

# Listening to those on the frontline: service users' experiences of London tuberculosis services

Markella Boudioni  
Susan McLaren  
Ruth Belling  
Leslie Woods

Institute for Leadership and Service Improvement, Faculty of Health and Social Care, London South Bank University, London, UK

**Aim:** To explore tuberculosis (TB) service users' experiences and satisfaction with care provision.

**Background:** Thirty-nine percent of all new UK TB cases occur in London. Prevalence varies considerably between and within boroughs. Overall, research suggests inadequate control of London's TB transmission; TB has become a health care priority for all London Primary Care Trusts. Service users' experiences and satisfaction with care provision have not been explored adequately previously.

**Methods:** A qualitative research design, using semi-structured face-to-face interviews was used. Ten service users, purposively selected in key risk groups across London, were interviewed. All interviews were digitally recorded with users' permission, transcribed verbatim, and analyzed thematically.

**Results:** Participants were treated in local hospitals for 6–12 months. Treatment was administered by TB nurses to inpatients and outpatients receiving directly observed therapy in consultation with medical staff and home visits for complex cases. Two participants did not realize the importance of compliance. Overall, they were satisfied with many TB services' aspects, communication, and service organization. Early access, low suspicion index amongst some GPs, and restricted referral routes were identified as service barriers. Other improvement areas were information provision on drug side effects, diet, nutritional status, and a few health professionals' attitudes. The effects on people varied enormously from minimal impact to psychological shock; TB also affected social and personal aspects of their life. With regard to further support facilities, some positive views on managed accommodation by TB-aware professionals for those with accommodation problems were identified.

**Conclusion:** This first in-depth study of TB service users' experiences across London offers valuable insights into service users' experiences, providing information and recommendations for a strategic framework for TB service organization and delivery. Overall, further research is needed; TB services – local, national, and international – need to be more closely aligned with service users' complex needs.

**Keywords:** qualitative study, interviews, TB, service organization, services improvement

## Introduction

Tuberculosis (TB) is a global problem that does not respect geographic boundaries. This is particularly true with regard to the multidrug resistant outbreaks affecting comparable sized cities with relatively well-developed health care systems.<sup>1</sup> With the exception of one comparative study focusing on Osaka City, Japan, and London, UK,<sup>2</sup> no documentary evidence was found comparing London's TB service models and infrastructure with those of similar urban contexts. However, approaches taken

Correspondence: Markella Boudioni  
Institute for Leadership and Service Improvement, Faculty of Health and Social Care, London South Bank University, 103 Borough Road, London SE1 0AA, UK  
Tel +44 20 7815 6745  
Email boudiom@lsbu.ac.uk

in other major cities have proved effective. New York, for example, has a high incidence of both TB and multidrug resistant (MDR)-TB and a well-developed health care system delivered through multiple providers. Since the start of the major TB outbreak in 1992, TB rates have declined from 51.1/100,000 to 11.9/100,000 in 2006.<sup>3</sup> Many factors have contributed to this decline, including among others a strong TB control and management plan; free testing and treatment for both active and latent TB at ten chest centers within the city; directly observed therapy (DOT) as the standard form of care offered to all patients; and management of multiple providers by a single organization with responsibilities for TB control across the whole city.<sup>4</sup>

London's specific TB goals are set within the context of England's national TB program goals.<sup>5</sup> In line with global concerns, the long-term aim is to reduce and ultimately eliminate the disease in England. Immediate national aims are three-fold: to reduce risk of people being newly infected with TB in England; to provide high-quality treatment and care for all people with TB; and to maintain low levels of drug resistance, particularly MDR-TB.

London currently accounts for half of all new TB cases in England.<sup>5</sup> London's incidence varies considerably from one geographical area to another,<sup>6</sup> and across risk groups, namely new UK entrants, the homeless, and people with human immunodeficiency virus (HIV). London's TB nature also continues to change, with 42% of cases ( $n = 11,851$ ) between 1998 to 2005 being resistant to one or more drugs.<sup>7</sup> Eleven percent of drug resistant cases are associated with homelessness, imprisonment, and drug misuse. The reported incidence of TB is slightly higher in males (54%) vs females (46%).<sup>8</sup> Growing numbers of London TB cases are UK born, adult males between the ages of 20–39.<sup>7</sup> Taken together, these figures suggest inadequate control of TB transmission in London. In response, National Health Service (NHS) London made TB a health care priority for 2007–2009 for all Primary Care Trusts (PCTs).<sup>6</sup>

