

**Tackling TB together : a community participatory study of the socio-cultural factors influencing an understanding of TB within the Somali community in Sheffield**

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*Sheffield Hallam University*

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**Kate Gerrish  
Mubarak Ismail  
Andy Naisby**

**2010**



# **Tackling TB together: a community participatory study of the socio-cultural factors influencing an understanding of TB within the Somali community in Sheffield**

Final report of the research to research partners and funders prepared by Kate Gerrish with the assistance of Mubarak Ismail and Andy Naisby.

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We wish to acknowledge and thank the research participants who shared their experiences and personal views with us.

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## Summary

This report presents the main findings from a study which sought to gain insight into the socio-cultural influences on how TB is perceived within the Somali community and how these perspectives affect the prevention, diagnosis and treatment of the disease. The study also gained an understanding of healthcare practitioners' perceptions of TB among the Somali community and their experiences of providing TB services to Somalis.

A community participatory research approach was used which involved Somali community researchers and healthcare practitioners working in partnership with university researchers to design and conduct the research with the support of a community-based project advisory group. Data were collected by means of interviews and focus groups with Somali community leaders, patients suffering from TB, members of the wider Somali community, healthcare practitioners providing TB services and primary care practitioners.

The findings identified a general awareness of TB among the Somali community in terms of the signs and symptoms of pulmonary TB, its treatment and prognosis. There was less understanding of non-pulmonary TB among Somali participants and some healthcare practitioners. Many Somalis lacked detailed understanding of how the disease was spread. Established community beliefs, for example that TB was a hereditary disease, or that it could be acquired by sharing eating utensils proved difficult for healthcare practitioners to challenge.

Somali people spoke of how TB was perceived to be stigmatised within the Somali community. Whereas a person suffering from TB would generally share the diagnosis with their immediate family, concerns remained about the possibility of being ostracised by members of the wider community if knowledge of the disease became more widespread. This carried implications for contact tracing. However, attitudes towards TB were changing. Community leaders emphasised that as people became more knowledgeable about TB then the stigma would diminish but it was acknowledged that deeply held beliefs about the causes and consequences of TB would take some time to change.

A number of barriers that hinder Somali people accessing TB services were identified. Some, like stigma, are embedded in cultural beliefs or are linked to socio-cultural activities such as chewing khat. A lack of trust and confidence in healthcare providers, especially some GPs arose from the protracted time it often took to diagnose TB. Healthcare practitioners lack of understanding of the Somali community and language barriers also hindered the uptake of primary care services.

Several avenues through which culturally appropriate strategies targeted at minimising the spread of the disease, ensuring timely diagnosis and effective management of TB were identified. These are captured in the recommendations arising from the study which identify the need for a more proactive approach to raising awareness of TB within the Somali community and among primary care practitioners. Interpretations of TB are culturally bound and in order for TB services the better to meet the needs of the Somali community there is a need to develop greater awareness among healthcare practitioners of the needs of Somali patients and overcome linguistic barriers through improved access to interpreting services, especially in primary care.

## **Introduction**

This report presents the main findings from a community participatory research study which sought to gain insight into the socio-cultural influences on how TB is perceived within the Somali community and how these perspectives affect the prevention, diagnosis and treatment of the disease. The study also gained an understanding of healthcare practitioners' perceptions of TB among the Somali community and their experiences of providing TB services to Somalis. The impetus arose from a shared concern expressed by healthcare practitioners and Somali community leaders to provide more culturally appropriate services focused on the prevention and management of TB.

The study underlines the need for accessible and appropriate information about TB for the Somali community and offers some insights and strategies to achieve this. It is also recognised that health care provision and the practice of healthcare practitioners need to be responsive to ethnic and cultural diversity.

The findings provide an evidence base to inform public health initiatives targeted towards improved TB control and the development of more culturally appropriate health care in regard to the screening, diagnosis and management of TB within the Somali community.

The report may be of interest to commissioners, policy makers and health care providers involved in the prevention and management of TB, to organisations representing and serving the Somali community as well as members of the Somali community. Although the study was undertaken in the city of Sheffield, the findings and recommendations have implications for policy and practice in other settings in the UK where Somali people reside.

## **Background**

Tuberculosis (TB) is a serious but treatable infectious disease which may affect different parts of the body, but most commonly affects the lungs or lymph nodes. In the UK approximately half of cases involve the lungs. The 'classic' symptoms of TB include a persistent cough, fever often with night sweats, weight loss, and loss of appetite and tiredness. However, the illness can take a very different form, depending on which part of the body is affected, so people might, for example, first complain of back pain (spinal TB), headaches or vision changes (TB of the brain). Non-respiratory TB is more common in children, in immigrants from countries with a high prevalence of TB and in people with impaired immunity (e.g. as a result of HIV infection). Most people are cured by a lengthy course of antibiotics, but sometimes the disease causes permanent damage or even death.

Although all cases of TB are theoretically infectious, for practical purposes TB is spread from person to person almost exclusively by the respiratory route. When a person with active pulmonary TB coughs, he/she produces airborne particles of different sizes which contain the tubercle bacilli. The larger droplets quickly settle onto surfaces where they aggregate with dust and are not involved in respiratory transmission. Smaller respiratory droplets evaporate rapidly to leave tiny infectious units of tuberculosis (droplet nuclei). An individual can become infected as a result of inhaling these droplet nuclei into the lungs. Normal air currents keep the droplet nuclei airborne for long periods and can spread them throughout a room or building. However, ventilation dilutes them and fairly prolonged close contact with an infectious person is generally required for transmission to occur. Transmission is mainly to the people who live in the same household, or have a similar degree of contact as a member of the household. Once a person is infected with TB it does not necessarily progress to TB disease: one of three courses may follow:

- The infection may heal spontaneously
- Active disease may develop over a period of weeks or months
- The infection may be contained and remain dormant (latent) sometimes for many years, but become active in later life.

Globally, a third of the world's population are infected by *Mycobacterium Tuberculosis* and around eight million people develop active TB each year (WHO web site). TB incidence in Britain has increased by 25% over the last 10 years and is still rising (Evans 2001; Health Protection Agency 2005). Most recent figures for the United Kingdom identify that 9,153 cases of tuberculosis were reported in 2009, a rate of 14.9 per 100,000 population. This represents an increase of 5.5% compared with the number of cases reported in 2008 (HPA 2010). Major differences exist geographically with the main burden of the disease concentrated in urban areas, especially in London. There are significant differences between population subgroups, with rates among Black Africans increasing (Rose *et al*, 2001; DH 2004). The majority of cases occur in persons who were born outside the UK (72%), the majority of which were from South Asia (55%) and sub-Saharan Africa (30%), and those aged between 15-44 years (61%) (HPA 2009).

There is a strong relationship between TB and deprivation. The rate of occurrence is nine times higher in the most deprived proportion of the population compared with the least deprived (NWPHO 2006). Factors such as extreme poverty, homelessness and poor housing tenure can limit access to health care and act as important barriers to effective TB control. Subsequent delays in diagnosis can increase transmission of the disease and lead to poor clinical outcomes (HPA 2010). People from minority ethnic communities are more likely to experience socio-economic disadvantage than the white majority population in the UK (HPA 2010) which impacts upon general health and wellbeing and make it more difficult to engage effectively with mainstream health care.

The UK Government identified TB as a priority for infection control with the publication of a national action plan in 2004 (DH 2004). Increasing awareness of TB, encouraging early treatment-seeking and ensuring that healthcare practitioners are able to recognise the disease promptly, are key priorities within the strategy. However, despite the focus on TB control in the past six years since the strategy was published, TB has remained a growing concern which merits further attention.

## **TB in Sheffield**

The rates for TB within Sheffield reflect the national upward trend (Sheffield Public Health Department, 2001, unpublished). In 2009, 78% of TB cases in Sheffield occurred in people whose country of origin was outside the UK (predominantly Somalia and Pakistan) (source HPA) compared to only 44% in 1996. While the Somali community in Sheffield numbers approximately 10,000<sup>1</sup> it accounts for an average of 20 new cases per year, i.e. approximately 20% of all cases. This equates to an incidence approximately 60 times higher than in the white population.

