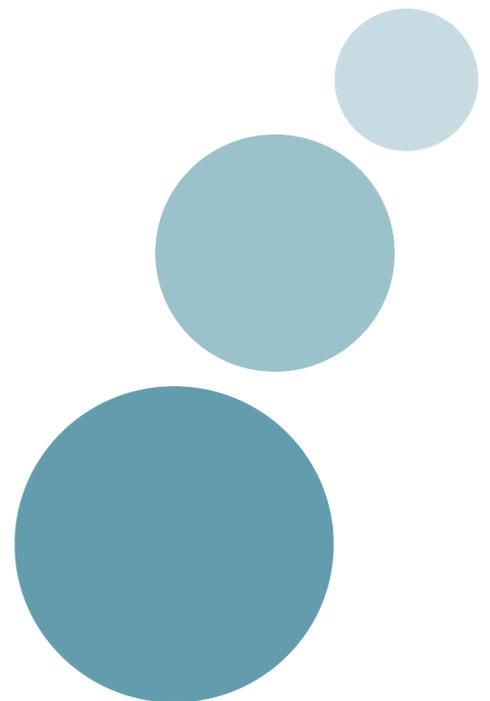




National Institute for Health and
Clinical Excellence (NICE)

Tuberculosis evidence review 1:
Review of barriers and facilitators

1 October 2010



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Any enquiries about this report should be directed to enquiries@matrixknowledge.com

Authors

Alison O'Mara, Isaac Marrero-Guillamón, Farah Jamal, Angela Lehmann, Chris Cooper, and Theo Lorenc

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Declaration of authors' competing interests

No authors have competing interests.

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1.0 Executive summary

1.1 Introduction

This report presents the findings of a systematic review of qualitative evidence on the factors that help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups.

The primary research question for the review was:

- What factors help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups, for example, the stigma associated with diagnosis, and how can the barriers be overcome?

The secondary research questions were:

- How do views vary between different hard-to-reach groups?
- What are the views of service providers?

1.2 Methods

To locate evidence, a range of databases and websites indexing relevant literature were searched. Study reports were included if they:

- had a focus on TB services of any kind;
- were conducted in an OECD country;
- were published in 1990 or later;
- presented data on the views of hard-to-reach people regarding perceptions of or attitudes to TB services;
- presented qualitative data;
- included data from any hard-to-reach group (hard-to-reach groups include: prisoners; problem drug users or people with alcohol problems; homeless people or people in temporary accommodation; asylum seekers, refugees and recent immigrants; travellers; and sex workers). Only migrant groups of relevance to England were included. Respondents did not necessarily have to be diagnosed with TB; and
- were reported in English.

The quality of included studies was assessed, and data were extracted, using the standard tools for NICE public health evidence reviews. Study findings were synthesised thematically using a framework adapted from the Health Belief Model because the themes identified in the evidence mapped well onto the model. This is

perhaps unsurprising given that the model originally developed in the context of TB screening uptake¹.

1.3 Findings

Twenty-five study reports were included in the review. Of these, nine came from the UK, ten from the USA, and two from Canada. The remaining four studies were from Italy, Norway, New Zealand, and Israel. The findings of the studies are summarised in the evidence statements below, with the overall quality rating for each study: [++], high quality; [+], medium quality; or [-], low quality.

Evidence statement 1: Views on susceptibility

Members of hard-to-reach groups frequently report incomplete or inaccurate information about the cause and transmission of TB. Factors correctly perceived to affect susceptibility to TB include smoking, poor diet and malnutrition, poverty, impaired immunity and concurrent other illnesses such as HIV/AIDS. Misconceptions about factors affecting susceptibility to TB include a dirty or wet environment, sharing of domestic objects, and punishment from God.

ES1.1 **Strong evidence from nine studies** suggests that hard-to-reach participants commonly view **smoking** as a risk factor for or cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants (e.g., immigrants, prisoners) in the UK (Brent Refugee Forum (BRF), 2007 [++]);
- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants (Chinese, Vietnamese) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]).

ES1.2 **Moderate evidence from five studies** reported that participants frequently thought **poverty** was a condition associated with contracting TB. These views were reported by studies of:

- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and Vietnamese immigrants in the USA (Houston et al., 2002 [+]).

¹ Abraham, C. & Sheeran, P. (2007). The Health Belief Model. In Ayers, A., Baum, C., McManus, S., Newman, K., Wallston, J., Weinman, and R. West (eds.). *Cambridge Handbook of Psychology, Health and Medicine (2nd ed)*, pp. 97-102 Cambridge: Cambridge University Press.

ES1.3 Weak evidence from five studies suggests that hard-to-reach participants may consider **food or diet-related** factors (such as poor diet or unripe/unwashed fruit) to increase the risk of TB. These views were reported by studies of:

- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]);
- African immigrants in the UK (Johnson, 2006 [-]) and Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants in the UK (Johnson, 2006 [-]).

ES1.4 Weak evidence from four studies suggests that hard-to-reach participants may believe that susceptibility to TB is higher when a person has another illness, such as:

- AIDS (homeless people in the USA; West et al., 2008 [+]);
- low immunity (Asian immigrants in the UK; Johnson, 2006 [-]);
- asthma (Somali immigrants in the UK; Gerrish et al., 2010 [++]); and
- pneumonia (African immigrants in the UK; Nnoaham et al., 2006 [++]). In the case of Somali immigrants in the UK, some participants thought that complications in asthma led to TB (Gerrish et al., 2010).

Other factors believed to affect susceptibility have less basis in fact, and yet cannot be claimed to be entirely incorrect, such as lack of self-care, sexual contact, and a hereditary transmission (since mother to infant transmission may occur).

ES1.5 Moderate evidence from seven studies suggests that hard-to-reach participants commonly view **lack of self-care** (“not looking after yourself”) or a health imbalance as risk factors for TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK ((BRF), 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Filipino immigrants in the USA (Yamada et al., 1999 [++]).

ES1.6 Moderate evidence from five studies suggests that hard-to-reach participants commonly attribute **hereditary** causes to TB infection. These views were reported by studies with a range of hard-to-reach and homeless participants in the UK (Johnson, 2006 [-]); mixed immigrant groups in Canada (Gibson et al., 2005 [++]) and New Zealand (Van der Oest et al., 2005 [-]); and African immigrants in the UK (Gerrish et al., 2010 [++]; Nnoaham et al., 2006 [++]).

ES1.7 Weak evidence from two studies suggests that hard-to-reach participants may believe that TB could be transmitted through sexual contact. These views were reported by studies with a range of hard-to-reach participants in the UK (Johnson, 2006 [-]); and mixed immigrant groups in the UK (Brewin et al., 2003 [+]).

ES1.8 **Weak evidence from two studies** suggests that hard-to-reach participants may believe that **stress** is a cause of TB. These views were reported by studies of Somali immigrants in the UK (Gerrish et al., 2010 [++]) and Vietnamese immigrants in the USA (Houston et al., 2002 [+]).

ES1.9 **Strong evidence from seven studies** suggests that hard-to-reach participants commonly view **environmental conditions** (such as a “dirty” or “wet” environment, or weather-related conditions) as a cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK (Brent Refugee Forum, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]; Johnson, 2006 [-]); and
- Asian immigrants (Chinese, Vietnamese, and Filipino) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]; Yamada et al., 1999 [++]).

ES1.10 **Moderate evidence from five studies** suggests that hard-to-reach participants sometimes consider the **sharing of objects** such as cigarettes, cutlery, and glasses as a likely transmission mechanism. These views were reported by studies with a range of hard-to-reach participants in the UK (Johnson, 2006 [-]); homeless people in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]); mixed immigrant groups in the UK (Brewin et al., 2003 [+]); and African immigrants in the UK (Nnoaham et al., 2006 [++]).

Applicability

Five of the 13 studies reviewed here were conducted in the UK, and the rest reported populations of relevance to the UK (e.g., Somali and Vietnamese immigrants). As such, we have no reason to believe that the views held by the samples here would not be transferable to populations in the UK.

Evidence statement 2: Views on severity

Members of hard-to-reach groups had mixed but fairly accurate views of symptoms; no reported understanding of latent TB; an understanding of the potential fatality of TB; but mixed understanding of the curability of TB. Some groups preferred approaches to treatment that included both traditional and modern medicines.

ES2.1 **Moderate evidence from four studies** suggests that hard-to-reach participants typically understand the main **symptoms** of TB (e.g., coughing), and many participants were familiar with other symptoms such as sweating, fever, weight loss, tiredness, and weakness (various vulnerable groups in the UK: Johnson (2006) [-]; Somali and Ethiopian immigrants in Norway: Sagbakken et al. (2010) [+]). Homeless participants in the USA had mixed knowledge of symptoms: participants in West et al. (2008) [+] had good knowledge, while participants in Kitazawa’s (1995) [+] study were generally unaware about typical symptoms of TB.

ES2.2 Weak evidence from two studies indicate that some hard-to-reach groups are unfamiliar with **non-symptomatic or latent TB**. Some Somali and Ethiopian participants in Norway thought that a lack of symptoms meant that they were healthy (Sagbakken et al., 2010 [+]) and one study explicitly reported no knowledge of latent TB in their sample of various vulnerable groups in London (Johnson, 2006 [-]).

ES2.3 Strong evidence from six studies suggests that participants are aware of the **fatality** of TB but did not always know whether it was **curable**. Fatality was discussed by:

- Somali participants in the UK (Gerrish et al., [++]);
- African immigrants in the UK (Marais, 2007 [++]);
- various vulnerable groups in the UK (Johnson, 2006 [-]); and
- homeless people in the USA (West et al., 2008 [+]).

Chinese immigrants in the USA viewed TB as a curable disease (Fujiwara, 2000 [-]), but a lack of understanding about curability was evidenced by African immigrants in the UK (Marais, 2007 [++]) and homeless people in the USA (Kitazawa, 1995 [+]).

ES2.4 Inconsistent evidence from five studies discussed participant views on **traditional and modern medicine**. Somalis in the UK (BRF, 2007 [++]), Filipinos in the USA (Yamada et al., 1999 [++]), and Vietnamese immigrants in the USA (Houston et al., 2002 [+]) all mentioned acceptance of the use of both traditional and modern approaches to treatment. Somalis in the UK (BRF, 2007 [++]); African immigrants in the UK (Marais, 2007 [++]); and Chinese, Maori, and Pacific Islanders in New Zealand (Van der Oest et al., 2005 [-]) generally preferred using traditional medicines first. In contrast, Somalis in New Zealand are happy to seek modern treatments first because of their experiences with TB-related deaths in their home country (Van der Oest et al., 2005 [-]). In other words, different immigrant groups in various Western countries had varying opinions about the role that traditional and modern medicines should play in treating TB.

Applicability

Four of the 11 studies in this section are from the UK. It is possible that knowledge about the severity of TB might be greater in non UK countries due to information campaigns or treatment service provision in those countries, although there is no reason from the evidence to assume this.

Evidence statement 3: Facilitators and barriers to testing and treatment

Several potential facilitators and many barriers to testing and treatment were identified. Families were identified as a factor that could be a facilitator to some participants (by offering support) and a barrier to others (by causing anxiety or being discouraging). Other potential facilitators included:

- religious beliefs and support; and

- culturally-sensitive and appropriate care.

Broad themes around potential barriers to testing and treatment included:

- lack of coping mechanisms;
- low standard of care;
- inadequate service provision and access;
- fear, anxiety, and denial;
- stigma;
- language and culture differences;
- the difficulties of treatment; and
- lack of symptoms.

ES3.1 **Inconsistent evidence from two studies** suggested that **families** can be a positive **coping mechanism** for some people or a barrier for others. For some Vietnamese refugees in the USA, families were identified as key in supporting compliance, while other participants often worried about what would happen to their dependents (Ito, 1999 [+]). HIV-infected patients with TB in respiratory isolation in the USA reported either support or discouragement to continue treatment from family members (Kelly-Rossini et al., 1996 [+]).

Potential facilitators

ES3.2 **Weak evidence from two studies** suggested that **religious beliefs** could be a **source of hope and a coping strategy**. For Somali participants in Sheffield, Islam was a source of hope (Gerrish et al., 2010 [++]). For some HIV-infected patients in the USA, religion offered a coping strategy to deal with respiratory isolation (Kelly-Rossini et al., 1996 [+]).

ES3.3 **Moderate evidence from three studies** found that **culturally-sensitive** and appropriate care increased **access and adherence** to treatment. Nnoaham et al.'s (2006 [++]) sample of African immigrants in the UK found that counselling from healthcare providers, personalised care from specialist nurses, and advice from well-informed peers could improve adherence to treatment. Many women and men from Muslim communities also noted the ability to access gender-compatible services as a facilitator to service access (Marais, 2007 [++]) Whoolery (2008 [++]) suggested that face-to-face support and good rapport with healthcare professionals from the time of diagnosis; appropriate care delivery; and positive hospital experiences were important facilitators in the successful treatment of homeless persons in London. Participants also stated that increased knowledge of their health state helped them feel empowered and build a positive relationship with their healthcare professional.

Potential barriers

ES3.4 **Inconsistent evidence from three studies** suggests that some participants viewed the **standard of care** as low. Common themes included feelings of staff being neglectful (HIV patients in respiratory isolation: Kelly-Rossini et al., 1996 [+]; drug users

in the USA: Curtis et al., 1994 [+] or disrespectful (Curtis et al., 1994 [+]). However, one study on Somali immigrants in Sheffield reported that patients were generally happy with their TB services (Gerrish et al., 2010 [++]).

ES3.5 Strong evidence from three studies indicated a **lack of information or awareness** about service availability or access for vulnerable groups in London (BRF, 2007 [++]), Somali immigrants in London (Marias, 2007 [++]), or Chinese immigrants in New York (Fujiwara, 2000 [-]).

ES3.6 Weak evidence from four non UK studies suggested that the **cost of TB services** was a concern for some participants, in particular, Chinese immigrants in New York (Fujiwara, 2000 [-]); various immigrants in New Zealand (Van der Oest et al., 2005 [-]); and homeless people in the USA (West et al., 2008 [+]). The authors of one study (Curtis et al., 1994 [+]) suggested that low uptake of preventive therapy might be due to a lack of funding for such therapies in the USA. In terms of applicability, it is important to note that none of the studies reporting this theme is from the UK, where access to medication and healthcare is free for low-income groups.

ES3.7 Strong evidence from five studies suggests that hard-to-reach groups (mostly African immigrants) have a lack of confidence in or are concerned about **misdiagnoses or delayed diagnosis by healthcare professionals**. Groups that mentioned these concerns included:

- Somalis in Sheffield (Gerrish et al., 2010 [++]);
- various vulnerable groups including HIV patients in London (Johnson, 2006 [-]);
- African immigrants in London (Marais, 2007 [++]) and Nnoaham et al., 2006 [++]; and
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]).

ES3.8 Strong evidence from five studies suggests that various hard-to-reach groups felt that **fear of death from TB** was a barrier to wanting to be screened. This was mentioned by:

- various vulnerable groups in London (BRF, 2007 [++]);
- Somali immigrants in Sheffield (Gerrish et al., 2010 [++]);
- Filipino immigrants in Hawaii and California (Yamada et al., 1999 [++]);
- homeless people in San Francisco (Kitazawa, 1995 [+]); and
- homeless people in the North-Eastern USA (Swigart and Kolb, 2004 [+]).

ES3.9 Strong evidence from ten studies indicates that stigmatisation is an important concern for people with TB and their families (see also ES3.10). **Social isolation** is a key feature of stigmatisation for many hard-to-reach groups (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Nnoaham et al., 2006 [++]; Van der Oest et al., 2005 [-]; Whoolery, 2008 [++]; Yamada et al., 1999 [++]). Participants in two studies reported feeling stigmatised by attitudes of healthcare staff (HIV patients in respiratory isolation: Kelly-Rossini et al., 1996 [+]; African immigrants in London: Marais, 2007 [++]).

ES3.10 **Strong evidence from three studies** indicates that perceptions of a **link between TB and HIV** increases concerns about stigmatisation for various immigrant groups in the UK (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]).

ES3.11 **Strong evidence from three studies** shows that language barriers between service users and service providers are a concern for many hard-to-reach immigrant populations. This was evident for Somalis in Sheffield (Gerrish et al., 2010 [++]); migrant Africans in London (Marais, 2007 [++]); and various refugee and minority ethnic groups in New Zealand (Van der Oest et al., (2005 [-]).

ES3.12 **Moderate evidence from six studies** suggests that the **difficulties of treatment** (length of treatment and side effects) are a barrier to compliance for some patients. Length of treatment was a concern for many participants from vulnerable groups in London (Johnson, 2006 [-]); Ethiopian refugee families in Israel (Chemtob et al., 2003 [-]); and homeless and drug/alcohol abusers in the USA (West et al., 2008 [+]). Side effects were mentioned as a reason for non compliance for various immigrants in Canada (Gibson et al., 2005 [++]) and Vietnamese immigrants in the USA (Ito, 1999 [+]). Adhering to TB treatment in the context of substance addiction or use and social exclusion was reported to be difficult for homeless persons in the UK (Whoolery, 2008 [++]).

ES3.13 **Moderate evidence from three studies** suggests that non compliance with treatment often occurs when a patient **no longer shows symptoms of TB**, even though their course of treatment has not finished. This was mentioned in relation to Somali patients in Sheffield (Gerrish et al., 2010 [++]); substance misusers in London (Johnson, 2006) [-]; and Vietnamese people receiving treatment in California (Ito, 1999 [+]).

Applicability

The cost of TB services was not raised as an issue in any UK study. This reflects the fact that individuals in the UK do not have to pay directly for TB services, unlike in the USA or New Zealand, and so these findings might not be transferable to the UK. However, people in the UK may have to pay to get to diagnosis and treatment centres, or to take time off work to attend, which can be a barrier to participation among poorer groups.

Concerns about misdiagnoses by healthcare professionals (ES3.5) were mostly limited to African immigrants and so might not transfer to other hard-to-reach groups.

The evidence from Chemtob et al. (2003 [-]) regarding a lack of equivalent terminology to describe TB might be rather specific to that language group (Amharic-speaking Ethiopians in Israel). No other study specifically mentioned this terminological problem.

This would only transfer to other populations that do not have a linguistic equivalent for the term 'tuberculosis'.

Evidence statement 4: Cues to action

ES4.1 **Weak evidence from three studies** reported on cues to action. A cue for **Chinese immigrants** in London can be a serious symptom (e.g., blood in sputum) (Johnson, 2006 [-]). The most common cue to action among 55 **homeless** people in the USA was family history, while concerns about lung problems, living in a shelter, and the pressures of shelter workers were less common but evident cues (Swigart & Kolb, 2004 [+]). Concerns about the seriousness of TB and concern for others were also mentioned by homeless people in the USA (Kitazawa, 1995 [+]).

Applicability

There is insufficient evidence on this research question for any hard-to-reach group to form clear conclusions about what cues lead people to seek out screening or treatment for TB.

Evidence statement 5: Views on the benefits and implications of using TB services

ES5.1 **Inconsistent evidence from five studies** discussed the views of hard-to-reach groups in relation to **benefits** of seeking or receiving TB services. Whoolery (2008 [++]) found that a positive outcome of being diagnosed and treated for TB for homeless persons in the UK was that they actively made positive changes or took on new responsibilities beyond healthcare in their lives, such as changing their living situation or building positive relationships with their families. However, all studies mentioned that benefits were juxtaposed by concerns. For immigrants in London, screening was both socially responsible and anxiety-provoking (Brewin et al., 2006 [+]). For Somalis in Sheffield, screening could provide relief from a definitive diagnosis as well as anxiety associated with stigma (Gerrish et al., 2010 [++]). Kampuchean refugees in New Zealand were happy to take treatment although this was largely fear-driven (Van der Oest et al., 2005 [-]). For HIV-infected patients in respiratory isolation, being alone was seen as positive by some and negative by other participants (Kelly-Rossini et al., 1996 [+]).

ES5.2 **Weak evidence from five studies on social, psychological, and economic implications** was identified. Although issues around losing jobs (Marais, 2007 [++]) or their children (Swigart & Kolb, 2004 [+]) arose, there was insufficient evidence on these themes. There was more evidence for loneliness and isolation (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Kelly-Rossini et al., 1996 [+]; Marais, 2007 [++]), which has been covered in the section on stigma.

ES5.3 Inconsistent evidence from two studies on implications regarding **deportation** was available. Fears of being deported or family not being able to emigrate after receiving a positive TB diagnosis were evident among Filipino immigrants to the USA (Yamada et al., 1999 [++]), but participants in a Chinese focus group in New York understood that TB sufferers would not be reported to immigration authorities (Fujiwara, 2000 [+]).

Applicability

Concerns and implications about enforced isolation for people with TB in the USA and Canada may not be as applicable to hard-to-reach groups in the UK where such isolation is rare. Given the lack of other evidence in this theme, it is unclear whether the findings are transferable.

Evidence statement 6: Variations in views between different hard-to-reach groups

ES6.1 **Weak evidence from two studies** suggested that **commonalities** emerged across different hard-to-reach groups. These were an understanding of the possible fatal consequences of TB (Johnson, 2006 [-]); the stigma associated with diagnosis (Johnson, 2006 [-]; Van der Oest et al., 2005 [-]); and the importance of language in communicating with immigrant and minority ethnic groups (Van der Oest et al., 2005 [-]).

ES6.2 **Weak evidence from two studies** noted **differences** between hard-to-reach groups. Differences related to preferences for traditional versus modern medicines and confidence in GPs or the healthcare system. **Somalis** in the UK had little confidence in GPs, preferring to go to Accident and Emergency (Johnson, (2006 [-]), while Somalis in New Zealand had high confidence in GPs (Van der Oest et al., 2005 [-]). **Chinese** people in the UK visited their GPs, but when they failed to improve they used Chinese practitioners who were seen to have more effective treatment (Johnson, (2006 [-]), while Chinese immigrants in New Zealand had a preference for traditional medications (Van der Oest et al., 2005 [-]). **Maori and Pacific Islanders** in New Zealand also had a preference for traditional medications and healers (Van der Oest et al., 2005 [-]). **People with HIV and prisoners** in the UK had little faith in healthcare services, and people with HIV preferred to self-medicate than go to the GP (Johnson, 2006 [-]).

Applicability

The low quality of the two studies reporting cross-group comparisons reduces confidence in the research findings.

Evidence statement 7: Service providers' views

ES7.1 **Strong evidence from four studies** (Belling et al., 2008 [++]; Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]) suggests service providers view a **lack of specialist services and coordination of care** as a major difficulty in TB service provision, since most GPs see few cases of TB a year.

ES7.2 **Moderate evidence from three studies** (Craig et al., 2008 [-]; BRF, 2007 [++]; Belling et al., 2008 [++]) suggested that the **complex social and clinical interactions** surrounding a patient with TB can be a challenge to participation and adherence, and that **outreach TB link workers** or social care workers can facilitate coordination of services.

ES7.3 **Strong evidence from four studies** (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Marais, 2007 [++]; Moro et al., 2005 [++]) suggested that healthcare workers find it challenging to meet the complex care needs of hard-to-reach groups with TB, especially where there are **cultural and language barriers** that make it difficult to interpret symptoms and explain about the disease and its treatment.

ES7.4 Moderate evidence from two studies (Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]) suggested that service providers thought **TB-related stigma** influenced whether people sought testing or complied with treatment.

ES7.5 Weak evidence from one study of service providers' views of their own compliance to testing indicated that service providers can also be afraid of the consequences of contracting TB, including becoming stigmatised. Non clinical healthcare workers may also have limited knowledge about TB, the need for screening and the implications of a positive test result (Joseph et al., 2004 [+]).

Applicability

It is important to note that two of the studies included in this section (Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]) did not focus explicitly/exclusively on hard-to-reach groups, although they did mention hard-to-reach people (namely immigrants). The findings from these studies therefore include the views of service providers that deal with both general population and hard-to-reach groups. Some of the experiences and views of services providers might only apply to the general population, but unfortunately this distinction was not made in the documents.

Studies from outside the UK might not be completely transferable because of the different service provision offerings, training/accreditation schemes for healthcare professionals, and prevalence of TB in different countries. Four of the nine studies included in this section were conducted outside of the UK:

- Italy – Moro et al. (2005 [++]);
- US – Joseph et al. (2004 [+]), Ito (1999 [+]); and
- Canada – Jackson & Yuan (1997 [+]).

1.4 Discussion

1.4.1 Evidence gaps

A number of gaps were found in the available evidence, including:

- cues to action for hard-to-reach people;
- views on the benefits and implications of using TB services; and
- variations in views between different hard-to-reach groups.

1.4.2 Conclusions

Members of hard-to-reach groups frequently reported incomplete or inaccurate knowledge about the cause and transmission of TB. Smoking and heredity were commonly thought to be causes of TB by these groups. Because of this, participants

did not always understand or appreciate their susceptibility to TB. Their knowledge about the severity of TB was also often incomplete or inaccurate. Although many knew that TB could be fatal, many were unsure whether TB could be treated and cured.

Various potential barriers to testing and treatment were identified. The most important barriers were concerns about stigmatisation and a fear of death that prevented many people from getting tested. Many respondents also raised concerns about the ability of GPs to diagnose TB. This point was also reflected in the views of service providers themselves, who raised concerns about the lack of specialist TB healthcare professionals. A few facilitators were mentioned in the literature, including family support and religion—although evidence on facilitators was sparse and inconclusive.

2.0 Aims and background

2.1 Objectives

The National Institute for Health and Clinical Excellence (NICE) has been asked by the Department of Health (DH) to develop guidance on a public health programme aimed at identifying and managing tuberculosis among hard-to-reach groups. The guidance will provide recommendations for agencies including health authorities, local authorities and other public, private or third-sector bodies, particularly those working with hard-to-reach groups.

Four evidence reviews will be undertaken to inform the guidance. This report refers to the first of these reviews, which included qualitative evidence on the factors that help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups. This report systematically reviews and synthesises relevant research to inform this topic. The remaining three reviews will explore quantitative evidence in relation to identifying TB, managing TB, and appropriate models for TB services for hard-to-reach groups.

2.2 Rationale

The incidence of TB in England was 15.5 cases per 100,000 people in 2008, an increase from 12.3 per 100,000 in 2000.² However, in particular geographic areas of the UK the incidence may be much higher, up to 40 per 100,000.³ Certain populations are at particularly high risk, as TB infection is strongly associated with social risk factors including homelessness, imprisonment, drug use, and immigration.⁴ Although overall rates of TB in high-income countries have steadily fallen, there remain high incidences among these typically hard-to-reach groups.⁵ These high-risk populations are not only much more likely to contract TB, but also more likely to be diagnosed at a late stage of the disease, and less likely to adhere to treatment. These latter factors contribute to the development of drug-resistant forms of the disease, which are much more difficult and costly to treat.

The central challenge to the control and surveillance of TB is therefore identifying and targeting these hard-to-reach, high-risk groups, due to the well-documented

² Health Protection Agency (2009) *Tuberculosis in the UK. Annual report on tuberculosis surveillance in the UK*. London: Health Protection Agency.

³ Department of Health (2007) *Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high quality services in England*. London: Department of Health.

⁴ Story, A., Murad, S., Roberts, W., et al. (2007). Tuberculosis in London: the importance of homelessness, problem drug use and prison. *Thorax* 62(8): 667-671; Lönnroth, K., Jaramillo, E., Williams, B. G., et al. (2009) Drivers of tuberculosis epidemics: the role of risk factors and social determinants. *Social Science and Medicine* 68(12): 2240–2246.

⁵ Fujiwara, P. I. (2000). Tide pools: What will be left after the tide has turned? *International Journal of Tuberculosis and Lung Disease* 4(12 suppl. 2): S111S116.

association of TB with poverty.⁶ Even within the developed world, the highest rates of the disease are evident within the poorest sections of the community. Social risk factors for TB linked to poverty, such as homelessness and drug abuse, also exacerbate difficulties in both the timely diagnosis and the successful treatment of TB patients. Individuals or groups who face barriers to accessing health services may benefit from targeted screening to promote early diagnosis of TB.⁷

Ensuring compliance with treatment is also a key aspect of TB control.⁸ TB treatment typically lasts for six months or more,⁹ and a substantial proportion of patients do not complete treatment. Non completion of treatment is a major factor in the emergence of multi-drug resistant TB (MDR TB), which is much more difficult and expensive to treat than 'normal' TB. The Health Protection Agency has found that only 79% of TB patients in the UK complete treatment, below the World Health Organization target of 85%.¹⁰ Currently 6.8% of cases in the UK are resistant to at least one first-line treatment, and 1.1% are multi-drug resistant.¹¹

While the highest proportion of cases of TB occur in foreign-born patients (75% of people with TB in London were born abroad¹²), evidence from a large outbreak of drug-resistant tuberculosis points to ongoing active transmission among marginalised groups.¹³ Studies of the spread of TB in prisons have concluded that improving prison conditions is a priority for any effective program to control TB and its spread back into the marginal communities from which prisoners are disproportionately derived.¹⁴ There is also evidence of substantial transmission within UK-born minority ethnic populations.¹⁵

The impact of TB is exacerbated by its link with HIV and AIDS, in particular, in groups such as drug users¹⁶ and immigrants.¹⁷ Globally, TB is a leading cause of death among

⁶ Lönnroth, K., Jaramillo, E., Williams, B. G. et al. (2009) Drivers of tuberculosis epidemics: the role of risk factors and social determinants. *Social Science and Medicine* 68(12): 2240–2246.

⁷ Health Protection Agency (2007). *Mobile targeted digital chest radiography in the control of tuberculosis among hard to reach groups: Key findings*. London: Health Protection Agency.

⁸ Interventions to promote adherence are reviewed in: Volmink, J., & Garner, P. (2000). Interventions for promoting adherence to tuberculosis management. *Cochrane Database of Systematic Review*, issue 4. This review has now been withdrawn and separate reviews of several different strategies are in preparation (directly observed therapy; reminder systems; education and counselling; and incentives) but most have not yet been published.

⁹ Health Protection Agency (2009). *Tuberculosis in the UK: Annual report on tuberculosis surveillance in the UK*. London: Health Protection Agency.

¹⁰ Ibid.

¹¹ Ibid.

¹² Ibid.

¹³ Antoine, D., Maguire, H., & Story, A. (2006). Epidemiology and response to the growing problem of tuberculosis in London. *Eurosurveillance* 11(3): 2528.

¹⁴ Levy, M. H., Reyes, H., & Coninx, R. (2000). Overwhelming consumption in prisons: Human rights and tuberculosis control. *Health and Human Rights* 4(1):166191; Jones, T. F., Craig, A. S., Valway, S. E., et al. (1999). Transmission of tuberculosis in a jail. *Annals of Internal Medicine* 131(8): 557563.

¹⁵ French, C. E., Antoine, D., Gelb, D., et al. (2007). Tuberculosis in non-UK-born persons, England and Wales, 2001–2003. *International Journal of Tuberculosis and Lung Diseases* 11(5): 577584.

¹⁶ Rodwell, T. C., Barnes, R. F. W., Moore, M., et al (2010). HIV–tuberculosis coinfection in Southern California: Evaluating disparities in disease burden. *American Journal of Public Health*, advance online publication.

people with HIV, and it is estimated that one third of the 40 million people living with HIV worldwide are co-infected with TB.¹⁸ In the UK, Ahmed et al.'s (2007) study found that 5.7% of TB patients were infected with HIV, with a substantial year-on-year increase over the period of their study (from 3.1% in 1999 to 8.3% in 2003).¹⁹ A further serious problem with the association of TB with the HIV/AIDS pandemic is the stigma connected with the latter condition, which leads to delayed treatment-seeking and poor adherence to treatment.²⁰ Programs that aim to increase the identification and management of TB must, therefore, address hard-to-reach groups at risk of HIV such as intravenous drug users (IDUs), prisoners, and sex workers.

In recent years, emphasis has moved away from a traditional top-down model of tuberculosis control to community- and patient-centred health services which are based on analysis of local factors affecting case-finding and adherence to treatment,²¹ and from a reactive model to one emphasising proactive approaches to locating and treating cases. For example, the Department of Health established the *Find and Treat* service which supports the detection, diagnosis and treatment of TB in hard-to-reach groups in London using mobile digital X-ray machines, advice and support services and follow-up care.²²

Different hard-to-reach groups are likely to have different needs and encounter different barriers in accessing services. The purpose of this review is to examine the views of members of hard-to-reach groups regarding barriers and facilitators to accessing and using TB services such as screening and treatment, complemented by the views of healthcare professionals on the same issues.

2.3 Research questions

The primary research question for the review was:

- What factors help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups, for example, the stigma associated with diagnosis, and how can the barriers be overcome?

The following secondary research questions were also developed to interrogate the data further, to the extent that relevant data were available:

- How do views vary between different hard-to-reach groups?
- What are the views of service providers?

¹⁷ Delpech, V., Antoine, D., Forde, J., et al. (2004). HIV and Tuberculosis (TB) co-infections in the United Kingdom (UK): Quantifying the problem. Paper presented at the 15th International AIDS Conference, Bangkok, 11-16 July 2004.

¹⁸ World Health Organization (2010). *Tuberculosis and HIV: Factsheet*. www.who.org. Accessed 9th March 2010.

¹⁹ Ahmed, A. B., Abubaker, I., Delpech, V. et al. (2007). The growing impact of HIV infection on the epidemiology of tuberculosis in England and Wales: 1999–2003. *Thorax* 62(8):672676.

²⁰ Grange, J., Story, A., & Zulma, A. (2001). Tuberculosis in disadvantaged groups. *Current Opinion in Pulmonary Medicine* 7(3):160164.

²¹ Ibid.

²² Health Protection Agency (2007). *Mobile targeted digital radiography in the control of tuberculosis amongst hard to reach groups: key findings*. London: Department of Health.

3.0 Methods

The review was conducted in accordance with the second edition of *Methods for the development of NICE public health guidance* (NICE, 2009).

3.1 Searching

The following database sources were searched for this review:

1. ASSIA
2. BL Direct
3. British Nursing Index
4. CRD (DARE, HTA, EDD)
5. CINAHL
6. Cochrane Library (Reviews)
7. Community Abstracts
8. Current Contents Connect (date limit 19982010)
9. Embase
10. ERIC
11. HMIC
12. Web of Science (and conference proceedings)
13. Medline
14. Medline in Process
15. PsycINFO
16. Social Policy and Practice
17. Social Abstracts
18. Social Services Abstracts

The full search strategies for each database source can be found in Appendix A. Members of the Programme Development Group were also consulted to locate relevant literature (see Table A2 in Appendix A).

The following websites were also searched for research papers relevant to the review questions:

Website	Web-link
1. Action Advocacy to Control TB Internationally	www.action.org
2. Centers for Disease Control and Prevention resources on TB	www.cdc.gov/tb
3. Centers for Disease Control National Prevention Information Network	www.cdcnpi.org/scripts/tb/index.asp
4. NICE, including former Health Development Agency	www.nice.org.uk
5. NHS Evidence	www.evidence.nhs.uk
6. Stop TB Partnership	www.stoptb.org
7. TB Alert	www.tbalert.org
8. UK Coalition to Stop TB	www.stoptbuk.org
9. World Health Organization	http://www.who.int/tb/en/
10. WHO Global Health Atlas	http://apps.who.int/globalatlas/dataQuery/default.asp
11. Health Protection Agency	www.hpa.org.uk
12. British Thoracic Society	www.brit-thoracic.org.uk
13. Public Health Observatories	www.apho.org.uk/resource/searchoptions.aspx
14. UK Clinical Research Network	http://public.ukcrn.org.uk/search/
15. National Research Register archive site	https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx

To supplement the database and website searches, the following steps were also taken to identify additional potential relevant records:

- scanning of citation lists of included studies obtained through database searching;
- 'forward' citation chasing on included studies using ISI Web of Knowledge, locating studies which cited them;
- scanning lists of included studies from all systematic reviews which met the inclusion criteria at the full text screening stage; and
- a call for evidence through the PDG committee, organised by NICE.

These records were entered into the database and screened as for the original searches.

3.2 Screening

All records from the searches were uploaded into a database and duplicate records were removed. Inclusion criteria were developed (see below) to facilitate identification of relevant studies. Initially, the records were screened on title and abstract. Where no abstract was available, a web search was first undertaken to locate one; if no abstract could be found, records were screened on title alone. A round of pilot screening was conducted on a random sample of ten abstracts to test and refine the inclusion criteria. Once the inclusion criteria were agreed upon, all records were screened by three reviewers independently using the abstract inclusion checklist in Appendix B. Double screening was conducted on 10% of the records; any differences were resolved by discussion and reference to a third reviewer if necessary. Agreement before reconciliation for the abstract screening was 96.3% ($n = 514$) and inter-rater reliability (Cohen's kappa) was $\kappa=0.51$.²³

The full text of records whose abstracts met the inclusion criteria, or for which it was unclear whether they met the criteria, were retrieved. The full text papers were then re-screened by two reviewers independently using the full text inclusion checklist in Appendix B, and any differences resolved by discussion and reference to a third reviewer if necessary. All full-text items were double-screened.

The inclusion criteria are presented below. Screening was hierarchical, such that answering 'yes' to a question indicates that the researcher should proceed down the list to the next question.

1. Does the study have a focus on TB services of any kind? (Studies need not focus on TB exclusively, but must present data relating to TB. Abstracts regarding infectious diseases in general, which do not mention TB, should be excluded. Studies of the microbiology of TB, or the pharmacokinetics of specific treatments, without reference to services, should be excluded.)
2. Was the study conducted in an OECD country?
3. Was the study published in 1990 or later?
4. Does the study present views data regarding perceptions of or attitudes to TB services? (This includes views of service users, professionals and other stakeholders. It includes views of existing services, preferences, past experiences or future expectations, knowledge and beliefs relating to testing, or potential barriers and facilitators of accessing services. Study methods include surveys, interviews, case studies, or ethnographic or action research. Both

²³It has been argued that Cohen's kappa or similar measures may under-rate reliability where scores are highly asymmetrical, i.e. numbers for one code (e.g. exclude) are much higher than for the other(s) (e.g. include) (Feinstein and Cicchetti 1990). This is the case here, because inclusion rates were fairly low, and hence there were many more studies excluded than included. For this reason, the kappa score is lower than standard guidance would indicate is acceptable, even though rates of agreement were high.

qualitative and quantitative views data should be included here. Studies of behaviour alone, using a questionnaire methodology, should be excluded. Studies of the effectiveness or cost-effectiveness of clinical treatments should be excluded. Systematic reviews including such studies should be included at this stage.)

5. Does the study present qualitative data?
6. Does the study include data from any hard-to-reach group? (Hard-to-reach groups include: prisoners; problem drug users or people with alcohol problems; homeless people or people in temporary accommodation; asylum seekers, refugees and recent immigrants; travellers; sex workers; or any other group considered by the researchers to be less likely than normal to access healthcare services. This criterion should be applied inclusively at abstract stage, i.e., any paper not specifically excluding such groups should be included.)
7. Is the study report in English?

At the full text screening stage, in consultation with NICE, an additional criterion was introduced. This criterion specified that studies must report on hard-to-reach groups relevant to the UK, to maximise the transferability of the findings to the UK context. As such, studies that exclusively focused on indigenous populations (e.g., Aboriginal Australians) or minority ethnic groups that were not recent immigrants or refugees were excluded.

3.3 Quality assessment

All included studies were quality-assessed using the tool in Appendix H of the *Methods for the development of NICE public health guidance* (NICE, 2009). This tool contains 12 questions which can be answered 'yes', 'no', or 'can't tell / not reported'. On the basis of the answers to these questions, and in line with the NICE guidance manual, each study was given an overall quality rating: [++], high quality; [+], medium quality; or [-], low quality. The tool was completed independently by two reviewers for a randomly selected sample of 10% of records ($n = 3$). For the other records, the tool was completed by one reviewer and checked by another, with any disagreements resolved by discussion. The results of the quality assessment are presented in section 4.3 below; two examples of completed quality assessment forms are presented in Appendix E.

3.4 Data extraction

Data were extracted from included studies using the tool for qualitative studies in Appendix K of the *Methods for the development of NICE public health guidance* (NICE, 2009). The tool was completed independently by two reviewers for a randomly selected sample of 10% of records ($n = 3$). For the other records, the tool was completed by one reviewer and checked by another, with any disagreements resolved by discussion or

reference to a third researcher. Data for each included study were extracted and are presented in the evidence tables (Appendix C).

3.5 Data synthesis and presentation

A framework loosely based on the Health Belief Model was used to synthesise the data for the primary research question. The Health Belief Model is a framework which categorises the potential determinants of health behaviours into six themes:

- perceived susceptibility (risk);
- perceived severity (consequences, such as mortality and morbidity);
- perceived benefits (predisposing factors);
- perceived barriers (factors that hinder);
- cues to action (motivating or precipitating forces, such as contact with someone else who has TB); and
- self-efficacy (ability to do something about it).

It was chosen as a base model for organising the review because the themes that emerged from the evidence reflected most of the themes in the model and it provided a coherent structure for the data synthesis. Moreover, the Health Belief Model was originally developed in the context of TB screening²⁴, making it particularly relevant.

The adaptations made to the Health Belief Model for the purposes of this review were:

- changed wording: We used the term “views” rather than “perceived” to de-emphasise the original focus of the health belief model on individual cognitions;
- broadened themes: We broadened “benefits” to be “benefits and implications” and broadened “barriers” to be “barriers and facilitators”;
- dropped theme: We did not locate data on self-efficacy, so this theme was not used in the framework.

We also added two subsections to the report to allow synthesis of the secondary research questions: differences in views between different hard-to-reach populations, and service providers’ views.

The findings data which had been extracted from the studies were read, and coded according to the thematic headings of the model, by two reviewers. Within the headings, subheadings were developed inductively where appropriate. The findings under each code were then drawn together into a narrative that synthesised the study findings. For each theme, this report presents first an overview of relevant studies, then a detailed narrative covering the studies, followed by a summary in the form of an evidence statement. For each study reported in the review, we only present detailed methodological information (e.g., what research methods the author used, who

²⁴ Abraham, C. & Sheeran, P. (2007). *Op.cit.*

conducted the interviews/focus groups) the first time a study is mentioned, to avoid repetition.

Evidence statements include a summary of the overall strength (quality, quantity, *and* consistency) of the evidence. The evidence statements reflect the strength of the conclusions made by the studies, the quality of the studies (as determined in the quality assessment), and any inconsistencies across studies. The summaries used are those described in NICE (2009):

- **no evidence** – no evidence or clear conclusions from any studies;
- **weak evidence** – no clear or strong evidence/conclusions from high quality studies and only tentative evidence/conclusions from moderate quality studies or clear evidence/conclusions from low quality studies;
- **moderate evidence** – tentative evidence/conclusions from multiple high quality studies, or clear evidence/conclusions from one high quality study or multiple medium quality studies, with minimal inconsistencies across all studies;
- **strong evidence** – clear conclusions from multiple high quality studies that are not contradicted by other high quality or moderate quality studies;
- **inconsistent evidence** – mixed or contradictory evidence/conclusions across studies.

4.0 Summary of included studies

4.1 Flow of literature through the review

Database searches located 9,868 records. A further 47 records were located through website searching and NICE's Call for Evidence. Finally, 125 records were located by forward citation chasing of the included studies. Thus, 10,040 abstracts were entered into our database. Of these, 4,954 were duplicate records and were removed. The remaining 5,086 abstracts were screened for inclusion.

A total of 4,932 references were excluded following screening of titles and abstracts. The remaining 154 references proceeded to full text retrieval. A further 126 records were excluded on full text (details of these are presented in Appendix E). Of these, 22 (17%) were excluded because they did not present qualitative research and 34 (27%) because they did not focus on hard-to-reach groups. The full text of four records could not be located. One further study was suggested by the PDG and was included in the review. The remaining 25 studies were included in the review (see Section 7 for the reference details of all included studies). The flow of literature through the review is illustrated in Figure 1.

4.2 Summary of included studies

The 25 included papers report studies conducted in the following countries:

- nine in the UK;
- ten in the USA;
- two in Canada;
- one in Israel;
- one in Italy;
- one in New Zealand; and
- one in Norway.

The details of the methodology and populations of the included studies are summarised in Table 1. Full study details are presented in the evidence tables (Appendix C). All studies used some form of interview or focus group methodology to collect qualitative data. Study population characteristics consisted of the following:

- twelve on immigrants and refugees (e.g., Somali, Ethiopian, Vietnamese);
- five on TB or other healthcare professionals;
- four on homeless and sheltered individuals;
- two with a broad mixture of hard-to-reach groups (including immigrants, prisoners, and homeless persons);
- one on drug misusers; and

- one on people with HIV (many participants reported current or previous illicit drug use and/or a history of incarceration).

Figure 1. Flow of literature

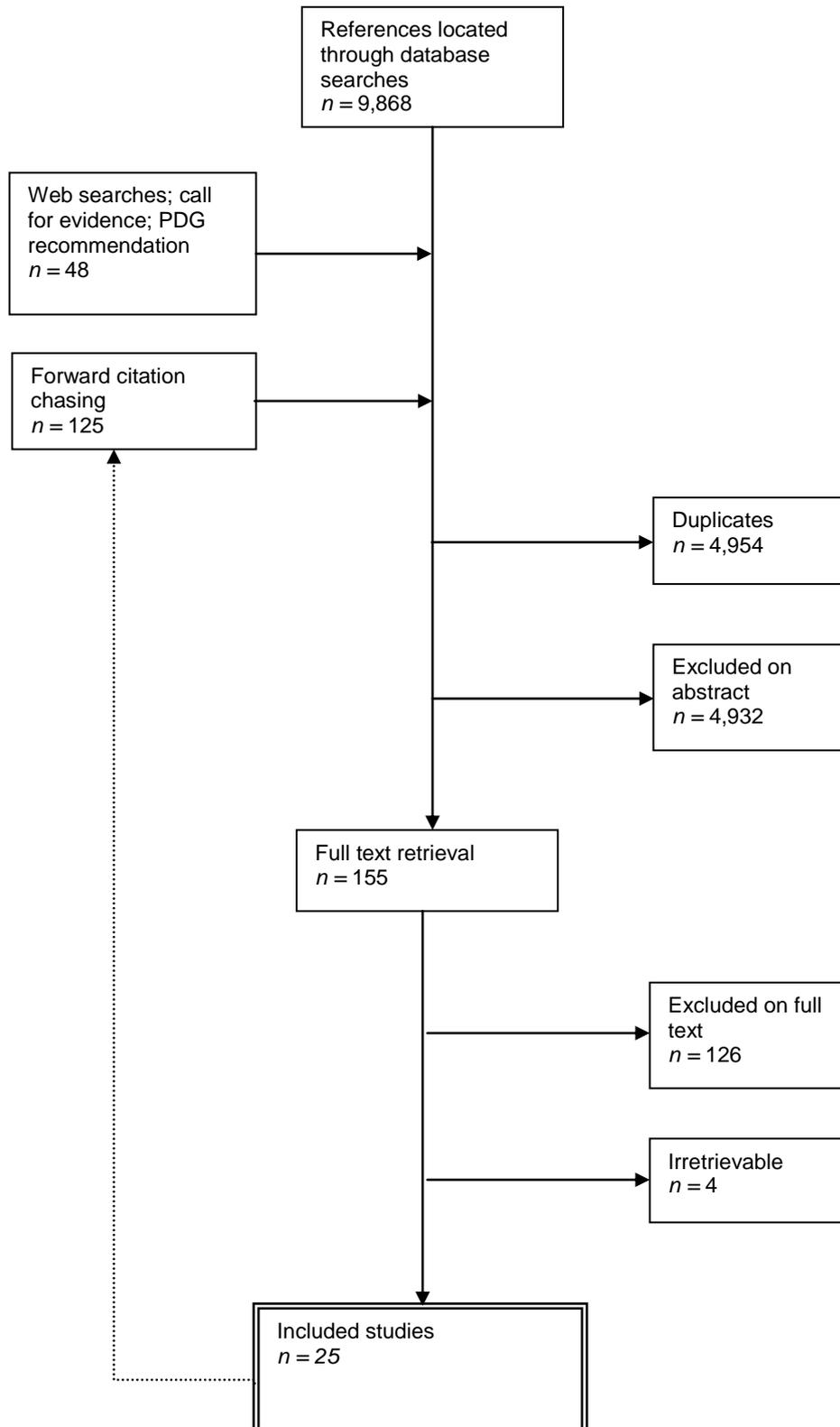


Table 1. Study characteristics

	Aim/s	Method and population	Location
Belling et al. (2008)	To conduct an audit of TB services in relation to the range of services and expertise required to control and treat TB in London.	Interviews with TB service users and TB service lead professionals. Focus groups with TB nurses and external respiratory physicians/epidemiology professionals.	London, UK
Brent Refugee Forum (2007)	To examine the level of knowledge, attitudes and perceptions of TB among groups at high risk of social exclusion and deprivation. To identify barriers that different groups face in accessing treatment, and understand how the cultural context of TB affects their lives.	Focus groups with participants from different ethnicities including refugees and asylum seekers, people who are HIV positive, homeless, and prisoners; male and female. Focus groups with healthcare professionals providing TB services to the same communities.	Brent, UK
Brewin et al. (2006)	To understand how acceptable tuberculosis screening is to immigrant groups and to explore immigrants' understandings of TB in relation to screening.	Interviews with adult immigrants from a variety of ethnicities who had been offered TB screening.	East London, UK
Chemtob et al. (2003)	To identify the barriers to diagnosis, prevention and treatment of TB among immigrants.	Interviews with immigrant Ethiopian families (ranging in size from 2 to 13 members); traditional healers and Israeli health and absorption professionals.	Israel
Craig et al. (2007)	To explore how a social outreach model of care, including a TB link worker, can be best implemented for marginalised groups with TB.	Interviews with TB care providers with experience of collaborative working.	UK
Curtis et al. (1994)	To examine the responses of Injecting Drug Users (IDUs) to current TB management strategies and to explore the implications of these responses for the implementation of Directly Observed Therapy (DOT).	Ethnographic interviews and observations in locations where drugs were sold and taken. Male and female IDUs were interviewed; Latino, black and white.	Brooklyn, New York, USA

	Aim/s	Method and population	Location
Fujiwara (2000)	To explore the development of culturally appropriate marketing campaigns for TB awareness, testing and treatment for immigrants from China.	Focus groups with male and female recent immigrants from China living in an area with high TB incidence.	New York, USA
Gerrish et al. (2010)	To identify socio-cultural influences on the prevention, diagnosis, and treatment of TB within the Somali community and to gain insight into healthcare practitioners' perceptions of and experiences with TB among the Somali community. To identify ways in which culturally appropriate health promotion initiatives regarding TB can reach the Somali community. To identify ways of supporting healthcare practitioners to provide culturally appropriate care in regard to the screening, diagnosis and management of TB within the Somali community.	Interviews with Somali community leaders. Interviews and focus groups with members of the Somali community including those with personal experience of TB. Interviews with healthcare practitioners including GPs, consultants, TB nurses and Somali nurses with experience of working with the Somali community.	Sheffield, UK
Gibson et al. (2005)	To examine socio-cultural factors influencing behaviour related to TB prevention and treatment in high-risk cultural groups.	Interviews with immigrants from Hong Kong, China, Philippines, Vietnam, Punjab, Eastern Europe and Aboriginal groups; included those with active TB, those who had taken directly observed treatment (DOT), those who had been offered DOT and refused and those with past history of TB, or a relative with TB.	Canada

	Aim/s	Method and population	Location
Houston et al. (2002)	To identify the cultural health beliefs regarding TB and barriers to completion of TB prevention programmes among the Vietnamese population.	Focus groups, individual interviews with people of Vietnamese ethnic origin, born in Vietnam, immigrated to USA as an adult (≥ 18 y) and < 5 years ago; included those who had had a positive skin test, people who had completed a TB treatment or prevention programme, people who had not had any treatment but might have indirect experiences of TB, people who had had contact with people with TB but were not in any programme.	California, USA
Ito (1999)	To investigate elements of 'health culture' which affect compliance with preventive treatment for inactive TB among Vietnamese refugees.	Individual interviews and observations with Vietnamese refugees; included individuals who were compliant with treatment and those who were non compliant. Interviews conducted with clinic staff and various community members who were apparently not receiving TB services.	California, USA
Jackson & Yuan (1997)	To identify the non clinical barriers family physicians may face in managing TB among patients and suggestions for overcoming these barriers.	Focus groups with primary care physicians, infectious disease specialists and respiratory physicians who work with TB patients.	Toronto, Canada
Johnson (2006)	To explore how specific cultural health beliefs regarding TB affect the awareness and understanding of the disease among at-risk communities.	Focus groups and interviews with members of the following at-risk groups: Chinese, Nigerian, women refugees, Vietnamese, substance misusers, HIV-positive people, homeless people and prisoners.	South East London, UK

	Aim/s	Method and population	Location
Joseph et al. (2004)	To identify the factors that influence healthcare workers' adherence to policies for routine tuberculin skin tests and treatment of latent TB infection.	Focus groups with healthcare workers from a range of occupations including clinical, janitorial, administrative, clerical and security staff; US and foreign-born.	USA
Kelly-Rossini et al. (1996)	To understand the experiences of respiratory isolation for HIV-infected patients with TB.	Interviews with males and females with a history of HIV infection or HIV risk behaviour, AFB positive sputum smears and confined to respiratory isolation; 30–51 years old.	New York, USA
Kitazawa (1995)	To gather the knowledge and views of homeless people living in group shelters concerning tuberculosis, tuberculosis medical care and health education.	Interviews with men and women in homeless shelters who were English and/or Spanish speaking.	San Francisco, USA
Marais (2007)	To identify the structural influences which operate across community and sector levels within the local context which may influence TB risk, healthcare access and outcome in migrant black African communities. To identify the resources to improve TB control which exist or could be strengthened within the sectors and within these migrant black African communities themselves.	Multi-method participatory research using questionnaires, in-depth interviews, community consultations and observations; migrant black Africans over 18 years old who had been in the UK for less than 10 years; key stakeholders including individuals and representatives of groups, organisations or institutions, which could significantly influence public health interventions for TB control.	London, UK
Moro et al. (2005)	To explore chest and infectious disease physicians' views of the barriers to effective tuberculosis control.	Focus groups with chest and infectious disease physicians offering TB care.	Emilia Romagna region, Italy
Nnoaham et al. (2006)	To describe the perceptions and experiences of African patients with TB, particularly relating to diagnosis, adherence and stigma.	Interviews with patients attending a TB clinic, either for preventive therapy or to receive a diagnosis; African-born; over 18 years.	London, UK

	Aim/s	Method and population	Location
Sagbakken et al. (2010)	To identify the factors associated with diagnostic delay for TB among immigrants in Norway.	Interviews with male and female immigrants from Somalia and Ethiopia who had been diagnosed with TB.	Norway
Swigart & Kolb (2004)	To examine the factors that homeless people report as influencing their decisions to accept or reject TB screening.	Interviews with homeless men and women who either resided in or were visiting shelters.	North-Western USA
Van der Oest et al. (2005)	To explore the opinions of refugee and minority group representatives about the significance of TB for their community and perceptions of TB services.	Community representatives were interviewed from the largest community groups, including Maori and Pacific Island groups, as well as immigrants from China, The Philippines, Somalia, and Kampuchea (Cambodia).	New Zealand
West et al. (2008)	To explore the knowledge, attitudes and beliefs about TB among homeless shelter residents and persons attending a drug/alcohol rehabilitation centre.	Focus groups of homeless participants at homeless shelters and people with drug/alcohol abuse problems attending a rehabilitation facility.	USA
Whoolery (2008)	To explore what it means for homeless people to have TB and how this impacts their opportunities to complete treatment.	Semi-structured interviews with homeless persons, some of whom were also drug users, commercial sex workers or HIV positive.	UK
Yamada et al. (1999)	To understand what Filipino immigrants to the USA know about TB and examine their attitudes and practices concerning TB.	Focus groups with male and female Filipino immigrants in two locations.	Hawaii and California, USA

4.3 Quality of the included studies

The results of quality assessment are presented in Table 2. The two areas in which many studies were lacking were the clarity of the role of the researcher and the richness of the data (e.g., how well are the contexts of the data described?). A third weakness across reviews was the poor reliability of the data analysis approach.

Nine studies were judged to be of high quality [++], **ten** of medium quality [+], and **six** of low quality [-], as follows:

- High quality [++]: Belling et al. (2008); BRF (2007); Gerrish et al. (2010); Gibson et al. (2005); Marais (2007); Moro et al. (2005); Nnoaham et al. (2006); Whoolery (2008); Yamada et al. (1999).
- Medium quality [+]: Brewin et al. (2003); Houston et al. (2002); Ito (1999); Jackson & Yuan (1997); Joseph et al. (2004); Kelly-Rossini et al. (1996); Kitazawa (1995); Sagbakken (2010); Swigart & Kolb (2004); West et al. (2008).
- Low quality [-]: Chemtob et al. (2003); Craig et al. (2008); Curtis et al. (1994); Fujiwara (2000); Johnson (2006); Van der Oest et al. (2005).

4.4 Applicability

As noted above, one third of the 24 studies were based in the UK. The remaining studies came from a range of different countries that will have differences in the TB services they offer to hard-to-reach groups. As such, although the non UK studies cover similar populations to those in the UK studies (primarily African immigrants and refugees and homeless people), their views of services will be dependent on the types of services offered in their countries.

We have no other concerns that the findings presented here cannot be transferred to the UK setting.

Table 2. Quality of the included studies

	Quality score	Is a qualitative approach appropriate?	Is the research question clear?	How defensible/rigorous is the research design?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Is the context clearly described?	Were the methods reliable?	Is the data analysis sufficiently rigorous?	Are the data rich?	Is the analysis reliable?	Are the findings convincing?	Are the findings relevant to the aims of the study?	Are the conclusions clear and plausible?	How clear /coherent is the reporting of ethics?
Belling et al. (2008)	++	Y	Y	Y	Y	NS	Y	Y	NS	M	Y	Y	Y	Y	Y
Brent Refugee Forum (2007)	++	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Brewin et al. (2003)	+	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Chemtob et al. (2003)	-	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N
Craig et al. (2008)	-	Y	Y	N	NS	N	N	Y	N	N	N	N	Y	Y	Y
Curtis et al. (1994)	-	Y	M	N	NS	N	NS	Y	N	NS	N	Y	Y	Y	N
Fujiwara (2000)	-	Y	Y	Y	Y	N	N	N	N	N	N	N	P	N	N
Gerrish et al. (2010)	++	Y	Y	Y	Y	Y	Y	Y	Y	Y	NS	Y	Y	Y	Y
Gibson et al. (2005)	++	Y	Y	Y	Y	Y	Y	Y	Y	NS	Y	Y	Y	Y	Y
Houston et al. (2002)	+	Y	Y	Y	Y	Y	NS	Y	Y	N	NS	Y	M	Y	NS
Ito (1999)	+	Y	Y	Y	Y	NS	Y	NS	NS	Y	NS	Y	Y	Y	NS
Jackson & Yuan (1997)	+	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N	M	Y	Y
Johnson (2006)	-	Y	N	N	N	N	Y	Y	N	N	N	N	Y	Y	NS
Joseph et al. (2004)	+	Y	Y	Y	Y	NS	N	Y	Y	Y	Y	Y	Y	Y	Y
Kelly-Rossini et al. (1996)	+	Y	Y	Y	NS	N	NS	Y	Y	Y	Y	Y	Y	Y	Y
Kitazawa (1995)	+	Y	Y	Y	Y	N	Y	NS	N	N	N	Y	Y	Y	Y

	Quality score	Is a qualitative approach appropriate?	Is the research question clear?	How defensible/rigorous is the research design?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Is the context clearly described?	Were the methods reliable?	Is the data analysis sufficiently rigorous?	Are the data rich?	Is the analysis reliable?	Are the findings convincing?	Are the findings relevant to the aims of the study?	Are the conclusions clear and plausible?	How clear/coherent is the reporting of ethics?
Marais (2007)	++	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moro et al. (2005)	++	Y	Y	Y	Y	NS	Y	Y	Y	Y	Y	Y	Y	Y	NS
Nnoaham et al. (2006)	++	Y	Y	Y	Y	NS	NS	NS	Y	Y	NS	Y	Y	Y	Y
Sagbakken et al. (2010)	+	Y	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	Y
Swigart & Kolb (2004)	+	Y	Y	Y	Y	N	Y	Y	Y	NS	Y	Y	Y	Y	N
Van der Oest et al. (2005)	-	Y	Y	Y	Y	N	N	NS	N	Y	N	N	Y	Y	N
West et al. (2008)	+	Y	Y	Y	NS	N	Y	Y	Y	N	Y	Y	M	N	N
Whoolery (2008)	++	Y	Y	Y	Y	Y	Y	Y	Y	Y	NS	NS	Y	Y	Y
Yamada et al. (1999)	++	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	NS

Note. N = No; Y = Yes; M = Mixed/Partially; NS = Not sure (not reported or inadequately reported); P = partially relevant; M = mostly relevant.

5.0 Study findings

5.1 Primary research question: Barriers and facilitators to the uptake of TB diagnosis and treatment services by people from hard-to-reach groups

The following section aims to answer the research question: What factors help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach groups, for example, the acceptability of different testing modalities, and how can the barriers be overcome?

Within this section, we present evidence on hard-to-reach people's views on:

- susceptibility;
- severity;
- facilitators and barriers;
- cues to action; and
- benefits and implications.

5.1.1 Views on susceptibility

Thirteen studies reported the views of hard-to-reach people on susceptibility. For the purposes of this review, susceptibility includes notions of causes, risk factors, and transmission mechanisms. The 13 studies were:

[++] Brent Refugee Forum (2007)

[++] Gerrish et al. (2010)

[++] Gibson et al. (2005)

[++] Nnoaham et al. (2006)

[++] Yamada et al. (1999)

[+] Brewin et al. (2006)

[+] Houston et al. (2002)

[+] Kitazawa (1995)

[+] Sagbakken et al. (2010)

[+] West et al. (2008)

[-] Fujiwara (2000)

[-] Johnson (2006)

[-] Van der Oest et al. (2005)

Ten broad themes emerged in terms of how people thought TB was transmitted. These are summarised in Table 3, followed by further details about the relevant studies. Note that not all participants within the studies below held all the views noted in the table.

Table 3. Themes on perceived susceptibility to TB infection across the 13 studies by hard-to-reach categories

Perceived causes	Total mentions	Mixed groups*	Homeless	Immigrants - mixed	Immigrants - African incl. Ethiopian & Somali	Immigrants - Asian incl. Chinese, Vietnamese & Filipino
Smoking	9	1 (a)	2 (h,l)	2 (b,e)	2 (d,j)	2 (c,g)
Environment (typically "dirty" or weather)	8	1 (a)	1 (l)	1 (e)	2 (d,g)	3 (c,g,m)
Lack of self-care, health imbalance	7	1 (a)	1 (l)	2 (b,e)	2 (d,j)	1 (m)
Heredity	6	1 (g)	1 (g)	2 (e,k)	2 (d,i)	
Food-related (typically poor diet)	6		2 (h,l)	1 (b)	2 (g,j)	1 (g)
Poverty	5		1 (l)	1 (b)	2 (d,j)	1 (f)
Sharing (e.g., cigarettes, cutlery)	5	1 (g)	2 (h,l)	1 (b)	1 (i)	
Other illnesses	4		1 (l: AIDS)		2 (d: asthma, i: pneumonia)	1 (g: low immunity)
Sexual contact	2	1 (g)		1 (b)		
Stress	2				1 (d)	1 (f)

Note. The number in each cell represents the number of studies that mentioned that particular theme. The letters in brackets denote the studies that mentioned the theme, where: a = Brent Refugee Forum (2007) [++]; b = Brewin et al. (2003) [+]; c = Fujiwara (2000) [-]; d = Gerrish et al. (2010) [++]; e = Gibson et al. (2005) [++]; f = Houston et al. (2002) [+]; g = Johnson (2006) [-]; h = Kitazawa (1995) [+]; i = Nnoaham et al. (2006) [++]; j = Sagbakken et al. (2010) [+]; k = Van der Oest et al. (2005) [-]; l = West et al. (2008) [+]; and m = Yamada et al. (1999) [++]. Note that Johnson et al. appears twice in some rows because that study reported multiple groups. *Mixed groups differed by study, but could include any of the following in the same study: immigrants, prisoners, people with HIV, and homeless people.

A recurring conclusion throughout the studies was that many participants had a lack of understanding about the causes, risk factors, and modes of transmission of TB. In some cases, the information appeared to be incomplete or vague, but in others, the views held were incorrect. However, it is important to note that within every study that referred to susceptibility, at least some people mentioned correct causes, risk factors, and transmission mechanisms.

Smoking was mentioned in the greatest number of studies as a cause of or risk factor for TB (BRF, 2007 [++]; Brewin et al., 2003 [+]; Fujiwara, 2000 [-]; Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Johnson, 2006 [-]; Kitazawa, 1995 [+]; Sagbakken et al., 2010 [+]; West et al., 2008 [+]). Although this is certainly a risk factor for TB infection, the misconception by some that smoking can actually cause TB might lead to false beliefs about a lack of susceptibility in non smokers. Another commonly-held belief was that TB is hereditary (Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Johnson, 2006 [-]; Nnoaham et al., 2006 [++]; Sagbakken et al., 2010 [+]).