National targets for successful TB control require all patients with suspected pulmonary TB to be seen by a TB team within 2 weeks of first presentation to health care providers. The national action plan called for better TB services organization through local multidisciplinary TB networks<sup>5</sup> and targeted services to those most at risk of developing TB. The Healthcare Commission (2007) has called for better PCT commissioning to improve public health and community services by better understanding of the local populations' health needs in order to target preventive measures more effectively and purchase relevant health care services.<sup>8</sup>

## TB services in London

TB services are provided across London by individual PCTs and partner hospitals. Five TB networks of services and professionals coordinate their development. A single 'Stopping TB in London' group was developed to oversee the management of the drug resistant outbreak in North/North East London, steer the pilot on TB early identification in high-risk groups, and maintain an overview of action.

London's specific TB goals are set within the context of England's national TB program goals.<sup>5</sup> Standards and targets for services still in development include appropriate measurement tools to (*unpublished data*):

- provide early access to specialist TB services;
- ensure early diagnosis;
- identify patients with complex needs;
- achieve a minimum of 85% treatment completion rates;
- and prevent further infection through contact tracing.

Although service mapping data and some information is available for all London sectors, providing a partial picture of sectors interim progress towards the draft targets,<sup>8</sup> users' experiences, and satisfaction with services are not captured.

Moreover, very few studies have been conducted with data from London's TB service users. Three cohort studies of active TB patients were conducted. Story et al concluded that high levels of infectious and drug resistant disease, poor adherence, and loss to follow-up care indicated TB was not effectively controlled among homeless people, prisoners, and drug users in a cohort study of 1941 eligible TB patients on treatment in Greater London.<sup>10</sup> Using a prospective cohort of 250 newly diagnosed adult TB patients in a London hospital, Craig et al showed that increased hospitalization was significantly associated with hostel/street homelessness, drug or alcohol use, and having no one to remind them to take medication.<sup>11</sup> Missed appointments were associated with drug/alcohol use and previous TB treatment. Extended treatment was also associated with drug/alcohol use, previous TB treatment, drug resistance, and those anticipating difficulties taking medication. They concluded greater emphasis was needed on developing a social model of care, including TB link workers to enable access to housing and support services. In a further study by Craig et al, community education and resources were recommended to support link workers where nurses were unable to perform educational outreach.<sup>12</sup>

Three studies exploring London TB service users' experiences were identified. A qualitative study of 24 multi-ethnic TB participants concluded that adherence to a 6-month regimen of daily isoniazid was better with a general knowledge

of TB extending beyond treatment. First appointment's attendance could be improved by a single daily tablet, warnings about dizziness, and discussing the difficulties of taking a 6-month treatment course.<sup>13</sup> A questionnaire study looking at knowledge, attitudes, and practice (KAP) found that while most educated and multilingual Somalians in inner London were aware of the infectious nature of TB, many were uncertain about coping with the disease and its effect on lifestyle. It concluded that uncertainties in TB knowledge need to be addressed with direct educational input.<sup>14</sup> A mixed-method community-based participatory research study concluded that postmigration living conditions, including lack of access to TB information and health care, are a risk factor in TB control in migrant African communities.<sup>15</sup>

All mentioned studies were conducted in high TB incidence London areas. Most were cohort studies; only two studies had qualitative aspects looking at service users' experience in depth. However, these were restricted to ethnic service users, one focusing on adherence,<sup>13</sup> the other on structural influences on epidemiology and control.<sup>15</sup> No study was identified exploring in-depth TB service users experiences, satisfaction, and suggested improvements to current service delivery across London.

## Aims and objectives

Building on the work of the Stopping TB in London Group's *Recommendations for the development of an appropriate workforce to deliver TB services in London*,<sup>9</sup> an evaluation of TB service structure, delivery, and required expertise to control and treat TB within London was commissioned.

A study protocol was developed and agreed by the project's steering group to guide the study. In accordance with this protocol, a component of this evaluation aimed to explore TB service users' experiences, particularly of those most at risk, and satisfaction with services.

## Methods

The design was qualitative, using semi-structured interviews with TB service users of tuberculosis services across London. The study was part of a wider service evaluation; it did not require NHS Ethics and Governance approval.

## Participants and setting

A purposive sampling framework, aiming to ensure service users' representation from the five geographical London sectors and main TB risk groups, was developed by the project steering group in two stages. In Stage 1, lead TB nurses in each London sector were asked to identify service users with

the following inclusion criteria that were considered to represent the full spectrum of TB service users. The main TB risk groups and those who complied with treatment included:

- compliant users (compliance was defined as adherence to drug treatment),
- immigrants,
- prison users,
- HIV coinfecting,
- and those with mental health problems.

