Beliefs and barriers related to understanding TB amongst vulnerable groups in South East London

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1 Abstract

Tuberculosis (TB) notification rates in South East (SE) London are increasing and the overall rate in this area (33.1 per 100,000 population in 2004) is almost three times the national average for England and Wales. Internationally, Sub-Saharan Africa has a very high incidence of TB and this is reflected in SE London by over half of all new cases being in Black Africans.

Successfully raising awareness about health issues amongst the general public needs to take into account specific social and cultural factors to be effective. Qualitative research has an important role to play in investigating the wider determinants of health that quantitative research cannot fully explore.

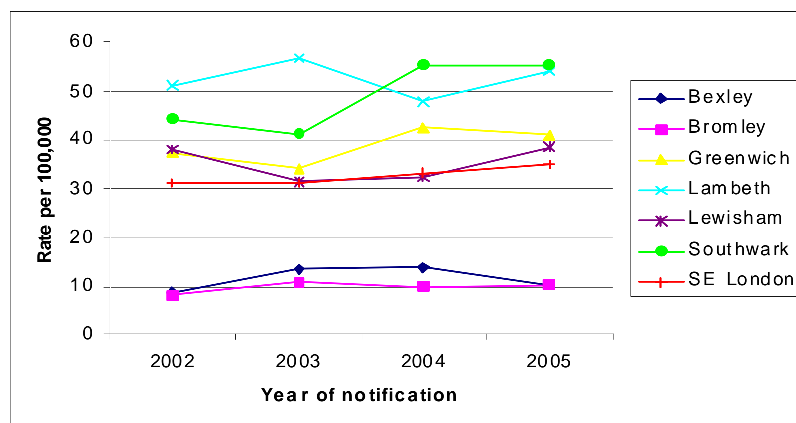
This research considers how specific cultural health beliefs regarding TB affect the awareness and understanding of the disease amongst some at-risk communities in this sector. These comprise several ethnic groups (including Sub-Saharan Africans, Chinese and Vietnamese), prisoners, homeless, substance misuse and HIV positive groups. Qualitative research techniques in the form of focus groups and semi-structured interviews were used to investigate the perceptions and knowledge held in these vulnerable groups.

Findings indicate stigma, particular cultural health beliefs and lack of access to health services as factors common to most groups. Results from the study will be used to inform future TB awareness activities developed by the South East London Health Protection Unit when targeting these groups. Some of the general findings can be applied to other diseases and inform their associated health promotion activities.

2 Introduction

This research is set against background of increasing rates of TB in London. The London TB Register has records of notification rates in SE London increasing by 6% between 2003 and 2004, and by a further 5% in 2005. Amongst the 2005 notifications, where country of birth was noted, 77% of cases were born outside of the UK, reflecting national trends.

Figure 1: TB incidence rates by South East London borough, 2002-2005



Source: London TB Register (taken from the 2005 Annual TB Report for South East London)

The Chief Medical Officer's Action Plan 'Stopping Tuberculosis in England'[1], published in 2004 stated as its long-term goal the eradication of TB in this country. Three objectives were also noted in order to reach this ultimate goal and include reducing the risk of people being

newly infected with tuberculosis in England, providing high quality treatment and care for all people with TB, and maintaining low levels of drug resistance, particularly multidrug resistant (MDR) TB. Action 1 of the Action Plan is increased awareness, and the aim is to: *maintain high awareness of TB, particularly among health professionals, high-risk groups and people who work with them, teachers and the public*. Underpinning Action 1 are the following 5 points, and those in red have been focused on for this research;

- Produce multilingual and culturally appropriate public information and education materials for national and local use and make them widely available,
- Ensure that general practitioners and other primary and community care staff are aware of: the symptoms and signs of the disease; local TB services; and local arrangements for referring patients with suspected TB,
- Use World TB Day in March each year to increase awareness, particularly among healthcare professionals and high risk communities, and encourage relevant national organisations to do the same,
- Maintain awareness, including through the media and community groups, and develop initiatives to support local awareness raising among high risk groups,
- Seek greater professional awareness through undergraduate, postgraduate and continuing professional education continuing professional education.

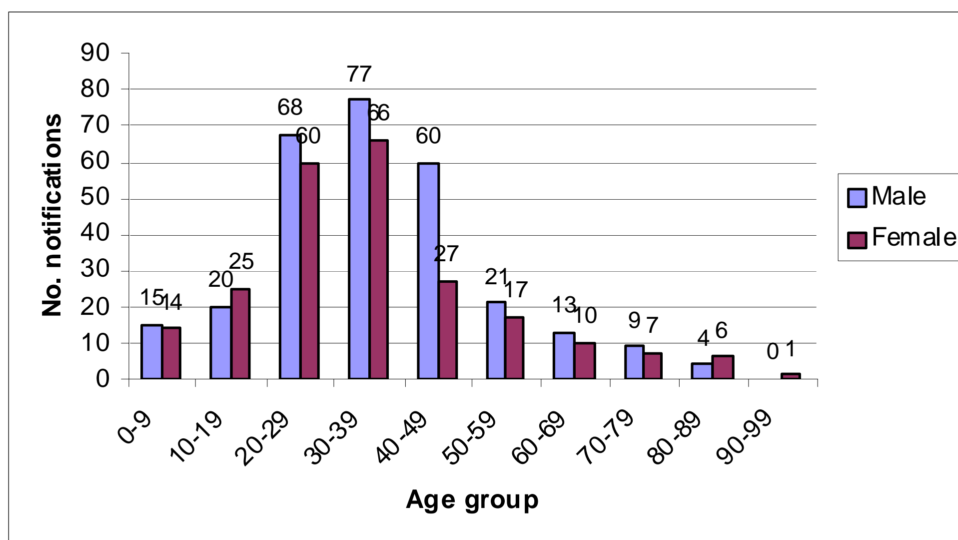
In addition to the CMO's Plan, London has its own specific targets regarding TB[2]. Of particular importance to this research is the target of referring patients with suspected TB to a chest clinic within 2 weeks. A recent sector audit revealed only 28% of patients were seen within 2 weeks, and only 54% within one month. Evidence suggests that "delays in diagnosis for TB is known to increase the risk of poor clinical outcomes including death and transmission of TB"[3]. These delays are important because of the possible reasons behind them. Some delays will be due to a lack of identification on the part of the health professional (mainly frontline doctors including A&E and GPs) but delays can also be attributed to the patients themselves and the findings from this report give us clues for these delays.

With this increase in TB notifications and delays in diagnosis in mind, the Action Plan's emphasis on the need to target public health efforts to where they are most needed - these being in particular people from the Indian Subcontinent and Sub-Saharan Africa whose TB rates are high, especially in their first few years of living in this country – is particular importance and relevance at this time. The Plan goes on to note "although anyone can get TB, our effort needs to be most intense in those cities with the highest burden of disease and among those population groups most at risk, recognising that these differ in different parts of the country".

Vulnerable groups do not just include people from countries where TB is endemic, but people who are immunocompromised (TB is now considered an AIDS defining disease) or those whose living conditions are poor, such as the homeless, prisoners, drug mis-users.

The Department of Health is currently funding a pilot project in London, offering mobile digital x-ray screening for TB to at-risk groups, including street and hostel homeless, drug users, prisoners and refugees and asylum seekers. From the London TB Register we can see that in South East London a higher proportion of TB cases in black and minority ethnic groups compared to their white counterparts. Nationally enhanced surveillance indicates that TB rates in patients born overseas are 23 times higher than for those born in the UK, with the highest rates occurring amongst the Black African, Pakistani and Bangladeshi ethnic groups[4]. The peak age groups for all notifications are in the 20-39 year age groups.

Figure 2: TB notifications by age and sex in South East London, 2005



Source: London TB Register (taken from the 2005 Annual TB Report for South East London)

SE London is an area of extremes; Bromley and Bexley are boroughs with few wards of high deprivation and the majority of the population is white. 1/3 of the total population of Lambeth, Southwark and Lewisham are from black and minority ethnic groups (BME) (see table below for a breakdown and compare these percentages to London as a whole, where 77% of the population is white).