Three studies reported knowledge that TB is contagious (Gibson et al., 2005 [++]; Johnson, 2006 [-]; Yamada et al., 1999 [++]) and three studies reported knowledge among the participants that it is an airborne virus (Gerrish et al., 2010 [++]; Johnson, 2006 [-]; West et al., 2008 [+]). This does not necessarily mean that participants in other studies were not aware of the contagiousness of TB or that it is an airborne infection—it simply means that these factors were not explicitly mentioned in other studies. In the studies that *did* report participants' knowledge about contagiousness and airborne transmission, there was generally widespread knowledge within the groups, suggesting that many people are likely to be aware of these facts. Details of the studies and their findings relating to susceptibility are reported below.

Nnoaham et al. (2006) [++] conducted semi-structured individual interviews with African patients receiving treatment at a TB clinic in Hackney, London. It is not clear who interviewed the participants, although interviews were reported to have occurred in private rooms in a hospital. The 16 participants, born in Africa and self-identified as African, were willing to be interviewed in English. Perceived causes of TB discussed included heredity, poisoning, and pneumonia. Some participants thought TB could be acquired by sharing cutlery or through sexual contact.

We used the same utensils, shared the same toilet, bathroom, cups and glasses. And we weren't using disinfectants. (37-year-old man, Nigeria, Nnoaham et al., 2006)

I thought... he passed it on to me through sex, like HIV. (25-year-old woman, Angola, Nnoaham et al., 2006)

Gerrish et al. (2010) [++] recruited participants from the Somali population in Sheffield. The authors used focus groups (4 focus groups of 28 Somali men, 4 focus groups of 28 Somali women) and individual interviews (10 Somali community representatives; 24

Somali individuals without personal experiences of TB; 14 Somali people with personal experiences of TB; 18 healthcare practitioners working with the Somali community) to gather information from the Somali community. The authors concluded that Somali people generally did not understand how TB spreads, although some mentioned airborne transmission, heredity, or other illness (asthma) as possible transmission mechanisms.

TB is a disease that affects the body, there is inherited TB and it will stay with you forever, your grandfather had it, then your father, then you. This type of TB is called Qaaxo in Somalia and it used to kill people. It is treatable but it won't disappear. (Focus group participant, Gerrish et al., 2010)

Gerrish et al. (2010) [++] also reported that some participants mentioned poor socio-economic circumstances (e.g., homelessness) and lifestyle factors (lack of sleep, poor nutrition, smoking and chewing *khat*²⁵) as causes of TB. Other causes cited included “something very bad in the past” that was being punished by Allah, and stress. Community leaders and healthcare practitioners mentioned that people might be at higher risk in *khats* (houses where Somali men socialise to smoke or chew *khat*).

Themes of punishment and *khat* usage were also raised in the Brent Refugee Forum study (2007 [++]), which focused on immigrant groups at high risk of social exclusion and deprivation in the London Borough of Brent. They conducted focus groups (run by members of the refugee community) and interviews in an unreported setting. Their sample consisted of 104 immigrants recruited from the community²⁶, 15 healthcare professionals, and one TB patient recruited from a healthcare setting. Some communities associated TB with poverty and a lack of personal hygiene. There was a considerable belief among Muslim communities that TB was a punishment from God. As in Gerrish et al.'s (2010 [++]) study, people from Somalia were concerned that social gatherings to consume *khat* may increase families' and children's vulnerability to developing TB, through overcrowding, sharing cups, and smoking during the gathering.

There are more Somali men who have positive results for TB than women. When they go to the Qat [khat] dens they close all the doors and windows. (Somali community group, BRF, 2007)

Hygiene and poverty were also mentioned in Brewin et al. (2006) [+], who sought the views on TB screening of immigrants in East London. The participants were 53 adult immigrants who had been offered TB screening. Semi-structured interviews were conducted by the authors in private rooms at a screening site. Perhaps surprisingly, many in the sample indicated that there was a lack of information on TB available in the UK, compared with their country of origin; what they knew had been learnt outside the

²⁵ *Khat* (or *qat*) is a flowering plant with stimulant properties. It is typically used by men and is popular among Somalis. 'Khats' or 'qat dens' are places where men socialise and chew or smoke *khat*.

²⁶ These participants were recruited through community organisations and were not recruited on the basis of having experiences with TB. However, some of the participants in this group incidentally had had previous experiences with TB, but the report did not document how many of the 104 had experiences with TB.

UK. Accurate perceived risk factors and transmission mechanisms for TB included smoking, coughing, and mothers putting food from their mouths into their children's mouths, coughing. Possibly inaccurate perceived risk factors and transmission mechanisms mentioned were: touching people, sharing plates or glasses, sexual contact, poor hygiene, and not washing fruit and vegetables. Homeless people and prisoners were correctly seen as high-risk groups.

I think you can get tuberculosis from the skin. You have it on the skin and then you transmit it, transmission to other people. (30-year-old African male, Brewin et al., 2006)

It's a hygienic thing, if you are dirty and don't care about your health you will get not only tuberculosis but other things as well, that's all I can say. (21-year-old Indian male, Brewin et al., 2006).

Johnson (2006) [-] conducted focus groups and semi-structured interviews in the southeast London area. A range of high-risk groups were represented in the sample of 67 participants, including: Chinese, Nigerian, Refugee Women's Group (majority Somali, also Ethiopian and Eritrean), Vietnamese, substance misusers (from a homeless residential centre), HIV-positive people, homeless people and prisoners. Two focus groups were held in a Christian day centre, six were held in the individual organisation's own venues, and one was held in an NHS facility. Although the ease of transmission was a cause of concern for all groups, few participants were certain that TB transmission was airborne. There was a common belief that TB is contagious even after receiving treatment. Examples of perceived means of transmission include: spitting on the streets, sleeping in the same bed, sharing clothes, and kissing. Details of perceived causes and transmission mechanisms of TB for each group in this study are detailed in Section 5.2.

Outside the UK, there was a similar lack of accurate knowledge in hard-to-reach groups. Sagbakken et al. (2010) [+] aimed to explore diagnosis issues among immigrants from Somalia and Ethiopia in Norway who had been diagnosed with TB. The researchers conducted in-depth interviews in (unspecified) locations chosen by the patients. The sample consisted of 22 people (10 males and 12 females). Participants typically thought that the cause of TB was usually related to poor diet or poverty, both of which are risk factors.

It is low-class people, a low-class disease. Because low-class people they don't get food that [is good], and they are exposed to many things. (Male participant, Sagbakken et al., 2010)

Environmental factors, such as moving from cold to warm elements, were also mentioned, as was the committing of sins (Sagbakken et al., 2010 [+]). Several participants also believed that living in a developed country for several years would protect them from TB.

I was shocked [. . .], because I haven't lived there [Ethiopia] since I was young. I was out for so many years [. . .] so how did I get this tuberculosis? (Participant, Sagbakken et al., 2010)

Gibson et al. (2005) [++] examined high-risk cultural groups in Canada through semi-structured individual interviews collected by associates from the communities investigated. A total of 133 participants from immigrant communities (Hong Kong, China, Philippines, Vietnam, Punjab, and Eastern Europe) and three Aboriginal groups were included (note that data relating to Aboriginal groups were not extracted here). The setting was not reported. Most knew that TB is contagious ($n = 92$). When asked about what they thought caused TB, participants cited “not taking care of yourself” ($n = 21$), “dirty environment” ($n = 10$), and heredity ($n = 8$). Ten people mentioned “vices” such as smoking and alcohol.

In the Philippines, I worked in a printing press. There are chemicals. Maybe, I don't know, I probably inhaled chemical fumes. Also I had vices before—I smoke and drink alcohol. (Participant, Gibson et al., 2005)

Van der Oest et al. (2005) [-] interviewed community representatives from refugee and minority groups about the significance of TB for their community in New Zealand. Open-ended qualitative interviews were conducted at the venue of the community representative's choice. It is unclear how many participants took part, although they covered a variety of groups (Kampuchea, China, The Philippines, Maori, Somalia, and Pacific Islands). Asian representatives stated that there is a widely held belief that TB is not common in New Zealand, while Kampuchean community representatives stated that many in that community believe that TB only occurs in a family group (suggesting a hereditary cause).

A number of studies based in the USA explored views about susceptibility to TB. Yamada et al. (1999) [++] conducted focus groups with Filipino immigrants to the USA. It was not clear who conducted the focus groups, which were held in community health centres. Many of the 36 participants had contracted TB and all were recent immigrants (approximately 1–8 years in the USA). The ages ranged by focus group: some groups had a mean age over 70, while others were in their 30s. Participants were predominantly male. The Filipino participants suggested various possible causes of TB, including natural or environmental forces, imbalances of the body, and contagion.

Houston et al.'s (2002) [+] study of Vietnamese people in California, recruited people who either had been diagnosed with TB, were in a TB programme, or had contact with people with TB but were not in any programme. They conducted focus groups and individual interviews (face-to-face and telephone follow-up) in Vietnamese. The 67 participants (53 in focus groups, 14 individual interviews) indicated the perceived role of stress in causing TB.

...there are two kinds of TB: psychological TB and physical TB. Psychological TB is due to too much work, too much worry and stress, which causes TB. Psychological TB does not have microbes ... For psychological TB, we need a cure for the mind. For physical TB, we need medicines [antibiotics] and good food (Female participant, Houston et al., 2002).

Fujiwara (2000) [-] conducted focus groups with facilitators from within target communities (recent immigrants from China, Dominican Republic, Puerto Rico, Ecuador and Haiti) in New York. They conducted four focus groups with 47 participants (20 males and 27 females). Some participants noted smoking, being exposed to air pollution, working in garment factories, and poor hygiene as possible causes of TB. The researchers concluded that the knowledge and information about TB among study participants was vague.

West et al.'s (2008) [+] US-based (North Carolina) study involved focus groups with Spanish-speaking immigrants, homeless shelter residents, and persons attending a drug/alcohol rehabilitation centre (note that we only extracted data relevant to the homeless and substance misuse groups). Eleven focus groups of 52 participants were conducted. Airborne transmission (coughing) was commonly reported in all focus groups. Sharing glasses, utensils, and dirty needles were also cited, as was holding hands, and blood transmission. Smoking, "malnutrition", sleeping in cold breezy places and wet floors, and "uncleanliness" were reported causes of TB among all participants. Participants of the alcoholic recovery group said that "street people" and the "homeless" are more likely to have TB, while other participants stated that persons with AIDS and a depressed immune system might be at higher risk. However, despite good knowledge held by some participants, the authors noted a general lack of knowledge about causation and transmission across participants and focus groups.

Kitazawa (1995) [+] examined the views of homeless people living in group shelters in San Francisco. Semi-structured, open-ended interviews were conducted (although it is unclear from the report who conducted the interview or where). The sample consisted of 20 participants from three homeless shelters. Some participants thought that TB is caused by smoking, worsening colds, or "eating unripe fruit". Several participants mentioned sharing of cigarettes ($n = 5$), food or utensils ($n = 4$), or saliva, blood or tears ($n = 5$), as transmission mechanisms. Although many participants thought that shelter residents might be at higher risk, fewer than half of the participants reported worrying about contracting TB.

In summary, it is clear that many hard-to-reach people have incomplete or inaccurate information about what causes TB and how it is spread. In other words, there is a widespread lack of understanding about the potential susceptibility to TB of hard-to-reach groups.

Evidence statement 1: Views on susceptibility

Members of hard-to-reach groups frequently report incomplete or inaccurate information about the cause and transmission of TB. Factors correctly perceived to affect susceptibility to TB include smoking, poor diet and malnutrition, poverty, impaired immunity and concurrent other illnesses such as HIV/AIDS. Misconceptions about factors affecting susceptibility to TB include a dirty or wet environment, sharing of domestic objects, and punishment from God.

ES1.1 **Strong evidence from nine studies** suggests that hard-to-reach participants commonly view **smoking** as a risk factor for or cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants (e.g., immigrants, prisoners) in the UK (BRF, 2007 [++]);
- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants (Chinese, Vietnamese) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]).

ES1.2 **Moderate evidence from five studies** reported that participants frequently thought **poverty** was a condition associated with contracting TB. These views were reported by studies of:

- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and Vietnamese immigrants in the USA (Houston et al., 2002 [+]).

ES1.3 **Weak evidence from five studies** suggests that hard-to-reach participants may consider **food or diet-related** factors (such as poor diet or unripe/unwashed fruit) to increase the risk of TB. These views were reported by studies of:

- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]);
- African immigrants in the UK (Johnson, 2006 [-]) and Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants in the UK (Johnson, 2006 [-]).

ES1.4 **Weak evidence from four studies** suggests that hard-to-reach participants may believe that susceptibility to TB is higher when a person has another illness, such as:

- AIDS (homeless people in the USA; West et al., 2008 [+]);
- low immunity (Asian immigrants in the UK; Johnson, 2006 [-]);
- asthma (Somali immigrants in the UK; Gerrish et al., 2010 [++]); and

- pneumonia (African immigrants in the UK; Nnoaham et al., 2006 [++]). In the case of Somali immigrants in the UK, some participants thought that complications in asthma led to TB (Gerrish et al., 2010).

Other factors believed to affect susceptibility have less basis in fact, and yet cannot be claimed to be entirely incorrect, such as lack of self-care, sexual contact, and a hereditary transmission (since mother to infant transmission may occur).

ES1.5 **Moderate evidence from seven studies** suggests that hard-to-reach participants commonly view **lack of self-care** (“not looking after yourself”) or a health imbalance as risk factors for TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK (BRF, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Filipino immigrants in the USA (Yamada et al., 1999 [++]).

ES1.6 **Moderate evidence from five studies** suggests that hard-to-reach participants commonly attribute **hereditary** causes to TB infection. These views were reported by studies with a range of hard-to-reach and homeless participants in the UK (Johnson, 2006 [-]); mixed immigrant groups in Canada (Gibson et al., 2005 [++]) and New Zealand (Van der Oest et al., 2005 [-]); and African immigrants in the UK (Gerrish et al., 2010 [++]; Nnoaham et al., 2006 [++]).

ES1.7 **Weak evidence from two studies** suggests that hard-to-reach participants may believe that TB could be transmitted through sexual contact. These views were reported by studies with a range of hard-to-reach participants in the UK (Johnson, 2006 [-]) and mixed immigrant groups in the UK (Brewin et al., 2003 [+]).

ES1.8 **Weak evidence from two studies** suggests that hard-to-reach participants may believe that **stress** is a cause of TB. These views were reported by studies of Somali immigrants in the UK (Gerrish et al., 2010 [++]) and Vietnamese immigrants in the USA (Houston et al., 2002 [+]).

ES1.9 **Strong evidence from seven studies** suggests that hard-to-reach participants commonly view **environmental conditions** (such as a “dirty” or “wet” environment, or weather-related conditions) as a cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK (BRF, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]; Johnson, 2006 [-]); and

- Asian immigrants (Chinese, Vietnamese, and Filipino) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]; Yamada et al., 1999 [++]).

ES1.10 **Moderate evidence from five studies** suggests that hard-to-reach participants sometimes consider the **sharing of objects** such as cigarettes, cutlery, and glasses as a likely transmission mechanism. These views were reported by studies with a range of hard-to-reach participants in the UK (Johnson, 2006 [-]); homeless people in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]); mixed immigrant groups in the UK (Brewin et al., 2003 [+]); and African immigrants in the UK (Nnoaham et al., 2006 [++]).

Applicability

Five of the 13 studies reviewed here were conducted in the UK, and the rest reported populations of relevance to the UK (e.g., Somali and Vietnamese immigrants). As such, we have no reason to believe that the views held by the samples here would not be transferable to populations in the UK.

5.1.2 Views on severity

Eleven studies reported the views of hard-to-reach people on the severity of TB. For the purposes of this review, severity includes preventability, symptoms, and health consequences of TB (including its treatability). The eleven studies were:

[++] Brent Refugee Forum (2007)

[++] Gerrish et al. (2010)

[++] Marais (2007)

[++] Yamada et al. (1999)

[+] Houston et al. (2002)

[+] Kitazawa (1995)

[+] Sagbakken et al. (2010)

[+] West et al. (2008)

[-] Fujiwara (2000)

[-] Johnson (2006)

[-] Van der Oest et al. (2005)

Members of hard-to-reach groups had mixed but fairly accurate views of symptoms, with most identifying coughing as a key symptom. The effects of treatment were more shrouded in uncertainty, and occasionally led to discussions about traditional versus modern medicines. The findings on participants' views of the severity of TB are detailed below.

Gerrish et al. (2010) [++] reported that many Somalis in Sheffield knew that TB could be treated but there was a common understanding that it can reoccur anytime. Somalis in Sheffield perceived TB, its severity and treatment in the context of their home country. This meant that they perceived TB to be a disease that leads to death and is often treated by keeping people in quarantine for long periods. BRF (2007) [++], from a sample of 104 immigrants in London, reported that Somali people often sought traditional medicine as a first point of contact, although all participants said they would be willing to seek help if they suspected that they had TB. In contrast, Somali community representatives in New Zealand stated that people in their community preferred treatment from medical services rather than traditional healers, as they have experienced TB-related morbidity and mortality in their native countries (Van der Oest et al., 2005 [-]).

The findings of the Gerrish et al. (2010) study were echoed by Marais (2007) [++], who examined the views of African immigrants in the UK. Marais conducted a multi-method, community-based participatory research project using questionnaires, in-depth interviews, community consultations, and observations. The sample consisted of 329 participants: African immigrants ($n = 312$) and key stakeholders from UK healthcare ($n = 17$). Two methods of treating TB were discussed by the participants: drinking camel milk and taking honey early in the morning. The participants felt more vulnerable in the UK because of lack of access to camel milk. Most participants said that many community members still associated TB with inevitable death, largely because of a general lack of knowledge about TB, the benefits from screening and curable treatment, as well as past experiences in Africa where treatment was often unavailable or unaffordable.,

We know TB is a bad thing in our country, no treatment and die. It's treated here in this country it's easy to treat but our people don't know. When we are in our country, oh TB it's a big thing, that person's going to be gone... In our community some people have it, they hide it, they are infecting the whole house... In our society it's a big thing when you have TB, they are scared, hiding it. (Participant, Marais, 2007)

You get isolated, people they look at you like you are going to die you cannot getting treated. It is a lack of knowledge obviously that it can get cured. (Participant, Marais, 2007)

Death was also a prominent response in Johnson's (2006) [-] study of vulnerable groups in London. Death was mentioned during every focus group (representing Chinese, Nigerian, Vietnamese, Refugee Women's Group, substance misusers, HIV positive people, homeless people, and prisoner populations) as an inevitable outcome for certain groups of people with TB, such as those who present late or those with HIV. All groups mentioned sweating, fever, coughing, weight loss and tiredness as symptoms of TB. Other symptoms mentioned included watery stools and vomiting. Few

participants had knowledge of latent TB. As in Gerrish et al. (2010) [++], all of the ethnic community groups mentioned a distinction between TB in their country of birth and TB in England.

A similar understanding of symptoms was reported by immigrants to Norway from Somalia and Ethiopia who had been diagnosed with TB (Sagbakken et al., 2010 [+]). Focusing on reasons for diagnostic delay, the authors conducted in-depth interviews in (unspecified) locations chosen by the patients. Twenty-two people (10 males and 12 females) participated. Cough, weight loss, fever, and weakness were correctly considered as normal TB symptoms. A generally held view among participants, however, was that the absence of one of those symptoms meant that TB was unlikely.

To be honest, I was drinking and smoking and [. . .] I feel that if I had real tuberculosis I wouldn't have been able to go out and party the next day. (Young girl with pulmonary TB, Sagbakken et al., 2010)

West et al.'s (2008) [+] study of homeless shelter residents and persons attending a drug/alcohol rehabilitation centre in the USA found that participants generally understood the severity of the disease (associated with morbidity and mortality). Participants knew there was a skin test for tuberculosis and many had previously undergone testing. Signs and symptoms mentioned included a persistent cough, coughing or spitting up blood, fever, and night sweats.

In contrast, Kitazawa's (1995) [+] study of 20 homeless people living in group shelters in San Francisco found mixed understanding about the severity of TB. Suggestions made by the study participants for the prevention of TB include: washing dishes thoroughly, not sharing cigarettes, and not wearing other people's clothes. Two participants indirectly referenced prophylactic isoniazid (INH) therapy as a preventive measure. Participants were generally unaware about typical symptoms of TB, though 60% mentioned coughing. Most participants ($n = 17$) thought that there "probably was" or "should be" a treatment for TB; though many were doubtful about its effects: "I know it's treated, but curable I don't know."

Recent immigrants from China in New York, USA, were generally confident that TB was a curable disease (Fujiwara, 2000 [-]).

Participant views on the use or value of Western and traditional medicines were offered in two US-based studies (Houston et al., 2002 [+]; Yamada et al. 1999 [++]) and one New Zealand study (Van der Oest et al., 2005 [-]). Vietnamese participants ($n = 67$) in the USA saw mental and physical health in a holistic fashion (Houston et al., 2002 [+]). They discussed the use of traditional Vietnamese health practices such as "coin rubbing" alongside the use of Western medicine. Similarly, Filipino immigrants in Hawaii and California considered treatment to include multiple elements including traditional medicine, modern medical medicine, changes in environment and correcting imbalances in the body (for example, through eating a balanced diet and getting rest

(Yamada et al., 1999 [++]). Other measures mentioned by participants included drinking the blood of a pure-black dog, drinking Carnation milk, and drinking large quantities of water. Traditional medicine was seen as an adjunct to modern biomedicine.

Van der Oest et al. (2005) [-] reported that Chinese, Maori, and Pacific Islanders' in New Zealand preferred to deal with traditional healers rather than the medical service.

Evidence statement 2: Views on severity

Members of hard-to-reach groups had mixed but fairly accurate views of symptoms; no reported understanding of latent TB; an understanding of the potential fatality of TB, but mixed understanding of the curability of TB. Some groups preferred approaches to treatment that included both traditional and modern medicines.

ES2.1 Moderate evidence from four studies suggests that hard-to-reach participants typically understand the main **symptoms** of TB (e.g., coughing), and many participants were familiar with other symptoms such as sweating, fever, weight loss, tiredness, and weakness (various vulnerable groups in the UK: Johnson, 2006 [-]; Somali and Ethiopian immigrants in Norway: Sagbakken et al., 2010 [+]). Homeless participants in the USA had mixed knowledge of symptoms: participants in West et al., 2008 [+] had good knowledge while participants in Kitazawa's (1995) [+] study were generally unaware about typical symptoms of TB.

ES2.2 Weak evidence from two studies indicate that some hard-to-reach groups are unfamiliar with **non-symptomatic or latent TB**. Some Somali and Ethiopian participants in Norway thought that a lack of symptoms meant that they were healthy (Sagbakken et al., 2010 [+]) and one study explicitly reported no knowledge of latent TB in their sample of various vulnerable groups in London (Johnson, 2006 [-]).

ES2.3 Strong evidence from six studies suggests that participants are aware of the **fatality** of TB but did not always know whether it was **curable**. Fatality was discussed by:

- Somali participants in the UK (Gerrish et al., [++]);
- African immigrants in the UK (Marais, 2007 [++]);
- various vulnerable groups in the UK (Johnson, 2006 [-]); and
- homeless people in the USA (West et al., 2008 [+]).

Chinese immigrants in the USA viewed TB as a curable disease (Fujiwara, 2000 [-]), but a lack of understanding about curability was evidenced by African immigrants in the UK (Marais, 2007 [++]) and homeless people in the USA (Kitazawa, 1995 [+]).

ES2.4 Inconsistent evidence from five studies discussed participant views on **traditional and modern medicine**. Somalis in the UK (BRF, 2007 [++]), Filipinos in the USA (Yamada et al., 1999 [++]), and Vietnamese immigrants in the USA (Houston et al., 2002 [+]) all mentioned acceptance of the use of both traditional and modern

approaches to treatment. Somalis in the UK (BRF, 2007 [++]); African immigrants in the UK (Marais, 2007 [++]); and Chinese, Maori, and Pacific Islanders in New Zealand (Van der Oest et al., 2005 [-]) generally preferred using traditional medicines first. In contrast, Somalis in New Zealand are happy to seek modern treatments first because of their experiences with TB-related deaths in their home country (Van der Oest et al., 2005 [-]). In other words, different immigrant groups in various Western countries had varying opinions about the role that traditional and modern medicines should play in treating TB.

Applicability

Four of the 11 studies in this section are from the UK. It is possible that knowledge about the severity of TB might be greater in non UK countries due to information campaigns or treatment service provision in those countries, although there is no reason from the evidence to assume this.

5.1.3 Views on facilitators and barriers to screening and treatment

This section reviews hard-to-reach people's views on the facilitators and barriers to TB screening, prevention, or treatment. This includes factors that might make it more likely that individuals will engage in screening or treatment of TB. Twelve studies discussed facilitators and barriers to service uptake or treatment compliance:

[++] Brent Refugee Forum (2007)

[++] Gerrish et al. (2010)

[++] Gibson et al. (2005)

[++] Whoolery (2008)

[+] Brewin et al. (2006)

[+] Curtis et al. (1994)

[+] Ito (1999)

[+] Kelly-Rossini et al. (1996)

[+] Kitazawa (1995)

[-] Chemtob et al. (2003)

[-] Fujiwara (2000)

[-] Van der Oest et al. (2005)

Several potential facilitators and many barriers to testing and treatment were identified. Facilitators included:

- family support;
- religious beliefs and support; and

- culturally-sensitive and appropriate care.

Broad themes around barriers to testing and treatment included:

- lack of coping mechanisms;
- low standard of care;
- inadequate service provision and access;
- fear, anxiety, and denial;
- stigmatisation;
- language and culture differences;
- the difficulties of treatment; and
- lack of symptoms.

Coping mechanisms

A number of coping mechanisms were mentioned in the literature—most notably the role of family and religion. Families were facilitators for some and barriers to others; religion was seen as a facilitator; and isolation (physical and/or social) was typically seen as a barrier.

For Vietnamese refugees in the USA, families were identified as key in supporting compliance (Ito, 1999 [+]).

When I first took it I felt hot. I was discouraged and wanted to stop. But my husband encourages me to eat a lot of vegetables and fruits. I have lasted because my husband encourages me. (34-year-old, female, compliant, Ito, 1999)

This importance of family was also true for 18 HIV-infected patients with TB in respiratory isolation in New York (Kelly-Rossini et al., 1996 [+]). The role of the family was mentioned as a positive enforcement for participants to adhere to treatment and stay in care. However, family can also act as a barrier to compliance. Families can be a cause of anxiety for patients in respiratory isolation, especially for those with dependents at home (Kelly-Rossini et al., 1996 [+]), while eight of ten non compliant clients in the Vietnamese study (Ito, 1999 [+]) reported discouragement from peers or families.

I have friends who take [INH] but they stopped before they finished the treatment and when I first started the medicine, they scared me saying don't take it because it's not for you. (21-year-old, female, non compliant, Ito, 1999).

As such, family can be both a facilitator and a barrier to compliance.

For Somali participants in Sheffield, Islam was important to how TB patients and their families responded to their illness (Gerrish et al., 2010 [++]). For example, participants mentioned that the illness was caused by fate, or that Islam provided hope. In addition

to the Somali patients in Gerrish et al. (2010) HIV-infected patients in Kelly-Rossini et al. (1996) [+] also mentioned religion as a coping mechanism:

I read the Bible. My husband comes and visits and that helps. (Participant, Kelly-Rossini et al., 1996)

Kelly-Rossini et al. (1996) [+] identified a range of other coping mechanisms for 18 HIV-infected patients in respiratory isolation in the USA. These included internal strength, and being in the discharge planning process. Those participants that had previously been in jail mentioned that they had already learned of strategies to cope with boredom and loneliness.

Having been in jail got me used to being idle and being in a pretty much enforced captivity type of thing... (Participant, Kelly-Rossini et al., 1996)

Participants reported that their isolation experienced would be improved by more human connection, diversions, and improved environmental hygiene.

...someone to talk to who will listen. (Participant, Kelly-Rossini et al., 1996)

If you had another room on the other side of this one and it had a window, you could say, 'Hey, how're you doing, George?' Wave at somebody or something like that. That's some kind of interaction. . . I mean even if they turn the TV on (I have the telephone, letters, books and everything like that), I'm still isolated as far as being social. I can't interact with a TV. (Participant, Kelly-Rossini et al., 1996)

Standard of care

Standard of care refers to the perceived quality of care provided by healthcare staff, rather than the services themselves. Common themes included feelings of neglect and condemnation from the staff, and misdiagnosis or delayed diagnosis leading to a lack of confidence in healthcare professionals. Barriers to diagnosis and/or treatment mentioned were the perceived negative attitudes of staff and delayed or misdiagnoses. Marais' (2007) [++] study of African immigrants in London found that the following were repeatedly identified by participants when asked what quality healthcare entails and how they would decide whether to access a service:

- being treated and respected as an individual;
- not being judged on the basis of colour or health needs;
- being listened to and engaged in care planning;
- continuity of care;
- having specialist providers who could create a supportive environment;
- mutual trust; and
- a reduced chance of being attended to by someone from a similar cultural/community background resident in the same area.

In a study of the experiences of respiratory isolation for 18 HIV-infected patients with TB in New York, Kelly-Rossini et al. (1996) [+] noted that staff were frequently reported to have left participants unattended or did not respond to calls. Participants mentioned this in the context of the time when they felt particularly sick or lonely.

I was feeling almost forgotten. (Participant in respiratory isolation, Kelly-Rossini et al., 1996)

Participants also reported a lack of communication between them and medical staff concerning the status of their TB infection or the days required to stay in care.

Why am I in isolation if my sputum is negative? (Participant in respiratory isolation, Kelly-Rossini et al., 1996)

I've been here for 12 days and I'm only supposed to be here for seven. (Participant in respiratory isolation, Kelly-Rossini et al., 1996)

The perceived quality of care can be complicated where TB patients are also drug users in treatment, in which they might be concurrently experiencing substance withdrawal. Curtis et al. (1994) [+] examined the responses of a sample of 68 injecting drug users or crack cocaine addicts (46 women and 22 men). Twenty-eight were Latino, 22 were black and 18 were white injecting drug users. They conducted 210 ethnographic interviews and observations and three case studies in Brooklyn. The three case studies all reported disrespect from hospital staff members. Case Study 1 encountered resistance after swearing frequently at staff during withdrawal:

I had a social worker there. She was a real bitch. She didn't do anything for me ... everything I asked this lady, she don't do that. She didn't do anything. (Injecting drug user in treatment, Curtis et al., 1994)

According to the report, this particular case study was not an easy patient for hospital staff. Only two injecting drug users among 16 who were asked about their experiences in hospital settings said that they had positive experiences.

In contrast, a study of 16 homeless persons in London found that the standard of care provided by healthcare professionals acted as a facilitator to diagnosis and treatment (Whoolery, 2008 [++]). Strong support from healthcare professionals, appropriate care delivery and a good rapport with healthcare staff enabled some participants to overcome or prevent negative feelings of stigmatisation or despair after diagnosis. . These participants reported that face-to-face interaction with healthcare professionals and a positive hospital experience helped facilitate a better route to treatment and improved their understanding of TB. Some participants also noted that an increased knowledge of their health state helped them to feel empowered and to build positive relationships with their healthcare professional.

Similarly, Gerrish et al. (2010) [++] reported that most Somali TB patients in Sheffield felt very satisfied with the standard of care received from TB services in hospital and primary care settings.

Concerns about **confidence in the abilities of GPs** and **experiences of misdiagnosis** were reported in five studies (Gerrish et al., 2010 [++]; Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]; Sagbakken et al., 2010 [+]).

Somali immigrant patients in Sheffield frequently reported that they were not treated seriously by their GP and had felt neglected by the system. As a result, some took alternative measures such as attending accident and emergency departments (Gerrish et al., 2010 [++]).

I visited my GP and I told the GP that I am feeling very sick. The GP prescribed a pain killer and told me nothing is wrong with me. (Somali patient, Gerrish et al., 2010)

This sub-theme was also emphasised in a sample of 312 African immigrants in London (Marais, 2007 [++]). Most of the participants with TB had experienced delays presenting with symptoms and starting treatment. These delays were due to a combination of individual factors and service provider factors (typically misdiagnosis).

I was coughing lots at night, could not sleep. I went to GP and for 6 months prescribing antibiotics but did not work. After more than 6 months GP sent me to hospital and in examination they said TB. (African immigrant, Marais, 2007)

A further study of 16 African immigrants in London found that several reported that healthcare providers did not diagnose TB early on (Nnoaham et al., (2006 [++]).

I was coughing and I went to the GP and he said it was a virus that will go after some weeks. I went back later and he said the same thing. (45-year-old man, Nigeria, Nnoaham et al. 2006)

I started coughing in November and it wasn't until mid January that I was referred to hospital for chest X-ray. (19-year-old man, Nigeria, Nnoaham et al., 2006)

I had chest pain . . . I was brought to the emergency . . . the doctor examined me and gave me a painkiller. As I was about to leave, I coughed and, it was all blood. (40 year-old woman, Nigeria, Nnoaham et al. 2006).

Such concerns were further emphasised in a sample of 22 Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]). Some participants with pulmonary TB who experienced one or more initial TB symptoms had a long diagnostic delay with multiple encounters with a healthcare professional. It was found that few participants

were referred for a chest X-ray or had a sputum test at their first visit to the clinic. Many participants were treated for other conditions including pneumonia, malaria or the common cold. Study participants noted that their worsening condition and misdiagnosis made them lose trust in their healthcare professional and, as a result, made visits to different doctors. For example, one participant had been diagnosed with malaria and had taken the required medications, with no effect. This led to a loss of trust in the system. Other feelings expressed by participants were humiliation because they were not taken seriously, and stress or depression from health professionals accusing them of not wanting to go to work. Some participants took a second or third chest x-ray, which eventually had led to a TB diagnosis. Other patients with pulmonary TB had a speedy diagnosis because of their accurate reporting of their medical history. Johnson (2006) [-] recruited 67 participants from various vulnerable groups in London (Chinese, Nigerian, refugee women's group, Vietnamese, substance misusers, HIV positive, homeless, and prisoners). The groups had diverse opinions on the NHS and the services they drew on, although several groups expressed concerns about a lack of confidence in GPs (typically regarding misdiagnosing TB as a cold). Participants said that if they felt unwell they would generally self-medicate, rather than go to the doctor as:

there is no guarantee that the doctor will diagnose TB and may well just prescribe cough mixture. (HIV-positive patient, Johnson, 2006)

Service provision and access

Three main subthemes—all of which were presented as barriers—emerged from the literature regarding service provision and access. These were: a lack of information or awareness about service availability or access; the cost of TB services; and lack of confidence in or misdiagnoses by healthcare professionals. Other issues raised included an inability to register with a GP, the desire for gender-compatible services, and logistical concerns such as the healthcare setting and transportation to the services.

A **lack of information or awareness** about TB services was discussed in three studies (BRF, 2007 [++]; Fujiwara, 2000 [-]); Marais, 2007 [++]). Many vulnerable groups (e.g., immigrants, prisoners, and substance misusers) in London represented in BRF's (2007) [++] study identified a lack of information or difficulty in accessing information about available services as a barrier. Some felt that TB service providers were not working closely enough with communities to break down barriers and follow-up cases. Participants noted that confidence of service providers needed to be raised in dealing with sensitive cultural and immigration issues.

Similar issues were raised in Marais's (2007) [++] study of 312 African immigrants in London. Of the participants who had never been treated for TB but had either lived with or cared for someone with TB, many stated that they had not been screened for TB as it had never been offered and they were unaware of the need for screening. Although

most participants would have liked to have been screened for TB, there was extensive confusion and lack of information about points and methods of access. There was a lack of awareness of the existence and purpose of healthcare services. In particular, most did not know they could attend a TB clinic without a GP referral.

Marais (2007) [++] reported a widespread confusion at both community and provider levels regarding the eligibility to healthcare, including TB screening and treatment, for asylum seekers and particularly failed asylum seekers and undocumented migrants. Many stated they were unsure whether they were entitled to receive healthcare in the UK. They reported receiving inconsistent and often conflicting advice from health providers. Some asylum seekers reported being denied screening. Several key stakeholders explained that, although health providers were aware such persons were eligible to receive TB treatment, the asylum seekers and migrants themselves, and community members representing and serving them, were unaware of this entitlement.

Lack of awareness was also evident in Fujiwara's (2000) [-] study. Chinese immigrants in New York were largely not aware of TB services that they could access, such as Department of Health chest clinics.

The potential **costs of TB healthcare** were raised in four studies (Curtis et al., 1994 [+]; Fujiwara, 2000 [-]; Van der Oest et al., 2005 [-]; West et al., 2008 [+]). Chinese immigrants in New York stated that their primary concern was the cost of healthcare and insurance (Fujiwara, 2000 [-]). Homeless people and drug/alcohol abusers in North Carolina commonly raised costly healthcare as a barrier to seeking care (West et al., 2008 [+]). In New Zealand, representatives from immigrant and minority ethnic groups reported that unemployment in their communities was a barrier to accessing services, since patients would be unable to pay the consultation fee charged to visit primary healthcare services (Van der Oest et al., 2005 [-]).

The costs of healthcare to service providers might also be a barrier to service access. According to one study (Curtis et al., 1994 [+]), preventive therapy was not provided to any of the injecting drug users that they interviewed. Although not directly derived from participants' views, the authors suggested that Medicaid does not reimburse physicians for TB preventive therapy visits, although it does reimburse for the treatment of active disease, which could explain why provision of preventive (Isoniazid, or INH) was low.

Access to services was often seen as being hindered by the requirements of **GP registration**. Marais's (2007) [++] study of African immigrants in London suggested that some participants, particularly asylum seekers, experienced great difficulty in finding a GP willing to register them. Reasons stated include:

- unhelpful and rude reception staff;
- being regarded as a temporary local resident;
- not having a permanent address;
- language barriers;
- long waiting lists; and

- lack of information and understanding of the actual process and meaning of registration.

These concerns were also reported in a study of mixed vulnerable groups in London:

I need accommodation and an address first before I register with a GP.
(Homeless person, BRF, 2007)

Some participants reported their HIV status as the main reason for not being accepted by, or registering with, a GP (Marais, 2007 [++]).

Three studies noted perceived **logistical issues** regarding accessing treatment, including **waiting times**, **transport**, and the **setting** in which the service was offered (Brewin et al., 2006 [+]; Ito, 1999 [+]; Kitazawa, 1995 [+]).

Brewin et al. (2006) [+] asked people from various immigrant groups in London about their experiences of TB services. While informants were generally positive about the setting in which they had been seen, not all settings were acceptable to all participants. Primary care was seen as 'easy', 'local' and appropriate. Some saw the GP surgery as 'safer and cleaner' (apparently in reference to hospital settings) and one commented that they felt safer at the GP:

because you are familiar with him and the way [the surgery] works (immigrant in London, Brewin et al., 2006)

Hospitals were also considered a good place to be screened because they are "better equipped, with everything" with "very specialised" staff. One participant pointed out that "they have to transfer you" so going direct to the specialist was better. Social services were seen as "easy and quick" because other benefits (such as food vouchers) were also available in the same place and there were no queues. One participant saw there was a benefit to screening in a social services centre because it was a condition that people knew little about.

Kitazawa (1995 [+]) found that participants from homeless shelters in San Francisco reported the waiting time for receiving medical care as a major barrier:

It's that once you get to the [shelter], you have to stay there, because if you don't stay there and stand in line, you're not going to get in. And food's the same way. You have to go stand in line for a couple hours, just so you can get something to eat. So you have to budget your time. (Homeless person, Kitazawa, 1995)

Other cited barriers reported in Kitazawa (1995 [+]) include distant location of services, high cost of public transportation, and physical disabilities. Four of the 20 participants stated that healthcare was easier for them to access at the shelter than if they were in standard housing. Vietnamese participants in California also reported problems with

transport to the clinic; were unsatisfied with the ambience of the clinic; or were worried about safety because of the high population of “junkies” and “vagrants” near the clinic (Ito, 1999 [+]).

Fear, anxiety, and denial

All studies that mentioned fear, anxiety, and denial presented them as barriers to screening or completion of treatment. The most commonly reported theme was a fear of death. Five studies suggested that participants would avoid being screened because they were afraid of the result:

- various vulnerable groups in London (BRF, 2007 [++]);
- Somali immigrants in Sheffield (Gerrish et al., 2010 [++]);
- Filipino immigrants in Hawaii and California (Yamada et al., 1999 [++]);
- homeless people in San Francisco (Kitazawa, 1995 [+]); and
- homeless people in North-Eastern USA (Swigart & Kolb, 2004 [+]).

Fear, isolation, and concerns about **death** were common among various vulnerable groups in London (BRF, 2007 [++]). There was a considerable response from Muslim communities that TB was a punishment from God. Many groups associated TB with HIV/AIDS and said they thought there were similar symptoms.

The Somali community see TB as a very bad illness. TB is to the Somali community the way HIV is to the rest of the world. It means death to many people. (Somali community group, BRF, 2007).

Somalis in Sheffield perceived TB, its severity and treatment in the context of their home country (Gerrish et al., 2010 [++]). This meant that they perceived TB to be a disease that leads to death and is often treated by keeping people in quarantine for long periods. They remembered TB treatment in Somalia to be inaccessible to many. As a result, TB was a source of great anxiety to many people interviewed. Common among all patients was the stress felt leading up to the confirmed diagnosis.

In a study of 16 homeless persons in London, being diagnosed with TB or being hospitalised triggered feelings of fear: fear of the side effects of treatment, fear of stigmatisation, fear of hospitalisation and fear of the unknown.

Some doctor told me I have TB ... nightmare ... months I am sad, I am cry not in the eye my heart cry [sic]. (Participant 9, Whoolery, 2008)

Homeless persons in this study reported that their sense of fear was heightened upon discovering the length of the treatment regimen or if they had drug-resistant TB. One participant felt that the diagnosis was a personal punishment.

I'm scared... It makes me feel miserable. Makes me feel as if I'm being punished for something that I've done, I don't know what I've done ... To start

with I didn't really know much about it (TB)... when they started putting masks and that on your face, I never thought I would survive that. (Participant 10, Whoolery, 2008).

Interestingly, the author notes that for many of the homeless participants, fear after diagnosis was a catalyst to behaviour changes; for example, refraining from drugs or alcohol use. This was described by the author as a “cutting-point”.

When I went into hospital I cut myself down [heroin]... going into hospital I didn't have a choice. I couldn't go out there and manage [heroin habit] because I couldn't stand up never mind walk. So I had to go on methadone, so I went on to that and that's when my priorities changed, being on methadone won't kill me, whereas the other things would so I had to get the TB sorted out, get my kidneys sorted out, and then sometime in the future I can worry about coming off the methadone. (Homeless participant 6, Whoolery, 2008)

A fear of death was also raised as a barrier to testing among homeless people in San Francisco (Kitazawa, 1995 [+]). Four of the 20 participants discussed the psychological barriers to testing:

It can be very degrading when you don't want [it] to be degrading. They'll say things that kind of won't sound right to the other person, and [the patient] will think, “Oh, God, I'm going to die. I just know I'm not going to get out of this”. (Participant, Kitazawa, 1995)

Am I going to be sorry when I get through? Am I going to the sanatorium²⁷? Are they shipping me out? When I got tested and the injection came back positive, I got real worried. I thought it was one of those diseases if you got it, you might as well start writing your will out. I decided not to go [back to the clinic]. (Participant, Kitazawa, 1995)

In a sample of 55 homeless participants from the USA (Swigart & Kolb, 2004 [+]), the participants who did not accept the screening test reported various reasons. These included: “I'm afraid of the result” (three people); “I just can't be bothered” (one person); “I just want to sleep” (one person); “I have no pain, so I don't have a problem” (one person); and a combination of the last two comments (one person):

Oh. They worry about what they would find. That they might have it, yeah. Because they smoke too much. We got a lot of smokers here. They are afraid they might find out what they have. And they don't want to 'cause they do love to smoke. (53-year-old sheltered female, Swigart & Kolb, 2004)

²⁷ A medical facility for long-term illnesses such as tuberculosis.

Focus groups of Filipino immigrants in Hawaii and California reported that victims of TB focus on their disease and perceived impending death to the exclusion of all else, with work and other aspects of life neglected (Yamada et al., 1999 [++]). Shame, isolation, and loneliness are common. As a result, some will avoid medical attention as they would rather not be aware of the diagnosis.

The **process of screening** itself raised anxieties for various immigrant groups in the UK (Brewin et al., 2006 [+]). These comments related to a lack of public health information and explanation given by staff:

She didn't know quite what was going on so she was worried. She thought something serious was happening but when the nurse explained what was happening, she calmed down. (35-year-old Polish female, Brewin et al., 2006).

She only say me I have to take my blood pressure and my urine from me, she haven't mentioned the tuberculosis test but when I came and she saw perhaps I am a black person, or something like that. I am not saying she is racist or something like that, but I think it is because I am African. (30-year-old African male, Brewin et al., 2006).

A major concern among 68 injecting drug users or crack cocaine addicts in New York was a **fear of detention**. One of three case studies reported discharging himself from hospital because he had been threatened with involuntary detention for non-compliance. When his symptoms returned he resisted going to a hospital because he had heard negative stories such as threats of detention and withholding methadone from injecting drug users in his gallery.

One study discussed the denial of diagnosis that African immigrants in London often reported (Nnoaham et al., 2006 [++]). Nine of 16 participants did not believe they had TB. These participants often had misconceptions about TB and had longer times to diagnosis and less previous experience of TB.

I didn't believe it, to be honest . . . there's nothing relating to TB in my family. If you have this thing [TB] in your family, then it may come to you, so me, I don't believe it. (31-year-old man, Ghana, Nnoaham et al., 2006)

I am not convinced it is TB I have. First, they say it is this illness [sarcoidosis], then they say it is TB. (38-year-old woman, Ivory Coast, Nnoaham et al., 2006)

I said "no I haven't got TB". I used to hear about it but I never knew it might come close to me . . . but you know until you know someone who has it, you do not feel it near you like that. (19-year-old man, Nigeria, Nnoaham et al., 2006).

Those who had had experience of TB reported differently:

[The diagnosis] was no problem because we know it. My cousin, everyone, they have TB before. So when I told them, look I have got TB, they said no problem. (20-year-old woman, Somalia, Nnoaham et al., 2006).

Stigma

Ten studies discussed the issue of stigma, all as a barrier to screening or treatment completion. Subthemes included **family or community shame of the infected person** (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Whoolery, 2008 [++]); **social isolation** (Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Nnoaham et al., 2006 [++]; Van der Oest et al., 2005 [-]; Yamada et al., 1999 [++]); **stigmatisation involving the whole hard-to-reach community** (Gibson et al., 2005 [++]; Marais, 2007 [++]); **stigmatisation by healthcare workers** (Kelly-Rossini et al., 1996 [-]; Marais, 2007 [++]; Whoolery, 2008 [++]); and the **link between TB and HIV** (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]).

Brent Refugee Forum (2007) [++] conducted focus groups with a range of vulnerable groups in London. Most groups described a sense of shame and forced or voluntary isolation resulting from a TB diagnosis, although stigma was expressed differently in different groups:

Even after the disease is treated and cured fully, the person is nicknamed “TB man” for the rest of his life. (Tamil community group, BRF, 2007)

Participants felt more effort is needed to reduce the effect of stigma. They reported that TB patients often face dual stigma—from their own communities and their host communities. The stigma associated with TB was often associated with their entire **family**:

Sick persons are afraid to attend the centre so as not to be rejected by the family. They end up hiding their sickness. (African-French speaking group, BRF, 2007).

Similarly, Somali participants in Sheffield reported stigma as a major issue when diagnosed with TB (Gerrish et al., 2010 [++]). This appeared to have its origins in the association between TB and poverty and family shame in Somalia before treatment was available:

When I was in Somalia people used to stay away from anyone who had TB, it was treated like if you have AIDS, they used to isolate him and tie him to a tree and warn people not get close to him or eat with him or eat with what he was eating... People even used to say “that person has TB so nobody talk to him” Anyone who has TB will be (socially) isolated not only him, but his family will be stigmatised... (Somali immigrant, Gerrish et al., 2010)

Some participants said that if TB patients chose to hide their disease, it could be difficult to take medication in secret. The issue of **isolation** was raised: patients found it hard to maintain social networks due to their symptoms:

I never told anybody (I had TB) because they think it is a big shame, some people, so my missus says don't worry nobody only you and us know. (Somali immigrant, Gerrish et al., 2010)

Gerrish et al. (2010) [++] noted that focus groups elicited more serious discussions around negative views of TB held in their community than individual interviews suggested.

Homeless participants in London reported that being diagnosed with TB was embarrassing and rarely discussed among the homeless **community** because of the stigma attached to TB in this population.

It's a disease not no one really talks about [TB/homeless people]. (Homeless participant 6, Whoolery, 2008).

One homeless person in Whoolery's (2008) [++] study reported that he experienced stigmatisation in the workplace and had lost his job and accommodation (which was part of his work package) as a result. Another individual lost his job because he was unable to work due to widespread stigmatisation in the workplace. A third participant experienced stigmatisation in the home and had decided to leave his sister's house and 'sleep rough'. Other participants mentioned that they felt stigmatised by professionals such as probation officers.

Gibson et al. (2005) [++] interviewed 133 participants from immigrant communities in Canada (Hong Kong, China, Philippines, Vietnam, Punjab, and Eastern Europe). Stigma was mentioned by several participants: five had experienced stigma; six did not tell people they had TB because of fears of stigmatisation; ten reported no problem with stigmatisation; four feared being stigmatised. Some community research associates who had conducted interviews with immigrants believed that stigma had influenced people's attitudes towards prevention and treatment:

People stayed away from each other, not sharing cigarettes and stuff like that. Just really kept to themselves. (Community research associate, Gibson et al., 2005)

The authors suggest that this observation represents a grey area between social stigmatisation and behaviour that displays a desire not to catch TB.

Nnoaham et al. (2006) [++] found that actual stigma was reported mostly with reference to isolation measures among 16 African immigrants in London:

I felt bad. I mean I am not an alien. You see all those nurses all masked up. It wasn't a good feeling. People treating you differently, you're separated from all others [hisses]. It was hard. (19-year-old man, Nigeria, Nnoaham et al., 2006).

One participant reported:

My nephew, who used to come and see me, when he heard that I had TB, started staying away. He thought that if he came close to me, he will contract it and will start dying. (40-year-old woman, Nigeria, Nnoaham et al., 2006).

Stigma was a common theme among several community representatives in New Zealand, particularly recent immigrants who came from high-prevalence countries and older generations of the Pacific Island or Maori population, who remember when TB was more prevalent in New Zealand (Van der Oest et al., 2005 [-]). Reactions typically included isolating the diagnosed individual. The Somali, Asian, and Maori community representatives had reported that stigma had been tackled in their communities with simple health education messages indicating that TB is curable.

Filipino immigrant participants in Hawaii and California said that the general attitude towards the TB victim was stigmatised (Yamada et al., 1999 [++]). The patient is thought to be dirty and is ostracised or isolated. Spouses of infected persons may refuse to have sexual relations and may seek a new partner:

They don't see you as a person when you have TB. (Filipino participant, Yamada et al., 1999)

Your family member don't come around because they feel you are dirty, and they are afraid that they will be infected by you. They don't want to talk to you. (Filipino participant, Yamada et al., 1999)

I remember in our family, one of our relatives had TB, and we isolated him. It used to scare the heck out of me. We would talk to him from a distance. (Filipino participant, Yamada et al., 1999)

Concern about **stigma regarding communities** as a whole was also expressed in two studies (Gibson et al., 2005 [++]; Marais, 2007 [++]). For African immigrants in London, some participants described how media and political debate contribute to a situation where the African immigrant participants felt they were being blamed for "importing" and "spreading" TB to the UK (Marais, 2007 [++]):

...there is TB here in the UK but people always put blame and the stigma. You know Africa is stigmatised, and it is damaging to us and community relationships, but it is just one of those things, you just have to learn to live with it really. (Participant, Marais, 2007)

They blame us for bringing TB to this country and spreading it around to people from the UK. But we didn't have any TB when we came here, we got it here in UK. The UK gave us TB! (Participant, Marais, 2007)

Similar concerns were raised in Gibson et al.'s (2005) [++] study of immigrants to Canada:

The reaction from the community workers [sic] was, "Don't make it such a big fuss, it's going to bring negative stereotyping to the clients. Don't splash all over the mainstream media that immigrants have TB; it will just make the discrimination that might exist, even higher." [...] But later, when we worked in the Chinese community itself, I think because so many people in the local Chinese community had some contact with TB services or TB, they understood the need to help others [eliminate] unnecessary fears or myths about TB. (Community research associate, Gibson et al., 2005)

Three studies reported concerns about **stigmatisation from healthcare staff** (Kelly-Rossini et al., 1996 [+]; Marais, 2007 [++]; Whoolery, 2008 [++]). According to 18 HIV-infected patients with TB in New York, staff members added to stigmatisation of participants by not entering their room or leaving their room as soon as possible, providing little interaction with patients and not picking up food trays from rooms. Participants reported that medical staff, including physicians, nurses and nursing assistants, were often unwilling to enter the isolation room to talk to the patient.

It makes me feel like I'm nothing but a germ. (Participant in respiratory isolation, Kelly-Rossini et al., 1996)

In a study of 16 homeless persons in London, the use of masks for infection control and isolation rooms led to fear and loneliness in participants and made friends or family afraid to visit them in hospital. The bacterial nature of TB led to further stigmatisation since the term 'germ' was often associated with being dirty or diseased. For most homeless participants in this study, hospitalisation was considered similar to imprisonment.

People were too scared to come near me ... I think people see it as a dirty thing ... they see, that only dirty people get that [TB]... it's the kind of feeling I get from it... (Homeless participant 1, Whoolery, 2008).

This theme was also evident in a sample of 312 African immigrants in London (Marais, 2007 [++]). Several participants in that study reported stigmatisation by service providers who displayed discomfort and fear of close contact, which reportedly compounded feelings of rejection and despair.

Three studies noted participants' views about the **link between TB and HIV** (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]). Participants from vulnerable groups in the southeast London area (Chinese, Nigerian, Vietnamese, Refugee

Women's Group, substance misusers, HIV positive, homeless, and prisoners) spoke about stigma associated with TB (Johnson, 2006 [-]). Many would not go to the doctor for risk of the community finding out. Many groups spoke about keeping TB secret. The labels attached to TB were thought to be long term. Some spoke about being ashamed of having had TB, especially in relation to HIV/AIDS. Many African participants spoke of TB as being similar to HIV or that "TB translates into HIV".

Marais (2007) [++] also reported an assumed link between TB and HIV among African immigrants in London, which increased stigmatisation. This produced a reluctance to attend TB clinics:

The first thing people will be thinking is, she is HIV positive ... so there is that taboo in the way people will treat me. So, I'd rather not tell them, so I am the one who is going to take the precaution and if they want to come and see me I'll be making up stuff, I'm busy, I'm not at home. (Participant, Marais, 2007)

Some respondents in Nnoaham et al.'s (2006) [++] study also mentioned the association of TB and HIV:

It is always like "He's got TB; he must be HIV positive". That's the way people look at it. I think people see that the symptoms look alike, so they just conclude that anyone with TB has HIV. (29-year-old man, Zambia, Nnoaham et al., 2006)

These days, if you have TB, they say it's AIDS. If you have pneumonia, they say it's AIDS. If you have common fever, make sure you stay inside your house! Once you lose one kilogram, you're finished. Some won't even shake your hands or eat with you. The stigma is too much. So people prefer to die. (37-year-old man, Nigeria, Nnoaham et al., 2006).

[My doctor] asked about TB, AIDS and sex. You could tell from the way he was asking the questions that he was suspecting I had AIDS. I wasn't happy at all. He just told me to do an AIDS test and moved on. (46-year-old woman, South Africa, Nnoaham et al., 2006)

Marais (2007) [++] found that **patient confidentiality** was not understood by many African immigrants. Several reported reluctance to attend TB clinics because of stigma and fear:

African communities don't understand what is confidentiality! Because to them, back in Africa... you going to visit somebody in the hospital, I leave the room and go to Reception and say – hey, what's up with him? It's like when you are sick, you don't have right to confidentiality... (Participant, Marais, 2007)

Language and culture

Language and cultural differences between patients and healthcare providers can be a barrier to service provision. Differences can be as fundamental as not having a standard term for TB, as well as suspicions among immigrant groups regarding Western medicine. The main subtheme, however, was language barriers.

Chemtob et al. (2003) [-] interviewed Ethiopian refugees in Israel. Interviews were conducted in absorption centres²⁸ and permanent settlements with 12 Ethiopian families (ranging in size from two to 13 members), three traditional healers, and 21 Israeli health and absorption professionals. Critically, participants did not have a **standard term for TB**. Therefore, the translator who informed patients in Amharic that they had TB would use words such as “*yesamba nekera*” (lung cancer) or “*yesal beshita*” (a common cold). This suggests to the reviewers that, where a patient’s native language does not hold an equivalent term for TB, healthcare professionals need to work with translators to better describe the disease.

Few Somali participants in a Sheffield sample had reported that they did “*not understanding [sic] what was going on*” and were “*being kept in the dark*” (Gerrish et al., 2010 [++]). This was reportedly often due to **language barriers** between the healthcare worker and patient. Patients valued that nurses came with a Somali health worker if the patient did not speak English. In some cases, language barriers persisted and patients reported that they did not understand why they were required to take medication for so long. Individuals from the wider Somali community stated that completing treatment would be difficult because instructions were not clear or understandable, especially for non-English speakers/readers.

Marais (2007) [++] also reported that language barriers were a concern for migrant Africans in London. The most common problems were the lack of availability of interpretation services offering a range of African languages and dialects, and severe delays in obtaining interpreters. These conditions resulted in additional delays. Some stated that, to access services, they resorted to using family, friends, neighbours and sometimes children to act as translators.

Similarly, language barriers were reported for refugee and minority ethnic groups in New Zealand (Van der Oest et al., 2005 [-]). Medical terminology was reported as difficult to understand. It was also noted that there was a lack of written information in different languages for health issues available (including TB), particularly pertaining to prescription instructions. There was a common need for interpreters and those interpreters would need to be acceptable to the family.

Different **cultural protocols and preferences** might also need to be taken into account in the healthcare setting. Van der Oest et al. (2005) [-] reported that community representatives of refugee and minority ethnic groups in New Zealand had different preferences for communication. Somali and Asian population representatives

²⁸ Absorption centres aim to help immigrants transition into Israeli culture through services such as housing and Hebrew language training.

reported that communication with the patient should normally be conducted via the head of the family, normally a senior male. In the Cook Island community, a family matriarch takes on this communication role. Common among all interviewees was the view that care should involve the entire family. Patients might also feel unable to identify with a healthcare provider who is not from their own cultural or linguistic background (Van der Oest et al., 2005 [-]).

Interviews with Vietnamese refugee community members not using TB services showed a **perception of Western medicine** in general as strong or aggressive (Ito, 1999 [+]):

The U.S. way is to attack everything. So they give you the strongest medicine. Americans are strong people, so this is okay for them. (Vietnamese participant, Ito, 1999)

Western medicine thinks everything is very serious, which is not necessarily the case. On many things Western medicine is accurate, but they are afraid of making mistakes, so it is not subtle. They prefer strong treatment-rapid and fast! [sharply clapping his hands and hitting the table in front of him]... Oriental medicine is slow [gentle]. (Vietnamese participant, Ito, 1999)

Some participants also expressed **suspicion** of the motives of the US government. This was particularly the case where people had received positive results to skin tests in the USA after being declared clear of TB when they left Vietnam.

In Thailand [refugee camps], people are checked and they are okay. Now they say we have TB. Here is paradise, everybody is healthy. This makes Vietnamese people so angry! We are not sick! We are being tricked. Americans treat us badly. They treat me like I am dirty. I bring disease. [...] It is insulting!" (Vietnamese participant, Ito, 1999)

People working for community organisations stated that public services were not sensitive to the community's needs, and that messages should be seen to come from community agencies rather than from the government (Ito, 1999 [+]). Vietnamese clinic staff tended to give biomedical explanations for side effects, or suggestions to mitigate them, which were sometimes not well understood by clients.

Conversely, consideration for cultural differences can be a facilitator for continued participation in treatment. Nnoaham et al.'s (2006) [++] sample of African immigrants in the UK found that counselling from healthcare providers, personalised care from specialist nurses, and advice from well-informed peers could improve adherence to treatment.

Many women and men from Muslim communities also noted the ability to access gender-compatible services as a facilitator to service access (Marais, 2007 [++]).

The difficulties of treatment

The **long duration** and **adverse effects** of TB treatments were reported in a few studies as barriers to compliance:

- Johnson (2006) [-] reported that many participants from vulnerable groups in London thought that the lengthy time of treatment was a barrier to completion;
- Chemtob et al. (2003) [-] reported that Ethiopian refugee families in Israel felt that the six-month pill treatment for TB was too long;
- West et al. (2008) [+] found that homeless and drug/alcohol abusers in the USA gave inconsistent responses when asked whether they would adhere to nine months of oral medication. The homeless shelter participants all agreed that they would take the medication for TB for nine months; however, when asked if they would take it despite feeling well, they responded, “it depends” or “not without a lot of tests”;
- Gibson et al. (2005) [++] reported that many immigrant participants in Canada who had been treated had problems with adverse effects;
- Ito (1999) [+] reported adverse effects as a reason for non compliance in a Vietnamese sample in the USA.

Ito (1999) [+] provided further details on the issue of adverse effects. Most Vietnamese participants (14/24) receiving treatment in California cited “hot” adverse effects (e.g., irritability, acne) as a reason for non compliance. They also cited other adverse effects (loss of memory, food becoming tasteless, nausea, and constipation). Non compliant clients cited the following reasons for not taking their treatment: no symptoms; being too busy; unable to take the treatments because of work or school; and perception that the treatments were bad for your health. Compliant clients cited the results of the medication taking too long as another possible reason for others’ non compliance.

Curtis et al. (1994) [+] discussed the treatment complications that were compounded by **concurrently undergoing methadone treatment** in injecting drug users in the USA. One case study describes a 33-year-old black woman injecting drug user who was taken to hospital with possible TB symptoms, and when her fever subsided began to experience withdrawal symptoms:

They didn’t want to detox me. They [the doctor] said that they cannot detox me and treat me at the same time. First of all, they said that they don’t want to give anyone methadone because it’s not helping us, anyway. (33-year-old black woman injecting drug user, Curtis et al., 1994)

The authors describe how this patient was later turned away from detox because of her TB diagnosis. The second case study was admitted to hospital with symptoms of TB, but once admitted, methadone was not given and the patient discharged himself from hospital. The patient said it was to alleviate his withdrawal symptoms and because he

felt threatened by the hospital staff and afraid of detention. Many injecting drug users who were interviewed reported that their efforts to obtain methadone therapy were met with resistance and contempt by hospital staff.

Homeless persons in London reported that taking care of their personal health in general, and adhering to their TB treatment in particular, were neglected or overshadowed by their desire to escape the harsh realities of social exclusion. The immediate needs of substance addiction or desire for substance use were prioritised over taking TB medication (Whoolery, 2008 [++]).

I did have other issues as well apart from the TB [drug & alcohol issues] ... sometimes it's difficult, I mean I'm an ex-user, cause I'm coming off a lot of other stuff as well ... so my heads kinda [sic] all over the place... there are times were it's kinda difficult to get ere [sic] (TB clinic)... it was a multiple habit it wasn't just a heroin habit, It was a heroin, crack cocaine, and alcohol habit (Homeless participant 1, Whoolery, 2008).

Lack of symptoms

Three studies reported that a barrier to compliance with treatment often occurred when a patient no longer showed symptoms of TB, even though their course of treatment had not finished:

- Gerrish et al. (2010) [++], in relation to Somali patients in Sheffield;
- Johnson (2006) [-], in relation to substance misusers in London;
- Ito (1999) [+], in relation to Vietnamese people receiving treatment in California.

...[Somali men] deny that they have TB, or they say they are feeling better and don't need to treatment. ... I don't know why this is the case, maybe it is something about the bravado of the young, they are invincible ... they think they don't need the medicines if they are starting to feel better. (Healthcare practitioner, Gerrish et al., 2010)

My friends say if you don't have any sickness right now, why take the pills? A lot of people don't take the medicine because they feel that taking it doesn't do any good for their health. Instead, it creates more problems. Some people after not taking the medicine, they get fatter, healthier, so they feel that there is nothing wrong with them ... So they think it's good not to take the medicine. (28-year-old, female, non compliant, Ito, 1999)

Summary of facilitators and barriers

Facilitators to testing and treatment reported in the literature included family support, religious beliefs and support, and the use of culturally-sensitive and appropriate care. However, factors that were facilitators for some participants were often barriers for others. For example, although families could provide support and comfort (facilitator), they could also be a source of anxiety (barrier). Other barriers to testing and treatment

included low perceived standard of care, inadequate service provision and access, and concerns about stigmatisation and isolation.

Evidence statement 3: Facilitators and barriers to testing and treatment

Several potential facilitators and many barriers to testing and treatment were identified. Families were identified as a factor that could be a facilitator to some participants (by offering support) and a barrier to others (by causing anxiety or being discouraging). Other potential facilitators included:

- religious beliefs and support; and
- culturally-sensitive and appropriate care.

Broad themes around potential barriers to testing and treatment included:

- lack of coping mechanisms;
- low standard of care;
- inadequate service provision and access;
- fear, anxiety, and denial;
- stigma;
- language and culture differences;
- the difficulties of treatment; and
- lack of symptoms.