In Stage 2, the characteristics of a further group of service users were identified and taken into account to include:

- UK born males, 20–39 years old, and single diagnosis of TB (growing numbers of London TB cases have been found to have these characteristics).<sup>7</sup>

To facilitate recruitment, the nurses were sent information sheets and consent forms to give directly to invited participants. All participants read the information and signed the consent form prior to the interview; anonymity and confidentiality were protected. All were aware of their voluntary participation and their right to withdraw at any stage.

Recruitment was difficult as many nurses were involved and some criteria appeared less frequent than others among service users; thus we do not know the exact number of service users that were asked to participate. Ten service users with the above inclusion criteria agreed to participate and interviews were conducted between November 2007 and March 2008. Participants' sociodemographic and risk/illness characteristics are summarized in Table 1.

The main topics discussed with them were experiences of and challenges for service delivery, reactions to being diagnosed with TB/living with TB, and support during and after treatment. Further details are given in Box 1.

All interviews were conducted at a time convenient to participants, usually after their regular appointment, at private and quiet consultation rooms at the clinics; they lasted 30–60 minutes. They were digitally recorded; additional field notes were also taken.

## Data analysis

The interviews were transcribed verbatim and transcripts checked against digital recordings for reliability. Data was analyzed manually using the principles of thematic analysis, thus coding data into units of meaning and building these into categories and themes based on similarities and differences.<sup>16,17</sup> Four core themes were identified; some direct quotes are provided for illustration of main themes and categories:

- A. experiences of service delivery;
- B. satisfaction and challenges with service delivery;

**Table 1** Participants' socio-demographic and risk characteristics

Interview	Sector	Gender	Age	Ethnic group	Risk group
1	SW	Male	28	Pakistani	Compliant user, immigrant
2	SW	Male	40s	Black African (Ugandan)	Compliant user, immigrant, HIV coinfect
3	NW	Male	50s	Black African (Ghanaian)	Prison user, immigrant, HIV coinfect (inpatient)
4	NE	Female	70s	White British	Compliant user, other conditions (stroke, meningitis)
5	NE	Male	35	European (mixed parentage)	IV drug user, immigrant, HIV coinfect
6	NW	Female	20	Black African (Somali)	Mental health issues, immigrant
7	NE	Male	30	UK born, Black British	TB single diagnosis
8	NE	Male	32	UK born, Asian British	TB single diagnosis
9	SE	Male	27	UK born, Black British	TB single diagnosis
10	SE	Male	25	UK born, Vietnamese	TB single diagnosis

C. effects, reactions, and support;

D. alternative support methods.

## Findings

### Experiences of service delivery

#### The diagnosis

The initial contact point for people with symptoms was their GP. In most cases people were initially given one or two courses of antibiotics to alleviate symptoms, resulting in delays in hospital referrals and perhaps indicating GPs' lack of knowledge of TB symptoms and/or misdiagnosis. They were later referred to hospital for further tests.

*"So when the antibiotics finished over 1 week I went back, booked another appointment, and I explained that the coughing is still ongoing so she gave me ... the one that she prescribed before was like a kind of commercial brand but the one she gave me afterwards was four times stronger but even after ... when taking that there was still no difference. So she sent me to get an X-ray here, just a few buildings down."*

The GPs' referral to the specialist clinics occurred usually 2 weeks to 1 month after their first GP visit. There were, however, unacceptable delays in referrals of three cases, resulting in a delayed diagnosis, ranging from 3 months to 3 years after the first GP visit. One person was eventually referred for scans 3 months after his first GP visit, following an asthma pump prescription and a delayed second visit. The results demonstrated extensive scarring of lung tissue and a TB diagnosis 3–4 months after his initial symptoms.

*"For about 2 to 3 months (I had the symptoms). ... No, but after about 2 weeks I went and told them (the surgery) I had a bad chest. ... So I just put it down to maybe 1 day fever or 24 hour bug and then I was given an asthma pump. ... So after about, after about 3 months of feeling like this, a friend said to me go to the doctors, if you want I'll come with you ...."*

In another case, the GP referred the person to the hospital for tests 4 months following the initial visit, following repeated prescriptions of painkillers, resulting in a diagnosis after 8 months. In the worst reported scenario, both GP and consultant reassured the person that coughing blood regularly was normal; a TB diagnosis followed more than 3 years after the first visit, with the additional appearance of a lump.

