

1 **Engaging with communities and civil society in the frontline to improve access to LTBI**
2 **screening for new-entrant migrants in England: a qualitative study**

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28 **Summary**

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

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

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

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

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

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56 INTRODUCTION

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

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

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79 LTBI testing and treatment is characterized by uncertainty and raises ethical issues.¹³⁻¹⁵ The
80 diagnostic tests have poor predictive value for development of active disease, and only 5 to
81 15% of persons with LTBI will develop active TB, thus, it is uncertain whether a person will
82 benefit from preventive treatment.^{1,14} Further, LTBI treatment may impose harm in the form
83 of adverse effects of medication.¹⁴ Although a person with LTBI has merely a potential future
84 risk for his or her own health should development of active TB occur, the risk of LTBI
85 reactivation is higher in certain groups such as migrants from high TB burden countries.^{14,15}
86 These migrants experience other dimensions of risk with respect to health; for instance, they
87 might fear deportation due to immigration status, lack clarity on how to engage with health

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

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

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

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120 **METHODS:**

121 **Study design**

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

152 UREC_1415_92, to conduct community-based research on TB. The Imperial College team co-
153 collected and accessed the data for public involvement purposes, to support funding bids for
154 large scale research. Participants understood the dual nature of the project, as both research
155 and public involvement, and were instrumental in garnering participation from their contacts.
156 Although ethical clearance is not required for public involvement activities, once the decision
157 to publish the results in a research journal was made, mitigating action was taken, recorded
158 and acknowledged to the University of East London's Research Ethics Committee's (UREC)
159 satisfaction. None of the research team members had relationships or interactions with the
160 stakeholders that could have affected their responses or influenced how stakeholders
161 approached the problems addressed by this study.

162 **Data analysis**

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

170 **RESULTS**

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

178 **Capacity and Collaboration**

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

181 *CBOs are a vital contact point; we wouldn't have a service if it wasn't for them. [...]*
182 *they will flag up things because they see [local people] on a different basis than I see*

183 *them. [...] They are part of the interview team, if you like. They are part of everything*
184 *we do and they are really very important to our whole practice and how we manage.*
185 *So it's a real partnership. (Female, 50s, Community outreach nurse)*

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

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

193 Other CBO leaders acknowledged public sector specialist knowledge.

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

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

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

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

210 *I know where elderly men can be found. It's about finding people who have that*
211 *information and can communicate from one language to another and having those*
212 *people then become champions for TB screening and then having those people*

213 *explain [the process, when it will happen and call] them up to say “don’t forget*
214 *tomorrow, you have to be screened.” (Male, 30s, CBO worker)*

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

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

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

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

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

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

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

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

242 *I organized an event in one of the churches. [...] In that event, all the health topics we*
243 *were going to discuss were thrown away and we were dealing with immigration.*
244 *Whereas health is very well important, but what they are mostly concerned with is*
245 *how to remain here.’ (Male, 50s, CBO manager)*

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

249 **Trust and Stigma**

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

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

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

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

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

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

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

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

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

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

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

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

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

304

305 **DISCUSSION**

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

315

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

330

331 The users and each sector have different priorities and some are in direct conflict: users fear
332 the consequences of their immigration status and undocumented migrants face major

333 challenges to access primary care.^{17, 18} As of 2014 NHS service providers are being
334 mandated to charge non NHS-eligible migrants and the uncertainty around its application and
335 the fear of detection and deportation for those without regular status can put up significant
336 barriers.^{19, 31, 32}

337

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

356

357 **Strengths and limitations**

358

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

366 individual meetings held throughout the networking phase. Moreover, reconvening all
367 stakeholders into a collective discussion enabled them to defend their individual opinions and
368 unite with their peers in collective positions.

369

370 **CONCLUSIONS**

371

372 There was agreement among stakeholders that CBOs could contribute to maximize the
373 effectiveness of the LTBI testing and treatment programme. However, CBOs should be more
374 than a mere point of engagement, having a complementary and active role in service design
375 and delivery. This study strengthens and supports previous work suggesting that LTBI
376 services should to be expanded into the communities ¹⁶ and CBOs are a core asset to bring
377 about this change. Commissioners should lead the early involvement of community members
378 and CBOs in planning community-based services adopting recently published
379 recommendations. ^{21, 37} Public service providers, community members and CBOs should be
380 brought together into a community-based model to support primary care delivery of testing
381 for LTBI and other communicable and non-communicable diseases, while facilitating GP
382 registration. The development and implementation of such a model should include a rigorous
383 outcome and process evaluation to assess its effectiveness, cost-effectiveness and long term
384 sustainability.

385

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403

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506 **Table 1.** Characteristics of study participants

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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

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518 **Table 2.** Topic guide

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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?

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521 **Figure 1 legend:** Main themes and codes derived from the participants' perspectives.

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