Table 1 Proportion of population from BME groups in SE London boroughs

Borough	White %	Black %	Asian %
Bexley	91	N/A	N/A
Bromley	92	N/A	N/A
Greenwich	77	11	7
Lambeth	62	26	5
Lewisham	66	24	4
Southwark	63	26	4

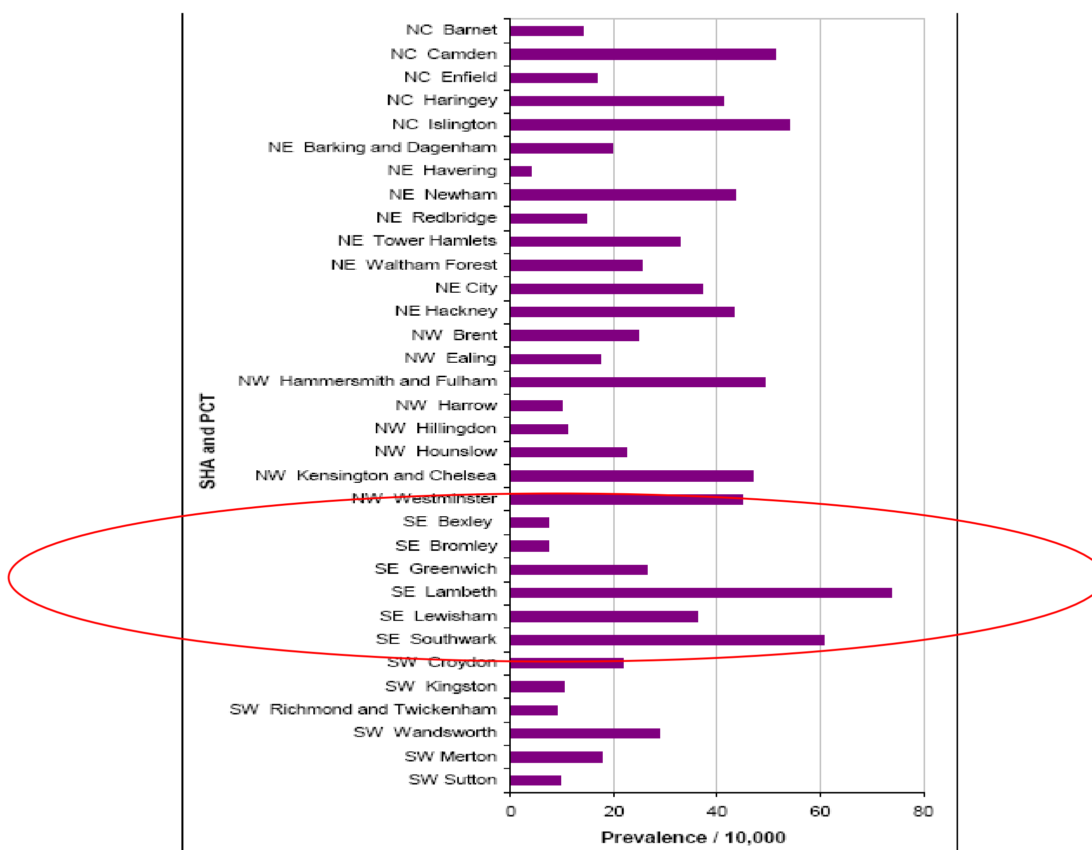
(Source: www.communityhealthprofiles.info/profiles.php - March 2006)

This epidemiological information was useful in determining which groups to approach as focus group for this research. The South East London Health Protection Unit's (SELHPU) 2005 TB Annual Report[5] informs us that the majority of TB cases are occurring in the Black African population and broken down further we can see that Nigeria and Somalia represent the countries of birth with the highest notifications (after the UK). In certain boroughs there are ethnic groups that fall into the 'other' category that have growing numbers in the TB cases in relation to their population size. Again from the London TB Register it is possible to distinguish from the 'other' category that the Vietnamese community contributes to a significant proportion of cases of TB in Greenwich.

A geographically representative sample of the groups that are more at risk of getting TB was essential. Other significant high-risk groups for having TB include prisoners, people who are

HIV +, the homeless and drug mis-users, including alcoholics. These groups were all approached to take part in this research also.

Figure 3: HIV prevalence rates by London PCT



There are 2 prisons (Brixton and Belmarsh) in SE London. In the last 2 years there have been about 18 cases notified from both prisons in total. 15% of the general prison population are Black (ESRC) and in particular of Brixton prison's population 56% of the prisoners are non-white.

St Thomas' Hospital also sees a significant number of homeless people with TB and this is unsurprising given the large homeless community in the central boroughs of SE London, especially in Lambeth.

Although the sample of participants is limited in number in this research, it does however, give us a snapshot of how these groups perceived TB during this period. This report offers observations and findings and puts forward recommendations that the SE London TB Sector Group and SELHPU may be able to take into account when organising activities associated with raising awareness of TB amongst the general public, particularly high-risk groups. This research was conducted between December 2005 and April 2006.

3 Method

3.1 Study design, scope and limitations

The methodology consisted mainly of focus groups and some semi-structured interviews carried out with key high-risk groups from the South East London sector. In addition, a search of the current literature was carried out. This literature review aimed to gather current

knowledge on the beliefs and understanding of TB the different at risk groups had. The focus groups and interviews were carried out to develop this health knowledge further and explore whether and how the current knowledge can inform the TB related organisations approach to developing health promotion activities.

3.1.1 Limitations of this study

- The literature review resulted in very little material and documents that were found were mostly unpublished papers or PCT briefings, therefore not peer reviewed.
- An inconsistency in methods used, as the majority of community groups were approached using focus groups. Some semi-structured interviews were also carried out due to one community group preferring to have individual interviews. Also, only some of the groups gave permission to be recorded by tape recorder. Taking notes as well as acting as the facilitator of the groups was difficult and some information during the discussions may have been missed.
- Facilitator not of same ethnic background and therefore could not speak the language
- Too many topics discussed for one session, however due to the short timeframe additional sessions were not possible. In addition if a focus group was not well attended it was not possible to reorganise it, therefore not all of the significant TB community perspectives were obtained.
- It was unclear to some participants what a focus group was so they came to their session with different expectations. No one left the sessions though and all groups mentioned how interesting and useful the discussions had been, not only in informing themselves of this health issue but also meeting other people from their community. In particular, the Vietnamese and Chinese groups spoke of feeling honoured to have been asked to take part in the research.
- Participants or volunteers in any research self select therefore those who are willing to take part are already of a particular ‘type’ of person.
- Setting up focus groups is not an easy process, very time consuming and was often met with a lack of interest or in some cases some organisations had been approached on many previous occasions and so had ‘focus group/research fatigue’. Lack of interest may have been due to the fact that the incentive was a voucher for a range of shops rather than cash. In many cases requests to be involved were either ignored or rejected. This effected the final groups included in the research, as although epidemiologically significant in terms of TB cases those groups may not have wanted to take part or not turned up at the focus group e.g. the Nigerian group.

3.2 Methodological approach for focus groups and interviews

Once the ethnic and other high-risk groups had been decided upon, open invitations were sent out to take part in the research by various means. Particular community organisations were purposefully chosen based on their provision of services for the high-risk groups that were focused on in SE London. These groups were contacted either through contacts at the Three Boroughs Primary Health Care team (using their Directory of organisations working with refugees and asylum seekers within Lambeth, Southwark and Lewisham) or from internet searches. Individual organisations were contacted for their London offices or members. Emails were cascaded and posters advertising the research were placed in different venues (clinics, internet cafes, GP practices, hairdressers in different boroughs) and this was successful in recruiting some participants (see Appendices for an example).

Due to time constraints, focus groups were limited to those that could be organised within a certain time period. 9 groups were organised. 2 were carried out in a Christian day centre, 6 were held in the individual organisations own venues (if there were appropriate facilities) and 1 was held in an NHS facility. Each focus group lasted between 2 and 3 hours.

Before each focus group discussion began, consent was obtained and some demographic information was sought from each person by questionnaire (see appendices). In some cases individuals were illiterate in English. There was some sharing of personal information between participants who helped with translating the questionnaire, which led inevitably to a lack of confidentiality. Keeping all other information confidential within the group was, however, essential. A more open and honest discussion was therefore facilitated, as participants who were worried that negative comments about their health services would be passed on were put at ease.

3.2.1 Topic guide development

The topic guide was largely defined by the findings from the literature review and having spoken to TB related professionals across the sector who have regular contact with patients with TB from a variety of backgrounds. From certain documents and meetings it became clear that there were particular issues that required exploration.

During the focus groups open-ended questions from the topic guide were used, especially if discussion was not forthcoming by the participants. The questions aimed to identify the extent to which they understood what TB is and whether there were any specific cultural beliefs that could affect the way a community behaved if a person had TB or how people accessed health care.

The semi-structured interviews used the same topic guide (see Appendices for topic guide.)

Qualitative comparative information was produced to a certain extent as most questions were asked during each focus group. Participants were given time to comment at length, however one session was found not to be long enough to cover all the topics in as much depth as was hoped for, however, in the timescale more than one session per group or sessions longer than 3 hours were not feasible.

3.2.2 Topic guide

Topic guide – the same guide was used for all of the groups and the following 4 areas were discussed using the following prompts:

Participants existing knowledge of TB

- Signs and symptoms
- Causes of TB
- Myths or misconceptions of TB
- Transmission
- Curable and if so, treatment options
- Who can catch TB

Participants current perceptions of TB

- How dangerous TB is
- Feelings if had a diagnosis of TB themselves

- Disclosure of TB to whom
- Community's feelings towards TB

Participants impressions of, and interactions with, the NHS

- Access to medical services
- Registered with a GP?
- Level of support and contact with the GP
- Ease of use of services
- Symptoms that would trigger contact with medical services

Views on effective health promotion approaches

- Where and how health information is sought or found
- Effective ways of getting health messages across to the community

3.3 Research design

Focus groups were chosen as they:

- provide an open ended forum where people can exchange and share views,
- are effective at generating ideas,
- gather a range of views over a short time.