ES3.1 **Inconsistent evidence from two studies** suggested that **families** can be a positive **coping mechanism** for some people or a barrier for others. For some Vietnamese refugees in the USA, families were identified as key in supporting compliance, while other participants often worried about what would happen to their dependents (Ito, 1999 [+]). HIV-infected patients with TB in respiratory isolation in the USA reported either support or discouragement to continue treatment from family members (Kelly-Rossini et al., 1996 [+]).

Potential facilitators

ES3.2 **Weak evidence from two studies** suggested that **religious beliefs** could be a **source of hope and a coping strategy**. For Somali participants in Sheffield, Islam was a source of hope (Gerrish et al., 2010 [++]). For some HIV-infected patients in the USA, religion offered a coping strategy to deal with respiratory isolation (Kelly-Rossini et al., (1996 [+]).

ES3.3 **Moderate evidence from three studies** found that **culturally-sensitive** and appropriate care increased **access and adherence** to treatment. Nnoaham et al.'s (2006) [++] sample of African immigrants in the UK found that counselling from healthcare providers, personalised care from specialist nurses, and advice from well-informed peers could improve adherence to treatment. Many women and men from Muslim communities also noted the ability to access gender-compatible services as a

facilitator to service access (Marais, 2007 [++]). Whoolery (2008) [++] suggested that face-to-face support and good rapport with healthcare professionals from the time of diagnosis, appropriate care delivery, and positive hospital experiences were important facilitators in the successful treatment of homeless persons in London. Participants also stated that increased knowledge of their health state helped them feel empowered and build a positive relationship with their healthcare professional.

Potential barriers

ES3.4 **Inconsistent evidence from three studies** suggests that some participants viewed the **standard of care** as low. Common themes included feelings of staff being neglectful (HIV patients in respiratory isolation: Kelly-Rossini et al., 1996 [+]; drug users in the USA: Curtis et al., 1994 [+]) or disrespectful (Curtis et al., 1994 [+]). However, one study on Somali immigrants in Sheffield reported that patients were generally happy with their TB services (Gerrish et al., 2010 [++]).

ES3.5 **Strong evidence from three studies** indicated a **lack of information or awareness** about service availability or access for vulnerable groups in London (BRF, 2007 [++]), Somali immigrants in London (Marias, 2007 [++]), or Chinese immigrants in New York (Fujiwara, 2000 [-]).

ES3.6 **Weak evidence from four non UK studies** suggested that the **cost of TB services** was a concern for some participants, in particular, Chinese immigrants in New York (Fujiwara, 2000 [-]); various immigrants in New Zealand (Van der Oest et al., 2005 [-]); and homeless people in the USA (West et al., 2008 [+]). The authors of one study (Curtis et al., 1994 [+]) suggested that low uptake of preventive therapy might be due to a lack of funding for such therapies in the USA. In terms of applicability, it is important to note that none of the studies reporting this theme is from the UK, where access to medication and healthcare is free for low-income groups.

ES3.7 **Strong evidence from five studies** suggests that hard-to-reach groups (mostly African immigrants) have a lack of confidence in or are concerned about **misdiagnoses or delayed diagnosis by healthcare professionals**. Groups that mentioned these concerns included:

- Somalis in Sheffield (Gerrish et al., 2010 [++]);
- various vulnerable groups including HIV patients in London (Johnson, 2006 [-]);
- African immigrants in London (Marais, 2007 [++]) and Nnoaham et al., 2006 [++]; and
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]).

ES3.8 **Strong evidence from five studies** suggests that various hard-to-reach groups felt that **fear of death from TB** was a barrier to wanting to be screened. This was mentioned by:

- various vulnerable groups in London (BRF, 2007 [++]);
- Somali immigrants in Sheffield (Gerrish et al., 2010 [++]);
- Filipino immigrants in Hawaii and California (Yamada et al., 1999 [++]);
- homeless people in San Francisco (Kitazawa, 1995 [+]); and
- homeless people in the North-Eastern USA (Swigart & Kolb, 2004 [+]).

ES3.9 **Strong evidence from ten studies** indicates that stigmatisation is an important concern for people with TB and their families (see also ES3.10). **Social isolation** is a key feature of stigmatisation for many hard-to-reach groups (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Nnoaham et al., 2006 [++]; Van der Oest et al., 2005 [-]; Yamada et al., 1999 [++]; Whoolery, 2008 [++]). Participants in two studies reported feeling stigmatised by attitudes of healthcare staff (HIV patients in respiratory isolation: Kelly-Rossini et al., 1996 [+]; African immigrants in London: Marais, 2007 [++]).

ES3.10 **Strong evidence from three studies** indicates that perceptions of a **link between TB and HIV** increases concerns about stigmatisation for various immigrant groups in the UK (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]).

ES3.11 **Strong evidence from three studies** shows that language barriers between service users and service providers are a concern for many hard-to-reach immigrant populations. This was evident for Somalis in Sheffield (Gerrish et al., 2010 [++]); migrant Africans in London (Marais, 2007 [++]); and various refugee and minority ethnic groups in New Zealand (Van der Oest et al., (2005 [-]).

ES3.12 **Moderate evidence from six studies** suggests that the **difficulties of treatment** (length of treatment and side effects) are a barrier to compliance for some patients. Length of treatment was a concern for many participants from vulnerable groups in London (Johnson, 2006 [-]); Ethiopian refugee families in Israel (Chemtob et al., 2003 [-]); and homeless and drug/alcohol abusers in the USA (West et al., 2008 [+]). Side effects were mentioned as a reason for non compliance for various immigrants in Canada (Gibson et al., 2005 [++]) and Vietnamese immigrants in the USA (Ito, 1999 [+]). Adhering to TB treatment in the context of substance addiction or use and social exclusion was reported to be difficult for homeless persons in the UK (Whoolery, 2008 [++]).

ES3.13 **Moderate evidence from three studies** suggests that non compliance with treatment often occurs when a patient **no longer shows symptoms of TB**, even though their course of treatment has not finished. This was mentioned in relation to Somali patients in Sheffield (Gerrish et al., 2010 [++]); substance misusers in London (Johnson, 2006) [-]; and Vietnamese people receiving treatment in California (Ito, 1999 [+]).

Applicability

The cost of TB services was not raised as an issue in any UK study. This reflects the fact that individuals in the UK do not have to pay directly for TB services, unlike in the USA or New Zealand, and so these findings might not be transferable to the UK. However, people in the UK may have to pay to get to diagnosis and treatment centres, or to take time off work to attend, which can be a barrier to participation among poorer groups.

Concerns about misdiagnoses by healthcare professionals (ES3.5) were mostly limited to African immigrants and so might not transfer to other hard-to-reach groups.

The evidence from Chemtob et al. (2003) [-] regarding a lack of equivalent terminology to describe TB might be rather specific to that language group (Amharic-speaking Ethiopians in Israel). No other study specifically mentioned this terminological problem. This would only transfer to other populations that do not have a linguistic equivalent for the term 'tuberculosis'.

5.1.4 Cues to action

This section summarises the self-reported cues to action of hard-to-reach people. These are the reasons that people seek screening or treatment, including motivating factors. Only three studies explicitly dealt with this issue:

[+] Kitazawa (1995)

[+] Swigart & Kolb (2004)

[-] Johnson (2006)

Johnson (2006) [-], noted that the precipitating factor persuading Chinese immigrants in London to seek medical advice for TB would be a serious symptom, such as blood in their sputum.

Swigart & Kolb (2004) [+] aimed to identify the factors that influence a homeless person's decisions to reject or accept a screening test (chest X-ray) for detection of TB in a north-eastern US city. The authors conducted in-depth semi-structured interviews in an environment that provided quiet, comfortable seating and privacy near a medical testing area. Fifty-one per cent of 55 participants reported a medical history or family history of such problems as influencing their decision:

My sister had it [TB] one time. She died from it. She used to smoke, then she had a half a lung ... and she got TB and she died. I thought I better be checked. (75-year-old female, sheltered, Swigart & Kolb, 2004)

Fifteen participants were living in shelters for recovering drug- or alcohol-addicted males. Twelve of those participants stressed the importance of self-care in the context of their screening and recovery:

I'm just trying to be focused on my basic hygiene. Hygiene, showering every day, uh, you know, brushing my teeth. There's a long road I have to travel, but I have to start somewhere. (42-year-old male, sheltered for two weeks, Swigart & Kolb, 2004)

I haven't been taking care of my health, 'cause I got hooked on drugs and alcohol, so it's better to get off drugs and alcohol, and they say it's about change if I want to get better with my life, so I think that's a part of it, to be concerned about my health. I couldn't better my life and not, disregard, you know, ignore my health. So that's why I'm interested in the chest X-ray or whatever health check, uh, I need. (51-year-old male, sheltered for one month, Swigart & Kolb, 2004)

Several people participated in the screening test because of curiosity of the condition of their lungs (21%) or the free/convenient service (27%):

Yes, I have a reason to come out because I got bad lungs and I have a breathing problem and I have to take medicine for it, an inhaler for it and stuff. I'm hoping to get better. I just come out to see if I was getting better through the medication. (60-year-old male, sheltered, Swigart & Kolb, 2004)

Where we sleep at, under the bridges, to get up there you have to climb. I fell and landed on my chest. I had some chest pain ... so it is good you know, to have a check up on your body. (35-year-old male, on the streets, Swigart & Kolb, 2004).

Five participants reported their perceptions of being in close quarters with others at the shelter as a trigger to go for screening:

Um, I figured that since I was passing through, and you know, that I would want to see, that I really didn't pick up nothing from being here. (42-year-old male, Swigart & Kolb, 2004)

In here with everybody, I don't know, whatever they get, you got. (68-year-old female, sheltered, Swigart & Kolb, 2004)

Some participants among those who were sheltered reported that they felt pressure from the shelter workers or personnel to agree to the screening test:

I was thinking about maybe not going, you know, like hide or, you know, just not going, but I knew Pauline would be on top of everything so I decided I better go. And like I said, she was on top of everything. (53-year-old male, sheltered, Swigart & Kolb, 2004).

I was trying to sneak out. I didn't think Sister Irene was up there. She nabbed me. (52-year-old male, sheltered, Swigart & Kolb, 2004)

Kitazawa (1995) [+] reported that the motivating factors for homeless participants in San Francisco to receive care were the perceived seriousness of TB and concern for others.

Evidence statement 4: Cues to action

ES4.1 **Weak evidence from three studies** reported on cues to action. A cue for **Chinese immigrants** in London can be a serious symptom (e.g., blood in sputum) (Johnson, 2006 [-]). The most common cue to action among 55 **homeless** people in the USA was family history, while concerns about lung problems, living in a shelter, and the pressures of shelter workers were less common but evident cues (Swigart & Kolb, 2004 [+]). Concerns about the seriousness of TB and concern for others were also mentioned by homeless people in the USA (Kitazawa, 1995 [+]).

Applicability

There is insufficient evidence on this research question for any hard-to-reach group to form clear conclusions about what cues lead people to seek out screening or treatment for TB.

5.1.5 Views on benefits from, and implications of screening and treatment

Benefits

This section deals with hard-to-reach people's views on the benefits to be gained from TB screening or treatment. Four studies discussed perceived benefits:

[++] Gerrish et al. (2010)

[+] Brewin et al. (2006)

[+] Kelly-Rossini et al. (1996)

[-] Van der Oest et al. (2005)

In a study of 53 adult immigrants who had been offered TB screening in East London, some participants saw it as a privilege and a good idea to be screened (Brewin et al., 2006 [+]). Screening was seen as socially responsible and some felt that screening should be particularly promoted to children:

I was looking forward to get the results to know I am okay and happy because it allow me to be sure I am not suffering from this disease. (30-year-old African male, Brewin et al., 2006)

Is better they should do for the children, the test tuberculosis. (28-year-old Polish female, Brewin et al., 2006)

However, Brewin et al. (2006) noted that, although respondents were generally positive about the purpose of screening, some expressed anxieties about the *process* of screening. These comments related to a lack of public health information and explanation given by staff.

One study of Somali individuals in Sheffield reported a sense of relief associated with diagnosis (Gerrish et al., 2010 [++]). This is because they now knew what was wrong with them and that it could be treated. It is important to note, however, that other patients felt shocked by the diagnosis and experienced ongoing anxiety, especially relating to how the community may perceive them (see section on stigma, above).

In terms of adherence to treatment, Van der Oest et al. (2005) [-] reported that Kampuchean refugees in New Zealand had a high level of treatment adherence. The representative describes that:

people in (her) community are very happy to (take medications), and are generally very diligent about taking and completing courses of medication prescribed to them. This appears to be a reflection of the fear and anxiety that they hold about TB, coupled with the vivid recollection of the people who died from TB in refugee camps, and in Kampuchea. (Community representative, Van der Oest et al., 2005)

One study of 18 HIV-infected patients with TB noted that a few participants found the peace and quiet of respiratory isolation to be a benefit (Kelly-Rossini et al., 1996 [+]):

I'm getting plenty of rest, that's for sure. It's brought a lot of things out since I'm off the drugs now a little bit and I'm thinking more. (HIV-infected patients with TB, Kelly-Rossini et al., 1996)

Social, psychological, and economic implications

This section summarises hard-to-reach people's views on the possible social, psychological, and economic implications of TB screening, prevention, or treatment. Six studies mentioned this:

- [++] Brent Refugee Forum (2007)
- [++] Gerrish et al. (2010)
- [++] Gibson et al. (2005)
- [++] Marais (2007)
- [++] Whoolery (2008).
- [+] Kelly-Rossini et al. (1996)

Marais (2007) [++] examined the views of 312 African immigrants in the UK. Participants with TB described the negative effects of the disease on their own and their families' **financial situation** in the UK. Many lost their jobs after diagnosis and struggled to buy food and pay bills. Two participants became homeless as a result of their diagnosis:

Well, London is hard. Even when I'm at work it's still hard. And now I've been off work with TB it is difficult because like, this month, all my sick pay that they paid me is going to go towards my rent. So this will be a difficult month for me, I must say, it's going to be so difficult. (Participant, Marais, 2007)

TB destroyed me ... now I'm bankrupt. I don't have a house. I was a star worker and I've lost my job as well because of the TB... (Participant, Marais, 2007)

Social outcomes mentioned were:

- becoming ostracised (Somalis in Sheffield; Gerrish et al., 2010 [++]);
- isolation of the patient from the community and self-isolation; negative effects on social relationships; reduced marriage prospects (for vulnerable groups in London; BRF, 2007 [++]); loneliness associated with isolation (African immigrants in London; Marais, 2007 [++]). Loneliness in sanatoria: *"It was not a good time for me. I had to stay in the hospital for nine months. I was lonesome for my parents, my mom, the kids, my sisters. I missed them a lot."* (Immigrants in Canada; Gibson et al., 2005 [++]).

Kelly-Rossini et al. (1996) [+] interviewed 18 HIV-infected patients with TB (13 male and 5 female between the ages of 30-51 years) in respiratory isolation in an urban academic medical centre in New York. Various implications of respiratory isolation were discussed:

- Some participants reported a **loss of freedom** because they were unable to leave isolation rooms as they pleased. Common words used to describe these feelings were "caged in", "locked up", "boxed in".
- **Boredom** was mentioned despite being provided with a television. "There is nothing to do in this room except lay down on the bed..."
- The **disruption of routines** (sleeping, bowel and bladder patterns, bathing) caused distress to some.
- Uncertainty of the number of days required to stay in care and concerns about others led to **depression**. *"It made me feel like crying, pulling my hair, a lot of things. It's pretty miserable in here."*

Concerns about **children's services** provided a barrier to compliance for a screening test in a women's shelter recruitment site (Swigart & Kolb, 2004 [+]). The research

team was unable to recruit any of the younger women from this site for interviews, but a shelter volunteer offered an explanation:

Um, I think some people are involved with Children's Services and I think they, they have a feeling that anything they do, the agency is gonna learn about it... and if someone hears about it, then they're gonna take the kids away. ...Or maybe they've gotten a "protection from abuse" court order against an abuser and if they have something medically wrong, that's gonna be a mark against them. So in general they feel health care is threatening. (Shelter volunteer, Swigart & Kolb, 2004)

Interestingly, concerns about **deportation** or immigration were not conclusively found to be a barrier. Although two studies (BRF, 2007 [++]; Jackson & Yuan, 1997 [+]) suggested that *physicians or healthcare providers* believed that recent immigrants might not seek testing because of fears of deportation (see Section 5.3.2), this issue was rarely raised in the literature on *immigrants'* views. One study on Filipino immigrants to the USA (Yamada et al., 1999 [++]) reported participants' concerns that TB sufferers would be unable to emigrate to the USA, which could be a barrier to getting tested. In contrast, participants in a Chinese focus group in New York understood that the Department of Health would not report people diagnosed with TB to the immigration authorities (Fujiwara, 2000 [+]). No other studies explicitly mentioned this issue.

One study reported a **positive outcome** from TB diagnosis and treatment. Whoolery (2008) [++], in her study of 16 homeless persons in London, found that that some participants experienced a sense of "self-realisation" after receiving a diagnosis of TB. This meant that participants began to make positive changes in their lives by examining its meaning and finding acceptance. Some homeless participants began to make links with family and others focused on becoming healthy or finding housing. For example, some individuals moved from "rough sleeping" to living in a hostel.

When I came here [hospital] with TB they give me three weeks to live, and it really freaked me out, I mean I got a second chance, so I have to try and do it properly this time (Homeless participant 3, Whoolery, 2008).

But I end up going in hospital and they say everything for a reason, maybe I needed this TB to get the start I needed, so that I can get a flat. Cause this, bed-sit is a start to getting a flat inat [sic]... (Homeless participant 11, Whoolery, 2008).

I had enough of it, and I put my hands out, I need help, and that's when I went back to the primary care unit and said, look, I need some help. And then they put me on the methadone program, and stabilised me and it means me not to go out shoplifting anymore [sic], it keeps me out of trouble, so I don't have to go shoplifting, keeps me out of prison, just got the alcohol to deal with now (Homeless participant 4, Whoolery, 2008).

Those homeless participants who were actively making psychological or practical changes in their lives also began to accept service support.

I'm trying to follow the process, and I do have this sort of support network. That's in the hostel as well as here [clinic], in that they've supported me through my TB ... just by being there, because I was seriously ill, and because of my situation I had just come off the street and that. I think they put in extra effort into me ... it has become easier to deal with, because they facilitated the medication and when I first had TB they use to come to my hostel and bring my medication and like sit there and make me take it in front of them, but they're not so strict now because I've got use [sic] that, so I get the medication at the chemist now ... I'm aware of what medication I'm taking and how I should be taking them. I'm always eager to know how I'm progressing and to learn...

(Homeless participant 5, Whoolery, 2008). **Evidence statement 5: Views on the benefits and implications of using TB services**

ES5.1 Inconsistent evidence from five studies discussed the views of hard-to-reach groups in relation to **benefits** of seeking or receiving TB services. Whoolery (2008) [++] found that a positive outcome of being diagnosed and treated for TB for homeless persons in the UK was that they actively made positive changes or took on new responsibilities beyond healthcare in their lives, such as changing their living situation or building positive relationships with their families. However, all studies mentioned that benefits were juxtaposed by concerns. For immigrants in London, screening was both socially responsible and anxiety-provoking (Brewin et al., 2006 [+]). For Somalis in Sheffield, screening could provide relief from a definitive diagnosis as well as anxiety associated with stigma (Gerrish et al., 2010 [++]). Kampuchean refugees in New Zealand were happy to take treatment although this was largely fear-driven (Van der Oest et al., 2005 [-]). For HIV-infected patients in respiratory isolation, being alone was seen as positive by some and negative by other participants (Kelly-Rossini et al., 1996 [+]).

ES5.2 Weak evidence from five studies on social, psychological, and economic implications was identified. Although issues around losing jobs (Marais, 2007 [++]) or their children (Swigart & Kolb, 2004 [+]) arose, there was insufficient evidence on these themes. There was more evidence for loneliness and isolation (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Kelly-Rossini et al., 1996 [+]; Marais, 2007 [++]), which has been covered in the section on stigma.

ES5.3 Inconsistent evidence from two studies on implications regarding **deportation** was available. Fears of being deported or family not being able to emigrate after receiving a positive TB diagnosis were evident among Filipino immigrants to the USA (Yamada et al., 1999 [++]), but participants in a Chinese focus group in New York understood that TB sufferers would not be reported to immigration authorities (Fujiwara, 2000 [+]).

Applicability

Concerns and implications about enforced isolation for people with TB in the USA and Canada may not be as applicable to hard-to-reach groups in the UK where such isolation is rare. Given the lack of other evidence in this theme, it is unclear whether the findings are transferable.

5.2 Secondary research question 1: How do views vary between different hard-to-reach groups?

Two of the included studies explicitly attempted to compare the views of different hard-to-reach groups; their main findings are synthesised in this section. Both studies were rated as low quality:

[-] Johnson (2006)

[-] Van der Oest et al. (2005)

Johnson (2006) [-] sought to understand how specific cultural health beliefs regarding TB affect the awareness and understanding of the disease among vulnerable groups in the SE London area, including Chinese, Nigerian, a refugee women's group (majority Somali, also Ethiopian and Eritrean), Vietnamese, substance misusers (from a homeless person residential centre), HIV-positive people, homeless people, and prisoners. The author found a number of cross-cutting themes across groups, as well as findings specific to some of the groups. In each case, beliefs about transmission, healthcare and health promotion were considered.

Common themes across groups included the perception of death as an inevitable outcome for certain groups of people with TB, such as those who present late or those with HIV (Johnson, 2006 [-]). The ease of transmission was a cause of concern for all groups and there was a common belief that TB infection is always contagious. Few participants had knowledge of latent TB, and few were certain that TB was spread by airborne transmission. Isolating an individual was considered by all groups as the best way of reducing the risk of others catching TB. It was well known among the groups that treatment is available but most thought the lengthy duration of treatment was a barrier to completion.

All the ethnic community groups mentioned a distinction between TB in their country of birth and TB in England (Johnson, 2006 [-]). For most participants, TB was a "disease of the past", a forgotten disease. Those from countries where TB is endemic drew on experiences and memories of their past in their homeland.

All groups spoke about stigma associated with TB. Some spoke about being ashamed of having had TB, especially in relation to HIV/AIDS. Many African participants spoke of TB as similar to HIV or that "TB translates into HIV". Many would not present to the

doctor for risk of the community finding out. Many groups spoke about keeping TB secret. The negative labels attached to TB were thought to be long term.

In relation to health promotion, all groups said they favoured face-to-face situations for receiving health information as it gave them the opportunity to ask questions and meet people. TB was not considered a “fashionable” subject like cancer and HIV and therefore raising awareness was deemed more difficult.

Group-specific findings: Note that these group-specific findings are based on the views of a few individuals (total n across groups = 67) and are not necessarily reflective of the views of most members of these hard-to-reach groups (Johnson, 2006 [-]).

- Somali-specific findings:* The Somali group thought that people who live in conditions where the temperature fluctuates to extremes were more at risk of catching TB. TB was also correctly identified by some in this group to be transmitted via cow’s milk. They showed little confidence in their GPs. Interpreters were needed but often could not be arranged to come at the appointment time or did not turn up, which was blamed on the practice. Some people had decided to go to Accident and Emergency 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. Many were illiterate in English and could not understand spoken English, yet most tuned in to the radio for the hour-long BBC programme in their own language. This was thought to be a good medium for raising awareness.
- Chinese-specific findings:* This group was aware that smoking and having a weaker immune system is associated with a higher chance of contracting TB. The Chinese group visited their GPs, but when they failed to improve, they used Chinese practitioners who were perceived to have more effective treatment. Western medical practices were questioned but were still used as a complementary service. The precipitating factor leading people to seek medical advice would have to be a serious symptom of TB, such as blood in their sputum. Talks and meetings were important for this group as a way of learning about these issues. Chinese radio stations and newspapers were widely used and regarded as viable media for health promotion.
- Vietnamese-specific findings:* Pollution and bad air were thought to cause TB, as well as eating the wrong food. Participants thought information should be presented in Vietnamese rather than English, and that using the BBC Vietnamese program could be useful. Community group newsletters were often read and helped spread news via word of mouth.
- HIV-positive-specific findings:* This group was very well informed and many had direct experiences of TB. One participant spoke of dreading going to the GP and this delay was described as a way of protecting oneself—to delay seeking treatment until the last possible moment. Participants said that if they felt unwell they would generally self-medicate, rather than go to the doctor as “there is no guarantee that the doctor will diagnose TB and may well just prescribe cough

mixture". One group mentioned that if you were African and HIV-positive, staff would assume you have TB. This group thought it would be useful to use the HIV-related media to raise awareness about TB. Posters and information at genito-urinary medicine clinics and on public transport were also considered potentially useful. The mainstream media was also discussed: it was suggested that UK television programmes like *Eastenders* and *Coronation Street* could carry TB-related story lines.

- *Homeless-specific findings:* Some people in this group thought TB was inherited. They associated it with "weaker people", especially those who get wet on the streets, and Eastern Europeans.
- *Substance misuse-specific findings:* Some thought that TB was inherited and it was suggested that the best way to prevent TB was to drink two pints of Guinness per day. These participants felt that if they were meant to take medication for a certain period of time but felt better, they would stop taking the medication.
- *Prisoners:* There was a mixed level of knowledge in this group. TB was thought to be spread through unprotected sex, kissing and pets. These participants also had little confidence in the healthcare they received in prison, and, similar to the Somali group, they believed that doctors had their own "cure all" (in this case, Deep Heat). While the mobile X-ray unit (MXU) had been visiting this prison regularly and most of prisoners were aware of the visits, not all had chosen to be screened. Often it was because they did not feel at risk, or because they had not known how to take up the opportunity. The prisoners suggested using the induction pack, the MXU van and a TB fact sheet (e.g., what are the symptoms of TB). Health awareness days should be held several times a year.
- *Nigerian-specific findings:* The Nigerian respondents thought that the weather was a cause and means of transmission of TB in Nigeria, due to winds blowing in from the deserts carrying TB germs.

Van der Oest et al. (2005) [-] explored the opinions of refugee and minority group representatives about the significance of TB for their community, the community's perceptions of TB services, and their thoughts about how these services could be improved. The study was conducted in New Zealand.

Chinese, Maori and Pacific Islanders' representatives mentioned the preference in the community of dealing with traditional healers rather than the medical service, which was partly attributed to a lack of information about the merits of medication over traditional medications. In contrast, the Somali representative stated that people in their community preferred treatment from medical service since they have experienced TB-related morbidity and mortality in their native country.

Those communities who had a high level of knowledge about TB also had high levels of treatment adherence. The Kampuchean representative, for example, described how people were, in general, happy to take medications and diligent about completing the courses of medication prescribed to them. The authors attributed this to:

the fear and anxiety that they hold about TB, coupled with the vivid recollection of the people who died from TB in refugee camps, and in Kampuchea.
(Kampuchean representative, Van der Oest et al., 2005).

Somali and Asian population representatives reported that communication with the patient should normally be conducted with the head of the family, normally a senior male. However, in the Cook Island community, a family matriarch takes on this communication role. There was a common need for interpreters who would also need to be acceptable to the family.

Commonalities and differences across groups across the studies

By looking across all of the studies in the review, we were also able to identify beliefs and fears related to TB that were held by various groups²⁹. One of the most commonly discussed themes across studies was the **fear of stigma**. In all nine studies that discussed stigma, it was presented as a barrier to screening or treatment completion. As elaborated on in Section 5.1.3, subthemes included fears relating to family shame (BRF, 2007 [++]; Gerrish et al., 2010 [++]); isolation (Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Nnoaham et al., 2006 [++]; Van der Oest et al., 2005 [-]; Yamada et al., 1999 [++]); community stigmatisation (Gibson et al., 2005 [++]; Marais, 2007 [++]); stigmatisation by healthcare workers (Kelly-Rossini et al., 1996 [+]; Marais, 2007 [++]), and the link between TB and HIV (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]).

Three beliefs about the cause or transmission of TB were particularly common across the studies. First, there was a common belief that **smoking** is a risk factor for, or cause of, TB. These views were reported by studies with:

- a range of hard-to-reach participants (e.g., immigrants, prisoners) in the UK (BRF, 2007 [++]);
- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants (Chinese, Vietnamese) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]).

²⁹ These findings differ from those based on the two studies that explicitly looked at different groups (Johnson, 2006 [-] and Van der Oest et al., 2005 [-]; described in the previous subsection) because the samples were from different studies. This means that different methods of recruiting participants, collecting data, and analysing data were used for each of the groups listed here, which might affect the comparability of findings across studies. Although this does not necessarily weaken the conclusions drawn across studies, it is important to make clear the distinction between the findings presented in this section and those derived from Johnson (2006) [-] and Van der Oest et al. (2005) [-].

Second, there was a common belief that TB can be caused by a **lack of self-care** (“not looking after yourself”) or a health imbalance in the individual. These views were reported by studies with:

- a range of hard-to-reach participants in the UK (BRF, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Filipino immigrants in the USA (Yamada et al., 1999 [++]).

Thirdly, hard-to-reach participants commonly view **environmental conditions** (such as a “dirty” or “wet” environments) as a cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK (BRF, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]; Johnson, 2006 [-]); and
- Asian immigrants (Chinese, Vietnamese, and Filipino) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]; Yamada et al., 1999 [++]).

In summary, there are some common perceptions across a variety of groups about the risk factors associated with contracting TB, namely smoking, a lack of self-care, and environmental conditions. However, there were also some points on which groups diverged:

- **Curability.** Chinese immigrants in the USA viewed TB as a curable disease (Fujiwara, 2000 [-]), but African immigrants in the UK (Marais, 2007 [++]) and homeless people in the USA (Kitazawa, 1995 [+]) were not always sure that TB can be cured.
- **Use of traditional or Western medicines.** Somalis in the UK (BRF, 2007 [++]), Filipinos in the USA (Yamada et al., (1999 [++]), and Vietnamese immigrants in the USA (Houston et al., 2002 [+]) all mentioned acceptance of the use of both traditional and modern approaches to treatment. Importantly, Somalis in the UK (BRF, 2007 [++]); African immigrants in the UK (Marais, 2007 [++]); and Chinese, Maori, and Pacific Islanders in New Zealand (Van der Oest et al., 2005 [-]) generally preferred using traditional medicines first. In contrast, Somalis in New Zealand are happy to seek modern treatments first because of their experiences with TB-related deaths in their home country (Van der Oest et al., 2005 [-]). In other words, different immigrant groups in various Western countries had varying opinions about the role that traditional and modern medicines should play in treating TB.
- **Misdiagnosis by healthcare professionals.** This theme was particularly common among African groups (Gerrish et al., 2010 [++]; Marais, 2007 [++];

Nnoaham et al., 2006 [++]; Sagbakken et al., 2010 [+]). It was not evident in the literature for other groups such as the homeless.

- **Benefits of screening or treatment.** Different groups indicated different perceived benefits. Immigrants in London felt that screening was socially responsible (Brewin et al., 2006 [+]). Somalis in Sheffield felt that screening could provide relief from a definitive diagnosis (Gerrish et al., 2010 [++]). Some HIV-infected patients in respiratory isolation suggested that being alone was good because it allowed some quiet time (Kelly-Rossini et al., 1996 [+]).
- **Fears of deportation.** Filipino immigrants to the USA (Yamada et al., 1999 [++]) were concerned that they might be deported after diagnosis, while Chinese immigrants in New York understood that TB sufferers would not be reported to immigration authorities (Fujiwara, 2000 [+]).

Evidence statement 6: Variations in views between different hard-to-reach groups

ES6.1 **Weak evidence from two studies** suggested that **commonalities** emerged across different hard-to-reach groups. These were an understanding of the possible fatal consequences of TB (Johnson, 2006 [-]); the stigma associated with diagnosis (Johnson, 2006 [-]; Van der Oest et al., 2005 [-]); and the importance of language in communicating with immigrant and minority ethnic groups (Van der Oest et al., 2005 [-]).

ES6.2 **Weak evidence from two studies** noted **differences** between hard-to-reach groups. Differences related to preferences for traditional versus modern medicines and confidence in GPs or the healthcare system. **Somalis** in the UK had little confidence in GPs, preferring to go to Accident and Emergency (Johnson, 2006 [-]), while Somalis in New Zealand had high confidence in GPs (Van der Oest et al., 2005 [-]). **Chinese** people in the UK visited their GPs, but when they failed to improve they used Chinese practitioners who were seen to have more effective treatment (Johnson, 2006 [-]), while Chinese immigrants in New Zealand had a preference for traditional medications (Van der Oest et al., 2005 [-]). **Maori and Pacific Islanders** in New Zealand also had a preference for traditional medications and healers (Van der Oest et al., 2005 [-]). **People with HIV and prisoners** in the UK had little faith in healthcare services, and people with HIV preferred to self-medicate than go to the GP (Johnson, 2006 [-]).

Applicability

The low quality of the two studies reporting cross-group comparisons reduces confidence in the research findings.

5.3 Secondary research question 2: What are the views of service providers?

We found eight studies that focused on or contained data on service providers' views:

[++] Belling et al. (2008)

[++] Brent Refugee Forum (2007)

[++] Gerrish et al. (2010)

[++] Marais (2007)

[++] Moro et al. (2005)

[+] Ito (1999)

[+] Jackson & Yuan (1997)

[-] Craig et al. (2008)

There are three main themes within this sub-section: service providers' views regarding service users' attitudes and circumstances; service providers' perceptions regarding organisational/structural issues; and service providers' views around their own testing. In all cases, we have discussed the findings in terms of barriers and facilitators to the successful delivery of TB services. A ninth study (Joseph et al., 2004 [+]) considered the barriers and facilitators to healthcare providers' own adherence to TB testing.

5.3.1 Structural or service facilitators and barriers

All eight studies addressed the views of the service providers regarding structural and organisational barriers and facilitators to testing or treatment (Belling et al., 2008 [++]; BRF, 2007 [++]; Craig et al., 2008 [-]; Gerrish et al., 2010 [++]; Ito, 1999 [+]; Jackson & Yuan, 1997 [+]; Marais, 2007 [++]; Moro et al., 2005 [++]).

Four studies (Belling et al., 2008 [++]; Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]) explicitly mentioned that one of the biggest difficulties was the lack of professional expertise in TB.

In Italy (a low-prevalence country), participants in Moro et al.'s (2005) [++] study talked about the "disappearance" of TB expertise and awareness among physicians—a crucial problem. The disappearance of specialist TB services had not been replaced by effective multi-function services, which were in fact regarded as lacking effective communication strategies and integrated care:

I think that there are too many people involved in the management of tuberculosis cases. (Participant, Moro et al., 2005)

Focus group participants in this study felt that effective TB control is hampered by ineffective service organisation and lack of essential resources. The lack of laboratory services and respiratory isolation rooms were deemed particularly relevant:

We have problems with isolation rooms when the diagnosis is not final: the patients are not receiving treatment and are highly contagious. (Participant, Moro et al., 2005)

Participants also considered there was a lack of professional TB nurses responsible for case holding, which was seen as a crucial problem in achieving effective TB control:

I feel very much the weight of the absence of the health nurse, who is accustomed to working inside the hospital and then visiting the patient at home, linking the hospital and the community. (Participant, Moro et al., 2005)

There are not enough nurses to bring the [directly observed] therapy to the home. (Participant, Moro et al., 2005)

The lack of an appropriate organisation of services was also discussed by participants in BRF (2007) [++]. Talking about services in the London borough of Brent, they discussed how referral to specialists can be slow, resulting in patients falling out of the system. In addition, immigrant dispersal units move people around, which may result in losing their chance to be seen by specialist medical services. There can also be delays caused by the difficulty of obtaining records when moving health practitioner:

You get this hiatus every time you try to get access to records and it can drag on and on and on. The records then go up and across and there is a delay. (Doctor, BRF, 2007)

It was recognised by participants in BRF (2007) [++] that TB is a complex social disease which affects all areas of a person's life, and yet health and social services are fragmented:

I think the other complication is that there are obviously so many other things on their agenda ... you know ... housing, money and all sorts of things, and sometimes, you don't have the time to get involved with the medical side. (Participant, BRF, 2007)

To be honest, being a TB nurse is like being part social worker, because you cannot just give medicine, you have to listen to their problems ... and to help sort them out. (Nurse, BRF, 2007)

The lack of specialist care matters most for effective management of TB. However, participants in Jackson & Yuan's (1997) [+] study said that the structure of family practices also reduced effective management of TB, because they see a variety of disorders and illnesses but very few TB cases. One participant asked:

If you see one case of TB every 3 years, does it make a lot of sense for you to invest a huge amount of energy into knowing about this disorder? (Family physician, Jackson & Yuan, 1997).

The specialist TB medical and nursing team in Gerrish et al.'s (2010) [++] study echoed the point above, reporting that it was more difficult to make a diagnosis of TB or to refer

appropriately when patients had atypical symptoms, where there were cultural barriers, or where they were a GP who did not encounter TB often.

Craig et al.'s (2008) [-] study of an outreach model of care including a TB link worker (TBLW) offers an interesting counter-example to the themes above. Participants mentioned various examples of how this collaborative model had facilitated a better service:

- Effective linkages between the patient, health and community:

The TBLW's done what the job implied: link the community, person and health service with a consistency of service you wouldn't otherwise get. With limited resources it's helped us to make appropriate criteria links, by accessing the medical to those most in need. (Social worker, asylum and refugee team)

- Emotional and practical support for patients and the opportunity to establish trust:

The TBLW knew more about the client and we could share experiences. There was extra support for the client which I wasn't able to give. (British Red Cross worker, Refugee Unit)

Once the client was diagnosed with TB he was quite unmotivated, missing appointments, and we worked jointly to help him re-motivate himself with the understanding he would feel weak, have a temperature and he wasn't just being lazy. Now we understand the symptoms and can be flexible around that. (Key worker, homeless hostel worker)

- Communication: interviewees expressed that the TBLW improved communication with doctors on the wards, particularly in relation to discharge planning. The status of the TBLW as a public health representative had an impact on decisions concerning discharge. The ability to forge links between hospitals and the TB clinic was seen to improve care continuity and this had a positive effect on adherence to treatment. A 'one-stop-shop' approach was reported as being an incentive for engagement:

They will have loads of other issues apart from their health and are more likely to turn up to the services if other issues can be addressed. It's like a day centre – get tea, see nurses, get help with housing and other issues. (Caseworker, Homeless healthcare agency)

- Greater awareness and access to services:

It's been good for the frontline staff to understand where TB links in, and get support accessing services. (Homeless Forum)

The role of the social care worker was seen by participants in Belling et al.'s (2008) [++] study as a positive step towards enhanced case management, interagency working, social support and reduced TB nursing workloads. In relation to this, participants in Marais (2007) [++] discussed the need for healthcare workers at community-based organisations. These organisations tended to focus on broader social, education and community issues but failed to address health, which was detrimental to a good service. Nurses in Belling et al. (2008) suggested an alternative model, based on nursing leaders with skills and experience to increase and develop nurse-led TB services.

Participants in Moro et al.'s (2005) [++] study felt that guidelines were not always useful in supporting clinical decisions in general:

Guidelines are black and white, with few grey tones: tuberculosis, in contrast, is completely grey. (Participant, Moro et al., 2005)

This concern was also mentioned by participants in Jackson & Yuan (1997) [+], who reported that guidelines did not address many issues, a situation which created a sense of uncertainty.

Participants in Moro et al.'s (2005) [++] study distinguished three specific subgroups of patients when discussing the barriers to the diagnosis and management of TB: the foreign-born, the elderly, and the immunocompromised. TB is often not considered in the diagnosis of elderly patients and is not easy to diagnose in foreign-born patients.

...General practitioners do not take into account tuberculosis in elderly, poor general health status patients with cough: they think of cancer, always. (Participant, Moro et al., 2005)

The problem is represented by Chinese, Pakistani and Indian patients: the pathological forms of tuberculosis in these groups of patients are different and unusual. (Participant, Moro et al., 2005)

Treating these groups is also perceived as challenging:

Severe side effects of tuberculosis treatments are more frequent in elderly patients, who often have liver diseases or may be addicted to alcohol. (Participant, Moro et al., 2005)

Some ethnic minorities are particularly difficult to communicate with: we need cultural mediators. (Participant, Moro et al., 2005)

One GP in Gerrish et al.'s (2010) [++] study pointed out the cultural interpretation of symptoms that make diagnosis challenging:

A Somali patient may complain of something that is affecting the whole half of the body... and it just does not fit with our traditional Western medical model of certain diseases... So the challenge for us is to find out what physical pathology might be going on that is being expressed through a different belief system and therefore is being experienced in a different way from the way that I might experience it. (GP, Gerrish et al., 2010)

This might explain why many immigrants discussed experiences of delayed diagnosis or misdiagnosis (cf. 'Standard of care' in Section 5.1.3). This point was also evident in Belling et al. (2008) [++], particularly in relation to treatment:

You can't always know everything. You might be used to dealing with Somalians and then get a group of Rwandans, whose health needs are different. I feel fairly comfortable with the Muslims who say, it's Ramadan, I can't take my tablets. I know exactly what to say and I can point to the passage in the Koran where it says it's OK to take tablets if you're ill. But somebody from Vietnam, I know nothing about their health beliefs. And you can't just send people on courses to find out because you just don't know what you're going to get. I've got a middle class mother who won't bring her child in because she doesn't believe in anything. And she's white, middle class. She lives in my suburb and her health beliefs are not available to me. (Participant, Belling et al., 2008)

Services which are unable to be sensitive to a certain community's needs and cultural beliefs are likely to encounter even greater difficulties. People working for community organisations participating in Ito's (1999) [+] study of Vietnamese refugees in Orange County, California, believed that messages should be seen to come from community agencies rather than from the government. Clinic staff were reported to give biomedical explanations for adverse effects, or suggestions to mitigate them, which were sometimes not well understood by clients, therefore reducing compliance.

The difficulties posed by the particular needs of certain groups were also discussed by participants in BRF (2007) [++]. GPs and nurses spoke at length about language and translation acting as barriers to successful treatment (a point echoed by key stakeholders participating in Marais' (2007) [++] study of TB in London). Phone translation systems were often used, but were regarded as unreliable and time consuming:

The accuracy of an interpreter depends very much on the grasp of the language within the clinical context and whether they have a positive element of the likelihood of being advocates. (GP, BRF, 2007)

The vulnerability of homeless, immigrant and refugee patients was also highlighted as a challenge for service BRF (2007) [++]. Some of the participants felt they did not know and could not keep up with immigration regulations and how health services

entitlements are affected. They felt it was difficult to get hold of up-to-date information about the regulations. It was noted that there was a potential impact of losing patients through fear of detailed information gathered about them:

And we ask about their immigration status, which can seem very threatening, you know. (Participant, BRF, 2007)

In addition, the allocated time slot for an appointment (10 minutes) for GPs to see their patients was felt by participants to be very inadequate to carry out health assessments for refugees and asylum seekers with complex needs.

So you've got a lot of contentious issues to start with ... and you've only got ten minutes. There's an awful lot of things to take on board. (Participant, BRF, 2007)

Participants suggested that although many agencies exist to support asylum seekers and refugee communities, health providers lacked knowledge about where these agencies were and how best to access their services. Greater collaboration between the Home Office and the Department of Health was suggested.

GPs also mentioned that they could not register homeless people if they did not provide an address, which was often a problem from the system. (This corroborates statements from TB patients about problems registering, as discussed in section 5.1.3 of this report.) Key stakeholders participating in Marais (2007) [++] discussed the relationship between TB and housing issues:

While there are questions about over-crowding, there's questions about movement of people, the other significant issue for Westminster is temporary accommodation. It is evil, absolutely. Temporary accommodation, two things: (1) standards or accommodation are not good, they are designed not to be good because they want people to move on of their own, and (2) even in temporary accommodation you've got significant shifts. The standards people have to live in is not good. There you've got the potential of a public health hazard moving around. (Key stakeholder, Marais, 2007)

This was echoed in BRF (2007), when participants discussed that these vulnerable groups are living in harsh conditions and may have more pressing issues than their health:

Some of the refugees live in conditions of overcrowding ... they live with family members and friends and people from the same area ... and generally the houses may not be in a good state of repair. (Participant, BRF, 2007)

5.3.2 Service providers' perceptions of service users' attitudes and circumstances

Service providers discussed a range of perceived attitudes that, in their opinion, could act as barriers to treatment. Participants in Gerrish et al. (2010) [++] discussed how TB-related stigma in their home country influenced how Somalis continued to feel in the UK. Even though health practitioners noted that attitudes towards TB were changing in a positive way with the availability of treatment and better information, they continued to be an issue for compliance. People were in general more willing to talk about TB, accept diagnosis and complete treatment but some patients were still reluctant to share information with healthcare practitioners, despite being assured that their identity would not be disclosed to contacts. Young men were especially reluctant to reveal contacts because of fear that they would lose standing among friends, or "street credibility", and become socially isolated. One GP participating in the study gave the example of a young woman who felt that her experience with TB removed her chance of marriage and therefore lowered her standing in the community.

Instances of hostility were also discussed in relation to different perceptions of health:

We had a young man with TB and he and his mother had arrived the past year or two from Somalia and his mother found it really difficult to accept the diagnosis of TB [...] Her argument was that "we are professional people", the implication being that TB happened to the lower classes and she was really very offended.
(Participant, Gerrish et al., 2010)

These findings resonate with those in Jackson & Yuan (1997) [+]. Participants discussed cases where individuals did not seek the appropriate medical care because of the stigma associated with the disease:

I am sure there [are lots] of TB cases in Canada just treating themselves with Tylenol and cold medicine. (Participant, Jackson & Yuan, 1997)

Another physician who saw active TB cases reported that patients who are recent immigrants fear that the diagnosis of active TB may lead to deportation. One specialist reported the case of a political refugee to Canada who did not have health insurance and could not afford testing or treatment (Jackson & Yuan, 1997 [+]).

Social and economic circumstances among some Somali patients were also mentioned in Gerrish et al.'s (2010) [++] study. One health worker noted the case of a single woman with several children who found it difficult to attend the clinic because of her responsibilities to take children to school while younger children accompanied her and she could not afford a taxi for everyone to go to the hospital. Participants in Gerrish et al.'s (2010) [++] study expressed their perceptions of "chaotic" lifestyles as a barrier to successful treatment:

I suspect that the reasons why people do not complete treatment are to do with other chaotic things in their lives ... there may be all kinds of other social difficulties that make it difficult for them to seek treatment. (Medical consultant, Gerrish et al., 2010)

Some healthcare practitioners reported that the late presentation of TB was strongly associated with the use of *khat* in the Somali community, particularly among men (BRF, 2007 [++]; Gerrish et al., 2010 [++]).

A lot of people who have been unwell for a long time will also be quite heavy users of khat. ... Heavy use of khat is like heavy use of any other drug, it's quite escapist. (Participant, Gerrish et al., 2010)

The GPs participating in Gerrish et al.'s (2010) [++] study also discussed their perceptions of Somali patients' views towards the healthcare system. GPs perceived a lack of understanding of the British healthcare system among some Somalis. GPs felt that Somali patients did not always appreciate the breadth of medical expertise available in general practice and often went straight to hospitals or wanted requests to do so. GPs reported this was the case because this would be the avenue of action in Somalia. GPs identified that Somali patients emphasise cure rather than treatment and this meant that some people did not continue with treatment medication after they began to feel better. This issue was also raised in BRF (2007) [++]:

The difficulty is getting them here, because after two months they may feel better again...and they might decide not to continue their treatment. (Participant, BRF, 2007)

5.3.3 Health professionals' own TST compliance

One study addressed the factors influencing healthcare workers' adherence to policies for routine tuberculin skin tests (TSTs) and treatment of latent TB infection (LTBI) (Joseph et al., 2004 [+]). The authors conducted 16 focus groups ($n = 106$) with a range of professionals (clinical, janitorial, administrative, clerical and security staff) based in two health departments and two hospitals in the USA. They found that both adherent and non adherent groups believed repercussions (including suspension and withholding pay) enforced adherence:

Let's put it this way, if we weren't forced or suspended, I don't think people would actually show up. (Participant, Joseph et al., 2004)

Both groups viewed in-site TST as "easy" and "convenient", and reported that adherence was easier when TST could be read by nurses outside of the employee health department. Extended hours and reminders also were seen to increase adherence. Most participants considered themselves to be at risk of TB infection and therefore considered TST reasonable:

I come into contact with a lot of patients ... that's why I know I need to be tested annually. (Participant, Joseph et al., 2004)

Participants were confident that treatment for LTBI almost ensured the prevention of active TB, but reported that adverse effects of treatment were deterrents to accepting treatment.

Participants acknowledged a lack of information for healthcare workers (clinical and non clinical staff) and raised questions about TB issues such as transmission, symptoms and treatment. Many requested more education which they said would help lessen fears about TST:

There were a number of people that tested positive and everyone got upset about it because no one knew about the germ itself ... They [Employee Health] had come out and did a little video about it to make people more aware of what the germ was and when it's full blown. It kind of relieved everybody. (Participant, Joseph et al., 2004)

It was also thought that better education could help reduce stigma and fear of co-workers who tested positive.

Participants in the adherent group said that the TST was an effective means of prevention:

It's a protection for us to find out if we do have it. (Participant, Joseph et al., 2004)

Some said that periodic testing gave them a sense of "relief" and made them feel safer. They also gave positive comments about the Employee Health departments and said that there was sufficient emotional support for those with LTBI.

Non adherent participants reported logistical difficulties in having the TST and having it read. Off-peak shift workers had particular difficulties. Many reported distrust and lack of confidence in the Employee Health office:

They [Employee Health] give all these tests year after year. Nobody is exposed. So, they're just giving tests. And maybe that's why some people really feel that all they're trying to do is get the numbers up for the number of TB tests that are done annually. (Participant, Joseph et al., 2004)

Some participants were apprehensive about the skills that the Employee Health staff had in delivering tests and reading results. Non adherent groups were also suspicious that LTBI treatment was harmful. Participants repeatedly described it as "terribly bad", "too aggressive" and "toxic":

[My private doctor] said she would not recommend [LTBI treatment]... that it was overkill. (Participant, Joseph et al., 2004)

Non adherent participants to LTBI treatment expressed anxiety, anger, fear and humiliation following their diagnosis:

I thought I was dying. (Participant, Joseph et al., 2004)

Misunderstandings about the transmission and epidemiology of TB were common among the non adherent groups.

Evidence statement 7: Service providers' views

ES7.1 Strong evidence from four studies (Belling et al. 2008 [++]; Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]) suggests service providers view a **lack of specialist services and coordination of care** as a major difficulty in TB service provision, since most GPs see few cases of TB a year.

ES7.2 Moderate evidence from three studies (Craig et al., 2008 [-]; BRF, 2007 [++], Belling et al., 2008 [++]) suggested that the **complex social and clinical interactions** surrounding a patient with TB can be a challenge to participation and adherence, and that **outreach TB link workers** or social care workers can facilitate coordination of services.

ES7.3 Strong evidence from four studies (BRF, 2007 [++]; Gerrish et al., 2010 [++]; Marais, 2007 [++]; Moro et al., 2005 [++]) suggested that healthcare workers find it challenging to meet the complex care needs of hard-to-reach groups with TB, especially where there are **cultural and language barriers** that make it difficult to interpret symptoms and explain about the disease and its treatment.

ES7.4 Moderate evidence from two studies (Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]) suggested that service providers thought **TB-related stigma** influenced whether people sought testing or complied with treatment.

ES7.5 Weak evidence from one study of service providers' views of their own compliance to testing indicated that service providers can also be afraid of the consequences of contracting TB, including becoming stigmatised. Non clinical healthcare workers may also have limited knowledge about TB, the need for screening and the implications of a positive test result (Joseph et al., 2004 [+]).

Applicability

It is important to note that two of the studies included in this section (Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]) did not focus explicitly/exclusively on hard-to-reach groups, although they did mention hard-to-reach people (namely immigrants). The findings from these studies therefore include the views of service providers that deal

with both general population and hard-to-reach groups. Some of the experiences and views of services providers might only apply to the general population, but unfortunately this distinction was not made in the documents.

Studies from outside the UK might not be completely transferable because of the different service provision offerings, training/accreditation schemes for healthcare professionals, and prevalence of TB in different countries. Four of the nine studies included in this section were conducted outside of the UK:

- Italy – Moro et al. (2005) [++];
- USA – Joseph et al. (2004) [+] and Ito (1999) [+]; and
- Canada – Jackson & Yuan (1997) [+].

6.0 Discussion and summary

6.1 Strengths and weaknesses of the review

This review was systematic in nature, based on the guidance set out in the second edition of *Methods for the development of NICE public health guidance* (NICE, 2009). Our search strategies were highly sensitive and included a wide range of potentially relevant sources.

We based our thematic analysis on the Health Belief Model as a framework, which provided a coherent structure for the data synthesis and seemed fitting as it initially developed in the context of TB screening. However, we adapted it to better reflect the themes emerging from the evidence. For example, we dropped the category of self-efficacy which was found not to be useful, and expanded other categories to include “implications” and “facilitators”.

Our synthesis was essentially thematic in nature, seeking to identify and collate common themes across the studies. Such thematic synthesis was supported by the nature of most of the primary studies, and helps to maintain the transparency of the synthesis process.

A limitation of thematic synthesis is that it tends to weight review findings as a function of frequency and study quality, which may not be an accurate guide to the importance or reliability of the given finding. Again, however, the potential loss of depth in the synthesis must be set against the gains in transparency.

Finally, any review is dependent on the quality of the material that it is reviewing. Across all 24 studies, 18 (75%) were medium quality or better. Specifically with reference to the UK evidence, half of the studies were high quality (4/8), one was medium quality, and three were low quality. The two areas in which many reviews were lacking were whether the role of the researcher was clearly described and whether the data were rich. A third weakness across reviews was whether the data analysis approach used was reliable. As such, some of the evidence synthesised here should be considered carefully.

6.2 Gaps in the evidence

We identified a number of issues for which there were insufficient data. These issues were:

- cues to action for hard-to-reach people;
- views on the benefits and implications of using TB services; and
- variations in views between different hard-to-reach groups.

Most of the studies we found reported views of immigrant groups to the UK and other countries. As such, much of the data reflects issues around language and cultural differences between these groups and healthcare providers, leading to knowledge gaps and misconceptions that may be specific to immigrant populations. We found relatively few studies on other hard-to-reach groups such as the homeless, drug misusers, and prisoners in the UK. We therefore cannot be sure how far the findings of this review are generalisable to all hard-to-reach groups.

6.3 Conclusions

The data reported in this review offer a number of strong conclusions. First, although some members of hard-to-reach groups had a basic understanding of the nature of TB transmission and risk factors that increase susceptibility to infection, it was clear that members of hard-to-reach groups frequently report incomplete or inaccurate knowledge about the cause and transmission of TB. That is, they did not always understand or appreciate their **susceptibility to TB**. For example, there was strong evidence from nine studies suggesting that hard-to-reach participants commonly view **smoking as a cause of TB**. While smoking increases susceptibility to infection and increases the severity of infection³⁰, people who believe that TB is caused directly by smoking may have a false sense of invulnerability to infection if they themselves do not smoke. These views were reported by studies of:

- a range of hard-to-reach participants (e.g., immigrants, prisoners) in the UK (BRF, 2007 [++]);
- homeless participants in the USA (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed immigrant groups in the UK (Brewin et al., 2003 [+]) and Canada (Gibson et al., 2005 [++]);
- Somali immigrants in the UK (Gerrish et al., 2010 [++]);
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]); and
- Asian immigrants (Chinese, Vietnamese) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]).

Strong evidence from seven studies also suggested that hard-to-reach participants commonly view **environmental conditions as a cause of TB** (such as a “dirty” or “wet” environment, or weather-related conditions). These views were reported by studies, including:

- a range of hard-to-reach participants in the UK (BRF, 2007 [++]);
- homeless participants in the USA (West et al., 2008 [+]);
- mixed immigrant groups in Canada (Gibson et al., 2005 [++]);
- African immigrants in the UK (Gerrish et al., 2010 [++]; Johnson, 2006 [-]); and
- Asian immigrants (Chinese, Vietnamese, and Filipino) in the UK (Johnson, 2006 [-]) and the USA (Fujiwara, 2000 [-]; Yamada et al., 1999 [++]).

³⁰ World Health Organization Tuberculosis factsheets: TB and smoking.
http://www.searo.who.int/en/Section10/Section2097/Section2106_10682.htm

Second, members of hard-to-reach groups had mixed but fairly accurate views of symptoms; no reported understanding of latent TB; an understanding of the potential fatality of TB but mixed understanding of the curability of TB; and preferred approaches to treatment that included both traditional and modern medicines. In other words, they had some conception of the **severity of TB**, but again their knowledge was often incomplete or inaccurate. In particular, there was strong evidence from six studies that participants are aware of the **fatality** of TB but did not always know that it could be **curable**. A lack of understanding about curability was evidenced by African immigrants in the UK (Marais, 2007 [++]) and homeless people in the USA (Kitazawa, 1995 [+]), while Chinese immigrants in the USA viewed TB as a curable disease (Fujiwara, 2000 [-]).

Fear of dying of TB was discussed by:

- Somali participants in the UK (Gerrish et al., [++]);
- African immigrants in the UK (Marais, 2007 [++]);
- various vulnerable groups in the UK (Johnson, 2006 [-]); and
- homeless people in the USA (West et al., 2008 [+]).

Third, many potential **barriers** and some **facilitators** to testing and treatment were identified. Barriers included:

- standard of care (perceived negative attitudes of staff and delayed or misdiagnoses);
- service provision and access (including a lack of information or awareness about service availability or access; the cost of TB services; and lack of confidence in or misdiagnoses by healthcare professionals)
- fear, anxiety, and denial (particularly in relation to death or being ostracised);
- stigma (from friends, family, the community, and healthcare workers);
- language and culture (where communication barriers arise);
- the difficulties of treatment (including duration and adverse effects); and
- lack of symptoms (where not adapted for the relevant culture).

Facilitators included:

- coping mechanisms (including family and religion);
- standard of care (when care is high quality and respectful); and
- language and culture (where adapted for the relevant culture).

Within those themes, there was strong evidence from three studies indicating a **lack of information or awareness** about service availability or access for vulnerable groups in London (BRF, 2007 [++]), Somali immigrants in London (Marias, 2007 [++]), or Chinese immigrants in New York (Fujiwara, 2000 [-]). There was also strong evidence from five studies that hard-to-reach groups (mostly African immigrants) have a lack of

confidence in or are concerned about **misdiagnoses by healthcare professionals**.

Groups that mentioned these concerns included:

- Somalis in Sheffield (Gerrish et al., 2010 [++]);
- various vulnerable groups including HIV patients in London (Johnson, 2006 [-]);
- African immigrants in London (Marais, 2007 [++] and Nnoaham et al., 2006 [++]); and
- Somali and Ethiopian immigrants in Norway (Sagbakken et al., 2010 [+]).

Some of these problems stem from **communication barriers**, reported by healthcare professionals as well as members of hard-to-reach groups. These language and cultural differences can cause problems in understanding the initial problems experienced by the patient and then in explaining and understanding about the disease and the need for adherence to a long course of medication. These views were expressed by:

- healthcare professionals working with homeless, immigrant and refugee patients in London (BRF, 2007 [++]);
- members of an outreach team involving TB link workers (Craig et al., 2008 [-]);
- healthcare professionals in London (Belling et al., 2008 [++]);
- Somalis in Sheffield (Gerrish et al., 2010 [++]);
- migrant Africans in London (Marais, 2007 [++]); and
- various refugee and minority ethnic groups in New Zealand (Van der Oest et al., 2005 [-]).

There was strong evidence from five studies that various hard-to-reach groups felt that **fear of death** was a barrier to getting screened. This was mentioned by:

- various vulnerable groups in London (BRF, 2007 [++]);
- Somali immigrants in Sheffield (Gerrish et al., 2010 [++]);
- Filipino immigrants in Hawaii and California (Yamada et al., 1999 [++]); and
- homeless people in the USA (Kitazawa, 1995 [+]; Swigart & Kolb, 2004 [+]).

Strong evidence from five studies indicated that **isolation** is a key feature of stigmatisation for many hard-to-reach groups (Gerrish et al., 2010 [++]; Gibson et al., 2005 [++]; Nnoaham et al., 2006 [++]; Van der Oest et al., 2005 [-]; Yamada et al., 1999 [++]; Whoolery, 2008 [++]). Fear of stigmatisation can lead to avoidance of testing and non compliance with treatment. Stigmatisation was further increased when people perceived a **link between TB and HIV**, as suggested by strong evidence from three studies of various immigrant groups in the UK (Johnson, 2006 [-]; Marais, 2007 [++]; Nnoaham et al., 2006 [++]).

Finally, the **views of service providers** suggest a general concern about the **lack of specialist service provision and coordination of care for patients with TB**. This

was supported by strong evidence from four studies (Belling et al., 2008 [++]; Gerrish et al., 2010 [++]; Jackson & Yuan, 1997 [+]; Moro et al., 2005 [++]).

6.4 **Implications identified by the review team**

The review team identified several implications from the evidence. There are numerous misconceptions and a lack of awareness about TB and TB services among hard-to-reach people. Word of mouth (Johnson, 2006 [-]; Kitazawa, 1995 [+]; Marais, 2007 [++]), cultural-specific Radio programmes (Fujiwara, 2000 [-]; Johnson, 2006 [-]) and dramatised television shows (Johnson, 2006 [-]; Marais, 2007 [++]) were identified by hard-to-reach people as potentially important media for disseminating accurate information about TB to hard-to-reach groups.

Much also needs to be done to reduce the stigma associated with TB, which could be partly achieved by spreading the knowledge that TB is curable. Working with community leaders to find ways to break down cultural stereotypes associated with TB (such as poverty and being dirty) that fuel stigma might also help to reduce concerns about being isolated from the patient's community. Also, community leaders could help to teach immigrants who are unfamiliar with the concept of patient confidentiality about their rights to privacy as a patient in the UK.

Finally, both patients and service providers were concerned about the level of specialist expertise on TB in healthcare. Establishing coordinated services, such as with TB link workers, should be considered as a way of providing GPs with specialist guidance on management of patients with TB, increasing confidence of patients in the system, and facilitating continuing adherence with treatment.

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7.3 Unsourced references

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8.0 Appendix A. Search strategies and results

8.1 Database searches

The search strategy was written at the Centre for Evidence and Policy, King's College, London, in partnership with Matrix Reviews, Dr Gill Craig of City University, London, and NICE. All results were imported into a bibliographic management tool for screening and management.

To control the specificity of results, the translated strategy (used for resources which do not support MeSH) did not use 'TB' as a term in the first line of the strategy. We extensively tested and sampled the literature using 'Tuberculosis or TB' then 'Tuberculosis' alone, with the latter performing more strongly and the former pulling a large volume of false negative responses. We saw a number of false negative hits where TB referenced the indexer, the abstract author, or an indexing line in the formatting of the record. This point was debated within the team and with external expert advice, with the conclusion that within the Social Science resources, the full phrase 'Tuberculosis' was most likely to appear and positive includes captured. Further testing, sampling and benchmarking of both examples was conducted until we were satisfied with this approach.

Searching in the ISI resources was conducted using the same strategy but, due to the inadequacies of the search interface concerning handling a full strategy, we had to run the strategy line-by-line and then de-duplicate the aggregated volume to find the final number of hits from these resources. Footnotes are included with the strategy below to define this approach.

After the searching was completed, the team's expert advisor (Gill Craig) noted that two terms had recently become popular in the literature that are used to denote the difference between UK citizens and immigrants to the UK. The terms were 'UK born' and 'non-UK born'. A test search in Medline was conducted to see whether we were likely to have missed relevant studies by not including these terms in the original search strategy. Of eight hits, only one was a unique reference (i.e., one study had not been identified in the original search), and it was clear that it should be excluded. We were therefore reassured that we did not miss any relevant studies by not including these terms in the search strategy³¹.

³¹ Note that we have included these terms in the strategies for the subsequent three reviews in this series.

