (Deputy Chair): People would understand that and they would understand, “Well I’m not in Brent, I’m in Harrow therefore, I’m not --” whatever.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): Dr Sahota actually made the point that it can be a patchy delivery, but we are endeavouring and trying to ensure that people are vaccinated. For instance they have just changed the way they count - the database that we use - so we are just reviewing how we can get the data to double-check what the percentages are across the CCGs in London.
We know that database is working well in some boroughs or CCGs, not working so well in others, so part of the work I am doing with the London Immunisation Board is to track the CCGs across London for those BCG rates.

**Dr Onkar Sahota AM (Chair):** When you say ‘we’ you mean your National Strategy Board of London is doing this? When you say, “We are mandating the CCGs to do this” who is ‘we’?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** The London TB Control Board and the London TB Network.

**Dr Onkar Sahota AM (Chair):** You make a recommendation to the CCG but it is up to the individual CCGs to take it on board or not?

**Dr Marc Lipman (Consultant Physician, Royal Free Hospital):** Yes.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** What was interesting was it actually became part of the maternity tariff about two years ago, so it can be offered without and additional cost to CCGs, and that is really important to note.

**Kit Malthouse AM MP:** Could I just ask about this word we keep using ‘offered’, because from memory I do not think we were offered, we were just told. There is a suite of things they come and do, they check they are not deaf, they do all that kind of stuff in the maternity and they stick a few needles in them and say, “Oh this is the right --” and there we go. When you offer is it ever turned down?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** Yes, I think it is sometimes.

**Professor Yvonne Doyle (London Regional Director, PHE):** It certainly is. It is a very interesting question. This is a debate. In America you are told to do it and you cannot go into school unless you have had your jabs, as they say. In this country it is offered, and people feel that is the right way to do it, because the vast majority of parents, with the right information, will accept, but some will not. We just have to respect that. My parents would not allow me to have the BCG in Ireland because I think they thought the risks of the vaccination were too high, so someone did not talk to them properly. With a trusted doctor or nurse to talk to the parents, the parents generally will accept that they want to reduce the risk for their children. It is an offer. My view is it should be offered. If you get into the kind of bullying around vaccination I think everyone feels very uncomfortable with that and it is mostly not necessary.

**Andrew Boff AM (Deputy Chair):** I am pleased you said that, because my group published a report back in 2009 recommending that the vaccination should be offered to everybody, in those boroughs where there is a high incidence. You are now saying pretty much everybody should be offered it, so that is an encouraging thing.

**Professor Yvonne Doyle (London Regional Director, PHE):** Yes.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** We have done regular reports so we are very happy to share those reports with you which update you on which boroughs are and are not able to offer.

**Jacqui White (Lead Nurse, North Central London Tuberculosis Service):** We are more likely to get a higher uptake when it becomes normalised as the standard practice at birth across London. The problem with the old selective policy was that it put doubt in people’s minds about it, “Well if they’re not having it do we
really need it?” It opens up that whole debate. Whereas if the whole of London is being offered the vaccine and it is normal practice we are probably more likely to see a better uptake.

**Kit Malthouse AM MP:** It used to be the case at the National Childbirth Trust (NCT), who run those classes, they had a big thing about, I think it was called syntometrine, which is an injection they give you immediately after birth to ensure the placenta detaches quickly, and they had a big downer on this. I can remember going to NCT classes and being told - this is my first child some time ago - saying, “You must not allow them to do this to you” and all this kind of stuff. I guess if some of those anti-natal classes are saying, “By the way, you will be offered this, you should be saying yes”.

**Professor Yvonne Doyle (London Regional Director, PHE):** Yes. We are very keen on the role of midwives in general about giving every child the best start in life, which this is. It is part of that package that you are offered to protect your children.

**Andrew Boff AM (Deputy Chair):** Do forgive me if we start to ask questions that you have already answered, and remind us that you have answered it. One of the questions I was going to ask is how will the TB strategy help control and manage TB in London and, Ms Altass, you have pretty much answered that.

How much is currently spent in London on TB control and management? What are the figures?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** We have estimated it for the impact assessment for the National Strategy and nationally it was estimated to be in the region of £50 million. If you estimate that 40% of TB is in London then you are looking at perhaps £20 million to £30 million across London.

**Andrew Boff AM (Deputy Chair):** £20 million to £30 million but that is an estimate.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** It is an estimate and it may not cover everything that we pay for.

**Andrew Boff AM (Deputy Chair):** OK. So the global figure is £50 million and we are making that assumption because 40% of the cases are in London.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** I know NHSE and PHE are investing £11.5 million, £10 million of which is for primary care-based latent TB, just in the treatment.

**Andrew Boff AM (Deputy Chair):** What proportion of that is allocated to London, do we know?

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** About 40%.

**Andrew Boff AM (Deputy Chair):** About 40% again, OK.

**Lynn Altass (National TB Strategy Implementation Manager, NHSE):** About £4 million.

**Professor Yvonne Doyle (London Regional Director, PHE):** About £4 million.

**Andrew Boff AM (Deputy Chair):** How many people do you expect to be tested for latent TB infection as a result of this? What is the target you are trying to hit with that?
Lynn Altass (National TB Strategy Implementation Manager, NHSE): In London the full year effect would be just under 30,000 potentially, and that is prospective, so we want GPs to offer it at the new patient health check, but we are also offering the money, because we have £10 million for this year. The programme has not completely started yet, so we have a bit of an underspend. We are also offering the opportunity for retrospective screening, so going through GP lists for people who have been in the country for five years or less, who fit the criteria of coming from a country of 150 cases of TB per 100,000 or more. We are quite happy for it to still have a full year effect, even though we may not be able to do it over a full year.

Andrew Boff AM (Deputy Chair): In answer to my last question, which you have fantastically anticipated, is that it will not be allocated by borough, it will be allocated by incidence. Is that correct?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): It is based on a formula, which is that the CCG has to have a TB rate of 20 per 100,000 or more, or, 0.5% of the total of England’s TB numbers.

