

Engaging with civil society to improve access to LTBI screening for new-entrant migrants in England: a qualitative study

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Running title: Civil society involvement and TB in migrants

Text word count: 3967

Summary word count: 190

Number of references: 37

Number of tables and figures: 2 tables and 1 figure

Keywords Latent, tuberculosis, community, migrant, prevention

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Summary

Setting The LTBI programme offers testing and treatment to new entrant migrants from high incidence countries in England. However, the rates of LTBI testing, treatment acceptance and completion are suboptimal and appropriate access must be improved.

Objective: To gain insights from the community, community-based organisations (CBOs), and public sector stakeholders on interventions that facilitate collaboration to improve health care outreach and delivery.

Design Three stakeholder meetings and five focus group discussions were held using thematic analysis to identify themes arising from the participants' perspectives.

Results Four overarching themes emerged from the discussions. These were capacity, collaboration, culture and trust. These highlighted the complementary skills sets different sectors bring to collaboration, as well as the barriers that need surmounting. Stigma could be reduced by making LTBI testing routine, and community members could act as champions for health promotion raising awareness on LTBI testing, and providing a bridge between communities and primary care services.

Conclusion Public service providers, community members and CBOs have a willingness to collaborate to support primary care delivery of testing for LTBI and other communicable and non-communicable diseases. Policy and commissioning support are needed to facilitate such workings.

INTRODUCTION

Asymptomatic latent tuberculosis (TB) infection (LTBI) serves as the reservoir of new active TB cases in the community.¹ The risk of reactivation from LTBI to TB disease can be minimised by preventive therapy and the WHO End TB strategy includes systematic testing and treatment of LTBI as a core component for TB elimination, especially in low incidence countries.^{2,3} In England, 74% of the 5,664 notified TB cases in 2016 were reported in people born abroad (mostly in high TB burden countries)⁴, and about four in five were due to reactivation from LTBI. Therefore, this population represents the main source of preventable new cases in England.⁵ Consequently, a key intervention within the Collaborative Tuberculosis Strategy for England 2015-2020 is a novel systematic programme for voluntary LTBI testing, counselling and treatment for all new entrant migrants aged 16 to 35 years, who entered the UK within the previous five years, and have lived for over 6 months in 72 high TB incidence countries ($\geq 150/100,000$ or sub Saharan Africa): LTBI testing is provided through primary care services.⁶⁻¹⁰

The implementation of the LTBI programme started in July 2014 with a pilot in the London borough of Newham and subsequent roll-out to 59 priority Clinical Commissioning Group (CCG) areas.⁴ Even though 20,905 migrants have been tested for LTBI until June 2017, the uptake has not been ideal, ranging between 7.3% and 83.7% testing acceptance. Moreover, treatment initiation also varies significantly between 12.5% and 77.2%.⁴ Thus, the major challenge for this £10 million per annum programme is to improve appropriate access and to increase testing uptake, treatment acceptance and completion.^{11,12}

LTBI testing and treatment is characterized by uncertainty and raises ethical issues.¹³⁻¹⁵ The diagnostic tests have poor predictive value for development of active disease, and only 5 to 15% of persons with LTBI will develop active TB, thus, it is uncertain whether a person will benefit from preventive treatment.^{1,14} Further, LTBI treatment may impose harm in the form of adverse effects of medication.¹⁴ Although a person with LTBI has merely a potential future risk for his or her own health should development of active TB occur, the risk of LTBI reactivation is higher in certain groups such as migrants from high TB burden countries.^{14,15} These migrants experience other dimensions of risk with respect to health; for instance, they might fear deportation due to immigration status, lack clarity on how to engage with health

services, or perceive a hostile environment when trying to register with a GP.¹⁶⁻¹⁹ Therefore it is important that people have access to culturally and linguistically appropriate communication, enabling understanding of individual versus public health risks and benefits of LTBI testing and treatment, and facilitating them to make an informed choice.¹⁵

