

## Health Committee – 8 July 2015

### Transcript of Agenda Item 4: Tuberculosis in London

**Dr Onkar Sahota AM (Chair):** That brings us to today's business, the main item, of tuberculosis (TB) in London. Can I please welcome our guests: Dr Sue Collinson; Dr Alistair Story; Steve Bradley; and Dr Jessica Potter. Maybe I will ask Steve, if you could introduce yourself and then your colleagues on your left-hand side can introduce themselves, so you know who is sitting where. Just to note that Steve has low vision and, therefore, we need to be mindful of that. Steve, if you would kindly give us your background of what brought you here.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes. I am a patient of TB, experienced the system of TB and how it was given to me and how I went through the whole system. Unluckily the medication has been so severe to me that it took my optic nerve away, and also all the nerves in my hands and legs. Therefore, not only is TB an issue, the medication that we have is a big issue too. That is my side of the story, and it was in 2008 when it started.

**Dr Onkar Sahota AM (Chair):** Thank you, Steve.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Hi, my name is Jess Potter, I'm a respiratory doctor and a registrar working in East London. I've been working in TB for the last couple of years and doing research at Queen Mary University of London, exploring access to healthcare for people with TB.

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

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I am a consultant nurse, now based at University College London Hospitals (UCLH) and I have been working in TB control for 17 years now in London. I established the Find & Treat Service. My specific interest is in outreach services to populations who are the most vulnerable and excluded.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** My name is Sue Collinson and I am the TB case worker at Homerton University Hospital. I am part of a multidisciplinary team. We do a lot of outreach work and we do a lot of integrated supportive care looking at the patient as a whole person rather than just someone with TB. We find that is a very effective way of working.

**Dr Onkar Sahota AM (Chair):** Good. Thank you very much. We will kick off. The first question – and this is to all members of the panel, and please feel free to intercept them and make a contribution as it comes to your mind – is to look at the role of community-based services for TB in the community. Why are community-based initiatives important for TB control and management in London as opposed to the work we do in some hospitals or inside other health institutions? Why are the community-based initiatives important? Perhaps we can start off with you, Alistair, you work in the community.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Quite simply you could divide people who experience TB into two simple groups really. There are those who would be able to recognise the symptoms, seek medical care and engage with the system. When I say 'engage with the system' that is a long process with a minimum of six months of drug treatment required, and there are those who do not. Those who do not, have difficulties accessing the system for a variety of reasons and have, most importantly, difficulty engaging with what is still a very long course of treatment. As the epidemiology of TB evolves, what we are seeing is really a

transition from TB as a disease of the general population to a disease that is now very much an issue with specific risk groups. Most of those risk groups share common difficulties and barriers in terms of accessing hospital building-based diagnostic services. From my own experience, the approach to tackling TB in the 21st century metropolitan environment, it is absolutely necessary to outreach. This will try to ensure that we move beyond an idea of waiting in a hospital to make a diagnosis, towards outreaching in the community to not only find active cases of disease, but to obviously put in the necessary measures to prevent transmission in future cases. Therefore, in the 21st century the community work is as, if not more, important than the hospital-based work.

**Dr Onkar Sahota AM (Chair):** Good. You referred to some target groups. Who are these target groups?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** TB is being defined as a social disease with some interesting medical consequences and I think that pretty much sums it up. The reality in the modern world is that TB is intrinsically linked to your income and opportunity. It correlates almost perfectly within the seas of deprivation in every major urban conurbation across the Western world. In its most extreme form, if we look at the epidemiology, TB in London for instance, the highest rate of disease that you will find in any one population group is amongst rough sleepers. They represent the tip of the iceberg in terms of the broader homeless population.

Obviously there is a variety of other factors associated with finding yourself homeless, not least poor diet, malnutrition, a range of other co-morbidities and other issues that place an immense stress upon your immune system, such as drug and alcohol use, etc. This quite clearly starts to redefine the aetiology of TB. Within the general population, exposure to mycobacterium TB is a relatively low risk issue. If you become infected and you are immunocompetent we know that only about 10% of people ever go on to develop active TB. In the populations that I work with the other factors that compromise their immunity put them at far, far higher risk of not only developing active TB in the future, but not recognising the symptoms and perhaps being in a position to transmit to others. Therefore, from the public health perspective and the personal health perspective it is imperative to outreach into the community.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Also out of that the majority of TB isn't treated in hospitals. People are outpatients, they are not admitted for their treatment, and so management in a community setting is what happens normally. As Alistair [Story] was saying, with the latest TB Strategy, which introduced screening for the dormant form of TB, it will be really important to reach out to the community. A lot of that screening will be community based.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Can I just say that with the community, we've been doing a lot of work with, say, the pharmacists, for example, because there is a great deal of stigma and a great deal of difficulty getting a doctor's appointment a lot of the time. Therefore, the first point of call with symptoms of any type may be your pharmacist. We are working quite hard with patients and others to say that a lot of the people know their pharmacists quite well, or they feel more comfortable to talk to them and would be able to say, "I'm not feeling well" and then pass on to further help. A lot of the time there is stigma involved and certain religions are very anti admitting to TB. There are all sorts of things we have difficulties with in trying to get people to start the first time with medication.

The other thing is people start to feel better quite quickly, so having the outreach is very important to try to keep them monitored, that they keep taking the medication, because a lot of people stop and then you get onto drug resistance and people getting worse. Therefore, it is very important to have the outreach.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Just to add on to what Steve [Bradley] was saying about the stigma issue, tackling stigma and ensuring people understand what TB is and are aware of the symptoms and feel capable of seeking help for that, will need to be community based and culturally relevant.

**Dr Onkar Sahota AM (Chair):** We will pick up the theme of the stigma as being one of the barriers.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I would just like to say that the team I work in has the best of both worlds, because we have one foot in our local hospital and one foot in the community and we do a lot of outreach work. However, outreach work as a community initiative will only work if you go to people at the right place and, critically, the right time. Therefore, as with Find & Treat and the mobile X-ray unit, you have to go out of ordinary working hours. I worked for many years on outreach and started at 11.00pm and finished at 3.00am, because we were trying to connect with the street sex working population in Hackney.

We also do something called directly observed therapy (DOT), so if people are at risk of not complying we actually visit them on a daily basis and observe them taking their medicines. If we have a hospital admission of someone who is at high risk of not completing, because perhaps they are homeless, or they have drug or alcohol problems, we follow them from their hospital bed out into the community and support them out there with a range of strategies, including housing the homeless ones. That gives very good outcomes.

**Murad Qureshi AM:** Something Steve just said, an aside, there is a religious stigma. I am aware of social and cultural ones, but religious ones?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Certainly in my experience with Somalian people, especially with young ladies, with TB they can be ostracised very quickly.

**Murad Qureshi AM:** OK, so it is Somalian.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** It shows that it actually affects your marriage prospects if you admit to having TB.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** The lady I know, she was put in a mental asylum because she had TB.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** That has certainly been our experience as well. The other issue to do with TB, with people from certain parts of the world, if you are given a TB diagnosis that means you have also automatically got human immunodeficiency virus (HIV) because they are closely linked in places like Sub-Saharan Africa, so that makes the stigma even greater.

**Murad Qureshi AM:** Yes, thanks. I was not aware of that.

**Andrew Boff AM (Deputy Chair):** Just to run back on what you said before, you are saying that in some parts, to have a TB diagnosis you are saying it is very likely that HIV is also present?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** No, no, sorry, misunderstanding.

**Andrew Boff AM (Deputy Chair):** Sorry.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** If you are from a Sub-Saharan Africa community and you get diagnosed with TB the assumption by the rest of your community will be --

**Andrew Boff AM (Deputy Chair):** It will be assumption.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** -- assumption. They are obviously closely related.

**Andrew Boff AM (Deputy Chair):** I am glad I asked for that clarification.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Some of them would prefer to have HIV and that is a very unusual statement, I know, but they would rather declare they had HIV than they would TB, because there is such a stigma.

**Dr Onkar Sahota AM (Chair):** Of course there must be an overlap with HIV. The immune status is already compromised, all right, so it is very likely.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Oh yes. We found very high numbers of comorbidity with TB and HIV in the street sex working population, because they obviously have massive drug habits and have a very, very poor rough lifestyle and a very high risk lifestyle as well. Therefore, they are highly likely to get both TB and HIV.