Andrew Boff AM (Deputy Chair): I can see that.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): That has given us 59 CCGs across England, of which 25 are in London.

Andrew Boff AM (Deputy Chair): OK, thank you very much.

Valerie Shawcross CBE AM: One of you said earlier on something along the lines of people have forgotten that a persistent cough needs investigation, so we are interested in these topics of knowledge awareness and stigma in the community. What do you think are the main barriers to raising awareness of TB in London in the community?

Professor Yvonne Doyle (London Regional Director, PHE): Jackie [White] may want to answer this because she is very close to the patient, and I am happy to bring in the perspective of some of our voluntary sector colleagues on the Board.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, that is fine. We have already mentioned stigma, which is a really big problem, especially amongst certain communities, the ones that we have mentioned already. Do you want me to tell you solutions, or just tell you the barriers?

Valerie Shawcross CBE AM: A bit of both. Tell us what problems you think you are facing. This is my first meeting on the Health Committee, I have to say, and I have other topics, so in many ways I am just a general punter when it comes to talking about health matters. I see nothing and I hear nothing about TB. I have been in my GP’s surgery in fact this week on something else and I saw nothing and I heard nothing on TB. What needs to be done and what is being done?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes. In terms of stigma one solution would be for us to get really into the communities where the stigma exists, in order to some health awareness training and to encourage them to access services when they become unwell. That is not straightforward. As local TB Services, part of our remit, which is in all of our job descriptions, is to health awareness raising in the community, which we do to a certain extent. It usually comes at the bottom of the pile of priorities, because our priorities are usually very much clinical, so it is hard to fit in that aspect of the role. That is the first issue.

One way around that is that we need to actually get advocates from within those communities to be working within the communities and bridge the gap between the TB Services and the communities. There are often big
issues with trust around healthcare professionals. For example, if you wanted to go and do awareness raising in a mosque, and they are great places to target, you would really need to be a male. There are a lot of cultural sensitivities and you have to be sensitive to the belief systems of particular communities in order to effectively raise awareness. There is much more to it than just being the role of TB Services. There is an awful lot of work that needs to be done to get into those communities. For example, if we were going to launch a London-wide awareness campaign on television (TV), on the sides of buses and in the Tube, I am not sure how effective that would be. I am not sure if the right people would be looking at it and understanding it. It needs to be much more personal in order to bring people forward to actually access help when they need it.

Valerie Shawcross CBE AM: Is there an actual programme of information, public education awareness raising?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, there is loads of great work going on in the city by TB Services and also by organisations like TB Alert. I do not know if you can think of any other ones.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): We also go out to colleges as well.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, and there are various resources that we have, usually provided by TB Alert, which are in the appropriate languages and with the appropriate information. That is a resource that we can use and a tool that we have.

Lynn Altass (National TB Strategy Implementation Manager, NHSE): One of the tools we use is the World TB Day.

Professor Yvonne Doyle (London Regional Director, PHE): World TB Day is great but actually we have some very good examples. Sorry to cut across you, but it is just it may help answer the question. There is outreach to some of the colleges where the students from these countries of high prevalence come, both in this city and in Birmingham. There is a housing and homeless project for Eastern Europeans in London. There is a Citizens Advice Bureau (CAB) programme for TB cases, which is happening around the country, the exemplar is the West Midlands and CAB are connected into that. The Refugee Council is involved in working with various groups and we have, of course, got the TB van – two vans now – which goes out and does multi-testing. We just launched a revamping of that van. It is run from Central London, it is attached to a homeless service, but it goes around the 32 boroughs of London, and finds cases, particularly those who will not really approach any services. We have in-reach in some of the prisons and we have Hackney and Newham doing exemplar work, particularly with housing and in-reach into vulnerable communities. TB Alert works with us at the board level to try to get bodies to get those who are identified to complete their treatment from their own communities.

Valerie Shawcross CBE AM: It is very much a targeted strategy you are talking about there.

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Valerie Shawcross CBE AM: Is that because there is a dilemma about the possibility of raising awareness in the non-target groups and creating demand for checks and services which really would be a waste of resources? Is that a reason why you have not done more in the mass media, for example?

Professor Yvonne Doyle (London Regional Director, PHE): Probably the reason it has not been done in the mass media, recently at least, because we have done quite a lot of mass media working with the *Evening*
Standard, working with the national media on TV to raise the profile, is just as we have said, it fell down the awareness list. However, there is a question as to whether it would be effective. I understand how the thinking on TB has changed. Now it is just another infection in certain Western countries, but with these communities this can be a huge issue of stigma and it attributes something more than it is to itself. Therefore, just general blasting the bus and the Tube will not actually get under the awareness and, “I must do something about this” or, “I must make sure that we talk about this”.

In these communities that we are describing we have worked with local government, for instance, with councillors, to try to raise it more generally in places like Newham. That can be quite effective as a general intervention, but just putting it across all London Buses I think probably would not.

Valerie Shawcross CBE AM: It would be counterproductive in some ways?

Professor Yvonne Doyle (London Regional Director, PHE): It could be.

Valerie Shawcross CBE AM: Can I just suggest, Jacqui, I would not at all be shy about sending women into a mosque. I have spoken in mosques, women worship in mosques. People want to hear health messages and I just reacted a bit when I heard you say you have to be a man, well actually you do not.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): I am just quoting an experience that I had.

Valerie Shawcross CBE AM: I have been welcomed into many mosques.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): I am sure that there are many mosques that would welcome females but it is just --

Valerie Shawcross CBE AM: Is public education on health issues targeted at women not often effective?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes.

Valerie Shawcross CBE AM: Is that not something we should maybe think about?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Maybe it was a bad example to use. It was just an experience that I had had, so I was relaying it.

Valerie Shawcross CBE AM: Yes, I know it varies from place to place, but equally it can be a very good --

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): My point was that you have to be very sensitive to the belief systems with the communities. I think it is important.