Few complex cases were already hospital inpatients or users of other services, so they were referred directly from them. One person found out that she had meningitis and TB whilst in hospital following a stroke; another was transferred directly from the immigration asylum to the clinic for tests. A referral to the hospital for further tests for an HIV positive person was made by HIV consultants, following nonreferral by his GP.

*"Anyway I wasn't feeling well and the GP said it was nothing ... It was nothing, just was a virus. And then I went to them, I went to see my HIV doctors. They saw me coughing and they asked me to do some tests. And then they test the cough, the spit, the blood, they made the test and they said, X-ray and they said it was TB."*

#### TB services and treatment management

Treatment was offered mostly in a local hospital clinic at the same or neighboring boroughs. For some complex cases, treatment was offered in more than one hospital or clinic.

Some did not know their treatment's intended duration, either because they were at the initial stages, the condition's progress was uncertain, or perhaps they had not assimilated the information. When known, the duration was between 6 to 12 months. Treatment for more than 6 months was due to not being clear of infection, either because of the mycobacterium's resistance or because users were not treatment compliant. The following excerpt reveals a misconception in understanding, when the person refers to a viral cause of TB.

**Box 1** Interview topic guide**Section 1: Experiences of and challenges for service delivery**

1. How did you find out you had TB?
2. Which TB service treated you? Where did you have your treatment?
3. How long did your treatment last?
4. Who managed your day-to-day care?
5. What did you have to do in terms of treatment?
6. What happened if you didn't do as doctor/nurse asked?
7. How satisfied were you with the treatment received?
8. What were your main challenges or difficulties?
  - In accessing the service?
  - In maintaining treatment over the entire prescribed course?
  - Incentives given?
9. How might these have been improved/made easier for you?
10. What did you find helpful about the TB service? What did you like most about it?
11. What are your views on:
  - Nurses dealing with housing, finance needs?
  - A 'one-stop', managed accommodation/hostel – would that have been helpful to you?
  - Accommodation run by people who understand TB and who, during a course of 6 months treatment, wouldn't evict you because you had broken a house rule? (eg, had alcohol on premises?)

**Section 2: Reactions to being diagnosed with TB/living with TB**

12. What were your main worries or concerns when you found out you had TB?
13. How did your family/friends/work colleagues/fellow students/teachers react?
14. What effects has having TB had on you?

**Section 3: Support during and after treatment**

15. What support did you have during and after treatment?
16. If someone like yourself was diagnosed with TB, what advice would you give them?

*"My treatment was in for say 9 months but it went more than 9 months. ... I had the proper, proper virus, so they said nine to a year, so the last time I came to the hospital I was speaking to the doctor, he said to me, he's going to give me 3 more months, because it's still sat in there."*

Although doctors visited frequently, TB nurses administered treatment to the inpatient. For outpatients, treatment was either administered at the hospital, eg, directly observed therapy (DOT) at regular times (eg, 5 days per week), or at monthly or bi-monthly appointments by TB nurses with doctors' consultations.

In some complex cases, TB nurses visited the users either initially or in a more permanent basis for assessment

and treatment administration. For example, on one occasion the person was initially visited by the nurse at his hostel for assessment and treatment administration. On another occasion, the nurses were visiting the person's home once per week for his first 3 months of treatment to administer it in a pill box and also check his progress.

Several users not being on DOT, had full responsibility for taking their medication at required times on a daily basis. In some cases, carers, partners, or friends supported their daily care by giving them tablets or supporting them emotionally through the process.

**Compliance with treatment**

Most users did not have any difficulties in maintaining treatment over the entire prescribed period. A couple had some difficulties getting used to the treatment initially, mainly because of the number of prescribed tablets. There were, however, occasions when users did not adhere because it was inconvenient or they forgot, ie, when staying out at friends' houses or under difficult personal circumstances. For example, someone missed some tablets due to bereavement and the associated distress and confusion.

*"... my father passed away about a couple of weeks ago so that time I missed it for about 4 days... Yes, the thing was, I actually ... obviously when my father passed away I wasn't thinking properly and plus my tablets ran out. It didn't run out, I thought it had run out but I actually had them and I thought it was run out ..."*

Two people did not realize the importance of taking the medication as instructed. Someone with a third TB recurrence admitted that his second occurrence was due to not realizing the importance of adherence to instructions the first time.