Some community leaders mentioned that people would be more likely to partake if there were other participants present rather than being interviewed alone, another reason to have focus groups. Costs were thus minimised by only using interpreters once per focus group, rather per separate interviews.

3.4 Recruitment

The following community groups were chosen to give a representative sample of vulnerable groups to TB from SE London:

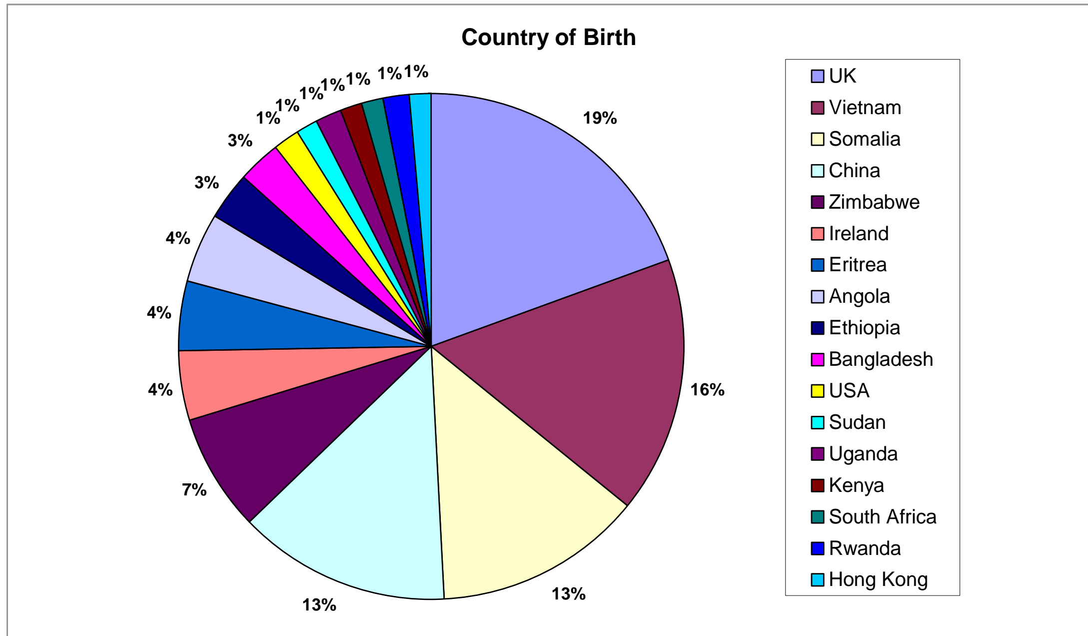
- Chinese
- Nigerian
- Refugee Women's Refugee Group (majority of whom were Somalis, but also some Eritreans and Ethiopians)
- Vietnamese
- Substance mis-users (from a homeless person residential centre)
- HIV positive (2 groups with participants with countries of birth including UK, Zimbabwe, Angola, Uganda & Kenya)
- Homeless (from a homeless day centre)
- Prisoners (a local prison)

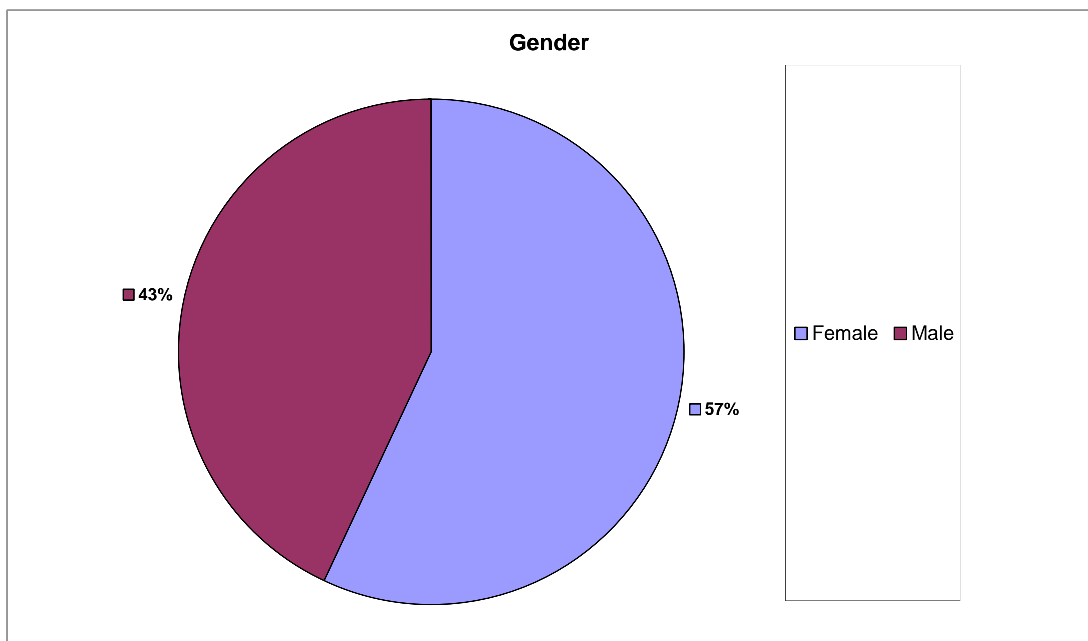
Some participants themselves or a family member had had TB in the past. This was not a requirement to join the group, nor were the participants asked to disclose this. If it was brought up in the discussion, further questions may have been asked of their experiences of treatment etc.

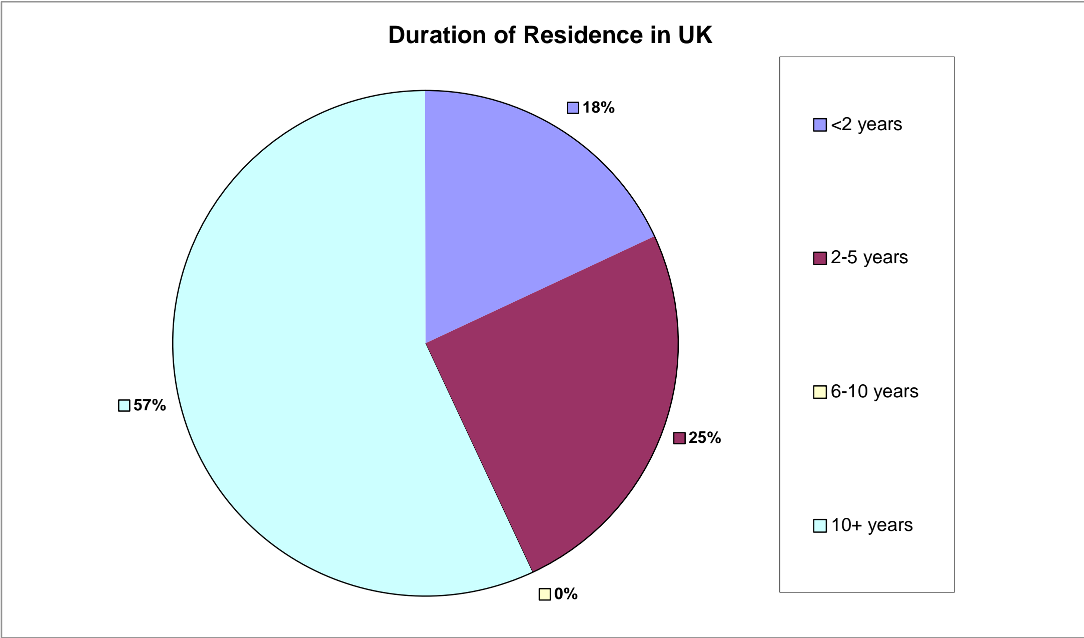
3.4.1 Participants

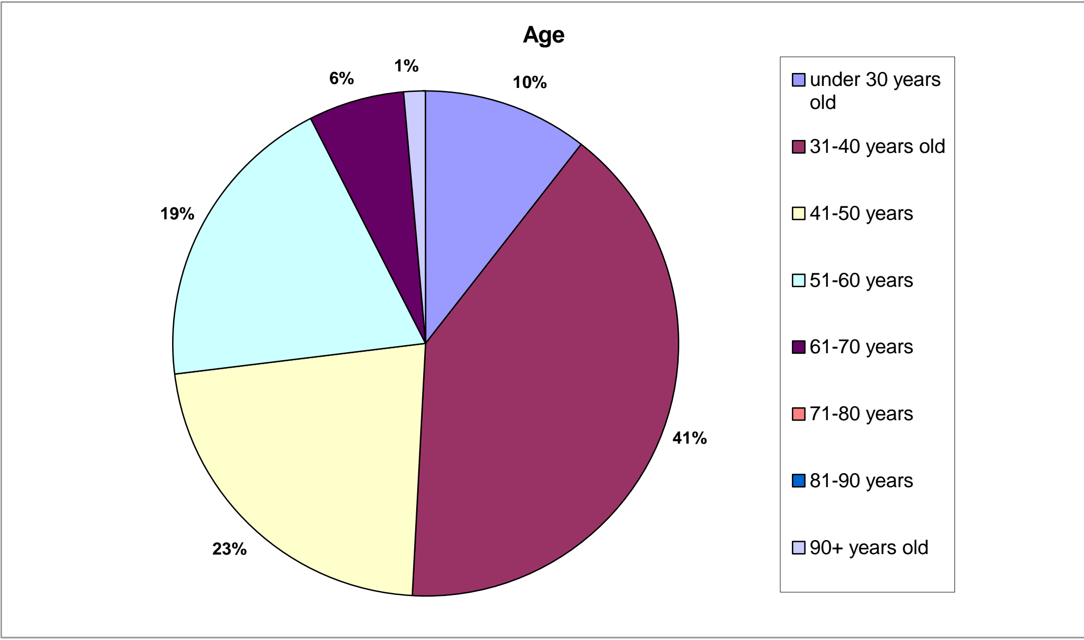
As mentioned an attempt was also made to have a geographically representative sample of participants from SE London. Bexley and Bromley were not well represented, however the number of participants is relative to the number of TB cases there are in these 2 boroughs.