The term civil society encompasses institutions and organizations outside of government such as community-based and faith-based organizations.²⁰ They form a social environment between the institutional level and individuals that can influence the general population.²⁰ In the context of TB, it has been advocated that civil society organizations along with members of the affected communities should participate in the development of LTBI programmes¹³, and the engagement of communities along with civil society organisations is at the heart of the End TB strategy.² The UK has well-established third sector organisations with expertise in working with the eligible populations of the LTBI programme.²¹ These organisations are considered key partners for the National Health Service (NHS) to improve health service delivery,²² and the Collaborative TB strategy for England acknowledges third sector organisations as important partners for the strategy to succeed.⁹ Migrants in England face barriers to access healthcare, and the individuals eligible for LTBI testing may be unable to access the programme due to the documented difficulty to navigate a new health system.^{16, 23}

To improve access to appropriate TB preventative programmes for migrant communities new ways of collaboration are needed that harness the communities and the strengths of different types of organizations. However, it is not straightforward to unify the work of multiple stakeholders to create sustainable partnership arrangements. To address this, we collected qualitative evidence using a bottom-up approach. We initiated discussions between stakeholders from the community, public sector organisations offering health services, academia and Community-Based Organisations (CBOs) with expertise working with migrant communities providing healthcare-related services and in other areas such as migrant law, human rights or advocating for specific ethnic minority groups. This was done with the aim of uncovering and describing barriers and enablers for cross-sector collaboration and programme implementation, and to gain insights on novel interventions and service delivery models that can harness CBOs and civil society to maximize the effectiveness of the LTBI programme while improving appropriate healthcare access for migrant communities.

METHODS:

Study design

We performed a networking phase over six months, holding separate meetings to gain insights on local resources, individuals and organisations with interest or experience in migrant health in the high TB incidence London boroughs of Newham, Brent, Redbridge and Tower Hamlets. Our research team comprised a social anthropologist (JB), a biomedical scientist (LCBA), a research nurse (HP), an epidemiologist and general practitioner (DZ), a medical academic (AL) and a respiratory physician (OMK). This team was fostered through a shared interest in engaging with communities to prevent TB, and was initiated through a mediator who also facilitated during the networking phase. This led to three stakeholder meetings, chaired by JB. The first, in July, with 10 participants, aimed to assemble relevant stakeholders to discuss the impact of TB in their communities and to share experiences on TB awareness projects. The second meeting was held in August, with 14 participants, six of whom had attended the July meeting. Reports from Newham and Redbridge on TB screening and education interventions, respectively, were given, with further insights from community leaders on outcomes of related projects (e.g.: HIV, legal advice). These led to the third stakeholder meeting, in November, with 23 purposively selected participants, (12 males/11 females, median age 50, IQR 20) (Table 1), including eight attendees from either of the previous two meetings. The meeting started with an opening address followed by a series of ten-minute presentations (Appendix). The stakeholders consented to participate in one-hour focus group discussions moderated by JB, DZ, LCBA and an unnamed facilitator; all moderators were public sector employees. The groups were purposely organized with representation of communities, different CBOs and public sector providers. Attendees convened for a further one-hour collective discussion using the same topic guide (Table 2). Participants received no financial remuneration but refreshments were provided and travel expenses covered. Three of the focus groups and the final discussion were audio recorded and transcribed verbatim; the fourth focus group did not consent to audio recording and reported their discussion via anonymous self-generated notes. Some participants from this group opted to participate in the final discussion. The meetings' minutes summarizing the main findings were shared with all participants to assess agreement and accuracy. The first and second meeting were held at the University of East London, the third meeting was held at Imperial College London. Ethical approval was granted to JB by the University of East London, UREC_1415_92, to conduct community-based research on TB.

The Imperial College team co-collected and accessed the data for public involvement purposes, to support funding bids for large scale research. Participants understood the dual nature of the project, as both research and public involvement, and were instrumental in garnering participation from their contacts. Although ethical clearance is not required for public involvement activities, once the decision to publish the results in a research journal was made, mitigating action was taken, recorded and acknowledged to the University of East London's Research Ethics Committee's (UREC) satisfaction. None of the research team members had relationships or interactions with the stakeholders that could have affected their responses or influenced how stakeholders approached the problems addressed by this study.