Valerie Shawcross CBE AM: I know, but I think most communities believe they want their people to be healthy and making the offer is important. That is a personal view.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, that is right, but I also think that with TB there is such bad stigma attached to it that people will walk in the other direction. I have had that experience. If you have a health promotion stall in a street, we have done one on the Holloway Road, people will not come near it because it has TB written on it. Some people would rather walk in the opposite direction because there is a fear about it, so we must not underestimate that fear that exists.
Andrew Boff AM (Deputy Chair): Will you be publishing leaflets and public information and stuff?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): We will be doing some work through the strategy to allay the fears about latent TB treatment, but also raise awareness of TB. I can give you an example.

Andrew Boff AM (Deputy Chair): Just on that point, you can get into every community in London, you just have to be sensitive. With regard to Newham, the Mayor of Newham has indicated that he does not want any leaflets in future printed in anything but English. Are we going to overcome that by any chance?

Lynn Altass (National TB Strategy Implementation Manager, NHSE): A lot of our leaflets, which we do work with on TB Alert are actually available electronically in many languages, so they can be printed off by the nurses as and when. I am probably making it sound easier than it actually is, but they can be printed off for patients, or contacts of patients, at the time in the language that they want. Or at least you can get a supply ready by downloading them.

It is an interesting point, because I used to be a Commissioner for Newham many years ago. We actually found that if they were illiterate in English they were often illiterate in their own language. Some of the leaflets we were doing for more general healthcare were just being put in the bin because people did not understand it. It is getting the middle line.

We did have a patient who has been a patient advocate. He was an Indian young man who was born and bred in this country and he told his temple that he had been on a diet because of the stigma, because he could not tell his community that he had TB.

Valerie Shawcross CBE AM: These things need to be challenged, do they not? I do not think it is necessarily culturally specific. From a white working-class community I remember people whispering and saying silly ill-informed things about not drinking from teacups. These things need to be challenged if we are going to move people on, but challenged positively.

Let us move on a little bit. Is there something that you want the Greater London Authority (GLA) or the Mayor to do? Is there an ask that you have to help progress the strategy and perhaps make it hit the spots that you need to hit to reach the people?

Professor Yvonne Doyle (London Regional Director, PHE): It is always a pleasure working with the Mayor as his adviser, because he has recently described quite graphically how inequalities can affect London. We have asked him to say things that we cannot say. He can say it. He connects with people. We need to give that some consideration as to what we would ask and how we would use the GLA and the Mayor in this circumstance. My guess is it could be around the latent TB screening, where we will be making a major effort to get people who would not feel unwell, but to come forward and accept the screening if they are in a high risk group, for their benefit first, their families and their communities. In saying that, through trusted health democracy would be enormously helpful. I would defer to my clinical colleagues as well as to where they feel the need for your help would be greatest. Marc might have other ideas about this.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): One of the key things that comes out of the discussion that I think everyone has had so far is this sense of diversity, that there is this thing TB and there is latent TB and there active TB, but if we are just focusing on the people who are at risk, actually there are so many different groups. There are the foreign born, there are the homeless, there are, as you say, people who maybe are not getting BCG, maybe they are at greater risk. There are a lot of uncertainties. We know
that immunosuppression, so the use of drugs for chemotherapy, the use of biological modifiers, that increases the risk of active TB. Therefore, healthcare itself is producing more and more groups at risk of TB.

The reason for that preamble is that I would see something like improving access or improving information as a really important thing that definitely the Mayor and GLA could push and promote. It is not just one size fits all, it is a number of different approaches. The discussion you were having with Jacqui [White] is really important about one area. As Yvonne [Doyle] and Lynn [Altass] were talking about, the mobile X-ray unit and the bus going around, that is going to be working perhaps with communities who maybe are homeless and do not get to access care in other ways. That can be seen as a massive health promotion vehicle for dental check-ups, which we know are incredibly important in the homeless because if they cannot eat they are really going to fail. It is less about a single thing and more about intellectual concepts. I know what you really want is something in substance so I would probably push for improving access or looking to reduce stigma, something like that. That would be on my wish list.

Valerie Shawcross CBE AM: A very specific thing, several times I have heard prisons mentioned. It is not something we have any responsibility for in the GLA or even in the local councils in London. It does concern me that prisons, Government-controlled institutions, might be problematic. It would be helpful if you just say two minutes as to why prisons are associated with risk factors. If you read the Government guidance it says prisoners are entitled to medical services and they get this and they get that. Having visited [HM Prison] Brixton Prison, which is in my constituency, I do get a sense that there are some serious problems around what is available. Is there something you can say knowledgeably about why we have a problem with prisons and how bad it is?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): We know that there is disease transmission within the prisons. We have cases of TB that have come from the prisons. In my sector I have got Pentonville and Holloway Prisons. Prisoners are at increased risk of TB. They usually will have one or more risk factors. Being in prison is one risk factor and they usually have a whole host of other risk factors. When they are in prison they are in close confines so there is ease of transmission of disease if they are infectious in the first place. Often they may have come from deprivation - not always, but sometimes - so there are those issues.

The prisons have got digital X-ray machines in them. What should happen is that every prisoner, on entry, should get an X-ray. That was great. At the moment the X-ray machine is not commissioned in Pentonville so prisoners are not getting that screening, which is obviously disappointing. It is a missed opportunity. About 8,000 people go through Pentonville every year. It is a remand prison, there is a very, very fast turnover. We know they are at risk of TB. It is the perfect opportunity to screen so they should definitely be getting the X-ray. When the X-ray machine was operational we were regularly getting referrals. Not all of them had TB but some did. It is really crucial to get the X-ray facilities up and working inside the prisons. That is one part of the strategy.

Valerie Shawcross CBE AM: Who has the power to make that happen?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): There are several reasons why they are not working properly at the moment. One is access. The X-ray particularly in Pentonville is not near their healthcare centre as I understand it. It is also the reading of the X-rays.

Kit Malthouse AM MP: You mean within the prison?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): It is within the prison.
Valerie Shawcross CBE AM: It is a physical problem with the layout of the prison.

Kit Malthouse AM MP: How big is the thing?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): It is a room.