Table A1. Database searches results

Database	Hits
Assia	184
BL Direct	0
British Nursing Index	14
CRD (DARE, HTA, EDD)	161 (DARE: 55 – NHS EED: 99 – HTA: 7)
CINAHL	466
Cochrane Library (Reviews)	163
Community Abstracts	2
CCC (date limit 1998-2010)	1423
Embase	2499
ERIC	21
HMIC	69
WoS (and conference proceedings)	1876
Medline	2485
Medline In-Process	105
PsycINFO	198
SPP	19
Soc Abs	125
Social Services Abstracts	58
<i>Total</i>	<i>9868</i>

1. Applied Social Science Index and Abstracts (ASSIA)

Cambridge Scientific Abstracts

Searched Friday, June 25th 2010

Hits: 184

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
6. (geograph* or transport* or physical and (barrier*))
7. (low* or poor* or negative and (quality adj2 life))

8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
11. prisoner*
12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
14. (parole or probation)
15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
21. (prostitution or sex work* or transactional sex* or prostitute*)
22. (poverty or deprivation or financial hardship*)
23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
24. (low* and (social class*))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. (health care worker* or (health care or health-care and (service provi* or provi*)))
28. (outreach or care or social or social care and (worker* or professional*))
29. (social care or social-care and (service provi* or provi*))
30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))

31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

2. British Library Direct (BL Direct)

<http://direct.bl.uk/bld/Home.do>

Searched Sunday, June 27th 2010

0 Hits

1. (Tuberculosis)
2. (qualitative*)
3. limit result to previous 7 days

Strategy: 1 and 2 and 3

3. British Nursing Index (BNI)

OID

Searched Sunday, June 27th 2010

14 hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3

5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.
13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/
17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-subscribed and (hous\$ or accommodation or shelter\$ or hostel\$ or dwelling\$))).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/

24. (poverty or deprivation or financial hardship\$.ti,ab.
25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)).ti,ab.
26. poverty/
27. (low\$ and (social class\$)).ti,ab.
28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
32. (support adj2 worker\$1).ti,ab.
33. (case adj2 worker\$1).ti,ab.
34. (social adj2 worker\$1).ti,ab.
35. social care professional\$1.ti,ab.
36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translats\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39. or/5-38
40. 1 and 4
41. 39 and 40
42. limit 41 to yr="1990 -Current"
43. animals/ not humans/
44. 42 not 43

4. Centre for Reviews and Dissemination (CRD)

<http://www.crd.york.ac.uk/crdweb/>

Searched Tuesday, June 29th

161 Hits

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or

- narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
 4. or/2-3
 5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
 6. (geograph* or transport* or physical and (barrier*))
 7. (low* or poor* or negative and (quality adj2 life))
 8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
 9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
 10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
 11. prisoner*
 12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
 13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
 14. (parole or probation)
 15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
 16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
 17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
 18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
 19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
 20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
 21. (prostitution or sex work* or transactional sex* or prostitute*)
 22. (poverty or deprivation or financial hardship*)

23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
24. (low* and (social class*))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. (health care worker* or (health care or health-care and (service provi* or provi*))
28. (outreach or care or social or social care and (worker* or professional*))
29. (social care or social-care and (service provi* or provi*))
30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*))
31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*))
32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

5. Cumulative Index to Nursing and Allied Health Literature (CINAHL)

EBSCOhost

Monday June 28th 2010

466 Hits

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
6. (geograph* or transport* or physical and (barrier*))

7. (low* or poor* or negative and (quality adj2 life))
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
11. prisoner*
12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
14. (parole or probation)
15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
21. (prostitution or sex work* or transactional sex* or prostitute*)
22. (poverty or deprivation or financial hardship*)
23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
24. (low* and (social class*))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. (health care worker* or (health care or health-care and (service provi* or provi*)))
28. (outreach or care or social or social care and (worker* or professional*))
29. (social care or social-care and (service provi* or provi*))

30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35

6. Cochrane Library

<http://www.thecochranelibrary.com/view/0/index.html>

Monday, June 5th 2010

163 Hits

1. (tuberculosis)
2. (qualitative or "focus group*" or "case stud*" or "field stud*" or interview* or questionnaire* or survey* or ethnograph* or "grounded theory" or "action research" or "participant observation" or narrative* or (life and (history or stor*)) or "verbal interaction*" or "discourse analysis" or "narrative analysis" or "social construct*" or "purposive sampl*" or phenomenol* or "criterion sampl*")
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or "personal view*" or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or "social* exclu*" or "social inequalit*")
6. (geograph* or transport* or physical and (barrier*))
7. (low* or poor* or negative and (quality NEAR/2 life))
8. ((vulnerable or disadvantaged or "at risk" or "high risk" or "low socioeconomic status" or neglect* or marginal* or forgotten or "non-associative" or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or "non-user*" or discriminat* or shame or prejud* or racism or "racial discriminat*")
10. ("social support" or "social conditions" or stigma or "Social Isolation" or (quality NEXT life) or prejudice)

11. prisoner*
12. ("recent* release*" and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or "detention centre*" or "detention center*" or incarcerat*))
13. ((prison* or penal or penitentiary or "correctional facilit*" or jail* or "detention centre*" or "detention center*") and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
14. (parole or probation)
15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
16. (immobile or (disabled and ("house bound" or "home bound"))) or (house or home and (bound)))
17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or "over-crowd*" or "over-subscribed" and (hous* or accommodation or shelter* or hostel* or dwelling*)))
18. ("rough sleep*" or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or "problem use*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder)))
20. ((alcohol* and (misus* or abuse or "problem* use*" or "problem drink*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder))) or alcoholic*)
21. (prostitution or "sex work*" or "transactional sex*" or prostitute*)
22. (poverty or deprivation or "financial hardship*")
23. ("low-income" or "low income" or "low pay" or "low paid" or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbour* or neighborhood* or famil*))
24. (low* and ("social class*"))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. ("health care worker*" or ("health care" or "health-care" and ("service provi*" or provi*)))
28. (outreach or care or social or "social care" and (worker* or professional*))
29. ("social care" or "social-care" and ("service provi*" or provi*))
30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and competen*))
31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or "foreign born" or (born NEXT overseas) or (displaced and (people or person*)))
32. or/5-31
33. 1 and 4

34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

7. Community Abstracts

Oxmill

Searched Sunday, June 27th 2010

2 Hits

1.tuberculosis

2.qualitative*

Strategy: 1 and 2

8. Current Contents Connect (CCC)³²

ISI

Searched Thursday, June 29th 2010

Before de-dup: 1423 post de-dup: 1027

1. ("tuberculosis")
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalitie*)
6. ((vulnerable or disadvantaged or stigma*) and (people or population* or communit* or neighbourhood* or neighbourhood* or group* or area* or demograph* or patient* or social*))
7. prisoner*

³² The ISI interface could not take the full syntax of the strategy, being limited to fifty linked boolean phrases in one search. We ran the strategy: 1 and 4 and 5 then 1 and 4 and 6 - and so on. Each search was date limited and the NOT animals cluster was applied before the results were imported into REFworks. The aggregated search was then imported into Matrix's bibliographic management tool and the results were de-duplicated against each other to give the final unique number of hits.

8. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
9. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
10. (parole or probation)
11. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
12. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
13. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or overcrowd* or over-crowd* and (hous* or accommodation)))
14. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
15. (illegal drug* or illicit drug or substance and (misus* or abuse or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
16. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
17. (prostitution or sex work* or transactional sex* or prostitute*)
18. (poverty or deprivation or financial hardship*)
19. (low-income or low income or low pay or low paid or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbour* or neighborhood* or famil*))
20. (low* and (social class*))
21. (traveller* or gypsies or gypsy or Romany or roma)
22. (mental* and (health or ill or illness))
23. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
24. 1 and 4
25. 24 and 5 – 23
26. (animal* or badger* or Cow or Cattle or bovine)
27. 25 NOT 26
28. limit 27 to yr="1990 -Current"

9. Embase

Ovid

Searched Sunday June 27th 2010

2499 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3
5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.
13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/
17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-

- subscribed and (housing\$ or accommodation or shelter\$ or hostel\$ or dwelling\$)).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
 21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
 22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
 23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/
 24. (poverty or deprivation or financial hardship\$).ti,ab.
 25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)).ti,ab.
 26. poverty/
 27. (low\$ and (social class\$)).ti,ab.
 28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
 29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
 30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
 31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
 32. (support adj2 worker\$1).ti,ab.
 33. (case adj2 worker\$1).ti,ab.
 34. (social adj2 worker\$1).ti,ab.
 35. social care professional\$1.ti,ab.
 36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
 37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translat\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
 38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
 39. or/5-38
 40. 1 and 4
 41. 39 and 40
 42. limit 41 to yr="1990 -Current"
 43. animals/ not humans/

44. 42 not 43

10. Educational Resources Information Center (ERIC)

Cambridge Scientific Abstracts

Searched Friday June 25th 2010

21 hits

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
6. (geograph* or transport* or physical and (barrier*))
7. (low* or poor* or negative and (quality adj2 life))
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
11. prisoner*
12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
14. (parole or probation)
15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))

17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
21. (prostitution or sex work* or transactional sex* or prostitute*)
22. (poverty or deprivation or financial hardship*)
23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
24. (low* and (social class*))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. (health care worker* or (health care or health-care and (service provi* or provi*)))
28. (outreach or care or social or social care and (worker* or professional*))
29. (social care or social-care and (service provi* or provi*))
30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

11. Health Management Information Consortium (HMIC)

OVID

Searched Sunday June 27th 2010

69 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.

2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3
5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhoood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.
13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/
17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-

- subscribed and (housing\$ or accommodation or shelter\$ or hostel\$ or dwelling\$)).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
 21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
 22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
 23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/
 24. (poverty or deprivation or financial hardship\$).ti,ab.
 25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)).ti,ab.
 26. poverty/
 27. (low\$ and (social class\$)).ti,ab.
 28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
 29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
 30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
 31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
 32. (support adj2 worker\$1).ti,ab.
 33. (case adj2 worker\$1).ti,ab.
 34. (social adj2 worker\$1).ti,ab.
 35. social care professional\$1.ti,ab.
 36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
 37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translat\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
 38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
 39. or/5-38
 40. 1 and 4
 41. 39 and 40
 42. limit 41 to yr="1990 -Current"
 43. animals/ not humans/

44. 42 not 43

12. Web of Science³³

ISI

Searched Tuesday 29th July 2010

Before de-dup: 1876 post de-dup: 1301

1. ("tuberculosis")
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalitie*)
6. ((vulnerable or disadvantaged or stigma*) and (people or population* or communit* or neighbourhood* or neighbourhood* or group* or area* or demograph* or patient* or social*))
7. prisoner*
8. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
9. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
10. (parole or probation)
11. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
12. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
13. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or overcrowd* or over-crowd* and (hous* or accommodation)))
14. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))

³³ The ISI interface could not take the full syntax of the strategy, being limited to 501224AZ| linked boolean phrases in one search. We ran the strategy: 1 and 4 and 5 then 1 and 4 and 6 - and so on. Each search was date limited and the NOT animals cluster was applied before the results were imported into REFworks. The aggregated search was then imported into Matrix's bibliographic management tool and the results were de-duplicated against each other to give the final unique number of hits.

15. (illegal drug* or illicit drug or substance and (misus* or abuse or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
16. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
17. (prostitution or sex work* or transactional sex* or prostitute*)
18. (poverty or deprivation or financial hardship*)
19. (low-income or low income or low pay or low paid or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
20. (low* and (social class*))
21. (traveller* or gypsies or gypsy or Romany or roma)
22. (mental* and (health or ill or illness))
23. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
24. 1 and 4
25. 24 and 5 – 23
26. (animal* or badger* or Cow or Cattle or bovine)
27. 25 NOT 26
28. limit 27 to yr="1990 -Current"

13. Medline

OID

Searched Sunday, June 27th 2010

2485 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3

5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.
13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/
17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-subscribed and (hous\$ or accommodation or shelter\$ or hostel\$ or dwelling\$)).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/

24. (poverty or deprivation or financial hardship\$.ti,ab.
25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)).ti,ab.
26. poverty/
27. (low\$ and (social class\$)).ti,ab.
28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
32. (support adj2 worker\$1).ti,ab.
33. (case adj2 worker\$1).ti,ab.
34. (social adj2 worker\$1).ti,ab.
35. social care professional\$1.ti,ab.
36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translats\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39. or/5-38
40. 1 and 4
41. 39 and 40
42. limit 41 to yr="1990 -Current"
43. animals/ not humans/
44. 42 not 43

14. Medline In-Process

OVID

Searched Sunday June 27th 2010

105 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or

- narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
 4. or/2-3
 5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
 6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
 7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
 8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhoood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
 9. poverty area/
 10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
 11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
 12. prisoner\$1.ti,ab.
 13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
 14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
 15. (parole or probation).ti,ab.
 16. *prisoners/
 17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
 18. (immobile or (disabled and (house bound or home bound)) or (house or home and bound)).ti,ab. or Homebound Persons/
 19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-subscribed and (hous\$ or accommodation or shelter\$ or hostel\$ or dwelling\$))).ti,ab. or housing/ st

20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))) .ti,ab. or exp homeless persons/
21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) .ti,ab. or *Substance-Related Disorders/ or Drug users/
22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1) .ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1) .ti,ab. or Prostitution/
24. (poverty or deprivation or financial hardship\$) .ti,ab.
25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)) .ti,ab.
26. poverty/
27. (low\$ and (social class\$)) .ti,ab.
28. (traveller\$1 or gypsies or gypsy or Romany or roma) .ti,ab. or gypsies/
29. (mental\$ and (health or ill or illness)) .ti,ab. or *mental health/ or Mentally Ill Persons/
30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$) .ti,ab.
31. (outreach adj2 worker\$1) .ti,ab. or Community health aides/
32. (support adj2 worker\$1) .ti,ab.
33. (case adj2 worker\$1) .ti,ab.
34. (social adj2 worker\$1) .ti,ab.
35. social care professional\$1 .ti,ab.
36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)) .ti,ab.
37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translat\$ or interpret\$ or (cultur\$ and (competen\$))) .ti,ab. or Communication Barriers/ or *Language/
38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))) .ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39. or/5-38
40. 1 and 4
41. 39 and 40
42. limit 41 to yr="1990 -Current"
43. animals/ not humans/
44. 42 not 43

15. PsycINFO

OVID

Searched Sunday June 27th 2010

198 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3
5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.
13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/

17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and bound)).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-subscribed and (hous\$ or accommodation or shelter\$ or hostel\$ or dwelling\$))).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/
24. (poverty or deprivation or financial hardship\$).ti,ab.
25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhoood\$1 or neighborhood\$1 or famil\$)).ti,ab.
26. poverty/
27. (low\$ and (social class\$)).ti,ab.
28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
32. (support adj2 worker\$1).ti,ab.
33. (case adj2 worker\$1).ti,ab.
34. (social adj2 worker\$1).ti,ab.
35. social care professional\$1.ti,ab.
36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translat\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39. or/5-38

40. 1 and 4
41. 39 and 40
42. limit 41 to yr="1990 -Current"
43. animals/ not humans/
44. 42 not 43

16. Social Policy and Practice

OVID

Searched Sunday June 27th 2010

19 Hits

1. exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2. (qualitative or focus group\$ or case stud\$ or field stud\$ or interview\$ or questionnaire\$ or survey\$ or ethnograph\$ or grounded theory or action research or participant observation or narrative\$ or (life and (history or stor\$)) or verbal interaction\$ or discourse analysis or narrative analysis or social construct\$ or purposive sampl\$ or phenomenol\$ or criterion sampl\$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups / or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3. (view\$ or barrier\$ or block\$ or obstacle\$ or hinder\$ or constrain\$ or facilitat\$ or attitude\$ or opinion\$ or belief\$ or perceiv\$ or perception\$ or aware\$ or personal view\$ or motivat\$ or reason\$ or incentiv\$).ti,ab. or exp Attitude/ or Motivation/
4. or/2-3
5. (hard\$ adj2 reach or hard\$ adj2 locate or hard\$ adj2 find or hard\$ adj2 treat or difficult adj2 locate or Difficult adj2 engage or social\$ exclu\$ or social inequalit\$ or difficult\$ adj2 reach or difficult\$ adj2 find or difficult\$ adj2 treat).ti,ab.
6. (geograph\$ or transport\$ or physical and (barrier\$)).ti,ab.
7. (low\$ or poor\$ or negative and (quality adj2 life)).ti,ab.
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect\$ or marginal\$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma\$ or inequitable) and (people or population\$ or communit\$ or neighbourhood\$1 or neighborhood\$1 or group\$ or area\$1 or demograph\$ or patient\$ or social\$)).ti,ab. or Vulnerable populations/
9. poverty area/
10. (Refuser\$1 or non-user\$1 or discriminat\$ or shame or prejud\$ or racism or racial discriminat\$).ti,ab.
11. social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12. prisoner\$1.ti,ab.

13. (recent\$ adj2 release\$ adj2 (inmate\$ or prison\$ or detainee\$ or felon\$ or offender\$ or convict\$ or custod\$ or detention centre\$ or detention center\$ or incarcerat\$)).ti,ab.
14. ((prison\$ or penal or penitentiary or correctional facilit\$ or jail\$ or detention centre\$ or detention center\$) and (guard\$1 or population or inmate\$ or system\$ or remand or detainee\$ or felon\$ or offender\$1 or convict\$ or abscond\$)).ti,ab.
15. (parole or probation).ti,ab.
16. *prisoners/
17. ((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))).ti,ab. or Homebound Persons/
19. ((hous\$ and (quality or damp\$ or standard\$ or afford\$ or condition\$ or dilapidat\$)) or (emergency or temporary or inadequate or poor\$ or overcrowd\$ or over-crowd\$ or over-subscribed and (hous\$ or accommodation or shelter\$ or hostel\$ or dwelling\$))).ti,ab. or housing/ st
20. (rough sleep\$ or runaway\$1 or (homeless\$ or street or Destitut\$ and (population or person\$1 or people or group\$ or individual\$1 or shelter\$ or hostel\$ or accommodation\$1))).ti,ab. or exp homeless persons/
21. (drug\$ or substance and (illegal or misus\$ or abuse or intravenous or IV or problem use\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
22. ((alcohol\$ and (misus\$ or abuse or problem\$ use\$ or problem drink\$ or illicit use\$ or addict\$ or dependen\$ or dependant or delinquency)) or alcoholic\$1).ti,ab. or *Alcohol-Related Disorders / or Alcoholics/
23. (prostitution or sex work\$ or transactional sex\$ or prostitute\$1).ti,ab. or Prostitution/
24. (poverty or deprivation or financial hardship\$).ti,ab.
25. (low-income or low income or low pay or low paid or poor or deprived or debt\$ or arrear\$ and (people or person\$1 or population\$1 or communit\$ or group\$ or social group\$ or neighbourhood\$1 or neighborhood\$1 or famil\$)).ti,ab.
26. poverty/
27. (low\$ and (social class\$)).ti,ab.
28. (traveller\$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
29. (mental\$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
30. (health care worker\$1 or health care adj2 service provi\$ or health-care adj2 provi\$).ti,ab.
31. (outreach adj2 worker\$1).ti,ab. or Community health aides/
32. (support adj2 worker\$1).ti,ab.
33. (case adj2 worker\$1).ti,ab.
34. (social adj2 worker\$1).ti,ab.
35. social care professional\$1.ti,ab.

36. ((social care adj2 service provi\$) or (social-care adj2 provi\$)).ti,ab.
37. ((language\$ or communicat\$ and (barrier\$ or understand\$ or strateg\$ or proficien\$)) or translats\$ or interpret\$ or (cultur\$ and (competen\$))).ti,ab. or Communication Barriers/ or *Language/
38. (immigrant\$ or migrant\$ or asylum or refugee\$ or undocumented or foreign born or born adj overseas or (displaced and (people or person\$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39. or/5-38
40. 1 and 4
41. 39 and 40
42. limit 41 to yr="1990 -Current"
43. animals/ not humans/
44. 42 not 43
45. Limit 44 to yr="1990 -Current"

17. Sociological Abstracts

Cambridge Scientific Abstracts

Searched

125 Hits

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
6. (geograph* or transport* or physical and (barrier*))
7. (low* or poor* or negative and (quality adj2 life))
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or

- population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
 10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
 11. prisoner*
 12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
 13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
 14. (parole or probation)
 15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
 16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
 17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
 18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
 19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
 20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
 21. (prostitution or sex work* or transactional sex* or prostitute*)
 22. (poverty or deprivation or financial hardship*)
 23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
 24. (low* and (social class*))
 25. (traveller* or gypsies or gypsy or Romany or roma)
 26. (mental* and (health or ill or illness))
 27. (health care worker* or (health care or health-care and (service provi* or provi*))
 28. (outreach or care or social or social care and (worker* or professional*))
 29. (social care or social-care and (service provi* or provi*))
 30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
 31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))

32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

18. Social Services Abstracts

Cambridge Scientific Abstracts

Searched June 25th 2010

58 HITS

1. (tuberculosis)
2. (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
3. (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
4. or/2-3
5. ((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
6. (geograph* or transport* or physical and (barrier*))
7. (low* or poor* or negative and (quality adj2 life))
8. ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
9. (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
10. (social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
11. prisoner*
12. (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))

13. ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
14. (parole or probation)
15. ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
16. (immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
17. ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
18. (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
19. (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
20. ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
21. (prostitution or sex work* or transactional sex* or prostitute*)
22. (poverty or deprivation or financial hardship*)
23. (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
24. (low* and (social class*))
25. (traveller* or gypsies or gypsy or Romany or roma)
26. (mental* and (health or ill or illness))
27. (health care worker* or (health care or health-care and (service provi* or provi*)))
28. (outreach or care or social or social care and (worker* or professional*))
29. (social care or social-care and (service provi* or provi*))
30. ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
31. (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
32. or/5-31
33. 1 and 4
34. 32 and 33
35. (animal* or badger* or Cow or Cattle or bovine)
36. 34 NOT 35
37. limit 36 to yr="1990 -Current"

8.2 Website searches

Table A2. Website searching details

Website	Web-link	Notes	Included on abstract
Action - Advocacy to Control TB Internationally	www.action.org	-	0
Centers for Disease Control and Prevention resources on TB	www.cdc.gov/tb		4
Centers for Disease Control TB-Related News and Journal Items Weekly Update mailing list archives	www.cdcnpin.org/lyris/ui/listservs.aspx	Directs to the same website as below	0
Centers for Disease Control National Prevention Information Network	www.cdcnpin.org/scripts/tb/index.asp		1
NICE, including former Health Development Agency	www.nice.org.uk	Searched for (TB or tuberculosis)	0
NHS Evidence	www.evidence.nhs.uk	Duplicate from database	0
Stop TB Partnership	www.stoptb.org	-	0
TB Alert	www.tbalert.org	-	0
UK Coalition to Stop TB	www.stoptbuk.org	-	0
World Health Organization	http://www.who.int/tb/en/	Searched the WHO Library database	1
WHO Global Health Atlas	http://apps.who.int/globalatlas/dataQuery/default.asp	-	0
Health Protection Agency	www.hpa.org.uk	-	0
British Thoracic Society	www.brit-thoracic.org.uk	-	1
Public Health Observatories	www.apho.org.uk/resource/searchoptions.aspx	-	0
UK Clinical Research Network	http://public.ukcrn.org.uk/search/	Searched for 'TB' and 'tuberculosis' under title/acronym	0
National Research Register archive site	https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx	Searched for '(tb OR tuberculosis) AND (qualitative OR interview OR survey OR focus group OR questionnaire)'	22

8.3 Call for evidence

Table A3. Results of the call for evidence

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
T-SPOT. <i>TB</i> test is superior to TST in identifying LTBI in prison population.	Porsa E, Cheng L, Graviss E. Comparison of an ESAT-6/ CFP-10 Peptide-Based ELISPOT Assay to Tuberculin Skin Test for Tuberculosis Screening in a Moderate Risk Population. <i>Clin. Vaccine Immunol.</i> 2007 Jun; 14(6): 714-9	N	-
T-SPOT. <i>TB</i> is not affected by crack cocaine use.	Grimes C, Hwang L-Y, Williams M, Austin C, Graviss E. Tuberculosis infection in drug users: interferon-gamma release assay performance. <i>INT J TUBERC LUNG DIS</i> 2007; 11(11):1183–1189	N	-
T-SPOT. <i>TB</i> identifies LTBI and active disease in undocumented migrants.	Bodenmann P, Vaucher P, Wolff H, Favrat B, Tribolet F, Masserey E, Zellweger JP. Screening for latent tuberculosis infection among undocumented migrants in Swiss healthcare centres; a descriptive exploratory study. <i>BMC Infect Dis.</i> March 2009;9(1):34.	N	-
Publication, sponsored by KNCV, IUATLD and WHO, stresses the importance of LTBI screening and subsequent treatment to control TB in low incidence countries: "Tuberculosis control and elimination strategies must aim at diminishing the incidence and prevalence of latent infection to reduce the pool of those with tuberculosis infection from which future cases of tuberculosis will emanate."	Broekmans <i>et al</i> <i>Eur Respir J</i> 2002;19:768	N	-
Use of T-SPOT. <i>TB</i> to identify LTBI in homeless population in Reading.	McPhedran K. Pulmonary tuberculosis among street	Can't find	N

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
	homeless populations. The magazine of the Health Protection Agency. Issue 13. 10 – 11.		
<p>I am contacting you after reading the HPA Tuberculosis Update Newsletter March 2010. In this it states 'Poor adherence to treatment can lead to prolonged infectiousness, relapse, and development of drug resistant or multidrug resistant disease'.</p> <p>I would therefore like to bring to your attention some work I did at the University of Birmingham Some while ago I developed a rapid point-of-care urine test to detect isoniazid metabolites in urine. This test was commercialised by a university spin-out company. The test is called <i>IsoScreen</i> and has been used by a number of units both in the UK and overseas to monitor treatment adherence. I attach further details and a copy of a recently published independent report.</p> <p>If you would like further details please let me know. Graham Cope [grahamcope@gfcdiagnostics.co.uk]</p>	 Isoscreen sales flyer (2).pdf	N	-
<p><u>Relating to Q4:</u> This research project “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.”</p> <p>Research examines existing knowledge and perception of TB, as well as stigma surrounding TB, in these communities. It also gathers the views of participants on their impressions of and interactions with the NHS and their views on effective health promotion approaches. The paper also conveys recommendations on each of these topics from the communities.</p>	<i>Beliefs and barriers relating to understanding TB amongst vulnerable groups in South East London;</i> Johnson, A on behalf of South East London Health Protection Unit, October 2006	Y	Y

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p><u>Relating to Q4:</u> “This report presents the findings and recommendations of a research study investigating the structural influences and their interplay; in terms of social, economic, legal, political and organisational (including institutional) factors; on the epidemiology and control of TB in migrant African communities in the borough of Westminster, London. The study employed a multi-method Community-based Participatory Research design which combined both quantitative and qualitative methods, and which engaged as research partners, from the outset and in all phases of the research process, members from these communities together with academic researchers and multiple sectors.</p> <p>The findings of this study suggest that, post-migration, a range of inter-connected structural influences may impact on the epidemiology and control of TB in migrant African communities in Westminster. These influences render them at increased vulnerability to TB by shaping: (a) the outcome of pre-existing TB infections, (b) the potential for acquiring and transmitting new infections, and (c) access to and the outcome of prevention and treatment measures. Therefore, post-migration living conditions in the UK (importantly including wide and easy access to TB information and healthcare) should be regarded as a risk factor and should be a focus of attention for improved control interventions.”</p> <p>“This report presents an extensive list of prioritised recommendations, grounded in the study findings, for contextually and culturally appropriate public health interventions toward improved TB control which will be relevant and beneficial to migrant African communities in Westminster.”</p>	<p><i>Toward the Improvement of Tuberculosis Control and Participatory Research, A multi-method Community-based Participatory Research study of TB in migrant African communities in the borough of Westminster, London;</i> Imperial College London, March 2007 (Marais)</p>	Y	Y
<p><u>Relating to Q4: Background:</u> The control of tuberculosis (TB) is founded on early case detection and complete treatment of disease. In the UK, TB is concentrated in subgroups of the population in large urban centres. The impact of homelessness, imprisonment and problem drug</p>	<p><i>Tuberculosis in London – the importance of homelessness, problem drug use and prison;</i> Story A, Murad S, Roberts W, Verheyen M, Hayward AC,</p>	N	-

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p>use on TB control in London is reviewed.</p> <p>Methods: A cohort study was undertaken of all patients with TB in Greater London to determine the point prevalence of disease in different groups and to examine risk factors for smear positivity, drug resistance, treatment adherence, loss to follow-up and use of directly observed therapy (DOT).</p> <p>Results: Data were collected on 97% (1941/1995) of eligible patients. The overall prevalence of TB was 27 per 100 000. An extremely high prevalence of TB was seen in homeless people (788/100 000), problem drug users (354/100 000) and prisoners (208/100 000). Multivariate analysis showed that problem drug use was associated with smear positive disease (OR 2.2, p,0.001), being part of a known outbreak of drug resistant TB (OR 3.5, p = 0.001) and loss to follow-up (OR 2.7, p,0.001). Imprisonment was associated with being part of the outbreak (OR 10.3, p,0.001) and poor adherence (OR 3.9, p,0.001). Homelessness was associated with infectious TB (OR 1.6, p = 0.05), multidrug resistance (OR 2.1, p = 0.03), poor adherence (OR 2.5, p,0.001) and loss to follow-up (OR 3.8, p,0.001). In London, homeless people, prisoners and problem drug users collectively comprise 17% of TB cases, 44% of smear positive drug resistant cases, 38% of poorly compliant cases and 44% of cases lost to follow-up. 15% of these patients start treatment on DOT but 46% end up on DOT.</p> <p>Conclusions: High levels of infectious and drug resistant disease, poor adherence and loss to follow-up care indicate that TB is not effectively controlled among homeless people, prisoners and problem drug users in London.</p>	for the London Tuberculosis Nurses Network, May 2008		
<p><u>Relating to Q4:</u> Brent Refugee Forum conducted quantitative (who is at risk and how) and qualitative (the patient experience and stigma) research amongst refugees, asylum seekers and homeless people in Brent.</p> <p>“Most of the findings were common across the groups, with few themes that were specific to certain communities. There were no vast</p>	<i>Knowledge, Perceptions, Barriers and the Social Meaning of Tuberculosis among Asylum Seekers, Homeless People and Refugee Communities in Brent 2004-2006; Brent Refugee Forum</i>	Y	Y

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p>differences in community perception, attitude and the way stigma affects TB control and management. The research findings demonstrated that the studies communities were affected by, and live with, recognised socio-economic risk factors of TB that are usually associated with poor living conditions. These factors are potentially increasing the vulnerability of the communities to developing the disease.</p> <p>There was general agreement that community perceptions, attitudes and cultural factors play a crucial role in preventing patients from seeking help.</p> <p>Common concerns across the focus groups were unemployment, low income, poor quality housing, overcrowding and sharing accommodations with strangers. A considerable number of participants believed that their immigration status may have affected their health and social care needs, and access to good quality service provision. As a result, their physical and psychological well-being may have been affected, leaving them extremely vulnerable to developing diseases such as tuberculosis. However, it was highlighted that health might not be the top priority for homeless people, many refugees and asylum seekers.”</p>			
<p>1. <u>Relating to Q4</u>: This research investigated the perceptions and practices surrounding tuberculosis (TB) in the Bangladeshi community of East London, UK.</p> <p>2. Qualitative research techniques in the form of semi-structured interviews and focus groups were used.</p> <p>3. Cultural health beliefs appeared to have little effect on patients’ presentation to medical services, although patients rarely interpreted their symptoms as being due to TB. Traditional healers appeared to complement rather than compete with Western medical practices. Adherence to medication did not depend on cultural factors, literacy or education, but rather respect for medical professionals, the desire to be cured and support by family, friends and medical services. Stigma associated with the disease was common,</p>	<p><i>Cultural Barriers to the Management of Tuberculosis in the Bangladeshi Community of East London</i>; Thesis submitted in fulfilment of the requirements for the degree of MD of the University of London, White V, 2005</p>	Y	N

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
with concerns about contagion, and for patients, anxieties regarding social status, marital prospects and rejection by the community.			
<p><u>Relating to Q4:</u> This research explores reasons why newly arrived people have a low attendance rate for TB screening. Newly arrived people include; international students, Refugee and Asylum Seekers, professionals working in the UK from overseas, economic migrants and transient groups. 80% of people new to Leeds are from Africa, plus this group have a low attendance rate for screening. Those invited for screening from Europe and Asia are more likely to attend appointments than those from Africa (Chest Clinic research, 2007).</p> <p>The rationale for this consultation involved a mixture of focus groups and questionnaires with no more than 10 groups. As well as questionnaires completed at popular local African businesses.</p> <p>This paper gives a summary of the focus group and questionnaire findings, around the issues that discourage newly arrived people from TB testing. As well as making recommendations for next steps.</p>	<p><i>Report, findings and recommendations from a consultation with newly arrived people focused on ways to improve uptake of and increase general awareness of Tuberculosis and Tuberculosis screening in Leeds; Carr R and Dukes R July 2009</i></p>	Y	N
<p><u>Relating to Q4:</u> This report is based on an evaluation of the TB Awareness pilot programme in Peterborough which ran over the period, January 2008 to March 2009. The pilot was specifically targeted at the Pakistani community through rolling out a programme of training aimed at both the community and health care professionals.</p> <p>Various community groups (Imams, senior citizens, Pakistani women, young people and a Zimbabwean group) were consulted during the process of developing the training, and the findings of these consultations is detailed in the report. The training was delivered to around 300 community members.</p> <p>The outcomes will inform the use of the future use</p>	<p><i>Peterborough TB Awareness Pilot Programme 2008/09 Report, produced by McGuire C and Pankhania G, Public Health, NHS Peterborough, April 2009</i></p>	Y	N

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
of culturally appropriate health promotion interventions.			
<p><u>Relating to Q4:</u> Authors performed “a systematic review of the literature on TB stigma to identify the causes and evaluate the impact of stigma on TB diagnosis and treatment. Several themes emerged: fear of infection is the most common cause of TB stigma; TB stigma has serious socioeconomic consequences, particularly for women; qualitative approaches to measuring TB stigma are more commonly utilized than quantitative surveys; TB stigma is perceived to increase TB diagnostic delay and treatment noncompliance, although attempts to quantify its impact have produced mixed results; and interventions exist that may reduce TB stigma. The literature review yielded 168 articles, 159 from the PubMed search and nine from the reference sections of identified articles. Of the 168 articles, 69 were excluded from this review. The most common reasons for exclusion included focus on the effects of HIV stigma on TB diagnosis and treatment.</p> <p>At-risk individuals report that fear of TB stigma and the social and economic impact of stigma affects their willingness to undergo TB screening and to seek medical care after the onset of symptoms associated with TB. Several studies suggest that health-care providers and at-risk community members perceive TB stigma to have a more substantial impact on women’s health-care-seeking behaviour than on men’s.”</p>	<p><i>Tuberculosis and Stigmatization: Pathways and Interventions</i>; Public Health Reports, Supplement 4, Volume 125, Courtwright A, Norris Turner A, 2010</p>	Y	Y
<p><u>Relating to Q4 & 3:</u> Aim. This paper is a report of a study to examine the impact of social factors on the management of tuberculosis including engagement with services, hospitalization and extended treatment.</p> <p>Background. Rates of tuberculosis in major European cities have increased greatly in the last 10 years. The changing epidemiology of the disease, concentrated in marginalized groups, presents new challenges to the control of tuberculosis.</p>	<p><i>The impact of social factors on tuberculosis management</i>; Blackwell Publishing Ltd, Craig G.M, Booth H, Story A, Hayward A, Hall J, Goodburn A & Zumla A, 2007</p>	Y	N

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p>Methods. A prospective cohort study of 250 newly diagnosed tuberculosis patients was conducted in London between January 2003 and January 2005. Data were collected by means of a risk assessment tool and from medical records. Outcome measures included missed appointments, frequency and duration of hospitalization and length of treatment.</p> <p>Results. The median age of the study sample was 33Æ82 (range 16Æ4–92Æ5) and 56Æ8% were male. Thirty-two per cent were hostel/street homeless or temporarily sharing accommodation with friends or relatives. Thirty-nine per cent were in receipt of welfare benefits and 13Æ2% had no income. Over a third anticipated difficulties taking their medicines and 30Æ3% had no-one to remind them of this.</p> <p>Increased hospitalization was associated with hostel/street homelessness, drug or alcohol use and having no-one to remind them to take their medicines (all P £ 0Æ01). Missed appointments were associated with drug/alcohol use and previous tuberculosis treatment. Extended treatment was also associated with drug/alcohol use; previous tuberculosis treatment, drug resistance and those anticipating difficulties taking medication (all P £ 0Æ001).</p> <p>Conclusions. The development of a social outreach model of care with an emphasis on prevention and support is an essential aspect of modern, international tuberculosis care.</p>			
<p><u>Relating to Q4 & 3:</u> Aim. This paper reports the findings from a qualitative meta-synthesis concerning people with, or at risk of, tuberculosis, service providers and policymakers and their experiences and perceptions of tuberculosis and treatment.</p> <p>Background. Directly observed therapy is part of a package of interventions to improve tuberculosis treatment and adherence. A Cochrane systematic review of trials showed an absence of evidence for or against directly observed therapy compared</p>	<p><i>Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis</i>; Blackwell Publishing Ltd, Noyes J and Popay J, 2007</p>	Y	N (duplicate)

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p>with people treating themselves.</p> <p>Method. Qualitative systematic review methods were used to search, screen, appraise and extract data thematic analysis was used to synthesize data from 1990 to 2002, and an update of literature to December 2005.</p> <p>Findings. Five themes emerged from the 1990 to 2002 synthesis: socio-economic circumstances, material resources and individual agency; explanatory models and knowledge systems in relation to tuberculosis and its treatment; the experience of stigma and public discourses around tuberculosis; sanctions, incentives and support, and the social organization and social relationships of care. Two additional themes emerged from the 2005 update.</p>			
<p><u>Relating to Q4 & 3:</u> Aim. This paper is a report of a study to develop a social outreach model of care, including the role of a link worker in developing collaborative care pathways, for marginalized groups with tuberculosis.</p> <p>Background. Social risk factors such as homelessness and substance misuse are associated with poor treatment outcomes. Models of interprofessional practice to address the health and social care of patients are needed to improve outcomes.</p> <p>Methods. A process evaluation involving a prospective cohort study of 100 patients and interviews with eight agencies involved in their care was conducted in London between January 2003 and April 2005. Outcome measures included a profile of patient need to guide service development; referrals to care providers; goal attainment; social improvement and treatment outcomes; and agencies' views on the benefits of link working.</p> <p>Findings. The median age of the sample was 32Æ4 years and 62% were males. Reasons for referral to the link worker included housing need (56%); welfare benefits (42%); immigration (29%) and clinical management issues (28%). One third of the patients were referred to other agencies. Goals, as agreed in the care plan, were attained totally or partially for 88% (59/67) of patients and 78% of patients successfully completed treatment.</p>	<p><i>Establishing a new service role in tuberculosis care: the tuberculosis link worker</i>, Blackwell Publishing Ltd, Craig G.M, Booth H, Story A, Hayward A, Hall J, Goodburn A & Zumla A, 2007</p>	Y	N (duplicate)

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved
<p>Barriers to attaining goals included service criteria which excluded some groups of patients and, in some cases, a patient's inability to follow a course of action.</p> <p>Conclusion. Link workers can mitigate some of the social risk factors that complicate the treatment of tuberculosis by enabling integrated health and social care.</p>			
<p><u>Relating to Q3:</u> This audit evaluation makes recommendations to inform the development of a strategic framework for future service delivery. It looks into new ways of working utilised to maximise detection, treatment and compliance, especially for socially disadvantaged groups. These recommendations are;</p> <p>Recommendations</p> <p>(i) Following on from evaluation of the London MXU service (HPA, 2007), this service should be implemented pan-London to extend active case finding through provision of more MXUs. Evaluation of the installation of static digital X-ray machines in five London prisons in 2007/8 (HPA, 2007, 2008) should also be conducted as part of a targeted programme of TB prevention in prisons.</p> <p>(ii) Link worker roles should be incorporated in service provision in line with skill mix requirements; evaluations of new roles e.g. prison TB nursing post should be proactively sought.</p> <p>(iii) The feasibility of providing safe housing and secure hostel accommodation supported by TB staff expertise should be examined further to support a pilot study evaluation.</p> <p>(iv) Awareness of incentives to promote adherence by service users e.g. cash, food and travel costs requires a stronger dissemination strategy to be developed and implemented.</p> <p>(v) Educational outreach approaches should be disseminated as means of increasing screening and more broadly, in raising awareness amongst primary care staff and service users about TB risks and services.</p>	<p><i>An Audit Evaluation of Pan-London TB Services and Training Needs; NHS London and London South Bank University, Belling R, Woods L, Boudioni M, McLaren S, 2008</i></p>	Y	Y

Evidence submission (Details of evidence that relates to the questions. Please specify which question you are referring to)	Full reference (e.g. author, date of publication, full title of paper/report and where can a copy be obtained from)	Included on abstract	Full text retrieved

8.4 Citation chasing

Forward citation chasing was conducted for all included studies using ISI Web of Knowledge. This yielded 125 references, of which 48 were duplicates of records already located through our searches. The remaining 77 unique hits were screened, and no references were included.

9.0 Appendix B. Screening checklist

Table B1. Screening checklist

1.	Does the study have a focus on TB services of any kind? (Studies need not focus on TB exclusively, but must present data relating to TB. Abstracts regarding infectious diseases in general, which do not mention TB, should be excluded. Studies of the microbiology of TB, or the pharmacokinetics of specific treatments, without reference to services, should be excluded.)	YES/UNCLEAR – go to Q2	NO – exclude 1_EX TB
2.	Was the study conducted in an OECD country? ³⁴	YES/UNCLEAR – go to Q3	NO – exclude 2_EX Country
3.	Was the study published in 1990 or later?	YES/UNCLEAR – go to Q4	NO – exclude 3_EX Date
4.	Does the study present views data regarding perceptions of or attitudes to TB services? (This includes views of service users, professionals and other stakeholders. It includes views of existing services, preferences, past experiences or future expectations, knowledge and beliefs relating to testing, or potential barriers and facilitators of accessing services. Study methods include surveys, interviews, case studies, or ethnographic or action research. Both qualitative and quantitative views data should be included here. Studies of behaviour alone, using a questionnaire methodology, should be excluded. Studies of the effectiveness or cost-effectiveness of clinical treatments	YES/UNCLEAR – go to Q5	NO – exclude 4_EX Views

³⁴ For the purposes of this review, OECD countries are taken to include: Australia; Austria; Belgium; Canada; Chile; Czech Republic; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Iceland; Ireland; Israel; Italy; Japan; Luxembourg; Mexico; the Netherlands; New Zealand; Poland; Portugal; South Korea; Slovakia; Slovenia; Spain; Sweden; Switzerland; Turkey; the UK; and the USA.

	should be excluded. Systematic reviews ³⁵ including such studies should be included at this stage.)		
5.	Does the study present qualitative data?	YES/UNCLEAR – go to Q7	NO – exclude 99_EX Quals
6.	Does the study include data from any hard-to-reach group? (Hard-to-reach groups include, but are not limited to: prisoners; problem drug users or people with alcohol problems; homeless people or people in temporary accommodation; asylum seekers, refugees and recent immigrants; travellers; and sex workers. Groups such as Aboriginal peoples or migrant populations that are not particularly relevant in the UK setting are not considered hard-to-reach for this review. This criterion should be applied inclusively at abstract stage, i.e. any paper not specifically excluding such groups should be included.)	YES/UNCLEAR – go to Q6	NO – exclude 5_EX Population
7.	Is the study report in English?	YES – include 7_IN English	NO – include 6_IN Non-English

For cases where inclusion is unclear, code as **8_QUERY** and save to discuss with screening team.

³⁵ A systematic review is one which clearly reports its search strategies and inclusion criteria. Reviews which are clearly non-systematic should be coded as 'exclude' at this point.

10.0 Appendix C. Evidence tables

Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Belling, R. Woods, L. Boudioni, M. McLaren, S.</p> <p>Year:</p> <p>2008</p> <p>Citation:</p> <p><i>Pan London Tuberculosis services: An audit evaluation.</i> Institute for Strategic Leadership and Improvement. London South Bank University: London.</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>To conduct an audit of pan-London tuberculosis (TB) services in relation to the range of services and expertise required to control and treat TB in London.</p> <p>Specific objective relevant to this review:</p> <p>To assess TB service user experiences and satisfaction with London's TB services, particularly those most at risk of not completing treatment.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>What methods:</p>	<p>What population were the sample recruited from:</p> <p>Four geographical London sectors</p> <p>How were they recruited:</p> <p>A pool of lead TB professionals (physicians, nurses, network managers) was identified within all London sectors and invited to take part.</p> <p>London TB nurses were contacted by several Steering Group members via email lists to notify them of opportunities for participation in a focus group. Information about the purpose of the focus group and what it would cover were provided and interested nurses were advised to contact the audit team directly for further information.</p> <p>External epidemiologists and respiratory or TB physicians, practising</p>	<p>Brief description of method and process of analysis:</p> <p>The audit included a non-systematic document evaluation of the delivery of TB services in the London area.</p> <p>For the purposes of this review, however, data has been extracted from semi-structure interviews with ten purposively selected service users from 4 geographical London sectors participated on a voluntary basis.</p> <p>Semi-structured interviews were also conducted with thirteen lead TB professionals (physicians, nurses and managers) working within the London sectors.</p> <p>Two focus groups, one with eight TB nurses and one with two external professionals (respiratory, TB physicians) were also completed.</p> <p>Interviews were tape recorded and transcribed and any identifying information removed to ensure anonymity and confidentiality. If noise interruptions prevented effective tape recording, hand written notes were taken.</p> <p>Thematic analysis was conducted using QSR Nu*Dist v.6 software.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p>	<p>Limitations identified by author:</p> <p>Overall, the purposive sampling framework did not consider gender; females are not equally represented, however, it should be noted that the reported incidence of TB is slightly higher in males (54%) versus females (46%) (HPA, 2007).</p> <p>Limitations identified by reviewer:</p> <p>Difficult to identify the particular risk group associated with quotations. Issues are not discussed which may be specific to these hard-to-reach groups.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>A more detailed, comprehensive picture of sector progress against draft targets is</p>

	<p>Semi-structured interviews and focus groups</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>Service user interviews were conducted at a private and quiet location, usually at a consultation room at the clinic.</p> <p>When:</p> <p>Between November 2007 and March 2008</p>	<p>outside London or not currently designated as London TB sector clinical professional leads at the time of this audit, were invited to attend a focus group.</p> <p>Service users were recruited using a purposive sampling framework developed by the project Steering Group in a two stage process. In Stage 1, lead TB nurses at each of the London sectors were asked to identify TB service users who met at least one of the criteria based on five risk groups below.</p> <ul style="list-style-type: none"> • Compliant users • Immigrants • Prison users • HIV co-infected • Mental health problems present <p>In Stage 2, following further advice from the Steering Group, lead TB nurses were asked to identify TB service users who met the following criteria:</p> <ul style="list-style-type: none"> • UK born males, 20-39 years old, single diagnosis of 	<p><u>Professional interviews and focus groups</u></p> <p><u>Access</u></p> <p>Participants indicated a wide variety of access routes into the TB service:</p> <p><i>“Mainly through A&E, GP, occasionally self-referral... Through contact tracing. Sometimes through other organisations, e.g. drug teams at XXXX, but not that often. Certainly, in the south of sector, there is a large homeless population and they have quite a good relationship with hostels and they would be referred in through their key worker. Also, the mobile x-ray unit.”</i></p> <p>Some wanted to develop faster access routes:</p> <p><i>“I’d like to look at a more rapid-access service, with a nurse on site three days a week, for example, so the referrers would know they could contact the nurses and get them in to see a doctor in urgent cases.”</i></p> <p>Many came through A & E rather than through a GP referral:</p> <p><i>“Quite a few people come in through A&E, usually the ones who haven’t got GPs.”</i></p> <p>It was suggested that delays were sometimes caused by GPs or other referrers not suspecting the patient had TB:</p> <p><i>“I think like everywhere we have a problem with people not recognising someone has TB and that leading to delay in proper contact, which we spend a huge amount of time</i></p>	<p>required to better establish how TB services operate across London as a whole. The authors recommend that the collection of this data is centrally co-ordinated by the Networks and then shared with NHS London and that performance data be collected as an ongoing exercise.</p> <p>Source of funding:</p> <p>NHS London</p>
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		<p>TB.</p> <p>The sampling framework aimed to ensure representation of service users from the five geographical London sectors; however due to difficulties in identifying service users with the selected criteria, NC sector is not represented. A total of ten interviews were conducted with TB services users who met the above selection criteria between November 2007 and March 2008.</p> <p>To facilitate recruitment, lead TB nurses were sent information sheets and consent forms that they could distribute directly to users, when they were first contacted, regarding voluntary participation. All participants read the information sheet and signed the consent form prior to the interview. All interviews took place at a time convenient to the participants, usually after their regular appointment, and lasted between 30 and 60 minutes..</p> <p>How many participants</p>	<p><i>doing.”</i></p> <p><u>Diverse needs</u> Many participants were very conscious of the diversity of patient groups and the complexity of needs within their sectors:</p> <p><i>“We’ve found an increasing proportion of the caseload here, homelessness, drug use, alcohol, sociopathic behaviour. It’s the only borough where those four problems really are. In XXXX it’s much more related to communication. Somali communities are very stable. XXXX is more mixed because it has more people from Indian sub-continent, south east Asia. They generally have strong family set ups. So it’s the delivery of treatment that can be difficult.”</i></p> <p>Within each group there are particular health beliefs:</p> <p><i>“You can’t always know everything. You might be used to dealing with Somalians and then get a group of Rwandans, whose health needs are different. I feel fairly comfortable with the Muslims who say, it’s Ramadan, I can’t take my tablets. I know exactly what to say and I can point to the passage in the Koran where it says it’s OK to take tablets if you’re ill. But somebody from Vietnam, I know nothing about their health beliefs. And you can’t just send people on courses to find out because you just don’t know what you’re going to get. I’ve got a middle class mother who won’t bring her child in because she doesn’t believe in anything. And she’s white, middle class. She lives in my suburb and her health beliefs are not available to me.”</i></p>	
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		<p>were recruited:</p> <p>33</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Service users who needed to meet at least one criterion based on six risk groups - compliant users, immigrants, prisoners, HIV co-infected, mental health problems, UK born males age 20-39 years with single diagnosis of TB.</p>	<p>Many TB teams are targeting the particularly well established cultural or ethnic groups:</p> <p><i>“About 50% of my patients are probably Muslim, so there’s the issue of trying to encourage them to take their medicine (see previous quotation.) It’s very difficult culturally. We have to do a lot of work with the mosque.”</i></p> <p>With other groups, such as prison users:</p> <p><i>“We reinvent the wheel each time. Protocols and guidelines would be helpful in avoiding that.”</i></p> <p>Communication with patients was often a challenge and took time. In some TB services, nurses could not always get translators instantly, whereas others, mainly hospital based, felt the interpretive services were more readily available.</p> <p>Some participants called for either more collaborative working or better co-ordination.</p> <p>Most participants said there were few specific care packages available to particular socially disadvantaged groups:</p> <p><i>“No separate special services for them. Vulnerability is assessed as part of clinical assessment and different levels of support offered as appropriate. Some alcoholic cases in one patch, but not actually homeless, so it hasn’t been a huge problem in this sector. There has been awareness raising with specific groups, e.g. Somali and Black</i></p>	
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			<p><i>African groups. Very high incidence of TB in these groups, so raising awareness of TB and HIV. Anxieties about stigma and concerns about TB not being treatable.”</i></p> <p>Cultural awareness and sensitivity was frequently raised in relation to some of the larger ethnic groups with the highest rates of TB, including Somali populations:</p> <p><i>“Other groups in our sector, Somali population probably requires special attention because of cultural backgrounds. They usually have high TB rates.”</i></p> <p>Drug users and homelessness were highlighted as needing targeted attention:</p> <p><i>“The more complicated patients are homeless, drug user, no shows, difficult to manage, lost to follow up. Find and Treat programme might help with those, or be able to reconnect them with the service.”</i></p> <p><u>Links and coordination</u> All participants who described interagency working said there was room for improvement in collaborating and building better links, particularly with cultural organisations:</p> <p><i>“There needs to be better links to the cultural organisations, e.g. the Bangladeshi Society, to enable better communication.”</i></p> <p><u>Service users</u></p> <p><u>Diagnosis</u> In most cases, the initial point of contact for service users was the GP: <i>“October 2006 and</i></p>	
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			<p><i>I went to see my GP and she just gave me Diclofenac, Diclofenac, Diclofenac painkiller and at the end of the January, she said it's out of like my hands so I can refer you to the (name of Hospital) and she just referred me to Dr (name), who is a very nice man as well... Like, she took like four months."</i></p> <p><u>TB services</u> Most patients had treatment for 6 months. For those given over 6 months treatment there was sometimes misunderstanding: <i>"My treatment was in for say nine months but it went more than nine months. I had the proper, proper virus, so they said nine to a year, so the last time I came to the hospital I was speaking to the doctor, he said to me, he's going to give me three more months, because its still sat in there."</i></p> <p><u>Management of care</u> Patient's who were not undergoing DOT found that having a carers, partners or friends assist their day to day care by giving the tablets to them or even making the process more pleasant: <i>"That guy needs to take nine o'clock this medicine, one o'clock this, six o'clock this. So do they help you with taking the medicine as well? Everything, even they just like... - I hate milk, so they just bought some bananas, brought milk in it, and they give me milkshake and in the evening they give me some cold chocolate and some sort of things, so I can take it.'</i></p> <p><u>Compliance</u> Most service users said that they did as doctors/nurses asked and that they were taking their medications as instructed. There</p>	
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			<p>were however occasions when they did not take their medication because it was not convenient or they forgot, i.e. when staying out at a friend's house or had some difficult personal circumstances.</p> <p><u>Treatment satisfaction</u> Overall the majority of service users were satisfied with the treatment received. Users identified good communication and service organisation as noteworthy. <i>"As I can say like, I can do anything for these guys, they help me very much....As I said like they treat me like a mum and son."</i></p> <p><u>Incentives</u> No participants were given incentives and none requested it.</p> <p>Support with housing and financial issues were welcome particularly from those with no fixed address. Many felt that nurses were too busy or were not trained to provide these services. <i>"I cannot see it have to do with them."</i> Some said nurses would be a useful source of information and help.</p> <p>Managed accommodation was seen as helpful but stigmatised. The most helpful form of accommodation support was considered hostel accommodation run by people who understood TB. This was particularly the case for homeless users: <i>"No, but then I, they could find me a place, because I don't have anywhere to go. They could find me a place and people who would work with me at that place... Yes, the thing is I don't have anywhere else anyway."</i></p>	
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			<p><u>Concerns about diagnosis</u> Most people who did not know about TB previously were shocked and compared the condition with other conditions, such as HIV and hepatitis. Concerns were also expressed that this was a condition for life. Disbelief and trying to think of the reasons for getting it were also common. Another concern was about passing the infection to others. The contagious nature of the disease, and its specific characteristics comparing with other diseases made some participants to act responsibly. In some occasions, there were feelings of being guilty: <i>“...It’s hard for me to ...you know there are stereotypes like HIV is probably the biggest one, but... like other diseases, you know. But one of the things about TB, you know, I think is more dangerous, because I can sneeze and give it to someone, you know, or cough, you know... whereas HIV’s more contained. Because I do have, you know that responsibility of me not giving it to other people, you know.”</i></p> <p><u>Effects of TB</u> TB affected sufferers to different extents, ranging from minimal for few to a great extent in most cases. TB affected several other aspects of sufferers’ lives. Some people’s sense of freedom was affected; they felt that they could not do many things anymore. <i>“I was feeling prisoned, I was feeling like I was in prison, I couldn’t see no-one, I couldn’t talk to no-one. I couldn’t go out...”</i></p> <p><u>Reactions of friends and families</u> The reactions from others were really mixed. The view was expressed that the general public do not know enough about tuberculosis</p>	
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			<p>and there are certain misconceptions about the condition. <i>“Because normally like if, like people listen, like somebody got a TB. So they just, tell them just people out, ‘oh man you’ve got TB just get out’, but because they don’t know what exactly it is, like, like my doctor said there is two kind of TB, one is infected to someone. And one is like don’t affect to anyone.”</i> Some did not tell others about their diagnosis and felt protective of their families. In most cases, however, families and friends were supportive. Religion was also mentioned a couple of times, either as an explanation of the condition or as supportive mechanism. <i>“And I’m Muslim, like, we say like, everything happens, like God knows, like, it’s better for us.”</i></p> <p><u>Support during and after treatment</u> Support was received from family and friends or other social networks, in terms of taking the medication or merely asking if the medication was taken. Friends and relatives were usually more attentive and caring than before the diagnosis.</p> <p><u>Advice for others with TB</u> The most common advice to give to other people diagnosed with TB would be to take their treatment, not to miss their medication, and to look after themselves: <i>“I can say like look after yourself, don’t miss your medication, it’s really important, people think like if they miss one time medicine, it doesn’t make any difference but personally makes a lot of difference, because they are working like back hand, they are working very hard for you. It’s worth it because life is not a game, if you lose it so you can just replay it or you can play it,</i></p>	
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			<i>it's a life. And life matters for yourself, for others. Don't be mean, like if you are suffering this, unless who cares? Loads of people suffer because of you, if something happened with me, so obviously my mum and dad they are very bothered."</i>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Brent Refugee Forum</p> <p>Year: 2007</p> <p>Citation: <i>Knowledge, perceptions and barriers and the social meaning of tuberculosis among asylum seekers, homeless people and refugee communities in Brent 2004 – 2006.</i> Brent Refugee Forum: London.</p> <p>Quality Score: (++, + or -) ++</p>	<p>What was/were the research questions: To gauge the level of knowledge, community attitude and perception of TB among groups at high risk of social exclusion and deprivation in the London Borough of Brent.</p> <p>To identify barriers different groups face in accessing treatment, and how the cultural context of TB affects their lives.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): NR</p> <p>How were the data collected: What methods: Focus groups and interviews</p> <p>By whom: Community focus groups were run by members of refugee community</p>	<p>What population were the sample recruited from: Immigrants, refugees and asylum seekers in Brent – the fourth most deprived borough in outer London and home to one of the largest refugee and asylum seeker populations in London.</p> <p>How were they recruited: Community focus group participants were drawn from contacts held by a number of local community refugee organisations.</p> <p>Patient interviewees were sourced through local GPs and chest clinics. The authors report problems recruiting patients and only one patient interview was conducted. This patient was recruited by sending the information and then contacting the patient by phone to ask if they would like to be interviewed.</p> <p>How many participants</p>	<p>Brief description of method and process of analysis: Participants from different ethnicities, backgrounds, genders and ages took part in ten community focus groups which were conducted in community languages. Participants were also given a questionnaire to gauge knowledge of TB prior to the session. Each group had between 8 and 10 participants. The sessions were recorded and transcribed and transcripts were validated by participants.</p> <p>Professionals involved with TB also took part in focus groups. Four nurses and 15 doctors participated in three groups which aimed to understand their experiences in working with immigrants and refugees and identify contributing factors for delayed diagnosis and treatment incompleteness. These groups were transcribed and analysed separately using thematic analysis.</p> <p>One semi-structured interview was conducted with a TB patient. This interview took around an hour and was recorded and transcribed.</p> <p>The data were analysed by three independent researchers using an integrative approach.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p>Community focus groups</p>	<p>Limitations identified by author: None noted besides lack of one-on-one interviews which were sought extensively with only one agreeing.</p> <p>Limitations identified by reviewer: The presentation of quotes is poor as it is unclear who is speaking and whether it is an interpretation of what was said or transcribed data.</p> <p>Evidence gaps and/or recommendations for future research: NR</p> <p>Source of funding: Brent Health Action Zone; Brent Primary Care Trust</p>

	<p>organisations who speak the same language as participants.</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>2004 - 2006</p>	<p>were recruited:</p> <p>104 immigrants (with or without TB experiences) 15 health professionals (4 nurses and 11 GPs) 1 TB patient</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Most findings were common across all the groups, with a few themes specific to certain communities. There were no significant differences in community perception, attitudes, and the way stigma affects TB control and management.</p> <p><u>Specific to Somali community</u> People from Somalia were concerned that social gatherings to consume <i>qat</i> (or <i>khat</i>, which is a flowering plant with stimulant properties) may increase families' and children's vulnerability to developing TB, through overcrowding, sharing cups and smoking during the gathering. <i>"There are more Somali men who have positive results for TB than women. When they go to the Qat dens they close all the doors and windows."</i> (Somali community group). Somali people often sought traditional medicine as a first point of contact however all participants said they would be willing to seek help if they suspected that had TB.</p> <p><u>Knowledge of TB</u> Knowledge of TB varied within the groups with some having quite a lot of knowledge because of their own experiences and feeling comfortable talking about TB, and others without basic knowledge of TB.</p> <p>The issue of traditional medicine as a first line of treatment was raised by some groups which some feared would result in delayed treatment. Some communities associated TB with poverty and a lack of personal hygiene.</p> <p><u>Perceptions of TB</u></p>	
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			<p>There was an association in responses between TB, fear and death across communities.</p> <p>Fear, isolation and a belief that TB is hereditary was common among participants. The stigma associated with TB was often associated with an entire family. <i>“Sick persons are afraid to attend the centre so as not to be rejected by the family. They end up hiding their sickness.”</i> (African-French speaking group)</p> <p>Many groups associated TB with HIV/AIDS and said they thought there were similar symptoms. <i>“The Somali community see TB as a very bad illness. TB is to the Somali community they way HIV is to the rest of the world. It means death to many people.”</i> (Somali community group)</p> <p>There was a considerable response from Muslim communities that TB was a punishment from God. The stigma from TB was often long lasting and those who take this view often developed deep shame and guilt if they contract TB.</p> <p><u>Attitudes towards TB</u> Discussions noted that TB resulted in isolation of the patient from the community and self-isolation. TB was said to negatively affect social relationships and some participants said people were not willing to marry into a family that had TB patients.</p> <p><u>Stigma</u> Most groups described a sense of shame and forced or voluntary isolation resulting from a</p>	
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			<p>TB diagnosis. Stigma was expressed differently in different groups. <i>“Even after the disease is treated and cured fully, the person is nicknamed ‘TB man’ for the rest of his life.”</i> (Tamil community group)”</p> <p>Participants felt more effort is needed to reduce the effect of stigma. It was reported that TB patients often face dual stigma – from their own communities and their host communities.</p> <p><u>Barriers</u> Many groups identified a lack of information or difficulty in accessing information about available services and poor signposting for TB services as being barriers. Some felt that TB service providers were not working closely enough with communities to break down barriers and follow-up with cases. Participants noted that confidence of service providers needed to be raised in dealing with sensitive cultural and immigration issues. <i>“I need accommodation and an address first before I register with a GP”</i> (Single homeless persons group)</p> <p><u>Professionals focus groups</u></p> <p><u>TB knowledge, skills and resources</u> Most GPs and nurses felt confident they could diagnose pulmonary TB. However some felt they would have difficulty diagnosing non-pulmonary TB because it is less obvious. Concern was expressed about pathways to diagnosis. <i>“In my capacity as a nurse, I have the knowledge and the skills but most refugees have more social problems, which I cannot really deal with.”</i> (nurse)</p>	
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			<p><u>Language and translation</u> GPs and nurses spoke at length regarding language and translation acting as barriers to successful treatment. Phone translation systems were often used which were unreliable and time consuming. <i>“The accuracy of an interpreter depends very much on the grasp of the language within the clinical context and whether they have a positive element of the likelihood of being advocates”</i> (GP).</p> <p><u>Transient populations</u> Referral to specialists can be slow resulting in patients getting lost. Immigrant dispersal units move people which may result in losing their chance to be seen by specialist medical services. There can also be delays caused by obtaining records when moving HP. <i>“You get this hiatus every time you try to get access to records and it can drag on and on and on. The records then go up and across and there is a delay.”</i> (doctor).</p> <p><u>Finance</u> Refugees often found it financially difficult to cope with repeated visits to GPs and chest clinics. <i>“I think there is a problem for refugee patients who are hard up, to actually trek from one hospital to another, and some of the services are dispersed.”</i></p> <p><u>Cultural issues</u> Some participants said they found it difficult to deal with cultural issues, while others felt more comfortable. It was recognised that women from some cultures have reservations about being examined by a male doctor. Different</p>	
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			<p>perceptions of health were considered to sometimes be an obstacle to treatment. <i>“The difficulty is getting them here, because after two months they may feel better again...and they might decide not to continue their treatment.”</i> Other cultural norms were seen as important in the spread of TB such as <i>qat (khat)</i> chewing in Somali communities. Cultural awareness was said to be sometimes confused by social stereotypes. It was noted that professionals need to be open and willing to learn and not make assumptions about a ‘group.’</p> <p><u>Stigma</u> Stigma was considered one of the most important factors in determining whether patient’s seek help if they become ill. <i>“Like recently the mobile unit has found some people in need. I think they have identified three people but they never came up to the clinic.”</i></p> <p><u>Access to health services and expectations</u> The participants said they felt unable to respond to all the needs presented, especially as some communities expected a full ‘MOT’ health check. <i>“You know, sometimes you feel like they’re going away disappointed or..let down is probably too strong a word but we haven’t met their expectations, if you like, because in the end we can’t deal with everything.”</i> (nurse). It was suggested that a mobile health record that is owned by the patient would be useful for all concerned in the management of TB. Participants suggested that although many agencies exist to support asylum seekers and refugee communities, health providers lacked</p>	
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			<p>knowledge about where these agencies are and how best to access their services. Greater collaboration between Home Office and Department of Health was suggested.</p> <p><u>Time restraints</u> The allocated time slot for an appointment (ten minutes) for GPs to see their patients was felt by participants to be very inadequate to carry out health assessments for refugees and asylum seekers with complex needs. <i>“So you’ve got a lot of contentious issues to start with...and you’ve only got ten minutes. There’s an awful lot of things to take on board.”</i></p> <p><u>Complexity of TB</u> It was universally recognised by participants that TB is a complex social disease which affects all areas of a person’s life. For patients, the amalgam of factors is part of the same experience, yet health and social services are fragmented. <i>“I think they other complication is that there are obviously so many other things on their agenda...you know...housing, money and all sorts of things, and sometimes, you don’t have the time to get involved with the medical side.”</i> <i>“To be honest, being a TB nurse is like being part social worker, because you cannot just give medicine, you have to listen to their problems...and to help sort them out.”</i></p> <p><u>Immigration laws and regulation</u> Some of the participants felt they did not know and could not keep up with immigration regulations and how health services entitlements are affected. They felt it was difficult to get hold of up-to-date information about the regulations. It was noted that there</p>	
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			<p>was a potential impact of losing patients through fear of detailed information gathered about them. <i>“And we ask about their immigration status, which can seem very threatening, you know.”</i></p> <p><u>Difficulties dealing with homeless people</u> GPs cannot register homeless people if they have no address. Housing was reported as often being a problem as frequent moves can lead to loss of patients.</p> <p><u>Vulnerability of refugees and homeless people</u> The participants said that for many, health might not be a top priority while settling into their new country, or for homeless people who have more immediate concerns. <i>“Some of the refugees live in conditions of overcrowding...they live with family members and friends and people from the same area...and generally the houses may not be in a good state of repair.”</i></p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Brewin, P. Jones, A. McDonald, M. Beasley, E. Sturdy, P. Bothamley, G. Griffiths, C.</p> <p>Year:</p> <p>2006</p> <p>Citation:</p> <p>Is screening for tuberculosis acceptable to immigrants? A qualitative study. <i>Journal of Public Health</i>. 28 (3): 253 – 260.</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To determine how acceptable tuberculosis screening is to immigrant groups. To understand immigrants' understandings of TB in relation to screening</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Semi-structured interviews</p> <p>By whom:</p> <p>Three of the authors (P.B., A.J. and M.K.)</p> <p>What setting(s):</p> <p>Private rooms at screening site</p>	<p>What population were the sample recruited from:</p> <p>Adult immigrants who had been offered TB screening in East London (the area of the highest incidence of TB in the UK).</p> <p>How were they recruited:</p> <p>The social services centre used posters and leaflets to advertise that screening would be offered to asylum seekers attending for benefits and advice. The primary care centre offered screening to all new patients during their registration health check. The hospital clinic sent written invitations for screening by post to addresses given by new entrants identified by port health teams at recent entry to the UK.</p> <p>Researchers directly approached those who were offered screening in the three settings (social services centre for asylum seekers; hospital clinic for new entrants; primary</p>	<p>Brief description of method and process of analysis:</p> <p>Participants had all been offered screening for tuberculosis as part of voluntary programmes in three settings: 1. a social services centre providing benefits and advice for asylum seekers ($n=24$), 2. A hospital clinic, screening new entrants to the UK ($n=15$) and 3. A primary health care centre, screening people registering ($n = 14$). The interviewers were presented as researchers, not as clinicians.</p> <p>44 of the interviews were conducted in English and 9 were conducted with the assistance of translation. Fluency and need for a translator was assessed informally while the study was being introduced. Interviews were piloted and they were semi-structured.</p> <p>The analysis was conducted in consultation with a multi-disciplinary team which met frequently during and after the interview phase. The research employed a constant comparison approach whereby new transcripts were compared with existing data which guided sampling and interview content. Data was analysed according to the framework method involving five key stages: familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation. A coding framework was agreed upon following a review of the transcripts. Dissonant cases were particularly sought after. Two researchers independently coded and reconciled the transcripts and data was systematically tabulated under seven</p>	<p>Limitations identified by author:</p> <p>Only a few participants that were recruited had decline screening therefore limited judgements can be made about why people do not attend.</p> <p>Limitations identified by review team:</p> <p>Little in-depth analysis by ethnicity. Possible selection bias may have resulted in a lack of diversity of views.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>Screening was voluntary and the authors suggest that further research should address the acceptability of compulsory screening.</p> <p>Source of funding:</p> <p>ELENoR (East London Network of Researchers), NELCRAD (North East</p>