Data analysis

Thematic analysis was applied to the transcriptions using an inductive thematic saturation methodology to gain new theoretical insights²⁴. JB, NK and HP individually coded the data to identify patterns that arose from the participants' perspectives. The themes derived from each individual analysis were compared and collated into categories using an Excel spreadsheet. No other software was used. Interrater reliability was not calculated, but consensus on coding and a number of overlapping themes was sought amongst the team. We used the consolidated criteria for reporting qualitative research (COREQ) to report this study.²⁵

RESULTS

Four broad themes emerged; capacity, collaboration, culture and trust. These were derived from numerous smaller topics (Figure 1). Capacity: flexibility, resources, timelines; Collaboration: agendas, partnership, roles; Culture: differences, stigma, language; and Trust: confidentiality, fear, relationships. Other topics arose but did not reach saturation including; homelessness, role of family, co-morbidities, differences between long standing and new entry migrants, and evidence of impact. The results here are presented in two sections: Capacity and Collaboration, followed by Trust and Culture.

Capacity and Collaboration

Stakeholders argued that CBOs and the public sector offer complementary, equal but different skill sets and roles.

CBOs are a vital contact point; we wouldn't have a service if it wasn't for them. [...] they will flag up things because they see [local people] on a different basis than I see them. [...] They are part of the interview team, if you like. They are part of everything

we do and they are really very important to our whole practice and how we manage. So it's a real partnership. (Female, 50s, Community outreach nurse)

There was a perception among CBOs representatives that the public sector may occasionally consider itself superior to the voluntary sector, and this was seen as a barrier for collaborative work.

The voluntary sector shouldn't just be seen to be the generator of referrals, or generator of individuals going for a screening, because [we] remain a contact point [who] stay and engage with the individual to help them stay on the care pathway (Female, 50s, CBO manager 2)

Other CBO leaders acknowledged public sector specialist knowledge.

There are some things that community organisations/voluntary organisations don't know about. [...] For example, TB. What is TB? What is latent TB? How does it infect people? What are the signs? How can it be prevented? It can only be done by professionals. [...] But to mobilise the community, [...] it is the voluntary organisations that energises the community to go for those services. (Male, 50s, CBO manager)

It was felt that each sector should try to benefit from the strengths of the other sector's sets of skills and specialist knowledge, and enhance effectiveness through collaboration.

The capacity of NHS to fit around the service users' needs is limited. The times and locations of NHS services can create barriers to interaction, and by collaborating with CBOs, who meet their groups on their terms, opens more opportunity for engagement.

The NHS is fine but it is very time-limited. [...] I don't want to be working every evening until 6, because my clinics already go on until 6 four times a week, so I'm quite restricted. So it is vital to have the voluntary sectors being aware of what we are talking about and then they can carry on with the conversation. (Female, 50s, Community outreach nurse)

I know where elderly men can be found. It's about finding people who have that information and can communicate from one language to another and having those people then become champions for TB screening and then having those people explain [the process, when it will happen and call] them up to say "don't forget tomorrow, you have to be screened." (Male, 30s, CBO worker)

CBOs are already working in communities and defend the role they play, not as agents of the public sector, but facilitators for meeting the needs of the people they serve. As the NHS has stricter structures of engagement, collaborating with CBOs widens potentials for increased user engagement, on the communities' terms.

There remain challenges to collaboration, however. Timelines in commissioning cycles, which demand rigid turnaround times for intervention delivery and results, do not take into account the real time involved in making such interventions happen in a meaningful way.