Valerie Shawcross CBE AM: It takes resource of officers to escort the people through to the area.

Kit Malthouse AM MP: To move the prisoner from the health centre to the X-ray and back.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): The actual issue we have at the moment is that the digital X-rays have to be read. We had a contract to have them read. The provider for that has stopped reading them.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): They never started!

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): There were a range of issues as well. The contract ended up getting terminated and we are looking for a new contractor at the moment. The health and the justice system team at NHSE London are working on that.

Valerie Shawcross CBE AM: That is a bit worrying.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Can I just add one more thing to that. At the moment the mobile X-ray unit goes into Holloway Prison once a month to do screening. I am trying to set that up to go into Pentonville Prison while the X-ray facilities are not working. We are proactively trying to screen.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): The reason for getting X-ray systems into the prison was because of the work of the mobile X-ray unit which was identifying the numbers of prisoners with TB. It was felt it would be cheaper, in the long run, to actually put the systems into the prisons. We have got five in London across our prisons and they are not really being used to a greater or lesser extent. Obviously staff have to be trained. There is a turnover of staff which does not help.

Valerie Shawcross CBE AM: Is the same procedure in place for detention centres?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): Not at the moment. They are looking at putting them into some of the immigration removal centres.

Valerie Shawcross CBE AM: Thank you.

Dr Onkar Sahota AM (Chair): Looking at raising awareness, some cities around the world have TB ambassadors. Do they have a role to play in this and does London have a TB Ambassador?

Professor Yvonne Doyle (London Regional Director, PHE): We do, that is Ms Emma Thompson. Her son, Tindy, was somebody who actually suffered from TB - this is well known - and was treated very well in London. She wanted to help and we asked her if she would be the Mayor’s Ambassador and she has agreed to that. Actually Tindy does the work. He comes along, helps and champions it. That is fantastic because there is a lot of traction with the various communities in London with Tindy, so that has been enormously helpful.
Dr Onkar Sahota AM (Chair): Have the TB ambassadors worked in other cities? Apart from Emma [Thompson] in London, how are cities using them?

Professor Yvonne Doyle (London Regional Director, PHE): I do not actually know. It probably depends on the interests of the person themselves. Mainly it is a kind of celebrity which gets at the stigma issue to say, “Look, it could happen to anybody”.

Valerie Shawcross CBE AM: It is an illness like any other.

Professor Yvonne Doyle (London Regional Director, PHE): “We are in it together.” It was enormously helpful when she came forward and destigmatised it in that way.

Dr Onkar Sahota AM (Chair): We should publicise more often that Emma Thompson is our TB Ambassador for London.

Valerie Shawcross CBE AM: We should invite her in, Chair.

Murad Qureshi AM: It is as much of a stigma out there, so to speak, if you go to places like Bangladesh. I do think our aid programmes have a contribution to make on that. That is what we have done with Ebola, for example. I trust that is something we all sign up to and we know the aid budget will be protected for the foreseeable future.

Professor Yvonne Doyle (London Regional Director, PHE): Thank you.

Murad Qureshi AM: In some ways I am dealing with the ‘prevention is better than cure’ bit. We have variously dealt with it but let us try to deal with it in a concrete way. Yvonne, what do you think are the main challenges with putting an emphasis on prevention?

Professor Yvonne Doyle (London Regional Director, PHE): The main challenge is the sheer flow-in and flow-out of London, the sheer turnover. It plays out in the prisons, this discussion, which I agree is concerning. The sheer turnover of people, finding them and identifying a way that they will accept the services. Preventive services are not where you are feeling ill, it is where you actually do something to avoid getting into that situation. Latent TB screening is the way into this. There are not many places in the world doing it. The Netherlands do it. We really will be at the leading edge of this.

The main thing is to get the population that is at risk and with the highest problems to accept it. We will all be working very hard on that. That is why I would be very grateful to come back to the GLA to ask for your help in ways that you could offer. That is a game-changer if we get this right. The technology has improved to the extent that it can be done at points of first contact, like general practice. It is quick and relatively cost effective now so it is a really important move.

Murad Qureshi AM: Essentially you are saying a less mobile and more stable London population is the ideal in this.

Professor Yvonne Doyle (London Regional Director, PHE): We have got to find them. The bedrock of finding the population is general practice. We have given other examples, like the van which we have secured. It was not secure years ago, it is now. Also, the outreach into schools. We have a team that do that and they are highly effective, going out to find people. We have got to go to people as well as just sit waiting for them.
Murad Qureshi AM: In terms of mobility, it is not just mobility coming into London as there is also a fair amount of mobility within London. You mentioned the homeless, but that is not the only group that is going to move around. If you look at the private rented sector and homes in multiple occupation, for example, I have seen a lot more movement recently than previously. Is that part of the issue as well?

Professor Yvonne Doyle (London Regional Director, PHE): It is a big issue and it will become an issue as people press outwards looking for accommodation. It is not just homeless populations that will move. In the future we may see TB beginning to move further eastwards, outwards into the 'doughnut' of London’s boroughs as people are looking for affordable housing. We may see risk travelling around more than it has at the moment, where it is quite concentrated in certain places. That is an interesting one to watch and we will have to keep mapping that.

Murad Qureshi AM: Have we eliminated all possibilities of any indigenous sort of TB coming up? We have tended to emphasise how it comes in and out with migration flows. It was one of the major battles we had after the war. Are we on top of that? There are not things coming out of London itself rather than the flows in and out of London?

Professor Yvonne Doyle (London Regional Director, PHE): As Jacqui [White] has said, the risk for populations born and reared here are social problems. A lot of people who have worked in various places in the past who become homeless, have mental health problems or are drug addicts and there will be a risk for them. There is no doubt TB is higher risk in those populations.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): For TB, 85% of the population in London is non-UK born.

Professor Yvonne Doyle (London Regional Director, PHE): I was trying to remember the statistics.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): Yes, it is 85%. So 15% is UK born. That can include people who are from non-UK origin communities, if that makes sense.

Kit Malthouse AM MP: Of the 15% who are UK born, how many would have parents or a relative who was non-UK born? You talked about transmission within families.