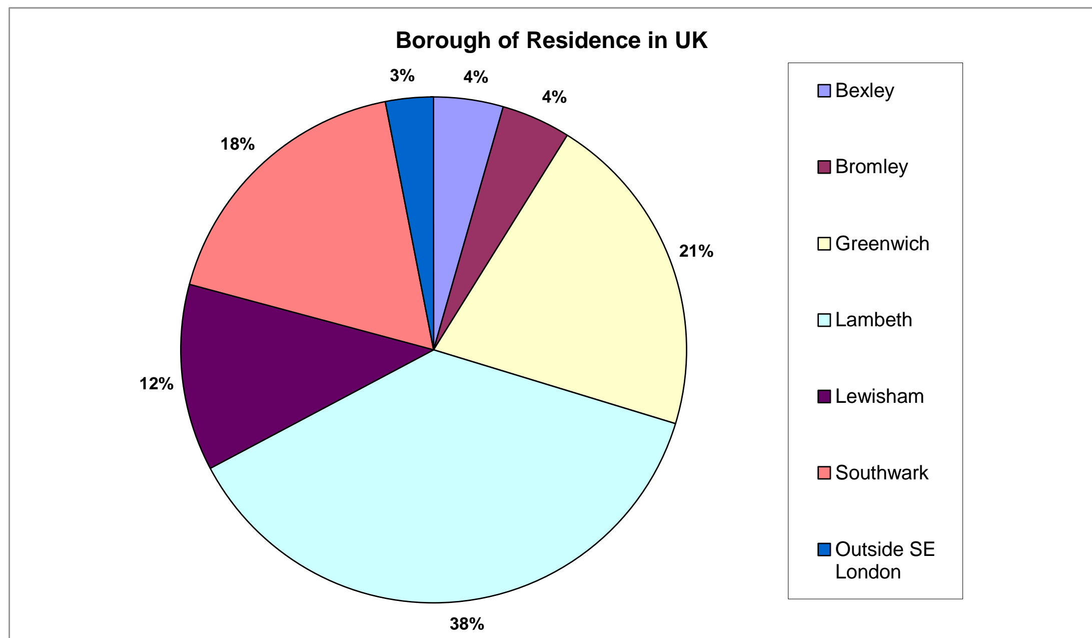
In total there were 67 participants. Below are some self-explanatory charts illustrating the diversity and demographic details of the participants. The youngest participants from all groups were in the Prison focus group.






Duration of Residence in UK
18%
25%
0%
57%
<2 years
2-5 years
6-10 years
10+ years


Age
1%
6%
10%
19%
41%
23%
under 30 years old
31-40 years old
41-50 years
51-60 years
61-70 years
71-80 years
81-90 years
90+ years old



3.5 Conduct of groups

Practicalities:

- Some venues were available at the community organisation offices and others were found through Lambeth PCT,
- The author acted as both facilitator and note taker,
- Breaks during the session were taken and appropriate refreshments offered to the groups, e.g. Chinese tea was available for the Chinese and Vietnamese groups,
- Groups were recorded (except the Prisoners group, homeless interviews and substance mis-user focus group) and notes were taken simultaneously,
- Interpreters were used for 3 groups – Arabic and Tigrinya (Women's Refugee Group), Vietnamese and Mandarin for the Chinese group.
- A £10 voucher was given as an incentive to each participant. However, for the Refugee Women's Group a traditional Somali meal was offered,

At the beginning of each focus group the order of the session was proposed to the group as outlined below;

- Welcome and thanks for participating,
- Introduction of facilitator and participants,
- Timing and aims of the session,
- Encourage open discussion and agree on confidentiality issues,
- Permission sought to record the session,
- Consent from and demographic questionnaire,
- Any questions?

At the end of each session time was set aside to give a short presentation about TB and leaflets in appropriate languages were given out. Often incorrect information had surfaced

during the sessions, so it was important to ensure that participants had the opportunity to ask questions and get the correct clinical information about TB.

4 Findings, observations and recommendations

This qualitative research identified cultural health beliefs regarding TB that affect the perception of the disease, amongst specific at-risk communities, which can be used to inform health promotion activities. Findings and observations are presented firstly from the literature review and then from the focus groups.

4.1 Literature review

The Three Boroughs Primary Health Care team have produced a number of very useful documents, which are aimed at health care professionals working with refugees and asylum seekers, some focusing on SE London. These papers gave important statistical and qualitative background useful to this research. Please see individual documents for further details[6 7 8 9].

The guide 'How to provide information well'[10] was useful when approaching and conducting the focus groups with certain community groups and the publication 'Producing patient information'[11] is a valuable resource for anyone developing health resources.

Regarding homeless people the publication by Crisis 'Out of the shadow'[12], although over a decade old now, was interesting.

Research has been conducted on the Bangladeshi community in East London[13], however this was the only piece of research found regarding TB and a specific ethnic group. A paper looking at the barriers to adhering to malaria prophylaxis in the African community in London[14] was useful as a similar methodology was used.

4.2 Themes arising from focus groups

4.2.1 Participants existing knowledge of TB

Crosscutting findings & themes

Several themes were brought up in the discussions by each group and these are reported below. Some of the 'answers' that were discussed were factually correct, others however illustrate some of the more common myths that are present amongst the general public.

Symptoms – the groups all mentioned coughing, fever, sweating, weight loss and tiredness as common symptoms of TB. Other symptoms were mentioned too e.g. watery stools, vomiting and muscle wasting. These symptoms and specific TB symptoms are fairly non-specific and can be associated with many other diseases (e.g. flu, HIV and other respiratory illnesses). Whether the correct symptoms were mentioned by default, rather than because the participants actually knew what the real symptoms are, remains unclear. Few participants knew that TB can lie dormant for years in some people.

Death & TB - death was highlighted during every focus group as an inevitable outcome for certain groups of people with TB, for instance those who present late to the doctor or those with HIV. Specifically, the Vietnamese group felt that TB led to an early death, even though the majority pf participants were aware that treatment is available. Again, a distinction was made between TB at home (their country of birth) and TB in England amongst the ethnic community groups. Of the African participants many spoke of how having TB in Africa will in

the majority of cases lead to death, whereas in England it was felt either no one has TB or good treatment is available.

Ease of transmission – this was a real concern for most participants and each group had discussions about this without any prompting. This ease and the misconception that TB is always contagious even during the whole length of treatment were common beliefs. Few participants were certain that TB was an airborne disease. The majority of groups spoke of a variety of ways of catching TB, most of which illustrate the lack of awareness that an extended period of time spent with an individual with infectious pulmonary TB is needed, for someone to be at risk of catching TB. Examples of the perceived means of transmission include:

- from people with TB who spit in the streets,
- sitting next to someone coughing on the bus or tube,
- sleeping in the same bed,
- sharing chopsticks, cutlery, cups and bottles etc,
- drinking out of the same bottle,
- picking up cigarette ends or sharing cigarettes,
- sharing needles,
- sharing clothes,
- having unprotected sex and
- kissing someone with TB.

Minimising risk to oneself – isolating the individual with TB in different ways was considered the best way of reducing the risk of catching TB. More specific examples that emerged from particular groups can be found in the specific findings section below.

Treatment – it was well known that there is treatment available for TB, however when informed that treatment has to be taken over a very long period of time, this was thought to be an obstacle in adherence for most.

Where TB can occur in the body – another common misconception was that TB only affects the lungs or respiratory system, rather than affecting any part of the body.

Specific groups findings

Nigerian group - the weather was thought to be a cause and means of transmission of TB. Specifically, the wind, which blows dust from the desert into the villages and towns, was mentioned. The dust was thought to carry TB germs in it. In Nigeria, covering of mouths and heads is a common custom employed to stop inhaling the dust.

Somali group - the weather came up again in this group but from a different perspective. People who live in conditions where there is a fluctuation in extremes of temperature (whether from being indoors and going outside or due to extreme weather conditions) were thought to be more at risk of catching TB. England was thought to come under the latter category. Wet winds were also mentioned as being a cause of TB.