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<sup>1</sup> Accurate statistics regarding the size of the Somali community in Sheffield are not available as Somali refugees once they have become EU citizens relocate from other European countries to the UK to join relatives or other incentives such as the perceived greater religious tolerance in the UK (verbal communication from the Somali Community Development Worker). It is therefore likely that the Somali community in Sheffield is considerably larger than current estimates. Similarly, the incidence of TB may be different from official statistics.

The experience of TB specialist healthcare practitioners in Sheffield, and the reports of local Somali community members, suggests that barriers to effective diagnosis, management and control of TB within the Somali population exist. Socio-cultural factors have been identified in other minorities as important influences on how individuals respond to TB (Long *et al*, 1999; Houston *et al*, 2002). However, there is a dearth of knowledge regarding these factors among Somalis. In Somalia, research has documented the extreme stigma and social isolation associated with TB which acts as a powerful deterrent to sufferers acknowledging their illness (Kwan-Gett 1998).

In the UK, despite free treatment being available, reports from healthcare practitioners suggest that stigma remains a barrier to the detection, treatment and prevention of TB although it is acknowledged that attitudes are changing. The Somali community of Sheffield is, however, diverse and dynamic, and we know little about how understandings of TB are developed and communicated, or the ways in which such stigma is articulated. Furthermore, it seems likely that other factors, many related to social and economic marginalisation, are also important contributors to how Somali people respond to TB. Very high levels of unemployment and economic inactivity, overcrowded housing and intense patterns of social interaction (including khat houses for men) may increase risk of TB in the community (Bhatti *et al*, 1995; Hawker *et al*, 1999; Mangtani *et al*, 1995; Llewellyn *et al*, 2000; Kempainen *et al*, 2001). In addition, language, religious, educational and power differentials mean that the ‘cultural distance’ between patient and healthcare provider is very great for some Somalis, making the likelihood of prompt care-seeking, diagnosis and treatment less likely.

NICE guidelines on the clinical diagnosis and management of TB and measures for its prevention and control (NICE 2006) provide clear guidance to healthcare practitioners on the ‘gold standard’ for the management of TB. The guidelines emphasise the importance of the patient’s relationship with healthcare practitioners and how a patient’s sense of involvement in the treatment process may, in conjunction with information provision, facilitate adherence to treatment.

In recognising that TB is not just a medical disease to be treated with antibiotic therapy but an entity with historical and cultural roots, it is important to develop an understanding of the socio-cultural factors affecting TB prevention, diagnosis and treatment in order to develop more culturally appropriate services (Gibson *et al*, 2002; 2005; Houston *et al*, 2002). This study sought to develop such knowledge in relation to the Somali community.

## **Aims of the study**

The impetus for this research arose from healthcare practitioners working in the field of TB in Sheffield and the research aims reflect their concerns regarding the need to provide more culturally appropriate services to people from the Somali community. Subsequent discussion with Somali community-based organisations and individuals confirmed that the research focus was also a priority issue for a significant proportion of the Somali community in Sheffield and other areas of the UK with a significant Somali population.

The aims of the study were:

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 avenues through which culturally appropriate health promotion initiatives regarding the prevention of TB can reach the Somali community by exploring barriers and

facilitators.

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.

It should be noted that the study focused on active TB and did not explore how latent TB and its treatment was viewed by the Somali community.

## **Methods**

The study adopted a participatory community research approach whereby university-based researchers worked in partnership with Somali community researchers and a healthcare practitioner with the support of a community-based Project Advisory Group to design, conduct and disseminate the research. The research design was based on a successful ethnographic model of research advocated by Professor Nancy Gibson, University of Alberta, which was used to examine socio-cultural factors associated with TB within immigrant communities in Alberta, Canada (Gibson et al 2002; 2005). The principal features of this approach include collaboration, mutual education, and acting on results developed from research questions that are relevant to the community. The knowledge, expertise and resources of the community are key to the success of the research (Macaulay et al 1999). In the current study members of the Somali community participated as co-researchers in order to ensure that the research questions, methods and interpretations placed on the data took account of cultural perspectives and to facilitate the development and implementation of culturally appropriate strategies for disseminating the findings.

The project also sought to build capacity within the Somali community by orientating individuals and key organisations to research methods, providing the community with an experiential base and a network of partners to initiate and carry out future research projects. In addition, the collaborative nature of the research was intended to foster closer working relationships between the Somali community-based organisations and health practitioners to support future initiatives to promote the prevention and effective screening, diagnosis and treatment of TB.

The core research team comprised an academic researcher with a joint university/NHS post in nursing (Professor Kate Gerrish) a Somali research assistant (Mubarak Ismail) and a TB specialist nurse (Andy Naisby) . In addition, four community researchers (three women and one man) were appointed part way through the project to assist with community interviews and interpretations. All Somali researchers were fluent in Somali and English.

The study comprised three stages:

### **Interviews with Somali community leaders**

Individual in-depth interviews were undertaken with a purposive sample of ten community leaders from a broad range of Somali community groups and organisations across Sheffield. Interviews focused on developing an understanding of the Somali community, to include history of migration, family structures, social networks, patterns of communication and information exchange, health beliefs and behaviours and TB related information. The support of community leaders was also sought in accessing the wider Somali community for subsequent stages of the study.

### **Individual interviews with members of the Somali community**

Semi-structured interviews were undertaken with 24 individuals (14 women and 10 men) drawn from the wider Somali community. Interviews were undertaken by Somali community researchers in the

preferred language of the participant. The majority were undertaken in Somali and subsequently translated into English. Participants were recruited through the community researchers' social networks to reflect the diversity within the Somali community in Sheffield, relating to, for example, age, gender, history of migration, generation, socio-economic background. The interviews sought to gain an understanding of health, perceptions of TB and related health seeking behaviours and explore wider socio-economic factors that impinge upon the opportunities and barriers for health promotion among the Somali community. Participants were given a choice regarding the gender of the person interviewing them.

### **Focus group discussions with members of the Somali community**

Separate focus group discussions were undertaken with four groups of men and four groups of women. A total of 28 men and 28 women participated in the focus groups. Focus groups varied in size from four to nine participants. Vignettes that provided a scenario relating to TB within the Somali community were used to prompt discussion relating to community norms, values and socio-cultural constructions relating to health/ill-health in general and TB in particular, together with the wider socio-economic factors that impinge upon the opportunities and barriers for health promotion and access to health care among the Somali community. The vignettes were developed from data collected earlier in the study. Focus groups were facilitated by researchers of the same gender as the participants. The discussions took place in Somali and the recordings were subsequently translated into English.

### **Individual interviews with Somali people with personal experience of TB**

Individual interviews were undertaken with a purposive sample of 14 persons (9 men and 5 women) with personal experience of TB. The sample included patients who were receiving treatment for TB and ex-patients who had completed treatment. Interviews sought to capture the experiences of TB patients, including the strategies adopted to 'manage' their condition, the roles of others including family, friends and healthcare practitioners, and factors that facilitate or hinder treatment and contact tracing. Participants were given choice regarding the professional background and the gender of the person interviewing them. Some participants chose to be interviewed by the TB specialist nurse accompanied by an interpreter with whom they were familiar, whereas other participants were interviewed by other members of the core research team. Interviews were undertaken in the preferred language of the participant.

### **Individual interviews with healthcare practitioners**

Individual semi-structured interviews were undertaken with a purposive sample of 18 healthcare practitioners who had experience of caring for Somali patients with TB. The sample included 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. The interviews explored participants' experiences of caring for Somali TB patients, their perceptions of how TB is viewed within the Somali community, their understanding of socio-cultural factors that might influence TB within the Somali community and ideas for how TB services might be developed to become more culturally sensitive.