Professor Yvonne Doyle (London Regional Director, PHE): We think between 30% and 40%. We will check that one but it is quite high still.

Kit Malthouse AM MP: So 30% or 40% of the 15%?

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Kit Malthouse AM MP: You are basically saying that essentially 90% of the TB population either was non-UK born or has a close relative who was non-UK born?

Professor Yvonne Doyle (London Regional Director, PHE): They have some contact, yes.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): It will change across CCGs across London, so you will see a different picture in some of the boroughs.
Dr Marc Lipman (Consultant Physician, Royal Free Hospital): If you look at the actual incidence - in other words the number of new cases occurring - in white, UK born individuals, it has not declined. In other words, it is not dropping off.

Kit Malthouse AM MP: Has it grown or is broadly stable?

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): There are two bits. Exactly what Lynn [Altass] and Yvonne [Doyle] are saying, the absolute number of cases is predominately in the non-UK born.

There is very clearly a relatively small number of individuals with TB who are white and UK born who seem to be extremely good at transmitting TB. That is probably why the number each year, although small, has not declined as you would expect. If you were able to control local TB then you would see a reduction in those cases of people who should not be being exposed, they should not have acquired it from abroad or whatever. Because that has not declined, that suggests transmission is occurring. We know that from the projects that have been running looking at the homeless, that there are very high rates of transmission. We have done some work looking at the prevalence of latent TB in homeless populations. One in five have evidence of previous TB infection. We predict that a proportion of those will go on and develop active TB. In other words, it is still ongoing.

That comes back to this point that one programme is never going to work. There has to be a variety of different approaches.

Kit Malthouse AM MP: Marc, maybe I missed it, but is the population you are talking about broadly stable in terms of numbers?

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): The difficulty, of course, with homelessness it depends on your definition. It comes very much back to your point about a transient population. Do we call someone who is a ‘sofa-surfer’, who is sleeping on friends’ couches, or who may move from here to here to here, homeless? In theory they are homeless because they do not have their own abode. Of course, the group we are mainly focusing on are those who are either living in shelters, hostels or genuinely street homeless. They are a much smaller number.

Kit Malthouse AM MP: Sorry to press the point, the indigenous population is broadly staying stable is what you are saying? Notwithstanding there are fluctuations. There will be issues about, as you say, detection, whether they are coming forward. Broadly, it is like reported crime is different from actual crime. What you would say then is the reported rate in that small population is staying broadly stable?

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Yes.

Kit Malthouse AM MP: Yes, OK.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Probably the actual rate too. We have got better at detecting it so we found more initially but although we are seeing a reduction in overall TB cases - and perhaps we will get on to talk about that - in London, which is really impressive, in the populations where that might be happening it is probably from a variety of things. It may well be that in the white UK-born there has not been the same reduction as you might see in other populations. That is important. Because this is an infection it is something to bear in mind that if we ignore that bit then we may see a resurgence and we may see, for example, more drug-resistant TB, which we know is strongly associated.
Kit Malthouse AM MP: On the prevention side, I wanted to ask what the effect age would have. Obviously there was a mass vaccination programme post-war which persisted right through until relatively recently. Was it the same vaccine all the way through? Did they develop it and did it become more effective over time? I would be surprised if there was not research into making it better. Therefore, is there a generational impact on the population? When we came up to The Whittington Hospital, we met an older lady who had been diagnosed with latent TB. She was quite elderly and she was born pre-war so would not have been vaccinated as a child. Is that likely to have an effect? For example, will the non-vaccinated population start to decline as they sadly die and then the vaccinated population come through and that have some kind of impact, albeit, Marc, you said the older you are the less resistance you have.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): The less benefit it confers.

Kit Malthouse AM MP: Yes, the less benefit it gives you. I think I am right in saying from our visit, the benefit when you are older is against the more severe forms, is that right?

Professor Yvonne Doyle (London Regional Director, PHE): The vaccine will not protect you at that stage. Marc will correct me if I am wrong here, it is not very common in older people. When it does blow up it is usually for either social reasons or that they have some other condition, particularly cancer or rheumatoid arthritis, where their immune system is not up to it to stop the disease.

Kit Malthouse AM MP: It is not common in older people?

Professor Yvonne Doyle (London Regional Director, PHE): No, our main problems are not in older people.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): It is the 20 to 40 year olds.

Professor Yvonne Doyle (London Regional Director, PHE): It is the young adult.

Kit Malthouse AM MP: The normal curve would be around 20 to 40?

Professor Yvonne Doyle (London Regional Director, PHE): Yes, that is the big group. It is not that it does not happen in other groups, but there is usually another reason for that.

Kit Malthouse AM MP: The mid-point of the population would be 30?

Professor Yvonne Doyle (London Regional Director, PHE): Yes, 30, 35. We identify it as a student to young to early middle-age population.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): Socially and economically active is the phrase.

Kit Malthouse AM MP: On that, is there a particular split, male-female? We have talked about ethnicity, more men than women or the other way around?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): Much commoner in men, mainly because of the migration issues. More men are coming in.

Kit Malthouse AM MP: A 35-year-old man is at the highest risk?
Professor Yvonne Doyle (London Regional Director, PHE): Yes, it is very difficult to say if you are walking out there and you are a 35-year-old man non-UK born --


Kit Malthouse AM MP: A non-UK born, 35 year-old man is in your -- ‘sweet spot’ is the wrong word.

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Murad Qureshi AM: I want to pursue the line of thinking that I had. It is useful to emphasise the social aspects. I was trying to get to the physical environment. One should not forget it was environmental health officers that started the intervention in social housing really. It was not housing problems. That came on the back of their interventions. I want to be reassured, you do not think there is any type of housing in London which is possibly associated with incidence of TB, as it was historically after the war in cities like London?

Professor Yvonne Doyle (London Regional Director, PHE): Housing is an important factor in this. The lack of housing or the lack of good housing can be but not because of stuff like mould growing that causes respiratory illness for other purposes or asthma. The classic thing we have been told about is beds in sheds, where people are very close to each other. It is simply that it enables transmission. That can be a problem, yes, absolutely. Overcrowding really rather than the housing issue itself.