**Andrew Boff AM (Deputy Chair):** Could I just ask, is the national TB Strategy giving enough focus to the need for community support services to tackle TB in London? I do not know who wants to start. Steve, you are shaking your head, let us go for you.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** To be honest with you things, I hope, have moved forward slightly since 2008, but I was not supported at all. The biggest trouble is that you had to have the background, and to be honest TB medication makes you feel very ill. We are dealing with 30-year-old medication. The biggest trouble is we are talking about something here that we can try to make better and do the best we can. The Bacillus Calmette-Guerin (BCG) is not a wonderful drug. It is not a wonderful inoculation. It does not work 100% like others. Therefore, we cannot just say, "Everybody has BCG and we will get rid of TB" it does not work that way. Then we have also got the medication, which is very old. We are not saying here we are doing new drugs, we are saying we are going to use what we have got. If we used what we have got better and the community is more involved then things will get better.

At the moment we have this situation where the jigsaw is not being put together as it should. That is what happened to me. I had no knowledge that these drugs were so toxic that I would lose my sight in two weeks. Can you imagine how serious that is? I went from 20/20 vision to being blind in two weeks, with a guide dog. That is how serious these drugs are. All the four main drugs they give you for six months make you feel very ill and, therefore, they take away the ability, often, for you to work. You may be the sole breadwinner in that home, so what happens then? There is still no support. Therefore, the community really does need to have the squaring of the circle, it just needs more support, because it will save money in the long run. If people can just do it for six months and end of story that is fantastic.

**Andrew Boff AM (Deputy Chair):** Has the TB Action Group been involved in the development of the national strategy?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes.

**Andrew Boff AM (Deputy Chair):** Because that was released back in January.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes.

**Andrew Boff AM (Deputy Chair):** You have been involved?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes.

**Andrew Boff AM (Deputy Chair):** Are you confident that the strategy represents your representations to them?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes.

**Andrew Boff AM (Deputy Chair):** Great. To the rest of the professionals here?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I would add that there are a lot of good words in the national strategy about community services. Often, particularly with TB, awareness in the community and outreach services are the things that are least well-funded, so when the money does come in the money does not tend to go to those areas first.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I am rather fortunate to have worked with a number of other TB services in different countries where they have succeeded in tackling TB. It strikes me that the service that we are providing in London is still very much a clinical service aimed at treating cases of active TB. The extreme example of that being services are in fact resourced in terms of the numbers of case managers that they would be deemed eligible to employ, based upon the number of active cases that they treat.

If we talk to a physician in New York or a physician in Rotterdam or Brussels or Barcelona, this is completely upside down. They do not see the diagnosis of a TB case as a success story. They see the diagnosis of a TB case as a failure to prevent TB. This is really what has been missing in terms of the United Kingdom (UK) mind set, is a public health vision to actually tackle TB which goes, as my colleagues have said, well beyond giving pills to people with active TB.

**Andrew Boff AM (Deputy Chair):** I am trying to not step on any other questions. Are you saying that the national TB Strategy is not doing enough for prevention? BCG has its contribution to make and back in 2005 there was the general ending of BCGs, was that a good thing or a bad thing?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** It was not ended. We stopped giving BCGs to school-aged children and we targeted it and it is now given to babies, essentially, within high-risk populations and within high-incidence locations, which is London.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** A point of clarification, the BCG is the most widely used vaccine on this planet and we have a global pandemic of TB, which tells us pretty much everything we need to know about the effectiveness of BCG.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** The difficulty is in giving the BCG, especially I have known recently of a school that has had an outbreak of TB, and that school was then given the BCG. However, all of those people in that school do travel, so where is the connection? You are not border-lining it, or you are not ring-fencing it, so the theory of giving them BCG just because -- I was in a home as well for older people, they were all given BCG suddenly because there was an outbreak. It is this sort of reaction to the BCG and it is not really -- I did not have a BCG --

**Andrew Boff AM (Deputy Chair):** Rather than coming to it and saying it is actually about high risk and doing it. Thank you for that.

I am getting the feeling of criticism here of the national strategy that it is not focused enough on prevention. Would that be an accurate representation of the national strategy?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would say that the interpretation of the national strategy is going to be where the proof of the pudding, will lie. The wording of the national strategy is certainly robust enough to enable people to interpret and commission services locally that have a strong community emphasis. The issue is that that is traditionally and historically not the way services have been provided.

**Andrew Boff AM (Deputy Chair):** Who will be doing the interpreting?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** The clinical commissioning groups (CCGs).

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** CCGs.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I just wanted to add, I obviously completely agree with Alistair [Story] and Jessica [Potter], but the fact of the matter is that if you look at countries which have tackled TB successfully those initiatives have been very well resourced, not just with money but also with personnel and other forms for resources. Unless we do that we are going to be plateauing out and not really getting to grips with the whole issue. Public health moving into the local authorities presents us with a wonderful opportunity for much more joined-up working with social services and housing and other services. However, unfortunately, public health funding has been cut quite radically and so that opportunity might slip away from us.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** One example that I can give you is that there is an LTbEx [London TB Extended Contact Tracing project] service within London which goes out and currently screens contacts in schools: where there has been a large outbreak they support the local TB service in their screening of contacts and treating contacts is a great way of preventing further onward cases in transmission. I understand that is under threat, although the national strategy does state that that should exist. Where there is funding, the allocation of that funding may not support the wording of the strategy.

**Andrew Boff AM (Deputy Chair):** Can I just go back? Public Health funding has been cut, because boroughs received a substantial increase in the allocation of funding. What do you mean by public health funding?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** In real terms the funds to public health directorates was cut when the Primary Care Trusts (PCTs) were disbanded. That is what we are hearing locally from our public health directorates: that they are having to make quite hard choices about what they will focus on and what they will not. If you have got ten top priorities and TB is number 11 it is going to slip down that agenda.

**Andrew Boff AM (Deputy Chair):** Therefore, it is within the public health programmes of each borough, you are saying?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** What you will find is your Joint Strategic Needs Assessment (JSNA) will identify priorities. If, like in Hackney, you have got a huge range of big priorities so that TB has ironically slipped down to number 11 and they are just going to pour their money into the top ten then --

**Andrew Boff AM (Deputy Chair):** So you are competing with things like smoking cessation and stuff like that.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Absolutely. Yes.

**Andrew Boff AM (Deputy Chair):** OK, I understand.

**Valerie Shawcross CBE AM:** You have said a little bit about some of the issues of stigma in communities, but I think there are probably other challenges. What do you see as the main challenges around engaging with at-risk groups and communities? Where are the really big difficulties for you in your outreach and education work?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The main challenge is the need to break away from the norm and innovate. As we have all said, move beyond this model of sitting in a building and waiting for people to come to you. There are many opportunities to target interventions which have proven to be highly cost effective. There are many opportunities to take technologies to the street and actually provide diagnostics to populations, real time, in the community. Unfortunately that is quite a different approach, I think it would be fair to say, than the model many other National Health Service (NHS) services follow. Consequently it can be a challenge to commission. I think another barrier, another obstacle, within the commissioning landscape is the fact that we commission services in relatively small footprints. Whilst we are unfortunate enough to have the highest number of TB cases in any capital city in Western Europe in London, in relative terms that is still quite a small health problem when compared to the big target issues such as cardiovascular disease etc. Consequently, commissioning services on the footprint of the CCG presents some challenges, not least in the inability to realise any economy of scale in those services, but similarly in certain obstacles related to people's ability to move freely across these invisible lines that criss-cross London and have a seamless care package.

**Valerie Shawcross CBE AM:** There are some particular issues around some target groups, are there not? We heard last week about the fact that prisoners seem to be particularly at risk.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** In a prison population you will find people with risk factors related to drug and alcohol use and homelessness overrepresented, and consequently prison represents an opportunity to reach a population who, in the community, are very difficult to access. In my mind it is a health opportunity and the health agenda needs to be promoted within the criminal justice system. If we were to more systematically screen and offer treatment for a range of conditions, not just TB, to the population who find themselves incarcerated, that would pay an enormous community dividend. You cannot view the prison population as a separate entity to the communities from which they come, because by and large people return to the community they come from.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I think the other thing to say is that the Find & Treat mobile X-ray unit is a really great example of innovative care and reaching out into the street. Where we are under researched, and I do not know quite what we are doing, is in the migrant communities in London who have much higher instances of TB within them than the general population. We do not really know very much about how we reach out to them.

**Andrew Boff AM (Deputy Chair):** Can I just ask for an emphasis on what you have just said about the prison population?

**Valerie Shawcross CBE AM:** Yes.

**Andrew Boff AM (Deputy Chair):** Prisoners are basically ignored when it comes to this subject. I find that quite astonishing.

**Valerie Shawcross CBE AM:** That is why I raised it because when it was discussed on 24 June 2015 - I cannot remember the name of the person giving evidence, forgive me - but it seemed to me that it was not necessarily a community resistance, it was simply a bureaucratic organisational problem, which seemed to me to be completely shocking.