What unites so much of the clinical practice and the voluntary sector practice that it is the commissioners' role to determine the outcomes [...] I think commissioners are expecting outcomes far too quickly if they work like this and they fail to acknowledge that engagement takes time and you can't have the quick tick boxes over engagement and still expect successful outcomes. [...] Part of the role is for everybody, is about re-educating commissioners, and getting them to understand that it's a false economy to expect quick wins on this. (Female, 50s, CBO manager 2)

There is a dilemma in timelines, because the stuff that we're talking about isn't measurable within the commissioning timelines, which is usually yearly. (Male, 50s, health policy maker)

Furthermore, voluntary and public sector institutions are by design different, one being comprised of many small organisations, and the other more top down in functionality.

Even though voluntary organisations are very specific and good at what they do, there are loads and loads of them, all with their different agendas, and it's really difficult to manage. (Female, 30s, CBO doctor)

As CBOs and the public sector have differing agendas and priorities, so do users. While health is important, other factors may take priority.

There are usually other factors, not just TB [...] in a way, people's priorities are so different. So if your priority is having a meal a day, everything else falls by the wayside. (Female, 50s, CBO manager 1)

I organized an event in one of the churches. [...] In that event, all the health topics we were going to discuss were thrown away and we were dealing with immigration.

Whereas health is very well important, but what they are mostly concerned with is how to remain here.’ (Male, 50s, CBO manager)

Collaboration and meeting diverse needs of all concerned have intrinsic and extrinsic barriers. Surmounting these barriers requires policy level changes, through agendas that facilitate partnership working and through attention to the wider determinants of health.

Trust and Stigma

Fear, as the opposite of trust, is also a factor. If encountering health services means fear of delayed or immediate deportation, potential users may avoid making contact with them.

[Many immigrants] don’t know how to access national services and I am thinking once the immigration issue is tackled, then accessing these services will be much easier. The fear factor will be removed. (Female, 30s, CBO worker)

Stakeholders further suggested that front line staff in primary care services, as well as vulnerable populations, e.g.: homeless or undocumented migrants, sometimes lack clarity about legality and rights to access health care, which create further barriers.

I’ve done quite a lot of work with GPs and with the receptionists and the practice managers and they say that all they’re trying to do is follow the rules. That’s where everything needs to be working together because it’s all well-and-good from one side, you know, we’re saying “You should be registered” but they’re also hearing from the home-office, “you need to be aware of visas, and health, and charging. (Female, 30s, CBO doctor)

It has to be two sided. There’s the part about empowering people to access and making them aware of the system and the knowledge they will need to access the services. But if they then get to the services and hit a brick wall because they’re not welcomed, if they’re asked for documents that are not essential, if they’re not really treated in a way that makes them feel like they ever want to come back, then that’s stopping that access.’ (Female, 50s, CBO manager 1)

The conflict of information, of confidentiality and of the state seeking to find, charge or deport migrants and users in need gaining access to health care can keep vulnerable people away from required services.

In addition, mandatory public health notification of active TB can cause shame and social exclusion in certain communities, leading to psychological and material consequences beyond the disease itself. The participants suggested that routine discussions about difficult health issues, and building trust relationships, may help reduce stigma.

I think [...] that making things routine will de-stigmatise. When I see someone, I routinely ask really sensitive questions about immigration, routinely ask about sexual health screening and I routinely ask as well, their mental health state and if they're hearing voices. All these things are actually quite like personal questions but by making it like, this is just what it is, then I think you de-stigmatise and people think "oh well, this is just what you do here". (Female, 30s, CBO doctor)

A lot of community members, if a GP tells them "you need this" they'll say, "Okay, I'll get round to it eventually and really they are thinking, "I'll never do that" but if it's someone they feel they have a connection with, an empathetic connection, [...] when they are told, "you need to get tested for TB" they will be like, "Okay, so this person obviously has taken an interest in my life prior to him telling me this information, I am going to take this information on board and 'I'm going to get tested.'" (Male, 30s, CBO worker)

As CBOs already have commitment and trust from their communities, working within these structures could further help educate around the disease and reduce social stigma.