*"And then I was treated, and then I stopped taking the medication because I was feeling better, which they told me was no good for me. That was when I caught it again, because obviously I did not comprehend the instructions. As soon as I started feeling well I said I'm okay now, why shouldn't I be, you know?"*

**Satisfaction and challenges with service delivery****Satisfaction**

All users expressed satisfaction with the care received from their TB doctor and nurses. Some commented on the good services organization and timely appointments; the attentive attitudes of health professionals.



The amount and quality of TB information provided by TB nurses was well perceived. Most appreciated nurses' friendly, caring, considerate approach, and good communication skills; the emotional support, encouragement, and understanding they provided.

*"I actually like the way they talk to you, they kind of encourage you. They deliver the service well; they deliver the service well, because sometimes when I used to come I find it hard taking the medication. You get someone sitting next to you and trying to get your mind off things, just to talk to you, ask you about other things apart from the disease and dah, dah dah, dah dah. So at the end of the day your mind, you kind of jump out of the situation you're in, and it helps you to take the medication, and to look at life with a different perspective as you're taking the medication ..."*

The TB doctors' attitudes were also well perceived. The inpatient appreciated the attentiveness and administration skills of a particular doctor visiting with his students. Other positive aspects mentioned were their knowledge, their information provision, communication skills, and manners.

*"Yes, I was, I was actually, Dr (named Dr), he was a very nice guy. And he was letting me know things; he was explaining things for me, that's why I'm running after him. Honestly, he's a very good doctor ..."*

### Suggested improvements

Service improvement suggestions were, provision of support to deal with side effects; advice on diet, nutrition, and putting on weight including alternative ways; and provision of follow-ups.

*"... but the only area I would probably change or improve is the follow-ups. Like you mentioned the diet thing, what do you eat, how do you eat, you could find this is better, you could find that is better. Because I remember when I was struggling to put weight back on, my wife went to Holland and Barratt's and got this formula that is supposed to help you put on weight ... And I was wondering, what do I do?...."*

Other potential improvement areas were communication and attitudes of some health professionals. One person expressed a slightly negative opinion on doctors' attitudes and communication skills in appointments. Another did not appreciate a nurse's communication skills; he found her attitude challenging and authoritarian.

*"Well there's one nurse that challenges me a lot. ... Like get up, walk around, do this, do that ... And all I need to sleep. I need to sleep. Yes, she doesn't like me to sleep, so I'm always arguing, you know, with her."*

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### Main challenges

Most service users did not voice any challenges or difficulties accessing the services. Exceptions, however, were those whose hospital referral and subsequent diagnosis were severely delayed. The person who was diagnosed 8 months after his first report of symptoms, because of referral delays, expressed anger and frustration with his GP. The start of appropriate treatment was clearly delayed and this put on hold many aspects of his life.

*"I was really fed up with my GP, I can say. Yes, very fed up! Then like, when Dr (name) told me that I'd got TB sort of thing and they do a skin test and this proved I got TB, then I'm really fed up with her (his GP) and she wasted 8 months, can you imagine October to May? If you think about it, it's loads of time, 8 months!!!"*

The person who was misdiagnosed by both GP and TB consultant and diagnosed more than 3 years after his first GP visit, was obviously also frustrated.

*"Yes that was too long ... Actually, after about 6 months (of coughing blood) I went to my GP. I told him so and so and he said okay let me make an appointment with the (named hospital) so the doctor should have, he should have... obviously he's a doctor and you trust your doctor and stuff, but he should have found out that it was TB because there's, there's, if it's TB you would know ..."*

### Effects, reactions, and support

#### Main concerns when diagnosed

Most people were shocked and compared the condition with other conditions, such as HIV and hepatitis. Fear of dying and worrying about life and death were also common reactions; some were concerned about leaving others behind, like children, parents, and families. Concerns were expressed that this was a condition for life. Disbelief and trying to identify the reasons for getting it were also common.

*"I thought bummer!!! that, I wasn't very happy but then at the same time it was kind of expected it because of my friend having it before and then giving it to my cousin as well and me having symptoms I just thought like yes, I got it now but I was like a little bit upset..."*

Another worry was about infecting others especially close family members. The contagious nature of the disease and its specific characteristics compared with other diseases made some users feel responsible for their activities. In some occasions, they were even feeling guilty.