It was in this group that TB being transmitted to people through drinking cow's milk was mentioned, although only a minority were aware of this.

Chinese group – it was thought that smokers are more likely to get TB as smoking affects one's lungs, as does TB. Also people with a "lower immune system" were thought to

be more at risk, especially those that do not have a balanced diet. TB was thought to be visibly noticeable in people by this group who thought that someone with TB has pale features and are very thin, perhaps even with some muscle wasting.

Vietnamese – this group were aware that TB can affect different parts of the body but those mentioned were all related to the respiratory system (throat, nose, lungs and mouth) and TB was thought to be similar to lung cancer and asthma. Similar to the Chinese group, this group thought that there was a particular 'look' that people with TB had due to the loss of weight that was very noticeable. People with TB were described as "looking like they're taking drugs".

Pollution and bad air were thought to be means of transmission and also eating the wrong types of food as these stay inside the individual and eventually come out of the body as TB. This group spoke at length of the need to give the person with TB separate eating utensils and keeping them isolated in a different part of the household.

HIV positive - these groups were very well informed and used the most accurate terminology. Their knowledge extended to multi drug resistance and the different strains of TB. Many had experiences of having TB first hand or had known of people to have it since becoming HIV positive. One group discussed how it is possible for people to die of TB in England today, especially since there is a vaccination, treatment and a free national health system.

Homeless – TB was thought by a couple of this group to be an inherited disease. Symptoms were well known by most and included night sweats, coughing, coughing up blood and loss of weight. TB was associated with "weaker people" (immunosupressed), those who get wet living on the streets and specifically Eastern Europeans[1].

Substance mis-users – from this small group it was again thought that TB can be passed on at birth. A suggested way of building oneself up to prevent TB was to drink 2 pints of Guinness a day especially for those who cannot eat a healthy diet as this will ensure they get the right nutrients.

Prisoners – There was a very mixed level of knowledge in this group that came though the discussions. TB was thought to spread through unprotected sex, kissing and from pets. Note – the participants wanted the person with TB to be put into a single cell away from healthy prisoners. They felt that this was unlikely to happen which made them feel vulnerable to catching TB.

4.2.2 Participants existing perceptions of TB

Crosscutting themes

'Disease of the past' – for most, TB was thought of as a forgotten disease, one that people associated with Victorian times. Participants from countries where TB is endemic drew on experiences and memories of TB being very common in their homelands but one that is not found in England. This lack of recognition that TB is not a disease that is diagnosed often, if at all, in England, is important as it may impact on a person's willingness to present for medical attention. The fact that the focus groups were about TB alerted the participants that TB might be on the come back or at least of rising importance. Some

[1] Since 2004 there has been an increase in immigrants from those Eastern European states that joined the EU. Research by Homeless Link states that the proportion of homeless who are Eastern European has also increased[1]. As TB is more prevalent in these areas, this has implications for TB management.

participants mentioned the presence of TB in the newspapers, especially the tabloids and how often articles associate immigration and an increase in TB in this country.

Stigma – all the groups alluded to this in many ways. The word stigma may not have been used explicitly and in some cases it was 'felt stigma' (this is the "impact on individual feelings such as shame, guilt, withdrawal, self-stigmatisation"[15]) rather than 'enacted stigma' ("relates to experiences. Individuals can be denied access to information, health services, company and the support they need. They can also face loss of job, compulsory testing, even violence and quarantine"[16]) that was referred to. Participants began at this stage to feel more at ease in the discussions and personal stories about TB emerged. Some participants spoke of feeling ashamed of having had TB in the past, especially in relation to HIV/AIDS. This particular issue was brought up by many of the African participants who spoke of the shame felt by those with HIV being similar to that of TB or that 'TB translates in to HIV' meaning that if you mentioned to someone at home that you had TB that they would assume you were HIV+ or vice versa.

The risk that a member of the community would find out that you had TB was enough for some people to declare that they would not present to the doctor, as they wouldn't want to know or that they would 'manage' or hide their TB. However, others said that there was a particular look that someone with TB has, and the loss of weight in particular is difficult to hide and would raise suspicions with some people.

The idea of separating the person with TB from your family or community perpetuates the myths and misconceptions that TB is easily caught and transmitted but illustrates the importance some groups give to protecting themselves and the rest of their family. Both the Nigerian & Somali groups spoke of keeping TB a secret, as their communities would gossip about the individuals. Due to the general belief that TB is always contagious there was a perception from the Chinese group that 'you didn't belong' and that you were excluded from the community. However, whether they were actually treated as outcasts was not clarified, reflecting the felt and enacted stigma. In the Vietnamese group the participants mentioned that the community would also marginalise the individual's relatives. The labels attached to TB are felt to be long term, hence the necessity to hide it.

Negative social connotations were widespread in most of discussions, for instance the Nigerian group spoke of TB as a 'dirty disease' that the 'underprivileged' had and displayed a lack of hygiene. Having TB said something about way you live, for example that "you don't look after yourself, or that you live in poor living conditions, and have let yourself go".

Those that were more at risk were again associated negatively, such as those with a low immune system, people who smoke, people who don't take care of themselves, like the homeless or those who live in crowded places - prisoners, schools, the military.

The consequences of the stigma are so detrimental, as the concerns about the social impact of the disease, rather than the health implications, lead to TB being diagnosed much later than it could be.

Specific findings

HIV positive – the participants were generally very anxious about TB, as the implications for them having TB are more serious. This anxiety was also related with the perceived greater risk of dying if they got TB. Personal experiences of having had TB emerged and stories of feeling like an outcast due to the behaviour of medical staff were told. For instance, participants spoke of being an inpatient at hospital and having been isolated in single rooms (sometimes necessary), but this exclusion was often not explained to them and in addition nurses would use gloves and masks every time they came into their room or leave their food

outside for them to collect added to their feeling that they were a dangerous patient to be near. This, they felt, would reinforce the negative attitudes that people have towards TB.

Prisoners – as mentioned above the prisoner group felt that normal precautions that would be taken outside the prison would not be taken if a fellow prisoner was diagnosed with TB. Whether factually correct or not, they wanted the 'carrier' to be isolated so that the possibility of spread was decreased. This was felt not to be a priority, nor was prison health in general felt to be an important consideration by the wardens or officers.

Chinese – the group focused on stigma for some time and it was discussed that the Chinese are very reserved people who do not share health information with others outside their close family. Support could be counted on from their families but not from neighbours or other community members, as the impression of TB was very negative and people believe you are contagious even after having taken treatment. It was thought that people would look down on the person with TB and tell others, thus participants would not take the chance to tell anyone else.

4.2.3 Participants interactions with and impressions of the NHS

There were no cross cutting themes under this theme and it was observed that the groups had fairly diverse perceptions and uses of the NHS and the medical services they drew on.

Somali – this group spoke of the little confidence they felt in their own GPs. Consultations would take place usually with another member of the family present that could speak English for the patient. Interpreters were needed but often could not be arranged to come at the appointment time or did not turn up. This was blamed on the practice.

Whatever the reason for presenting at the practice the participants joked that paracetamol was the treatment offered. In their experiences paracetamol as a 'cure all' did not work. Some people had decided to go to Accident and Emergency instead when they were unwell, as they felt that they received better care, the doctors listened more carefully, asked more questions and did not just prescribe paracetamol. Interpreters were perceived to be more available at A&E too.

HIV positive – from one of these groups participants spoke of dreading going to the GP, even though they felt that their health was a priority. This delay was described as a way of protecting oneself - to leave seeking treatment until the last possible moment (blood in their sputum). Participants said that if they felt unwell they would generally self medicate, i.e. take extra Anti-Retrovirals, Night Nurse etc, rather than go to the doctor as "there is no guarantee that the doctor will diagnose TB and may well just prescribe cough mixture". Others felt that not going to seek help was "playing with their life". Going to their HIV specialist was where it was generally felt that the best care was received. However, one group mentioned that if you are from Africa and you are HIV+, the medical staff at their particular hospital will assume you have TB, which, they felt, could lead to bad treatment.

Prisoners - As already mentioned this group displayed little confidence in the health care that they receive at the prison. Similar to the Somali group their own 'cure all' was Deep Heat, rather than paracetamol, and again this was prescribed as the appropriate treatment regardless of the diagnosis.

The mobile x-ray unit has been visiting this prison regularly since the pilot in London began and most of prisoners were aware of the visits, however not all had chosen to be screened during any of these occasions. Often it was because they didn't feel at risk therefore no need to checked out, or because they had not known how to take up the opportunity, and had

thought that it was only certain people who were being screened and not an opportunistic screening session.

Substance mis-users – this group felt that they know their bodies well enough so that if they were meant to take medication for a certain period of time but felt better they would stop taking them regardless.

Chinese – this group visit their GPs, however they mentioned that when they fail to get better they then use their own Chinese practitioners who they feel have more effective treatment that is more in tune with their own beliefs and understanding of health. Western medical practices were questioned but this group still used it as a complementary service rather than disregarding it altogether. The precipitating factor for TB in order to seek medical advice would have to be a serious symptom, such as blood in their sputum, due to the negative connotations that their community had for TB and wanting to postpone the possibility of having the disease.