That's where [...] charities, local organisations, can come in and break down those barriers by educating them and showing them that this is not about saying "Someone is this because they've had that", [... but by letting] people know what the real situation is and the dangers of not doing anything about it and burying their heads in the sand. (Male, 40s, CBO outreach worker)

Also working with their leaders. You can educate their leaders to make sure they are very much aware of what's happening. Because there are some of these churches and mosques, they have health programmes established [already]. (Male, 50s, CBO manager)

Working with local communities and leaders within them, to tackle specific fears can help reduce stigma and shame, replace these with trust, support and encouragement to engage in screening and treatment, rather than shy away from it.

DISCUSSION

CBOs, civil society organisations and affected communities are considered key stakeholders for TB control.^{26, 27} While the LTBI testing programme was devised in conjunction with primary care,^{6, 8, 9} it was early acknowledged that the programme would require engagement with third sector organisations because of the differences in health seeking behaviour of the eligible populations.⁸ CBOs offer a flexible user-centric model aiming to meet users' needs and provide services to support the most vulnerable and stigmatised members of society.²⁸ Stakeholders agreed that some of the success of CBOs with their communities may be explained by differences around mode of engagement, which includes language of communication, times of day, and locations of interaction.

In our study those who work in the public sector highlighted a lack of time to meet users' needs as they aim to meet the demands of their own work schedules. The work of CBOs is about meeting users' needs, whether as a faith group in the community, or as an organisation set up for meeting particular health, legal or other needs. Therefore, models based on cross-sector collaboration are effective for improving access and quality of TB care²⁹ and the role of CBOs in tackling TB must be beyond the mere provision of a contact point for generating referrals³⁰. The differing modes of engagement, toward users' needs or toward administrative directives, underline the differences in facilitating access for vulnerable 'user' groups and underscore the need to collaborate to make services truly accessible. It was noted that collaboration brings its own barriers, including commissioners' annual reporting schedules. In a user priority model, commissioners would recognise the value of cross-sector collaboration and facilitate integration of the diverse working methods of each sector. Such collaboration requires dedication and immersion along with education and a clear view on the time required to build relationships to achieve better results.

The users and each sector have different priorities and some are in direct conflict: users fear the consequences of their immigration status and undocumented migrants face major challenges to access primary care.^{17, 18} As of 2014 NHS service providers are being mandated to charge non NHS-eligible migrants and the uncertainty around its application and the fear of

detection and deportation for those without regular status can put up significant barriers.^{19, 31,}

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Feelings of stigma influence immigrants' attitudes towards TB prevention, diagnosis and treatment.^{16, 33} Although stigma, as a social determinant of health arising from institutional and community norms along with interpersonal attitudes, has an impact on the health and healthcare seeking behaviours of individuals at risk for TB, there is a dearth of effective and rigorously evaluated interventions to reduce it.^{34, 35} Our study suggests that making tests routine and using groups familiar within communities, can help to reduce stigma and may increase uptake in LTBI testing because at risk populations may feel more secure. LTBI can be diagnosed by a single, validated blood test (interferon gamma release assay (IGRA) and it makes LTBI testing possible anywhere.¹⁰ Offering LTBI testing on a routine basis in alternative venues such as CBOs with a health focus may enable a wider group of people to be involved in supporting at risk groups to seek diagnoses. However, collaboration with NHS would be essential as CBOs may be limited in their expertise to recognise incidental findings of active TB, manage adverse effects of prophylaxis treatment or support co-morbidities. Our results align with the views of migrant community-care leads in London and reaffirm the relevance of designing, implementing and evaluating community-based approaches.¹⁶ In parallel, community members could be directly involved as peer educators and champions for health promotion raising awareness on TB/LTBI testing, facilitate GP registration and act as bridge between communities and primary care services.^{16, 36}

Strengths and limitations

This study involved a diverse group of stakeholders, two participants previously treated for TB were included. While CBO representatives may offer appreciation of user experience, those with LTBI and at risk of developing TB as well as TB patients should be included in future studies. Likewise, inclusion of GPs may also have offered further insights. The confusion between TB and LTBI was common among stakeholders and suggests a lack of clarity between the two conditions, which needs further direct exploration. The minutes of every meeting were shared with all stakeholders and results triangulated with the notes of the individual meetings held throughout the networking phase. Moreover, reconvening all stakeholders into a collective

discussion enabled them to defend their individual opinions and unite with their peers in collective positions.