### **Data analysis**

Focus groups and individual interviews were tape recorded with the participants' permission and subsequently transcribed. Interviews/focus groups conducted in Somali were translated into English

during transcription. Data analysis drew upon the principles of the ‘framework’ approach to qualitative analysis outlined by Ritchie and Spencer (1994). This involves the five stages of a) familiarisation with the data, b) identifying a thematic framework for coding data from the data collection tools and initial scrutiny of the transcripts/field-notes, c) coding individual transcripts by applying the thematic framework, d) organising the coded data into major themes, e) mapping the relationships between different themes by interpreting the data set as a whole.

In presenting the findings the close networks within the Somali community have been taken into consideration. In order to minimise the risk of individuals being identified participants are generally referred to as gender neutral, i.e. the plural ‘they/their’ has been used instead of ‘his/her’. In qualitative research the verbal accounts that participants provide are very powerful in portraying depth of experience and feeling. However, we were mindful that if we provided detailed quotes from Somali participants relating to their personal experiences it may be possible for others within the community to recognise them. In order to preserve the anonymity of Somali research participants it is with some regret that we have felt it necessary to summarise many of the issues they raised rather than illustrate them with detailed quotes. Where we have felt it possible to ensure anonymity of individuals we have quoted directly from the transcripts.

### **Ethical considerations**

Ethical approval was obtained from the Sheffield Research Ethics Committee and research governance approval obtained from Sheffield PCT and Sheffield Teaching Hospitals NHS Foundation Trust. The research design respected and responded to the multiple sensitivities surrounding the study. From the outset, the research team were aware that Somali research participants may have particular concerns regarding the confidentiality of data collected and their anonymity as research participants. It was recognised that the social stigma associated with TB and its treatment could lead to participants being stigmatised by taking part in the study. We were also mindful that some potential participants could feel threatened when approached to take part in the study because of a fear of institutional interrogation and legal repercussions.

Every effort was made during the recruitment phase of the study to explain to potential participants the ethical standards to which the research team would adhere and how the confidentiality of information shared and the anonymity of participants would be ensured. On the advice of the Somali community leaders, no personal biographical information, other than gender, was collected from research participants in order to maintain their anonymity as far as possible.

We were also mindful that interview questions on health experiences associated with TB may cause participants emotional distress and that community researchers may find the interview stressful if they shared similar experiences to the research participants. Ensuring that these issues were addressed appropriately was an important part of the training provided to community researchers and opportunities for debriefing were provided following interviews.

## **Findings**

### **An overview of the Somali community**

The study was undertaken in Sheffield, a city with one of the largest and longest established Somali populations in England. There exist few reliable statistics for the number of Somalis living in the UK as a whole or Sheffield in particular. This is partly because the national census combines many African identities under the general category ‘Black African’. It also asks for people’s country of

birth, but in publishing the results combines many smaller categories into a single category South and Eastern Africa. Additionally, because Somalis have a long history of migration to the UK there are many British born Somalis who are not included in these figures. Recent estimates indicate approximately 10,000 Somali people live in the city (Sheffield City Council 2006). The Somali population resides primarily in six neighbourhoods in Sheffield (Broomhall, Burngreave, Darnell, Firth Park, Netherthorpe, Sharrow) which are areas with high economic deprivation.

The population comprises people with varied histories of migration and includes early economic migrants from the 1930s, refugees from the civil war in the 1990s, recent migrants from Somalia through family reunions and European Somalis who have migrated mainly from the Netherlands and Scandinavia. Interestingly, some participants attributed the migration of Somalis from other European countries to the UK to the fact that British people were perceived to be more tolerant of ethnic diversity. As community leaders pointed out, the Somali community is not static. Whereas the number of asylum seekers has fallen recently, a significant number of Somali people have migrated from other European countries, and others have left Sheffield to join family who reside elsewhere in the UK or Europe, or to return to Somalia. Therefore, there is a degree of fluidity within the Somali population of Sheffield.

Although there are a growing number of older Somali people, (early economic migrants or recently arrived older migrants who have joined their families) the population is by and large fairly young. Most Somali people live together as part of a family unit and there are a notable number of single parent families where the husband is absent. This may be because the husband is no longer alive, is working elsewhere, or because of separation or divorce. Extended family networks are in evidence across the city. Many Somali individuals living in Sheffield are related, often distantly, to other Somali's living in the city and this provides a strong sense of 'community'. Somalia is a Muslim country and most Somalis living in Sheffield actively practice their faith. The teachings of the Koran influence all aspects of Somali life, including responses to health and ill-health. Illness is attributed to the will of Allah but the individual is responsible for how they manage their illness. Traditional remedies for treating illnesses were used by many participants, for example black seed, camel's milk and camel's butter were considered to have healing properties for a number of diseases and well as more general positive effects on health.

The community has well established social networks with members coming together for social events such as weddings and funerals. Men and women tend to socialise separately. The women generally socialise through their family and child care responsibilities whereas men often congregate at specific locations across the city such as coffee houses or to chew 'khat'<sup>2</sup>. Whereas khat is legal in the UK, community leaders and several of the women interviewed expressed concern about the detrimental health, social and economic consequences of heavy reliance on khat by some Somalis.

Many Somali people who have migrated to Sheffield are from professional and business backgrounds. However, it has often proved difficult, if not impossible, for them to gain equivalent employment in the UK. This is due primarily to their qualifications not being recognised and the difficulty of securing a suitable post in a competitive market place. Although a number of men and women within the community are economically active, others aspire to paid work but have found it hard to secure suitable long-term employment. Many Somali families are therefore reliant on state benefits.

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<sup>2</sup> The use of khat has a long-standing history among some Somalis as well as other refugee communities. Before the civil war in Somalia, khat chewing was a traditional social activity and would bring people together for relaxation and to stimulate conversation. Khat houses or 'Marfesh' are located in UK towns where Somalis reside, including Sheffield



Community leaders identified that although individuals may be keen to secure employment, the salaries paid are often lower than the state benefits they receive so they would be financially disadvantaged if they took up employment. Moreover, the sluggish response of the social security system to adjust benefits in response to short-term employment meant that many Somali's felt unable to take up short-term job opportunities for fear of losing their benefits income on which they were reliant. Consequently, many Somali people live in deprived areas of the city and find themselves in experiencing socio economic hardship. Despite experiencing these difficulties, the Somali people we interviewed shared considerable pride in their community, and through their social networks shared a collective ownership for assisting other Somalis who were in need.

As a community, Somalis are characteristically resolute and determined to help themselves. A number of community organisations across the city, often staffed by volunteers, provide a range of support to community members, including homework clubs, language classes, luncheon clubs, citizen's advice, and traditional Somali dance classes. However, much of this work is based on short term funding, and is not sustainable. In contrast to South Asian communities in Sheffield, the Somali community currently lack strategic support from local statutory agencies, although Sheffield City Council is now beginning to address the socio-economic hardships affecting the community through developing specific action plans targeted at the Somali community.

Community leaders voiced some concern regarding younger Somali people. It was reported that although a number of young Somalis progress through school to university, others become disenfranchised from main stream education. Concern about inter-generation tensions and rising crime among some younger Somalis was highlighted by several people interviewed. Community leaders were working closely with Sheffield City Council, with education services and with the police to address these issues and although some progress had been made, there was still much to do.

Whereas a number of Somalis, especially those educated in England, are fluent in English, a substantial proportion of the community, most notably women, do not speak English. Many Somali people are not literate in either English or Somali. In part this reflects the oral tradition of the community. Communicating by word of mouth through stories, poetry and song as well as social conversation is deeply embedded culturally. Verbal networks of communication are fundamental and appear to work very effectively across the community. However, concern was often expressed about the possibility of confidentiality being breached when personal information is shared in professional encounters where interpreters are used. There was a strong sense in which an interpreter needed to be known to and deemed trustworthy by the individual, before they would agree to them acting as an interpreter. The fear that an interpreter might engage in 'gossip' and disclose personal information to others in the community was very real. Community leaders stressed how the linguistic and cultural barriers that many Somalis experience create significant obstacles to accessing and using a range of services effectively, including health care provision.