**Andrew Boff AM (Deputy Chair):** Yes.

**Valerie Shawcross CBE AM:** Which is why I raised it again.

**Andrew Boff AM (Deputy Chair):** Sorry about that.

**Valerie Shawcross CBE AM:** Yes, thanks, Andrew, I am glad you agree.

**Andrew Boff AM (Deputy Chair):** I do, yes.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** In prisons people ignore the thing of drugs, alcohol, because it should not happen and the TB thing should happen as a natural thing, and maybe HIV and other things but, yes, definitely what you brought up is that it is typical that it is being ignored.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Another barrier is actually finding people. We have got, as everybody knows, a large under the radar, not here legally, population and those people are very fearful of using anything that looks like a government institution or a health service. Therefore, actually they tend not to be diagnosed until they are extremely unwell. They are being brought in by ambulance very, very ill with advanced disease. Then once you have them in hospital you diagnose them and you have to treat them and they either then remain as bed-blockers or you have to do something with



them, because if you just put them out into the community again they will disappear below the radar. They do not tend to be in large masses, they tend to be in twos and threes, or the odd person here and there. While they remain undiagnosed they do infect all the people who are also washing up in the kitchen at the back of a restaurant, or wherever else they are trying to work for money, cash in hand.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** I work a lot for the Care Quality Commission and there was a man from Afghanistan who had TB and he was in the isolation ward. That is exactly a typical situation. He was a bed-blocker because really he needed medication but the minute you put him out of the ward protection he was an illegal immigrant, so it was a difficult situation that we had to treat, but we also had to deal with the situation of he is not here legally.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** The problem along with that is that when people have no recourse to public funds there is no support for them once they are out in the community. Anyone who has no recourse to public funds, this might be people who are born in the UK but just do not have the paperwork to show it, have no access to housing. Housing is not just enough on its own, they need food, ability to get to and from clinics and there is no real money to support that.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I am going to say something in praise of my own team. We actually have an arrangement now with the local authority in Hackney, so if we have someone with no recourse to public funds, here illegally, whatever, we have the wherewithal to house them for the whole course of treatment, six, nine, 12 months. TB Alert have given us a fund so we run a foodbank so we can feed these people and our own hospital provides us with money for bus passes so that they can come to the hospital. We put them all DOT - we literally see them six out of seven days a week taking their medication. They are secure, they are very grateful to have somewhere to live. They understand it is only temporary and they are going to have to leave at the other end but it has solved a lot of problems for us and works extremely well.

**Valerie Shawcross CBE AM:** Is that a common model? Is that something you would like to promote basically?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** We would very, very much like to promote it. It is very, very cost effective. A week in temporary accommodation is cheaper than one day in a hospital bed.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** There are some other boroughs that are starting to take that up, or have done other similar things, where they have a pot of money that they put aside to help support this, but it is few and far between.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** In 2001 in response to a huge challenge in treating people who were, to all intents and purposes, destitute on the street, we opened a project in collaboration with the St. John of God Hospitaller Service and we took over the top floor of a hostel. Many of those we treated had the unfortunate label of no recourse to public funds, so they were legally entitled to remain but not entitled to welfare assistance, and many had extremely complex drug-resistant forms of disease, requiring 24 months of treatment including injectables. That service has not only saved lives in the last four or five years, it has saved hundreds of thousands of pounds, because as Sue [Collinson] pointed out languishing in a negative pressure room in a hospital at £1,000 a day is --

**Valerie Shawcross CBE AM:** Also it has contained spread, presumably within the community.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** It does. It prevents onward transmission as well.

**Valerie Shawcross CBE AM:** There is a good cost benefit analysis for that, apart from the humanitarian.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** It is huge, and it is not an old idea. There is nothing new under the sun. We look back to a paper written in 1955 by the author McGregor where there was a TB hostel in Bethnal Green in East London that was specifically opened with the need to accommodate people who were getting treatment and would be otherwise street drinkers on discharge.

**Valerie Shawcross CBE AM:** The homeless community they were dealing with. Yes.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Correct.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** You could almost see our current failure to deal with homeless people with TB as a failure of care in the community. In a sense it is a similar trajectory to mental health and when they closed the big asylums they actually put in place in the community supportive housing and so on and so forth for their patients, on the basis that being treated in the community is much nicer, much more pleasant and much more normalising. When we closed our large TB asylums we did not put anything into the community to scoop up those vulnerable people who we are now looking at trying to help.

**Valerie Shawcross CBE AM:** I notice that there are a number of local authorities who have outreach models to help. Is that something, again, that is universal?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** No. For example the London Borough of Newham does not have a TB outreach worker and they have the highest incidence of TB in London.

**Valerie Shawcross CBE AM:** Oh my gosh, shocking.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** That has been the case for some time, so there are not TB outreach workers for every borough in London.

**Dr Onkar Sahota AM (Chair):** This national strategy, how is it being implemented across London? Who is responsible for it?

**Valerie Shawcross CBE AM:** If it is a national strategy your question is: how can it be so uneven?

**Dr Onkar Sahota AM (Chair):** Yes.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The issue is, as we all know, you have to look back to look forward. It has to be accepted that the organisation of services plays a major role in how effectively the system functions. Let me give you some examples. New York at its height, in terms of their TB problem, had a population of 9.2 million people and tackled TB across the city from ten clinics. Amsterdam, one clinic; Rotterdam, one clinic; Paris, five clinics; Berlin, five clinics; Barcelona, one clinic; London, 30 clinics, all

providing a very different model of care, all very dependent upon local commissioning arrangements, all with very different arrangements. There is a need to rationalise the provision of TB services across London.

**Andrew Boff AM (Deputy Chair):** Sorry. Are they talking amongst themselves, the CCGs? Because they want to save money like anyone else, and it sounds to me like it is the most cost-effective way of doing it is talk to your neighbour.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I can tell you that in East London we had a meeting only last week, which had CCG representatives, as well as the NHS Trust representatives from three or four different boroughs, to look at TB in East London, at how we implement the latent TB screening part of the strategy, which is the newest part of the strategy. The rest of the strategy, not much has changed compared to previously. As Sue [Collinson] was saying before, what is happening in your local borough and the priorities there will depend on how much money you CCG will allocate to that.

**Dr Onkar Sahota AM (Chair):** It sounds like this is an issue right across the 32 boroughs. Some entity has to be able to pull it together to look at a London-wide strategy. Where is that planning going on?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The planning body is now supposed to be the TB Control Board in London. There are conversations about trying to do exactly what was suggested in terms of having a lead commissioning function, because it just makes no sense to duplicate the commissioning process at so many levels within the system.

**Valerie Shawcross CBE AM:** Do they have enough teeth then and any money?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The reality is that under the current system the money has gone locally and any opportunity to commission services on a pan-London basis is incredibly challenging. The service I run is a pan-London service and we have a rather interesting helicopter view of what is happening across London in different services and there is an extraordinary level of variation in terms of the care.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** There is money that is specifically allocated to the latent TB screening part of the strategy, which will not be swallowed up in another way, but that is the only bit, as far as I understand it, that is really ring-fenced.

**Valerie Shawcross CBE AM:** I should ask the question about public education. Sorry, we took off there, so probably I have trod all over the other people's questions but it is so shocking as well as interesting.

What are the benefits and risks of raising public awareness about TB? I must admit I did my local newspaper column about TB after last week's meeting and there was a bit of me that thought, "I wonder if the local GPs will thank me for this" but by and large most people do not know much about TB because it is still a minority experience, even though it is dangerously around. Are we going to swamp you with the worried well if we do that?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I do not think you will swamp us with the worried well. The problem we have always had with raising TB awareness is that 83% of TB cases in London occur in people who were born abroad.

**Valerie Shawcross CBE AM:** Yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Therefore, inextricably it is linked to immigration and no one wants to talk about immigration and so that slant is often put on it in the press and I think that is challenging. These are people who are sick and we have a global community nowadays. It just so happens that some places have been better at controlling TB, or have less TB than other places, and those people who are most at risk of TB happen to have been born in places where there is lots of TB, so they are more at risk.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would not challenge that, that might be too robust a word, but I think buried within that concept of 80% of the cases are born overseas comes a gross myth that therefore 80% of cases are imported.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** From looking at the molecular typing data and from looking at the evidence generated through cohort review and meticulously documenting contact investigations etc, we know very clearly that for a lot of people who arrive in London their risk of exposure remains high. It is not a simple question to say this is an imported case and this is a case that was acquired post-migration. We also know that within the aetiology of TB the vast majority of people who are infected will never develop active disease ever. Ever. The process of migration and the stresses of migration and the accommodation and the living circumstances of many people actually deteriorate post migration and there are many studies demonstrating that their risk of progression is perhaps higher in this country than it is in their country of origin.