4.2.4 Views on effective health promotion approaches

Cross-cutting themes

When asked how they would like to receive their health information all groups said that they favoured the face-to-face group meetings like the ones being held. This gave them the opportunity to ask personal questions, to meet health professionals from around their area and also other members of their community.

TB was not considered a 'fashionable' subject unlike other illnesses such as cancer and HIV. Therefore, raising awareness of it was deemed more difficult but just as important. As TB was thought to have not been a disease of consequence in the UK this meant that it should be brought to the public's attention.

Specific findings

Somali – this group was composed of very few women who could speak English, hence the need for 3 languages being interpreted. Many of the women were also illiterate in their own language, so even if information were available in the correct language it would not be useful to them. Those who can read said that they had never seen any health information in Amharic or Tigrinya. Every day however, they tune into BBC radio as there are hour-long programmes in their own languages. This was thought to be an ideal way of raising awareness of important health issues as it is listened to faithfully everyday.

Within this particular group it seemed that there was a strong bond and attachment to the community group that they attended regularly for sewing classes, English lessons etc. And although it is not possible to attribute this bond either to the Somali culture or the respect that the leaders of the group had from the members, however it was noticeable how they relied on the group for daily interactions with others from their own countries.

Chinese - Talks and meetings are important for this group as a way of learning about different issues and a raft of other diseases were mentioned that they would like to be informed about, such as several different types of cancer in particular.

Posters would be useless for those who are illiterate but for those who can read, it would need to be in their own language, not in English. Appropriate venues for leaflets and posters were thought to be in Chinese community clubs, libraries, GP surgeries, and Chinese practitioners clinics.

Chinese radio stations and newspapers were also widely used and again could be used to raise awareness. The radio station they mentioned was from 6-7pm every day (FM 558) in

Cantonese and from 5-6pm in Mandarin and usually there were news, health items and music. There are free newspapers available in China Town in Central London that most people read, for instance, the UK Chinese times (www.ukchinese.com) and Chinese Business Gazette (PO Box 4215, 1F2 Gerrard Place, London W1D 5PB 020 7287 9469 chinesebg@onetel.net). These newspapers would be a valuable channel to use for featuring health related information as they are written here in the UK rather than the Vietnamese newspapers, which are imported.

Note - Mandarin and Cantonese script is generally universal, except the mainland Chinese use a modernised simplified script, while others use a more traditional script[17].

HIV positive – TB is less well represented than HIV, where there is already a strong voice, including a wide range of HIV related media, magazines, organisations (and these organisations own health promotion leaflets), support groups etc. Both focus groups thought it would be sensible to use this ‘positive literature’ e.g. Positive Nation, Positively Women, NAM etc, to raise awareness of TB, especially since they are a vulnerable group regarding TB. Having personal experiences written in these magazines could be a useful way to personalise the health promotion messages.

Education is thought to be paramount so as to de-stigmatise the disease and in time minimise the isolation that some people with TB go through. Posters and leaflets could be put up in venues where the general public are a captive audience, such as GUM clinics, the tube and buses and bus stops. Magazines and free newspapers too could be effective methods such as Heat magazine, Cosmopolitan, the Metro newspaper that has a huge audience, especially on the tube in the morning (now Londoners have an even bigger choice since the expansion of the free newspapers e.g. the London Paper, City AM, Standard Lite).

Posters need to be graphic, perhaps with some shock factor, for example similar to the NHS ‘stop smoking’ posters where lungs infiltrated with tar are on display. Frequent reminders for those who are at risk (homeless, prisoners, immunosupressed etc), such as those that women receive reminding them to have their smear tests every 3 years, was another suggestion.

Eastenders and Coronation Street were suggestions of soap operas that could have TB related story lines and that these would help to rid the general public of their lack of knowledge about TB or as one participant stated “complacency that they have towards TB as a disease that does not exist in the UK anymore”.

Schools’ curriculum could include subjects such as TB. Patient groups were thought to be useful so that people can talk to other patients rather than disclose their illness to family and friends (however, those with infectious TB could pose a problem).

Prisoners – this group thought that there were several ways of raising awareness in the prison. For instance, every new prisoner receives an induction pack in the first few days and this could include information about the health services available, the MXU van and its monthly screening sessions and a TB factsheet with the basic information, such as what symptoms to look for, and finally a protocol of what happens in the event of a fellow prisoner/cell mate having TB. Health awareness days could be held several times during the year, due to the high turnover of prisoners and education sessions such as this one could be held more often. A2 posters could be put up in the waiting areas around the prison with common symptoms or MXU dates and times.

Vietnamese – the group suggested that the majority of the community is able to read in their own language, therefore leaflets in their language may have some impact and could be put in GP surgeries, and women's groups (e.g. Nightingale in Woolwich Common) etc. BBC radio is thought to be a useful method and a monthly newsletter written by this community group is sent out to its members, and these common methods of communication could be reproduced amongst other community groups across London. The group believed that in their community they inform other each other of information they receive or that they have learnt about and that word spreads quite effectively.

Vietnamese newspapers are imported so it would not be to use this as an effective means of communicating health messages. The Internet would not be of particular use yet for this community although perhaps for the younger generation it could be. Other meetings like this focus group would be valued, especially on issues such as MRSA, bowel cancer, avian flu etc.

5 Recommendations

Recommendations are grouped according to the topic guide themes as discussed in the findings above, with the exception of 'Participants existing knowledge of TB' as recommendations related to this are covered, principally, by the section Views on effective health promotion approaches.

5.1 Participants current perceptions of TB

- Tackling TB should not be focused purely on medical factors but should take account of cultural beliefs. A major barrier to people presenting to health professionals is the stigma associated with TB.
  - Whilst the ideal would be to tailor the information according to the range of differing perceptions, such a degree of tailoring would be unfeasible. Therefore some account should be taken of the perceptions shown, but focusing on those that are most common, such as the assumption that TB is more contagious than it is (i.e. can be caught from sharing cutlery).
  - Use research findings to improve understanding amongst TB-related health care personnel (frontline staff in primary and secondary care) as this will have a knock on effect on the public's own awareness.

5.2 Participants impressions of, and interactions with, the NHS

- So as to decrease the possibility of contacts etc not attending screening appointments it is important that communication is clear and in plain English, rather than medical jargon is used. Having appointment letters translated could also decrease the number of DNAs. When sending letters to patients for appointments etc including information such as the list below is useful to keep the patient as fully informed as possible and more likely to turn up (see www.communicate-health.org.uk/card/):
  - exact location of the clinic, using a map preferably,
  - what time to arrive (including leaving enough time to fill in forms etc),
  - how long consultation will be for,
  - what will be done during consultation,
  - that the consultation is free and
  - that even if diagnosed with TB the **treatment will be free** too.
- Health care should be culturally sensitive in order to help defuse anxieties, for example having an understanding of the reasons for an ethnic or religious groups:
  - clothing,
  - diet,
  - traditional medicine,
  - religious festivals, such as Ramadan (i.e. alter timings of tablets to fit in with fasting).
- Focus on the personal risk to the individual of not completing the course of treatment to increase the likelihood of adherence.

5.3 Views on effective health promotion approaches

- Improve traditional channels (leaflets and posters) but do not over-rely on them.
  - Straight translations can be unreliable, and often the tone does not correspond with the ethnic group, resulting in a translation that is too technical or confusing.
  - Develop resources with the chosen community. Pilot resources and pictures as these can be misinterpreted or words can have different meanings or not even exist in the language.
  - Health professionals should use the Three Boroughs resource pack as it given details of the difficulties that might be encountered such as language differences, entitlements, differences in understanding of health and disease.
- Utilise ‘other channels’
  - The importance of community group leaders should not be underestimated or under-utilised when tackling health promotion issues.
  - Health professionals need to use more appropriate health promotion approaches with a community e.g. radio stations (Somali, Chinese and Vietnam), through the church (Nigerian) or religious leaders (Imams in the Muslim community).
  - Make links with African and HIV organisations in South East London.
  - Build local links with community groups, using cultural events and working with the community leaders who know the best approach to get messages to their community’s audience. Care needs to be taken however, to ensure that this doesn’t lead to further stigmatisation of a particular group with TB.

A Appendices

A.1 Example of poster

Are you HIV positive? Interested in taking part in some research on TB?

We are looking for volunteers to take part in a **focus group** in late February 2006 in the Waterloo area.

We'll be talking about tuberculosis but no prior knowledge of TB is necessary. People from all walks of life, who may or may not have had TB in the past are welcome, however, participants must be HIV positive.

We need up to 2½ hours of your time and a £10 voucher is offered as a thank you. Travel expenses are reimbursed. Confidentiality and small group size are assured.