### **An overview of TB services in Sheffield**

TB services in Sheffield are provided jointly through Sheffield Teaching Hospitals NHS Foundation Trust, NHS Sheffield (formerly Sheffield PCT) and Sheffield Children's Hospital. Consultant-led adult inpatient TB services and outpatient clinics are provided at both the Royal Hallamshire Hospital (RHH) and Northern General Hospital (NGH) sites. The majority of patients are referred to the RHH for diagnosis and treatment, although a recent expansion of the service at the NGH has led to a shift towards more patients being seen at this site. Separate inpatient and outpatient services for children are provided at the Sheffield Children's Hospital. A TB specialist nursing service is based within the PCT, however the nursing team work across both primary and secondary care. Consultant medical

teams in different hospitals communicate with each other, particularly in the case of adults and children within the same family suffering from TB. The TB nursing service also provides an important link between adult and children's services across the city.

Diagnosis and treatment of TB is under the jurisdiction of consultant medical staff based within the hospital. Individuals suspected of suffering from TB may be referred from general practice or from other medical teams. Once a diagnosis has been made patients are often admitted as an inpatient for a short period to commence therapy. Longer term oversight of treatment is managed through outpatient clinic and the TB specialist nursing service. Each patient is followed up by a specialist nurse, with more focused intervention in situations where patients may be experiencing difficulty in completing their course of medication. The patient's GP is kept informed of the treatment regime but is not involved directly, although they may see the patient for other health problems during this time.

A number of TB patients experience social and economic hardships which compound their situation. There is no dedicated social work support, and although referrals can and indeed are made to the generic social work team, often it is the TB nurses who provide holistic health and social support to patients, for example advising on appropriate referrals for re-housing. The TB nursing service is also responsible for contact tracing and acts as an information resource for GPs by providing advice and support to GPs about individual patients who may have contracted TB as well as acting as a more general resource to GPs on matters relating to TB.

### **TB within the Somali community**

Although TB in the Somali community was identified as a research topic by both Somali community leaders and healthcare practitioners, it was acknowledged that the prevalence of TB was not unduly high in this community in comparison to other African communities with similar patterns of migration. Participants were anxious that the research did not lead to TB being labelled inappropriately as a Somali 'problem' as it is a disease affecting all ethnic groups in Sheffield. The findings of the report need to be read with this in mind.

The number of Somali people diagnosed with TB has remained fairly steady in recent years despite a perceived growth in the population. In 2007 there were 24 TB notifications of Somali origin and in 2008, the year of the study, there were 21 Somali people treated for TB. It is widely believed that the Somali community is growing so this would suggest a falling incidence of TB within this community. The swiftest growth in TB has been amongst people of African origin generally, who in 2008 made up 43% of all Sheffield TB notifications. The rate of TB is higher in asylum seekers than the established community or migrants from other European countries. Improved TB control in Somalia together with recent trends in migration with fewer Somalis seeking asylum suggest that the rate of TB may fall. Table 1 provides a breakdown of the number of new TB cases of Somali origin for the past five years for which data are available.

**Table 1: Number of new cases of TB among the Somali population as a percentage of the total number of TB cases in Sheffield**

Year	Total notifications	Number of new cases	
		number	Somali % total notifications
2004	107	25	23.4
2005	111	28	25.2
2006	115	21	18.3
2007	123	25	20.3
2008	111	21	18.9

Ten years ago the community was concentrated largely within a few localities. These areas remain popular but the community has also become more dispersed across the city. Some of the more established areas of Somali settlement which experienced high numbers of TB cases in the years immediately following the civil war diaspora, now have a lower prevalence of TB as the community becomes more settled. This is in line with national prevalence patterns which see higher TB rates in the early years following immigration. The peak age for TB within this predominantly young population is 16 to 30 years old, with greater numbers of males being affected than females.

Some GP practices in Sheffield had developed considerable expertise in meeting the needs of the Somali community and a high awareness of TB. One practice recorded 23 cases of TB in their Somali patients in 2001. Two practices employed Somali reception staff which was favourably commented on by a number of research participants. However, it was recognised that because the Somali population is now more dispersed across the city, awareness of the community and its health needs by primary care practitioners may be lower in areas where the community is small.

### **TB in Somalia**

During the course of the study, it became clear that the views on TB held by Somalis living in Sheffield were influenced by their understanding of how TB had been managed in Somalia. This influenced their views on the treatment and prognosis of the disease and the social consequences for someone who contracted TB. It is appropriate therefore, to provide a brief summary TB in Somalia from information gleaned from the World Health Organisation.

Somalia is amongst the high TB incidence countries of the world with an estimated incidence of 324 cases per 100,000 of the population. This has been exacerbated enormously by the long running civil war with its attendant displacement, loss of life and destruction of infrastructure. Despite high levels of malnutrition and illiteracy, large numbers of internal refugees, and a strong traditional nomadic culture, there is a lot to celebrate in terms of TB control. In recent years the internationally unrecognised territory of Somaliland has enjoyed relative stability and with support from NGOs and the WHO has been very successfully expanding TB treatment centres. Their goal is to achieve the WHO target of 85% treatment success by the end of the 5 year program. Some centres are reporting treatment success outcomes broadly similar to those reported in the UK through the enhanced surveillance system. This might be expected to have a positive impact on TB rates in the Somali communities in the diaspora including our local area of Sheffield. The TB treatment centres give treatment as daily directly observed therapy (DOT) as a first option where this is possible in line with WHO recommendations. Many of treatment centres seek community involvement to support the

patient with friends or family members co-opted to support therapy and report problems. In some models, the patient has to find two guarantors (Dagreed) who are asked to stand surety for treatment adherence and completion. Treating the patient as part of the community is seen as an essential component of success.

Somali health workers whom we interviewed confirmed that they had encountered this approach to managing TB when they had visited Somalia. They reported favorably on the success of the community approach whereby family and friends shared responsibility for supporting the patient to complete the course of treatment.

*In Somalia they give the message that they can cure the whole community if they have the facilities, you see they do not give the patient the medication to take home, what they do, they make appointment so everyone has to come in each morning to take the medication. People do this. Everyone they have to take two people, well known from the community, and the tribe they come from because if the patient runs off they will fine them. They will ask the patient which tribe they are from and ask them to identify someone who will vouch for them and that person signs a form to say that they will follow the treatment and the health workers say that if we lose the patient we will come to you.*

## **Understandings of TB among Somalis**

### ***Knowledge***

Knowledge about TB varied among Somali community members. Several community leaders had a good understanding of TB in terms of its cause, how it was transmitted, the signs and symptoms, treatment and prognosis. Indeed, some community leaders provided accounts of how they had urged individuals who they felt showed possible symptoms of TB to consult with their GP and on occasions had accompanied the individual if they did not speak English. However, community leaders felt that TB was less well understood within the wider community and this was borne out by the interviews and focus group discussions with Somali men and women. Many Somalis were aware that TB was a disease that could be treated and that patients could make a good recovery but they lacked a more detailed understanding. There was a prevalent belief that TB could not be cured completely and that the disease could reoccur at any time. Some people based their understanding of TB on how the disease had been viewed in the past in Somalia before treatment was available. In Somalia, TB had been seen as a very serious disease which could lead to death and because of the fear of cross infection people suffering from TB were kept in quarantine for long periods. Although treatment for TB was now available in Somalia, there was a perception that not everyone was able to access this, or complete the course of medication successfully. As a result, TB remained a serious disease with significant social consequences for the individual and their family. The debilitating nature of the illness together with the fear of social isolation meant that TB was a cause of great anxiety to many of the Somali people interviewed.

Somali people generally had limited understanding about how TB infection spread. Some people identified it as an airborne disease and that people became infected by 'breathing in the germ' and once infected, they could pass it on to family members. Enclosed spaces, such as khat houses where men spent a lot of time in close proximity socialising together were identified by both community members and healthcare practitioners as places where people might be at greater risk. However, other views about how TB spread were prevalent. For example, many people thought that it was an inherited disease that could affect several generations in succession and although treatable could not

be eradicated completely, as one focus group participant explained.