	<p>When:</p> <p>NR</p>	<p>health care centre).</p> <p>Recruitment stopped once data saturation was reached.</p> <p>How many participants were recruited:</p> <p>53</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Immigrants (newly arrived)</p>	<p>themes. MAXqda software was used to handle the data.</p> <p>The analysis was presented to a focus group consisting of four patients to test validity.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Positive views of the acceptability of screening</u> The interviewees overwhelmingly responded positively to screening and were reassured by the process. Some saw it as a privilege and a good idea. Screening was seen as socially responsible and some felt that screening should be particularly promoted to children. <i>“I was looking forward to get the results to know I am okay and happy because it allow me to be sure I am not suffering from this disease.” (30-year-old, African male)</i> <i>“Is better they should do for the children, the test tuberculosis.” (28-year-old Polish female)</i></p> <p><u>Reasons for rejecting screening</u> Only four people were identified for this research who had declined screening during the study. They were found not to be adverse to screening <i>per se</i>: two thought it was unnecessary because they had been vaccinated and two preferred to be screened by their general practitioners. One respondent who had mental health issues felt that she was being ‘singled out’ at the social services and that it should not be just asylum seekers who are offered testing. <i>“Oh I didn’t want it because when I was in my country they gave me already the vaccination.” (32-year-old female from Burundi).</i> <i>“It is better at the GP. I go to my GP if I have problems.” (35-year-old</i></p>	<p>London Consortium for Research and Development) and the North East London TB Network.</p>
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			<p>Algerian male) <i>"I think all of us [should be screened], they should start with the kids, we don't mind having it...[but] I am scared of it, it is like they are calling us, they are pushing us, we are being singled out."</i> (26-year-old African female).</p> <p><u>Anxieties about the process of screening</u> Although respondents were generally positive about the purpose of screening, some expressed anxieties about the <i>process</i> of screening. These comments related to a lack of public health information and explanation given by staff. <i>"She didn't know quite what was going on so she was worried. She thought something serious was happening but when the nurse explained what was happening, she calmed down."</i> (35-year-old Polish female) <i>"She only say me I have to take my blood pressure and my urine from me, she haven't mentioned the tuberculosis test but when I came and she saw perhaps I am a black person, or something like that. I am not saying she is racist or something like that, but I think it is because I am African."</i> (30-year-old African male – accepted screening).</p> <p><u>Screening setting</u> While informants were positive about the setting in which they had been seen, not all settings were acceptable to all participants. Primary care was seen as 'easy', 'local' and appropriate. Some saw the GP surgery as 'safer and cleaner' and one commented that they felt safer at the GP <i>"because you are familiar with him and the way [the surgery] works."</i> Hospital was considered a good place to</p>	
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			<p>screen because it was “better equipped, with everything” with “very specialised” staff. One participant pointed out that “they have to transfer you” so going direct to the specialist was better.</p> <p>Social services were seen as “easy and quick” because other benefits (such as food vouchers) were also available in the same place and there were no queues. One participant saw there was a benefit to screening in a social services centre because it was a condition that people knew little about.</p> <p><u>Understandings of TB and their relationship to screening</u></p> <p>The explanatory models of TB reflected notions about germs and infection. Most understood that TB was a disease that affected the chest and several identified it as one of many ‘killer’ diseases. Many were unsure but most considered TB as an infection that affected the lungs. Transmission understanding varied substantially. According to the participants, ways of contracting TB included: smoking, touching people, sharing plates or glasses, mothers putting food from their mouths into their children’s mouths, coughing, sexual contact and not washing fruit and vegetables. Some population groups such as the homeless and incarcerated were seen as high risk. Some were unsure about the distinction between the vaccination and testing. Most saw TB as being treatable with long term courses of medicine.</p> <p>Many highlighted a lack of information and education compared with their country of origin and said that their knowledge was</p>	
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			<p>based on what they learned before entering the UK.</p> <p><i>"I think you can get tuberculosis from the skin. You have it on the skin and then you transmit it, transmission to other people."</i> (30-year-old African male). <i>"It's a hygienic thing, if you are dirty and don't care about your health you will get not only tuberculosis but other things as well, that's all I can say."</i> (21-year-old Indian male). <i>"I knew about this from my country but not from here."</i> (30-year-old Latvian woman).</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Chemtob D, Leventhal A, Weiler-Ravell D.</p> <p>Year:</p> <p>2003</p> <p>Citation:</p> <p>Screening and management of tuberculosis in immigrants: the challenge beyond professional competence. <i>International Journal of Tuberculosis and Lung Disease</i> 7: 10: 959-966</p> <p>Quality Score: (++, + or -)</p> <p>-</p>	<p>What was/were the research questions:</p> <p>To analyse (from the perspective of a National Tuberculosis Control Programme, NTP) the following questions:</p> <p>1) What are the demands of the NTP in the context of immigration?</p> <p>2) <i>What are the barriers to diagnosis, prevention and treatment of TB among immigrants that need to be identified by the host authorities?</i></p> <p>3) What is the potential spread of the disease to the host population?</p> <p>4) What could be an overall strategy for an NTP to deal with immigration and TB?</p> <p>For the purposes of this review we are strictly interested in the second objective listed (that has used qualitative research methods) and have extracted only that data here.</p> <p>What theoretical</p>	<p>What population were the sample recruited from:</p> <p>Israel</p> <p>How were they recruited:</p> <p>NR</p> <p>How many participants were recruited:</p> <p>12 Ethiopian families (ranging in size from 2 to 13 members); 3 traditional healers and 21 Israeli health and absorption professionals</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Brief description of method and process of analysis:</p> <p>This study made use of anthropological interviews conducted with Ethiopian families, traditional healers and Israeli health and absorption professionals.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Understanding TB</u> Participants did not have a standard term for tuberculosis. Therefore, the translator that informed patients in Amharic that they had TB would use words such as “<i>yesamba nekera</i>” (lung cancer) or “<i>yesal beshita</i>” (a common cold).</p> <p><u>Treatment and adherence</u> Patients felt that the 6 month pill treatment for TB was inappropriate.</p> <p>TB nurses thought that the interventions that make use of a simple questionnaire, used by welfare social workers, were ineffective.</p>	<p>Limitations identified by author:</p> <p>NR</p> <p>Limitations identified by review team:</p> <p>This paper does not provide any information on the process of analysis or sufficient detail on the methods conducted.</p> <p>The findings are not coherent and are mixed with interpretive data, conclusions and other literature.</p> <p>Very little reporting of data from the interviews conducted was provided.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>NR</p>

	<p>approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected: What methods:</p> <p>Interviews</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>Absorption centres and permanent settlements</p> <p>When:</p> <p>1997 (over a 5 month period)</p>			
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Craig, G. Booth, H. Hall, J. Story, A. Hayward, A. Goodburn, A. Zumla, A.</p> <p>Year:</p> <p>2008</p> <p>Citation:</p> <p>Establishing a new service role in tuberculosis care: the tuberculosis link worker. <i>Journal of Advanced Nursing</i>. 61 (4): 413 – 424.</p> <p>Quality Score: (++, + or -)</p> <p>-</p>	<p>What was/were the research questions:</p> <p>To determine how a social outreach model of care, including a TB link worker (TBLW), can be best implemented for marginalized groups with tuberculosis.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>Semi-structured interviews (face-to-face and telephone) and group interviews</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>January 2003 – April</p>	<p>What population were the sample recruited from:</p> <p>Care providers with experience of collaborative working in Britain.</p> <p>How were they recruited:</p> <p>The agencies were sent a written invitation to participate in the research.</p> <p>How many participants were recruited:</p> <p>Eight semi-structured and one group interview with professionals from eight care providers.</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Brief description of method and process of analysis:</p> <p>There were multiple methods used for this process evaluation of the TBLW service role including quantitative analysis of forms and patient records and profiling patient need. This data is not relevant to the purposes of this review and has therefore not been extracted here.</p> <p>Of relevance here is the qualitative component of this study involving semi-structured interviews conducted with service providers to gather feedback on collaborative care.</p> <p>Both group discussions and face-to-face and phone interviews were held with agencies. The interviews focused on the role and value of the link worker post and collaborative practice. Interviews were held at the end of tuberculosis treatment and the agencies were representative of the type of referrals made by the TBLW and patient's presenting problems.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Benefits of TB link workers</u></p> <p><u>Additional time and the intensive support.</u> The TBLW was also seen as able to offer the sharing of information and raise awareness of the disease. The ability to advise of potential difficulties experienced by a patient which could have a negative impact on treatment,</p>	<p>Limitations identified by author:</p> <p>The study was located in an area characterised by high levels of homelessness and a concentration of agencies working with this group. Other localities may have fewer resources which may be a factor when considering the generalisability of the work.</p> <p>It is likely that those participants in the interviews were those with a positive experience of inter-professional practice.</p> <p>The researcher offered strategic direction and was a stakeholder in the project.</p> <p>Limitations identified by review team:</p> <p>Little diversity of opinion may indicate selection bias.</p>

	2005		<p>such as warning signs for disengagement, was valued by the agencies. <i>“Once the client was diagnosed with TB he was quite unmotivated, missing appointments, and we worked jointly to help him re-motivate himself with the understanding he would feel weak, have a temperature and he wasn’t just being lazy. Now we understand the symptoms and can be flexible around that.”</i> (Key worker, homeless hostel worker)</p> <p><u>Effective linkages between the patient, health and community.</u> <i>“The TBLW’s done what the job implied: Link the community, person and health service with a consistency of service you wouldn’t otherwise get. With limited resources it’s helped us to make appropriate criteria links, by accessing the medical to those most in need.”</i> (Social worker, asylum and refugee team).</p> <p><u>Greater awareness of tuberculosis and access to services</u> This was mentioned including the preventative aspect of the role. <i>“It’s been good for the frontline staff to understand where TB links in, and get support accessing services.”</i> (Homeless Forum)</p> <p><u>Emotional and practical support</u> for patients and the opportunity to establish trust was mentioned. <i>“The TBLW knew more about the client and we could share experiences. There was extra support for the client which I wasn’t able to give”</i> (British Red Cross worker, Refugee Unit).</p> <p><u>Housing</u></p>	<p>Evidence gaps and/or recommendations for future research: Future evaluations could explore the use of a partnership tool to assess the strengths of collaborative working pre- and post-intervention.</p> <p>Source of funding: King’s Fund, The Henry Smith Charity, The Sir Halley Stewart Trust, The Kirby Laing Foundation and The Adint Charitable Trust.</p>
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			<p>There were benefits for the statutory housing services in terms of housing support and improved needs assessment. The importance of demonstrating that support was in place before housing service would accommodate certain groups was stressed.</p> <p><i>“Its been really valuable when trying to put forward a case to get housing. The TBLW provided good evidence of the availability of support post (hospital) discharge, which helps to secure accommodation.” (Statutory housing officer)</i></p> <p><u>Communication</u> Interviewees expressed that the TBLW improved communication with doctors on the wards, particularly in relation to discharge. The status of the TBLW as a public health representative had an impact on decisions concerning discharge. The ability to forget links between hospitals and the TB clinic was seen to improve care continuity and this had a positive effect on adherence to treatment. A ‘one-stop-shop’ approach was reported as being an incentive for engagement. <i>“They will have loads of other issues apart from their health and are more likely to turn up to the services if other issues can be addressed. Its like a day centre – get tea, see nurses, get help with housing and other issues.”</i> (Caseworker 2, Homeless healthcare agency).</p> <p><u>Meeting deadlines</u> A further advantage was reported to be that the TBLW could provide ‘evidence’ of need within very tight deadlines which could reduce in the risk of increased vulnerability caused by delays.</p>	
Study Details	Research Parameters	Populations and sample	Outcomes and methods of	Notes

		selection	analysis/Results	
<p>Authors:</p> <p>Curtis, R. Friedman, S. Neaigus, A. Jose, B. Goldstein, M. Des Jarlais, D.</p> <p>Year:</p> <p>1994</p> <p>Citation:</p> <p>Implications of directly observed therapy in tuberculosis control measures among IDUs. <i>Public Health Reports</i>. 109 (3): 319 – 327.</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To examine the responses of Injecting Drug Users (IDUs) to current TB strategies and to explore the implications of these responses for the implementation of DOT.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>How were the data collected:</p> <p>What methods:</p> <p>210 ethnographic interviews and observations</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>The study was conducted in Brooklyn, New York. The community contained several major drug selling areas. It had one TB chest clinic staffed by one physician and 2 nurses</p>	<p>What population were the sample recruited from:</p> <p>The research was conducted in a community that was predominantly Latino and had a population of 102,572 people, 42,066 of whom had received some form of public benefit in 1990. Thousands of IDUs and crack smokers, many of them homeless, resided in or used drugs in that neighbourhood.</p> <p>How were they recruited:</p> <p>NR</p> <p>How many participants were recruited:</p> <p>68 – 46 women and 22 men. 28 were Latino, 22 were black and 18 were white.</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Injecting Drug Users or</p>	<p>Brief description of method and process of analysis:</p> <p>This ethnographic research was part of a larger study in which 796 structured interviews with IDUs were conducted with an emphasis on HIV risk factors. As a part of this research, the participants were asked “Have you ever been told by a doctor, nurse, or other health care professional that you had tuberculosis”. People that answered yes were asked how long ago they received their diagnosis and what their most recent TB diagnosis was.</p> <p>The interviews were semi-structured, informal and were tape-recorded and transcribed. Observations were collected as field-notes.</p> <p>Interview respondents were paid \$10, but were paid nothing for informal or casual interviews that were not recorded. Before each interview or extended visit to a drug-use setting, the participants were told about the research and consent was obtained.</p> <p>The authors do not discuss analysis methods, but data is presented as three case studies.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Lack of TB knowledge of IDUs</u> The three case studies highlight that there is a serious lack of understanding of TB among IDUs. Two of the case studies believed they had active TB, despite medical records indicating that they did not. They reported that</p>	<p>Limitations identified by author:</p> <p>Authors note that the weakness of the ethnographic technique employed is that it is difficult to generalise from small samples that have been purposely, rather than randomly selected.</p> <p>Limitations identified by review team:</p> <p>There were few quotes from the interviews used within the article. Lack of diversity of opinions due to case study methodology. Lack of clear methodological explanation for many anecdotes.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>Quantification is needed of the numbers of noncompliant TB patients and sick IDUs who do not comply with medical treatment. Models of infectious</p>

	<p>who saw around 90 people per day.</p> <p>Observations were conducted in shooting galleries, crack houses, abandoned buildings and apartments where drugs were shared. Interviews conducted in the research store front while some were conducted in settings such as shooting galleries, apartments and cars.</p> <p>When:</p> <p>1990 - 1993</p>	<p>crack cocaine addicts</p>	<p>their doctors had told them that they had TB but were temporarily 'cured' but the cure was dependent on them continuing to take medication.</p> <p><u>Methadone treatment and TB</u> One case study describes a 33-year-old black woman IDU who was taken to hospital with possible TB symptoms, and when her fever subsided began to experience withdrawal symptoms. <i>"They didn't want to detox me. They the doctor said that they cannot detox me and treat me at the same time. First of all, they said that they don't want to give anyone methadone because it's not helping us, anyway."</i> The authors describe how this patient was later turned away from detox because of her TB diagnosis.</p> <p>The second case study was admitted to hospital with symptoms of TB, but once admitted methadone was not given and the patient discharged himself from hospital. The patient said it was to alleviate his withdrawal symptoms and because he felt threatened by the hospital staff and afraid of detention.</p> <p>Many IDUs who were interviewed reported that their efforts to obtain methadone therapy were met with resistance and contempt by hospital staff.</p> <p><u>Fear of incarceration</u> The interviews demonstrate that there is a fear of detention among IDUs with possible TB diagnosis.x Case Study 2 reported discharging himself from hospital because he had been threatened with involuntary detention for noncompliance. When his</p>	<p>person-days in the community could be developed based on such research.</p> <p>Source of funding:</p> <p>National Institute on Drug Abuse (USA)</p>
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			<p>symptoms returned he resisted going to a hospital because he had heard negative stories such as threats of detention and withholding methadone from IDUs in his gallery.</p> <p><u>Healthcare staff</u> The three case studies all report disrespect from hospital staff members. Case Study 1 encountered resistance after swearing frequently at staff during withdrawal: <i>"I had a social worker there. She was a real bitch. She didn't do anything for me...everything I asked this lady, she don't do that. She didn't do anything."</i> This case study was not an easy patient for hospital staff. Only two IDUs among 16 who were asked about their experiences in hospital settings said that they had positive experiences.</p> <p>Preventative therapy was not provided to any of the IDUs interviewed. The authors suggest that this may be because Medicaid does not reimburse physicians for TB (Isoniazid, INH) preventive therapy visits, although it does reimburse for the treatment of active disease.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Fujiwara P.</p> <p>Year: 2000</p> <p>Citation: Tide pools: what will be left after the tide has turned? <i>International Journal of Tuberculosis and Lung Disease</i> 4: 12: S111-S116</p> <p>Quality Score: (++, + or -) -</p>	<p>What was/were the research questions:</p> <p>To reduce the incidence of tuberculosis among recent immigrants from China, Dominican Republic, Puerto Rico, Ecuador and Haiti through the development of culturally appropriate marketing campaign; increasing awareness of TB related issues among individuals, communities and health care workers; and increase the number of people who are tested, evaluated and treated for TB.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected: What methods:</p> <p>Focus groups</p> <p>By whom: Focus group facilitators</p>	<p>What population were the sample recruited from:</p> <p>New York city recent immigrants from China, Ecuador, Haiti and Dominican Republic</p> <p>How were they recruited:</p> <p>Participants of Chinese origin were recruited from advertisements in Chinese language newspapers.</p> <p>How many participants were recruited:</p> <p>4 focus groups with 47 participants (20 males and 27 females).</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Brief description of method and process of analysis:</p> <p>There were four phases to the project: 1) formative research, 2) educating medical providers, 3) concept testing and 4) marketing campaign.</p> <p>Extracted here is the formative research data conducted by focus group discussions with recent immigrants. There is no sufficient data relevant to the aims of this review from the other phases of the research. Only data from Chinese focus groups has been extracted here (since the country of origin of other focus group members has little transferability to the UK context).</p> <p>Four focus groups were conducted targeted the four populations for this study. All study participants consisted of immigrants that had been in the USA for less than five years and that resided in zip codes with high numbers of TB cases.</p> <p>Participants were prompted to answer standardized questions that were developed in meetings with Tuberculosis Control Program Staff. The facilitators for the focus groups were recruited from within the targeted communities. Gratitude for participation was given by the provision of a light meal and transportation cards.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p>Chinese focus groups</p>	<p>Limitations identified by author:</p> <p>NR</p> <p>Limitations identified by review team:</p> <p>Since participants were recruited by newspaper, they were likely to be literate and be able to obtain knowledge of TB (in Chinese perhaps). The focus groups may therefore reflect the views of more educated Chinese immigrants.</p> <p>There is little information on how data was analysed and how themes were derived. There is also little detail in the reporting of findings, especially considering the long list of questions asked in focus groups.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p>

	<p>from within target communities</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>NR</p>		<p>The primary concern for participants was the cost of health care and insurance. Participants were also not aware of TB services that they could access such as Department of Health chest clinics.</p> <p>The knowledge and information on TB among study participants was vague. Some participants perceived that one could contract TB by smoking, being exposed to air pollution, working in garment factories or by poor hygiene. However, participants did feel that TB was a curable disease.</p> <p>It was understood by study participants that the New York City Department of Health (NYCDOH) would not report people to Immigration and Naturalizations Service because of TB diagnosis.</p> <p>The participants reported that the most effective way of transferring knowledge about TB and services is through newspapers or radio broadcasting.</p>	<p>NR</p>
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Gerrish K, Ismail M, Naisby A</p> <p>Year:</p> <p>2010</p> <p>Citation:</p> <p><i>Tackling TB together: a community participatory study of the socio-cultural factors influencing an understanding of TB within the Somali community in Sheffield.</i> Sheffield: Sheffield Hallam University.</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>This study aimed to:</p> <ol style="list-style-type: none"> 1. To identify socio-cultural influences on the prevention, diagnosis and treatment of TB within the Somali community 2. To gain insight into healthcare practitioners' perceptions of TB among the Somali community and their experiences of providing TB services to Somalis. 3. To identify ways in which culturally appropriate health promotion initiatives regarding TB can reach the Somali community 4. To identify ways of supporting healthcare practitioners to provide culturally appropriate care in regard to the screening, diagnosis and management of TB within the Somali community. <p>It should be noted that the study focused on active</p>	<p>What population were the sample recruited from:</p> <p>All participants were recruited from the Somali population in Sheffield, UK.</p> <p>The sample of health practitioners were recruited from the population of medical consultants with expertise in TB, GPs with experience of caring for Somali patients, TB specialist nurses, a nurse consultant with responsibility for refugee and asylum seekers, community/hospital nurses with experience of caring for Somali TB patients and Somali health workers in Sheffield, UK.</p> <p>How were they recruited:</p> <p>Individual Somali participants were recruited through the community researchers' social networks.</p> <p>Recruitment of focus group participants, community representatives and health practitioners is not report.</p>	<p>Brief description of method and process of analysis:</p> <p>The study used a participatory community research approach where researchers worked with Somali community researchers and health care practitioners (with support of a Project Advisory Group) to design, conduct and disseminate the research study.</p> <p>The majority of the interviews and focus groups were conducted in Somali and later translated into English.</p> <p>Multiple methods were used in this study:</p> <p><i>Interviews with Somali community leaders:</i> to understand the history, family structure, social networks, communication, health beliefs and behaviours and TB related info of Somali community.</p> <p><i>Individual interviews with members of the Somali community:</i> To understand perceptions of TB, health seeking behaviours and wider socio-economic factors that affect health promotion among Somali's.</p> <p><i>Focus group discussions with members of the Somali community:</i> To understand norms, values, socio-cultural aspects of health and TB and wider socio-economic factors that affect health promotion among Somali's.</p> <p><i>Individual interviews with Somali people with personal experience of TB:</i> To understand experiences of TB patients in managing their</p>	<p>Limitations identified by author:</p> <p>Authors point out that patients, GPs, community representatives, other specialists may not be representative of their respective populations.</p> <p>Patients were recruited by the TB specialist nurse and therefore the sample studied may comprise of people who have been relatively stable (housing, follow-up etc) and were easier to access and recruit.</p> <p>Limitations identified by review team:</p> <p>NR</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>Sheffield Health and Social Research Consortium</p>

	<p>TB and not latent TB .</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected: What methods:</p> <p>Interviews and focus groups</p> <p>By whom:</p> <p>Focus groups were facilitated by researchers of the same gender as the participants.</p> <p>Individual interviews with Somali individuals with personal experiences of TB were interviewed by either a specialist nurse with interpreter or core research team</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>NR</p>	<p>How many participants were recruited:</p> <p><i>Interviews:</i> 10 Somali community representatives</p> <p>24 Somali individuals</p> <p>14 Somali people with personal experiences of TB</p> <p>18 health care practitioners</p> <p><i>Focus groups:</i> 4 focus groups of 28 Somali men</p> <p>4 focus groups of 28 Somali women</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>condition, roles of people close to the, and barriers and facilitators to treatment and contact tracing.</p> <p><i>Individual interviews with healthcare practitioners:</i> To understand the experiences of caring for Somali TB patients.</p> <p>The focus groups and individual interviews were all tape recorded and transcribed. Those focus groups/interviews that were conducted in Somali were translated into English. Data was analysed by the following process:</p> <ul style="list-style-type: none"> a) Familiarisation with data b) Identifying thematic framework for coding data/scrutiny of transcripts c) Coding individual transcripts by applying thematic framework d) Organizing codes into major themes e) Mapping relationships between themes <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Understandings of TB among Somalis</u></p> <p><u>Knowledge:</u> Several community leaders had a good understanding of the cause, transmission, symptoms, treatment and prognosis of TB. However, they had noted that TB is not well understood in their community. This knowledge gap was also displayed in focus groups and individual interviews.</p> <p>Many Somalis knew that TB could be treated but there was a common understanding that it can reoccur anytime.</p>	
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			<p>relaxed than the interview participants would suggest.</p> <p>Community leaders, health care practitioners and a Somali health worker all reported that the attitudes, particularly around stigma, are changing in a positive way in the community. People are more willing to talk about TB; people are accepting diagnoses, prepared to complete treatment (though there were exceptions).</p> <p><u>Experiences of TB – patients’ experiences of living with TB</u></p> <p><i>Experiences leading up to a diagnosis of TB:</i> Common among all patients was the stress felt leading up to the confirmed diagnosis. Patients, at this time, found it hard to maintain social networks due to their symptoms.</p> <p>Many patients had reported that they were not treated seriously by their GP and had felt neglected by the system.</p> <p><i>“I visited my GP and I told the GP that I am feeling very sick. The GP prescribed a pain killer and told me nothing is wrong with me.”</i></p> <p>As a result, some took alternative measures such as attending A & E wards.</p> <p><i>Response to diagnosis:</i> Many patients expressed a sense of relief after being diagnosed since they knew what was wrong with them and knew it could be treated.</p> <p>Other patients felt shocked by the diagnosis and experienced on-going anxiety, especially relating to how the community may perceive them. All patients shared diagnosis with their</p>	
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		<p>immediate family members and were supported by them. They did not however feel comfortable expressing this to the larger community because of a fear of isolation.</p> <p><i>"I never told anybody (I had TB) because they think it is a big shame, some people, so my missus says don't worry nobody only you and us know."</i></p> <p>When some patients opened up to friends, they found that their friends also shared that they were previously infected or knew others that were. Others saw that their friends kept a distance from them after opening up.</p> <p>Islam was important to how TB patients and their families responded to their illness – that the diagnosis was fate or Islam provided hope for example.</p> <p><i>Experiences of treatment</i> Most patients felt very satisfied with the standard of care received from TB services in hospital and primary care settings.</p> <p>Few participants had reported that they did <i>'not understanding what was going on'</i> and were <i>'being kept in the dark'</i>. This was often due to language barriers between the healthcare worker and patient.</p> <p>Patients were also very satisfied with the nursing service and valued that the nurses came with Somali health worker if they did not speak English.</p> <p>In some cases, language barriers persisted and patients reported that they did not understand</p>	
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			<p>why they were required to take medication for so long.</p> <p><i>Living with TB</i> Though patients knew that TB could be treated, many stated that they did not believe it could be cured completely and may return in the future.</p> <p>Even after treatment had been completed, TB had carried implications for many of the patients' social relationships:</p> <p><i>Even when he has had treatment for TB, when he coughs they think he has TB again. They are fearful; they will keep away even if he just have flu.</i></p> <p>A GP had given an example of a young woman who felt that her experience with TB removed her chance of marriage and therefore lowered her standing in the community.</p> <p>Individuals of the wider Somali community stated that completing treatment would be difficult because instructions were not clear or understandable, especially for non-English speakers/readers.</p> <p>Other participants stated that TB sufferers may experience special hardship when adhering to medication and treatment if they don't have a permanent home and had to "keep moving on" since their routine is often broken.</p> <p>Some participants said that if TB patients chose to hide their disease, it could be difficult to take medication in secret.</p> <p>Healthcare practitioners reported some cases</p>	
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			<p>where patients did not adhere to treatment, particularly among young Somali men.</p> <p><i>...they deny that they have TB, or they say they are feeling better and don't need to treatment. ... I don't know why this is the case, maybe it is something about the bravado of the young, they are invincible...they think they don't need the medicines if they are starting to feel better. – health care practitioner</i></p> <p><u>Providing TB services: healthcare practitioners' experiences</u></p> <p><i>Contact tracing</i> Some patients were reluctant to share information with healthcare practitioners, despite being assured that their identity would not be disclosed to contacts. This reluctance was largely associated with stigma in the Somali community.</p> <p><i>We have had a number of families where they won't be screened because there is stigma associated with TB and that's quite a difficult barrier to break down.</i></p> <p>Young men were especially reluctant to reveal contacts because of fear that they would lose standing among friends “street credibility” and become socially isolated.</p> <p><i>Diagnosis</i> The specialist TB medical and nursing team reported that it was difficult to make diagnosis of TB because of patients atypical symptoms, cultural barriers or because they were a GP that did not encounter TB often. This meant that provisional diagnosis and referrals were difficult to make.</p>	
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			<p>One GP pointed out the cultural interpretation of symptoms that make diagnosis challenging:</p> <p><i>A Somali patient may complain of something that is affecting the whole half of the body... and it just does not fit with our traditional Western medical model of certain diseases. ...So the challenge for us is to find out what physical pathology might be going on that is being expressed through a different belief system and therefore is being experienced in a different way from the way that I might experience it.</i></p> <p>GPs valued the opportunity to contact the TB specialist nurses to receive advice about diagnosis.</p> <p>Some health care practitioners had reported that the late presentation of TB was strongly associated with the use of <i>Khat</i> in the Somali community (particularly among men).</p> <p><i>A lot of people who have been unwell for a long time will also be quite heavy users of khat. ...Heavy use of khat is like heavy use of any other drug, it's quite escapist</i></p> <p>A general perception was that stigma in the community is declining. However, there were instances where patients were hostile to the diagnosis:</p> <p><i>We had a young man with TB and he and his mother had arrived the past year or two from Somalia and his mother found it really difficult to accept the diagnosis of TB. ...Her argument was that 'we are professional people' the implication being that TB happened to the lower classes</i></p>	
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			<p><i>and she was really very offended...</i></p> <p><i>Management</i> Healthcare workers found that Somali patients were generally accepting of diagnosis and treatment. For some patients, this was more challenging – largely because of a lack of understanding concerning treatment or stigma. <i>"I suspect that the reasons why people do not complete treatment are to do with other chaotic things in their lives ... there may be all kinds of other social difficulties that make it difficult for them to seek treatment". (Medical consultant)</i> Social and economic circumstances among some Somali patients made TB management difficult for them. For example, a healthcare worker noted a case of a single woman with several children who found it difficult to attend the clinic because of her responsibilities to take children to school while younger children accompanied her and she could not afford a taxi for everyone to go to the hospital.</p> <p>Those TB specialist nurses that provided social support were valued by patients because of a fear amongst Somali's of the role of social workers.</p> <p><u>Barriers to Somali people accessing treatment for TB</u> The following barriers are explored in previous sections of this extraction. They are summarised here:</p> <ol style="list-style-type: none"> a) <i>Lack of knowledge about the disease and treatment</i> b) <i>Lack of trust in general practitioners</i> c) <i>Lack of confidentiality (hiding illness due to stigma)</i> d) <i>Language barriers</i> 	
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			<p>e) <i>Use of khat by some men</i></p> <p><u>Facilitators to effective health promotion, diagnosis and management of TB</u> <i>Raising awareness of TB within the Somali community through provision of more factual information through the presentation of leaflets or through spoken word for those who are not literate. Raising awareness would help change stigma associated with TB. Participants noted that the messages would need to be culturally appropriate and could make use of engaging the younger population, community leaders and using the setting of community gatherings.</i></p> <p><i>“The Somali community needs to be more involved, and they need to be giving out a clear message that it is actually OK to have TB, because you can get rid of it, and it’s not death sentence.”</i></p> <p><i>Somali health workers are limited in number in Sheffield. They are needed to provide support, act as interpreters, develop understanding and facilitate access to healthcare.</i></p> <p><i>Improved access to interpreting services for those patients that do not speak English is needed. Interpreting services are offered at hospitals or with visits to TB specialist nursing service, but not at GP’s prior to diagnosis or in primary care, where there was instead, heavy reliance on patients identifying someone to interpret for them. Participants indicated that interpreters had to be known and trusted individuals.</i></p> <p><i>Improved understanding of TB among General Practitioners was desired. Many patients felt that</i></p>	
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			<p>there had been delays in diagnosis on account of GPs not giving referrals. Patients thought that GPs lacked understanding of TB, especially when they did not have classical symptoms.</p> <p><i>Developing the cultural awareness of healthcare workers</i> was noted as an issue of concern. This was related to GPs listening to patients and giving them more time in consultation, as these were often rushed. A better understanding of Somali culture was suggested to inform GP practice.</p> <p><i>Addressing issues of social exclusion and economic disadvantage:</i> Many Somali people were unemployed, living in poverty, had poor housing or reliant on state benefit. This makes it difficult for treatment adherence and has implications for wider public health agenda.</p> <p><u>Perceptions of primary healthcare services</u> This related to a perception that GPs often prescribed medication without taking detailed history or given diagnosis. Participants generally lacked trust in GPs because of previous incorrect or delayed diagnosis.</p> <p>GPs were thought to be disrespectful and have a general negative attitude towards Somali patients. Women found it difficult to talk with male doctors.</p> <p><i>Some of the doctors who work at the surgery are very good... But there are other GPs who people complain about. People complain about... they don't give them enough time, they quickly prescribe medication without finding out what it wrong with them. This brings disappointment, which makes people not take the prescribed</i></p>	
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			<p><i>medication whether it is the right treatment or not, because they believe that the GP has not diagnosed them correctly and they did not listen to their problem.- Somali participant</i></p> <p>Social networks in the Somali community have played a large role in transmitted knowledge, negative and positive about people's individual experiences.</p> <p><u>GPs perceptions of Somali patients views towards healthcare system</u> GPs perceived a lack of understanding of the British health care system among some Somalis. GP felt that Somali patients did not always appreciate the breadth of medical expertise available in general practice and often went straight to hospitals or wanted requests to do so. GPs reported this was the case because this would be the avenue of action in Somalia.</p> <p>GPs identified that Somali patients emphasize cure rather than treatment and this meant that some people did not continue with treatment medication after they began to feel better.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Gibson N, Cave A, Doering D, Ortiz L, Harms P</p> <p>Year:</p> <p>2005</p> <p>Citation:</p> <p>Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada. <i>Social Science and Medicine</i> 61: 931-942.</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>To examine socio-cultural factors influencing behaviour related to TB prevention and treatment in high-risk cultural groups in Canada</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Theoretical approach based on Kleinman's (1981) model of individual behaviour and Triandis' (1994) model of socio-cultural context, combined with a community-based participatory action research model.</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Semi-structured individual interview</p> <p>By whom:</p> <p>Community associates from the communities</p>	<p>What population were the sample recruited from:</p> <p>Immigrant communities (Hong Kong, China, Philippines, Vietnam, Punjab & E Europe), three Aboriginal groups (not extracted here).</p> <p>Within each sociocultural group, four groups of TB experience were sought: (1) with active TB; (2) had taken DOT; (3) had been offered DOT and refused; (4) with past history of TB, or a relative with TB.</p> <p>How were they recruited:</p> <p>For immigrant communities, participants from groups (1) and (2) were recruited from clinic records & contacted by their primary healthcare provider. For (3), recruited from the Alberta Health TB database. (4) recruited from suggestions of clinic nurses. Further participants located from referrals. Participants received cash (amount NR) or a culturally appropriate gift.</p>	<p>Brief description of method and process of analysis:</p> <p>The community advisory committee established principles of the project and monitored the ethical and cultural aspects of the research project. The CAC were involved in the hiring of the community research associates (CA). These associates had gone through 2 ½ days of training in the history of tuberculosis, semi structured interviewing, and analysis of qualitative data.</p> <p>The CA's collected qualitative interview data from study participants and assisted with interpretation and evaluation. The interviews were first manually coded by theme and then by using qualitative analysis software NUD*IST (non-numerical unstructured data indexing searching and theorizing).</p> <p>Validity was ensured by using multi-rater coding and analysis. The CAC and CA's cooperated to discuss the emergent themes and interpretation. The CAC's advised on ways for information dissemination for the respective communities involved in the study. Those involved in the research process (CAC, CA research teams) were provided an opportunity to provide feedback through questionnaires or telephone interviews.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Explanatory models (causes of TB).</u> Ten people thought TB was caused by 'vice'</p>	<p>Limitations identified by author:</p> <p>None reported</p> <p>Limitations identified by review team:</p> <p>Generally very sound methods. The data is not very rich and quotes appear to come from only a couple of interviews. Immigrant and aboriginal groups are not clearly distinguished.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>None reported</p> <p>Source of funding:</p> <p>Alberta Heritage Foundation for Medical Research and the First Nations and Inuit Health Branch, with in-kind support from the Capital Health Authority and Canadian Heritage.</p>

	<p>investigated (trained by research co-ordinators who were also of Aboriginal / immigrant heritage)</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>July 1999 - March 2001</p>	<p>How many participants were recruited:</p> <p>133</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR other than those stated above</p>	<p>(e.g. smoking, alcohol). <i>"In the Philippines, I worked in a printing press. There are chemicals. Maybe, I don't know, I probably inhaled chemical fumes. Also I had vices before—I smoke and drink alcohol."</i></p> <p>Participants also cited 'not taking care of yourself' (N=21), 'dirty environment' (N=10), and heredity (N=8). Most knew that TB is contagious (N=92), but some of these also cited other explanations.</p> <p><u>Stigma.</u> 5 reported stigma, 6 did not tell people they had TB, 10 reported no problem with stigmatization, 4 feared being stigmatized. Some CAs that had conducted interviews with immigrants believed that stigma had influenced people's attitudes towards prevention and treatment. <i>"People stayed away from each other, not sharing cigarettes and stuff like that. Just really kept to themselves."</i> The authors suggest that this observation represents a grey area between social stigmatization and behaviour that displays a desire not to catch TB.</p> <p>Concern about stigma regarding communities as a whole was also expressed. <i>"The reaction from the community workers was, 'Don't make it such a big fuss, it's going to bring negative stereotyping to the clients. Don't splash all over the mainstream media that immigrants have TB; it will just make the discrimination that might exist, even higher.' [...] But later, when we worked in the Chinese community itself, I think because so many people in the local Chinese community had some contact with TB services or TB, they understood the need to help others [eliminate] unnecessary fears or myths about TB."</i> Two</p>	
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			<p>participants said they faced stigma from healthcare providers.</p> <p><u>Treatment</u> Many participants who had been treated had problems with side-effects. All in groups (1) and (2) reported completing treatment. Five people had spent time in sanatoria and described it as a lonely experience. <i>"It was not a good time for me. I had to stay in the hospital for nine months. I was lonesome for my parents, my mom, the kids, my sisters. I missed them a lot."</i></p> <p><u>Knowledge</u> Participants expressed concern about the lack of knowledge in their communities regarding TB. <i>"They knew that TB was infection, they had to be careful. But I still felt that our Chinese community lacked information on TB. They thought about infection and didn't know much about TB disease."</i> They felt people did not distinguish TB from other lung diseases (cancer, asthma). Participants with lower self-reported knowledge had worse experiences and more negative attitudes. Participants identified a range of ways in which education about TB could be carried out (pamphlets, workshops, TV etc.); they emphasized the importance of providing materials in community languages.</p> <p>One participant pointed out that despite the provision of information, some people would always be unwilling to learn. <i>"I: Do you think people close their ears to TB? Why do you feel it's a low priority or do you think they're eager to learn? P: It works both ways: some are eager to learn; others will turn a deaf ear. They're going to turn a deaf ear on it, and [say] "It's never going to happen to me. And that's the ones that</i></p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Houston H, Harada N, Makinodan T</p> <p>Year:</p> <p>2002</p> <p>Citation:</p> <p>Development of a culturally sensitive educational intervention program to reduce the high incidence of tuberculosis among foreign-born Vietnamese. <i>Ethnicity and Health</i> 7(4): 255-265.</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To identify the cultural health beliefs and barriers among the Vietnamese population of Orange County, California. Specifically (p. 258): (1) to identify and define cultural health beliefs, (2) to identify wellness strategies used in maintaining good health, (3) to identify health-seeking strategies used during illness, (4) to identify cultural health beliefs about TB, (5) to identify cultural attitudes toward TB, (6) to identify side-effects associated with existing TB treatments, and (7) to identify cultural barriers which hinder the completion of TB prevention therapy programs.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p>	<p>What population were the sample recruited from:</p> <p>Foreign- (i.e. Vietnamese-) born Vietnamese in Orange County. Authors sought to recruit from (1) people who had had a positive skin test, (2) people who had completed treatment or a prevention programme, (3) people who had not had any treatment, (4) people who had had contact with people with TB but were not in any programme.</p> <p>How were they recruited:</p> <p>Via community organisations with a predominantly Vietnamese clientele, including English language programmes, citizenship and social service programmes, media organisations, churches, temples, schools and healthcare organisations.</p> <p>Staff members in these organisations actively approached potential participants in the course of their operations.</p>	<p><i>we have to fear for.”</i></p> <p>Brief description of method and process of analysis:</p> <p>Manual analysis using grounded theory methodology. Three phases: (1) initial thematic coding, (2) ‘axial’ coding, (3) ‘selective’ coding identifying variations, exceptions and explanations; followed by integration into overall theoretical framework. (NB. Only findings from the qualitative phase of the study are extracted here.)</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p>Participants saw mental and physical health in a holistic fashion. They discussed the use of traditional Vietnamese health practices such as ‘coin rubbing’ alongside the use of Western medicine. Participants saw TB as two distinct illnesses, one psychological (<i>lao tam</i>) and one physical (<i>lao luc</i>). Psychological TB is characterised by fatigue, loss of appetite and lethargy, and caused by poor environmental conditions, not by contagion. Physical TB is characterised by persistent coughing and a heavy feeling in the chest, and is caused by exposure to airborne microbes. “...<i>there are two kinds of TB: psychological TB and physical TB. Psychological TB is due to too much work, too much worry and stress, which causes TB. Psychological TB does not have microbes ... For psychological TB, we need a cure for the mind. For physical TB, we need medicines [antibiotics] and good food”</i> (female participant).</p>	<p>Limitations identified by author:</p> <p>NR</p> <p>Limitations identified by review team:</p> <p>Data are not very rich and are limited in extent. Many themes identified as study objectives are not reported on.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>Agency of Health Care Policy and Research, the California Endowment, and the VA Medical Research funds.</p>

	<p>Grounded theory</p> <p>How were the data collected: What methods:</p> <p>Focus groups, individual interviews (face-to-face and telephone follow-up) conducted in Vietnamese</p> <p>By whom:</p> <p>The lead author and a bilingual, bicultural focus group moderator / interviewer</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>June-Dec 1997</p>	<p>Participants received \$50.</p> <p>How many participants were recruited:</p> <p>67 (53 focus group, 14 individual interviews)</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Vietnamese ethnic origin, born in Vietnam, immigrated to USA as an adult (≥18 y) and <5 years ago.</p>		
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Ito K.</p> <p>Year: 1999</p> <p>Citation: Health culture and the clinical encounter: Vietnamese refugees' responses to preventive drug treatment of inactive tuberculosis. <i>Medical Anthropology Quarterly</i> 13(3): 338-364</p> <p>Quality Score: (++, + or -) +</p>	<p>What was/were the research questions: To investigate elements of 'health culture' which affect compliance with preventive treatment for inactive TB among Vietnamese refugees in the USA.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): NR</p> <p>How were the data collected: What methods: Individual interviews (in English or Vietnamese) and observation</p> <p>By whom: Lead researcher and interpreter</p> <p>What setting(s): Clinic and community sites</p>	<p>What population were the sample recruited from: Vietnamese refugees in Orange County, California. Researchers sought individuals who were compliant with treatment and those who were non-compliant, and also conducted interviews with clinic staff and various community members who were apparently not receiving TB services.</p> <p>How were they recruited: Unclear; apparently face-to-face by researcher. Participants received \$20.</p> <p>How many participants were recruited: 24 with people receiving treatment; others NR</p> <p>Were there specific exclusion criteria: NR</p> <p>Were there specific inclusion criteria: NR</p>	<p>Brief description of method and process of analysis: Analysis not described</p> <p>Key themes (with illustrative quotes if available) relevant to this review: Some non compliant participants reported problems with transport to the clinic. Some participants were unsatisfied with the ambience of the clinic and/or staff attitudes. Several were worried about safety because of the high population of 'junkies' and 'vagrants' near the clinic. 70% of non compliant and 14% of compliant clients recalled receiving an informational handout on TB.</p> <p>Clinic staff believed that very few clients were fully compliant with treatment. They all said that noncompliance was due to the side-effects of isoniazid, described in terms of Vietnamese health concepts as 'hot' (e.g. irritability, acne). Most participants (14/24) also cited 'hot' side effects as a reason for non compliance. They also cited other side effects (loss of memory, food becoming tasteless, nausea, and constipation). Compliant clients cited the following other reasons: having no symptoms of disease, the demands of work or school, being lazy or not caring, not having transportation, the results of the medication taking too long, and being temperamentally unreasonable.</p> <p>Non compliant clients cited the following: no symptoms, too busy, work or school, and bad for your health. However, most compliant clients (as</p>	<p>Limitations identified by author: None reported</p> <p>Limitations identified by review team: Lack of clarity in study methodology (e.g. numbers of non-client participants) which reduces reliability of findings. Differences between compliant and non-compliant clients are only mentioned in passing.</p> <p>Evidence gaps and/or recommendations for future research: Focused research on the clinical encounter to explore the hermeneutic processes involved. Community-based (rather than clinic-based) investigation of the health culture of Vietnamese Americans.</p> <p>Source of funding: Centers for Disease Control and Prevention,</p>

	<p>When: May-Nov 1992</p>		<p>well as all non compliant) reported experience of side effects.</p> <p>Many compliant clients identified families as key in supporting compliance. <i>"When I first took it I felt hot. I was discouraged and wanted to stop. But my husband encourages me to eat a lot of vegetables and fruits. I have lasted because my husband encourages me."</i> (34-year-old, female, compliant). Several mentioned specific family members in this regard. However, 8/10 noncompliant clients reported discouragement from peers or families. <i>"I have friends who take [INH] but they stopped before they finished the treatment and when I first started the medicine, they scared me saying don't take it because it's not for you."</i> (21-year-old, female, non compliant).</p> <p>Lack of symptoms as a reason for non compliance was also said to be reinforced by peer pressure by 3 non compliant clients. <i>"My friends say if you don't have any sickness right now, why take the pills? A lot of people don't take the medicine because they feel that taking it doesn't do any good for their health. Instead, it creates more problems. Some people after not taking the medicine, they get fatter, healthier, so they feel that there is nothing wrong with them.... So they think it's good not to take the medicine."</i> (28- year-old, female, non compliant).</p> <p>5/10 non compliant clients were motivated to return to the clinic so they could get a completion card which was important for school or getting a job. Clinic staff reported that they used the completion cards to encourage compliance.</p>	<p>Division of Tuberculosis Elimination</p>
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			<p>Interviews with community members not using TB services showed a perception of Western medicine in general as strong or aggressive. <i>“The U.S. way is to attack everything. So they give you the strongest medicine. Americans are strong people, so this is okay for them.”</i></p> <p><i>“Western medicine thinks everything is very serious, which is not necessarily the case. On many things Western medicine is accurate, but they are afraid of making mistakes, so it is not subtle. They prefer strong treatment-rapid and fast! [sharply clapping his hands and hitting the table in front of him].... Oriental medicine is slow [gentle].”</i></p> <p>Some participants also expressed suspicion of the motives of the US government. This was particularly the case where people had received positive PPD tests in the US after being declared clear of TB when they left Vietnam. <i>“In Thailand [refugee camps], people are checked and they are okay. Now they say we have TB. Here is paradise, everybody is healthy. This makes Vietnamese people so angry! We are not sick! We are being tricked. Americans treat us badly. They treat me like I am dirty. I bring disease. [...] It is insulting!”</i></p> <p>People working for community organisations stated that public services were not sensitive to the community’s needs, and that messages should be seen to come from community agencies rather than from the government. Vietnamese clinic staff tended to give biomedical explanations for side effects, or suggestions to mitigate them, which were sometimes not well understood by clients.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Jackson L, Yuan L</p> <p>Year: 1997</p> <p>Citation: Family physicians managing tuberculosis. Qualitative study of overcoming barriers. <i>Canadian Family Physician</i> 43: 649-655</p> <p>Quality Score: (++, + or -) +</p>	<p>What was/were the research questions: To identify the non-clinical barriers family physicians may face in managing TB among patients and suggestions for overcoming these barriers.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): NR</p> <p>How were the data collected: What methods: Focus groups</p> <p>By whom: Research team (one facilitator and one moderator)</p> <p>What setting(s): NR</p> <p>When:</p>	<p>What population were the sample recruited from: Participants were chosen from primary care physicians, infectious disease specialists and respiratory physicians in metropolitan Toronto, Canada.</p> <p>How were they recruited: The details of potential participants were obtained by a list of the physicians that the study authors personally knew and those physicians referred initial contacts.</p> <p>How many participants were recruited: 15</p> <p>Were there specific exclusion criteria: NR</p> <p>Were there specific inclusion criteria: NR</p>	<p>Brief description of method and process of analysis: Each focus group consisted of two or three family physicians and at least one specialist (infectious disease or respiratory physician) and two of the groups included a resident. Some of the physicians worked in practices that had a large number of immigrants or HIV-infected persons.</p> <p>In the focus groups, physicians were asked the following questions: Do you perceive TB guidelines to be useful in the management of TB and what are the nonclinical obstacles (if any) you believe influence the management of TB? All focus groups were audio-taped and transcribed verbatim by a member of the research team (moderator of focus group). Each tape was then replayed by another member of the research team to ensure the accuracy of the transcription. Discussions were analysed for common phrases and words by each member of the research team independently and then compared across members until agreement was reached. The process of constant comparative analysis was conducted until saturation.</p> <p>Key themes (with illustrative quotes if available) relevant to this review: The focus groups revealed that many physicians were impaired by the realities of specific situations when trying to do what they are supposed to in order to prevent TB effectively.</p>	<p>Limitations identified by author: Participants in this study were working in a large city and therefore views may not be transferable to those physicians working in more rural areas. Also, family physicians may have been less inclined to report some of their views because of the presence of specialists and the relations of expertise between them.</p> <p>Limitations identified by review team: Though it was the objective of the research study to illicit concrete examples of barriers experienced to effective TB management, little detail or case examples were provided in this study.</p> <p>Evidence gaps and/or recommendations for future research: NR</p>

	NR		<p>They reported some non clinical obstacles:</p> <p><u>Guidelines</u> Some study participants reported that the guidelines to manage TB did not address many issues, which created a sense of uncertainty. Other participants indicated that the guidelines were not always relevant to the practice.</p> <p><u>Structure of family practice</u> The structure of family practices was reported to reduce effective management of TB. Participants reported that at family practices they see a variety of disorders and illnesses and very few TB cases.</p> <p><i>“If you see one case of TB every 3 years, does it make a lot of sense for you to invest a huge amount of energy into knowing about this disorder?” (family physician)</i></p> <p><u>Patient non compliance</u> One specialist reported that it is, “<i>imperative that you work on compliance [to treatment].</i>” Another physician that saw active TB cases reported that patients who are recent immigrants fear that the diagnosis of active TB may lead to deportation. A third participant (family physician) had said that good medical practice is not centred on patient compliance, but should be about giving patients accurate information so that they can make an informed choice.</p> <p><u>Patients’ socioeconomic circumstances</u> One specialist reported the case of a political refugee who did not have health insurance and could not afford testing/treatment.</p> <p><u>Stigma related to TB</u></p>	<p>Source of funding:</p> <p>NR</p>
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			<p>One family physician reported that some individuals did not seek the appropriate medical care because of the stigma associated with the disease.</p> <p><i>"I am sure there [are lots] of TB cases in Canada just treating themselves with Tylenol and cold medicine."</i></p> <p><u>Availability of experts for consultations</u> Family physicians reported that they have readily available support available to them for the management of TB. They relied on specialists (infectious disease or respiratory physician) for consultations related to active TB cases. Others relied on public health.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Johnson, A.</p> <p>Year: 2006</p> <p>Citation: <i>Beliefs and barriers related to understanding TB amongst vulnerable groups in South East London.</i> Health Protection Agency: London</p> <p>Quality Score: (++, + or -) -</p>	<p>What was/were the research questions: To understand how specific cultural health beliefs regarding TB affect the awareness and understanding of the disease amongst at-risk communities.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): NR</p> <p>How were the data collected: What methods: Focus groups and semi-structured interviews</p> <p>By whom: The author</p> <p>What setting(s): Two focus groups were held in a Christian day centre, six were held in the individual</p>	<p>What population were the sample recruited from: The participants were recruited from the following community groups which are representative of vulnerable groups in the SE London area: Chinese Nigerian Refugee Women's Group (majority Somali, also Ethiopian and Eritrean) Vietnamese Substance misusers (from a homeless person residential centre) HIV Positive Homeless Prisoners</p> <p>How were they recruited: Community groups were contacted either through contacts at the Three Boroughs Primary Health Care team using their director of organisations working with refugees and asylum seekers, or from internet searches. Individual organisations were then contacted and</p>	<p>Brief description of method and process of analysis: Demographic information was collected in a questionnaire prior to the commencement of the focus groups. Participants were not asked to disclose their TB status. Focus groups lasted between two and three hours and followed a topic guide which was developed based on a review of literature and consultation with TB-related professionals. The focus groups were asked open-ended questions from the topic guide and semi-structured interviews used the same guide. Participants were given the opportunity to respond at length prompting for discussion on the following topics: participants existing knowledge of TB; participants current perceptions of TB; participants impression of and interactions with the NHS; views on effective health promotion. Focus groups were recorded in all cases except the prisoners, homeless group and substance misusers group and notes were taken simultaneously by the facilitator. Interpreters were used when needed and participants were given a £10 voucher. At the end of the session a short presentation about TB was given. Analysis: NR</p> <p>Key themes (with illustrative quotes if</p>	<p>Limitations identified by author: Inconsistency in methods used as while the majority of community groups were approached for focus groups, some preferred to have individual interviews. Only some groups gave permission for the use of a tape recorder. The facilitator spoke only English and there were difficulties in recruiting focus group participants. Possible selection bias in terms of those who did participate.</p> <p>Limitations identified by reviewer: This research does not clearly explain the analytical approach to the data.</p> <p>Evidence gaps and/or recommendations for future research: NR</p> <p>Source of funding:</p>

	<p>organisation's own venues and one was held in an NHS facility.</p> <p>When:</p> <p>December 2005 – April 2006</p>	<p>asked for details of their members. Emails were sent to members and posters advertising the research were displayed in a variety of venues, such as clinics, internet cafes, GP practices and hairdressers in different boroughs</p> <p>.</p> <p>How many participants were recruited:</p> <p>67</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>available) relevant to this review:</p> <p><u>Participants existing knowledge of TB</u></p> <p><i>Cross-cutting themes</i></p> <p>All groups mentioned sweating, fever, coughing, weight loss and tiredness as symptoms of TB. Other symptoms mentioned included watery stools and vomiting. Few participants had knowledge of latent TB.</p> <p>Death was mentioned during every focus group as an inevitable outcome for certain groups of people with TB such as those who present late or those with HIV. All of the ethnic community groups mentioned a distinction between TB in their country of birth and TB in England.</p> <p>The ease of transmission was a cause of concern for all groups and there was a common belief that TB is contagious even after receiving treatment. Few were certain that TB was airborne. Examples of perceived means of transmission include: spitting on the streets, sleeping in the same bed, sharing clothes, kissing.</p> <p>Isolating an individual was considered by all groups as the best way of reducing the risk of catching TB. It was well known amongst the groups that treatment is available but most thought the lengthy time of treatment was a barrier to completion.</p> <p><i>Nigerian specific findings:</i> The Nigerian respondents thought that the weather was thought to be a cause and means of transmission of TB due to winds blowing in from the deserts in Nigeria seen as carrying</p>	<p>South East London Health Protection Unit</p>
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			<p>TB germs.</p> <p><i>Somali specific findings:</i> The Somali group said that people who live in conditions where the temperature fluctuates to extremes were more at risk of catching TB. TB was also thought by some in this group to be transmitted via cow's milk.</p> <p><i>Chinese specific findings:</i> Smoking was thought to lead to a higher chance of contracting TB and people with a lower immune system were more likely to get the disease.</p> <p><i>Vietnamese specific findings:</i> Pollution and bad air were thought to cause TB and eating the wrong food.</p> <p><i>HIV positive specific findings:</i> these groups were very well informed and many had direct experiences of TB.</p> <p><i>Homeless specific findings:</i> Some in this group thought TB was inherited. It was associated with "weaker people" especially those who get wet on the streets and Eastern Europeans.</p> <p><i>Substance misuse specific findings:</i> Some thought that TB was inherited and it was suggested that the best way to prevent TB was to drink 2 pints of Guinness per day.</p> <p><i>Prisoners:</i> There was a mixed level of knowledge in this group. TB was thought to be spread through unprotected sex, kissing and pets.</p> <p><u>Participant's existing perceptions of TB</u></p>	
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			<p>unwell they would generally self medicate, rather than go to the doctor as “there is no guarantee that the doctor will diagnose TB and may well just prescribe cough mixture”. One group mentioned that if you are from Africa and you are HIV positive, staff will assume you have TB.</p> <p><i>Prisoners</i> - These participants also had little confidence in the health care they received in prison. Similar to the Somali group, their own ‘cure all’ was Deep Heat, rather than paracetamol. While the mobile X-ray unit had been visiting this prison regularly and most of prisoners were aware of the visits, not all had chosen to be screened during any of these occasions. Often it was because they did not feel at risk therefore no need to checked out, or because they had not known how to take up the opportunity.</p> <p><i>Substance misusers</i> - These participants felt that if they were meant to take medication for a certain period of time but felt better they would stop taking them.</p> <p><i>Chinese</i> - The Chinese group visited their GPs, but when they failed to improve they used Chinese practitioners who were seen to have more effective treatment. Western medical practices were questioned but were still used as a complementary service. The precipitating factor for TB in order to seek medical advice would have to be a serious symptom, such as blood in their sputum.</p> <p><u>Views on effective health promotion</u></p>	
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			<p><u>approaches</u></p> <p><i>Cross cutting themes</i> All groups said they favoured face-to-face groups for receiving health information as it gave them the opportunity to ask questions and meet people. TB was not considered a 'fashionable' subject like cancer and HIV and raising awareness was deemed more difficult.</p> <p><i>Group specific findings</i></p> <p><i>Somali</i> – Many were illiterate in English and could not understand spoken English yet most tuned into the BBC radio for the hour-long programme in their own language. This was thought to be a good medium for raising awareness. There was a strong bond to the community group and they regularly attended meetings and classes.</p> <p><i>Chinese</i> – Talks and meetings were important for this group as a way of learning about issues. Posters were considered useless for the illiterate but in Chinese for the literate, not English. Chinese radio stations and newspapers were widely used.</p> <p><i>HIV positive</i> - These groups thought it would be useful to use the HIV related media to raise awareness. Posters and information at GUM clinics and on public transport were also raised as potentially useful. It was suggested that UK television shows <i>Eastenders</i> and <i>Coronation Street</i> could carry TB related story lines.</p> <p><i>Prisoners</i> –The prisoners suggested using the induction pack, the MXU van and a fact sheet. Health awareness days should be held several times a year.</p>	
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			<p><i>Vietnamese</i> - Information should be presented in Vietnamese rather than English and the BBC Vietnamese program could be useful. Community group newsletters are often read and helps spread news via word of mouth.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Joseph, H. Shrestha-Kuwahara, R. Lowry, D. Lambert, L. Panlilio, A. Racher, B. Holcombe, J. Poujade, J. Rasmussen, D. Wilce, M.</p> <p>Year:</p> <p>2004</p> <p>Citation:</p> <p>Factors influencing health care workers' adherence to work site tuberculosis screening and treatment policies. <i>American Journal of Infection Control</i>. 32 (8): 456 – 461.</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To identify the factors that influence health care workers (HCWs) adherence to policies for routine tuberculin skin tests (TSTs) and treatment of latent TB infection (LTBI).</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Grounded theory.</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Focus groups</p> <p>By whom:</p> <p>Professional moderator</p> <p>What setting(s):</p> <p>Four health care facilities (2 health departments and 2 hospitals)</p>	<p>What population were the sample recruited from:</p> <p>NR</p> <p>How were they recruited:</p> <p>The departments responsible for TB screening and treatment of health care workers with LTBI used databases to find and recruit health care workers based on whether or not they had adhered to TST and LTBI treatment. The focus groups were then established by the employment health department.</p> <p>How many participants were recruited:</p> <p>106</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Brief description of method and process of analysis:</p> <p>The study sites were chosen to maximise variation among possible responses. The two health departments and two hospitals were selected based on local TB incidence, number of TB patients receiving care, and geographical location as well as the willingness of the sites to participate</p> <p>A range of occupations were represented in the focus groups including clinical, janitorial, administrative, clerical and security staff. They were both US and foreign- born.</p> <p>The moderator of the focus groups had not been involved with local or national infection control policy or practice. This moderator facilitated all 16 focus groups. A standard discussion guide was used however, in each group there was a chance for participants to engage in unstructured discussion.</p> <p>Each focus group contained between four and eight HCWs. Participants were given a monetary incentive for participating and TB educational materials were available at the end of the session. Focus group sessions lasted between 90 minutes and 2 hours and were audio-taped and transcribed.</p> <p>Qualitative research software was used to analyse the transcripts and a framework was developed using findings from previous literature and infection control guidelines.</p>	<p>Limitations identified by author:</p> <p>The authors note that group segmentation was not uniform across the four sites because of different Employee Health systems. A further limitation was that the classification of TST positive participants as non-adherent was applied in some cases despite them not being formally recommended for treatment so were commenting on a process they were not necessarily directly involved in. Potential limitations of generalisability were also raised.</p> <p>Limitations identified by review team:</p> <p>The division of groups into 'adherent' and 'non-adherent' groups may have influenced the way discussions progressed as opposed to having mixed sessions.</p>