Andrew Boff AM (Deputy Chair): Can I just add to that, Murad? 330,000 children are being brought up in overcrowded conditions in London. Is that a contributory factor?

Professor Yvonne Doyle (London Regional Director, PHE): Overcrowding is a contributory factor for people who have the risk there. Where it lights up or they are already infectious.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): The percentage of children over the years has not really changed. It is static. It is disproportionately smaller than the population of children in London so it is about 5%.

Valerie Shawcross CBE AM: It is associated with their parents being at risk?


Murad Qureshi AM: That is useful, Onkar [Sahota AM] to establish. For example, beds in sheds, there is a big concentration in Ealing and certain boroughs.

Dr Onkar Sahota AM (Chair): Also other parts of London.

Murad Qureshi AM: I did not want to emphasise that but at least Ealing acknowledges the problem and they are trying to deal with it. This is an associated problem the health sector is having to deal with. Also, in Newham you will find the building fabric of most of the housing is very poor.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): We do have an Environmental Health officer on our London team control board. He was from Newham originally.

Murad Qureshi AM: Good. I am glad to hear that. I picked that up from my involvement in housing in London. I am glad to see that is being brought into the prevention initiatives that you are taking.
Valerie [Shawcross AM] did touch on using the Mayoralty and the GLA. Is there any more you want to add on that point that you think could help increase screening, vaccination and contact tracing?

**Professor Yvonne Doyle (London Regional Director, PHE):** This has been very helpful. Keeping this raised this morning is very helpful in itself so we do not lose a beat on TB, we keep it under scrutiny. Some of the issues you have raised around prisons and so on are all things we will have to deal with to make sure we get it right and that access is better. It has been helpful to highlight that.

Communicating would be the next thing for us really. It is the preventive end of this, making sure that people accept the prevention that is offered and see it as something in their families’ interests would be very helpful. The best thing we could say is if we could come to you, when we have reflected back on what we heard this morning, where we feel it would be most helpful to ask for your help. We might all say different things here this morning.

**Murad Qureshi AM:** On the prevention front there is a lot of experience. Valerie [Shawcross AM], during the time when she was chairing the London Fire and Emergency Planning Authority, helped move the emphasis from dealing with fires to actually preventing them in the first place. The same kind of thinking is required.

**Professor Yvonne Doyle (London Regional Director, PHE):** Yes, that was tremendously successful. You are a public health champion.

**Valerie Shawcross CBE AM:** It was something worthwhile.

**Jacqui White (Lead Nurse, North Central London Tuberculosis Service):** The other important thing to remember - and a very key part of prevention of the disease - is that we treat the disease fully when it is diagnosed. That can get a bit lost. Maybe it has got a little bit lost in these discussions this morning. A key point is when a patient is diagnosed with TB they receive their treatment for the full course of that treatment. It could be six months, it could be nine, it could be 12, or it could be up to 20 or 24 months if they are multi-drug resistant. We need to ensure that they complete their treatment for the duration of the treatment right to the very end. Otherwise there is a risk their disease will become drug resistant or they will become infectious and transmit it in the community. A very important direction of attack is that we ensure patients are case managed by TB Services, by the TB nurse specialists and their colleagues, to ensure treatment completion happens.

One of the difficulties we have with some of our particularly complex patients is that if they have not got stable accommodation - we have covered this already - it is very difficult. How do you treat a patient for a long period of time effectively if they have got no fixed abode? It becomes incredibly challenging. Often the patients who do not have accommodation are your most complex patients. They will have numerous other issues. They might have other illnesses. They might have addictions. They might have immigration issues. These are the patients in our service who take up a very large proportion of our time.

One of the suggestions I would like to put into the pot is that the Mayor may like to consider helping to fund some sort of supported accommodation for TB patients while they are going through the duration of their treatment. There are various way that could be done. It could be some sort of facility or spot purchase of beds at local level. It is key that TB patients are housed. With that housing ideally they would get a care package as well which can signpost them and hopefully help to improve their lives once their disease is cured. We have got real examples of that in London where the TB workforce have done really great work with patients who were previously homeless and are now actually contributing to society, working and have turned their lives around. TB Services can make a real difference. The key is that they need to have stable housing in order for us to effectively treat them.
Dr Onkar Sahota AM (Chair): Jacqui, we will come back to some of these issues. I know Marc is very keen to go. I want to take his question before we come to yours, Kit [Malthouse AM] because it is about treatment and I know Marc will be able to do more than the others. We will carry on the discussion but, Marc, may I just talk to you about treatment specifically? You started touching on it, Jacqui, about the difficulty we have in London. Marc, your contribution of how difficult is it to treat TB successfully in London, what are the main challenges of the treatment programme? Also talk about the challenge of the multi-drug resistant treatment of TB in London.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): The point is that generally people are told to take treatment for a minimum of six months with toxic drugs. That is difficult. There is no doubt about that. We have touched on stigma. That is really important. People are then going to be taking a drug which will stain their urine a different colour and will make them feel sick. There is also the sense we are saying very often to people, “Right, you need this treatment. Remember this is TB so we are going to not just treat you but ask you questions about who you might have infected.” You can see how pejorative the whole thing could potentially be.

One of the most interesting things is when we were doing a review of the TB Service in London we asked individuals who had been involved in those TB services - in other words treated for TB - what was their take on the TB Service. Very often they said the TB Service was one of the few people they could talk to, they could actually share their fears and concerns with. The reason for mentioning that is there is treatment which is about, “Take the medicine and you will get better, you will reduce your risk of transmission to others and so forth”. There is also the supportive bit. They go completely hand in hand. The thing we have learnt in TB treatment is the multi-disciplinary approach, working with a group. We have been lucky in our sector - highlighted through some of the work initially that Lynn [Altass] was doing and then Jacqui [White] picked up together with me - that we have a social care team. In other words, the social work component is a really key bit of treatment. That is thinking about housing and thinking ahead and saying, “OK, this person is going to come out of their six-month treatment course but we want to try to change their trajectory. We do not want the progressive decline. We want to put them back into, or get them into, the workforce.”