*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.*

Alternatively some Somali participants identified a causal link between TB and other diseases, seeing it as a complication that might arise from illnesses such as asthma or influenza.

*It (TB) starts with flu and then gets worse and becomes a chest infection and if the infection is not treated and medication taken and then it will change to TB.*

Many Somali interviewees held the view that it could be spread through using the same eating utensils as someone with TB and several participants indicated that they would not wish to drink out of the same cup as someone who had TB even when it had been washed thoroughly.

Others recognised a link between poor socio-economic circumstances and the disease, in particular living rough due to homelessness, or they believed that it was attributable to lifestyle - lack of sleep, poor nutrition, combined with smoking and chewing khat were seen collectively to predispose to TB.

*People who chew khat lose appetite and don't eat anything at all. When you are eating well then your body defence against disease is very strong but someone who is at the Marfesh<sup>3</sup> doesn't eat, they are malnourished and weak, lack of sleep and smoking. These all contribute to getting TB, and when Somalis are talking to each then the air will be shared so they can infect each other.*

*People get TB because of hunger, living rough, not being healthy, from the environment. The Somali men even if they are hungry, they don't eat food, they will chew khat, smoke and they don't sleep for two to three days and all that combined together causes TB - this is how people get it.*

Several people felt that someone who developed the disease in the UK had contracted it in Somalia rather than becoming infected in the UK. Additionally, some participants expressed the view that people could contract TB as a result of having done 'something very bad in the past' and it was a punishment from Allah.

Interestingly, several patients and ex-patients did not have a good understanding of how they had contracted the illness even though healthcare practitioners confirmed that they had discussed the aetiology of the disease when the patient was first diagnosed with TB. Like members of the wider Somali community, patients often attributed it to 'eating and drinking with someone who has TB' 'inheriting it from someone in the family' 'the result of an untreated chest infection' 'shaking hands with someone with TB' 'poverty, hunger, and lack of sleep'. The following quotes capture some of the patients' perspectives on why they thought they had developed TB.

*I was a business lady, buying and selling in a small village (in Somaliland) before the civil war, but when the war started we lost everything and our money was taken. All our wealth and assets had been looted and I think that maybe the worry and the stress has caused me this disease.*

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<sup>3</sup> A Marfesh is a cafe or house where men congregate to chew khat

*You can get TB from touching, drinking from the same cup or eating from the same plate, or smoking shisha<sup>4</sup> pipe ... I don't know how I got TB.*

*I think I inherited it from them (grandparents who had TB) because Somali people always say you had TB because it was in your family.*

Many community members were aware of the most common signs and symptoms of pulmonary TB, i.e. persistent cough, sputum, loss of appetite, weight loss, fever and night sweats. Others referred to a more general malaise and tiredness. However, some patients also highlighted more diffuse symptoms that they had experienced and attributed these to the early signs of the disease; this included hair loss, pain in the legs, difficulty walking and headaches. Community participants generally understood that TB was a disease which most commonly affected the lungs and a few were also aware that it could affect other organs such as the brain, intestines and spine. However, there were a number of participants who had no understanding of how TB could present.

Many Somali participants appreciated that TB could be treated successfully by taking medication. There was less understanding among community members of the importance of completing a lengthy course of treatment and a view that people may not complete treatment either because they do not understand the importance or because they start to feel better and no longer consider it necessary. Concordance with treatment was also seen to be influenced by how patients perceived others in the community would view them, as one Somali participant explained.

*They (TB patients) will feel better after few tablets and they will say 'I haven't got it any more, I am better' and they will stop taking their medicine. They will stop medicine so that other people believe they are better.*

There was a general lack of understanding about the length of time a person diagnosed with TB remained infectious. Several community members considered that a patient was infectious until they had completed the full six month treatment regime and thought that the patient should be kept in hospital during this time, or live in relative isolation at home. Patients and ex-patients generally had a much better understanding of the above issues. Whereas most believed that they had been cured or would be cured once treatment was completed, some felt that because they had been diagnosed late, the disease had left permanent damage and that they would never be healthy again.

### ***Attitudes***

The initial impetus for undertaking the study had arisen from concerns expressed by healthcare practitioners that TB was strongly associated with stigma in the Somali community and this had an impact on how people responded to a diagnosis of TB as well as the treatment regime. Interviews with Somali participants indicated that the stigma appeared to have its origins in how TB was viewed in Somalia before treatment was available. It was a disease that was associated with poverty and brought shame on a family. People reported that in Somalia, TB patients had in the past been isolated by their family, often being forced to live apart, as the following quotes from Somali participants illustrate:

*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 with and even keep away from his breath, basically everything. People even used to say 'that person has TB so nobody talk to him'*

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<sup>4</sup> A tobacco pipe with a long flexible tube connected to a container where the smoke is cooled by passing through water. A shisha pipe is shared between people at social gatherings.

*In Somalia when people are walking near the TB clinic they used to cover their mouth and nose with their clothes or hats, there was no one entering the hospital, even people who had family members in the hospital wouldn't go. Anyone who has TB will be (socially) isolated not only him, but his family will be stigmatised and that's why they don't tell anyone because they don't want to be isolated.*

Perceptions of the social stigma associated with the disease in Somalia still influenced peoples' attitudes in the current study. Some described TB as a 'very bad and dangerous' disease and as a result felt that people with TB should keep the disease secret and not tell anyone, including their family and close friends, for fear that they would become socially isolated. People who felt that TB was a sign of poverty were afraid of losing their standing in the community if they were diagnosed with the disease. The perceived shame associated with the disease led to fear of others within the community finding out that they had TB and sharing this information more widely. The following quotes from the focus group discussions highlight the stigma with which the disease was viewed:

*Somalis are not ashamed of illnesses like diabetes and blood pressure, but anyone who has TB, as soon he tells someone that person will keep distance because they think they will get it from him and people will start saying 'he has TB stay away from him' and then kids will start to follow him and calling him names. Even mothers and old woman will tell their kids 'he has TB so stay away from him and don't sit next to him'. People are only human and when they feel people are going to treat them like this, they will hide it and then they will develop stigma and it might also affect them mentally, they become depressed.*

*People don't tell anyone that they have TB. He thinks people will call him names and verbally abuse him, so everybody will treat him bad, even his best friends that he loves most will cut him off and stop seeing him. That's why people are scared to tell anybody.*

*When they get ill with TB they don't tell anybody because they're afraid of being insulted by others. People would talk about their TB, but they are scared of how other people will treat them and the insults they will get. You know when we see someone with TB how we react, we say 'he has TB so let's keep away from him', we don't want him near us.*

Interestingly, strongly negative attitudes towards TB were more often expressed in group discussions than during individual interviews: it appeared that personal knowledge and opinions of TB are ahead of community norms. A Somali health worker also observed that attitudes and behaviour towards people with TB had changed in Somalia in recent times and contrasted sharply with many of the participants descriptions of how TB is perceived in Somalia.

*I went to Somalia a while ago and I went to a TB hospital. And I will be honest with you; the people in Somalia are more open about TB. We went to the hospitals and the two nurses with me, they explain that this man has TB and he used to be a teacher and this woman had TB and she used to have a shop. Nobody bother about it, there was a whole clan of people and no one felt uncomfortable, everyone was relaxed about it, it was much better than here in the UK. ... During the civil war, everyone had TB, if you are poor or if you have a good life, everyone had TB, so people don't think of it as a disease that the poor get. So things have improved, but here, people have carried on with the old views.*

Several participants mentioned that members of the community were prone to jump to conclusions if they spotted one of the TB specialist nurses visiting a home or if they heard that someone had been admitted to the particular hospital ward where TB patients were normally treated. Some young people indicated that they would be reluctant to disclose if they had TB in case it affected their future

prospects of getting married or their friendships. A minority of participants thought that even after completing treatment a patient might not be fully accepted by other members of the Somali community. Community leaders endorsed that these views were prevalent within the Somali community but felt that attitudes were starting to change and Somalis were becoming more open in talking about TB.