*"... But one of the things about TB, you know, I think is more dangerous, because I can sneeze and give it to someone, you know, or cough, you know... whereas HIV's more contained. Because I do have, you know that responsibility of me not giving it to other people, you know. Do I wait until I get well? Even visiting family, you know and it was near Christmas time, you know and I wanted ... I did go and see the family but you know you have to think, be more responsible about your actions."*

### Effects of TB on the person

TB affected people to a different, negative, or positive extent. It had a minimal effect for those complex cases with multiple risk factors or multiple diagnoses such as HIV or stroke. These conditions were considered more serious or life-threatening than TB. In one case the person had not told his family, because he felt ashamed and afraid of their reactions; only his girlfriend knew about the condition.

*"No, I didn't tell them (two brothers and family)..."*

*Because I am ashamed, innit?... Mother of my baby, she knows."*

Several users experienced treatment side effects, such as nausea, dizziness, itching and skin rashes, leg and neck cramps, and cold fingers, which affected their everyday lives. Physically, some people felt less energetic or active, and more tired than usual. Some also found that they had to rely on others for specific tasks until they regained their energy.

TB also affected social aspects of people's lives, work, and studies seriously; in most cases people had to take time off work, cancel, or postpone studies. It also restricted personal relations, some friends were not visiting or even avoiding the person; sexual relations and wedding plans were also influenced. Participants' sense of freedom was limited; they felt isolated with restricted socializing. They thought that the condition in association with its apparent isolation may even precipitate psychological and mental problems.

*"I don't suffer from depression but I feel that it can for some people because you're cut off from what your normal routine is of. Even interacting with people, because you're ill and can't really socialize you know or be ... I mean some lifestyles may be packed with, you know, like going*

*to the gym. I can't do it ... I mean you can get bored and depressed."*

Conversely, it had a positive effect on others. One young person not only retained his psychological strength and confidence, but his physical strength; he also put weight on, which he considered a positive influence. Some, once past the initial shock and disbelief, realized the seriousness of the condition and changed long-lasting habits, adopted a healthier life style, took up exercise, and reviewed their whole lives as a result.

*"And I stopped smoking cannabis as well... I'd rather not be high and be healthy ... So without it I find I have to deal with life more now ... At times I feel maybe a little bit depressed and stuff because I don't have anything, you know, but I'm happy, I'm learning to cope, so .... I think since I've had, since it's happened to me I've taken a very serious look at my life now ... Yes, now I'm, I enjoy each day and I give thanks for waking up and stuff and you know, I take it much more importantly to try and look after my health, my family and ..."*

### Reactions and support from others

Mixed reactions were perceived from other people. It was said that the general public has limited TB knowledge and certain misconceptions about the condition. Some negative reactions from family and relatives, in particular, were considered to be due to lack of TB awareness and knowledge and its contagious or noncontagious nature. Their attitudes, however, improved when they had more TB information and understanding.

*"Oh they weren't really happy about it, at all. They started seeing me as like being a bit diseased, do you know what I mean?.....Yes, that's their initial reaction but now they're more fine about it ... They know that you don't have to, at first they thought we can't use the same cup or plate, they had to keep it all separate, I told them that is not because I've been given information like it's not that. It's infectious and contagious but it's not that contagious, you have to be around that person for a while for long periods. And yes, so there was less, less like angry about it and they was more acceptable."*

In a few cases, close relatives were shocked and tried to protect other family members from TB. Friends, work colleagues, or fellow students sometimes also reacted negatively and felt protective about their own families.

In most cases, however, family, friends, and relatives were very supportive, attentive, and caring. They worried about the person's health, had their best interests at heart and

were most commonly enquiring or reminding about medication. Even in cases where people lived alone, emotional and practical support was received with regular visits and practical support, ie, cooking and cleaning, by family and friends. On one occasion, a person's flatmates were helping him with medication, as well as supporting him with practical daily tasks and nutrition, to the extent that someone left his job and undertook the carer's role.

*"They are very, very much worried about me, they are coming with me daily here, they don't leave me alone at any time of day, one of my friends they just leave their job because of me because doctor say, like my technicians like have somebody with me all the time, because I can't sit and I can't take anything with me, so they give me breakfast, lunches, everything on time, as doctor said."*

## Alternative models of support

No incentives in the form of payment were given to participants, even though they were available; most did not express the desire for any payment when asked. A homeless user would have liked the idea of incentives' provision; he was aware of refunds and was claiming his travel money. Another, being unaware of any travel refund or vouchers, said that he would have found them useful, as he was out of work and education because of TB.

When asked about the potential of nurses dealing with housing and finance needs, some considered this role as separate from what nurses were trained for and that they are busy with the nursing aspects of their work. Others, however, would have found it helpful; nurses could act as contact points for housing and financial support, providing information about sickness benefits, freedom passes, and travel refunds.