I have given you a slightly ‘woolly’ answer. The medicine is relatively easy, apart from drug resistance. What is really key is the bigger picture, the whole package.

Kit Malthouse AM MP: I was not going to ask my question because we have covered it as it was about diagnosis. I was going to ask about research into other treatments and whether there are programmes ongoing. If you look at Hepatitis C, which had a painful process before, that was only 40% effective and now there is this pill which is once a day for six weeks with 95% efficacy. Gilead Sciences came up with the first one and they are negotiating with the National Institute for Health and Care Excellence to get it in at £85,000 a pop. Is there going to be something on the horizon for TB?

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): There is and there is not. Until recently with TB there just was not the interest. You mentioned a pharmaceutical company. They are going to make a lot of money out of those highly expensive protease inhibitors for Hepatitis C.

Kit Malthouse AM MP: £14 billion they reckon. It is going to be the biggest drug ever.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): That is a lot of cash. TB does not have that same cachet, in part because the predominant areas of the world where there is TB are where the annual amount spent on a health budget is $50. That is not going to cover anything.
Having said that, there is an appreciation that giving people six months’ treatment for TB is way too long. People will just not do it. They drop off the end. There is a push towards trying to reduce the duration of therapy. So far that has been unsuccessful but that is likely to become successful soon. Could we treat TB for a month is the ultimate aim. For latent TB - someone who is completely well to whom you say, “You are at risk of progressing to active TB” - at the moment the shortest duration of time is three months with similar drugs. You are asking people who feel well to take a drug for three months and to possibly feel unwell. They certainly have to give up time to come to clinical settings and so on and so forth. There is a whole load of stuff. There is a very, very big push to try to minimise the amount of time, reduce the amount of tablets, have more thought about the impact of adverse events and so forth.

**Kit Malthouse AM MP:** Is there a research programme at Cambridge University or the London School of Hygiene and Tropical Medicine (LSHTM) trying to develop some silver bullet?

**Dr Marc Lipman (Consultant Physician, Royal Free Hospital):** I can bore you - I promise I will not - but it is a very big area. The thing is about the drug treatments and also improving the immune system itself. It is a two-sided thing. Using a good drug to kill the bug and actually boosting immunity. The best example is HIV. Antiretroviral therapy has made the single biggest impact on TB. There is no doubt about that. The number of deaths, the number of people getting infected, the number of people progressing globally has massively reduced courtesy of antiretroviral therapy.

Talking of research, here in the UK just last week we published in *The Lancet HIV* that through PHE the antiretroviral programmes that are being driven in the UK have massively reduced the risk now to background levels of TB in the highest populations, that is black Africans. Interestingly in the white UK born - again that funny population - it is still ten times greater despite antiretroviral therapy.

**Kit Malthouse AM MP:** So there are some strands of research hope?

**Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England):** There is a department at the LSHTM as well that is for TB.

**Dr Marc Lipman (Consultant Physician, Royal Free Hospital):** There is more than that, there are lots.

**Kit Malthouse AM MP:** That is key. What you are saying is that the next stage - which is where it comes out of academia and they need £1 billion to get it through clinical trials and into human beings - may be troublesome?

**Dr Marc Lipman (Consultant Physician, Royal Free Hospital):** What is really, really important is the implementation thing. We were talking about that with BCG. It does not matter how good the drug is if you are not making sure it is being delivered to people and that people understand why they are taking it and ensuring adherence. There is a big drive for directly observed therapy, in other words watching someone take medication.

We are running a study at the moment across London - which is one of the few multi-centre bits of work that has happened in TB research in the UK - where we are comparing directly observed therapy, “Please take your medicine and I will watch you”, with video observed therapy, “Please record yourself on a phone taking your medication and we will watch that”. That, of course, cuts out having to travel or someone having to come somewhere and hopefully eliminates stigma. It is those sorts of things that are going to have the biggest single impact because they are relatively cheap. They are much more about working with an individual.

**Kit Malthouse AM MP:** Technology may help beyond a new wonder drug.
Professor Yvonne Doyle (London Regional Director, PHE): Just to complement that, getting a shorter duration of treatment would be difficult but there is some very interesting research on genomics and how you link the strain of TB, so if cases are related to each other you can find them. There is some really good work on spatial analysis of clusters of cases which picks up the multi-drug resistant stuff. There is a lot of work going on with the latent TB diagnostic test where there are several now coming onto the market. There is a lot of very interesting work going on in TB just now.

Kit Malthouse AM MP: Good.

Dr Onkar Sahota AM (Chair): Can I welcome the pupils from Avonmore Primary School in Hammersmith and Fulham. Welcome. Good to see you guys.

Dr Lipman, you also go for cohort management at your TB centre. Has that helped at all?

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): This is the pioneer here, Jacqui.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): A number of years ago a small group of us went over to New York to look at how they ran their TB services on the back of their success. We learnt loads but one of the things we picked up was that they do the cohort review process which is basically the systematic audit of all TB cases, their treatment outcomes and also the outcome of their contacts and any instance that may arise as a result of their contacts. It is a meeting that happens once every three months. Every case of TB undergoes a review process in a standardised approach.

It is basically an opportunity for the multi-disciplinary team – everyone who is responsible for the patient – to reflect, to learn, to peer review. It promotes good practice. It identifies gaps in service delivery. Most importantly it promotes accountability at all levels. We implemented that in North Central London exactly five years ago, we have just had our fifth anniversary. It has ticked all those boxes but it has also provided us with really robust data in order to help guide how we plan services for the future.