Nevertheless, the politics of TB unfortunately remains very clearly focused on the incorrect assumption that we can tackle TB at the border. We have to get our own shop in order and we have to accept that London provides an extremely effective environment within which TB can transmit. We have the largest outbreak of drug-resistant TB ever documented in Western Europe in London and plenty of evidence to suggest that current efforts to contain transmission, even occurring at a household level, are insufficient. It will take more than a political aspiration to tackle TB at the border to bring TB under control.

**Valerie Shawcross CBE AM:** Is it advantageous in tackling the disease for there to be broader public awareness?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Yes.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The challenge is “pouring fuel on the fire” because it works on two levels. If you were an aspiring politician and I was to give you the box marked TB you would open it and within it you would find a variety of career-shredding issues. You would find immigration, you would find imprisonment, you would find homelessness and you would find drugs and alcohol. Many of these issues are deemed distasteful and intractable within the tenure of politics. One of the reasons why it has not been effectively picked up and dealt with in the UK is because the system, from a political perspective, does not provide the kind of continuity to do what the Dutch and the Americans did. TB is a slow burner, it requires a ten to 15-year investment.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** The other thing to say is if you go to the other side of the coin with HIV that was a political nightmare as well and you gave a lot of awareness to the population. In fact, we were all going to die of acquired immune deficiency syndrome (AIDS), if you remember we had these adverts saying how terrible it all was.

**Valerie Shawcross CBE AM:** That is right.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Then there was this thing, well the drug companies wanted to get profits, so they invested tremendously. This is something TB has never had. There is cure for it there, if they made an effort to investigate on drugs and new drugs but we have not got that. What we have at the moment is the need to make the awareness more. I walked into my doctor's, who happens to be an Indian lady, and I said, "I have TB". She said, "Oh I thought it had gone in the 1950s". What chance have I got when she is in Enfield, which has a very high population of different populations? How can I possibly have a doctor saying to me she thought it went in the 1950s? It is ridiculous. We do need awareness. Medically we need awareness. The whole thing is HIV was a political nightmare just the same, so if I hand you that box of TB and it does cause issues, well you should be accredited with it, because TB will cost the country - and if you look at the statistics - a tremendous amount of money at the end of the day if you do not get hold of it. Stop kicking the can down the road, pick up the can and let us get on with it. That is the biggest trouble with TB.

**Valerie Shawcross CBE AM:** We appreciate that. We will just turn Alistair's model around on you. This is a personal thing, and I would say it is not so much that it is dangerous when you open the box, because we are capable of bravery, are we not? I think the problem is there are not votes in it, is it not? By definition it is a marginalised community.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Valerie Shawcross CBE AM:** By definition they do not have a voice. By definition they are not on the electoral register probably.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Also by definition people who work with marginalised communities become marginalised.

**Valerie Shawcross CBE AM:** There are great traditions of care and charity and campaigning in British community, however, so I think there is a lot to be said for raising awareness of decision makers in the very broad sense, but shocking.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** It has to be done.

**Valerie Shawcross CBE AM:** The interplay with the GPs, I get that as well. Your other report, Onkar [Sahota AM] was -- I saw in the newspaper recently we are likely to lose 10% of our GPs in London, GPs are overcrowded. Let us face it, there is uneven quality amongst GPs, even within any single practice, you might go to sometimes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** You also have to remember that a GP might encounter one or two cases of TB in ten years, depending on

where they work. Yes, I totally appreciate that with someone working in an area where there is lots of TB, we need to educate them better.

**Valerie Shawcross CBE AM:** Some currency of popular awareness would help, yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes, absolutely.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Absolutely.

**Dr Onkar Sahota AM (Chair):** You were drawing parallels between HIV, right, and TB. Of course TB is an infectious disease where HIV is a contact, right, in the sense that you cannot get HIV just by being in the room. That is where I am drawing distinction. How well is our contact tracing once we make the diagnosis of TB in a patient? Do we have a good service for contact tracing, finding out, or have we reduced our levels of contact tracing? My own perception is that we do not go as far out as we used to do.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** This question dovetails very nicely into your first question. I will give you a narrative, an example. If I based the idea of contact investigations around the concept of inviting people into a clinical environment and asking them who they infected I will get a very different answer than if I was to take the service into the community in a culturally appropriate way and ask the question, "Why do you think you've got TB?" It is more expensive to take it into the community and do it that way. It is more time consuming. It requires innovation and effort, but it is internationally proven to be the most effective way of doing it. This relates to what we see across London in terms of a significant variation in the way services are provided. In some areas you will get a home visit, perhaps more than one home visit. There will be an admirable effort to try to turn every stone in terms of identifying people who potentially could benefit from tests for infection. However, in many other areas, unfortunately, it will be a clinical-based exercise, interviewing people in a clinical environment where the answers to the questions are invariably very different.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** TB nurses will notoriously tell you that TB patients have no friends. Because when you ask them, as I was saying, in a clinical setting, "Who do you live with? Who do you work with?" they do not want to give up that information because of the stigma associated with having the diagnosis.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Absolutely.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** You go and visit them in their home and there are six other people there then you have your contacts.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** The other problem, again referring to people who are here, for undocumented migrants is that they are very frightened to even give their own names, and they certainly will not give the names of anybody else, particularly if that person is also, like them, under the radar. The most vulnerable people are the most frightened to give thorough details. We have had several patients who have gone through the entire treatment using someone else's name and then only tells us right at the end of treatment.

**Andrew Boff AM (Deputy Chair):** In those circumstances, in between, non-governmental organisations can provide some kind of support? You were talking earlier about working on street sex workers and presumably organisations like Open Doors which operate in --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I was working with Open Doors, yes.

**Andrew Boff AM (Deputy Chair):** Are those organisations helpful in getting people to come forward to resolve those medical --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Street sex workers are interesting, because they do not even use their own names. They will be known as Blondie, or Frenchie, or something like that. They have very, very chaotic lifestyles. You cannot possibly work out the number of people they have had sex with during the course of a night and trace them. They do not know the names of their punters either. People in those sorts of chaotic transient groups who are living from day to day, and really have a sort of diminished citizenship, shall we say, just are not interested in helping us to find their contacts.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I can put it simply for you. When I get TB I am going to infect everybody I am ever likely to infect within the first 12 to 14 days, and they will be my family. This will be transmission that is occurring in the household setting. This is what contact investigation is very much geared up to identify, individuals known to you. Take TB out of the traditional household setting, put it in a place where people congregate to sleep, to keep warm, perhaps where people congregate to drink, and the entire process of contact investigation breaks down, for the reasons that Sue just identified. People do not know who they have infected. If they did they might not want to tell me. If they did tell me I cannot find them. If I can find them they tell me where to go. Therefore, we have to move away from the traditional model of contact investigating around cases, when we know the transmission is likely to have occurred outside of a household setting, and that requires a lot more effort and a lot more thought.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Just going back to what you said about third sector organisations and can they not pick up those gaps, I think that third sector organisations --

**Andrew Boff AM (Deputy Chair):** It is not to pick up the gaps, it is to provide an interface.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Andrew Boff AM (Deputy Chair):** I would not say that -- no, that is not what I was suggesting.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I was going to say I think that would be quite a dangerous model. We need to be thinking more like a lot of what those organisations do, in terms of how we improve our accessibility to those vulnerable groups. Médecins Du Monde [Doctors of the World UK] are a GP organisation based in East London. They see a lot of our undocumented migrants. We have gone in to them recently to raise awareness about TB. They can refer directly to the TB service.

**Andrew Boff AM (Deputy Chair):** Do you use printed material to raise awareness of TB, like leaflets and stuff?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** We can do.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** We can do. TB Alert produce a lot of leaflets.

**Andrew Boff AM (Deputy Chair):** Is it particularly helpful that in Newham, which you cited earlier, that the Mayor of Newham has said that there should be no documents printed in anything other than English?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I did not realise the Mayor of Newham had said that, but we have been in discussion with some of the CCGs and Newham have done really good work on TB. In fact, we know that some of the awareness raising materials are not suitable for certain cultures. As far as I understand it, the Somali community do not engage very well with leaflets and we need to think about other ways of engaging that community so that whatever material we use they need to be language-appropriate and culturally-appropriate.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** When you say hard to reach people, sometimes it is very difficult to put it into words, as such, but with TB Alert we have had this situation where we try to incorporate people, like we have a Somalian lady and we have that lady go into that community so the stigma and the understanding of TB is at local level. As the gentleman was saying, it is very easy to try to say, "Well they are hard to reach" but we have to have a different way of doing things. It can be a little outside the box and a bit more expensive but it does work.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I suppose a challenge is that if we look at nearly every other disease group where there is an active patient advocacy group they are invariably lifelong conditions. TB is not a lifelong condition.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Exactly, that is why the drug companies will not fund it.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** There is a short episode of illness and most people want to forget as soon as it is over. Finding someone who is willing to talk about it and champion change is difficult.