*People's attitudes are starting to change. TB is no longer seen with the same stigma. As people become more educated about TB, they are not so afraid of it. People will talk more about it. But it takes a long time to change. .. We are moving in the right direction, but it is a slow process.*

Moreover, several community leaders suggested that people who had suffered from TB might be more open to sharing the fact. This view was also endorsed by some community members who spoke of friends who had experienced TB and shared this with them.

*People's attitude has changed a lot and people think that TB is easy to treat, and don't cause death if treated. There are other diseases that are more dangerous than TB around the world which people don't talk about. But now when people talk about health they might say I had TB and was treated. So it is not such a big issue now, and I do see some young people who talk about it openly.*

A Somali health worker reflected in the changes she had observed over a relatively short period of time whereby patients were becoming more open about TB.

*Attitudes are changing. People are beginning to change, if your friend has TB and she tells you, and another one has TB and she tells you, you think yes, why should I be suspicious about it. So I think we had a good couple of patients who are not bothered about it and they tell other people. When I started everyone was suspicious, but the last couple of years, maybe people understand it more and are less afraid.*

Interviews with healthcare practitioners also indicated that during the two years since the study was first conceived and the interviews undertaken, attitudes did appear to be changing among Somalis diagnosed with TB. Patients appeared more accepting of the diagnoses and prepared to complete treatment, although there were exceptions. GPs reported that they were encountering more patients who queried whether TB might be the cause of the symptoms they were experiencing. Interviewees attributed this shift in attitude to a greater awareness of the disease amongst the community, and in particular an understanding that the majority of patients made a good recovery. However, although attitudes did appear to be changing, the stigma associated with the disease, and in particular the reluctance for some newly diagnosed patients to identify people with whom they socialised regularly, meant that contact tracing was sometimes difficult.

### **Experiences of TB – the patient's journey**

This section focuses on patients' experiences of living with TB. The accounts come primarily from patients who were interviewed but also include observations from the wider Somali community and healthcare practitioners regarding other Somali people they knew who were suffering from TB, but were not interviewed as part of the study. It cannot be assumed that the patients who were interviewed are representative of Somali TB patients in Sheffield. Patients were recruited by the TB specialist nurse and the sample may well reflect patients who led relatively stable lives, and were therefore easier to access and recruit than patients whose way of life was less predictable, for example those who were homeless.



The patients who were interviewed were at different stages of their journey of experiencing TB. Some patients were newly diagnosed, others were receiving treatment and a number had completed treatment and been discharged from the TB service. Patients provided varied accounts of their experiences of living with TB. One patient, in particular, was very positive despite experiencing a debilitating illness that required readmission to hospital on several occasions. This patient was very open about the illness and sought to change people's attitudes by talking about TB with family and friends. Other patients, although appearing resolute about their diagnosis were more circumspect about its affect on their lives and a small number had found much of the experience both physically and psychologically distressing.

### ***Experiences leading up to a diagnosis of TB***

All patients found the time leading up to a confirmed diagnosis distressing. Patients were concerned about the symptoms they were experiencing and uncertainty about the diagnosis caused considerable anxiety. Fear of cancer was especially prevalent. Whereas some patients experienced the classic symptoms associated with pulmonary TB, others had presented with more diffuse symptoms which were not so readily attributable to TB. Most patients reported that they felt very tired, lacked energy and had increasing difficulty maintaining their normal activities of living.

*I was very tired, not mentally, but physically - for the first time I was resting a lot, I was losing energy, I could not understand it because I was very active, I used to walk a lot. I could not understand what is happening. Day after day I was feeling weaker and weaker.*

The psychological impact of the illness prior to diagnosis was felt keenly by a number of patients. They reported feeling anxious, stressed and powerless and this was intensified the longer it took to obtain a diagnosis. The social impact of their illness over a prolonged period of time was also notable. Patients found it hard to maintain normal social networks with friends and family as they felt too tired and unwell. One patient had dropped out of college as they were no longer well enough to attend and three patients had been unable to continue working.

All patients had visited their GP shortly after they began to feel unwell. Some patients with classical symptoms of TB were diagnosed relatively soon after initially approaching their GP.

*In two months I see myself losing weight and temperature going up, not sleeping well, coughing, coughing. I went to the GP and couldn't understand what was up and they send me to have chest x-ray and then they find out I had TB.*

However, many patients voiced concern about the length of time it took from first visiting their GP to a diagnosis of TB being confirmed. Indeed, for several patients the delays in the diagnostic stage was the cause of considerable frustration and anger. Patients reported that they had visited their GP repeatedly, in some cases for well over a year before they knew what was wrong. In the interim they had been prescribed antibiotics and pain killers which had not alleviated their symptoms.

*For two years I had problems, I went to the GP. I was a very worried man. Every time I went they used to tell me that I was stressed and your muscles are tired. I had pain in my upper chest, they prescribed me something for the muscles ...but it did no good.*

Several patients felt that their concerns had not been treated seriously by their GP during this time, and they felt neglected and let down by the system. There was a perception that some GPs had been slow in referring patients to hospital when their symptoms persisted and the patient had requested a referral. By way of example, one patient outlined the distressing, convoluted process of obtaining a diagnosis.

*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. But the tablets did not help. I went back to the GP and asked if they can investigate and take some blood and urine samples. They took blood samples and told me to come back in seven days. They said nothing is wrong with your results so keep taking the pain killers, which I did. The situation continued like that and I was keeping going back to the GP, and every time I get different tablets. I ask them to refer me to hospital but they refuse ..... Several months later they check me and see that I had a high temperature and told me that my blood result shows that there is an infection but they don't know what is the infection.*

The patient's illness continued for several months longer before they were finally referred to the infectious diseases department and a diagnosis of TB made. During this period, the patient became more anxious in the light of the failure to confirm a diagnosis.

*The GP said we don't know what is wrong with you. This made me very suspicious and sometimes I thought I might have a serious illness and they don't want to tell me, because it is also difficult to believe that with all these tests done and doctors around nobody knows anything about my illness. Every time they take an X-ray but it comes out nothing, they take it again and it's nothing so at last the GP decided to refer me to the specialist. .... All that time I was suffering and nobody could do anything about my problem.*

Some patients who felt that their concerns were not being addressed appropriately by their GP took alternative measures – for example one patient who had been experiencing considerable pain attended A&E on a number of occasions only to be referred back to their GP, and another sought a second opinion from a private doctor in Germany in order to obtain a diagnosis. The time it took to reach a diagnosis led to a number of patients expressing a lack of confidence in their GP and this is elaborated on further in a later section of the report.

### **Response to diagnosis**

Patients responded to the confirmation of their diagnosis in different ways. Many patients were relieved that after being unwell for some time, they finally knew what was wrong and that the illness could be treated.

*I was very happy because I have been feeling ill for a long time and every time they took some blood samples and X-rays and then tell me 'we don't know what is your illness'. When the woman doctor told me what was my illness (TB) I was relieved and happy to know because whether you die or live, only known illnesses have a chance to be treated.*

However, a few patients felt shocked by the diagnosis and found it hard to accept that they had TB – for them it was an illness that caused considerable on-going anxiety.

*I was shocked, very shocked. People are scared of TB because they think they will die, and they can pass it to their families and their children. .... I was very upset because Somali people think TB is very bad and anyone who hides will suffer a lot and if you tell them about it they will stay away.*

All the patients interviewed had felt comfortable with sharing their diagnosis with immediate family members and had been well supported by them. However, some patients had not wanted their wider family and friends to know that they had TB because of the perceived stigma associated with the disease and the fear that they may become isolated if people were no longer willing to socialise with them.