If you are interested in taking part or would like more information please contact Alix Johnson on 020 7716 7106 or by email at alix.johnson@lambethpct.nhs.uk

A.2 Demographic questionnaire (Refugee women's group)

Age:

Under 20 years old ☐

20 – 30 years old ☐

31 – 40 years old ☐

41 – 50 years old ☐

51 – 60 years old ☐

61 – 70 years old ☐

71 years old or over ☐

Sex:

Male ☐

Female ☐

Born in:

UK ☐

Somalia ☐

Eritrea ☐

Ethiopia ☐

Sudan ☐

Other ______

Employed? ☐

Student ☐

Unemployed ☐

Which borough in South East London or area of London do you live in?

Lambeth ☐

Lewisham ☐

Southwark ☐

Greenwich ☐

Bexley ☐

Bromley ☐

South West London ☐

North West London ☐

North East London ☐

Lived in UK for:

Under 1 year ☐

2 - 5 years ☐

5 – 10 years ☐

More than 10 years ☐

Single?

☐ Single

☐ Not single

A.3 Languages in SE London sector

This information is useful for determining where the refugees and asylum seekers come from and who have the language difficulties (requiring interpreters).

Lambeth

Languages spoken	Languages for face to face interpretation	Languages for telephone interpretation
Somali	Spanish	Spanish
French	Somali	Somali
Lingala	Portuguese	Portuguese
Spanish	French	Mandarin
Mandarin	Cantonese	Arabic
Portuguese	Bengali	Tigrigna
Farsi	Arabic	Farsi
Kurdish	Turkish	French
Amharic	Tigrigna	Turkish
English	Vietnamese	Cantonese

Southwark

Languages spoken	Languages for face to face interpretation	Languages for telephone interpretation
English	Spanish	Spanish
French	Vietnamese	Farsi
Somali	Cantonese	Kurdish
Mandarin	Turkish	Arabic
Spanish	Somali	Turkish
Vietnamese	Portuguese	Cantonese
Arabic	Bengali	Portuguese
Krio	Mandarin	Mandarin
Kurdish	Arabic	Tigrigna
Chinese	French	French

Lewisham

Languages spoken	Languages for face to face interpretation	Languages for telephone interpretation
Spanish	Spanish	Somali
Somali	Farsi	Farsi
Portuguese	Kurdish	French
Mandarin	Arabic	Mandarin
Arabic	Turkish	Vietnamese
Tigrigna	Cantonese	Turkish
Farsi	Portuguese	Cantonese
French	Mandarin	Albanian
Turkish	Tigrigna	Kurdish
Cantonese	French	Spanish

(Source: LSL stats. Source 3 boroughs team Briefing No 7. June 2005.
Lambeth is 4th, Southwark 9th and Lewisham is 14th among the top London boroughs that support asylum-seekers.)

Bexley

Languages for face to face interpretation
Punjabi
Turkish
Catonese
Vietnamese
Czech
Somali
Albanian
Kurdish
Tamil
Polish

This may also not be the correct list for what languages are spoken as I know we have a high number of Gujarati and Urdu speaker but they do not require interpreters.

Bromley

Data from Croydon council – never received.

Greenwich

Languages for face to face interpretation
Punjabi
Gujerati
Hindi
Urdu
Vietnamese
Cantonese
Turkish
Somali
Albanian
Tamil

(Source: Queen Elizabeth Hospital interpreting services.)

A.4 Topic guide themes

1. TB

TB knowledge:

- What do you think of when you hear the words TB?
- What do you know about TB?
    - **How you get it**
    - **Symptoms**
    - **Causes of TB**
    - Latency/dormant for years
    - Passed on to others? Infectious? How long do you have to be with someone before you can catch it?
    - What part of the body it affects? Different types?
    - Curable
    - Who is at risk of catching it?
    - Treatable?
- **How serious is it?** In relation to other diseases – what is worse than TB? Dangerous disease?
- **How at risk do you feel for catching TB?**

Beliefs about TB:

- **Friends or relatives** - different views to you?
- How is TB dealt with/talked about on a **personal and community level**?
- Would cultural perceptions of TB affect the speed at which you would go to doctor or adhere to treatment?
- Any **myths** that you know of regarding TB?
- Are there any **negative associations** with TB?
    - Stigma – does stigma affect that way you might deal with TB?
    - Embarrassment
    - Shame - If you were diagnosed who would you disclose it to?
    - Anxiety
    - Fear

Experiences of TB (only ask if someone already mentioned has had TB in the past):

- So you had TB x years ago…?
- What was it like?
- What did you do?
- If you had these symptoms – what would you do? How long would it be before you would seek advice?

2. Health services

- If you are unwell what do you do?
- What makes you go to the doctor? Precipitating factor?
- Where do you go?
- What do you think about medical services in your area?
- GP registered? How was registering with the GP?
- What is your relationship like with the GP?
- Is there a healthcare professional that you have a good relationship with? Why is it positive? Trust advice? Listening to you? …
- How do you feel healthcare professionals treat you?
- Attitude to taking/complying with medication/medical recommendations?
- What would stop you taking your tablets?
- Would you tell your doctor you'd stopped taking your medication?

3. Health promotion activities

Preventative measures:

- Is it possible to reduce risks of getting TB?
- What do you do?
- Is it effective?
- **Best ways to deliver health promotion campaigns about TB?**

Explore solutions:

- Can you suggest anything we can do about that?
- Have you any ideas about how we can begin to tackle this?
- Another group suggested… what do you think about this?

- Responses to information from media and other sources about TB
- **Where do you get your info from about health issues/diseases etc?**
- **Who do trust to give you good information?** Newspapers, friends etc

- Can you think of any health promotion campaigns in general? Any specifically for TB?
- What campaigns do you remember/like/made an impact with you/dislike – why?
- Show some examples of work – leaflets, posters, TB/GB poster.

A.5 Refugee languages by country of origin

Source: Refugee Council (www.refugeecouncil.org.uk/index.htm)

Afghanistan

Pushto and Persian are the two official languages. In Afghanistan, the Persian language is known as Dari. Although standard written Persian is taught in schools, spoken Dari is a different dialect to Farsi. Most Afghan refugees in Britain speak Dari or Pushto as their first language.

Algeria

Arabic is the official language and is spoken by the majority of the population. Algerians speak a Magrebi dialect of Arabic. Magrebi is not understood by Arabic speakers from outside the region. However, standard modern Arabic is the form of written language that is taught in all Arabic speaking countries, and is taught to children in Algeria.

Angola

The official language in Angola is Portuguese. The most important African languages are Umbundu, Ovimbundu and Kikongo. All of these languages are Bantu languages, which use the Roman script in their written form. Educated Angolans are likely to speak French.

Bosnia

Bosnian is the official language. It is written in a Roman script. Prior to 1992, the majority languages of Serbia, Croatia and Bosnia were known as Serbo-Croat. Although written in two different scripts (Roman and Cyrillic) Serbo-Croat was generally considered to be one language with regional variations. Since the break up of former Yugoslavia, the new countries have asserted that they speak different languages, and different written forms are emerging.

China

More people speak Chinese than any other language in the world. When people refer to Chinese, they normally mean the main Chinese dialect, Mandarin, which is spoken by about two-thirds of the population, and is the official language of the People's Republic of China (including Hong Kong), Singapore and Taiwan. There are many different dialects spoken in China. The other major dialect is Cantonese, which is spoken by 45 million Chinese in the southern provinces.

Democratic Republic of Congo (formerly Zaire)

French is the official language in the Democratic Republic of Congo. Four other languages are given official status: Swahili (a dialect known as Kingwana), Tshiluba, Kinkongo and Lingala.

Eritrea

Tigrinya is the official language, although since 1991 English has been the medium of secondary education. The predominant Muslim community in northern Eritrea speaks Tigre. Tigrinya and Tigre are written in the Ethiopic script. Other languages spoken in Eritrea include Arabic, Saho and Beja, the latter two languages being recently scripted in the Roman script. Among Eritrean refugees living in Britain, most speak Tigrinya.

Ethiopia

Amharic is the language of government and is spoken by about 30 per cent of the population. Tigrinya is spoken by about 10 per cent of the population. Both Amharic and

Tigrinya are Semitic languages and written in the Ethiopic alphabet. Oromo is spoken by about 40 per cent of the population. Amharic, Tigrinya and Oromo are spoken by Ethiopian refugees in Britain.

Federal Republic of Yugoslavia (Kosovo, Serbia and Montenegro)

Throughout the Federal Republic of Yugoslavia people speak Serbo-Croat, Albanian, Gorani, Roma. However, the majority of refugees coming to the UK from this region are Kosovar Albanians - they speak Albanian.

Former USSR

Following the break up of the Soviet Union, former Soviet republics such as the Ukraine, Moldova, Georgia and Latvia became independent states. The Russian Federation is the largest state and Russian is the official language. The new independent states adopted their own official languages but Russian is also widely used as a working language.

Gambia

The official language in Gambia is English. The most important African languages are Malinke, Fulani and Wolof.

India

Indian nationals who have sought asylum in the UK are largely from the Punjab. Their first language is Punjabi, an Indo-European language written in the Gurukhi script in India and the Perso-Arabic script in Pakistan. Hindi or Urdu is the Lingua Franca of India and Pakistan.