I do not think it is over dramatic to say that was really quite a defining moment in the way we manage TB patients. It has provided a framework for the TB services to provide really comprehensive case management activities. It has highlighted key issues around the way that we run the service. An example is that we identified an awful lot of time was spent with quite high grade nurses going out into the community delivering medicines to patients. We are talking about very intensive work, having to go out every day. With some of our more complex patients you may have to spend an hour with them and then you have to factor travelling time into that. It was quite expensive and very labour intensive. We identified they probably were not best placed to be doing this work. On the back of cohort review we did a business case for a community outreach team to administer directly observed therapy in the community. That is a team of four outreach staff. They have enriched our service. That facility is not available across London where there are various community staff working in various sectors. I think we are probably the only sector who have a co-ordinated community outreach team with the specific remit of delivering directly observed therapy. We know that those patients who receive directly observed therapy will complete their treatment in most scenarios because we actually observe them. These are the patients who are really very complex and very challenging. That was one of the real positives that came out of cohort review.

Cohort review also made us aware of the importance of measuring performance. As a result of cohort we set performance targets which we measure ourselves. They have been used all over London and now nationally. It has been rolled out nationally and it is mandatory. All TB Services need to do cohort review. It is regarded as being best practice.
Dr Onkar Sahota AM (Chair): It sounds very promising and very tractable. I know, Dr Lipman, that you are keen to go. You are welcome to stay longer if you want to. If you decide to leave let me at this moment thank you very much for coming along and for contributing. Do stay for as long as you wish to.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): Funnily enough, I am going to be doing a presentation on the national TB strategy and how it applies to where I work at 12.30. Thank you so much.

Dr Onkar Sahota AM (Chair): Thank you very much. Of course, if you think of something you want to say to us, Dr Lipman, or some suggestion you want to make to us, do feel free to write to us.

Dr Marc Lipman (Consultant Physician, Royal Free Hospital): I will do. It has been great. Thank you.

Kit Malthouse AM MP: The question they have given me is, why is early detection so important? I cannot think of a disease where late detection is a good idea. We have covered some of the issues around this so I was not going to detain you any further.

I was going to ask a question about drug development and treatment development. While your work is fantastic and you are dealing with difficult circumstances, much of the difficulty seems to come from the mode of treatment. It is not just the population which is difficult to get hold of but the length, style and the seemingly random nature of the treatment. I understand it is very effective and if you do your full term pretty much you will be cured.

Professor Yvonne Doyle (London Regional Director, PHE): Yes.

Kit Malthouse AM MP: The only question I had which I was not quite sure about was if I get TB and do my full term – I get through my six months and I am cured – does ‘cured’ mean I return to full health or am I in some way damaged, or will that depend upon the stage at which I have been diagnosed?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): ‘Cure’ is cure.

Kit Malthouse AM MP: It is full cure back to full budding fitness and off I trot?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes. Obviously there will be exceptions to that if patients have other health issues.

Kit Malthouse AM MP: No permanent damage to the lungs or anything like that?

Professor Yvonne Doyle (London Regional Director, PHE): You would probably see the results of the cavitation on the lung.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): You may see some scarring on a chest X-ray but it would not inhibit their lives in any way.

Kit Malthouse AM MP: I would be able to go and play a full game of squash?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Yes, you should.
Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): If you have spinal TB there are issues with some of the rarer forms of the disease. Some people have been left disabled after that, requiring wheelchairs and things.

Kit Malthouse AM MP: That is quite small numbers?

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): It is exceptionally rare.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Small numbers and usually associated with late diagnosis where the damage to the spine is severe.

Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): It is not infectious TB because they are not coughing. These are the people who go to the doctors with several months of pain in their back.

Kit Malthouse AM MP: The final question that I had - I am conscious of time - was about this division between boys and girls, that it is largely men. Given that early diagnosis is important, how much of that is our unfortunate tendency to resist going to the doctor generally about all diseases and how much of it is that it is actually more likely to be in men because of the nature of the population?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): It is more likely in males but the bigger issue is about services being accessible and flexible. We want all patients who may have TB to be able to access services easily. There is a message in there about accessibility and flexibility of services. Also about knowing when to access help and where you access it.

Kit Malthouse AM MP: I understand. There are cultural differences across the world but one of the common things amongst men is they believe they are immortal - and probably infallible - and therefore do not go to the doctor. We see it in cancer and all sorts of things that men just do not go.

Professor Yvonne Doyle (London Regional Director, PHE): There is no gender difference in TB. It does not have a preference for men. It is just there are more men in that age group in those risk groups.

Kit Malthouse AM MP: Because there are more male migrants from those countries?

Professor Yvonne Doyle (London Regional Director, PHE): Yes. A lot of them are single.

Kit Malthouse AM MP: Right. Fine.

Dr Onkar Sahota AM (Chair): Once they have completed treatment, how long do you follow them up for? There is reactivation TB. How long after they have completed treatment do you follow them up for?

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Normally they will complete their treatment and they will have an outpatient appointment at the very end of their treatment where they will be seen by the doctor. If it is pulmonary TB they will have a chest X-ray done at the end of their treatment to check that they are in fact cured. If they do not have any other issues and their disease has been quite straightforward and it has been fully sensitive to the standard antibiotics then they would be discharged from services with the message that they can always come back. That would be a straightforward patient with standard TB, fully sensitive disease. More complex patients who are drug resistant or multi-drug resistant would be followed up for a longer period of time.
Lynn Altass (National Tuberculosis Strategy Implementation Manager, NHS England): Can we also add that TB is one of those few diseases that you can get again.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Because you can be re-infected.

Kit Malthouse AM MP: I have two small children and I live quite close The Whittington Hospital. We see the stairs onto the Holloway Road. I am very conscious every time they get a cough. It is like everything at a ‘parent moment’, every time they get very hot I think, “Oh my God, they’ve got meningitis” and every time they get a cough I think, “Oh my God, they’ve got TB”.

Jacqui White (Lead Nurse, North Central London Tuberculosis Service): Time it, three weeks or more.

Kit Malthouse AM MP: Three weeks or more, thank you.

Dr Onkar Sahota AM (Chair): Thank you all very much for coming along and giving your time. Of course one of the questions we keep asking is what can the Mayor and the London Assembly do. If you come across any ideas then do, please, let us know and feel free to write to us.