*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.*

There was also concern that even after a patient's treatment had been completed, their friends would still shy away from them because of fear that TB could not be cured and that they continued to be at risk of spreading the disease. However, these fears were not necessarily well founded as some community members who had become aware of people with TB confirmed that they did not ostracise friends who contracted TB.

*When I heard that my neighbour had TB I felt I was powerless to help and there nothing that I can do. God decides who gets ill so there was nothing I can do. My relationship with him didn't change. I used to help him and the family by looking after their children when they go to the hospital. I was not scared, if you believe in God then you would not be harmed in anyway ... there is no problem in visiting and seeing them.*

As the above quote illustrates, Islam played an important part in how participants responded to TB, either as a patient, or someone in close contact with a person suffering from TB.

In situations where the patient's wider social network of family and friends became aware of the diagnosis, their responses varied. Some patients were surprised to find that some friends disclosed to them that they or a close relative had also suffered from TB and this shared knowledge strengthened their friendship. Others felt that their friends began to keep a distance, did not visit so often, and when they did visit would not share food with them. Such responses were a cause of considerable distress to patients.

Healthcare practitioners involved in the care of TB patients also shared similar views. There was a general view that the stigma associated with TB was less evident among Somalis than it had been four to five years ago. In their experience, most patients were accepting of the diagnosis and willing to disclose information to enable contact tracing to be undertaken and to adhere to the treatment regime. However, they did still experience the occasional patient who was reluctant to accept the diagnosis and this presented challenges in terms of contact tracing and concordance with the medication plan.

Many of the Somali community participants held more negative views about how the diagnosis of TB would be received by the patient and by their social networks. There was a general view that patients would keep their diagnosis 'secret' and would not even tell immediate family members because of fear about how people might react. In particular, TB sufferers might lose their good standing in the community and people would not want to socialise with them. There was also concern expressed that people might experience verbal abuse from others in the community. As a number of people held the view that TB could not be cured, someone with TB could suffer prolonged social isolation if their diagnosis became widely known.

### ***Experiences of treatment***

The majority of patients were very satisfied with the standard of care they had received from the TB services in both hospital and primary care settings. They felt that once they had been referred to the TB clinic, or in a few cases had been admitted directly as an inpatient, investigations had led relatively quickly to a diagnosis being confirmed and treatment commenced. For a few patients with atypical symptoms diagnosis had taken longer and they expressed some frustration. They complained about 'not understanding what was going on' and 'being kept in the dark'. This was often compounded because of poor communication between the patient and healthcare practitioners due to language barriers.

Patients generally felt confident about the treatment they were receiving and that it would lead to recovery. Most patients had been admitted to hospital for a short period to commence treatment and a few had required readmission because of complications associated with their condition. After discharge, patients were followed up in the community by the TB specialist nursing service who liaised with them regarding treatment and contact tracing. Patients expressed trust and confidence in the nursing service and indicated that they valued the support provided by the nurses and the Somali health worker who accompanied the nurses when they visited patients who did not speak English. The nurses were the first port of call for patients during their period of treatment. Patients were reassured that they had ready access to the nurses if they had any concerns and that they received practical assistance to help resolve both health and wider social problems which were impacting on their illness. The Somali health worker based with the TB nursing team was also highly regarded; she was seen as someone of standing within the community and a person who could be trusted. Healthcare practitioners also valued her contribution. They considered that she had developed a very good understanding of TB and its treatment, and was therefore well placed not only to translate, but also to check patients' understanding their illness and actively promote adherence to medication. The Somali health worker also acted as a conduit between patients who could not speak English and healthcare practitioners. She was proactive in initiating contact with patients to check on their progress as well as being an initial point of contact for patients who had concerns.

Patients were generally of the opinion that they received appropriate information about their illness and the treatment regime from medical consultants and specialist nurses. Most patients were aware of the importance of completing the full course of medication, however as indicated above, not all patients had a good understanding of how TB was spread. Moreover, language barriers meant that some patients did not fully understand why they had to take medication for so long.

### ***Living with TB***

After an initial period of treatment, most patients began to feel better and to gradually resume their normal life. Many patients were well supported by family and friends during the time that they were receiving treatment. However, there were some patients who felt that people around them had become cautious about socialising with them. They experienced loneliness because friends stopped visiting. Those who had given up work or college due to their illness lacked confidence to look for other employment because of how the disease might be viewed by employers and colleagues. This led to patients experiencing varying degrees of social isolation during the course of their illness which caused them distress.

Although patients believed that TB could be treated and they could make a good recovery, several expressed the view that it could not be cured completely and were concerned that it might reoccur at some time in the future.

*I have taken the tablets, it was a long time, six months, they tell me I am cured, but the TB, I think it may come back.*

This was a cause of anxiety, not only because of the return of distressing symptoms and the necessity to complete a prolonged treatment regime, but also because it carried implications for social relationships. Family and friends may be reluctant to resume normal social interactions because of fear that they might contract TB.

*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.*

Healthcare practitioners shared insights into the longer term consequences of the disease for some of

their other patients. A GP highlighted a situation where a young woman who had experienced TB affecting the brain remained concerned that the illness had removed her chance of marriage and thereby reduced her standing in the community. Other patients were reported to have experienced long term physical disability, for example difficulty in walking where TB had affected the spine. Several healthcare practitioners highlighted the need for on-going support for patients who experienced longer term physical or psychological consequences of the disease after the course of treatment had been completed successfully and voiced concern that the current level of support was limited.

Although the patients who were interviewed had adhered to the complex and prolonged course of medication, it had not been easy for them.

*It was not easy for me, I have never been sick or used to take any medication, the only thing that I used to have is one pain killer tablet and I used to find it hard to swallow that. When I was given 30-40 tables a day to take it was very difficult, but now I am used it.*

Members of the wider Somali community suggested that people often found it hard to complete the treatment. This was because instructions were not always clear and easily understandable, especially if the person did not speak or read English. Others identified the particular difficulties that TB sufferers may experience if they did not have a permanent home and had to 'keep moving on' - the lack of stability in these patients' lives made it difficult to follow a strict routine of taking medication. Alternatively, participants suggested that if people chose not to disclose the disease to those with whom they lived, taking regular medication in secret would be difficult.

Community members also perceived that TB patients could experience significant social isolation. Many participants were of the opinion that people with TB were not welcomed to socialise in the Somali community and that people often avoided contact with them for fear of contracting the disease.

The majority of patients understood the need to complete the course of medication and adhered to it. However, healthcare practitioners reported some instances where a patient's concordance with treatment had been problematic. Young men in particular could present a challenge.

*Some young men are very responsible, they have a diary and are very organised, but not all of them. Some of them are very difficult, 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, nothing affects them, they think they don't need the medicines if they are starting to feel better.*

## **Providing TB services: healthcare practitioners' experiences**

### ***Contact tracing***

The TB specialist nursing service was responsible for contact tracing and arranging appropriate follow up and referral of people deemed to be at risk of developing TB as a result of their contact with someone during the infectious stage of the disease. Contact tracing was relatively straight forward in many cases with patients willing to share the details of people with whom they had contact. However, some patients were reluctant or unwilling to share information with healthcare practitioners despite assurances that the patient's identity would not need to be disclosed to people being followed up.

*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.*

*One man became a TB patient and we wanted to screen his young son, but he says there is no need, they don't live together. He did not want us to screen them so we had to leave them alone, and the younger son, he became a TB patient. When I went to the house I talked to his wife and I said 'do you know anybody with TB, your family, your neighbours, anybody?', and she says 'no', and she was telling the truth, but he had not told her, and he used to bring the child to the TB clinic but he would not tell his family. There are some families that share information and will share with friends that family has had TB, but some Somali people, they do not share that information.*

Young men in particular were often reluctant to share details of contacts. It was surmised that they were anxious that their friends might withdraw; they would lose their 'street credibility' amongst their peers and become socially isolated.