Back to the issue of written materials, there is a considerable body of literature around the various ways of trying to promote awareness and engagement and for some people maybe a written leaflet would do something. For the vast majority it is not really a useful intervention. It needs narrative, it needs word of mouth and, most importantly, I am delighted to say, we have one of our peer educators in the audience today, it needs people who can provide a living experience. It needs people who can actually be not only living proof that TB is curable and there is light at the end of the tunnel, it needs people who have first-hand experience of actually trying to access services and complete treatment.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** It comes back also to outreach work, so going out to your various communities within your catchment area and doing awareness raising and presentations. You have to be very careful in terms of making them appropriate for that group in terms of their culture, possibly their politics, possibly gender. I remember going one Sunday afternoon to some wacky



Kurdish left-wing liberation front and going into a very crowded room and most of the people only spoke Kurdish, so I had an interpreter.

**Murad Qureshi AM:** We know who you are talking about.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** My point is that since the whole room realised it was a health issue all the men stood up and left, so I was talking exclusively to the women, so that was very interesting. It is very important to talk to the women and then they will look after the rest of the family and the community and pass the message on, I hope.

**Murad Qureshi AM:** I am thinking a lot of what I was going to ask has been covered but I'll say the two questions anyway and try to tailor it to what I have heard. It is in the general area of prevention and diagnosis.

Jessica, you mentioned earlier the latent TB tracing and contact tracing. Can you tell us where you think the state of play is in London and what we need to do to improve it?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

The national strategy introduced latent TB screening, which is screening for a dormant version of TB and treatment into the strategy for the first time for people who are at risk, which are people in a certain age group from countries where there is a lot of TB. We will offer screening in the community and then treatment in secondary care is the current model, as far as I understand it. There are a couple of other places trying other approaches. There is money behind that from NHS England and Public Health England (PHE) to support that, but because it is brand new people are working out how to implement it. It is not going to be rolled out until, my guess is, later on in the year. Some places like Homerton University Hospital have been doing that type of screening for quite a long time, not quite exactly the same as the national strategy lays out, but very similar, particularly in East London, learning what they have done. Newham have a big trial going on looking at treatment in a community versus treatment in secondary care and whether or not that works. As far as I understand, the current model will be screening with your GP followed, if you have a positive test, by a referral to secondary care.

**Dr Onkar Sahota AM (Chair):** This screening is based on a blood test?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Yes, predominantly based on a blood test. The blood test will tell you whether or not your body has ever or not seen TB before, but it will not differentiate between active and latent TB. You then have a clinical screen to determine whether or not you have any symptoms at all, and a chest X-ray. If you are asymptomatic but have a marker of infection, which may be a blood test or a skin test, then you will be offered treatment for latent TB.

**Dr Onkar Sahota AM (Chair):** The GP would draw up a list of target patients?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Yes.

**Dr Onkar Sahota AM (Chair):** Offer them blood tests?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):**

Yes.

**Dr Onkar Sahota AM (Chair):** That practice might show there is exposure to TB at some stage of their life?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Dr Onkar Sahota AM (Chair):** They will then go for a chest X-ray.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Plus have a symptom screen and examination.

**Dr Onkar Sahota AM (Chair):** OK. In the GP practice?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** In the GP practice. Some of that, if they are positive, may be done in secondary care. Those parts of the model have not been ironed out yet, but certainly the invitation to screening will occur in primary care. Initially the plan is to do that at registration, if it is new patients registering, and then perhaps a look back on top of that to make sure you get your currently registered patients. Again, that model has not quite been worked out exactly what is going to happen.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** There is a downside in that obviously you have to get your patient back twice. That is if you can get them there once.

**Murad Qureshi AM:** That sounds as though that is what a GP can do with people registered and what-have-you. You have mentioned rough sleepers, people in prisons. What is the screening effort aimed at them? For example, can I --

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** This strategy does not cover anyone who is not registered with a GP.

**Murad Qureshi AM:** OK.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Is that fair to say, Alistair?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I think I need to frame the latent tuberculosis infection (LTBI) debate, because it is poorly understood. If we were to talk about what works in terms of controlling TB, on the top of the list is finding people with active TB and getting them through a complete course of treatment. Next is finding their contacts and making sure that they are appropriately managed, if they have any evidence of infection or active disease. Way down the list is looking for people with evidence of infection who may benefit from preventative treatment, for the simple reason that I would probably need to treat tens of individuals with a complete course of preventative treatment. I would need to identify and successfully treat tens, maybe 50, maybe more individuals with a positive test for this infection in order to prevent one case. Let us not allow the current emphasis on LTBI screening to detract from the two most important things necessary to control TB, and that is finding people with active disease as soon as possible through seamless services, referral from general practice, etc, and active case finding in risk groups where necessary, and comprehensive investigation of their contacts. That is where the bang for the buck is.

**Dr Onkar Sahota AM (Chair):** Here we have a population who are at most risk, right, are not registered with a GP in the first place, so where is the logic of this coming from? It is part of a national TB Strategy and who designed this scheme?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** The logic of it is if you look at the sequencing. There is still a lot of transmission. You can come over here as a migrant and pick up your TB here. However, there is also a significant proportion of people who initially acquired their TB abroad and because of the migratory process or various other issues which might impair that balance between your immune system and the TB, the TB wakes up and you get reactivation of the TB. That type of TB can affect any part of the body and it may not be infectious TB but it is still TB and needs treating. It can kill people or make them seriously unwell.

As Al [Alistair Story] was saying, only about 10% of people with latent TB will go on to get active TB in their lifetime, so it is a small proportion of people. The papers show that if you screen and treat people from high-incidence countries – and that is over 150 per 100,000 population incidence of TB – that it is cost-effective to do that and offer treatment because if we treat those people, you reduce the risk of them reactivating by about 60% to 70% in the future.

However, like Alistair [Story] was saying, while this is the latest prevention strategy and that is the rationale behind it, we must not forget the really important parts of TB while we are introducing this new, additional element of TB control.

**Murad Qureshi AM:** In some ways, given you have put in my head two clear groups, rough sleepers and those in the prison service, is there screening happening in supported housing and the prison service, and if so, how much?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** There is one unit in London. It has just been replaced by UCLH buying a second unit; the old unit is being retired. This one unit screens almost 10,000 people a year in London. Increasingly, we are called out nationally in response to incidents and outbreaks. There is one unit.

**Murad Qureshi AM:** One unit?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** We initiated this project by borrowing one of the Dutch fleet in 2002.

**Murad Qureshi AM:** Right.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** That tells you pretty much all you need to know. There is one unit. I am pleased to say the national strategy has three areas of commitment for new investment: first, they will fund TB control boards; second, they will fund an expansion of the latent TB screening initiative; and third, they will try to roll out nationally a more proactive approach to finding and treating patients who are vulnerable and marginalised on the edge of our society.

**Murad Qureshi AM:** In the London context, how many do we need? You are saying we only have one.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** My service team have evolved and we have evolved away from just TB because we put so much work and effort into getting face-to-face with a population who are pretty much off the map and invisible in terms of routine health services.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Yes.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** We know that they are a co-morbid population, and we have been evaluated independently twice, by PHE and by the National Institute for Health and Care Excellence (NICE) themselves. We are NICE-recommended. We could add serious value to the service by building on the opportunity of encounter. What Steve was saying earlier about the diagnostics for TB; I can carry in my hand a point-of-care test for hepatitis C, HIV and hepatitis B that requires one blood spot and gives me a result in seven minutes. That is technology that I can take to the street, and that is what we will do. The new unit is a mobile health unit and it goes way beyond TB.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** That opportunity that you have when you encounter people who do not often encounter healthcare services should be used for all of the things that Alistair [Story] was talking about, including within the prison service as well.

**Murad Qureshi AM:** Yes, but even with supported housing and prisons, elements of those groups are in contact with services. There are rough sleepers who do not get picked up --

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Our work has shifted to the street, exactly that.

**Murad Qureshi AM:** Yes, on the street. For example, the only time they register is probably at Christmas time when they take up two days accommodation.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** We also have Travellers as well, and things like that, which do not --

**Murad Qureshi AM:** Come up.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** -- have any TB connection.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Plus a large canal network.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** I mean, 'hard to reach' we do not use so much but there is a bigger group than just alcohol or rough sleepers. Travellers are exactly the same.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I think --

**Murad Qureshi AM:** Is that not more of a general point? There are always going to be people moving around, whether it be their lifestyle choice or not. Being settled and getting registered is actually quite a big thing to do for certain people. You mention the canals: I have seen communities on the canals at Paddington for decades.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes, and many do not have permanent mooring so their access to register with GPs is limited.