Iran

Persian is the official language in Iran. The language is generally called Farsi in Iran. It is an Indo-European language written from right to left in the Perso-Arabic script. Iranian refugees living in Britain include Armenian, Assyrian and Kurdish minorities, who may speak their respective languages at home, as well as Persian and English.

Iraq

Arabic is the official language of Iraq. Arab refugees from southern Iraq speak Arabic as their first language. The exodus of refugees from Iraq also includes minority groups such as the Assyrians and Kurds. Assyrians speak Assyrian, a Semitic language closely related to the Aramaic of Biblical times. Assyrian is written from right to left in the Nestorian script. Iraqi Kurds speak a dialect of Kurdish called Sorani as their first language.

Ivory Coast

French is the official language. It is widely spoken and has emerged as the lingua franca. More than 50 African languages and dialects are used, and many of them are still not scripted.

Kenya

The official language is Swahili although the language of upper primary, secondary and tertiary education is English. Swahili is widely understood, as is English. Other important languages include Kikuyu (like Swahili, a Bantu language) and Luo, a Nilotic language.

Kosovo

Kosovar Albanians speak Albanian as their first language. They call their language ëshqipí. It is an Indo-European language, but not closely related to other languages of the region. Albanian has a standard written form, and two main spoken dialects: Tosk and Gheg.

Nigeria

The official language is English. The most widely spoken African languages are Hausa, Yoruba, Ibo, Fulani, Efik, Ibibio, Tiv, Ijo, Urhobo and Idoma.

Polish (Roma)

Polish refugees who have arrived since 1994 have largely been from the Romany minority. Their home language is likely to be Romany, although many households will also use Polish. Romany is an Indo-European language, most closely related to north Indian languages such as Hindi and Bengali. There is considerable dialectal difference in spoken Romany, but most Polish Roma in Britain speak Polish Lowland Romany. The language is scripted and uses the Roman alphabet, but few Roma adults and children have had the chance to study Roma. Those who are literate are more likely to read and write Polish.

Rwanda

All Rwandans speak the same indigenous language - Kinyarwanda. French and English are the languages of government, business and education.

Sierra Leone

English is the official language of Sierra Leone. Krio and English based Creole is the language of communication in Sierra Leone. The most important African languages are Temne and Mende.

Somalia

The largest refugee community in the UK originates from Somalia. The majority of refugees from Somalia speak Somali. It is a Semito-Hamitic language written in the Roman script (its letters follow an Arabic based word ordering). Somali has only been recently scripted, and as a result, written Somali shows differences in spelling, as a standard form has not fully emerged. Somali is also heavily dialectised and different dialects may not be mutually intelligible. The exodus of refugees from Somalia also includes two minority groups: the Bravanese who speak Brava or Chimini (a dialect of Swahili) and Arabic speaking minorities.

Sri Lanka (Tamils)

Almost all refugees from Sri Lanka belong to the Tamil minority. Their home language is Tamil. This belongs to the Dravidian language family has its own script dating back at least 1,500 years. Tamil has a standard written form, but the dialects spoken in south India and Sri Lanka differ. A minority of Sri Lankan refugees are Sinhalese. Many Sri Lankans speak English in addition to their home language.

Sudan

Arabic is the official language of Sudan and the medium of instruction in schools. People in northern Sudan speak Arabic. Sudanese speak their own dialect of Arabic, although literate Arabic speakers can write standard Arabic. Among refugee communities from southern Sudan, Dinka, Nuer, Shilluk, Zande and Bari are home languages.

Turkey (Kurds)

The majority of refugees from Turkey belong to the Kurdish minority. Most Kurds speak Kurdish, using the Kurmanji dialect, and the language is central to their identity. However, in Turkey the speaking and writing of Kurdish Kurmanji was forbidden until 1992, and as a result few adults or children are literate in Kurdish Kurmanji. (Kurdish Kurmanji is written in the Roman script). Turkish Kurds are more likely to be literate in Turkish, although levels of illiteracy among Turkish Kurds are high.

Uganda

The official language is English and it is widely spoken and written among refugee communities from Uganda. The most important African language is Luganda. Other important languages spoken by Ugandan refugees in Britain are Acholi, Swahili and Nyankole.

Vietnam

Most Vietnamese refugees in Britain are ethnic Chinese and will speak Chinese Cantonese as their home language. Many ethnic Chinese will also speak and write good Vietnamese, as will the ethnic Vietnamese community.

Zimbabwe

English is the official language in Zimbabwe, but Shona and Ndebele are also spoken.

6 Links

Refugees, asylum seekers & ethnic minorities

www.cnhlc.org.uk/english.html

Chinese National Healthy Living - aim to promote healthy living, and to provide access to health services, for the Chinese community in the UK. The Centre takes an holistic approach, tackling both the physical and psychological aspects of health. Health promotion leaflets and videos available.

www.ecre.org/about/

The European Council on Refugees and Exiles (ECRE) is the umbrella organisation for co-operation between European non-governmental organisations concerned with refugees.

www.equip.nhs.uk/index.html#top

Gateway to quality health and social care information for UK patients, their families and carers. Help yourself to find out about risks, symptoms and treatment options where to seek support and advice (in UK).

www.harpweb.org.uk/index.php

Three websites, each developed in collaboration with health professionals working with asylum seekers and refugees in the UK. They are designed to enable you to easily access the wealth of information, practical tools, and articles that have been written by health care professionals, NGOs, academics and research bodies with expert knowledge of working with asylum seekers and refugees, both in the UK and other countries. Includes Communicate - Multilingual and Multicultural Health Resources contains the Multilingual Appointment Card used by thousands of professionals in contact with asylum seekers and refugees.

www.heron.nhs.uk/pidsearch.asp

This website provides comprehensive and searchable source of available health and social care information in a range of community languages and formats, e.g. audio, Braille, video and information for people with learning difficulties.

www.surgerydoor.co.uk/3cities/index_audio.html

Arabic, Bengali, Chinese, English, Gujerati, Punjabi, Somali, Urdu – 9 health issues including TB – audio.

www.medact.org/ref_about_network.php

Medact is a global health charity tackling issues at the centre of international policy debates. Led by its health professional membership it undertakes education, research and advocacy on the health implications of conflict, development and environmental change, with a special focus on the developing world. Good email network.

www.multikulti.org.uk/

Information, advice, guidance and learning materials in community languages. And database of local agencies.

www.refugee-arrivals.org.uk/index.php

Refugee Arrivals Project (RAP) is an independent charity set up to assist newly arrived asylum seekers and refugees. It is the only voluntary organisation working with asylum seekers directly after they arrive at airports in the South East of England.

www.southwarkalliance.org.uk/involving/voluntaryorgs.htm

Local strategic partnership of voluntary organisations including population profiles.

southwark.gov.uk/YourCouncil/GettingInvolved/CIDU/southwarkrefugeecommunitiesforum.html

Southwark Refugee Communities Forum meetings

SRCF holds bi-monthly meetings of refugee organisations based and working in Southwark. The Forum meetings offer opportunities for service-providing agencies across all thematic and geographical areas to reach out to refugee communities.

The membership of SRCF currently includes 28 Southwark-based Refugee Community Organisations.

An estimated 7,000 people from refugee backgrounds across Southwark are in direct contact with SRCF members and participate in their activities on a regular basis.

www.smff.org.uk/

Southwark Multi-Faith Forum (SMFF). The SMFF works with the Council, the Police, voluntary & community organisations and in collaborations of its own members, with the aim of making Southwark a better place to live for all its people of all ethnicities and beliefs.

www.ukvisas.gov.uk/servlet/Front?pagename=OpenMarket/Xcelerate/ShowPage&c=Page&cid=1134650060850

Health screening general Q&A

www.lienviet.org.uk/communities.htm

Vietnamese Community in London info see appendix…

Somali

www.waaberi.org/index.htm

To the benefit of Somali refugees in need living in South London to relief poverty, to advance education, preserve and protect health and provide or assist in the provision of facilities for recreation or leisure- time occupation with the object of improving the conditions of life of such persons.

www.lamsom.org.uk/

Lambeth Somali community association is based in London Borough of Lambeth. Our aim is to address the welfare, social, cultural and development needs of the Somali people.

HIV

www.africanhealth.org.uk/

AHEAD works to provide awareness education and information for African communities on HIV/AIDS and other issues of sexual health and gathers and develops materials to support this work.

www.aidsmap.com/en/cats/2C88FEF3-A031-4147-9ACE-8494EE29D4A0.asp

nam – TB info especially for people who are HIV+

www.avert.org/

HIV/AIDS community organisations in London - www.avert.org/hivlondon.htm

www.hivsouthlondon.org.uk/boroughs/index.htm

Services in south London for HIV+

Homeless

www.homeless.org.uk/

Frontline services in partnership forming an umbrella organisation.

7 Acknowledgements

All focus group participants

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Stockwell Women's Refugee Group

Robertson Street Project, Thames Reach Bondway

The Prison Service

The Manna Day Centre

Homeless Link (Linda Briheim-Crookall)

Caldecot Centre

Lighthouse South

Paolo Boldrini

Florence – Africa Development Network

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