	<p>When:</p> <p>NR</p>		<p>Additional concepts emerged from the data.</p> <p>Codes were continuously revised and reviewed and tested for inter-reliability.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Themes common to adherent and non adherent groups</u></p> <p>Focus group participants believed that the TST was mandatory for staff at their facility, whether or not it was and said that follow-up and repercussions with employee health staff and supervisors enforced adherence. Repercussions included suspension and withholding pay. <i>“Let’s put it this way, if we weren’t forced or suspended, I don’t think people would actually show up.”</i></p> <p>Conducting TST at the work site was mentioned as being “easy” and “convenient”. Participants reported that adherence was easier when TST could read by nurses outside of the employee health department. Many suggested that hours for testing should be extended and providing reminders.</p> <p>Many focus group participants felt their jobs put them at risk for TB infection and perceived the risk to be related to contact both with patients and the general public. Routine TST were considered reasonable because of perceptions of elevated risk <i>“I come into contact with a lot of patients...that’s why I know I need to be tested annually.”</i></p> <p>Participants were confident that treatment for LTBI almost ensures the prevention of active</p>	<p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>NR</p>
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			<p>Non-adherent participants reported logistical difficulties in having the TST and having it read. Off-peak shift workers had particular difficulties.</p> <p>Many reported distrust and lack of confidence in the Employee Health office. <i>“They [EH] give all these tests year after year. Nobody is exposed. So, they’re just giving tests. And maybe that’s why some people really feel that all they’re trying to do is get the numbers up for the number of TB tests that are done annually.”</i> Some participants were apprehensive about the skills that the EH staff had in delivering tests and reading results. Non-adherent groups were suspicious that LTBI treatment was harmful. Participants repeatedly described it as “terribly bad”, “too aggressive” and “toxic”.</p> <p>Participants that were non-adherent often reported that their private doctors had discouraged them from starting treatment. <i>“[My private doctor] said she would not recommend [LTBI treatment]...that it was overkill.”</i> Non-adherent participants to LTBI treatment expressed anxiety, anger, fear and humiliation following their diagnosis. <i>“I thought I was dying”</i>.</p> <p>Misunderstandings about the transmission and epidemiology of TB were common among the non-adherent groups.</p>	
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<p>Authors:</p> <p>Kelly-Rossini L, Perlman D, Mason D.</p> <p>Year:</p> <p>1996</p> <p>Citation:</p> <p>The experience of respiratory isolation for HIV-infected persons with tuberculosis. <i>Journal of the Association of Nurses in AIDS Care</i> 7:1: 29-36</p> <p>Quality Score: (+, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To understand the experiences of respiratory isolation for HIV-infected patients with TB.</p> <p>The following questions were addressed:</p> <p>How do patients with TB describe the experience of respiratory isolation?</p> <p>Do these descriptions change over time?</p> <p>What factors do patients identify as making the experience more difficult?</p> <p>What have patients reported concerning how experiences could be made better?</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data</p>	<p>What population were the sample recruited from:</p> <p>Urban academic medical centre, New York, USA.</p> <p>How were they recruited:</p> <p>NR</p> <p>How many participants were recruited:</p> <p>18 (13 male and 5 female between the ages of 30-51 years. Two thirds of the participants reported current or previous illicit drug use and seven reported a history of incarceration)</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Participants were invited to participate in the interview if they were, English speaking, with a history of HIV infection or HIV risk behaviour, AFB positive</p>	<p>Brief description of method and process of analysis:</p> <p>This study used qualitative (interviews) and quantitative (questionnaire) methods. Only data relating to the qualitative study has been extracted here.</p> <p>A TB isolation interview questionnaire was developed, consisting of open ended questions to explore participants' feelings about isolation for TB. The interview questionnaire was reviewed by three nurse experts in HIV and TB, one infectious disease physician for validity and administered to three patients with HIV-TB co-infection to test the tool.</p> <p>The open-ended questions were then presented to study participants and responses were tape recorded. The interviews took place during the first three weeks of isolation. The responses were transcribed verbatim. The audiotapes were reviewed alongside the transcriptions to ensure accuracy. The study authors extracted themes from the interview data. A peer review group of clinicians and researchers validated the thematic analysis of the authors.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Dichotomy of aloneness</u> Some participants felt lonely during isolation while others reported that they enjoyed the quiet and peace. "You don't have anybody to speak with, and</p>	<p>Limitations identified by author:</p> <p>The qualitative interviews were administered in English only and therefore many participants were unable to participate and those that did may not have been able to express themselves fully.</p> <p>The study did not make use of a comparative group of persons not in isolation or a sample of TB patients without HIV co-infection.</p> <p>Limitations identified by review team:</p> <p>Participants were likely at different stages of recovery or admission, however, this information was not made explicit in the presentation of the responses.</p> <p>The authors did not compare or present the findings (quotes from interviews) by sub groups (particularly</p>

	<p>collected: What methods:</p> <p>Interviews and questionnaire (only interview data is extracted)</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>Interviews took place in the private isolation room of each participant.</p> <p>When:</p> <p>February-July 1994</p>	<p>sputum smears; and were confined to respiratory isolation.</p>	<p><i>then you feel lonely and you start thinking negative things.., being lonely is the worst thing in life."</i></p> <p><i>"I'm getting plenty of rest, that's for sure. It's brought a lot of things out since I'm off the drugs now a little bit and I'm thinking more."</i></p> <p><u>Confinement</u> Some participants reported a sense of loss of freedom because they were unable to leave isolation rooms as they pleased. Common words used to describe these feelings were: "caged in," "locked up," "boxed in".</p> <p><u>Boredom</u> Participants felt bored in isolation. Though televisions were provided to most patients, they noted that this was not sufficient to keep occupied.</p> <p><i>"There is nothing to do in this room except lay down on the bed..."</i></p> <p><u>Disruption of habits</u> The disruption of routines such as waking up and sleeping, bowel and bladder patterns and bathing were cited as causing distress to study participants. The disruption to personal routines was said to be caused by either hospital rules or by TB related symptoms or medication. It was noted that the isolation rooms often did not have a clock or calendar provided.</p> <p><i>"I can't even eat right. I can't sleep."</i></p> <p><u>Depressed mood and despair</u> Uncertainty about the future, particularly concerning the days they are required to stay in</p>	<p>gender) which would have been insightful.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>Further study is recommended into the effects of behavioural interventions during the inpatient phase of treatment.</p> <p>Source of funding:</p> <p>The Beatrice Renfield Division of Nursing Education and Research, Beth Israel Medical Centre.</p>
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			<p><i>"I've been here for 12 days and I'm only supposed to be here for seven."</i></p> <p><u>Role of the family</u> The role of the family was either a positive enforcement for participants to adhere to treatment and stay in care or a source of anxiety (especially for those with children at home).</p> <p><i>"I worry about my son and I worry about my mother."</i></p> <p><u>Coping enhanced by internal and external factors</u> Participants reported the following ways of coping with isolation: religion, internal strength, survival strategies learned during previous incarceration, support of their families and being in the discharge planning process. Some participants reported that confinement in prison was easier than the hospital. Those participants that had previously been in jail mentioned that they had already learned of strategies to cope with boredom and loneliness.</p> <p><i>"Having been in jail] got me used to being idle and being in a pretty much enforced captivity type of thing..."</i></p> <p><i>"I read the Bible. My husband comes and visits and that helps."</i></p> <p><u>Strategies for improving the experience</u> Participants reported that their isolation experienced would be improved by more human connection, diversions, and improved environmental hygiene. <i>"someone to talk to who will listen."</i></p>	
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			<p><i>"If you had another room on the other side of this one and it had a window, you could say, 'Hey, how're you doing, George?' Wave at somebody or something like that. That's some kind of interaction. . . I mean even if they turn the TV on (I have the telephone, letters, books and everything like that), I'm still isolated as far as being social. I can't interact with a TV."</i></p>	
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<p>Authors: Kitazawa S.</p> <p>Year: 1995</p> <p>Citation: Tuberculosis health education needs in homeless shelters. <i>Public Health Nursing</i> 12: 6: 409-416</p> <p>Quality Score: (++, + or -) +</p>	<p>What was/were the research questions:</p> <p>To gather the knowledge and views of homeless people living in group shelters concerning tuberculosis, tuberculosis medical care and health education. To formulate recommendations for TB education programs for people living in group shelters.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Health Belief Model framework</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Semi-structured open-ended interview</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p>	<p>What population were the sample recruited from:</p> <p>The researcher selected participants from three homeless shelters in San Francisco, US. These include: a city-funded shelter housing approximately 350 men per night; a second city-funded shelter housing approximately 325 men and women a night; and a third shelter, privately and publicly funded, housing about 70 homeless people living in family groups including children.</p> <p>How were they recruited:</p> <p>Homeless shelter workers identified English and/or Spanish speaking persons that could participate in the study. Participants were offered \$5USD as gratitude.</p> <p>How many participants were recruited:</p> <p>20</p> <p>Were there specific</p>	<p>Brief description of method and process of analysis:</p> <p>Prior to interviewing study participants, a pilot interview session was conducted to verify the clarity and simplicity of questions.</p> <p>The researcher conducted anonymous semi-structured interviews, lasting 20-25 minutes with study participants covering five topic areas: knowledge of TB; knowledge of medical care related to TB; perceived problems or barriers; improving access to and use of medical care for TB; and learning regarding TB.</p> <p>The researcher read interview questions aloud to each participant, prompting for responses. The interviews were audio taped. During each interview, after receiving responses from the first two questions, the researcher gave a brief presentation about tuberculosis in order for the subjects to be able to respond to the remaining three topic questions.</p> <p>The audiotapes were then transcribed. The Spanish language tapes were translated into English by a bilingual transcriptionist. The researcher did not reject interview data about any subject, even when Responses reflected considerably disorganised thought processes that were not apparent during the selection process.</p> <p>Analysis of the transcriptions were done by findings response patterns and reviewing themes that emerged.</p>	<p>Limitations identified by author:</p> <p>Limitations of this study include: the small sample size and the exclusion of those people with noticeable psychiatric or substance use, which may cause bias.</p> <p>Limitations identified by review team:</p> <p>The study would have benefited from a comparison of subgroups (i.e. age, gender) in their sample or by matching responses to particular subgroups.</p> <p>There is limited information regarding how the data was analysed, which can affect the credibility of the findings.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p>

	<p>NR</p> <p>When:</p> <p>NR</p>	<p>exclusion criteria:</p> <p>Those people who had psychiatric problems or had noticeable effects of substance use were not invited to participate.</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Knowledge of tuberculosis</u> Three participants thought that TB was a blood disease, other participants thought that TB is caused by smoking, worsening colds or “eating unripe fruit”. Common misconceptions among participants concerned transmission of the disease such as through sharing cigarettes (n=5), sharing food or utensils (n=4), sharing saliva, blood or tears (n=5).</p> <p>Fewer than half of the participants worry about contracting TB, even though many reported that they could contract it from anyone and that shelter residents may be at higher risk. Only two participants mentioned HIV as a risk factor for contracting TB.</p> <p>Participants were generally unaware about typical symptoms of TB, though 60% mentioned coughing.</p> <p><u>Understanding of medical care for tuberculosis</u> Most participants (17) thought that there “probably was” or “should be” a treatment for TB; though many were doubtful about its effects:</p> <p><i>“I know it’s treated, but curable I don’t know.”</i></p> <p>The suggestions provided for prevention of TB by study participants include: washing dishes well, not sharing cigarettes, not wearing other people’s clothes. Only one participant mentioned skin test screening and two indirectly referenced prophylactic isoniazid (INH) therapy as a preventative measure.</p>	<p>Source of funding:</p> <p>NR</p>
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			<p><u>Problems with access</u> The wait time for receiving medical care was reported as a major barrier:</p> <p><i>It's that once you get to the [shelter], you have to stay there, because if you don't stay there and stand in line, you're not going to get in. And food's the same way. You have to go stand in line for a couple hours, just so you can get something to eat. So you have to budget your time.</i></p> <p>Four participants discussed psychological barriers including fear of testing as a barrier:</p> <p><i>It can be very degrading when you don't want [it] to be degrading. They'll say things that kind of won't sound right to the other person, and [the patient] will think, "Oh, God, I'm going to die. I just know I'm not going to get out of this."(participant)</i></p> <p><i>"Am I going to be sorry when I get through? Am I going to the sanatorium? Are they shipping me out? When I got tested and the injection came back positive, I got real worried. I thought it was one of those diseases if you got it, you might as well start writing your will out. I decided not to go [back to the clinic]"(participant)</i></p> <p>Other cited barriers include: distant location of services, high cost of public transportation and physical disabilities.</p> <p><u>Suggestions for improving access</u> Most participants had difficulty responding to the question: "what would make it easier" to obtain medical care related to TB. Four subjects stated that health care was easier for them to access at</p>	
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		<p>the shelter than if they were in standard housing.</p> <p><u>Education regarding tuberculosis</u> Almost all of the participants had learned about TB from another person such as friends, prison or medical staff.</p> <p><i>“Word of mouth is the fastest and most productive way of getting the message through. Because it stays on people’s minds... I relate to that more.”</i></p> <p>Reported learning about TB was through acquaintance with someone who had active TB or through pamphlets or fliers (n=9) (which was the most preferred method):</p> <p><i>“ A person may have the wrong information, but, with a pamphlet, you get the truth.”</i></p> <p>Other ways of learning included video, which was preferred by seven participants.</p> <p><i>“Video is one of the greatest in the world. I’ve seen it in action in other situations when you’re dealing with people just starting from zero. I’ve seen it work.”</i></p> <p><i>Group sessions:</i> <i>“Just have a group meeting like we used to have at school. And you would get everybody’s undivided attention.”</i></p> <p><i>Redundancy:</i> <i>“The more you put it in my face, the more I’m apt to pay attention.”</i></p> <p><i>Showing genuine concern:</i> <i>“Because like some of us, all our lives-just on</i></p>	
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			<p><i>the streets, and nobody would really come up and talk to you, or say anything to you, so just, just the idea, just going out and helping.”</i></p> <p>The most motivating factor facilitating participants to receive care was the perceived seriousness of TB and concern for others.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Marais, F.</p> <p>Year: 2007</p> <p>Citation: <i>Towards the improvement of tuberculosis control and participatory research: A multi-method Community-based Participatory Research study of TB in migrant African communities in the borough of Westminster, London.</i> Community Advisory Panel, Department of Primary Care and Social Medicine Imperial College London: London.</p> <p>Quality Score: (++, + or -) ++</p>	<p>What was/were the research questions:</p> <p>Data has been extracted for the following research objectives: 1. To identify the structural influences which operate across community and sector levels within the local context which may influence TB risk, healthcare access and outcome in migrant black African communities in Westminster. 2. To identify the resources to improve TB control which exist or could be strengthened within the sectors and within these migrant black African communities themselves.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Grounded theory</p> <p>How were the data collected:</p> <p>What methods:</p>	<p>What population were the sample recruited from:</p> <p>The City of Westminster, London</p> <p>How were they recruited:</p> <p><u>Migrant African participants:</u> Participants were recruited via multiple treatment and non-treatment sites (e.g., social and commercial venues, social networks) through a variety of methods such as snowballing, posters, leaflets, articles, direct approach and purposive sampling at TB clinics.</p> <p><u>Key stakeholders:</u> Both snowballing and purposive recruitment were used.</p> <p>How many participants were recruited:</p> <p>329.</p> <p>Migrant Africans – n = 312, Key stakeholders from UK healthcare – n =</p>	<p>Brief description of method and process of analysis:</p> <p>This research used both quantitative and qualitative methods. Only data from the qualitative component is extracted here. Qualitative methods were: semi-structured interviews with migrant Africans with no experience of TB treatment, semi-structured interviews with migrant Africans with experience of TB treatment, community consultations with migrant Africans, semi-structured interviews with key stakeholders from multiple sectors, qualitative observations (minutes and notes from the community advisory panel (CAP) meetings, and notes from all planned and unplanned discussions and consultations).</p> <p>In this study a key stakeholder was regarded as any individual, group, organisation or institution which could significantly influence public health interventions (policies, services and/or programmatic responses) for, and outcomes of, TB control.</p> <p>The qualitative data were analysed manually, using a thematic approach. Recurring factors were clustered into themes and sub-themes. The CAP and community research fieldworkers (CRF) participated in the data analysis process. They fulfilled a critical participatory role by shaping the interpretation of the data, and by ensuring the validity of the interpretation and that of the study conclusions.</p>	<p>Limitations identified by author:</p> <p>The authors note that there was a necessity for non-random sampling.</p> <p>Limitations identified by review team</p> <p>The role of the researcher and relationship to participants is not clearly defined.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>Advocates using participative research methods for future research into migrant communities and TB.</p> <p>Source of funding:</p> <p>UK Medical Research Council, Westminster Primary Care Trust and Imperial College London</p>

	<p>Multi-method community-based participatory research using questionnaires, in-depth interviews, community consultations, observations.</p> <p>By whom:</p> <p>The Principal Investigator (the author) and a further two academic researchers from Imperial College London, and the Community Advisory Panel (CAP) partners (representing the various migrant African communities), and the Community Research Fieldworkers (CRFs) (also representing the various migrant African communities).</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>November 2003 to May 2006</p>	<p>17.</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p><u>Migrant African participants:</u></p> <ul style="list-style-type: none"> - Migrant black African - 18 years old or above - In the UK for not more than 10 years - Resident or attending services within Westminster <p>A sub-group of the study was included if they had received or were receiving treatment for latent and/or active TB.</p>	<p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Knowledge of TB</u> The qualitative data showed that TB knowledge was poor among the migrant Africans and was a source of concern. <i>"I did not know anything about TB.... if I knew I could have started fighting it earlier."</i> <i>"My community members need to be educated about TB and let them know that there is medicine for treating it, they don't know this."</i></p> <p><u>Opportunity to acquire knowledge about TB</u> The migrant participants agreed there was a general lack of opportunity to acquire knowledge about TB. Most participants explained that both in Africa and the UK information about TB was not readily available to them, and they did not know where to obtain such information. Some had received partial, often inaccurate, information from within their respective African communities, passed down the generations. Others reported that some information was obtainable from GPs and certain health clinics but it was inaccessible to most community members because leaflets were printed in inappropriate languages and that many community members did not attend these health services. Most participants said opportunities for migrant African communities to discuss TB were not available. There were often conflicting priorities such as financial survival which took precedence over obtaining TB knowledge.</p> <p><u>The value of camel milk and honey to improve health</u></p>	
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			<p>Two methods of treating TB were discussed by the participants: drinking camel milk, and taking honey early in the morning. The participants felt more vulnerable in the UK because of lack of access to camel milk.</p> <p><u>Perceptions of TB</u> Most migrant participants regarded TB as a growing problem in the UK due to a lack of information and knowledge, poor housing, poor diets, stress and depression. Participants explained that TB was discussed as a cause of concern privately but was not discussed communally because of stigma.</p> <p>All key stakeholders perceived TB as a growing problem in the UK due to migration, poor living conditions, and difficulty accessing high risk populations.</p> <p><u>Stigma of TB and concealment of diagnosis</u> TB was found to be highly stigmatised in all the African migrant communities. There were feelings of fear, both of acquiring and spreading the infection in all communities. Most participants said it was because of a general lack of knowledge about TB, screening and curable treatment, coupled with past experiences in Africa where treatment was often unavailable or unaffordable, many community members still associated TB with inevitable death. This resulted in reinforcement of social stigma and rejection. In the group which had received treatment for TB, participants said they had received support from family members but were distanced from the community. Several also reported stigmatisation by service providers who displayed discomfort and fear</p>	
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			<p>of close contact. This compounded feelings of rejection and despair.</p> <p><i>“We know TB is a bad thing in our country, no treatment and die. It’s treated here in this country it’s easy to treat but our people don’t know. When we are in our country, oh TB it’s a big thing, That person’s going to be gone... In our community some people have it, they hide it, they are infecting the whole house... In our society it’s a big thing when you have TB, they are scared, hiding it.”</i></p> <p><i>“You get isolated, people they look at you like you are going to die you cannot getting treated. It is a lack of knowledge obviously that it can get cured.”</i></p> <p><u>Experiences of TB</u></p> <p>Several participants (never treated for TB) had either lived with or cared for someone with TB both in Africa and the UK. The same participants stated that they had not been screened for TB as it had never been offered and they were unaware of the need for screening. The findings suggest that of all participants with TB ($n=11$) only 2 had knowingly lived with or cared for someone with the disease in the UK. Both stated that, at the time, screening was not offered to them and they did not know that it was available.</p> <p><i>Low coverage of TB screening</i></p> <p>Most participants explained that they had never been screened for TB, prior to or since entry into the UK, because it had never been offered. The qualitative findings suggest that most participants expressed the concern that they had not been offered screening. Although most participants would like to be screened for TB there was extensive confusion and lack of</p>	
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			<p>information about points and methods of access.</p> <p><i>Effects of TB</i> Participants with TB described feelings of loneliness associated with isolation. Several talked about the pain of leaving communities in Africa and then finding themselves isolated in hospitals. Hospital isolation of persons with infectious TB in the UK was alien to most participants as this is not standard practice in Africa. The data shows widespread confusion about the need for, and lack of understanding of, the purpose of hospital isolation.</p> <p>There was a widespread concern that TB was assumed to be linked to HIV which increased stigmatisation. This produced a reluctance to attend TB clinics. <i>“The first thing people will be thinking is, she is HIV positive... so there is that taboo in the way people will treat me. So, I’d rather not tell them, so I am the one who is going to take the precaution and if they want to come and see me I’ll be making up stuff, I’m busy, I’m not at home.”</i></p> <p>The participants described how media and political debate, compounded by the attitudes of some service providers, are creating a situation where the migrant African participants felt they were being blamed and stigmatised for “importing” and “spreading” TB. <i>“...there is TB here in the UK but people always put blame and the stigma. You know Africa is stigmatised, and it is damaging to us and community relationships, but it is just one of those things, you just have to learn to live with it really.”</i> <i>“They blame us for bringing TB to this country and spreading it</i></p>	
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			<p><i>around to people from the UK. But we didn't have any TB when we came here, we got it here in UK. The UK gave us TB!"</i></p> <p>Participants with TB described the negative effects of the disease on their own and their families' financial situation in the UK. Many lost their jobs after diagnosis and struggled to buy food and pay bills. Two participants became homeless as a result of their diagnosis. <i>"Well, London is hard. Even when I'm at work it's still hard. And now I've been off work with TB it is difficult because like, this month, all my sick pay that they paid me is going to go towards my rent. So this will be a difficult month for me, I must say, it's going to be so difficult". "TB destroyed me... now I'm bankrupt. I don't have a house. I was a star worker and I've lost my job as well because of the TB..."</i></p> <p><u>Healthcare uptake</u> GPs were the first point of contact for most participants for all health advice and related matters. There was a widespread lack of awareness and understanding of the meaning and implications of patient confidentiality. Several reported reluctance to attend TB clinics because of stigma and fear. <i>"African communities don't understand what is confidentiality! Because to them, back in Africa... you going to visit somebody in the hospital, I leave the room and go to Reception and say – hey, what's up with him? It's like when you are sick, you don't have right to confidentiality..."</i></p> <p><u>Features of an acceptable healthcare service</u> The following were repeatedly identified by</p>	
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			<p>participants: (a) being treated and respected as an individual, (b) not being judged on the basis of colour or health needs, (c) being listened to and engaged in care planning, (d) continuity of care, (e) specialist providers who could create a supportive environment, (f) mutual trust, and (g) a reduced chance of being attended to by someone from a similar cultural/community background resident in the same area. The ability to access gender compatible services was also noted by many women and men from Muslim communities.</p> <p><u>Confusing and discriminatory healthcare policies</u> The findings suggested widespread confusion at both community and provider levels regarding the eligibility to healthcare, including TB screening and treatment, for asylum seekers and particularly failed asylum seekers and undocumented migrants. Many stated they were unsure whether they were entitled to receive healthcare in the UK. They reported receiving inconsistent and often conflicting advice from health providers. Some asylum seekers reported being denied screening. Several key stakeholders explained that although health providers were aware such persons were eligible to receive TB treatment, these persons themselves and CBOs representing and serving them were unaware of this entitlement.</p> <p><u>Difficulties registering with a GP</u> The findings suggest some, particularly asylum seekers, experienced great difficulty in finding a GP willing to register them. Reasons stated include: (a) unhelpful and rude reception staff, (b) being regarded as</p>	
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			<p>a temporary local resident, (c) not having a permanent address, (d) language barriers, (e) long waiting lists, and (f) lack of information and understanding of the actual process and meaning of registration. Some participants reported their HIV status as the main reason for not being accepted by, or registering with, a GP.</p> <p><u>Problems with language barriers and translators</u> Language was reported by participants as a major barrier to accessing healthcare. The most common problems were the lack of availability of interpretation services offering a range of African languages and dialects, and severe delays in obtaining interpreters. These conditions resulted in additional delays. Some stated that, to access services they resorted to using family, friends, neighbours and sometimes children to act as translators.</p> <p>Healthcare providers also reported problems with language and the suitability of some interpreters especially for service users originating from countries with tribal/ethnic conflict.</p> <p><u>Delays in receiving treatment</u> Most of the participants with TB had experienced delays presenting with symptoms and starting treatment. These delays were due to a combination of individual factors and service provider factors. <i>"I was coughing lots at night, could not sleep. I went to GP and for 6 months prescribing antibiotics but did not work. After more than 6 months GP sent me to hospital and in examination they said TB"</i></p>	
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			<p><u>Lack of awareness of healthcare system and services</u> There was a lack of awareness of the existence and purpose of healthcare services. Most did not know they could attend a TB clinic without a GP referral.</p> <p><u>Lack of healthcare workers at community-based organisations</u> Barely any CBOs employed health workers. These organisations tended to focus on broader social, education and community issues but failed to address health. Participants felt that this was detrimental to both individual and community health. Key stakeholders said that funding had been lost for such positions.</p> <p><u>Lack of information about TB</u> There was perceived to be a widespread lack of information about TB. Language was cited as a major barrier. Most did not know where or how to get information about TB.</p> <p><u>Poor housing conditions</u> Asylum seekers often lived in a succession of poor standard temporary accommodation for prolonged periods of time while their immigration applications were under consideration. Particular concern was expressed for the health and wellbeing of single men and women who arrived on their own in the UK. The data shows that growing number of community members had no choice but to share accommodation with others, while an increasing number were becoming street homeless. <i>"I was quarantined because TB is contagious. I couldn't work and because I</i></p>	
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			<p><i>couldn't work I could not pay my rent and my landlord kicks me out. They gave me a note to housing but of course they wouldn't give me a house because they felt that I was discharged. So right now I'm roaming the streets".</i></p> <p>Key stakeholders reported difficulties in securing accommodation for those being treated for TB. <i>"While there are questions about over-crowding, there's questions about movement of people, the other significant issue for Westminster is temporary accommodation. It is evil, absolutely. Temporary accommodation, two things: (1) standards of accommodation are not good, they are designed not to be good because they want people to move on of their own, and (2) even in temporary accommodation you've got significant shifts. The standards people have to live in is not good. There you've got the potential of a public health hazard moving around."</i> (Key stakeholder)</p> <p>Poor nutrition and unemployment were also discussed by migrant participants.</p> <p><u>Methods for disseminating knowledge</u> Word of mouth was thought to be the most effective means of communicating health messages with African communities. Culturally appropriate leaflets and social care workers could also be effective. Community-based health workshops were seen to be effective. Dramatised television shows were also a valuable information source for the communities.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Moro, M. Resi, D. Lelli, B. Nicoli, A. Gagliotti, C. Falcone, F.</p> <p>Year:</p> <p>2005</p> <p>Citation:</p> <p>Barriers to effective tuberculosis control: a qualitative study. <i>International Journal of Tuberculosis and Lung Disease</i>. 9 (12): 1355 – 1360.</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>To explore chest and infectious disease physicians' views of the barriers to effective tuberculosis control.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Grounded theory</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Focus groups</p> <p>By whom:</p> <p>Three of the authors (DR, CG and BL) facilitated the focus groups alongside an observer</p> <p>What setting(s):</p> <p>NR</p> <p>When:</p> <p>September 2002 –</p>	<p>What population were the sample recruited from:</p> <p>The Emilia Romagna region of Italy.</p> <p>How were they recruited:</p> <p>All hospitals and community units that offer specialised TB care in the region were asked to send at least one physician to the focus groups and all but two care units were represented in the final sample.</p> <p>How many participants were recruited:</p> <p>49 (34 chest physicians and 15 infectious diseases physicians).</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Chest or infectious diseases specialist physician offering TB care</p>	<p>Brief description of method and process of analysis:</p> <p>The first eight focus groups included between six and eight physicians. All included a mix of chest and infectious diseases physicians, a facilitator and an observer. The facilitators encouraged open discussion and kept the discussion relevant, while probing areas that needed further clarification. Opening questions were used to begin the discussion and these were structured in order to not lead to pre-defined answers. Open-ended questions were used and questions were not led along a predetermined path.</p> <p>All focus groups were recorded with permission and fully transcribed. Two researchers also took detailed notes during the sessions.</p> <p>Data analysis used grounded theory methodology and was carried out in three phases. Transcripts were read and re-read to identify key categories and then reviewed several times to confirm that concepts relating to the same phenomena were placed in the same category. After these codes were developed the same data were re-coded two weeks later to ensure the results compared. Two investigators independently coded the data and discussed discrepancies. Coding was aimed at identifying more general and abstract categories and identifying connections between themes and levels (e.g., micro, meso, eso, macro).</p> <p>Key themes (with illustrative quotes if</p>	<p>Limitations identified by author:</p> <p>The authors note a potential bias of using self-selected volunteers for focus groups rather than a randomly selected sample. Bias may also arise from subjective coding, classification and interpretation.</p> <p>Limitations identified by review team:</p> <p>Limited to one geographical region which may affect generalisability. Potential bias in purposely selected sample.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>NR</p>

	<p>February 2003</p>	<p>in the Emilia Romagna region.</p>	<p>available) relevant to this review:</p> <p><u>Specific subgroups of patients</u> The focus group participants agreed that there are barriers to the diagnosis and management of TB related to three specific patient groups: the foreign-born, the elderly and the immune-compromised.</p> <p>Most participants agreed that the available guidelines do not give sufficient guidance regarding the daily problems of these groups. TB is often not considered in the diagnosis of elderly patients and is not easy to diagnose in foreign-born patients. <i>“...General practitioners so not take into account tuberculosis in elderly, poor general health status patients with cough: they think of cancer, always.”</i> <i>“The problem is represented by Chinese, Pakistani and Indian patients: the pathological forms of tuberculosis in these groups of patients are different and unusual.”</i></p> <p>Treating these groups is also perceived as challenging. <i>“Severe side effects of tuberculosis treatments are more frequent in elderly patients, who often have liver diseases or may be addicted to alcohol.”</i> <i>“Some ethnic minorities are particularly difficult to communicate with: we need cultural mediators.”</i></p> <p>Guidelines were not always perceived by the participants as useful in supporting clinical decisions. <i>“Guidelines are black and white, with few grey tones: tuberculosis, in contrast, is completely grey.”</i> <i>“Any tuberculosis care is specific to the patient; guidelines offer a general framework that each physician can</i></p>	
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			<p><i>follow or not...</i>"</p> <p><u>Organisational factors</u> Focus group participants felt that effective TB control is hampered by ineffective service organisation and lack of essential resources. The lack of laboratory services and respiratory isolation rooms were deemed particularly relevant. <i>"We have problems with isolation rooms when the diagnosis is not final: the patients are not receiving treatment and are highly contagious."</i></p> <p>The participants considered there was a lack of professional TB nurses responsible for case holding. This was seen as a crucial problem in achieving effective TB control. <i>"I feel very much the weight of the absence of the health nurse, who is accustomed to working inside the hospital and then visiting the patient at home, linking the hospital and the community."</i> <i>"There are not enough nurses to bring the [DOT] therapy to the home".</i></p> <p><u>Barriers in a low-prevalence country</u> The physicians agreed that there was a disappearance of TB expertise and awareness among physicians and this was seen as a crucial problem relevant to all medical staff. The disappearance of dedicated TB services has not been replaced by effective multi-function services. There was a perceived lack of communication among services and a lack of integrated and standardised care for TB and its different levels. <i>"I think that there are too many people involved in the management of tuberculosis cases."</i></p>	
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Study Details	Research Parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Nnoaham K, Pool R, Bothamley G, Grant A.</p> <p>Year:</p> <p>2006</p> <p>Citation:</p> <p>Perceptions and experiences of tuberculosis among African patients attending a tuberculosis clinic in London. <i>International Journal of Tuberculosis and Lung Disease</i> 10(9): 1013-1017</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>To describe the perceptions and experiences of African patients with TB in London, particularly relating to diagnosis, adherence and stigma</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Grounded theory</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Semi-structured individual interview</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>Private room in hospital</p> <p>When:</p> <p>NR</p>	<p>What population were the sample recruited from:</p> <p>Patients attending a TB clinic in Hackney, London, who had been on treatment for active TB.</p> <p>How were they recruited:</p> <p>Enrolled consecutively face-to-face</p> <p>How many participants were recruited:</p> <p>16</p> <p>Were there specific exclusion criteria:</p> <p>Individuals attending clinic either for preventive therapy or to receive a diagnosis for the first time.</p> <p>Were there specific inclusion criteria:</p> <p>Born in Africa; self-identified as African; willing to be interviewed in English; age ≥18 years.</p>	<p>Brief description of method and process of analysis:</p> <p>Interviews using semi-structured schedule. Answers probed for additional detail. Interviews lasted 45-75 minutes and were tape-recorded if permission was given. Interim analysis was carried out to refine the questions.</p> <p>Themes were coded using Nvivo and compared within and between interviews to generate higher-order generalisations. Important themes were explored further in subsequent interviews.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Misconceptions regarding TB</u> Several aetiologies were ascribed to TB including heredity, poisoning and pneumonia. Some participants thought TB could be acquired by sharing cutlery or through sexual contact. <i>"We used the same utensils, shared the same toilet, bathroom, cups and glasses. And we weren't using disinfectants."</i> (37-year-old man, Nigeria). <i>"I thought. . . he passed it on to me through sex, like HIV."</i> (25-year-old woman, Angola). However, participants knew that TB not affecting the lungs was not transmissible.</p> <p><u>Symptom misinterpretation</u> Participants often misinterpreted initial symptoms, leading to delays in seeking treatment. <i>"It started as a lump which grew bigger and bigger. I first thought it was a boil. I left it like that for about three months during which it kept getting bigger."</i> (20-year-old</p>	<p>Limitations identified by author:</p> <p>Small and non-representative sample.</p> <p>Limitations identified by review team:</p> <p>Overview of findings is fairly brief; diversity within sample not explored.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>A National Public Health Career Scientist award from the Department of Health; NHS Culyer allocation</p>

		<p>woman, Somalia) <i>"I suspect it must have been food poisoning. I think it must have contributed to the illness or triggered it."</i> (37-year-old man, Nigeria) <i>"I thought it was because of the heavy load I carried. I did not report the chest pain for about three weeks. When I coughed and saw blood, then I came to the doctor."</i> (31-year-old man, Ghana).</p> <p>Several reported that healthcare providers did not diagnose TB early on. <i>"I was coughing and I went to the GP and he said it was a virus that will go after some weeks. I went back later and he said the same thing."</i> (45-year-old man, Nigeria) <i>"I started coughing in November and it wasn't until mid January that I was referred to hospital for chest X-ray."</i> (19-year-old man, Nigeria) <i>"I had chest pain . . . I was brought to the emergency . . . the doctor examined me and gave me a painkiller. As I was about to leave, I coughed and, it was all blood."</i> (40-year-old woman, Nigeria).</p> <p><u>Denial of diagnosis</u> 916 participants did not believe they had TB. These participants often had misconceptions about TB and had longer times to diagnosis and less previous experience of TB. <i>"I didn't believe it, to be honest . . . there's nothing relating to TB in my family. If you have this thing [TB] in your family, then it may come to you, so me, I don't believe it."</i> (31-year-old man, Ghana) <i>"I am not convinced it is TB I have. First, they say it is this illness [sarcoidosis], then they say it is TB."</i> (38-year-old woman, Ivory Coast) <i>"I said 'no I haven't got TB'. I used to hear about it but I never knew it might come close to me . . . but you know until you know someone who has it, you do not feel it near you like that."</i> (19-year-old</p>	
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			<p>man, Nigeria). "</p> <p>Those who had had experience of TB reported differently: <i>"[The diagnosis] was no problem because we know it. My cousin, everyone, they have TB before. So when I told them, look I have got TB, they said no problem."</i> (20-year-old woman, Somalia). However, participants reported high adherence.</p> <p>Factors influencing adherence included counselling from healthcare providers, personalised care from specialist nurses, and advice from well-informed peers.</p> <p><u>Contexts of stigma</u> Actual stigma was reported mostly with reference to isolation measures. <i>"I felt bad. I mean I am not an alien. You see all those nurses all masked up. It wasn't a good feeling. People treating you differently, you're separated from all others [hisses]. It was hard."</i> (19-year-old man, Nigeria). Otherwise, actual stigma was uncommon. One participant reported: <i>"My nephew, who used to come and see me, when he heard that I had TB, started staying away. He thought that if he came close to me, he will contract it and will start dying."</i> (40-year-old woman, Nigeria). <i>"After they told me, I came home and said there are some things I use and nobody should use it. I kept my own cup, my own spoon . . ."</i> (39-year-old man, Congo).</p> <p><u>HIV 'cross-stigmatization' of TB</u> Some respondents reported that the association of TB and HIV. <i>"It is always like 'He's got TB; he must be HIV positive'. That's the way people look at it. I think people see that the symptoms look alike, so they just conclude that anyone</i></p>	
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<p>Authors:</p> <p>Sagbakken M, Bjune G, Frich J</p> <p>Year:</p> <p>2010</p> <p>Citation:</p> <p>Experiences of being diagnosed with tuberculosis among immigrants in Norway – Factors associated with diagnostic delay: A qualitative study. <i>Scandinavian Journal of Public Health</i> 0: 1 – 8</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>To understand the experiences of being diagnosed with TB among immigrants from Somalia and Ethiopia in Norway and to identify factors associated with diagnostic delay.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>What methods:</p> <p>In-depth interviews</p> <p>By whom:</p> <p>One author conducted all interviews</p> <p>What setting(s):</p> <p>The interviews took place in (unspecified) locations chosen by the patients.</p>	<p>What population were the sample recruited from:</p> <p>Immigrants to Norway from Somalia and Ethiopia who had been diagnosed with TB.</p> <p>Participants were recruited from the following primary healthcare services and hospitals: Ulleva University Hospital, Aker University Hospital, Akershus University Hospital, Asker and Bærum Hospital, and Lovisenberg Diakonale Hospital.</p> <p>All locations of recruitment were in Oslo and the surrounding county of Akershus in Norway.</p> <p>How were they recruited:</p> <p>A TB coordinator or a nurse was notified every time a new TB patient from Somalia or Ethiopia was diagnosed in one of the primary healthcare facilities or hospitals. Those diagnosed persons were given written information about the study and were asked to contact the</p>	<p>Brief description of method and process of analysis:</p> <p>In-depth semi structured interviews, lasting one to three hours, were conducted and tape-recorded.</p> <p>An interview guide was developed in order to provide themes to facilitate the interviews. The questions in the guide were broad and open-ended. The themes which the guide covered include:</p> <p>(a) symptom identification and health related behaviour; (b) experiences related to the diagnostic process; (c) information and understanding of the disease; (d) social support factors; (e) Perceptions and experiences as a TB patient in the context of DOT.</p> <p>Eight participants had a second interview to gauge whether perspectives had changed throughout treatment and explore ambiguous themes.</p> <p>The audiotapes of the interviews were transcribed and coded by two authors independently. All three authors agreed on the final codes/ themes and analysis of content.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p>Only the findings relating to homeless people's experiences with TB have been extracted here.</p>	<p>Limitations identified by author:</p> <p>Participant's reporting of experiences was based on retrospective accounts which can lead to bias with respect to severity, onset, or symptoms. Some participants had limited ability to communicate in Norwegian or English.</p> <p>Limitations identified by review team:</p> <p>The article would benefit from more depth and detail in its presentation of the findings. The diversity of views among study participants could have been better explored.</p> <p>Accounts of health professionals were not included.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p>

	<p>When:</p> <p>1 June 2007 – 30 June 2008</p>	<p>researcher for participation and consent.</p> <p>The final sample was chosen based on a purposeful strategy so that there was adequate variation with respect to educational background, gender, age and types of TB.</p> <p>How many participants were recruited:</p> <p>22 (10 males and 12 females)</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>Participants had to have originated from either Somalia or Ethiopia and be diagnosed with TB.</p>	<p>The data gathered in this study on experiences of homelessness in general has not been extracted.</p> <p><u>Patients' understanding of TB</u></p> <p>TB was considered to be a life-threatening disease among study participants. Comments that showed some participants' misconceptions or lack of knowledge about TB include: the belief that it only manifests in the lungs and the lack of knowledge about bacteria. All participants were aware that TB transmission was interpersonal, but thought that the cause of TB was actually based on circumstance such as a poor diet or poverty.</p> <p><i>"It is low-class people, a low-class disease. Because low-class people they don't get food that [is good], and they are exposed to many things."</i> (male participant)</p> <p>Others noted that TB is essentially caused by an imbalance in a person's equilibrium. For example, moving from cold to warm elements or going in and out of bars. Another reported cause of TB was committing sins.</p> <p><u>Patient interpretation and response to initial symptoms</u></p> <p>Cough, weight loss, fever and weakness were considered as normal TB symptoms. A generally held view among participants was that the absence of one of those symptoms meant that TB was unlikely.</p> <p><i>"To be honest, I was drinking and smoking and [. . .] I feel that if I had real tuberculosis I wouldn't have been able to go out and party the next day."</i> (young girl with pulmonary TB)</p>	<p>Norwegian Foundation for Health and Rehabilitation and the Norwegian Heart and Lung Association</p>
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			<p>Participants reported the different responses to TB from communities in their home countries compared to Norway. They state that people in their home countries avoid people with a heavy cough for fear of TB transmission, while in Norway no one paid attention to coughs. Participants were under the impression that by living in a rich country for several years, they would not contract TB.</p> <p><i>“I was shocked [. . .], because I haven’t lived there [Ethiopia] since I was young. I was out for so many years [. . .] so how did I get this tuberculosis?”</i></p> <p>One participant did not share TB related symptoms with their healthcare professional because of a fear that his TB status would follow on his national identity number.</p> <p><u>Experiences with the health services</u> Some patients with pulmonary TB had a speedy diagnosis because of their accurate reporting of their medical history. Other participants with pulmonary TB that experienced one or more initial TB symptoms had a long diagnostic delay with multiple encounters with a healthcare professional. It was found that few participants were referred for a chest X-ray or had a sputum test at their first visit to the clinic.</p> <p>Many participants were treated for other conditions including: pneumonia, malaria or the common cold. Study participants noted that their worsening condition and miss-diagnosis made them lose trust in their health professional and as a result made visits to different doctors. For example, one participant had been diagnosed</p>	
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			<p>with malaria and had taken the required medications that did not have an effect. This led to a loss of trust in the system. Other feelings felt by participants were, humiliation because they were not taken seriously and stress or depression from health professionals accusing them of not going to work. Some participants took a second or third chest X-ray, which eventually had led to a TB diagnosis.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Swigart V, Kolb R</p> <p>Year: 2004</p> <p>Citation: Homeless persons' decisions to accept or reject public health disease-detection services. <i>Public Health Nursing</i> 21: 2: 162 – 170</p> <p>Quality Score: (++, + or -) +</p>	<p>What was/were the research questions: To identify the factors that influence homeless person's decisions to reject or accept a screening test (chest X-ray) for detection of TB.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): NR</p> <p>How were the data collected: What methods: In-depth semi-structured interviews</p> <p>By whom: Interviewer (The research team composed of: family nurse practitioner and researcher; family practice physician; public health nurse working with the homeless; physician with in-depth knowledge of homelessness; a</p>	<p>What population were the sample recruited from: Sample was recruited from a population of sheltered and street-dwelling homeless persons. These persons resided or were visiting one of the seven shelters in an unnamed north-eastern US city.</p> <p>How were they recruited: Shelter supervisors and a volunteer from an organization serving the homeless population identified and recruited the sample. Every fifth person was invited to participate in an interview as long as they met the inclusion criteria.</p> <p>Note: the interviews took place during the implementation of a larger project that was providing on site chest X-ray screening.</p> <p>How many participants were recruited: 55</p>	<p>Brief description of method and process of analysis: After the recruitment team (shelter supervisors and volunteer from an organization serving the homeless) had identified and recruited participants, they introduced the homeless sample to the interviewer who then explained the study and obtained consent.</p> <p>All semi structured interviews began with the following opening question: "<i>Can you tell me about your main reasons for deciding whether to have the TB screening or not?</i>" A narrative by the participant would follow, with the interviewer using probes and prompts as necessary in order to illuminate the decision making process of the participant. Each participant was given a small radio as a gratitude for the interview.</p> <p>The interviews were recorded by tape, transcribed and systematically assessed using constant comparative techniques. The transcribed interviews were re-read by the interviewer while listening to the recorded tape of the interview to ensure accuracy of the transcription. Non-verbal behaviour that was noted during the interview was added to the text. The transcribed interviews were themed/ coded and disagreements were reconciled until agreement was reached. The text was then inserted into the computer software program Ethnograph and the assigned themes/codes were tagged to the text data.</p> <p>To ensure credibility, the findings were presented and discussion with six homeless</p>	<p>Limitations identified by author: Generalisability is weak because all interviews were carried out at shelters and because data was collected at the same time of a planned disease detection program. It is also likely that the more sociable were likely to participate. The inclusion criteria limited the range of opinions presented. For example, those who had language or communication problem or severe emotional problems were not invited to interview.</p> <p>Limitations identified by review team: In general, the study was carried out well. However, the diversity of perspectives does not seem to be adequately explored. The study presented original data (quotes) of the most common views among the sample and little data of those whose views</p>

	<p>formerly homeless person.)</p> <p>What setting(s):</p> <p>In an environment that provided quiet, comfortable seating and privacy near a medical testing area.</p> <p>When:</p> <p>NR</p>	<p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>The person had to have been, 1) homeless, either residing or visiting shelters or living on the street, for more than 7 days before the interview date; 2) able to read or hear and understand interviewer; 3) able to speak English language; 4) able to participate in a 15-minute interview.</p>	<p>persons at one of the shelters.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Factors facilitating acceptance of disease detection</u></p> <p>Among those interviewed, fifty people accepted the TB screening offered by the health department. Factors that influenced their decisions varied, and some people noted multiple factors.</p> <p>51% of participants reported medical history or family history of such problems as an influencing their decision.</p> <p><i>“Yes, I have a reason to come out because I got bad lungs and I have a breathing problem and I have to take medicine for it, an inhaler for it and stuff. I’m hoping to get better. I just come out to see if I was getting better through the medication.”</i> (60 year old male, sheltered)</p> <p><i>“Where we sleep at, under the bridges, to get up there you have to climb. I fell and landed on my chest. I had some chest pain...so it is good you know, to have a check up on your body.”</i> (35 year old male, on the streets).</p> <p><i>“My sister had it (TB) one time. She died from it. She used to smoke, then she had a half a lung...and she got TB and she died. I thought I better be checked.”</i> (75-year-old female, sheltered)</p> <p>15 participants were living in shelters for recovering drug or alcohol addicted males. 12 of those participants stressed the importance of self-care in the context of their recovery.</p>	<p>deviated from the majority. Little elaboration was provided from the interviews of the homeless sample that refused screening services.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>Otis A. Childs Trust of PNC Bank and the Mercy Foundation, Pittsburgh, PA.</p>
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		<p><i>“I’m just trying to be focused on my basic hygiene. Hygiene, showering every day, uh, you know, brushing my teeth. There’s a long road I have to travel, but I have to start somewhere.”</i> (42-year-old male, sheltered for two weeks)</p> <p><i>“I haven’t been taking care of my health, ’cause I got hooked on drugs and alcohol, so it’s better to get off drugs and alcohol, and they say it’s about change if I want to get better with my life, so I think that’s a part of it, to be concerned about my health. I couldn’t better my life and not disregard, you know, ignore my health. So that’s why I’m interested in the chest X-ray or whatever health check, uh, I need.”</i> (51-year-old male, sheltered for one month)</p> <p>Far less people participated in the screening test because of curiosity of the condition of their lungs (21%) or the free/convenient service (27%).</p> <p>Five participants reported their perceptions of being in close quarters with others (at shelter):</p> <p><i>“Um, I figured that since I was passing through, and you know, that I would want to see, that I really didn’t pick up nothing from being here.”</i> (42 year old male)</p> <p><i>“In here with everybody, I don’t know, whatever they get, you got.”</i> (68-year-old female, sheltered)</p> <p><u>Role of shelter personnel</u> Some participants among those that were sheltered reported that they felt pressure of the shelter workers or personnel to oblige with the screening test.</p>	
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			<i>...Or maybe they've gotten a "protection from abuse" court order against an abuser and if they have something medically wrong, that's gonna be a mark against them. So in general they feel health care is threatening.</i>	
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<p>Authors:</p> <p>Van der Oest C, Chenhall R, Hood D, Kelly P.</p> <p>Year:</p> <p>2005</p> <p>Citation:</p> <p>Talking about TB: Multicultural diversity and tuberculosis services in Waikato, New Zealand. <i>New Zealand Medical Journal</i> 118: 1216: 1-12</p> <p>Quality Score: (++, + or -)</p> <p>-</p>	<p>What was/were the research questions:</p> <p>The purpose of this study is to explore the opinions of refugee and minority group representatives about the significance of TB for their community; the community's perceptions of the level of TB services and the community representatives' thoughts about how these services could be improved.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Open-ended qualitative interviews</p> <p>By whom:</p> <p>What setting(s):</p> <p>At the venue of the community representative's choice</p>	<p>What population were the sample recruited from:</p> <p>Waikato Health District, New Zealand.</p> <p>How were they recruited:</p> <p>The community representatives were selected by using the contact list in the <i>New Settlers Handbook</i>. The handbook lists all immigrant communities and the contact details of community representatives. Seven of the largest community groups were contacted and given information about the study and were requested to participate.</p> <p>How many participants were recruited:</p> <p>NR</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p>	<p>Brief description of method and process of analysis:</p> <p>Interviews were recorded in note form by the interviewer and transcribed at interview completion. There were not sufficient funds for this project to tape record interviews or receive participant feedback on the notes collected. However, the interviewer clarified statements and collected feedback during the interview and in some cases, later by telephone.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>TB beliefs</u> All participants had reported that TB was well understood by members of their community. However, some community representatives mentioned that the symptoms of TB were often not attributed to the disease and instead to other conditions.</p> <p>Asian representatives stated that there is a widely held belief that TB is not prevalent in New Zealand (NZ). Representatives from the Kampuchean community stated that there are specific socio-cultural beliefs about TB transmission. For example, that it only occurs in a family group.</p> <p><u>Improving Services suggestions</u> The Filipino representative suggested that</p> <p><i>Doctors could help improve the treatment of people by helping to reduce the overcrowding that often occurs with these families, when two</i></p>	<p>Limitations identified by author:</p> <p>The study used community representatives as a proxy for the community members and therefore may not be representative of the entire community's attitude or perceptions.</p> <p>Other limitations include over and under reporting and a misclassification of responses due to the specific characteristics of study questions.</p> <p>The authors also note that a lack of resources and funding prevented return visits and the transcription of interviews.</p> <p>Limitations identified by review team:</p> <p>The most common or generalised views and perceptions are only reported since data was collected by representatives of entire communities rather than</p>

	<p>When:</p> <p>January 2002 to March 2002</p>	NR	<p><i>families may decide to occupy one house.</i></p> <p><u>Stigma</u> Stigma was a common theme among several community representatives. This was especially true for those recent immigrants that come from countries with higher levels of TB and the older generation of Pacific Island or Maori population (who remember when TB was more prevalent in NZ).</p> <p>The Kampuchean representative reports that: <i>the family will react to an individual who has been diagnosed with TB by isolating him in different degrees because of the significant fear that TB engenders for most Kampucheans.</i></p> <p>The Somali, Asian and Maori community representative had reported that stigma had been tackled in their communities with simple health education messages indicating that TB is curable.</p> <p><u>Barriers to access to healthcare services</u> All representatives discussed barriers in their communities to accessing healthcare services.</p> <p>All representatives reported unemployment in their communities as a barrier, since they would be unable to pay the consultation fee charged to visit primary healthcare services.</p> <p>Chinese, Maori and Pacific Islanders' representatives mentioned the preference in the community of dealing with traditional healers rather than the medical service. In contrast, the Somali representative stated that people in their community preferred treatment from medical service since they have experienced TB-related</p>	<p>individuals of those communities. There is little information provided on how data has been analysed and themes derived.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>The feasibility and costing of developing ethno-specific primary healthcare services aimed at the cultural needs of minority populations was recommended.</p> <p>Source of funding:</p> <p>NR</p>
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			<p>morbidity and mortality in their native countries.</p> <p><u>Service provision in the healthcare setting</u> Representatives were asked about any difficulties their community members might experience in the healthcare setting.</p> <p>Somali and Asian population representatives reported that communication with the patient should normally be conducted with the head of the family, normally a senior male. In the Cook Island community, a family matriarch takes on this communication role.</p> <p>Common among all interviewees was that care should involve the entire family. All representatives also reported that patients from their communities may feel unable to identify with a health care provider that is not from their own cultural or lingual background.</p> <p>The Samoan representative described that <i>individuals need to be consulted and seen in a familiar environment by nurses, healthcare workers and social workers who are of their ethnic background and speak their language, in conjunction with the public health nurse or physician who is treating them.</i></p> <p>Communication barriers, particularly around language, were a commonly reported barrier. Even when patients are fluent in English, the medical terminology is difficult to understand. It was also noted that there was a lack of written information in different languages for health issues available (including TB), particularly pertaining to prescription instructions. There was a common need for interpreters and those interpreters would need to be acceptable to the</p>	
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			<p>family.</p> <p>Those communities who had a high level of knowledge about TB also had high levels of treatment adherence.</p> <p>The Kampuchean representative describes that <i>people in (her) community are very happy to (take medications), and are generally very diligent about taking and completing courses of medication prescribed to them. This appears to be a reflection of the fear and anxiety that they hold about TB, coupled with the vivid recollection of the people who died from TB in refugee camps, and in Kampuchea</i>.</p> <p>It was reported that the lack of information about the merits of medication over traditional medications meant that Pacific Island and Maori communities do not always adhere to treatments.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>West E, Gadkowski L, Ostbye T, Piedrahita C, Stout J.</p> <p>Year:</p> <p>2008</p> <p>Citation:</p> <p>Tuberculosis knowledge, attitudes, and beliefs among North Carolinians at increased risk of infection. <i>North Carolina Medical Journal</i> 69: 1: 14-20</p> <p>Quality Score: (++, + or -)</p> <p>+</p>	<p>What was/were the research questions:</p> <p>The purpose of this study is to explore the knowledge, attitudes and beliefs about TB among Spanish-speaking immigrants, homeless shelter residents and persons attending a drug/alcohol rehabilitation centre.</p> <p>Only data on the homeless and drug/alcohol rehabilitation participants has been extracted here.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>Grounded theory</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Focus groups</p> <p>By whom:</p> <p>NR</p>	<p>What population were the sample recruited from:</p> <p>Participants were recruited from various sites in Chapel Hill, Durham and Raleigh, North Carolina in the USA. Participants were selected from three populations: Spanish-speaking immigrants (data of which is not extracted here); homeless; and drug/alcohol abusers.</p> <p>How were they recruited:</p> <p>Participants were recruited using a convenience sample of persons that were at a study site and willing to participate at that time.</p> <p>How many participants were recruited:</p> <p>11 focus groups of 52 participants</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p>	<p>Brief description of method and process of analysis:</p> <p>Four reviewers read the transcripts of the focus groups independently looking for key words and themes. After half of the focus groups had been completed and transcribed, researchers compared the analysis for accuracy and consistency.</p> <p>A list of key words and themes were maintained throughout the process which resulted in an analysis template which was used to organize and code the data.</p> <p>Findings were circulated among the research team and consensus was reached before they were finally considered.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p>It should be noted that the data extracted here is only from those focus groups of homeless people or drug/alcohol users. Findings that could not be deciphered between these population groups and Spanish-speaking immigrant groups were not extracted. Findings that were consistent themes throughout all focus groups are extracted here.</p> <p><u>What did the participants know about tuberculosis?</u></p> <p><i>Signs, symptoms, and contagiousness</i></p> <p>Reported causes of TB among all participants were: smoking, "malnutrition", sleeping in cold breezy places and wet floors, and</p>	<p>Limitations identified by author:</p> <p>The participants in this study were recruited by convenience sample and may not be representative of their respective populations.</p> <p>Each focus group had a small number of participants (especially from drug/alcohol centres) which contributed to reduced generalisability of the findings.</p> <p>No demographic data was available for persons from drug/alcohol centres or homeless shelters.</p> <p>The authors also mentioned that the English-speaking focus groups were conducted by a white female, which may have affected the group dynamics.</p> <p>Limitations identified by review team:</p> <p>NR</p>

	<p>What setting(s):</p> <p>Focus groups of homeless participants were conducted at four homeless shelter sites. Focus groups of persons with drug/alcohol abuse were conducted at a rehabilitation facility.</p> <p>When:</p> <p>NR</p>	<p>NR</p>	<p>“uncleanliness”. Participants in all focus groups commonly reported that TB was transmitted by the cough of an infected person. Other beliefs of transmission were by using the same glass or utensil, holding hands or from dirty needles, by blood and even “like AIDS”.</p> <p>The authors note that there was a general lack of knowledge about causation and transmission.</p> <p>Participants knew there was a skin test for tuberculosis and many had previously undergone testing. Participants understood the severity of the disease (associated with morbidity and mortality). Signs and symptoms among all groups of TB reported: persistent cough, coughing or spitting up blood, fever, and night sweats.</p> <p>Participants did not have a good understanding of TB treatment and there was mixed knowledge about whether there was a treatment.</p> <p><u>Attitudes and beliefs about the diagnosis and treatment of tuberculosis</u></p> <p>Certain groups of people were thought by some focus group participants to be more likely to have TB than others. The participants of the alcoholic recovery group said that “street people” and the “homeless” are more likely to be infected. Other participants stated that persons with AIDS and a depressed immune system may be at higher risk.</p> <p><u>Trust of the healthcare system and healthcare professionals</u></p> <p>Common in all focus groups was the theme of costly health care as a barrier to seeking care. <u>Prejudice and Stigma</u></p>	<p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>NR</p>
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			<p>Participants from the alcoholic recovery group reported that they were at risk of TB because of their regular contact with “street people” and unknown people in Alcoholics Anonymous meetings.</p> <p>Participants from the homeless (women) focus group stated that people of “low income” and “low social status” were more likely to be infected.</p> <p><u>Willingness to take medication</u> There were inconsistent responses by participants when asked whether participants would take nine months of oral medication to prevent TB and when asked whether they would take the nine-month medication even though they may feel well and not ill. For example, the homeless shelter participants all agreed that they would take the medication for TB for nine months. However, when asked, if they would take it despite feeling well, they responded, “it depends” or “not without a lot of tests”.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors: Whoolery, M</p> <p>Year: 2008</p> <p>Citation: Survivalising among homeless people with tuberculosis: a grounded theory study. <i>PhD Thesis</i>. Faculty of Society and Health Bucks New University, Brunel University, UK.</p> <p>Quality Score: (++, + or -) ++</p>	<p>What was/were the research questions: What does having tuberculosis mean to homeless people and how does this impact their opportunities to complete treatment?</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified): Grounded theory</p> <p>How were the data collected: What methods: In depth semi-structured interviews.</p> <p>By whom: Researcher (author).</p> <p>What setting(s): Clinic facility</p> <p>When: NR</p>	<p>What population were the sample recruited from: Homeless persons from three Central London TB/chest clinics.</p> <p>How were they recruited: Participants from the clinics (identified by the author) volunteered to participate.</p> <p>Remuneration of £10 was given to participants, to reimburse any expenses incurred for participation (i.e. time and travel).</p> <p>How many participants were recruited: 16 participants: 10 male and 6 female; ages 22-57; 5 were on methadone treatment for heroin use, 3 were commercial sex workers, 2 were diagnosed with HIV.</p> <p>Were there specific exclusion criteria: 1) Under the age of 18 years old. 2) Diagnosed with multidrug resistant</p>	<p>Brief description of method and process of analysis: Interview questions were semi-structured providing a standardised set of open-ended questions. However, the process was treated more like a 'conversation' whereby participants focused on topics they wanted to discuss. An interview guide was prepared, but the questions changed depending on emerging concepts during the course of the interview and from feedback on the questions provided by participants. Most interviews lasted 45-60 minutes.</p> <p>Interviews were audio taped after consent was given. Observations and emerging concepts from the interviews were documented by the researcher after recording (and after the participant had left). Tape recordings were listened to twice and transcribed four to six times (for coding purposes) verbatim. Field notes were also collected on the same day as interviews and contained information on the environmental setting, communication between research and participant, quality of interaction and any problems that arose.</p> <p>Data was coded (using substantive and theoretical coding) and constant comparative analysis was used. Data analysis continued until the point of data saturation. The researcher generated a theoretical model developed from the data analysis process that seeks to explain homeless/TB phenomenon.</p> <p>Data was managed by hand mostly. An Excel</p>	<p>Limitations identified by author: The sample population (16 people) were all based in London and were recruited from TB clinics where they had a support staff, which limits the transferability of the study findings. Participants in this study were volunteers and therefore may not represent the most vulnerable, unwilling or unable members of the homeless population. . The grounded theory of <i>Survivalising</i> is difficult to evaluate because there are no comparative theories in the literature.</p> <p>Limitations identified by review team: In parts of the report, it is difficult to differentiate between data reported by individuals and interpretations of the data by the author. However, the author does provide direct quotations from participants, which were</p>