**Murad Qureshi AM:** Yes, exactly. Precisely.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would say there is no epidemiological evidence whatsoever to say that there is a higher burden of undetected TB in that population.

**Murad Qureshi AM:** There is no evidence?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** None whatsoever.

**Murad Qureshi AM:** OK. I had heard that so I thought I would go with that. Alistair, given your comments earlier about politicians – and I would defend ourselves as Val [Shawcross CBE AM] did, that we do sometimes do things which do not get us votes – what can the Mayor do to improve prevention and diagnosis?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Well, the first unit was launched in 2005 on the steps of this building, as you may well know, and that commitment and profile gave us an incredible boost. The second unit was launched on January 19 of this year by the now Rt Hon Lady Victoria Borwick MP, who was then Deputy Mayor of London. That was launched on the steps of Portcullis House. Again, a huge thanks for the commitment. The issue of direct funding is one that is an ongoing conversation but the issue of political, pragmatic support is necessary, essential and welcome.

**Murad Qureshi AM:** OK. Has it done more than Emma Thompson [Mayor's TB Ambassador] has to publicise the issue?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Tindy was there. He was on the unit.

**Murad Qureshi AM:** Right. Sorry, that is Emma Thompson's son?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Her son.

**Murad Qureshi AM:** Yes. Sorry. OK, he was there. There is the publicity stuff and the support; is there anything like – I do not know – bringing people around or things like that?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I will answer this question from a perspective of the social determinants, as it were.

**Murad Qureshi AM:** OK.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** If I want to eradicate TB amongst rough sleepers, then I not only need to provide medical services outreach to rough sleepers, I need to address the reasons why people become rough sleepers. Therein lies an irony because, as we all know, the proportion of people who are finding themselves on the street in numbers, sheer numbers, has increased quite dramatically in recent years. This has forced us to change the way we target the service. We have increasingly been more dependent upon working with the faith-based sector and taking services to street venues where people are gathering to receive soup, or just sandwiches out of the boot of a car in some instances.

We have seen a contracture, shall we say, in terms of the capacity within some of the statutory services to actually accommodate people. As you know, there are voids in many of the hostels because they are now restricted to people who have a local area connection, despite the fact that there are people on the street in

those boroughs. Consequently, we have had to take the service to the street. This provides a unique challenge but it is one we are certainly up for. We cannot tackle TB without addressing the reasons why people are appearing and becoming vulnerable in the first place.

**Murad Qureshi AM:** I think, Chair, I have heard a very good case for why the Mayor needs to deal with the housing crisis amongst rough sleepers. Thank you very much.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I would just like to say, in terms of hard-to-reach groups, that hard-to-reach groups are not always immiserated, poverty-stricken rough sleepers. Coming back to earlier on when we were talking about faith groups, some of the largest groups that we find most difficult to access are the Christian African churches. They tend to have large congregations of hundreds, perhaps even thousands. When we have, in the past, diagnosed someone from one of these communities with TB, they have absolutely not wanted the pastor, members of their family or anybody to know because the stigma is so great.

Talking about what the Mayor could do, the Mayor could go along and address one of these massive congregations on a Sunday, Alistair [Story] could park the mobile X-ray unit outside and they could all go out, follow the Mayor's example and have a chest X-ray to show how simple, non-interventionist and community-minded that sort of activity is.

**Valerie Shawcross CBE AM:** I go and speak to a lot of African evangelical churches --

**Murad Qureshi AM:** Yes, in your constituency, yes.

**Valerie Shawcross CBE AM:** -- in my constituency.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Sorry?

**Valerie Shawcross CBE AM:** I go to a lot of African evangelical churches, mostly Nigerian but also Ghanaian. They are very welcoming and they want to hear good public messages so it is not at all a hard-to-reach community, actually, but I understand what you are saying. One of them I encountered had an in-house GP practice and they were trying to address the issue of HIV and AIDS. You do get --

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would totally support that. If you can engage properly and mediate properly, it is not a problem.

**Valerie Shawcross CBE AM:** Yes. It is not difficult.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** My experience was that when I once did manage to track down the church the patient was attending and go and talk to the pastor - I was very careful; I just said I felt that someone in his congregation has TB and we would like you to give the following message - he would not do it, and he was the pastor.

**Andrew Boff AM (Deputy Chair):** However, I am not sure another white person telling black churches what to do is the most effective route.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** The thing --

**Andrew Boff AM (Deputy Chair):** That has to come from --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** However, you said, "What can the Mayor do?"

**Andrew Boff AM (Deputy Chair):** That has to come from --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** The Mayor is a very charismatic figure --

**Andrew Boff AM (Deputy Chair):** He is a charismatic guy but --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** -- and liked across the board, I think.

**Murad Qureshi AM:** I am just wondering about the last time he went to an African church.

**Andrew Boff AM (Deputy Chair):** Who, the Mayor?

**Murad Qureshi AM:** Yes.

**Andrew Boff AM (Deputy Chair):** I do not know. He has been probably been.

I have dealt with some issues with Nigerian churches with regard to human trafficking and it is not something you can impose from the outside; it has to come from the community itself. I am always wary about wheeling out the Mayor to go and tell people what to do. I am not sure that is the best route.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Perhaps raising public awareness of TB, latent TB --

**Valerie Shawcross CBE AM:** It is a very well-educated community.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** -- and addressing some of the stigmas that are associated with that that are culturally specific may be something that the Mayor could do.

I also totally back Alistair's [Story] 'social determinants of health' look at improving housing, reducing overcrowding, perhaps backing the London Living Wage and ensuring there is access to GPs for all migrants, particularly with the Immigration Act coming in. That is going to be a huge impediment. Those undocumented already delay their health-seeking when they are unwell; for those people to now have to pay to access services could have a further impact. I think we should be thinking about integrating health and social care much better. That includes all patients with infectious disease, particularly, whether they have recourse to public funds or not. I think those are things that we can look at pan-London.

**Murad Qureshi AM:** I think our local authority colleagues are doing a fair amount of that. I am not sure we have got, necessarily, those powers, but health and wellbeing responsibilities with the social services is where a lot of effort can be focused.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** There is a mechanism to be evolved through the London TB control board which should include good representation from the local authority. That would be an independent voice to provide continuity in terms of the scrutiny function and ensure that the aspirations of the Strategy are translated into something that is meaningful and helpful for London.

**Andrew Boff AM (Deputy Chair):** The treatment for TB is quite complicated.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** It can be extremely complicated.

**Andrew Boff AM (Deputy Chair):** Yes. I have understated it there. A little optimistic, maybe. How do outreach services support patients through the treatment, and are there enough of these services available to cope with the current and future demand?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** I do a lot of peer support which tries to explain what they are going through because I have gone through it. Some people do not understand the medication: how important it is to keep going with it, the side effects of it, informing their consultants of the side effects, all sorts of things.

I do peer support because it is an emotional thing, especially. I know a lot of people that have had financial difficulties because they cannot work: they are not well enough. If you try to get six months off because you are not well, it is difficult. It may be they do not want to tell their employer they have TB, etc. The whole thing is very difficult when you do feel very ill. There are also different lines of medication: the first line might not work so you have to go onto the second line. I had to go onto injections daily. You cannot be at work; there is just no possibility.

You could just take six months and be fine and come out the other side, but you must also understand it is a very toxic regime and the regime must be completed. That is where we fail, a lot of the time.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** If we do not complete it, that is when we get increasing rates of drug resistance, which is vastly more expensive than standard TB, has a much higher mortality rate and takes much longer to treat. People become more unwell when they do not complete their treatment.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** In terms of how outreach or community-based services can support people, it entirely depends on the circumstances of the individual. Before we had our automatic housing scheme, I did what we call directly DOT. I have been to squats, underground garages, park benches and crack houses; in the end, all arrangements break down because no one stays on the park bench for six months. No one stays in the crack house for six months. That is why we introduced our scheme. Having no recourse to public funds means you are immediately eligible for housing. As soon as I find someone who is homeless, within 48 hours I can have them in accommodation for the duration of treatment. I think homelessness is the greatest impediment to successful completion of treatment.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I think your question is getting to the nub of it and I am going to take the liberty of doing the honesty moment. We talk about short courses of antibiotics and that is invariably seven or ten days. How many people have ever failed to complete a short course of antibiotics? We are asking people to take a minimum of six months of daily medication. This is a big ask. They will feel better usually within about ten to 14 days, the symptoms will have gone, and then they just have



to soldier on with the medication. It cannot be a pill delivery service; it has to go beyond a pill delivery service. It has to support people to actually address the other obstacles and barriers to continuing to self-medicate.