*"Yes, yes (nurses could deal with housing), they could put you in touch with the right people that ..."*

*And is it the same with finances?...*

*"Then again they could just say well this is how you get in touch with and, yes."*

*So it's like a point of contact really. Yes."*

Support with housing and financial issues was welcomed as well as the option of managed accommodation or hostel, particularly from those who were on benefits or had accommodation problems.

*"Maybe I mean... Not all services would be needed. Maybe I would like to stay at home but you know, maybe a little financial help with transport or food, you know.... Yes, yes. But some people would like to take maybe a full program*

*if you had it like moving into a center that would cater for that person."*

However, although they realized the benefits of such accommodation, others mentioned stigmatization and felt that it could possibly resemble 'prison'.

*"Yes it could have been. Maybe if there was someone who never had anyone as in like he's by himself and he's really bad as in like ... a lot of people with TB may be really bad, they can't really do everything. For them maybe it would be all right but for me ... if I'm in a place like that I'd be really maybe, I don't know, no I'd just have to come out of it ... No I'd feel like I'd been in a prison or something."*

The option of accommodation run by people who understand TB was considered the most helpful option discussed. The combined benefits of accommodation, being with professionals who understand TB, receiving appropriate medical care, and related social benefits were recognized, particularly for homeless people, one of the most difficult to reach high-risk TB groups.

*"Oh yes, because it's not included in the hospital, and plus all those people can understand each other. I know if the virus can have only one person and the next person, it's not going to travel, because already the next person has the problem. But that would be nice ... And socialize, yes, and talk to each other. There (at the hospital, as inpatient) you can't talk to no one, you're locked to your room."*

## Discussion

Challenges identified for service delivery were GPs' low index of suspicion and lack of TB awareness amongst patients, primary care staff, and services with restricted referral routes leading to delayed referrals, diagnosis, and misdiagnosis. With regard to referral pathways and access, London's TB service targets focusing on GP referral implicitly acknowledge that TB is difficult to suspect and therefore, by the time GPs may come to suspect it, the disease may be more advanced than if a patient had self-referred to a specialist clinic or Accident and Emergency. There is a need for GPs' continuous professional education since delayed diagnosis or frequent misdiagnosis infringes national diagnosis targets.

Early access to specialist TB services is one of the draft London TB targets. The findings suggest more needs to be done to achieve this. Alternative referral pathways may need to be explored within the context of integrated care pathways



(ICPs). In summary, ICPs can provide explicit standards to reduce unnecessary variations in care and outcomes, since they incorporate specific criteria for referral; milestones and evidence-based assessments; protocols; guidelines; standard; and measurable, valid, and reliable outcome measures. Multidisciplinary responsibilities for steps/activities can be also incorporated. No exemplars of locally developed ICPs for TB, however, were found related solely to London TB services. The development of a TB specific ICP could enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing use of resources, including multidisciplinary working, within and across sectors.<sup>18</sup>

Treatment compliance was high among participants; this corresponds with national statistics showing that London does well in reporting completion rates.<sup>19</sup> Information appears to be a common key factor in promoting adherence. Not all service users within the current study understood the adherence's importance to prescribed medication, which supports the conclusions of San Sebastian and Bothamley that adherence is better with a general knowledge of TB extended beyond treatment.<sup>13</sup> Lack of access to TB information was also identified by Marais as a risk factor for TB control.<sup>15</sup> Our findings highlight the need for TB professionals to enhance service users' understanding of the disease, to avoid promoting misconceptions and its transmission, together with a need for information about coping with it and its side effects, ie, fatigue, mood disturbances, and impact on relationships and work. In addition, the treatment of some participants lasted more than 6 months, which may be associated with complex needs such as drug use, previous TB treatment, drug resistance, and some difficulties taking medication.<sup>11</sup>

Interestingly, all participants, regardless of experienced diagnosis' delays, were satisfied with care received from doctors and nurses, some noting good communication, administrative skills, and services' organization. Areas identified for service improvement included dealing with side effects, dietary advice, and improving nutritional status, attitudes of particular professionals, and communication/more time with doctors. More information and warnings about side effects were also suggested by San Sebastian and Bothamley.<sup>15</sup>