		<p>(MDR-TB) tuberculosis.</p> <ol style="list-style-type: none"> 3) Any infectious tuberculosis patients. 4) With severe mental illness. 5) With learning disabilities. <p>Were there specific inclusion criteria:</p> <ol style="list-style-type: none"> 1) Over the age of 18 years. 2) Homeless: People who are either literally roofless or who live in insecure, overcrowded, dangerous, illegal or temporary accommodation. 3) Diagnosed with TB. 4) On tuberculosis treatment for more than two weeks (therefore no longer infectious). 5) Patients receiving care and support from the host clinic. 6) Living in London. 7) Speaking English. 8) Willing to share their experiences and perspectives. 	<p>spreadsheet was used to provide an audit trail of the process.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Neglect and survival</u> Homeless participants reported that personal health was often neglected or overshadowed by a desire to escape the harsh realities of social exclusion through activities such as substance use. The author refers to this behaviour as “zoning out” or “bottoming out”. Almost all participants had at least one substance addiction that directly impacted adherence to their TB treatment. The main concern for participants was to meet their immediate needs and desires and therefore taking TB medication was not prioritised.</p> <p><i>I know I'm not looking after myself enough. Sometimes I feel rough and down like...most of the time I feel rough... run out, drained (P2)</i></p> <p><i>I did have other issues as well apart from the TB [drug & alcohol issues]...sometimes it's difficult, I mean I'm an ex-user, cause I'm coming off a lot of other stuff as well...so my heads [sic] kinda all over the place...there are times were [sic] it's kinda difficult to get ere [sic] (TB clinic)...it was a multiple habit it wasn't just a heroin habit, It was a heroin, crack cocaine, and alcohol habit... (P1)</i></p> <p><u>Diagnosis and fear</u> Being hospitalised or being diagnosed with TB was a crisis for participants and triggered changes in behaviour. Participants reported that</p>	<p>helpful in this regard.</p> <p>The author has not reported a diversity of perspectives. This may be because the results are grouped (or themed) by the phases of the theory (Survivalising) (i.e. zoning out, bottoming out etc), which often masks experiences that may differentiate from this single social process identified.</p> <p>The data was coded by a single reviewer (author) which may have led to bias.</p> <p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding: University bursary and Worshipful Company of Curriers</p>
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			<p>they were in a state of fear: fear of the side effects of treatment, fear of stigmatisation, fear of hospitalisation and fear of the unknown.</p> <p><i>some doctor told me I have TB...nightmare... months I am sad, I am cry not in the eye my heart cry (P9)</i></p> <p>For most participants, diagnosis largely came as a shock.</p> <p><i>...I hadn't been to see a doctor for about ten years and I thought it was just side effects of the heroin or whatever. And I didn't realise I was ill [TB]... Like I never knew I was ill till [sic] I collapsed (P6)</i></p> <p>Participants' fear and anxiety was also heightened when they discovered the length of the treatment regime or that they had drug resistant TB. One individual reported that they felt the diagnosis of TB was a personal punishment of some kind.</p> <p><i>I'm scared...It makes me feel miserable. Makes me feel as if I'm being punished for something that I've done, I don't know what I've done...To start with I didn't really know much about it (TB)...when they started putting masks and that on your face, I never thought I would survive that (P10)</i></p> <p><u>Experiences with hospitalisation</u> Participants' experience in the hospital setting was largely negative, though some individuals mentioned some positive experiences. Hospitalisation was considered similar to imprisonment for most participants.</p>	
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			<p>Isolation rooms triggered feelings of stigmatisation where individuals felt dirty or that others thought they should be removed from social contact.</p> <p><u>Stigmatisation from TB</u> Having a diagnosis of TB was also considered embarrassing and was rarely discussed among homeless people because of the stigma attached to TB in this community.</p> <p><i>It's a disease not no one really talks about [TB/homeless people] (P6)</i></p> <p>The use of masks for infection control also led to a sense of fear and isolation for participants. They reported that it made visitors afraid to visit the homeless person in the hospital. The bacterial nature of TB led to further stigmatisation since the term 'germ' was associated by participants with being dirty or diseased.</p> <p><i>... people were too scared to come near me...I think people see it as a dirty thing...they see, that only dirty people get that [TB]...it's the kind of feeling I get from it... (P1)</i></p> <p>One individual reported that he experienced stigmatisation in the workplace and had lost his job and accommodation (which was part of his work package). Another individual lost his job because he was unable to work due to stigmatisation in the workplace. A third participant experienced stigmatisation in the home and had decided to leave his sister's house and 'sleep rough'. Other participants mentioned that they felt stigmatised by professionals such as probation officers.</p>	
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			<p>The author states that some participants experienced little or no negative feelings after diagnosis. This was attributed to the strong support from health professionals from the point of diagnosis onwards, appropriate care delivery, good rapport with staff and a lack of stigmatisation. These participants reported that face-to-face interaction with health professionals and a positive hospital experience helped facilitate a better route to treatment and their understanding of TB. Participants stated that an increased knowledge of their health helped them feel empowered, and positive relationships with healthcare professionals increased self-esteem, all of which were important factors in their successful treatment.</p> <p><i>When I went into hospital I cut myself down [heroin]...going into hospital I didn't have a choice. I couldn't go out there and manage [heroin habit] because I couldn't stand up never mind walk. So I had to go on methadone, so I went on to that and that's when my priorities changed, being on methadone won't kill me, whereas the other things would so I had to get the TB sorted out, get my kidneys sorted out, and then sometime in the future I can worry about coming off the methadone (P6)</i></p> <p><u>Self-realisation</u> The author described how some participants experienced a sense of "self-realisation". This meant that participants began to make positive changes by examining meaning in their lives and finding acceptance. Some participants began to make links with family and others focused on becoming healthy or finding housing. For example, some individuals moved from 'rough</p>	
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			<p>sleeping' to living in a hostel.</p> <p><i>...when I came here [hospital] with TB they give [sic] me three weeks to live, and it really freaked me out, I mean I got a second chance, so I have to try and do it properly this time (P3)</i></p> <p><i>But I end up going in hospital and they say everything for a reason, maybe I needed this TB to get the start I needed, so that I can get a flat. Cause this, bed-sit is a start to getting a flat inat [sic]... (P11)</i></p> <p><i>I had enough of it, and I put my hands out, I need help, and that's when I went back to the primary care unit and said, look, I need some help. And then they put me on the methadone program, and stabilised me and it means me not to go out shoplifting anymore, it keeps me out of trouble, so I don't have to go shoplifting, keeps me out of prison, just got the alcohol to deal with now (P4)</i></p> <p>Participants who were actively making mental or practical changes in their lives also began to accept service support.</p> <p><i>...I'm trying to follow the process, and I do have this sort of support network. That's in the hostel as well as here [clinic], in that they've supported me through my TB... just by being there, because I was seriously ill, and because of my situation I had just come off the street and that. I think they put in extra effort into me...it has become easier to deal with, because they facilitated the medication and when I first had TB they use to come to my hostel and bring my medication and like sit there and make me take it in front of them, but they're not so strict now</i></p>	
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			<p><i>because I've got use that [sic], so I get the medication at the chemist now...I'm aware of what medication I'm taking and how I should be taking them. I'm always eager to know how I'm progressing and to learn...(P5)</i></p> <p><u>Theory of 'Survivalising'</u> The author generated a theory from the data gathered in this project, titled <i>Survivalising</i>. This refers to the four-stage social process experienced by her study participants (homeless people with TB): Zoning out, Bottoming out, self-realisation and healing. Zoning out refers to the activities homeless people engage in for survival from the realities of social exclusion (where health is neglected in favour of immediate desires). Bottoming out refers to a point of crisis (for example, diagnosis of TB), which often acts as a catalyst for change. Self-realisation refers to a shift to positive attitudes towards health and living. Finally, healing refers to making lifestyle changes such as seeking new housing, making new relationships and focusing on TB treatment.</p>	
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Study details	Research parameters	Populations and sample selection	Outcomes and methods of analysis/Results	Notes
<p>Authors:</p> <p>Yamada, S. Caballero, J. Matsunaga, D. Agustin, G. Magana, M.</p> <p>Year:</p> <p>1999</p> <p>Citation:</p> <p>Attitudes regarding tuberculosis in immigrants from the Philippines to the United States. <i>Family Medicine</i>. 31 (7): 477 – 482.</p> <p>Quality Score: (++, + or -)</p> <p>++</p>	<p>What was/were the research questions:</p> <p>To examine what Filipino immigrants to the USA know about TB and their attitudes and practices concerning TB.</p> <p>What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):</p> <p>NR</p> <p>How were the data collected:</p> <p>What methods:</p> <p>Focus groups</p> <p>By whom:</p> <p>NR</p> <p>What setting(s):</p> <p>Community health centres</p> <p>When:</p> <p>1994</p>	<p>What population were the sample recruited from:</p> <p>Filipino immigrants in Hawaii and California.</p> <p>How were they recruited:</p> <p>Participants were recruited from the patient populations of four community health centres by staff members of the health centres. One of the two groups in Hawaii specifically recruited veterans of World War II who were admitted to the USA in the 1990s. Recruitment ceased once a sufficient number for functional focus groups were reached.</p> <p>How many participants were recruited:</p> <p>36</p> <p>The first Hawaiian group had six participants – four female and two male. They had lived in the USA for one to eight years. The second group consisted of nine male World War II</p>	<p>Brief description of method and process of analysis:</p> <p>Four focus groups were conducted - two in California and two Hawaii. The Hawaiian focus groups were conducted in Ilocano (a Filipino language) and the Californian focus groups were conducted in the Tagalog/Filipino national language.</p> <p>Each focus group session was recorded and transcribed. Each question was discussed, and every member was allowed to express their opinion. Three authors reviewed the focus group transcripts independently. The most commonly expressed themes were extracted and tabulated and individual quotations were identified.</p> <p>A cultural advisory panel of Filipino health care workers was held to review the focus group results over six sessions. Field notes were taken at these sessions.</p> <p>A reiterative process of reviewing and revising took place and confirmation and consensus on the validity of the data was reached by the panel.</p> <p>Key themes (with illustrative quotes if available) relevant to this review:</p> <p><u>Theories of causation</u> TB is considered as caused by multiple factors according to Filipinos including natural/environmental forces, imbalances of the body and contagion. To prevent the</p>	<p>Limitations identified by author:</p> <p>The authors note that the focus group participants were not randomly selected to represent Filipinos in the USA, and therefore cannot be generalised. The major themes expressed were identified by individual focus group members. All opinions could not be used in the report. Some of the individuals who conducted the focus groups were involved in the interpretation of results which may present an opportunity for bias.</p> <p>Limitations identified by review team:</p> <p>Many of the quotes given were about life in the Philippines, rather than life as an immigrant in the USA. The views of older and younger people were not differentiated, nor differences between sites.</p>

		<p>veterans, all of whom had TB infection. They had lived in the USA for a mean of 1.5 years and had an average age of 72.</p> <p>The first of the two Californian groups had seven participants – five female and two male and a mean length of residence in the USA of eight years, and a mean age of 36. The other group had 14 participants – two female and 11 male with a mean age of 76 and a mean length of stay in the USA of 7.1 years.</p> <p>Were there specific exclusion criteria:</p> <p>NR</p> <p>Were there specific inclusion criteria:</p> <p>NR</p>	<p>spread of TB, the clothes of a sufferer have to be boiled.</p> <p><u>Social implications</u> Participants in all four groups believed that the TB patient was contagious and required isolation. All groups said that the general attitude towards the TB victim was stigmatised. The patient is thought to be dirty and is outcast or shunned by society. <i>“They don’t see you as a person when you have TB”.</i> <i>“Your family member don’t come around because they feel you are dirty, and they are afraid that they will be infected by you. They don’t want to talk to you.”</i> Spouses of infected persons may refuse to have sexual relations and may seek a new partner. <i>“I remember in our family, one of our relatives had TB, and we isolated him. It used to scare the heck out of me. We would talk to him from a distance.”</i> It was also reported that sufferers were unable to emigrate to the USA.</p> <p><u>Psychological implications</u> The focus groups reported that victims of TB focus on their disease and impending death to the exclusion of all else, with work and other aspects of life neglected. Shame, isolation and loneliness are common. As a result, some will avoid medical attention as they would rather not be aware of the diagnosis. Some may become mentally incapacitated. Features of clinical depression were reported as characterised by TB sufferers.</p> <p><u>Treatment</u> Just as the cause of TB was considered to have multiple factors, so the treatment was</p>	<p>Evidence gaps and/or recommendations for future research:</p> <p>NR</p> <p>Source of funding:</p> <p>Centers for Disease Control and Prevention (U.S.A.).</p>
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			<p>considered to include multiple elements including traditional medicine, modern medical medicine, changes in environment and correcting imbalances in the body (for example through eating a balanced diet and getting rest). Traditional medicine was seen as an adjunct to modern bio-medicine. <i>“If it is in the Philippines, it is very hard because there are no regular checkups, especially in the rural areas. In the rural areas, we depend on faith healers and leaves, which we don’t even know if they can cure us or not.”</i> Other measures mentioned by participants included drinking the blood of a pure-black dog, drinking Carnation milk, and drinking large quantities of water.</p>	
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11.0 Appendix D. Studies excluded at full text stage

Table D1. Studies excluded on full text

Study	Abstract	Reason for exclusion
AhChing et al. (2001)	The research reported here examines knowledge, attitudes, and practices related to tuberculosis (TB) among Samoan immigrants through the use of a focus group. Samoan health workers to discuss participants' explanatory models regarding TB convened a focus group of eight Samoan living in Hawaii. The participants expressed a belief in the extreme contagiousness of TB. This leads to social stigma and isolation. Most agreed that biomedical treatment is necessary. Traditional herbal medicine was seen as adjunct to biomedical treatment. Focus group participants were found to subscribe to largely biomedical explanatory models regarding TB, but belief in traditional medicine also persists. TB was believed to be more transmissible than it actually is. TB continues to be a stigmatised disease.	EX6. Not hard-to-reach group
Ailinger and Dear (1997)	Kleinman's framework for eliciting an explanatory model was used in interviews with 65 Latino immigrants enrolled in preventive therapy in a county health department. The focus of the interview was their beliefs concerning the cause of their infection, their fears about it, and the results they hoped to achieve in preventive therapy. Found that most of the immigrants did not know the cause of their infection. (Original abstract - amended)	EX6. Not hard-to-reach group
Alvarez-Gordillo et al. (2000)	Objective. To identify health perceptions and practices and non-adherence to therapy among tuberculosis patients. Material and methods. Qualitative research work consisting of 11 group interviews with 62 tuberculosis patients during 1997-1998 in the Central, Highlands, and Border Regions of Chiapas, Mexico. Results Perceived causes of tuberculosis included contagion via food utensils, excess work, malnutrition, and cold, as well as other causes unrelated to person-to-person contagion. The resulting incapability to work resulted in an economic crisis for both the patients and their family members. As a result of the social stigma imposed by the disease, patients perceived a negative impact on their personal life, family, work, and community. Lack of knowledge regarding tuberculosis is an important factor in the selection of and adherence to different care alternatives. Inadequate care provided by health services, including an unsatisfactory physician-patient! Relationship resulted in diagnostic delay and non-adherence to therapy. Education programs to promote basic knowledge regarding tuberculosis and its treatment are necessary in this region.	EX6. Not hard-to-reach group
Alvarez-Gordillo et al. (2001)	The lack of knowledge about TB encourages people to consider various alternatives for their care. Tuberculosis control in Chiapas requires an optimal utilisation of the health services that exist in the state as well as a program of health education. TB control in Chiapas	EX6. Not hard-to-reach group

	must take into account the social, cultural, and economic reality of the population.	
Alvarez-Gordillo et al. (2003)	<p>Objective: To implement a training program for physicians and patients and assess its effectiveness in terms of patient compliance with the pulmonary tuberculosis treatment regimen in the border region of Chiapas, Mexico. METHODS: A controlled intervention study was performed with patients over 15 years of age who had pulmonary tuberculosis diagnosed by direct microscopy (bacilloscopy) between 1 February 2001 and 31 January 2002 in health units randomly selected in the border region of Chiapas, Mexico. The sample was made up of patients who sought consultation at 23 and 25 health units over that period (intervention and control group, respectively). The intervention group took part in a training program for health personnel in which the following were discussed: the social, cultural, and economic aspects of tuberculosis; the theoretical and practical underpinnings of the diagnosis and treatment of the illness, and the establishment of self-help groups. Selfhelp groups were also created for all patients at the 23 units where the intervention group sought consultation. All patients were given a short-term treatment regimen with isoniazid, rifampin, pyrazinamide, and ethambutol for a total of 25 weeks, until completing a total of 105 doses. Patient follow-up was extended through December 2003. The intervention and control groups were compared by means of the chi square test, and Student's t test was used to compare means. The relative risk of non compliance (RR) was calculated along with 95% confidence intervals (95% CI). Results: Eighty-seven patients participated in the study; 44 were exposed to the intervention, and 43 made up the control group. Compliance with treatment was considerably greater in the intervention group than in the control group (97.7% vs. 81.4%, respectively; RR = 1.20; 95% CI: 1.03 to 1.39; P = 0.0015). It was noted that physicians in the border region of Chiapas gear their activities toward curative medicine, rather than preventive medicine or understanding the social determinants of disease. Conclusions: As a result of the educational activities that were part of the intervention, there was an increase in the proportion of patients who complied with treatment. Health services can improve tuberculosis control in Chiapas with the resources that are available to them at present. Physicians should be taught to view health problems in Chiapas as part of an integral set of conditions, and efforts should be made to improve the doctor-patient relationship. Steps should also be taken to incorporate educational activities and community participation in health services in order to address public health problems in a comprehensive way.</p>	EX5. Not qualitative research
Anderson (2008)	Health inequalities between migrants and host populations in many western countries, including New Zealand, have been associated with low healthcare utilisation. This research used an ethnographic approach based on participant observation and semistructured interviews to examine Asian migrants' use of primary health services	EX1. Not focused on TB

	<p>in New Zealand. Participant observations were undertaken in migrant organisations, and clinical and domestic settings. In addition, semi-structured interviews were conducted with 23 migrants from India, South Korea and Mainland China, and six with New Zealand healthcare professionals. Migrants used a variety of strategies to negotiate New Zealand's healthcare system. These were influenced by their knowledge of it, their experience with healthcare systems in their home countries, language difficulties, structural barriers, divergent understandings of health and the extent of their local support networks. Social networks were found to play fundamental roles in migrants' healthcare strategies and, if promoted through community development, could increase the utilisation of primary health services and reduce health inequalities in New Zealand and other host countries.</p>	
Anon (2004)	<p>The consequences of a bad observance of the treatment are serious for the patient and for the community: relapse, prolongation of the treatment, increase of the risk of death (x 4), prolongation of the period of contagiousness and development of multiresistant strains. If a suitable antimycobacterial treatment was prescribed, observance is the essential element of success. There is no consensual definition of a bad observance in the literature. According to authors, bad observance can be defined as: 1) an interruption of treatment for at least two consecutive weeks; 2) drug intake inferior to 80% of the total prescribed amount. The risk factors for bad observance are numerous. The three principal ones frequently found in literature are: 1) absence of permanent residence (40 to 50% of bad observance); 2) alcoholism; 3) drug-addiction (especially IV). Other factors are also reported: cultural and linguistic barriers, psychoses, difficulty to find adequate transport to come to consultation, inadequate consultation schedules or other conditions considered by the patient as more important than taking the treatment.</p>	EX4. No views data
Asch et al. (1994)	<p>Physician groups are concerned that legislation requiring physicians to report illegal immigrants to immigration authorities will delay curative care. In particular, patients with tuberculosis may delay seeking care for infectious symptoms and spread the disease. We surveyed 313 consecutive patients with active tuberculosis from 95 different facilities to examine the relationship of immigration-related variables, symptoms, and delay in seeking care. Most patients (71%) sought care for symptoms rather than as a result of the efforts of public health personnel to screen high-risk groups or to trace contacts of infectious persons. At least 20% of respondents lacked legal documents allowing them to reside in the United States. Few (6%) feared that going to a physician might lead to trouble with immigration authorities. Those who did were almost four times as likely to delay seeking care for more than two months, a period of time likely to result in disease transmission. Patients potentially exposed an average of 10 domestic and workplace contacts during the course of the delay. Any legislation that increases undocumented immigrants' fear that healthcare professionals will report them to</p>	EX5. Not qualitative research

	immigration authorities may exacerbate the current tuberculosis epidemic.	
Atkins et al. (X)	<p>Background. Qualitative synthesis has become more commonplace in recent years. Meta-ethnography is one of several methods for synthesising qualitative research and is being used increasingly within health care research. However, many aspects of the steps in the process remain ill-defined. Discussion. We utilized the seven stages of the synthesis process to synthesise qualitative research on adherence to tuberculosis treatment. In this paper we discuss the methodological and practical challenges faced; of particular note are the methods used in our synthesis, the additional steps that we found useful in clarifying the process, and the key methodological challenges encountered in implementing the meta-ethnographic approach. The challenges included shaping an appropriate question for the synthesis; identifying relevant studies; assessing the quality of the studies; and synthesising findings across a very large number of primary studies from different contexts and research traditions. We offer suggestions that may assist in undertaking meta-ethnographies in the future. Summary. Meta-ethnography is a useful method for synthesising qualitative research and for developing models that interpret findings across multiple studies. Despite its growing use in health research, further research is needed to address the wide range of methodological and epistemological questions raised by the approach.</p>	EX4. No views data
Baker et al. (2003)	<p>Objective: A pilot study was designed to determine the general health problems of inner city sex workers. Sample: The researchers worked with an agency that provides outreach services to these sex workers. Through this agency, they had access to a purposive sample of sex workers in a large Midwest city. Methods: Nonparticipant observation was used to gather information about their health problems, the nature of information they may need, and the barriers to obtaining health care and health information. Results: Sex workers (n = 75) ranged in age from nineteen to 61 years old. They identified a number of physical or psychological problems, such as rape, depression, and tuberculosis. HIV/AIDS was never mentioned. A major barrier to health care is a lack of information about where to go for treatment or how to obtain health insurance. Conclusions: More research needs to be done by library and information science professionals to determine the information needs of sex workers and the agencies that provide them with health and social services.</p>	EX4. No views data
Bakhshi and Ali (1995)	There is a significant difference in the basic knowledge about TB between the white and non white ethnic patients. Tuberculosis is a high-risk illness for the non white community and education about the disease should play an important role in its prevention and control in the UK.	EX5. Not qualitative research
Barca et al. (1999)	Inmates under age 25 held in prisons who manifest first degree level health problems demonstrate a degree of rejection towards preventive treatment which periodically requires reconsideration of	EX5. Not qualitative research

	<p>the methods employed by the interdisciplinary teams in these centers. Our main objective is to evaluate the degree of rejection that these inmates demonstrate towards preventive campaigns against tuberculosis and to try to relate their lack of collaboration to such negative psychosociological factors as drug addiction, immunodeficiency due to HIV, and prolonged prison stays. For this study, a total of 50 inmates having similar characteristics were selected. A high rate of a negative attitude was shown in these circumstances: towards preventive treatment with Isoniacide, in relationship to the degree of immunodeficiency, a rejection of treatment with antiretroviruses and length of prison stay. Nursing programs for penitentiary inmates must take into consideration psychological and sociological aspects.</p>	
Bechtel et al. (1995)	<p>Migrant farmworkers and their families have restricted access to health and human services because of their frequent relocation between states, language and cultural barriers, and limited economic and political resources. Living and working in substandard environments, these families are at greater risk for developing chronic and communicable disease. In an assessment of health patterns among 225 migrant workers and their families, using personal observations, unstructured interviews, and individual and state health records, children's immunizations were found to be current, but dental caries and head lice were epidemic. Among adults, almost one third tested positive for tuberculosis exposure. Urinary tract infections were the most common health problem among women. Primary and secondary prevention were almost nonexistent because funds for these services were not readily available. The patriarchal system contributes to these problems by limiting access to family-health and social service needs. Although providing comprehensive health care to migrant communities presents unique challenges, nurses can demonstrate their effectiveness in reducing morbidity through strategic interventions and alternative uses of health delivery systems.</p>	EX4. No views data
Bernitz (2008)	<p>Aims: The European Union (EU) enlargement of 2004 brings both opportunities and challenges for public health. It is believed that further integration will bring direct health benefits, mainly through improved socioeconomic conditions, but there are also risks associated with the EU expansion, in particular cross-border health risks, such as the impact of the internal EU market policy of free movement and migration on communicable disease patterns. Against this background, this article examines communicable disease policy development in Finland, Norway and Sweden in response to changing European political frontiers, in particular the EU accession of the Baltic States. The emphasis is on HIV/AIDS and tuberculosis. Methods: The study is based on a qualitative and quantitative approach, using two complementary methods: documentary analysis and stakeholder analysis. Results: The article identifies a distinct pattern in communicable disease policy development between 1990 and 2005. The turn of the new</p>	EX4. No views data

	<p>millennium saw a sharp increase in national attention and the priority assigned to communicable diseases in Finland, Norway and Sweden. The article argues that this development is likely to be related to the rising national, regional and European awareness of the public health challenges associated with communicable diseases in today's borderless Europe. It also shows that the Baltic health situation is a particular concern for Finland. Conclusions: Although there is increasing national and regional activity within the communicable disease area, there is a need for a more effective European approach to tackle the future communicable disease challenges that may follow in an increasingly interdependent and integrated Europe.</p>	
Black and Bruce (1998)	<p>The resurgence of tuberculosis gives cause for alarm. Compliance with an effective medication regimen leads to cure; yet, many patients fail to comply. This paper discusses factors affecting compliance and the essential role of social work, from an ecological perspective, when intervening to increase compliance. The authors relate comments made by patients at the only hospital originally and still serving as a TB sanatorium in relation to literature on compliance. Changes at the hospital include the development of a social work department which uses the ecological perspective in working with patients whose histories include non compliance, as well as alcoholism, homelessness, loneliness, joblessness, and AIDS. The content of interviews with patients reveal and identify problems for future research.</p>	EX6. Not hard-to-reach group
Blakely (1996)	<p>Aims: To determine the health needs of refugees in the Porirua region. To develop options for health promotion for refugees in the Porirua region. Methods: Twelve families were interviewed (eight Cambodian and four Vietnamese) representing 68 individuals. Questions were asked of health and other needs, health service utilisation and barriers to healthcare, particularly language. Additionally, eight key informant interviews were conducted. Results: Families reported 26 out of 68 individuals (38%) as suffering from poor health; asthma, hepatitis B and treated tuberculosis being the three most common conditions. Open questions elicited many vague somatic complaints that may overlay psychiatric morbidity or stress. Health service utilisation was as high, or higher, than a comparable needs assessment in the Porirua region of a population based random household sample in 1993/4. Only six of the 27 refugees (22%) aged 16 or over, by their judgement, considered themselves competent enough in English to communicate independently with a general practitioner or other service provider. This is despite a mean length of residence in New Zealand of four years. Key informant interviews suggested undiagnosed psychiatric morbidity and problems accessing interpreting services, particularly in primary care. Conclusions: The major unmet health need for this group of refugees is interpreting services. Mental health needs are strongly suspected. The health promotion priority is provision of adequate interpreting services. The new Code of Health and Disability</p>	EX1. Not focused on TB

	Services Consumers' Rights legally enforces the right to a competent interpreter.	
Bollinger (2008)	This paper will explore the health implications of changes in mobility patterns with the goal of understanding both the real and perceived risk of contracting tuberculosis.	EX4. No views data
Cabrera et al. (2002)	The incidence and prevalence of tuberculosis are far more common among third world populations immigrating to the USA than among US-born citizens. Immigrants' failure to comply with an anti-tuberculosis treatment can impede completion of care and further confound this public health problem. Barriers to patient-provider communication can negatively influence adherence to a medical regimen. Patients who are unable to comprehend medical advice and do not see it as personally salient are less likely to follow their provider's medical advice. In this paper, the authors focus on efforts to develop a patient education tool targeting Spanish-speaking Latino immigrant patients to facilitate communication with tuberculosis clinicians. A description of the multi-stage developmental processes is presented including conducting a needs assessment, development of visual and written messages, review/critique by tuberculosis experts, field-testing, revisions, and distribution. Formative evaluation and field testing indicates promise for improving communication using this tool.	EX6. Not hard-to-reach group
Carey et al. (1997)	Objective: To identify newly arrived Vietnamese refugees' beliefs about tuberculosis (TB) and TB education needs. Methods. In 1994, the New York State Health Department and the Centers for Disease Control and Prevention conducted a survey of 51 newly arrived adult Vietnamese refugees in two New York counties. After being trained in interview methods, two bilingual researchers asked 32 open-ended questions on the causes of TB, TB treatment, and the disease's impact on work and social relationships. Results: Respondents correctly viewed TB as an infectious lung disease with symptoms such as cough, weakness, and weight loss. Hard manual labor, smoking, alcohol consumption, and poor nutrition were believed to be risk factors. Many respondents incorrectly believed that asymptomatic latent infection is not possible and that infection inevitably leads to disease. Nearly all respondents anticipated that having tuberculosis would adversely impact their work, family, and community activities and relationships. Conclusions. Targeted patient education is needed to address misconceptions about TB among Vietnamese refugees and to help ensure adherence to prescribed treatment regimens.	EX5. Not qualitative research
Chang et al. (2004)	Introduction: Tuberculosis (TB) studies have concentrated on clinical outcomes; few studies have examined the impact of TB on patients' quality of life (QOL). Methods: A systematic review of published medical literature using specific MESH terms: [Tuberculosis] and 1 - [Outcome], 2 - [Outcome Assessment], 3 [Quality of Life], 4 - [Mood Disorder], 5 - [Cost and Cost Analysis], 6 - [Religion], 7 - [Perception], 8 [Social Support], 9 - [Optimism], 10 - [Stress], 11 - [Signs and Symptoms], and 12 - [Cost of Illness]. This yielded 1972	EX4. No views data

	<p>articles; 60 articles met inclusion criteria and were reviewed. Results: TB somatic symptoms have been well studied, but there were no studies of effects on physical functioning or general health perceptions. Patients tend to be worried, frustrated, or disappointed by their diagnosis, but it is unknown how emotional health changes with treatment. Diagnosed patients are less likely to find work, and less able to work and care for their families. TB creates the greatest financial burden on the poor. In developing countries, patients and their families are ostracized by society, and families sometimes ostracize patients; the extent of TB's social stigma in the developed countries is unknown. Conclusion: There has been relatively little research on TB QOL and even less in developed countries. A better understanding may help improve treatment regimens, adherence to treatment, and functioning and wellbeing of people with TB.</p>	
Clark et al. (1997)	<p>Tuberculosis (TB) has made a disconcerting come-back in the USA in recent years. In 1994, Texas ranked third nationally in total number of TB cases and fifth in annual TB case rates. This is of great concern to the Texas Department of Health (TDH) and has led to the development of TB Innovative Demonstration Projects under the Tuberculosis Elimination Division of the TDH. One such project involves identifying high-risk communities by utilizing a computer-based geographic information system and then sending field-workers door-to-door offering free skin testing. Because this project was so successful in identifying positive skin test reactors, numerous requests have been made to duplicate its methods. One area of improvement is to increase individual and family participation. The purpose of this article is to present a survey of the literature on nonresponse in door-to-door soliciting, analyze the project's methods of soliciting and nonresponse, and propose ways nonresponse can be decreased in future projects of this nature.</p>	EX4. No views data
Classen et al. (1999)	<p>Background: Tuberculosis (TB) is transmitted by close contact with an infectious person. It is assumed that close contact occurs amongst household members and that contact outside the house is "casual" and does not play a major role in the transmission of TB. Methods: This study was conducted in an impoverished area with a high incidence of TB and a low! HIV seropositive prevalence. Thirty three households with 84 TB patients were identified between February 1993 and April 1996 and the transmission of TB was studied by combining Mycobacterium tuberculosis fingerprinting with in depth sociological interviews. Results: 42 strain genotypes were identified in the 84 patients. In 15 households all the patients had identical strains, in nine households all the patients had different strains, and in nine households some patients had identical strains and one had a different strain. In 26 houses at least one patient had a strain which formed part of a larger community cluster and in 12 of these households the patient(s) had contact with a community member who had the identical strain. In 58% of the cases the contact took place while drinking in social groups. Conclusion: In high incidence areas contact outside the household may be important for</p>	EX2. Not OECD country

	<p>the transmission of TB. This contact often takes place during recreation which, in the case of this study of impoverished people, consisted of drinking in social groups. Social interaction patterns should be studied and understood for effective implementation of control strategies.</p>	
Coker et al. (2006)	<p>Well-established tuberculosis screening units in Western Europe were selectively sampled. Three screening units in Norway, two in the UK, one in the Netherlands and one in Switzerland were evaluated. The aim of this study was to describe a range of service models used at a number of individual tuberculosis units for the screening of new entrants into Europe. Semi-structured interviews were conducted with clinicians, nurses and administrators from a selected sample of European tuberculosis screening units. An outline of key themes to be addressed was forwarded to units ahead of scheduled interviews. Themes included the history of the unit, structure, processes and outputs involved in screening new entrants for tuberculosis. Considerable variation in screening services exists in the approaches studied. Units are sited in transit camps or as units within hospital facilities. Staff capacity and administration varies from one clinic per week with few dedicated staff to fully dedicated units. Only one site recorded symptoms; tuberculin testing was universal in children, but varied in adults; chest radiograph screening was universal except at one site where a positive tuberculin skin test or symptoms were required in those < 35 years of age before ordering a radiograph. Few output data are routinely and systematically collected, which hinders comparison and determination of effectiveness and efficiency. Service models for screening new immigrants for tuberculosis appear to vary in Western Europe. The systematic collection of data would make international comparisons between units easier and help draw conclusions that might usefully inform service development.</p>	EX4. No views data
Collinson (2007)		EX4. No views data
Collinson (2010)	<p>The economic recession has left many undocumented migrants from the European Union accession states stranded and unemployed in the UK, without recourse to public funds. The TB team at Homerton University Hospital found a significant number of eastern Europeans squatting in derelict buildings in the London borough of Hackney. Because of the high rate of tuberculosis (TB) in Hackney, the team developed an outreach clinic to screen people for TB. During this screening initiative, which took place between August 2008 and March 2009, team members compiled a database of 98 eastern European citizens, and screened 62 for TB. Team members became aware during this time that, while eastern Europeans had significant health problems ranging from alcohol dependency to trench foot and scabies, very few of them had access to any form of health care except the local accident and emergency department. The team extended the screening program to other homeless people. It has developed strong, collaborative links with a range of agencies to</p>	EX4. No views data

	sustain its work with Hackney's vulnerable populations.	
Colson et al. (1994)	Discusses the resurgence of tuberculosis (TB) among the homeless, especially in cases where their immune systems have been weakened by HIV. A prophylactic program designed to address the dangers of TB infection among homeless, mentally ill men in New York City is described. The program explores attitudes affecting program adherence and addresses tangible barriers to adherence.	EX4. No views data
Coly and Morisky (2004)	Setting: Two health clinics in Los Angeles County, California. Objective: To identify factors associated with completion of care among foreign-born adolescents treated for latent tuberculosis infection (LTBI). Design: A total of 766 low-income adolescents (79% participation rate), including 610 foreign-born, were recruited. In prospective face-to-face interviews, data were obtained on socio-demographic and lifestyle characteristics, psychosocial factors and clinic-related variables. Medical chart data were abstracted regarding clinic appointment keeping and completion of treatment. Univariate and multivariate logistic regression analyses were performed to identify factors associated with completion of care. Results: Foreign-born adolescents were more likely to complete care than US-born adolescents, with 82% completion of care rate. In logistic regression analyses after controlling for age, medication taking behaviour (OR 1.26, 95%CI 1.15-1.39), living with both parents (OR 1.74, 95%CI 1.02-2.97), sexual intercourse (OR 0.66, 95%CI 0.36-1.19) and speaking mostly or only English with parents (OR 0.39, 95%CI 0.15-1.03) were independently associated with completion of care. Conclusion: These findings contribute to our understanding of the factors that may explain why some adolescents complete care whereas others do not. They provide supportive evidence that tailored intervention programs should be developed to support the screening and completion of treatment of foreign-born adolescents.	EX5. Not qualitative data . Not qualitative research
Coreil et al. (2004)	A cultural feasibility study was conducted among persons of Haitian origin in South Florida to identify factors which might influence utilization of screening and treatment services for latent tuberculosis infection in this population. Five focus group interviews conducted among men and women explored cultural beliefs and practices related to TB, barriers and incentives to screening, and approaches to increasing treatment adherence. Key findings include the influence of social stigma and fears related to confidentiality of medical status as disincentives to screening. Cultural sensitivity to being labeled as a high risk group for these infections also emerged as a critical variable. Community-based approaches to health education for this population are described. Study recommendations include the planning of programs based on a service delivery model that stresses respect and personal attention to clients, improved interpersonal skills of health center staff, and coordination of services between private doctors and public health agencies.	EX6. Not hard-to-reach group
Court-wright and Turner	The institutional and community norms that lead to the stigmatization of tuberculosis (TB) are thought to hinder TB control. We performed a systematic review of the literature on TB stigma to identify the	EX4. No views data

(2010)	causes and evaluate the impact of stigma on TB diagnosis and treatment. Several themes emerged: fear of infection is the most common cause of TB stigma; TB stigma has serious socioeconomic consequences, particularly for women; qualitative approaches to measuring TB stigma are more commonly utilized than quantitative surveys; TB stigma is perceived to increase TB diagnostic delay and treatment noncompliance, although attempts to quantify its impact have produced mixed results; and interventions exist that may reduce TB stigma. Future research should continue to characterize TB stigma in different populations; use validated survey instruments to quantify the impact of TB stigma on TB diagnostic delay, treatment compliance, and morbidity and mortality; and develop additional TB stigma-reduction strategies.	
de Souza and da Silva (2007)	This study is a report on care practice. Its objective was to develop a proposal for education in health care from a group of people with tuberculosis, seeking to increase the effectiveness of their treatment. The data was obtained through a proposal for education in health care, developed through a living group. Two interrelated themes resulted from the process of analyzing the data: the perception of tuberculosis and its care and treatment, and social isolation. These represent the elements that influence education in health care for people with tuberculosis, as well as the meaning that such a situation has to these people.	EX2. Not OECD country
Dievler and Pappas (1999)	Explores how social class and race affect the public health policy-making process in an urban area. Ethnographic methods were used to collect and analyze information about HIV/AIDS and tuberculosis policy-making by the Washington, DC Commission of Public Health. Kingdon's conceptual model of policy making was used to analyze and understand the process.	EX4. No views data
D'Lugoff et al. (2002)	Tuberculosis (TB) is endemic and epidemic throughout the world. More people will die of TB this year than in any previous year in modern history. However, in the USA successful TB control programs have resulted in low morbidity and low mortality here. Globalization and immigration threatens this control potentially bringing the infection to a here-to-fore complacent United States. This article describes a unique partnership between a community health program of a School of Nursing and a local health department chest clinic to find, screen and treat a population of Hispanic immigrants otherwise difficult to reach because of legal, language, cultural and socioeconomic barriers. Working through community organizations and limiting, and/or eliminating cultural barriers accomplished a high level of screening and treatment in a population with a significant incidence of latent tuberculosis infection. The program was of great satisfaction to the students and faculty involved; the personnel of a seriously under-financed health department and the community participants involved.	EX4. No views data
Draus (2001)	Tuberculosis is a deadly disease, the treatment of which is medically straightforward but socially complex. The illness itself is intimately entangled with conditions of poverty, addiction and powerlessness.	EX4. No views data

	<p>Poor communication between those suffering from tuberculosis and those in the medical profession regularly results in unsuccessful treatment of tuberculosis. A better understanding of the social dimensions of tuberculosis may lead to more successful treatment by addressing the social gulfs that separate patients and medical staff. In addition, it may serve to raise awareness of the social forces that underlie many health issues. This study employs both ethnographic and epidemiological methods to examine the social context of tuberculosis as it is experienced and treated in a contemporary urban setting. Written from the perspective of the field-based public health worker, it attempts to make connections between issues of individuals, institutions, and communities. Semi-structured interviews were conducted with tuberculosis patients concerning their illness experience, their relations with the health care system, their living conditions, and their social contacts in the community. These interviews provide the main empirical foundation for the study. The study also employs participant observation, case studies, historical research on the tuberculosis experience, and discourse analysis of rhetoric and stigma surrounding the disease. Chapters of the dissertation deal with such topics as: the history and epidemiology of tuberculosis disease, focusing on the resurgence of the 1990s; the environment of the public hospital, where tuberculosis is typically encountered and defined by the medical system; and the environment of the inner city neighborhood, where tuberculosis is most commonly transmitted and experienced. Other chapters use case history narratives and analysis of interview data to provide a nuanced perspective of the disease, which is based on the patient's experience, and which critically examines many of the standard practices of medicine and public health. The research revealed how a sociological approach can enrich and improve these practices. It also points toward an epidemiological approach that recognizes the fundamental role that social factors play in shaping and constraining the occurrence of disease as well as treatment outcomes.</p>	
<p>Driver (2005)</p>	<p>Setting: Large urban tuberculosis control program. Objectives: To determine the frequency and characteristics of treatment interruptions, and the factors associated with the different types of treatment interruptions. Design: This was a case-control study using culture-positive tuberculosis (TB) patients verified in 1998-1999. Case patients included those in whom any of the following mutually exclusive categories of treatment interruption: default with return to therapy, directly observed therapy non-adherence, default without return to therapy, or multiple types of interruptions. Controls were selected randomly from the cohort. Results: Overall, 6.0 percent of patients had treatment interruptions. All types of treatment interruption were associated with prolonged treatment course and decreased treatment completion rates. The median number of months to treatment interruption was 4.0 (range, 0.5-28.9 months). Two factors were significantly associated with every type of interruption: homelessness and lack of awareness of the severity of</p>	<p>EX5. Not qualitative data . Not qualitative research</p>

	<p>TB disease. In multivariate analysis, only lack of awareness of the severity of disease remained independently associated with all interruption types. Conclusion: Efforts to improve patients' understanding of TB disease and related treatment issues may be an important TB control program strategy and should be emphasized at the initiation of therapy and at intervals throughout the treatment course to minimize treatment interruption.</p>	
Durante et al. (1998)	<p>Objective, To determine the prevalence, incidence and risk factors for Mycobacterium tuberculosis infection, as well as to assess TB knowledge and attitudes, among a group of known drug users in a city with low TB incidence (11.3 per 100 000 in 1995). Methods. Patients of an urban drug treatment facility enrolled in opioid substitution, opioid antagonist and other drug treatment programs were screened for TB, including tuberculin skin testing and standardized data collection on TB risk factors. A subsample of clients was interviewed about TB knowledge and attitudes. Results. Between 1 June 1995 and 31 May 1996, 1055 individuals were screened. The prevalence of infection was 15.7% (CI: 13.2-18.2%). PPD positivity was associated with older age (per annum, OR=1.08, CI: 1.05-1.11), non white race (OR=2.81, CI: 1.72-4.60), foreign birth (OR = 4.24, CI: 2.35-7.62) and a history of injecting drug use (OR = 1.89, CI: 1.14, 3.12). The incidence of infection was 2.9 per 100 person years (CI: 1.8-4.7). Thirty-two per cent of 79 drug users interviewed about TB knowledge and attitudes thought TB could be prevented by bleaching or not sharing needles/syringes. Fifty-one per cent thought anyone with a positive TB skin test was contagious. Conclusion. M. tuberculosis infection was common in this population and associated with injecting drugs and several demographic factors. The incidence of new infection was relatively low. In this non-endemic environment, the detection and treatment of latent infection are important aspects of TB control. Misconceptions about TB transmission were also widespread in this population. Drug treatment programs can play a key role by undertaking screening programs that educate about TB and identify infected subjects who would benefit from preventive therapy.</p>	EX5. Not qualitative data . Not qualitative research
Feldmann and Middleman (2003)	<p>Homeless youth are at alarmingly high risk for a myriad of physical and psychological problems as a result of both the circumstances that preceded their homelessness, and as a direct consequence of life on the streets. Sexually transmitted infections (STIs), pregnancy, trauma, tuberculosis, uncontrolled asthma, and dermatologic infestations are a few of the health problems with which these youth commonly present. These somatic problems are compounded by high rates of drug and alcohol abuse as well as depression and suicide. Despite the obvious need for medical services, homeless youth often do not receive appropriate medical care due to numerous individual and systems barriers impeding health care access by this population. In addition to the barriers experienced by the adult homeless population, homeless adolescents confront further hurdles stemming from their age and developmental stage. Some of these</p>	EX4. No views data

	<p>impediments include a lack of knowledge of clinic sites, fear of not being taken seriously, concerns about confidentiality, and fears of police or social services involvement. Improved access to appropriate health care is necessary if we are to better support and care for this population of young people. To effectively manage and treat homeless youth, individual providers must be aware of the diagnoses associated with homelessness, as well as the community resources available to these youth. Finally, providers need to be the voices advocating for improved services for this disadvantaged and silent population.</p>	
Fraisse et al. (2005)	<p>Introduction: The management of tuberculosis has been the subject of renewed interest in France. Recently, the recommendations and the regulations concerning the disease have been updated. However, the resources that are actually available and the processes in place in different French departments are not clearly known. A national survey was thus carried out by a working group of the SPLF in charge of the recommendations concerning the medical, social and administrative management of the disease. Methods: A questionnaire was sent to the 100 French departmental Antituberculous Services (SLAT). This explored the structures, activity, organisation involved, and difficulties encountered in Tuberculosis management. Results: Ninety SLAT took part in the study. Their answers reveal: a discordance between a number of cases notified to the Department of Sanitation and Health (DDASS) and the number of cases known to the SLAT; a disparity between means involved in this study and the number of patients followed up as well as the choice of populations targeted for tracing); a willingness to deal with contact tracing although the investigations around individual cases and the definition of which subjects should be followed up were variable; a demand for protocols, networks and national recommendations. Conclusions: The SLAT are involved in the fight against tuberculosis with 20 years experience. The needs expressed in this survey point the way towards future priority actions to improve tuberculosis control nationally.</p>	EX5. Not qualitative research
Gany et al. (2005)	<p>Objectives. We explored an innovative strategy for targeted testing and disease management among immigrant communities at risk for tuberculosis. Methods. Taxi drivers were recruited at an airport holding lot to undergo tuberculin skin testing (Mantoux). After receiving their test results in a location convenient for them, drivers with positive results were referred for evaluation and treatment. We conducted baseline and follow-up assessments. Results. Of 123 drivers who participated, two thirds (82) were at high risk for tuberculosis. Seventy-eight (63%) of the 123 returned for test readings; 62% of these drivers had positive test results. All drivers with positive results received a complete physician evaluation, but 64% of those evaluated were not treated for latent TB infection. Of the untreated drivers, 37.5% were at high risk. Systemic and physician barriers (e.g., lack of knowledge, erroneous beliefs regarding vaccines) affected adherence to evaluation and treatment.</p>	EX5. Not qualitative data . Not qualitative research

	<p>Conclusions. Targeted testing and treatment are important to the control of tuberculosis. The results of this study highlight the need for an aggressive physician educational campaign to identify latent tuberculosis infection and to tailor service delivery to meet the unique needs of foreign-born communities.</p>	
Gelberg et al. (2000)	<p>Objectives. (1) To present the Behavioural Model for Vulnerable Populations, a major revision of a leading model of access to care that is particularly applicable to vulnerable populations; and (2) to test the model in a prospective study designed to define and determine predictors of the course of health services utilization and physical health outcomes within one vulnerable population: homeless adults. We paid particular attention to the effects of mental health, substance use, residential history, competing needs, and victimization. Methods. A community-based probability sample of 363 homeless individuals was interviewed and examined for four study conditions (high blood pressure, functional vision impairment, skin/leg/foot problems, and tuberculosis skin test positivity). Persons with at least one study condition were followed longitudinally for up to eight months. Principal Findings. Homeless adults had high rates of functional vision impairment (37 percent), skin/leg/foot problems (36 percent), and TB skin test positivity (31 percent), but a rate of high blood pressure similar to that of the general population (14 percent). Utilization was high for high blood pressure (81 percent) and TB skin test positivity (78 percent), but lower for vision impairment (33 percent) and skin/leg/foot problems (44 percent). Health status for high blood pressure, vision impairment, and skin/leg/foot problems improved over time. In general, more severe homeless status, mental health problems, and substance abuse did not deter homeless individuals from obtaining care. Better health outcomes were predicted by a variety of variables, most notably having a community clinic or private physician as a regular source of care. Generally, use of currently available services did not affect health outcomes. Conclusions. Homeless persons are willing to obtain care if they believe it is important. Our findings suggest that case identification and referral for physical health care can be successfully accomplished among homeless persons and can occur concurrently with successful efforts to help them find permanent housing, alleviate their mental illness, and abstain from substance abuse.</p>	EX4. No views data
Glyn-Jones (2002)	<p>Contribution to a supplement on respiratory care, produced in conjunction with the Association of Respiratory Nurse Specialists. A specialist tuberculosis nurse describes how breaking down barriers enabled her to help a patient complete his treatment for pulmonary tuberculosis.</p>	EX4. No views data
Grace and Chenhall (2006)	<p>In the Northern Territory (NT) of Australia, the rate of active tuberculosis (TB) is thirty four times higher in the Indigenous than the non-Indigenous Australian-born population. In 2000, of the 38 notified cases, 14 (37 percent) were associated with one of a number of Aboriginal communities where TB is endemic. Despite effective treatment of patients with active TB over the past decade,</p>	EX6. Not hard-to-reach group

	<p>compliance with latent TB infection (LTBI)¹ has remained low. In 2003-04 a qualitative study was conducted in order to assess the level of awareness & understanding of TB & latent TB infection (LTBI) in this community, & identify the factors that militate against early presentation with active TB, & acceptance &/or compliance with treatment for LTBI. We found there to be a low level of knowledge about TB, & even less of LTBI. While the seriously ill usually seek treatment at the local health clinic, early presentation is not the norm. Late or non presentation with active TB appears to be due to a combination of Indigenous attitudes toward illness & a reluctance to seek attention at the local clinic unless absolutely necessary. Many residents are said to feel uncomfortable discussing their physical problems with the clinic's non-Indigenous medical staff, & in some cases communication is difficult as the level of English literacy varies, being low among some groups resident there. Local Council & Health Board members interviewed believe the best way to deal with this problem is to have more local people working in the clinic & engaged in outreach activities informing those most at risk about the symptoms of active TB. Unfortunately there is no point at present in encouraging those with LTBI to accept treatment, as there are insufficient resources available at the clinic to offer it to those at risk. The local clinic has a range of chronic & acute case loads to manage with limited staff, & preventative programs are time consuming, & not of immediate, critical concern. At the same time, local council & health board members have little power to influence policy &/or funding decisions that are made at the Territory level & determine what medical services are offered, nor how they are delivered in their "community."</p>	
Guo et al. (2009)	<p>Introduction: Tuberculosis remains a major public health problem worldwide. In recent years, increasing efforts have been dedicated to assessing the health-related quality of life experienced by people infected with tuberculosis. The objectives of this study were to better understand the impact of tuberculosis and its treatment on people's quality of life, and to review quality of life instruments used in current tuberculosis research. Methods: A systematic literature search from 1981 to 2008 was performed through a number of electronic databases as well as a manual search. Eligible studies assessed multi-dimensional quality of life in people with tuberculosis disease or infection using standardized instruments. Results of the included studies were summarized qualitatively. Results: Twelve original studies met our criteria for inclusion. A wide range of quality of life instruments were involved, and the Short-Form 36 was most commonly used. A validated tuberculosis-specific quality of life instrument was not located. The findings showed that tuberculosis had a substantial and encompassing impact on patients' quality of life. Overall, the anti-tuberculosis treatment had a positive effect of improving patients' quality of life; their physical health tended to recover more quickly than the mental well-being. However, after the patients successfully completed treatment and were microbiologically</p>	EX5. Not qualitative data . Not qualitative research

	<p>'cured', their quality of life remained significantly worse than the general population. Conclusion: Tuberculosis has substantially adverse impacts on patients' quality of life, which persist after microbiological 'cure'. A variety of instruments were used to assess quality of life in tuberculosis and there has been no well-established tuberculosis-specific instrument, making it difficult to fully understand the impact of the illness.</p>	
Hadley and Maher (2000)	<p>Decentralising tuberculosis control measures beyond health facilities by harnessing the contribution of the community could increase access to effective tuberculosis care. This review of community-based health care initiatives in developing countries gives examples of the lessons for community contribution to tuberculosis control learned from health care programmes. Sources of information were Medline and Popline databases and discussions with community health experts. Barriers to success in tuberculosis control stem from biomedical, social and political factors. Lessons are relevant to the issues of limited awareness of tuberculosis and the benefits of treatment, stigma, restricted access to drugs, case-finding and motivation to continue treatment. The experience of other programmes suggests potential for an expansion of both formal and informal community involvement in tuberculosis control. Informal community involvement includes delivery of messages to encourage tuberculosis suspects to come forward for treatment and established tuberculosis patients to continue treatment. A wide range of community members provide psychological and logistic support to patients to complete their treatment. Lessons from formal community involvement indicate that programmes should focus on ensuring that treatment is accessible. This activity could be combined with a variety of complementary activities: disseminating messages to increase awareness and promote adherence, tracing patients who interrupt treatment, recognising adverse effects, and case detection. Programmes should generally take heed of existing political and cultural structures in planning community-based tuberculosis control programmes. Political support, the support of health professionals and the community are vital, and planning must involve or stem from the patients themselves.</p>	EX2. Not OECD country
Hance et al. (2007)	<p>Background. For a regional project in four low-incidence states, we designed a customizable tuberculosis outbreak response plan. Prior to dissemination of the plan, a tuberculosis outbreak occurred, presenting an opportunity to perform a field assessment of the plan. The purpose of the assessment was to ensure that the plan included essential elements to help public health professionals recognize and respond to outbreaks. Methods. We designed a semi-structured questionnaire and interviewed all key stakeholders involved in the response. We used common themes to assess validity of and identify gaps in the plan. A subset of participants provided structured feedback on the plan. Results. We interviewed 11 public health and six community stakeholders. The assessment demonstrated that (1) almost all of the main response activities were reflected in the plan;</p>	EX4. No views data

	<p>(2) the plan added value by providing a definition of a tuberculosis outbreak and guidelines for communication and evaluation. These were areas that lacked written protocols during the actual outbreak response; and (3) basic education about tuberculosis and the interpretation and use of genotyping data were important needs. Stakeholders also suggested adding to the plan questions for evaluation and a section for specific steps to take when an outbreak is suspected. Conclusion. An interactive field assessment of a programmatic tool revealed the value of a systematic outbreak response plan with a standard definition of a tuberculosis outbreak, guidelines for communication and evaluation, and response steps. The assessment highlighted the importance of education and training for tuberculosis in low-incidence areas.</p>	
Hansel et al. (2004)	<p>Tuberculosis (TB) is a persistent problem in the USA; however, little is known about its impact on functioning and quality of life (QOL) among people with TB. The purpose of this study is to describe the impact of TB on patients' QOL by using focus groups to assess the domains of QOL that are affected. Participants included patients (n = 10) who received treatment for active TB and physicians (n = 4) and nurses (n = 9) caring for patients with TB at a public health clinic in Baltimore, Maryland. TB affected all predicted domains of QOL, including general health perceptions, somatic sensation, psychological health, spiritual well-being, and physical, social and role functioning. Social stigmatization, isolation, pill burden, long duration of therapy, sexual dysfunction, loss of income, and fear were additional specific problems related to TB. Surprisingly, 11% (33) of the comments described benefits of TB illness, including increased spirituality and improved life perspectives. In addition, four additional QOL domains and three elements of treatment specific to TB which substantially impact QOL were identified. While patients and clinicians both identified issues in many areas of QOL, only patients mentioned the impact on sexual function, spirituality and improved life perspectives. Despite available curative therapy, TB and its treatment still have significant short and long-term consequences on patients' QOL.</p>	EX6. Not hard-to-reach group
Harrar (2008)	<p>Many people thought that "public health" mean health for poor people. Further, they thought that the most serious global health threats were diseases like anthrax and smallpox—conditions in US news headlines in the post-9/11 world due to bio-terrorism concerns. Most participants in the focus groups knew that HIV/AIDS was a serious problem, but considered tuberculosis and malaria to be diseases of the past, and no longer problematic. As we realized that our series would be an introduction to global health for many viewers in our audience, we struggled with how to define the term for ourselves. Because we had limited budget and broadcast time for this public health series, we elected to focus primarily on infectious diseases, rather than on chronic diseases.</p>	EX1. Not focused on TB
Harrington et al.	<p>Explores why TB has staged a devastating comeback and interviews three health professionals working to turn around a global</p>	EX4. No views data

(1999)	emergency.	
Hawthorne (1994)	British Asians make up 3% of the population. There is evidence that Asians have difficulty obtaining good quality health care, appropriate to their needs. This article examines some of this evidence, with examples of specific communities in Britain. In the past, specific health education programmes for Asians have targeted their 'special' needs such as rickets, tuberculosis and thalassaemia. In fact the population itself perceives its needs differently--improved communication, easier access to services, and more information on asthma, diabetes, ischaemic heart disease and skin disorders. It is important to appreciate that the 'Asian' community is made up of disparate groups with widely differing needs and expectations, and that each community should be considered by health service planners as unique within the context of the health authority within which they lie. Reasons for the mismatch between need and service provision are discussed in the light of the recent reforms in the National Health Service and recommendations for change are given.	EX4. No views data
Heijnders and Van Der Meij (2006)	In many health conditions, people are severely affected by health-related stigma and discrimination. A literature review was conducted to identify stigma-reduction strategies and interventions in the field of HIV/AIDS, mental illness, leprosy, TB and epilepsy. The review identified several levels at which interventions and strategies are being implemented. These are the intrapersonal, interpersonal, organizational/institutional, community and governmental/structural level. Although a lot of work has been carried out on stigma and stigma reduction, far less work has been done on assessing the effectiveness of stigma-reduction strategies. The effective strategies identified mainly concentrated on the individual and the community level. In order to reduce health-related stigma and discrimination significantly, single-level and single-target group approaches are not enough. What is required is a patient-centred approach, which starts with interventions targeting the intrapersonal level, to empower affected persons to assist in the development and implementation of stigma-reduction programmes at other levels.	EX4. No views data
Heldal et al. (2008)	Setting: Countries with low or intermediate tuberculosis (TB) incidence. Objectives: 1) To gather information on individuals and TB patients who are undocumented migrants and their access to TB diagnostic and treatment services; 2) to discuss interventions to strengthen diagnosis and treatment and 3) to formulate recommendations on how to ensure adequate TB prevention and control. Design: Questionnaires sent to members of the Working Group (WG) on Trans border Migration and TB, managers of national TB programmes and EuroTB correspondents; literature research and development of a paper by a writing committee through consultation. Results: Undocumented migrants represent 5-30% of immigrants and 5-10% of TB cases. Most countries reported full access to diagnosis and treatment, but in practice there were limitations. Most countries also reported that they could and did deport cases who were on TB treatment. A variety of activities to	EX5. Not qualitative data . Not qualitative research

	<p>ensure access were reported from different countries. Conclusion: The WG recommends that 1) health authorities and/or health staff should ensure easy access to low-threshold facilities where undocumented migrants who are TB suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials. Health authorities should remind health staff that they have an obligation of confidentiality; 2) each country should ensure that undocumented migrants with TB are not deported until completion of treatment; and 3) authorities and non governmental sectors should raise awareness among undocumented migrants about TB, emphasising that diagnosis and treatment should be free of charge and wholly independent of migratory status.</p>	
Hender-son et al. (2008)	<p>Objective: To assess reasons for low uptake of immunization amongst orthodox Jewish families. Design: Qualitative interviews with 25 orthodox Jewish mothers and 10 local health care workers. Setting: The orthodox Jewish community in north-east London. Main outcome measures: Identification of views on immunization in the orthodox Jewish community. Results: In a community assumed to be relatively insulated from direct media influence, word of mouth is nevertheless a potent source of rumours about vaccination dangers. The origins of these may lie in media scares that contribute to anxieties about MMR. At the same time, close community cohesion leads to a sense of relative safety in relation to tuberculosis, with consequent low rates of BCG uptake. Thus low uptake of different immunizations arises from enhanced feelings of both safety and danger. Low uptake was not found to be due to the practical difficulties associated with large families, or to perceived insensitive cultural practices of healthcare providers. Conclusions: The views and practices of members of this community are not homogeneous and may change over time. It is important that assumptions concerning the role of religious beliefs do not act as an obstacle for providing clear messages concerning immunization, and community norms may be challenged by explicitly using its social networks to communicate more positive messages about immunization. The study provides a useful example of how social networks may reinforce or challenge misinformation about health and risk and the complex nature of decision making about children's health.</p>	EX1. Not focused on TB
Herce et al. (2010)	<p>We conducted a qualitative study employing structured interviews with 38 community health workers, known as health promoters, from twelve rural municipalities of Chiapas, Mexico in order to characterize their work and identify aspects of their services that would be applicable to community-based tuberculosis (TB) control programs. Health promoters self-identify as being of Mayan Indian ethnicity. Most are bilingual, speaking Spanish and one of four indigenous Mayan languages native to Chiapas. They volunteer 11 h each week to conduct clinical and public health work in their communities. Over half (53%) work with a botiqu�n, a medicine cabinet stocked with essential medicines. Fifty-three percent identify TB as a major problem affecting the health of their communities, with</p>	EX6. Not hard-to-reach group

	<p>one-fifth (21%) of promoters reporting experience caring for patients with known or suspected TB and 29% having attended to patients with hemoptysis. One third of health promoters have access to antibiotics (32%) and one half have experience with their administration; 55% complement their biomedical treatments with traditional Mayan medicinal plant therapies in caring for their patients. We describe how health promoters employ both traditional and allopathic medicine to treat the symptoms and diseases they encounter most frequently which include fever, diarrhoea, and parasitic infections. We contend that given the complex sociopolitical climate in Chiapas and the state's unwavering TB epidemic and paucity of health care infrastructure in rural areas, efforts to implement comprehensive, community-based TB control would benefit from employing the services of health promoters.</p>	
Hernandez (2004)	<p>Introduction: Morbidity incidence of tuberculosis in the world population shows differences regarding gender, it is 1.7 times more frequent in men than in women. However, it remains to be determined if these differences correspond to a gender inequality, meaning a sociocultural construction of the analysis. Objective: To investigate how the social support networks operated in a group of lung tuberculosis patients from two communities of the state of Veracruz. Material and methods: We used qualitative tools, such as a detailed interview and a semi-open questionnaire aimed to reconstruct the type of social network that supported the patient during his/her ailment. Results: A clear gender disparity was found in the type of social network that supported the patients. The disease represented a social disadvantage for female patients, while in male patients, their life quality increased due to the ample social support networks.</p>	EX6. Not hard-to-reach group
Hirsch-Moverman et al. (2006)	<p>Tuberculosis in the USA is increasingly noted among the foreign-born, with many individuals at risk being managed by international medical graduates (IMGs). We utilized anonymous surveys using hypothetical scenarios to assess and compare the attitudes of IMGs and US medical graduates regarding the treatment of latent tuberculosis infection (LTBI) to identify how attitudes and intentions may influence physician behaviour. IMGs were less likely to treat LTBI in almost all scenarios. Educational efforts should focus on IMGs to encourage attitudes more consistent with US guidelines.</p>	EX5. Not qualitative data . Not qualitative research
Ho (2004)	<p>The resurgence of tuberculosis in recent years has obliged LIS to reconsider the existing explanations of the disease. Whereas biomedical literature tends to explain tuberculosis in terms of biological factors (e.g., bacterial infection), social scientists have examined various Cultural, environmental, and politico-economic factors. In this paper, socio-cultural approaches to tuberculosis are reviewed according to their emphasis on cultural, environmental, and politico-economic factors. Then how the public health establishment considers biological, cultural, environmental and politico-economic factors will be examined through a Case Study of immigrant tuberculosis. While public health facilities emphasize biological</p>	EX4. No views data

	<p>factors in the control of immigrant tuberculosis, an ethnographic study of tuberculosis among Chinese immigrants in New York City provides detailed contexts that illustrate the cultural, environmental, and politico-economic forces shaping tuberculosis and supports an emerging theorization Of tuberculosis that encompasses a heterogeneous collection of factors. Finally, a number of implications for public health interventions will be discussed.</p>	
Ho (2004)	<p>Setting: Outreach services and chest clinics of the Department of Health in New York City. Objective: To investigate the health-seeking behaviour patterns of Chinese immigrant patients enrolled in the directly observed therapy (DOT) program in New York City, and to suggest service provision strategies. Design: Data were collected by means of participant observation, semi-structured interviews, and patient narratives. These data were then analyzed statistically as well as qualitatively, based on grounded theory. Results: Of 60 patient informants, 38 had sought treatment for the relief of symptoms, and 22 were diagnosed by physical examination. Among 125 consultations made by 38 symptomatic patients during the period of their illness, there were more Chinatown physicians, including traditional Chinese practitioners, than other types of health providers, but they proportionally made the fewest referrals to the DOT program. Conclusions: Chinatown physicians are the main health providers to whom Chinese immigrants with tuberculosis resort. Education and collaboration with Chinese doctors, practitioners of both biomedical and traditional Chinese medicine, in New York City's Chinatown, are essential to reduce enrolment delays in the DOT program. The free services of the DOT program should be made more widely known to the Chinese immigrant population.</p>	EX4. No views data
Isralowitz et al. (2006)	<p>Based on the high rates of injection drug use & infectious disease such as HIV, HCV & tuberculosis in their home country, immigrants from the Former Soviet Union (FSU) comprise a high-risk population in the USA. Yet, little is known about their drug abuse & health problems relative to other immigrant populations like Hispanics. The objectives of this exploratory study were to identify disease risk behaviour, & utilization of & barriers to treatment services among drug using immigrants from the FSU. Focused interviews were conducted with 27 public officials & administrators in New York City. This study found that FSU immigrants tend to have culturally unique drug abuse patterns & behaviour, such as rapid transition to injection drug use, & suspicion & avoidance of traditional drug treatment approaches. The findings of this exploratory study point to the need for further research & the need to take immediate steps to promote culturally appropriate treatment & prevention services that can address the spread of harmful behaviour that threatens the public health of FSU immigrants & others.</p>	EX1. Not focused on TB
Jackson et al. (2009)	<p>Setting: Contact investigation resulting from specimens sent to the Scottish Mycobacteria Reference Laboratory. Objective: To characterise patients and types of exposures associated with</p>	EX4. No views data

	<p>transmission of a prevalent Mycobacterium tuberculosis genotype in Scotland. Design: A combined approach using molecular epidemiology and semi-structured patient interviews for social network enquiry. Results: We investigated social connections between 64 patients diagnosed between 1994 and 2004. Fifty-five per cent had ≥ 1 identifiable contact. One third ($n = 14$, 32.6%) of the 43 epidemiological links detected were discerned as a result of patient interviews and were not previously recorded on surveillance reports, nor recognised by nurse specialists (all were non-household contacts). Sixteen putative sites of exposure were identified, 11 were public houses. Rather than a single-source outbreak, eight pockets of transmission were identified, the largest involving UK-born alcohol-misusing males frequenting several public houses. Conclusions: Using a standardised approach to explore themes around which individuals may have been exposed to TB resulted in the detection of previously unrecognised epidemiological links. Epidemiological data obtained from cluster investigations, e.g., risk and social behaviours that increase the risk of infection and sites of putative exposure, can enhance the development of more appropriate questions for the contact tracing interview.</p>	
Jimenez (2003)	<p>This study examines the consequences of stigmatization that occurred during a tuberculosis outbreak concentrated among Puerto Rican clients enrolled in a Chicago drug treatment center. Using ethnographic methods, I examine three factors that contributed to the stigmatization of those with TB. One factor concerns the fear elicited by the deadly disease that aroused reactions among Puerto Rican community members that were derived from earlier experiences. A second factor involves traditional public health measures enacted in response to the outbreak that facilitating labeling of those with TB, further fueling stigmatization. A third factor concerns the re-articulation of group boundaries occurring among drug program inhabitants, whereby TB-impacted persons were marginalized in order to reaffirmed the status of others whose identity had been compromised by the epidemic. The study's implications for public health are discussed and suggestions are offered for developing innovative intervention approaches.</p>	EX6. Not hard-to-reach group
Jimenez et al. (2002)	<p>Introduction: Tuberculosis continues to be a disease that provokes high morbidity and mortality throughout the world. Screening programs are based on the Mantoux tuberculin skin reaction test, which is usually performed by nurses. The aim of this study was to evaluate knowledge of the Mantoux test among nurses working in primary care, according to the guidelines drawn up by the International Union against Tuberculosis and Lung Disease (IUATLD). Material and method: Design: Descriptive cross-sectional study. One hundred health centers throughout the country were selected through random sampling stratified by Autonomous Communities. All the nursing professionals in each of these centers were included and given a self-administered questionnaire in the presence of an investigator to determine their knowledge of the</p>	EX5. Not qualitative research