Partnership working is key. We very rarely find someone who is totally unknown to all other services, and by working imaginatively with people in the housing sector, in the hostels, people in the drug treatment services and with pharmacists, we can build a network of highly capable treatment supporters and observers, people who can provide something local, something personal, in terms of supporting people to continue taking their treatment. We are doing a randomised control trial at the moment using smartphone technology to enable people to video themselves taking their treatment and send it in. That works.

The nightmare on the horizon is drug resistance. We are seeing the emergence of resistance to both Rifapentine and Isoniazid, two of the key drugs in our four-drug regimen internationally and in London. The analysis of the first three years of data that we have looking at those social risk factors should be a wake-up call because it says that homelessness is now an independent risk factor for multidrug-resistant (MDR) TB, in London. We are seeing the emergence of strains of TB that are incredibly difficult to treat. They require up to two years of treatment – a minimum of 20 months, including injectables – and the idea of trying to complete two years of treatment as a rough sleeper is anathema.

We are going to have to have a serious think about how we support people through very long-term TB treatment because, unfortunately, as Steve [Bradley] has put it so eloquently, there has been rather a lack of investment in new pharmaceuticals for TB. We have not had a new drug since 1972, with the exception of Bedaquiline recently, and we are stuck with a very old cocktail of drugs that, while they do work, are not risk-free and do require a long, long course of treatment.

**Andrew Boff AM (Deputy Chair):** You have mentioned support, going and observing people who are taking this drug therapy; are there the community organisations out there to do the work?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** For the last ten years we have been building a network across London. We work with over 320 different services across London.

**Andrew Boff AM (Deputy Chair):** Right. That is interesting.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Again, there is variation, but invariably people step up to the plate. Most of the big providers now, in terms of residential hostel-based services, will provide a good, solid foundation in terms of health support for their clients. Health is on the map. That is great. Therefore, if you are living in a residential service, in a hostel, the person who is best-placed to support your treatment continuity is your key worker. You do not need --

**Andrew Boff AM (Deputy Chair):** They would do the observation?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** They prompt and observe. They are not prescribing.

**Andrew Boff AM (Deputy Chair):** No.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** They are not dispensing. They are just checking --

**Andrew Boff AM (Deputy Chair):** Prompt.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Exactly. Clarifying their role and supporting them to feel comfortable with their role is what we have invested in.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** We also use pharmacies ad-hoc, particularly with people who are on methadone programmes, they can come in every day for their methadone and they can be seen to take their TB treatment at the same time --

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I have seen that happen, yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** - but that tends to be ad hoc. Some places are really helpful; some want just money.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Yes. There is the issue around support staff in hostels. One of the big problems that we find is that their job description does not allow them to actually handle medication. If, for example, I go to a hostel and I have some medication and I am going to do DOT and the resident is not there, I cannot hand those pills to the hospital workers and say, "Please will you give them to him?" I have to have, for example, the door opened and leave the medicines somewhere in the person's room before I go away. I will never know if those medicines actually got consumed on that day. One of the reasons why we do a DOT is to absolutely be 100% sure that people are taking their medication.

**Andrew Boff AM (Deputy Chair):** Obviously DOTs are resource-hungry?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Yes, but it is highly effective.

**Andrew Boff AM (Deputy Chair):** Because of the qualification of the person who has to do the observation.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Hopefully the video trial will reduce the number of resources that are required. We have huge numbers of patients who are on this trial in our centre and they love it. It is great for the patient and it reduces the number of encounters that you need to have with people.

**Andrew Boff AM (Deputy Chair):** You are getting positive feedback from patients?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Yes. I mean, I am blinded to it because I am one of the principal investigators (PIs) but the early results for this trial, for the preliminary work, are extremely positive.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** My experience on it is very much ad hoc. This is a trial and we need to wait for the results to come out, but what our patients tell us is they really enjoy it.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Are these homeless people? Sorry, I am not aware.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Not all.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Some.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** How do you supply a smartphone to a homeless person?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The reality is that 80% of people who are on the street have a phone - not so many a smartphone - but for the purposes of this trial, they get a Samsung Galaxy.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** They get given one?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** They are given a Samsung Galaxy with a free data deal with unlimited texts, internet and calling.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** It is not being given to Cash Converters five minutes later?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** It seems to be that, because they are used to having a pay-as-you-go arrangement, they really value the contract; and, as we all know, you become rather attached to your phone.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Can I just say a final word in support of DOT and it being done human-to-human? A large number of homeless people also have a lot of mental ill health and distress and I think having that face-to-face contact you can actually give a lot of support, including psychological interventions, when you are seeing people who are suffering from mental illness. That may be another impediment, if you just leave them to it, to them not taking their medicines.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** It is multi-faceted, as we have all discussed.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Absolutely.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** It is not a one --

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Correct. There is no one --

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** There is no one solution.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** No one size fits all, yes.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** It is very multi-faceted.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** It's biopsychosocial.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Yes. All of this together works because we are all doing bits and pieces. The thing is it needs someone to look after the whole bubble. That is what is not there.

**Andrew Boff AM (Deputy Chair):** I see. The trial is going on at the moment. We are going to find the outcome of that trial at some point, and then what is that going to be?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Another option.

**Andrew Boff AM (Deputy Chair):** Another option?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Andrew Boff AM (Deputy Chair):** Not the option, another option. How should TB control be integrated with other local government or mayoral functions such as housing, planning and all those things? Are there changes that are required at the strategic level?

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** The housing, I see really as the most important factor in anybody's life. If you do not have a roof over your head and a key to a door, then life is very, very difficult, nigh impossible. I think that it really behoves local authorities to look at providing what I originally described as a form of care in the community literally in terms of bricks and mortar, as well as the other psychological and social support we can give. Housing is so central to their success. We have not had a homeless person who did not complete treatment since we started housing them. We have 100% completion straight through.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Which is very cost-effective, then.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Highly cost-effective, yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** People need to understand the impact that addressing these types of things has on ill health, on getting through TB treatment and on reducing transmission; and that it is cost-effective.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** From my perspective, I do not work with anybody who just has TB. I work with people who have TB and a range of other problems that are going to be potential barriers to them being able to engage with long-term care. Consequently, I have moved well away from just trying to sterilise their body of the pathogen and moved far more towards a more psychosocial model to address the reasons that put them at risk in the first place. As I am renowned for saying, it is a recovery agenda that we need to build into the care of TB patients. It comes at the end of a long and hard road for a lot of the people that we work with, and the reasons why people have TB need to be addressed simultaneously with the therapy to treat the infection.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Once you have someone in housing and with a certain amount of stability in their lives, there is a huge amount you can do for them: looking for their eligibility for things like benefits, their eligibility to be in the country, their other health issues,

their psychological issues, their issues with supporting their partners and families -- because we do not just house the person with TB: if they have a family or a partner and they are all homeless, we house all of them. As Alistair said, it is a completely person-centred exercise and you tailor what you offer and the support you give to the needs of the person.

**Andrew Boff AM (Deputy Chair):** My last question appears superfluous now, which was, “What should the Mayor and Greater London Authority (GLA) do to support better treatment outcomes?” Assuming you have all said housing, what is the next one on the list?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The next one is to be vocal and ensure good representation on the TB Control Board, to make sure that the interpretation of the TB Strategy translates into resources to take treatment in the community.

**Andrew Boff AM (Deputy Chair):** Into the community. Good stuff.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Housing should not just come on its own. It should come with access to food.

**Andrew Boff AM (Deputy Chair):** Food?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Yes.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** You can give someone a house but if they have no money and no access to food, no bedding. They need the basics for someone to be able to feel comfortable enough that they can cope with being ill and taking medications which make them feel ill. That includes travel to and from their clinic appointments if you cannot go out to the community or when they need to come into those settings.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** The housing issue is not quite as simple as a key, either, because I work with a lot of people who would find it very difficult to independently sustain a tenancy.

**Andrew Boff AM (Deputy Chair):** People tend not to be rough sleepers just because they do not have a house.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** For a reason, exactly. Yes. That is why we opened the Ollalo House, because it is more of a therapeutic community. It is a place of recovery. It is a place to address the alcohol issues, etc.

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** I was just thinking about the thing we are all saying and what they do say, that TB is ‘curable’. It is a very interesting word because I know someone who is 26 and has had it three times. The reason is that he did not continue with that regime. What we all have to remember is every time someone fails that regime, we put ourselves even more at risk. If we do not try to bolt the door at the beginning, we really have got a big snowball coming down because the situation is, at the end of the day, we will not have anything to look after this TB. We have at the moment: we just need to do it better.