CONCLUSIONS

There was agreement among stakeholders that CBOs could contribute to maximize the effectiveness of the LTBI testing and treatment programme. However, CBOs should be more than a mere point of engagement, having a complementary and active role in service design and delivery. This study strengthens and supports previous work suggesting that LTBI services should to be expanded into the communities¹⁶ and CBOs are a core asset to bring about this change. Commissioners should lead the early involvement of community members and CBOs in planning community-based services adopting recently published recommendations.^{21, 37} Public service providers, community members and CBOs should be brought together into a community-based model to support primary care delivery of testing for LTBI and other communicable and non-communicable diseases, while facilitating GP registration. The development and implementation of such a model should include a rigorous outcome and process evaluation to assess its effectiveness, cost-effectiveness and long term sustainability.

Acknowledgements: The authors thank William Gemegah, Amna Mahmoud, Rita Chadha, Lucy Jones, Mike Mandelbaum, Dr Jessica Potter, Prof Peter Beverly and Claire Puddephatt: without their support this study would have not been possible.

Contributors LCBA, JB, HP, OMK, AL and DZ planned the study. LCBA and JB conducted the field work and data collection. JB, NK and HP analysed the data. LCBA and JB wrote the manuscript. All authors reviewed and edited the manuscript, and approved the final draft.

Funding: The research was funded by the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Respiratory Infections at Imperial College London in partnership with Public Health England (PHE). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health or Public Health England. JB was funded by an Early Career Research Grant and a Knowledge Exchange Grant, both from UEL.

Competing interests: DZ is head of the tuberculosis screening unit at Public Health England and has national responsibilities for the Latent TB screening programme in England.

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Table 1. Characteristics of study participants

Sector	Participant's main role representing	Number and Sex	Specialist area	Community groups which are served	Dual Role and experience
Public	Nurses	3 Females	Public Health/TB	All community groups Homeless New entrant migrants	Local community member
Public	Consultant epidemiologist/ General Practitioner	1 Male	Public Health/TB	All community groups	Policy maker
Public	Academics	2 Males 3 Females	Public Health Epidemiology Social science	All community groups	Doctor Experience of TB
Public	Representative of London Government	1 Female	Public health	All migrant groups	Doctor
Civil society	Local Community Organisation Managers	2 Males 2 Females	Migrant Rights Community Health Faith	All migrant groups	Experience of migration
Civil society	Local Community Organisation workers	3 Males 3 Females	TB HIV Public health	All migrant groups Homeless	Doctor
Civil society	Other local community members	2 Males 1 Female	N/a	N/a	Therapist Students in Health

Table 2. Topic guide

Introduction
Brief introduction by each participant: reason for attending the meeting and type of work they do.
Questions on partnership between communities, CBOs, statutory sector and academia to improve access to eligible populations.
What type of work do CBOs do with the eligible populations of the LTBI testing and treatment programme?
What are the main hurdles for cross-sector collaboration between CBOs and the statutory sector, and how it could be facilitated?
How can CBOs and local communities be harnessed to increase uptake of LTBI testing and treatment?
How can CBOs and local communities be harnessed to support the collaborative TB strategy for England?
Questions on barriers to access eligible populations and healthcare
What are the difficulties in accessing the eligible populations of the LTBI programme, and how it could be improved?
What are the main factors that influence the acceptance of LTBI testing by eligible migrants?
What are the weaknesses and strengths of the current model of providing LTBI testing in primary care?
What would you do differently to increase the uptake of LTBI testing and treatment?

Figure 1 legend: Main themes and codes derived from the participants’ perspectives.