	<p>correct procedures to be followed in the conservation, administration, reading and interpretation of the tuberculin test. Other variables concerning professional experience, training and specific activity related to the Mantoux test that could influence degree of knowledge were also studied. Results: Knowledge was greater on the form of administration (62.2% correct answers) and reading of the test (52% correct answers) while knowledge of conservation of the preparation (44% correct answers) and its interpretation (only 30% correct answers) was deficient. Analysis of related factors showed that knowledge of international guidelines was greater among nurses who had received specific training (increasing the probability of having a high level of knowledge by 40%) and in those who carried out the procedure more frequently (nurses who performed the procedure at least once a week had an 80% greater chance of being in the group with a high level of knowledge). Discussion: The results of this study show that the correct performance of the tuberculin skin test cannot be guaranteed, especially because of the deficiencies found in conservation of the preparation. Consequently, the probability of false negatives may be high. Knowledge is increased by experience in the job, frequent performance of the test, and training.</p>	
Joseph et al. (2008)	<p>Objective A study was conducted to describe the sociocultural aspects of tuberculosis (TB) among Mexicans in the U.S. and to provide TB programs with practical recommendations for serving this population. Methods In-depth, structured, open-ended interviews were conducted with 50 persons from Mexico living in the U.S. Local bilingual, bicultural researchers conducted the interviews with respondents recruited from TB clinics and surrounding communities. Both qualitative and quantitative strategies were used to analyze the data. Results We found diverse TB perceptions and attitudes, but few were associated with specific participant characteristics. We detected widespread misperceptions about TB transmission and low perceptions of risk. Anticipated TB stigma among those with no history of disease was qualitatively greater than reported stigma among those who had TB disease. We also detected missed opportunities for TB education. Reported barriers to care included lack of transportation, limited clinic hours, cost of services, inconvenient clinic location, and communication problems with staff. Conclusions To address the diverse needs of Mexican-born clients, we recommend that TB programs provide culturally-appropriate, patient-centered care. We suggest several strategies aimed at raising risk awareness and reducing stigma. Finally, we encourage programs to facilitate access by providing language-appropriate services, extending clinic hours, and facilitating transportation.</p>	EX6. Not hard-to-reach group
Kai et al. (2001)	<p>The case of being able to respond effectively to cultural and ethnic diversity in health care is attracting increasing debate in medical education. However research exploring the perspectives of learners is lacking. The authors sought medical learners' perceptions and their perceived training needs in relation to cultural and ethnic</p>	EX1. Not focused on TB

	<p>diversity in healthcare. A series of nine focus group interviews was conducted with 55 medical learners, including undergraduate students in a UK medical school and a group of postgraduate general practitioners in training. Interview data were analysed using qualitative methods. Participants had a broad but superficial awareness of multicultural issues. This focused upon 'difference' with students emphasising their need to acquire knowledge of different beliefs and practices. Current teaching was perceived as inadequate and limited largely to ethnic patterns of disease. Most felt a need for greater training. They regarded development of particular communication skills, such as working with interpreters as helpful. Beyond avoiding stereotyping, learners rarely identified reflecting upon their attitudes or the issue of racism as important. Students anticipated a range of potential problems for further training, but sought learning that was relevant, practically oriented and stimulating. The study points to learners' experience of inadequate training but suggests a willingness to learn more. The possible predominance of a 'difference' perspective might drive a narrow focus upon learning cultural knowledge at the expense of promoting a balance with self-reflection upon attitudes and developing generic skills. Educators might heed learners' views about how they should be taught successfully.</p>	
Kandula et al. (2004)	<p>Background: Two months of rifampin and pyrazinamide (RIF/PZA) for tuberculosis prevention has been advocated as a way to improve adherence in mobile populations, such as recent immigrants. However, RIF/PZA requires intensive patient and laboratory monitoring for hepatotoxicity. Objectives: To describe the feasibility and outcomes of using RIF/PZA for TB prevention during a tuberculosis outbreak in a Mexican immigrant community, where 23 adults and 11 children were treated with RIF/PZA between August 2001 and October 2001. Methods: Retrospective chart review and interviews with health department employees were conducted to assess completion rates, hepatotoxicity, cost, and feasibility of monitoring. Results: Ten (91%) children and 13 (57%) adults completed RIF/PZA. One child (9%) and four adults (17%) developed drug-induced hepatitis. Cultural barriers affected care. The adults resisted the biweekly blood draw, believing it would "drain them of energy." RIF/PZA, plus monitoring, was twice as costly as 4 months of rifampin. Conclusions: RIF/PZA was associated with significant hepatotoxicity, poor completion, and cultural barriers to monitoring, and was more costly than standard therapy. Tuberculosis prevention must address potential clinical, cultural, and economic barriers to completion and monitoring of short-course therapy in immigrants.</p>	EX5. Not qualitative research
Kelly (1999)	<p>Explored how a sample of patients with active tuberculosis experienced their illness. The analysis suggested that patients understood tuberculosis through the medical model and perceived themselves as disease vectors. After their diagnosis became known, almost all patients felt that their family and friends avoided or</p>	EX6. Not hard-to-reach group

	shunned them. Patients responded to these attitudes by isolating themselves and becoming secretive about their illness.	
Kovachovich et al. (1991)	We reviewed the records of all 66 cases of tuberculosis in St. Paul between 1986 and 1989. Two thirds of the patients were foreign born. Some of these patients experienced problems in adherence to therapy because of cultural barriers. Resistance of the organism to anti-tuberculosis medications was also a significant problem.	EX4. No views data
Lawrence (2008)	This paper critically examines the ways that tuberculosis (TB) has been represented in the print media in New Zealand over recent years (2002–2004). Our broad contention is that, notwithstanding its biomedical reality, TB is socially constructed by, and through, human experience. Further, public health practitioners depend, to a large extent, on the media to alert the public to threats of disease and opportunities for protection. However, the messages conveyed are sometimes neither helpful nor accurate. In our analysis of TB coverage in three major daily newspapers in New Zealand, we enumerate and classify references to the disease, as well as undertake a discursive analysis of the revealed themes. Of the 366 texts we retrieved in the database search, we selected 120 for in-depth analysis. Our examination indicated the importance of bovine TB within the national consciousness, the stigmatised character of TB and the association between TB and immigrants. We observe that newspaper 'stories' in general and commentaries by public health officials in particular, are invariably offered on a 'case by case' basis. We conclude that this specificity in time and place avoids more challenging discourses linking TB with deeply embedded determinants of health such as the strong link between TB and poverty.	EX4. No views data
Lobato et al. (2004)	Objective: To assess the extent that 20 large jail systems and their respective public health departments collaborate to prevent and control tuberculosis (TB). Methods: Data were collected through questionnaires sent to jail medical directors and TB control directors, interviews, and on-site observation in each of the jails. Results: Only 35% of jail systems and health departments reported having effective collaboration in TB prevention and control activities. Four barriers were reported by a majority of the jail systems: funding (65%), staffing (60%), staff training (55%), and communication (55%). Lack of advance notice of a patient's release was rated as the greatest barrier to discharge planning. Fifty percent of the jail systems reported that they scheduled appointments for soon-to-be released patients with TB, and 10% did so for patients being treated for latent TB infection (LTBI). Fewer patients actually received appointments: seven (39%) of 33 released patients with TB had documentation in their medical record of appointments, and one of 46 released patients on treatment for LTBI had them. Characteristics associated with increased collaboration include having designated liaisons between jail systems and health departments and holding periodic meetings of staff. Conclusions: Health departments and jail systems in the same jurisdiction have implemented	EX5. Not qualitative research

	recommendations regarding collaboration to a limited extent. Such collaborations need strengthening, especially discharge planning and evaluation of TB control activities.	
Lomax (2007)	n/a	EX4. No views data
MacDonald et al. (2010)	Tuberculosis (TB) continues to be a serious health issue for some Aboriginal populations in Canada. In this article we build on two previous studies partnered with an Aboriginal community organization to examine TB in Montreal, Quebec. The current study draws on qualitative interviews with Aboriginal participants who had either themselves contracted TB or knew someone who had the disease. Thematic analysis revealed a high level of experiential knowledge among participants, although gaps in biomedical knowledge about the disease and available resources were apparent even among those who had been ill. Negative memories and experiences relating to the colonial history of TB treatment emerged as significant for many participants, helping to explain a silence around the topic of TB in the community. Barriers to TB testing were identified, including the fear of positive test results, the burden of long-term treatment for either latent or active disease, and systemic barriers within and mistrust of the health system. Community support for, as well as negative reactions toward, individuals ill with TB were identified. We conclude with a number of community health lessons to address the treatment and prevention of TB in urban populations.	EX6. Not hard-to-reach group
MacFarlane and Kelleher (2002)	Fifty-one older people in the Republic of Ireland were interviewed using a semi-structured schedule on their health and illness experiences at three different time points in their lives: as children, as young adults, and presently. Of particular interest were their views about the causes of heart disease, cancer and tuberculosis and their experiences of the prevailing health care system during their lifetime.	EX6. Not hard-to-reach group
Macq et al. (2006)	Tuberculosis (TB) stigma is considered a vague concept, because it is not easily assessed. The purpose of this article is to review methodological approaches for assessing TB stigma. We reviewed the published studies & the gray literature. We also present the main features of a qualitative & quantitative assessment of TB stigma, which has been done in one specific project in Nicaragua. As a whole, we illustrate the variety of TB stigma in terms of domains, consequences, determinants & methods used; some features emerge more frequently than others from the studies. However, results of the review show a relative scarcity of the TB stigma assessment experiences, mainly in looking at the consequences for the TB patient & in the use of quantitative methods & scales. Additional assessment studies in diverse contexts are needed so that stigma will be considered a priority in the organization of care for people affected by tuberculosis.	EX2. Not OECD country
Macq et al. (2007)	Objectives To review the available published and non-published literature on patient empowerment in tuberculosis (TB) control, describe what it entails, identify possible trends and conclusions, and suggest areas both for informing policy makers and for orienting	EX4. No views data

	<p>further research. Methods We searched MEDLINE and PSYCINFO databases, used World Wide Web research tools and included conference abstracts and specific project reports. Results Experience shows that operational definitions, potential barriers towards empowerment and contextual issues need to be considered. Four types of experiences were reported: (1) enabling patients to take more responsibility for their health, especially regarding adherence to treatment, (2) organizing TB patients into groups and clubs, (3) building patient-centred care in TB and general health services, and (4) using TB patients' advocacy skills to improve TB control. Conclusions Patient empowerment conceptions through interventions and studies should primarily involve TB patients themselves. Patients' activism - their role, the shape it takes and resulting effects - is insufficiently documented.</p>	
<p>Marra et al. (2004)</p>	<p>Background: With effective treatment strategies, the focus of tuberculosis (TB) management has shifted from the prevention of mortality to the avoidance of morbidity. As such, there should be an increased focus on quality of life (QoL) experienced by individuals being treated for TB. The objective of our study was to identify areas of QoL that are affected by active TB using focus groups and individual interviews. Methods: English, Cantonese, and Punjabi-speaking subjects with active TB who were receiving treatment were eligible for recruitment into the study. Gender-based focus group sessions were conducted for the inner city participants but individual interviews were conducted for those who came to the main TB clinic or were hospitalized. Facilitators used open-ended questions and participants were asked to discuss their experiences of being diagnosed with tuberculosis, what impact it had on their lives, issues around adherence to anti-TB medications and information pertaining to their experience with side effects to these medications. All data were audio-recorded, transcribed verbatim, and analyzed using constant comparative analysis. Results: 39 patients with active TB participated. The mean age was 46.2 years (SD 18.4) and 62% were male. Most were Canadian-born being either Caucasian or Aboriginal. Four themes emerged from the focus groups and interviews. The first describes issues related to the diagnosis of tuberculosis and subthemes were identified as 'symptoms', 'health care provision', and 'emotional impact'. The second theme discusses TB medication factors and the sub-themes identified were 'adverse effects', 'ease of administration', and 'adherence'. The third theme describes social support and functioning issues for the individuals with TB. The fourth theme describes health behaviour issues for the individuals with TB and the identified sub-themes were "behaviour modification" and "TB knowledge." Conclusion: Despite the ability to cure TB, there remains a significant impact on QOL. Since much attention is spent on preventative or curative mechanisms, the impact of this condition on QoL is often not considered. Attention to the issues experienced by patients being treated for TB may optimize adherence and treatment success.</p>	<p>EX6. Not hard-to-reach group</p>

Matlow et al. (2006)	<p>Background: Provider-caregiver communication is a key ingredient in quality health care and patient safety, and effective communication has been shown to affect compliance and outcomes. Objectives: To identify and compare communication issues among three paediatric outpatient clinics. Methods: In this prospective, qualitative study, a questionnaire was used to survey physicians, nurse practitioners and caregivers at three different infectious diseases clinics. Results: There was a statistically significant preponderance of families in the tuberculosis clinic for whom English was not the mother tongue and who were not fluent in English. Patients in the HIV clinic were less likely to be at their first appointment than were patients attending the other clinics. Patients in the general clinic were less likely to have been seen by the same physician on the previous visit. Parents from all three clinics were satisfied with the care they received, with communication and with rapport with their child. There was a trend toward parents in the tuberculosis clinic being happier with their clinic visit and less likely to complain about the wait time. Conclusions: Language proficiency and lack of continuity of provider care were identified as potential risks for patient safety in the ambulatory setting. Further studies are necessary to identify language and cultural issues that may affect patient care in a tertiary paediatric hospital servicing a multiethnic population.</p>	EX5. Not qualitative research
Mayho (1999)	<p>Former tuberculosis patient (and previously a nursing student) Paul Mayho explains how barrier nursing made him feel like a prisoner. Notes that for some patients, isolation is a terrible experience, making them feel lonely, abandoned, inferior, frustrated and stigmatised, and they may often take these emotions out on the nurse. Considers how, with a little understanding and hindsight, nurses can make the patient's stay in isolation a lot more comfortable and their relationship with staff a lot easier.</p>	EX4. No views data
McEwen (2001)		EX6. Not hard-to-reach group
McEwen (2005)	<p>This article reveals how the multiple and disparate explanations of latent tuberculosis infection (LTBI) from the USA and Mexico professional health sectors and the popular sector are used to inform the explanatory model (EM) of LTBI for Mexican immigrants residing in the US–Mexico border region. Fourteen immigrants, nine diagnosed with LTBI (n = 9) and their spouses (n = 5) participated in this critical ethnographic study. Because care seeking and treatment decisions are influenced by EMs, the results indicate that it is imperative that interventions for Mexican immigrants with LTBI are built on an understanding of their illness experience and are contextually meaningful.</p>	EX6. Not hard-to-reach group
McGrath (1991)	<p>Although Inuit have a traditional pattern of behaviour for how to die, their culture has not provided a pattern for how to be seriously sick or disabled, since such conditions did not last long in a hunting-gathering society. Tuberculosis provided Canadian Inuit with a harsh</p>	EX6. Not hard-to-reach group

	and bitter lesson in how to be sick in the twentieth century. The tuberculosis experience is an important part of modern Inuit history and an understanding of how they viewed it goes some way towards explaining some of the attitudes Inuit have toward the health system in the North today. The way Inuit regard illness is evident in their traditional oral literature as well as in more recent written accounts of the disease that devastated their lives only a few decades ago.	
McLeod (2000)	Findings are discussed relative to current literature and the Children's Health Belief Model. Methodological issues are discussed and suggestions for use of the findings to guide continuing research and parent education policies are offered.	EX6. Not hard-to-reach group
Menegoni (1996)	Tuberculosis continues to be a serious disease among the poor, indigenous population of Highland Chiapas, southern Mexico. Ethnographic fieldwork among Tzeltal Indians has focused on how cultural perceptions of illness and curing influence the Indians' utilization of health care services for tuberculosis diagnosis and treatment. This article presents the views on tuberculosis and health-seeking activities of several patients in the Tzeltal hamlet of Yochib (municipality of Oxchuc). In this community, religious change (Protestantism) and the presence of a health clinic promoted biological interpretations of illness and acceptance of Western medical treatments. While patients in Yochib do not understand tuberculosis in biomedical terms, they nonetheless utilize Western services (both local and urban) to obtain treatment. Because of the long duration of tuberculosis therapy, however, these patients manifest contrasting attitudes. The article focuses on the cultural factors that influence patients' medical choices, curing strategies, and their decisions to adhere to long-term treatment regimens.	EX6. Not hard-to-reach group
Metcalf et al. (2007)	Background: Although tuberculosis (TB) is relatively rare in the UK, its diagnosis is important because diagnostic delays can result in worse outcomes for patients and expose others to the risk of infection. Atypical presentations may be common, and patients' help-seeking behaviour may influence the diagnostic process in primary care. Little is known about the process of diagnosing TB in primary care in developed countries. Aim: To understand the process of diagnosing TB in UK primary care. Design of study: Qualitative inductive study with paired semi-structured interviews. Setting: Communities and general practices in south-east Wales. Method: Interviews were conducted with 17 patients diagnosed with TB in the previous six months and 16 GPs involved with their care. Data were analysed thematically. Results: In response to expected classical features, GPs generally ordered specific tests. Both GPs and patients reported atypical presentations, and then the diagnostic and referral net was appropriately widened in most cases. Identified barriers to prompt diagnosis included atypical presentations and low clinical suspicion of TB, lack of continuity of care, workload demands that limit time with patients, and suboptimal clinician-patient communication. GPs recognised the growing problem of TB nationally and the need for improved education among health	EX6. Not hard-to-reach group

	<p>professionals. Conclusion: GPs' and patients' accounts about the process of diagnosing TB suggest that delays can occur, although they are not typical. Where diagnosis is clear, GPs generally test specifically and refer appropriately; where diagnosis is less clear, the diagnostic net is cast further. It is only when certain core values of general practice are not applied (including continuity of care, considering context appropriately, and eliciting and responding appropriately to patients' explanatory models) that clinicians and patients identify a suboptimal diagnostic process.</p>	
<p>Michaels et al. (2008)</p>	<p>Purpose: The purpose of this article is to explore the phenomenon of saying "no" to secondary prevention recommended by healthcare providers. Data sources: Extracted findings from two qualitative studies in which participants have said "no" to provider recommendations for secondary prevention, specifically screening mammograms or treatment for latent tuberculosis infection, are discussed. Conclusions: Although these two studies focus on different aspects of secondary prevention, both studies emphasize how client values and beliefs impact health decisions. In evidence-based practice (EBP), both scientific evidence and client values and beliefs must be considered. Nurse practitioners (NPs) have the skill set and are in a position to assist clients to mediate between their values and beliefs and current scientific evidence. Implications for practice: Several findings from the two qualitative studies are relevant for practice: qualitative studies provide information about values and beliefs for EBP, and findings from these particular qualitative studies demonstrated that women were protective about their health even though their values and beliefs did not align with current scientific evidence. Through client narratives, NPs can facilitate clients aligning personal values and beliefs with current scientific evidence in relationship to caring for self.</p>	<p>EX4. No views data</p>
<p>Mitty and Flanigan (2004)</p>	<p>n/a</p>	<p>EX4. No views data</p>
<p>Moller (2007)</p>	<p>Objective: To examine how Inuit in Nunavut experience and make meaning of TB, its history, protocols and regimes, and how this and the effects of historical and continuing colonization in Nunavut influence current levels of TB in Nunavut. Design and methods: The study was qualitative, conducted through seven months of fieldwork in two Nunavut communities utilising ethnographic methods including 42 taped interviews, casual conversations, participant observation and document review. Results: Inuit participants include explanations other than biomedical when making meaning of TB, and health and disease generally. Also, Inuit participants express a preference for methods of health education different from those presently employed. Lastly, and perhaps more importantly, this study suggests that the history of colonization and continuing colonization play a significant role in how some Inuit experience TB, other disease, and health, and in the high incidence of TB in Nunavut. Conclusion: In order to decrease incidence of TB and increase levels of health in</p>	<p>EX6. Not hard-to-reach group</p>

	Nunavut decolonizing measures are necessary.	
Montero-Mendoza et al. (2003)	To explore gender differences in the disease process, interview & survey data obtained from 21 women and 19 men with tuberculosis living in the Sierra de Santa Marta, Veracruz, Mexico, are drawn on to investigate their experiences of the disease from initial symptoms to treatment. Supplementary data were obtained from interviews with health officers and practitioners and a review of secondary sources. Informants' use of a Western (biomedical) vs a traditional model of health & disease to interpret their experiences is described, noting a mixture of both types; no gender differences were revealed. Though choice of explanatory model did not determine choice of health agent for medical attention, women tended to seek medical attention more often & sooner than men; no gender differences were found in choice of preferred health agent. Factors impacting the likelihood of successful treatment are identified, with failures attributed primarily to the poor quality of health care & economic factors; gender-related factors also compromised women's obtaining effective treatment.	EX6. Not hard-to-reach group
Morrow et al (2003)	This case-tuberculosis in a homeless men's shelter-is one of a series of teaching cases in the Case-Based Series in Population-Oriented Prevention (C-POP). It has been developed for use in medical school and residency prevention curricula. The complete set of cases is presented in this supplement to the American journal of Preventive Medicine. Tuberculosis presents a significant public health challenge. In this teaching case, medical students are given information about four cases of active tuberculosis that occurred over a short period of time in residents of a homeless men's shelter. The students then walk through the steps that a local health department takes to identify and screen those individuals at risk for transmission of tuberculosis during an outbreak. During this process, they learn skills in epidemiology (such as defining "epidemic" and distinguishing uses for incidence and prevalence) as well as in population-based prevention of tuberculosis. Finally students discuss health policy as it relates to the control and prevention of tuberculosis.	EX4. No views data
Munro et al. (2007)	Background: Tuberculosis (TB) is a major contributor to the global burden of disease and has received considerable attention in recent years, particularly in low- and middle-income countries where it is closely associated with HIV/AIDS. Poor adherence to treatment is common despite various interventions aimed at improving treatment completion. Lack of a comprehensive and holistic understanding of barriers to and facilitators of, treatment adherence is currently a major obstacle to finding effective solutions. The aim of this systematic review of qualitative studies was to understand the factors considered important by patients, caregivers and health care providers in contributing to TB medication adherence. Methods and findings: We searched 19 electronic databases (1966–February 2005) for qualitative studies on patients', caregivers', or healthcare providers' perceptions of adherence to preventive or curative TB treatment with the free text terms "Tuberculosis AND (adherence OR compliance OR concordance)". We supplemented our search with	EX4. No views data

	<p>citation searches and by consulting experts. For included studies, study quality was assessed using a predetermined checklist and data were extracted independently onto a standard form. We then followed Noblit and Hare's method of meta-ethnography to synthesize the findings, using both reciprocal translation and line-of-argument synthesis. We screened 7,814 citations and selected 44 articles that met the pre-specified inclusion criteria. The synthesis offers an overview of qualitative evidence derived from these multiple international studies. We identified eight major themes across the studies: organisation of treatment and care; interpretations of illness and wellness; the financial burden of treatment; knowledge, attitudes, and beliefs about treatment; law and immigration; personal characteristics and adherence behaviour; side effects; and family, community, and household support. Our interpretation of the themes across all studies produced a line-of-argument synthesis describing how four major factors interact to affect adherence to TB treatment: structural factors, including poverty and gender discrimination; the social context; health service factors; and personal factors. The findings of this study are limited by the quality and foci of the included studies. Conclusions: Adherence to the long course of TB treatment is a complex, dynamic phenomenon with a wide range of factors impacting on treatment-taking behaviour. Patients' adherence to their medication regimens was influenced by the interaction of a number of these factors. The findings of our review could help inform the development of patient-centred interventions and of interventions to address structural barriers to treatment adherence.</p>	
Nachman (1993)	<p>Data from interviews with 38 Haitian tuberculosis patients & informal discussion with nonpatients & medical personnel are used to examine health & other conditions at a FL-based detention camp (Krome) for illegal entrants run by the US Immigration & Naturalization Service. Reactions of detainees to conditions at Krome are examined, & reasons why patients accused camp officials of trying to justify exclusionary immigration practices by treating Haitians as "disease ridden" are discussed. Also discussed are patient reactions to their diagnoses & dehumanizing practices at Krome. It is argued that the problems at Krome are linked to the competing definitions of health & illness among camp staff & patients.</p>	EX6. Not hard-to-reach group
Naidoo et al. (2009)	<p>Our aim with this study was to explore the factors that contribute to tuberculosis patients' adherence and non-adherence to the Directly Observed Treatment Short Course strategy. A qualitative, phenomenological research design was used. Fifteen male and female participants between the ages of 18 and 57 years were recruited through purposive sampling at a primary care clinic located in a disadvantaged area, and in-depth interviews were conducted. The data analysis indicated that the factors found to influence adherence were social and economic resources; causal attributions assigned to TB; the social, cultural, economic, disease-related, and psychological challenges faced as a consequence of having TB;</p>	EX2. Not OECD country

	quality of health care received; use of the traditional healing system; and the participants' HIV status. Factors found to be associated with non-adherence included poverty, HIV co-infection, stigma, unsupportive social and work environments, and a high prevalence of helplessness and hopelessness.	
Nolan (1999)	Treatment of latent infection due to Mycobacterium tuberculosis will likely increase in importance as a strategy to prevent tuberculosis in the USA. This review was undertaken to assess how targeted testing and treatment of latent tuberculosis infection are currently organized, with a focus on the extension of those services from public health clinics to other community sites. Targeted testing programs are now being implemented in primary care neighbourhood clinics, syringe-exchange programs, jails, and teen health clinics. Organizational issues at those new sites include the need for a tracking system for clinical follow-up and for incentives to promote adherence. There is increasing experience with directly observed treatment of latent tuberculosis infection. Communities that receive large numbers of immigrants and refugees should prioritize the evaluation of those whose chest radiographs are suggestive of tuberculosis. Current studies continue to point out imperfections in the current tools, such as the tuberculin skin test and isoniazid. Finally, the advent of managed care, especially for Medicaid recipients, presents both opportunities and challenges for expansion of population-based preventive health services.	EX4. No views data
Nolon and O'Barr (1993)	Hudson Valley Migrant Health (HVMH) (a Public Health Service program) collaborated with the Center for Disease Control (CDC) and the New York State Department of Health (NYSDOH) on a study of the incidence of sexually transmitted diseases and tuberculosis among migrant farmworkers in the mid-Hudson region of New York. CDC research personnel screened 115 migrant workers from August 31 to September 12, 1992, distributed results, and initiated treatment. HVMH assumed primary responsibility for follow-up. Other agencies offered support during both phases of the study. Screening results indicated a 36 percent tuberculosis positivity, 6 percent HIV positivity, and 32 percent syphilis positivity. In addition, 32 percent lacked immunity to the Hepatitis B virus. Barriers to providing screening and health care include: (1) limited hours of access both by farmworkers to health care, and by providers to farmworkers because of work schedules; (2) underdeveloped linkages with county departments of health; (3) travel distances and lack of transportation for follow-up; (4) inefficient transfer of medical information upstream and downstream; and (5) limited staff and financial resources of HVMH for the extensive follow-up required. Nine recommendations are offered; they include adopting more positive attitudes toward farmworkers; improving collaboration and coordination among agencies; coordinating interstate Medicaid coverage; establishing outreach, health education, translation, and transportation services; and increasing the role of the Public Health Service.	EX4. No views data
Noyes and	Aim: This paper reports the findings from a qualitative meta-	EX4. No

Popay (2007)	<p>synthesis concerning people with, or at risk of, tuberculosis, service providers and policymakers and their experiences and perceptions of tuberculosis and treatment. Background: Directly observed therapy is part of a package of interventions to improve tuberculosis treatment and adherence. A Cochrane systematic review of trials showed an absence of evidence for or against directly observed therapy compared with people treating themselves. Method: Qualitative systematic review methods were used to search, screen, appraise and extract data thematic analysis was used to synthesize data from 1990 to 2002, and an update of literature to December 2005. Two questions were addressed: 'What does qualitative research tell us about the facilitators and barriers to accessing and complying with tuberculosis treatment?' and 'What does qualitative research tell us about the diverse results and effect sizes of the randomized controlled trials included in the Cochrane review?' Findings help explain the diverse trial results in a Cochrane systematic review of directly observed therapy and tuberculosis and consider implications for research, policy and practice. Findings: Five themes emerged from the 1990 to 2002 synthesis: socio-economic circumstances, material resources and individual agency; explanatory models and knowledge systems in relation to tuberculosis and its treatment; the experience of stigma and public discourses around tuberculosis; sanctions, incentives and support, and the social organization and social relationships of care. Two additional themes emerged from the 2005 update. Conclusion: The qualitative meta-synthesis improved the relevance and scope of the Cochrane review of trials. The findings make a major contribution to the development of theory concerning global WHO-branded disease control and the practicality of local delivery to people.</p>	views data
Nyamathi et al. (2005)	<p>This study examines the predictors of perceived health status among homeless adults with latent tuberculosis (TB) in Los Angeles, especially in relation to gender differences. Total, 415 men and women enrolled in a TB-adherence trial completed baseline assessments concerning health status. Results indicated that women were more likely than men to report being in fair or poor health and to have experienced health problems. More women than men self-reported daily drug use and poor mental health. Homeless women were also more likely than their male counterparts to receive support from non-drug-users. Homeless adults who reported fair or poor health were also more likely than those who reported better health to have used injection drugs, to report experiencing depressive symptoms and poor mental health, and to have been homeless more than three years. Predictors of fair or poor health included being female and experiencing more depressive symptoms.</p>	EX4. No views data
Oliveira et al. (2009)	<p>This study aimed to assess, according to patients' perception, the performance of the Health Services responsible for tuberculosis (TB) control, concerning the dimensions family focus and community orientation. A cross-sectional evaluative research was carried out with 108 TB patients. A questionnaire developed by Starfield and</p>	EX5. Not qualitative research

	<p>Macinko was used, adapted for TB care by Villa and Ruffino-Netto. Results evidence, in the first dimension, that health professionals (HP) are concerned with patients' signs and symptoms; and, at a lower level, with other health problems of relatives, endangering the comprehensive healthcare. In the second dimension, HP show little concern with the active search of cases, deficiency in HP training, and low rates of examined contacts. Results show the need to broaden HP's epidemiological view, as their attention is focused on patients, with few preventive actions concerning family/community. This evidences the need for a closer relationship among HP/patients/family/community.</p>	
Ormerod (2000)	n/a	EX4. No views data
Pathak et al. (2008)	n/a	EX2. Not OECD country
Perlman et al. (1997)	<p>The project began in March 1995 at an exchange that has over 8000 registered participants. Describes how screening is conducted and strategies used to obtain chest radiographs. TB screening at a syringe exchange program is feasible and is acceptable to active drug users who view it as an extension of harm reduction.</p>	EX4. No views data
Pio et al. (1997)	<p>Since 1990 the WHO Global Tuberculosis Programme (GTB) has promoted the revision of national tuberculosis programmes to strengthen the focus on directly observed treatment, short-course (DOTS) and close monitoring of treatment outcomes. GTB has encouraged in-depth evaluation of activities through a comprehensive programme review. Over the period 1990–95, WHO supported 12 such programme reviews. The criteria for selection were as follows: large population (Bangladesh, Brazil, China, Ethiopia, India, Indonesia, Mexico, and Thailand); good prospects of developing a model programme for a region (Nepal, Zimbabwe); or at advanced stage of implementation of a model programme for a region (Guinea, Peru). The estimated combined incidence of smear-positive pulmonary tuberculosis was 82 per 100,000 population, about 43% of the global incidence. The prevalence of infection with human immunodeficiency virus (HIV) was variable, being very high in Ethiopia and Zimbabwe, but negligible in Bangladesh, China, Nepal and Peru. The programme reviews were conducted by teams of 15–35 experts representing a wide range of national and external institutions. After a two- to three-month preparatory period, the conduct of the review usually lasted two to three weeks, including a first phase of meetings with authorities and review of documents, a second phase for field visits, and a third phase of discussion of findings and recommendations. The main lessons learned from the programme reviews were as follows: programme review is a useful tool to secure government commitment, reorient the tuberculosis control policies and replan the activities on solid grounds; the involvement of public health and academic institutions, cooperating agencies, and nongovernmental organizations secured a broad</p>	EX2. Not OECD country

	<p>support to the new policies; programme success is linked to a centralized direction which supports a decentralized implementation through the primary health care services; monitoring and evaluation of case management functions well if it is based on the right classification of cases and quarterly reports on cohorts of patients; a comprehensive programme review should include teaching about tuberculosis in medical, nursing, and laboratory workers' schools; good quality diagnosis and treatment are the essential requirements for expanding a programme beyond the pilot testing; and control targets cannot be achieved if private and social security patients are left outside the programme scope. The methodology of comprehensive programme review should be recommended to all countries which require programme reorientation; it is also appropriate for carrying out evaluations at four- to five-year intervals in countries that are implementing the correct tuberculosis control policies. [References: 16]; Over the period 1990–95, the World Health Organization (WHO) conducted 12 reviews of national tuberculosis programs, with emphasis on passive case finding; directly observed treatment, short-course (DOTS); drug supply; and treatment outcome monitoring. Criteria for program selection were: large population (Bangladesh, Brazil, Chile, Ethiopia, India, Indonesia, Mexico, and Thailand); good potential for developing a model regional program (Nepal, Zimbabwe); or advanced stage of implementation of a model program (Guinea, Peru). The two- to three-week review process included interviews with authorities, document reviews, field visits, and discussions of findings. The estimated combined incidence of smear-positive pulmonary tuberculosis was 82/100,000 population—about 43% of the global incidence. These reviews suggested the following observations: 1) program review is a useful tool to secure government commitment, reorient tuberculosis control policies, and replan activities on a more solid basis; 2) the involvement of academic and public health institutions, cooperating agencies, and non governmental organizations secures broad support for new policies; 3) program success is linked to a centralized direction that supports a decentralized implementation through the primary healthcare system; 4) monitoring and evaluation of case management function well if based on the correct classification of cases and quarterly reports on cohorts of patients; 5) a comprehensive program review should include teaching about tuberculosis in medical, nursing, and laboratory workers' schools; 6) good quality diagnosis and treatment are essential requirements for expanding a program beyond pilot testing; and 7) tuberculosis control targets cannot be achieved if private and social security patients are excluded from program coverage.</p>	
<p>Poss (1998)</p>	<p>The timely diagnosis and treatment of tuberculosis is an important public health problem in both developed and developing nations. In the USA, migrant farmworkers are estimated to be about six times more likely than other employed adults to develop tuberculosis. The</p>	<p>EX6. Not hard-to-reach group</p>

	<p>purpose of this study was to investigate explanatory models of tuberculosis among Mexican migrant farmworkers working in western New York state. In-depth interviews were conducted with 26 farmworkers using an open-ended question format. All interviews were conducted in migrant camps and were audio-taped, translated and transcribed by the researcher. Data analysis was performed using Glaser and Strauss grounded theory method of analysis which involves continuous and simultaneous data collection, coding, and analysis. Study participants included 21 males and 5 females ranging in age from 18 to 65. Respondents had worked as migrant farmworkers an average of 10 years and had an average of five years of schooling. Two-thirds of the participants had previously attended a tuberculosis education program, and four had received treatment for tuberculosis infection in the past. Farmworkers' explanations of tuberculosis etiology, severity, symptoms, prevention, treatment, and social significance are described as well as their beliefs about tuberculosis skin testing and the bacillus Calmette-Guerin (BCG) vaccine. Migrant farmworkers' explanatory models were similar in many aspects to the medical model of tuberculosis, although farmworkers had numerous misconceptions about BCG vaccination. Health care workers should be aware that Mexican migrant farmworkers may have beliefs about tuberculosis that are very compatible with participation in testing and treatment programs in such programs are made accessible to them.</p>	
Poss (1999)	<p>This article details the use of qualitative data in the construction of a Spanish-language, quantitative research instrument designed for a study of Mexican migrant farmworkers' participation in tuberculosis screening. In the qualitative study, 19 Mexican migrant farmworkers were interviewed in Spanish to elicit their explanatory models (EMs) about tuberculosis. The Tuberculosis Interview Instrument (TII) was developed from the results of the qualitative study and concepts from a theoretical framework consisting of a combination of the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA). After its development, the TII was subjected to translation and back-translation procedures to insure the equivalency of the English and Spanish versions, and it was reviewed for content validity. Internal consistency reliability, based on the responses of 206 subjects, was satisfactory for all subscales. Future testing of the TV is recommended to evaluate its stability among Mexican migrant farmworkers in other parts of the United States.</p>	EX4. No views data
Poss (2001)	<p>This article discusses the development of a new model representing the synthesis of two models that are often used to study health behaviors: the Health Belief Model and the Theory of Reasoned Action. The new model was developed as the theoretic framework for an investigation of the factors affecting participation by Mexican migrant workers in tuberculosis screening. Development of the synthesized model evolved from the concern that models used to investigate health-seeking behaviors of mainstream Anglo groups in the United States might not be appropriate for studying migrant</p>	EX4. No views data

	workers or persons from other cultural backgrounds.	
Proudfoot (2005)	Tuberculosis (TB) is a serious infectious disease that has, in recent years, re-emerged in industrialised countries primarily due to immigration, poverty, loss of public health controls, diagnostic and clinical skills, drug resistance and HIV infection. This is reflected by outbreaks in particularly vulnerable groups such as homeless people, substance abusers and individuals from less developed countries. This article describes how a screening programme was set up in an English city (Chester) by a primary care trust (PCT) employing a TB community nurse to screen and assess the prevalence among at risk groups, support the treatment of infected individuals and raise awareness of the problem among fellow health professionals. Similar screening programmes have been set up before. One such programme by Kong et al (2002) in the USA describes a TB screening programme using symptom screening and tuberculin skin testing but was mandatory in nature as opposed to the one in Chester which was voluntary.	EX4. No views data
Rayner (2000)	Tuberculosis (TB) is an old infectious disease that has re-emerged in recent years and is responsible for many deaths throughout the world. Homeless people residing in shelters and hostels within inner city areas of the UK and the USA are at risk from this serious disease. Interventions to control the spread of TB are described in the literature researched; these include the introduction of inducements to encourage participation in screening programmes and the recommendation of directly observed therapy. The literature reflects the partial success of these programmes in the UK and USA. Targeting homeless persons most at risk is challenging as is gaining accurate information on those who are affected by TB. Effective coordination of care by healthcare providers in hospital and the community is imperative. It appears that healthcare professionals are becoming more prescriptive in their approach which is relinquishing the homeless population from taking responsibility for their own health care.	EX4. No views data
Rennie et al. (2008)	Background: To research patient perceptions of medicines and illness in a multicultural setting, it is appropriate to translate research materials. However, the translation procedures should be valid and reliable to assure accuracy. Objectives: To translate into 3 languages-Turkish, Urdu, and Bengali-a research questionnaire investigating illness and medicines perceptions of tuberculosis patients and to validate the translation. Methods: A four-stage protocol for the translation and validation of research questionnaires investigating illness and medicines perceptions was designed and implemented. This involved forward and back-translation, group-validation, and post hoc conceptual equivalence rating in three different languages. Results: The translation protocol was found to be very useful in identifying discrepancies between original and translated versions; a total of 83 amendments were required. Post hoc evaluations also demonstrated improvements for two of the three language translations. Some redundancy was apparent and an	EX4. No views data

	improved protocol was suggested by the authors. Conclusions: This study demonstrated that including a protocol for translation and validation of the translation is crucial to assure accuracy in multicultural research.	
Reyes (2007)	<p>Almost 10 years ago, attention was drawn to the many pitfalls involved in the treatment of tuberculosis (TB) in prison settings, based on field experience from the ICRC (International Committee of the Red Cross) (Coninx et al., 1995). Since that time, the ICRC has continued working in the field of TB in prisons, either directly, or by supporting the local programmes in different countries. Further experience gained since then has, if anything, confirmed and reinforced the worries caused by the specific problems posed both by the prison environment and by "prisoner-patients" for the treatment of TB. Medical staff working in prisons need to be familiar with these issues if tuberculosis is to be managed and treated successfully. With the menace of drug-resistant TB no longer merely a marginal problem but arguably becoming a direct menace to public health, it becomes all the more important to be aware of these pitfalls. This paper addresses the following: * why prison settings are especially difficult for TB detection and management; * why prisoners can be particularly difficult patients; * how different resistant strains of TB are produced or enhanced in prisons; * added difficulties in treating MDR-TB in prisoners; * and how and why the association of TB and HIV complicate TB, and MDR-TB, treatment in prisons even further.</p>	EX4. No views data
Reyes-Guillen et al. (2008)	<p>Objective: To analyze the perceptions and interactions of the actors involved in anti-tuberculosis treatment, and to explore their influence in treatment defaulting in Los Altos region of Chiapas, Mexico. Material and methods: From November 2002 to August 2003, in-depth interviews were administered to patients with PTB, patients' family members, institutional physicians, community health coordinators, and traditional medicine practitioners. RESULTS: We found different perceptions about PTB between patients and their families and among health personnel, as well as communication barriers between actors. Defaulting is considered to be mainly due to the treatment's adverse effects. Conclusions: It is necessary to conduct research and interventions in the studied area with the aim of changing perceptions, improving sensitization, quality and suitability of management of patients with PTB in a multicultural context, and promoting collaboration between institutional and traditional medicine.</p>	EX6. Not hard-to-reach group
Rideout and Menzies (1994)	<p>Non compliance is the most important cause of failure of anti-tuberculous therapy throughout the world. In 1990 and 1991, an outbreak of tuberculosis occurred on the Mistassini Cree territory in Northern Quebec, Canada, and a number of cases of active tuberculosis occurred among known tuberculin-positive contacts who were non-compliant with preventive therapy. To better understand the factors affecting compliance with preventive treatment, a review of patients prescribed preventive treatment over the past 10 years</p>	EX5. Not qualitative research

	<p>was conducted. A freely-translated, interviewer-administered questionnaire was used to measure personal/lifestyle factors and knowledge/attitudes about tuberculosis. Clinic dossiers were reviewed to assess compliance. One hundred and two (102) subjects prescribed preventive treatment between 1981 and 1991 were interviewed, of whom 33.7% were judged to have been compliant. The most significant factor associated with compliance with preventive therapy was year of therapy. Between 1981 and 1985, 78% completed treatment, compared to less than 20% since 1986 ($p < .0001$). The major factor identified as associated with this sudden change was a shift in responsibility for tuberculosis treatment follow-up from native community health workers to non-native nurses in 1985/86. We conclude that tuberculosis control programs must be tailored to take into account the importance of cultural factors in promoting compliance with therapy.</p>	
Rowell (1997)	<p>Describes similarities & differences in the experiences of acquired immune deficiency syndrome (AIDS) programs targeting Navajos in rural Chinle, AZ, & Native Americans in New York City. Site-specific barriers that prevent or discourage access to health care for Native Americans living with human immunodeficiency virus/AIDS were identified. On the Navajo reservation, the critical issues were confidentiality, lack of faith in local medical services, & lack of access to nonlocal medical services (a function of both finances & transportation). In New York City, the critical issues were dual or multiple diagnosis (eg, substance addiction & tuberculosis infection), budget cuts, lack of adequate housing, & confusion about cultural values.</p>	EX1. Not focused on TB
Searle et al. (2007)	<p>Setting: A community-based ethnography of tuberculosis (TB) treatment of 'European' New Zealanders in Auckland was completed in 2003. Objective: To document and analyse the nature of the process of care in this population where the majority of patients are older with other health and social complications. Design: Data collection included repeated semi-structured interviews with all patients who were willing and able to give consent, semi-structured interviews on health and TB with matched participants without TB, discussions with health care providers, participant observation with TB patients, readings of patient records and monitoring of TB in the media. Reiterative inductive analyses were made of transcripts, field notes and textual materials. Results: Eight patients from 2003 (out of a possible nine) and one patient from 1997 participated. All were aged 47–75 years. They represent a wide socio-economic range. All completed treatment. The contribution of multidimensional care, from initial acceptance through exigencies of treatment to successful recovery, is evident in the participants' narratives. The public health nurse is a key support and a lynchpin in the patients' support network. Conclusion: A model of care including alliances between patients and care givers as part of treatment is clearly successful in this population group. This study has implications for older cohorts in other low-incidence countries.</p>	EX6. Not hard-to-reach group

Shetty et al. (2004)	<p>The objectives were to study knowledge, attitudes, and practices (KAP) regarding tuberculosis (TB) among Somalian subjects in inner London. We administered structured, fixed response KAP questionnaires to 23 patients (culture proved TB), and two groups of controls: 25 contacts (family members) and 27 lay controls (general Somali immigrant population). Responses were summed on a five-point scale. Most were aware of the infectious nature of TB but uncertain of other risk factors. Many were uncertain about coping with the disease and its effect on lifestyle. Belief in biomedicine for TB was unequivocal with men having a significantly higher belief score than women ($p = 0.02$); the need to comply with TB medication was unambiguously understood. Somalians interviewed were educated, multilingual, and aware of important health issues. Uncertainties in core TB knowledge need to be addressed with direct educational input, especially in women and recent entrants into the country. Volunteers from the established Somalian community could play a valuable part as links in the community to fight TB.</p>	EX5. Not qualitative research
Shrestha-Kuwahara et al. (2003)	<p>Setting: Little is known about why some tuberculosis (TB) patients identify few or even no contacts. Objectives: To describe patient perceptions of the contact investigation interview and determine potential factors associated with identifying TB contacts. Design: A total of 13 focus groups were conducted: 10 groups with previously smear-positive pulmonary TB patients born in the USA or Mexico, and three with program staff to discuss attitudes toward and perceptions of the contact investigation interview. Patients were recruited into separate groups by country of birth and number of contacts identified. Results: The data indicated that patients—even those who identified few contacts—overwhelmingly reported identifying contacts easily and willingly. Understanding the purpose of the contact investigation and seriousness of TB facilitated naming contacts, while miscommunication and misconceptions about TB hindered the process. Patients felt strongly about informing their contacts before the health department contacted them. Staff respondents reported that education and effective communication were critical during contact investigation interviewing. Conclusion: Data indicated that patients, including those identifying few contacts, reported wanting to name their contacts. However, misconceptions may affect their understanding of who their contacts are, and hence the quantity and quality of the contacts identified. These findings underscore the need for effective communication and education.</p>	EX6. Not hard-to-reach group
Stiefelhagen (2007)		EX4. No views data
Storla et al. (2008)	<p>Background: Early diagnosis and immediate initiation of treatment are essential for an effective tuberculosis (TB) control program. Delay in diagnosis is significant to both disease prognosis at the individual level and transmission within the community. Most transmissions occur between the onset of cough and initiation of treatment. Methods: A systematic review of 58 studies addressing delay in diagnosis and treatment of TB was performed. We found</p>	EX4. No views data

	<p>different definitions of, for example, debut of symptoms, first appropriate health care provider, time to diagnosis, and start of treatment. Rather than excluding studies that failed to meet strict scientific criteria (like in a meta-analysis), we tried to extract the "solid findings" from all of them to arrive on a more global understanding of diagnostic delay in TB. Results: The main factors associated with diagnostic delay included human immunodeficiency virus; coexistence of chronic cough and/or other lung diseases; negative sputum smear; extrapulmonary TB; rural residence; low access (geographical or sociopsychological barriers); initial visitation of a government low-level healthcare facility, private practitioner, or traditional healer; old age; poverty; female sex; alcoholism and substance abuse; history of immigration; low educational level; low awareness of TB; incomprehensive beliefs; self-treatment; and stigma. Conclusion: The core problem in delay of diagnosis and treatment seemed to be a vicious cycle of repeated visits at the same healthcare level, resulting in non specific antibiotic treatment and failure to access specialized TB services. Once generation of a specific diagnosis was in reach, TB treatment was initiated within a reasonable period of time.</p>	
Sumartojo (1993)	<p>Several conclusions about measuring adherence can be drawn. Probably the best approach is to use multiple measures, including some combination of urine assays, pill counts, and detailed patient interviews. Careful monitoring of patient behaviour early in the regimen will help predict whether adherence is likely to be a problem. Microelectronic devices in pill boxes or bottle caps have been used for measuring adherence among patients with tuberculosis, but their effectiveness has not been established. The use of these devices may be particularly troublesome for some groups such as the elderly, or precluded for those whose life styles might interfere with their use such as the homeless or migrant farm workers. Carefully designed patient interviews should be tested to determine whether they can be used to predict adherence. Probably the best predictor of adherence is the patient's previous history of adherence. However, adherence is not a personality trait, but a task-specific behaviour. For example, someone who misses many doses of antituberculosis medication may successfully use prescribed eye drops or follow dietary recommendations. Providers need to monitor adherence to antituberculosis medications early in treatment in order to anticipate future problems and to ask patients about specific adherence tasks. Ongoing monitoring is essential for patients taking medicine for active tuberculosis. These patients typically feel well after a few weeks and either may believe that the drugs are no longer necessary or may forget to take medication because there are no longer physical cues of illness. Demographic factors, though easy to measure, do not predict adherence well. Tending to be surrogates for other causal factors, they are not amenable to interventions for behaviour change. Placing emphasis on demographic characteristics may lead to discriminatory practices. Patients with social support</p>	EX4. No views data

	<p>networks have been more adherent in some studies, and patients who believe in the seriousness of their problems with tuberculosis are more likely to be adherent. Additional research on adherence predictors is needed, but it should reflect the complexity of the problem. This research requires a theory-based approach, which has been essentially missing from studies on adherence and tuberculosis. Research also needs to target predictors for specific groups of patients. There is clear evidence of the effect on adherence of culturally influenced beliefs and attitudes about tuberculosis and its treatment. Cultural factors are associated with misinformation about the medical aspects of the disease and the stigmatization of persons with tuberculosis. Culturally sensitive, targeted information is needed, and some has been developed by local tuberculosis programs.</p>	
Tardin et al. (2009)	<p>Objectives: In a low incidence area for tuberculosis (TB), a computerized database identified an unusually high proportion of patients coming from one single country between 2004 and 2006. To determine whether they constituted a cluster, whether clustering was due to recent transmission, and to understand what undermined the efficacy of the contact tracing procedure, we conducted a retrospective study of all patients with TB from this country. Methods: Mycobacterium tuberculosis isolates of 15 TB cases originating from the same country over a 21/2 year period were analysed by restriction fragment length polymorphism (RFLP) and/or Rep-PCR. To identify links between patients, we revisited the social worker's files, cross-matched contacts' databases, and performed internet searches. A cultural evaluation was conducted by an anthropologist and an expert physician, through patient and community key informant interviews and a literature review. Results: Genotyping confirmed that 11 of 15 patients had identical isolates. Additional data revealed an unsuspected complex network of social links between 9 of these 11 patients. The transcultural evaluation pointed out the major obstacles to efficient contact tracing, such as importance of social stigma related to TB, differences in communication style and health beliefs, and linguistic barriers. Conclusion The combined finding of identical genotypes and important social links between patients confirmed the suspicion of a TB cluster due to recent transmission. The cultural evaluation helped to explain the difficulties encountered during the contact tracing procedure, and offered strategies to improve its efficacy despite the magnitude of the social stigma attached to TB in this community.</p>	EX5. Not qualitative research
Tato et al. (2000)	<p>Studied the efficacy of a home care intervention program for 329 male and female HIV-positive adults (mean age 35.8 yrs) in Spain. Data on sociodemographic variables, risk factors, drug use, clinical and psychological symptoms, and treatment response were obtained by semistructured interview. The program involved clinical and psychological evaluation, drug-dependency treatment, individualized health education for Ss and family members, emotional support for Ss and family members, legal aid, and home help. The results were</p>	EX1. Not focused on TB

	evaluated according to age, sex, marital status, number of family members, family type, economic and legal situation, city of residence, health status at entry, and drug relapse. Ss were followed for a mean of 11.4 mo. The results indicate that 86 percent were iv drug abusers, 38 percent presented with tuberculosis as admitting diagnosis, that 114 Ss left the program, but that the relapse rate was low for Ss staying with the program.	
Thompson et al. (2009)	The incidence of tuberculosis (TB) has increased in the UK over the last 15 years. In England, the TB rate in 2006 was 15.5 per 100,000 of the population. The rates varied in different parts of the country, with London having the highest rate (44.8 per 100,000). Greater Manchester had the highest rate in the northwest of England (16.6 per 100,000), and there were variations within the county, with Manchester having the highest rate (37.4 per 100,000) and Bury having the lowest rate (2.2 per 100,000). A recent study set in London reported that TB rates in the prison population are much higher than average (208 per 100,000). Late diagnosis, overcrowding, poor ventilation and repeated prison transfer of infectious individuals encourages the spread of infection within the prison environment. TB incidents in prisons are challenging to manage and cause significant anxiety in prisoners and staff.	EX4. No views data
Tooley (2000)	n/a	EX4. No views data
Tseng et al. (1997)	The implementation of a selective neonatal BCG immunisation policy adopted in south east London boroughs of Lambeth, Southwark, and Lewisham in 1992 has been audited. A survey conducted 18 months after the policy was implemented showed that only 11% of infants identified as eligible for neonatal BCG immunisation had been immunised. The results of the survey were fed back to neonatal units, which were encouraged to improve access to BCG immunisations for eligible infants. A second survey 17 months later showed that 14% of eligible infants had been immunised. Difficulties in applying complex selection criteria, rapid turnover of trained staff in acute units, and short neonatal stay were thought to contribute to the poor uptake of the selective programme delivered in the neonatal units. A community based BCG immunisation service has been commissioned to improve uptake.	EX1. Not focused on TB
Tuberculosis Along the US-Mexico Border Work Group, Centers for Disease Control and Prevention	Converging factors contribute to elevated tuberculosis (TB) incidence and complicate case management in the US states bordering Mexico. These factors include a) Mexico's higher TB rate; b) low socioeconomic status and limited access to health care in the border area; c) frequent border crossings and travel in the United States for employment, commerce, health services, and leisure; d) language and sociocultural differences; and e) lack of coordinated care across health jurisdictions on both sides of the US-Mexico border. Prevention and control efforts that address the challenges created by border-crossing populations require collaboration among local, state, and national TB control programs in both countries. In June 1999, to facilitate future discussions with Mexican counterparts, CDC	EX4. No views data

(2001)	convened a meeting of TB control officials from the four U.S. states bordering Mexico (i.e., California, Arizona, New Mexico, and Texas) to address TB prevention and control in the border area. Focus areas included a) surveillance needs, b) case management and therapy completion, c) performance indicators and program evaluation, and d) research needs. Meeting participants' deliberations and resulting proposals for action by CDC and state and local TB control programs are detailed in this report.	
Tulsky et al. (1999)	Objectives: To measure knowledge and perceived susceptibility to tuberculosis among homeless adults in San Francisco and attitudes toward control measures used to improve adherence to treatment for tuberculosis. Design: A cross-sectional survey via interview of homeless shelter residents was done at five shelters. Results: Of 292 persons interviewed, 21.6% reported a positive skin test, and 57.1% of the positives had received preventive therapy. Over 60% had misconceptions about transmission, in particular confusion with transmission of the human immunodeficiency virus (HIV). Knowledge of skin testing procedures and symptoms was generally good, and most reported health care providers as the main source of information. Over half reported concern about catching tuberculosis and over 80% favored controls to ensure adherence, in particular directly observed therapy. Higher TB knowledge score ($P = 0.0155$) and male sex ($P = 0.0357$) were associated with a favorable attitude toward directly observed therapy. Conclusions: Health care providers should expand educational messages beyond skin testing. Greater knowledge about tuberculosis may increase acceptance of control measures. Targeted education plus social norms favoring completion of therapy may improve screening and treatment outcomes in this population.	EX5. Not qualitative research
Upshur et al. (1999)	Setting: Selected schools in East York, an ethnically diverse municipality of 110,000 people within Toronto. Objective: To explore school staff's attitudes and beliefs about the nature of tuberculosis and its possible effect on the function and culture of schools. Design: Four focus groups of six to eight school staff, lasting from 1 to 1.5 hours, were held in the spring of 1997 at four different schools deemed to be at high risk for tuberculosis contact tracing. Results: The study identified the following dominant themes: fear of tuberculosis and its impact on school, lack of knowledge and the need for education concerning tuberculosis, and issues in multiculturalism. Conclusion: Tuberculosis was perceived by staff of East York schools to be a source of fear. Lack of accurate and reliable information concerning tuberculosis contributes to this situation. Staff identified age-specific and culturally relevant, educational initiatives as means to reduce this fear.	EX6. Not hard-to-reach group
Van Brakel (2006)	Stigma related to chronic health conditions such as HIV/AIDS, leprosy, tuberculosis, mental illness & epilepsy is a global phenomenon with a severe impact on individuals & their families, & on the effectiveness of public health programmes. To compare stigma measurement in different disciplines, a literature review was	EX2. Not OECD country

	<p>conducted. References were obtained through a search of literature databases & through examining relevant bibliographies. Sixty-three papers were selected that addressed the issue of measurement of stigma or related constructs & that contained a sample of the instrument or items used. Five unpublished studies were also included in the review. The aspects of health-related stigma used for assessment can be grouped in five categories. First, the experience of actual discrimination &/or participation restrictions on the part of the person affected; second, attitudes towards the people affected; third, perceived or felt stigma; fourth, self or internalized stigma; & fifth, discriminatory & stigmatizing practices in (health) services, legislation, media & educational materials. Within each of these areas, different research methods have been used, including questionnaires, qualitative methods, indicators & scales. The characteristics of the instruments considered most promising are described & compared. The purpose of stigma assessment is to increase our understanding of stigma & its determinants & dynamics, to determine its extent or severity in a given setting or target group & to monitor changes in stigma over time. The conclusions from this review are that (a) the consequences of stigma are remarkably similar in different health conditions, cultures & public health programmes; (b) many instruments have been developed to assess the intensity & qualities of stigma, but often these have been condition-specific; & (c) development of generic instruments to assess health-related stigma may be possible. To achieve this aim, existing instruments should be further validated, developed or adapted for generic use, where possible.</p>	
Walsh (2008)	<p>Background Infectious diseases kill more than 10 million people worldwide every year. It is therefore vital that doctors receive a good education in this field. Online learning is one way in which doctors can learn new knowledge and skills. We conducted this study to determine whether the infectious diseases interactive online learning packages enabled primary care professionals to increase their knowledge and skills in the area of infectious diseases. Description We built a series of interactive case histories on the following topics: tuberculosis; hepatitis B; hepatitis C; influenza; meningitis; mumps; helicobacter pylori; chlamydia; and genital herpes. The modules involved a pre-test, a number of interactive cases and/or a summary of up-to-date knowledge in that area and a post-test. Results The learning modules were completed by 3,956 users. Wilcoxon's test showed that learners increased their knowledge to a statistically significant degree ($p < 0.001$) and qualitative data showed that users found the tool useful. Discussion The results appear to demonstrate that online modules are effective in helping health professionals learn more about infectious diseases.</p>	EX4. No views data
Westaway (1990)	<p>A sample of 201 adult black hospital inpatients with tuberculosis (TB) were interviewed to ascertain their knowledge and attitudes about the disease. The major signs and symptoms were cough by 89%, loss of appetite by 67%, weight loss by 63% and night sweats by</p>	EX2. Not OECD country

	<p>62%. Although 87% thought that TB affected many people, it was rarely discussed; they considered their families were not at risk, it was easy to prevent, there was complete recovery after treatment and it was an acceptable disease to family and friends. It was concluded that denial of personal involvement and a positive attitude towards cure and prevention may be factors that allow tuberculous patients to cope with their disease.</p>	
White et al. (2003)	<p>Jails are a unique setting for health education. The Tuberculosis (TB) Prevention Project was designed to improve completion of care for latent TB infection in released inmates. As part of an ongoing clinical trial to improve rates of completion, educators provided TB-focused educational sessions to 1,027 inmates. This article describes the educational sessions and illustrates some of the barriers to working in a jail setting and strategies to overcome them. The nature of the jail itself, inmate characteristics, the characteristics of educators, and the educational sessions themselves interacted in different ways to enhance or impair the interaction. Jail is a setting in which the population is at high risk for a number of health problems and health education is increasingly important.</p>	EX4. No views data
Wilce et al. (2002)	<p>To describe the policies and procedures used by 11 urban tuberculosis control programs to conduct contact investigations, written policies were reviewed and semistructured interviews were conducted with program managers and staff. Qualitative analysis showed that contact investigation policies and procedures vary widely. Most policies address risk factor assessment and contact prioritization; however, none of the policies provide comprehensive guidance for the entire process. Staffing patterns vary, but, overall, staff receive little formal training; informal monitoring practices predominate. Comprehensive guidelines and programmatic support are needed to improve the quality of contact investigation processes.</p>	EX4. No views data
Wyss (2004)	<p>Those invited to be part of the study were individuals who had a medical diagnosis of latent TB and were adults (18 years or older). Twenty-three people were interviewed, but since one who been treated in the past, his data was not used. The interview questions (see Appendix A) were open-ended and informal. Demographic data was gathered and then the rest of the interviews were conducted with specific questions as guides. Interviews were conducted in English or Spanish with the assistance of a paid interpreter. The interpreter was a migrant who had a good grasp of the language and the situation being researched. In the growing season of 2003, observations took place in the homes, and throughout the camps. Participants were observed for their social roles, their expectations and specific characteristics. A research fieldwork journal was kept. Included in the journal were ideas, reactions, and observations of the experience. Data was analyzed to ascertain migrant belief systems. The goal of the study was to better understand Hispanic migrant motivations to take or not take medication for latent TB, so that TB and other infectious diseases could be treated more effectively. Migrants' overall beliefs were examined with two major themes</p>	EX6. Not hard-to-reach group

	<p>noted; environment and beliefs. Sub-themes identified included for beliefs—internal variables, external variables, control, state of health, family support, importance of the diagnosis and world-view within each major theme. For the environment themes the sub-themes were economic factors, influence of gender, education, religion, and documentation status. These themes/sub-themes led to a better understanding of the migrant beliefs about medication compliance. They painted a picture of Mexicans with a strong cultural heritage that felt healthy and did not believe there were any serious health threats. These individuals (especially men) felt that job responsibilities came first, because of significant financial obligations. As a result of the study, many "external" changes have been implemented to make the testing, treating and medication compliance easier for the migrants.</p>	
Wyss and Alderman (2007)	<p>Tuberculosis (TB) is a serious health threat to migrant farm workers in the Midwestern USA. This article describes characteristics of migrant culture and lifestyle, economic, and health challenges that may impact screening, diagnosis, and adherence with complex medication regimens associated with TB. A brief overview of TB discusses the historical perspective of the disease and describes the stages, transmission, and incidence among migrant populations. Several theoretical models, such as the Health Belief Model (HBM) and social cognitive theory, were considered by the authors to guide understanding of migrant beliefs about TB. A qualitative research study conducted with 23 Hispanic migrants with latent TB infection is presented. Discussion of the research findings describes environmental, cognitive, and social factors that were barriers to screening, diagnosis, and treatment. The article concludes with a description of recent migrant health clinic updates designed to improve the worker' health status and considerations for environmental and educational change.</p>	EX6. Not hard-to-reach group
Yamagishi et al. (2002)	<p>We sent a questionnaire to hospitals with beds for tuberculosis in Japan to know current situation of daily life of tuberculosis patients treated in hospitals. It was evident that some services of daily life facilities was delayed; e.g. the difficulty in using stores in a hospital, no dining rooms and no installation of a personal television set. The use of personal computers was not allowed in many hospitals. Tuberculosis patients were subjected to a marked restriction in the hospital in spite of their isolation from the family and the society. Patients were prohibited to go out from the ward except when they undergo certain examinations in the hospitals, to take a walk in the hospital compound and to go out or stay overnight outside the hospital. In the majority of hospitals, patients were allowed to take a walk or to stay overnight outside the hospital only after the negative conversion of tubercle bacilli in sputum. Judging from the above findings, it appears that many tuberculosis patients under hospital treatment are not spending a pleasant daily hospital life.</p>	EX6. Not hard-to-reach group

12.0 Appendix E. Example quality assessment forms

Gibson et al. (2005)	
1. Is a qualitative approach appropriate?	Comments
Appropriate	
2. Is the study clear in what it seeks to do?	Comments
Clear	
3. How defensible/rigorous is the research design/methodology?	Comments
Defensible	
4. How well was the data collection carried out?	Comments
Appropriately	
5. Is the role of the researcher clearly described?	Comments
Clearly described	Use of community research assistants - considerable info on their role & relation to the research staff & participants
6. Is the context clearly described?	Comments
Clear	Plenty on broad context, some on specific setting
7. Were the methods reliable?	Comments
Reliable	Use of CA i/vs and 'evaluation weekend' (p. 936) – not explicitly about validating findings, but fair enough
8. Is the data analysis sufficiently rigorous?	Comments
Rigorous	
9. Is the data 'rich'?	Comments
Not sure	Not massive detail & not much on diversity, but good contextualisation
10. Is the analysis reliable?	Comments
Reliable	Various strategies for validation, see p. 935
11. Are the findings convincing?	Comments

Convincing	Clearly reported and coherent
12. Are the findings relevant to the aims of the study?	Comments
Relevant	Findings are clearly linked to aims and research question
13. Conclusions	Comments
Adequate	
14. How clear and coherent is the reporting of ethics?	Comments
Appropriate	
15. How well was the study conducted?	Comments
++	Overall, methods are reliable and findings are convincing and well-reported.

Houston et al. (2002)	
1. Is a qualitative approach appropriate?	Comments
Appropriate	
2. Is the study clear in what it seeks to do?	Comments
Clear	
3. How defensible/rigorous is the research design/methodology?	Comments
Defensible	
4. How well was the data collection carried out?	Comments
Appropriately	
5. Is the role of the researcher clearly described?	Comments
Clearly described	See discussion of role of bicultural focus group moderators, p. 259
6. Is the context clearly described?	Comments
Not sure	Some information but not much

7. Were the methods reliable?	Comments
Reliable	Triangulation between qualitative and quantitative data
8. Is the data analysis sufficiently rigorous?	Comments
Rigorous	See detailed description p. 259f.
9. Is the data 'rich'?	Comments
Poor	Nothing on diversity; very few quotes
10. Is the analysis reliable?	Comments
Not sure	Unclear if multiple coders; not validated with participants
11. Are the findings convincing?	Comments
Convincing	Clearly reported and coherent
12. Are the findings relevant to the aims of the study?	Comments
Partially relevant	Not all objectives listed on p. 258 are reflected in findings
13. Conclusions	Comments
Adequate	Although there are few conclusions
14. How clear and coherent is the reporting of ethics?	Comments
Not reported	
15. How well was the study conducted?	Comments
+	