**Dr Onkar Sahota AM (Chair):** I was going to focus on the critical aspects of TB but I think we have covered a lot of the area already; I will not just ask the question for the sake of filling airspace up. I do want to get the picture of how local authorities are involved in the process right across London. From what you are telling us, it is very variable and patchy. How can local authorities play a bigger role in investing in TB in their particular areas and how can we work more collectively across London?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I think the mapping of TB is fascinating. I think it would be good if local authorities were to bring to bear some of the intelligence available to them in terms of multiple occupancy, overcrowding, accommodation, etc, and work more closely with PHE in terms of understanding the distribution of the disease across London and, more importantly, trying to identify where resources need to be focused. It is not a scattergun approach. We have the intelligence to actually target a culturally appropriate intervention, but that needs to be properly informed, first and foremost.

I do feel there is a bit of a gap in the market in terms of using geographical information systems and some of the more high-resolution data that is available to local authority and invariably not married with the more clinical epidemiological and microbiological data that exists within PHE, for instance. We do not want to throw a net over London, in inverted comma; we need to be mindful of the fact that we have to target specific interventions and efforts in particular communities, and first and foremost we need to understand where and who they are.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Some local authorities are quite well-engaged with the TB services and some are less so. Cohort review is one way in which services evaluate what is going on in their local area. Some places where they have cohort reviews have CCGs and local authority attendance, and some do not ever come despite being invited every time. I think that if we have the CCGs and local authorities in that room when they can hear what is going on about TB in their patch and what the issues are that people face - it is not just a clinical discussion because, as we have heard, TB is not just a clinical disease - then that engagement will be better. We can work on what problems we are encountering within our cohort of patients in that area and how we can address them as a team. We cannot - as clinicians, nurses and doctors - address them on our own.

**Dr Onkar Sahota AM (Chair):** Is it happening, though?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I know that --

**Dr Onkar Sahota AM (Chair):** That is what should happen, but is it happening?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** For example, in one of the boroughs that is served by the trust that I work for, the CCG and local authority do not come to cohort review and in another, they do. The engagement is clearly different, and how we progress and the things that are being done in the boroughs that engage are much better than in the boroughs that do not engage.

**Dr Onkar Sahota AM (Chair):** Would the aspiration be that there would a London TB board?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** It clearly states that with cohort reviews, CCGs and local authorities should be attending for public health. I think

we need to be putting pressure on them to attend those meetings. As well as their involvement with the TB Control Board, the cohort reviews tend to be more local. We have a northeast sector cohort review which involves a number of different trusts – they will have one in the northwest and various other areas – where you learn between trusts about your experiences, across CCGs and local authorities.

**Dr Onkar Sahota AM (Chair):** When you say, “We should put pressure”, who is “we”?

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Anyone involved within the TB world.

**Dr Onkar Sahota AM (Chair):** OK. This would be one leadership role of, possibly, the Mayor, or through the health board?

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would also say that local authorities play a far more significant role in the provision of housing and homeless care services than CCGs do and could be a little more vociferous in terms of supporting the need for routine screening and support for treatment continuity within those services. The model should not be to expect people to travel across London and be observed in a clinic, the model should be to actually provide the service where they are.

**Dr Onkar Sahota AM (Chair):** This is an opportunity for you to say things which you think we should have covered but we have not covered.

**Andrew Boff AM (Deputy Chair):** Actually, before we finish, Val [Shawcross CBE AM] raised a question about prisons and I just wondered if we had asked enough questions to come up with a good enough recommendation in the report that we produce while we have got our guests.

**Valerie Shawcross CBE AM:** I was cogitating whether or not we should be suggesting somebody does a rapporteurship on health in prisons, because this is not the only --

**Andrew Boff AM (Deputy Chair):** I am astonished, when you have got a literally captive audience, that you are still neglecting them in terms of their health needs. It is astonishing to me.

**Dr Onkar Sahota AM (Chair):** Did we not hear this evidence last week, that this was actually seen--

**Valerie Shawcross CBE AM:** Yes.

**Andrew Boff AM (Deputy Chair):** We did. It was just hearing it again. It was just --

**Valerie Shawcross CBE AM:** Yes. No, I think we have a problem, do we not?

**Andrew Boff AM (Deputy Chair):** It is a real --

**Valerie Shawcross CBE AM:** Indulge me for a minute because I have visited HM Prison Brixton some time ago. It is a very popular prison, actually.

**Dr Onkar Sahota AM (Chair):** As a visitor?

**Valerie Shawcross CBE AM:** As a visitor. It is near Brixton and families can visit, but the facilities are really appalling. It is not just about the physical facilities, it is about staffing: they have not got enough staff to move people about. One of the things I felt was that the rest of the public sector does not know about the prisons. Local authorities do not know about the prisons, the health service does not seem to know about them, we do not know about them; they seem to be little public sector islands. There are clearly some of the most vulnerable people you have ever met --

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Absolutely, yes.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** Coming in and out of prison, back into our community, and with no communication between services, or very poor communication.

**Valerie Shawcross CBE AM:** Yes.

**Dr Onkar Sahota AM (Chair):** Mental health is a big issue with those communities.

**Valerie Shawcross CBE AM:** Absolutely.

**Dr Onkar Sahota AM (Chair):** I can see a rapporteurship coming up here.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Mental health and substance misuse.

**Dr Onkar Sahota AM (Chair):** Into the health of individuals in the prison services.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I could tell you the prison health service is severely under pressure and not coping. To just give you one anecdote, I had a patient who was in prison when he got TB. I do not know whether he caught it in prison, but it took him six months to get an appointment to see the prison doctor and to get TB diagnosed from the point when he started feeling very, very unwell. Just that in itself, not even reaching health services within the prison as a prisoner, I think demonstrates how thinly stretched those services are.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I would urge you to not limit that work to TB, though.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** Quite, yes.

**Valerie Shawcross CBE AM:** No, of course not. Mental health --

**Andrew Boff AM (Deputy Chair):** That is a useful comment, actually, because it is broader than just TB.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** Yes.

**Andrew Boff AM (Deputy Chair):** You are suffering from a problem that other areas could prevent. Thank you, Chair.



**Dr Onkar Sahota AM (Chair):** If you think that we have missed something, we should have covered something or you remember something later on, you can always write to us, or there is an option for you to sum up now if you wanted to make any closing remarks. Steve, do you want to make any closing remarks?

**Steve Bradley (Patient Advocate, Tuberculosis Action Group):** Really, just for the patient side of things, we have a pathway with TB. A pathway, that we need to succeed. That does not mean to say it cannot. We do have a structure in place that just needs better supervision, really, and more resources. We have only one van; the other van has been retired because it was quite elderly. We should be very embarrassed that New York can do it, and Amsterdam. I mean, Amsterdam. Please. We should be very embarrassed and we should put efforts into this because we will be financially worse off, definitely, but also morally worse off if we do not. Thank you.

**Dr Jessica Potter (Medical Research Council Research Fellow, Queen Mary University of London):** I think we have talked a lot about the most vulnerable members of society; I would also urge you to consider the fact that there are a large number of people who get TB who have just one of the issues that we have talked about, or are one of those people who do have housing but maybe are working four or five jobs just to make ends meet. They have some ability to access healthcare but it is limited. I think we need to think about every aspect of healthcare accessibility for all people, not just the most vulnerable but some of the people that may be less on the radar that we talked about today.

**Dr Alistair Story (Clinical Lead, Find & Treat Service):** I have found it a very productive discussion. I would just reiterate with a look back to the great Hermann Biggs, who was Mayor of New York<sup>1</sup> at the turn of last century and came up with the rather insightful phrase, “Public health is purchasable within limits and the city can determine its own death rate”. He found the high rate of TB in New York back then abhorrent and did something about it, and also coined the phrase that this was a clear example of how much the city valued the lives of its citizens. TB is a gross inequality. It is a barometer of social justice across London and the moral issue is very large.

**Dr Sue Collinson (Tuberculosis Outreach Worker, Homerton Hospital):** I would just like to say I think we are now bringing very much to the forefront of things both the sort of clinical and the social issues. I think the thing that is now lagging behind is mental health and psychological interventions, not just for homeless people with TB but for homeless people as a whole. I know there is some interesting new work going on about creating psychologically informed environments for people working with homeless people and I think we really must not neglect the psychological aspects of this.

**Dr Onkar Sahota AM (Chair):** Thank you very much for your contributions.

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<sup>1</sup> Subsequent clarification received after the meeting: Hermann Biggs was the General Medical Officer of the New York City Department of Health (and never held the office of Mayor of New York).

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