Effects and reactions to a TB diagnosis varied enormously. Initial shock, disbelief, and fear from those diagnosed and a general lack of TB knowledge from general public, friends, and relatives were discussed. TB awareness and education seems to be of paramount importance. Other research supported the value of educational outreach programs intended to promote screening in GP practices

in relation to TB diagnosis.<sup>12</sup> Given the nature of TB risk groups, the need to improve links with a range of voluntary organizations, particularly those in the areas of addiction, mental health, HIV, refugees, and asylum seekers should also be acknowledged. Community education and resources to support link workers and nurses to perform educational outreach were also highlighted elsewhere.<sup>19</sup> Reaching and educating ethnic communities that may be less TB aware has also been highlighted elsewhere.<sup>14</sup>

Emotional and practical support from families and friends, including support with taking medication was acknowledged as very important in this study. Craig et al highlighted that having no one to remind patients taking medication is associated with increased hospitalization.<sup>11</sup>

With regard to further support facilities, socially disadvantaged service users valued and appreciated incentives to promote treatment adherence, although awareness of these was limited. Interviews highlighted a preference for safe housing and managed accommodation, preferably supported by TB professionals, for difficult-to-treat patients with accommodation problems, despite some negative views about potential stigmatization. Provision of managed accommodation therefore remains an option for addressing the treatment and compliance challenges posed by complex, socially disadvantaged patients. However, feasibility requires further examination as part of a broader London plan to support those most difficult to complete treatment, as highlighted by Maguire et al (*unpublished data*) encompassing local support systems to enable DOT and an increase in the staff availability with the necessary skills to provide outreach and support, as part of a multidisciplinary team.

Both positive and negative views were expressed about nurses' involvement in housing, finance, and travel. Underlying the perceived benefits is a clear need for individuals, nurses or not, to act as key contact points to enable access to this information. Other London studies focusing on patients with complex needs also concluded that greater emphasis was needed on developing a social model of care.<sup>11,14</sup>

Useful insights may be also gained into options for future management and organization of London's TB services by analyzing effective approaches used in New York. Factors that contributed to the decline of TB there included among others DOT as the standard form of care offered to all patients (although voluntary for the most part, New York has a wider range of legal enforcement measures available in managing infectious nonadherent MDR-TB patients.) It also included TB awareness raising, publicity and education provided centrally by the Bureau of Tuberculosis Control (BTBC)

**Table 2** Main recommendations

These should be addressed, facilitated, or provided
1. Awareness, education, and training for GPs and other health professionals to recognize TB symptoms and offer prompt diagnosis
2. Managed accommodation for difficult to treat patients, ie, small, dedicated facilities run by TB professionals for those most at risk with treatment non-compliance
3. Safe housing and secure hostel accommodation supported by TB staff
4. Promotion and awareness of incentives to service users, eg, cash, food, and travel costs for promoting adherence
5. TB services teams' collaborative ways of working with non-NHS and voluntary organizations to raise awareness and provide information
6. Addressing information needs of service users regarding TB understanding, drug adherence, drug side effects, coping with emotional, and social consequences
7. Service users' experiences informing the development of integrated care pathways to contribute to improvements in service quality

and management of multiple providers being carried out by a single organization with responsibilities for TB control across the whole city.<sup>4</sup> More recent developments include chest centers opening outside normal business hours and piloting of a videophone project for patients needing DOT twice a day.<sup>3</sup>

## Limitations

This is a small local qualitative study. The sampling framework aimed to ensure service users' representation from the five geographical London sectors, the high TB risk groups – homeless, prisoners, drug users, and recent immigrants – and another group that presents high growing numbers, namely, UK born young adult males between the ages of 20–39.<sup>7</sup> However, due to the sampling framework and recruitment difficulties, one sector and females are not equally represented. In addition, some participants were not fluent in verbal English and this may have affected the quality of their responses.

## Conclusions

The UK TB incidence increase deserves major consideration. This study, despite its limitations, is the first in-depth study of TB service users' experiences across London. Qualitative findings from the interviews offer valuable insights into service experiences, providing information and recommendations (Table 2) that can be used to inform a pan-London strategic framework, building on findings of *Recommendations for the delivery of an appropriate workforce to deliver TB services in London*.<sup>9</sup> Further funding and development of this study would be to examine in detail the geographical differences in

service provision from a service user's perspective, with a larger number of service users participating in each London sector.

TB education and awareness of workers and vulnerable people is of paramount importance.<sup>8,20</sup>

Further research may address sensitivity of screening tests used, issues of population risk and the needs of specific high-risk groups. Educational outreach programs can play a wider role in raising TB awareness amongst service users and primary care staff. Overall, further research is needed on TB service users' needs and experiences, especially those most at risk. Moreover, TB services, not just in London, but also nationally and indeed internationally, need to be more closely aligned with service users' complex needs.

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