*A young man, he was living with the family and he didn't tell them that he had TB. They did not know, he hid it from them even when he was in hospital he said to them that he had a different problem, he did not tell them that he had TB. They did not know that he had treatment for TB. ... He wanted to just be healthy and good looking, and married, whatever. But if he had TB this would not happen. So he lied about everything. He denied that he had TB. Yes, he was scared; he was ashamed, because of how people may react. He has a huge group of friends .... It is very hard to contact trace for him as he would not talk to us, but we were aware that he has a lot of friends.*

Healthcare practitioners also gave examples of patients who had disclosed only partial information regarding contacts, for example they were open about immediate family members with whom they lived but not the wider network of family and friends with whom they socialised on a regular basis. This wider network was sometimes discovered when new patients presented who identified the original patient as a contact. Healthcare practitioners attributed the reluctance to disclose contacts primarily to the stigma associated with TB within the Somali community. They perceived that there was a general understanding among Somalis that although in the past TB had not been curable and often resulted in death, people could now be treated and would make a good recovery from the illness. Rather, the stigma associated with TB was concerned with the social consequences of the disease. The fear of being ostracised and losing one's standing in the community meant that some patients were reluctant to disclose information about those with whom they had contact.

### **Diagnosis**

The specialist TB medical and nursing team acknowledged that making a diagnosis of TB could be very difficult, especially when patients presented with atypical symptoms. Even following extensive investigations, it was not always possible to confirm the diagnosis and it was only retrospectively when a patient responded positively to treatment that TB was confirmed. This made it difficult for GPs to make a provisional diagnosis and appropriate referrals, especially when patients presented in the early stages of the disease and with general symptoms. GPs pointed out that whereas patients who presented with classical symptoms of pulmonary TB were relatively straightforward to diagnose, other forms of TB were more difficult and this may account for the concerns that patients outlined regarding the length of time it took to reach a diagnosis. One GP explained:

*We have notorious difficulty diagnosing TB spine and usually people are coming saying they have got pain and that they need help and attention for it for quite a long period of*

*time before they have the diagnosis. So I think that is just a difficulty of the condition itself. Also TB meningitis, we have had two people with that and they were very difficult to diagnose, partly because these people are presenting symptoms that other people have who don't have TB ... All the people with TB spine have had at some stage normal chest x-rays so you can't pick it up easily by tests we can do in general practice, whereas at least for lung TB we can do x-rays and tests and we can ask people so I think it is more difficult with certain types of TB.*

One GP also pointed out that reaching a diagnosis may be more challenging among the Somali population because of different cultural interpretations that may be placed on symptoms.

*A Somali patient may complain of something that is affecting the whole half of the body and it might be tingling or it might be pain and it just does not fit with our traditional Western medical model of certain diseases. There is just no match at all and 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. That is one thing, but also to find out whether there is some sort of psychological distress or mental health problem that is being expressed with this and what does this represent for this person. It is a big challenge. Yes, it is very complex and also I think people express their distress in different ways culturally, leaving aside physical signs and symptoms.*

Where a practice population comprised a significant number of patients who were recent migrants, or at high risk of contracting the disease, then GPs were perceived by their hospital colleagues to be generally 'on the ball' in thinking about TB as a possible diagnosis. However, it was perceived to be much harder for GPs who might see only a single case of TB in a year, as one medical consultant explained.

*A small number of GP practices see the bulk of the TB so clearly they are quite keyed up about TB and are quite quick to pick it up, whereas other people might only see one or two cases a year for example. You know you can't really expect people to keep up their skills and keep TB in the front of their minds, that's an area for us to focus on.*

The specialist TB team acknowledged that there were instances where patients could have been referred from general practice earlier. In an attempt to address this concern, the TB specialist nurses attended staff development meetings at GP practices to raise understanding about the disease, and these had been well received. GPs also spoke very positively of the opportunity to contact the TB specialist nurses to discuss any patients who they thought might have contracted TB.

Overall, there was a sense that GPs were becoming more aware of TB as a possible diagnosis and referring potential patients to the TB services.

*I have seen an increase in the number of referrals of people who may have TB and it turns out that they haven't – and that is good, you want to have a few of them, because it means that GPs are more aware of it - otherwise you sense that you'd be missing cases.*

As mentioned earlier, several of the patients who were interviewed complained about the length of time and number of visits made to the GP before a referral was made to the TB services. However, whilst recognising that this was the experience of a number of patients, the specialist healthcare practitioners also perceived that some patients had been reluctant to seek help when they first experienced symptoms, possibly because of fear regarding the diagnosis.

*For people who have pulmonary TB and they sense a high level of stigma, it often takes them about six months before they will go and seek help and of course that's six months when they're potentially infectious to other people.*

There was also a perception that late presentation of TB was strongly associated the heavy use of khat, as one healthcare practitioner explained.

*A lot of people who have been unwell for a long time will also be quite heavy users of khat. I can understand their reluctance. Heavy use of khat is like heavy use of any other drug, it's quite escapist, but also if they were found to have TB they are going to lose their entire social life because who wants you to go down to the Marfesh if you have TB, so they would be isolated and ostracised. And when you are chewing plenty, you feel OK, you feel good about yourself.*

There was a general perception amongst healthcare practitioners involved in the care of Somali patients with TB that the stigma associated with the disease was declining. As one GP explained, as a result patients were generally more accepting of the diagnosis a few years ago.

*My impression when I first came to work at this practice a few years ago was that TB was a taboo subject that nobody (in the Somali community) talked about and if you thought that somebody had got TB, if you said that to them, they were horrified. My impression now is that patients would rather know so I think there is a bit of a change. People come asking 'could I have TB?' whereas we were the ones thinking of it before. I don't know whether that is just experience of knowing other families who have had TB and have had it treated and are fine, whether that is kind of rubbing off amongst people that they know.*

However, there were still instances where patients were hostile to the diagnosis.

*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. There was no doubt he had TB and her argument was that 'we are professional people' the implication being that TB happened to the lower classes and she was really very offended that we had made this diagnosis of TB of her son.*

Healthcare practitioners reported that patients who had experienced distressing symptoms for some considerable time were often very relieved when a diagnosis had been confirmed. However, there were still some patients who were reluctant to accept the diagnosis and this created challenges in terms of supporting the patient through treatment and in contact tracing.

*Some patients don't seem to see it as a major stigma, a major problem, it's just something that's an infection that they will be treated for, and then you have the other group of patients who have major problems with taking their treatment, we have had a number of challenging families recently, challenging in terms of taking the medication.*

### **Management**

Hospital consultants sought to present a positive view of the treatment and prognosis of TB to their patients. TB was explained in terms of a disease which could be cured if the treatment regime was adhered to. In their experience, the majority of Somali patients were accepting of the diagnosis, adhered to treatment and had a positive outcome as one consultant explained.



*My sense over the years here has been that it is rare for people not to complete treatment even if they have not wanted anybody else to know they have got it, but on the whole people are completing treatment because they are probably slightly more afraid of TB and the consequences of not taking medication ... 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)

However, there were some patients where this proved more challenging. Patients often felt better a few weeks into the treatment regime and it was at this point that a few patients stopped taking treatment. This was attributed to a lack of understanding of the importance of completing the treatment and also to stigma associated with the disease. Stopping treatment reduced their risk of being stigmatised. In addition, some patients were reported to be fearful of the side effects of their medication which resulted in them not completing the course.

*I have got Somali and Asian adolescents who won't take their treatment. But if you do not have good family support that is bound to impact more on compliance. If you have a family structure where there is a mum and a dad with firmer control of the family then you feel that they are likely to be better at getting the teenager to come to clinic and to take their medicines. Whereas where you have a bit of chaotic family, they don't come to clinic and no one is making sure that they take their medicines, I think that there is probably more of a compliance problem but it is not solely in the Somali population, it is more to do with family structures.*

It was acknowledged that completing a complex six month course of medication was difficult for many patients, irrespective of their ethnic background. However, it was recognised that the social and economic circumstances of some Somali patients created additional difficulties for them. For example, a woman who was a single parent with several children had found it difficult to attend clinic at a specified time when she had children to take to school, other younger children had to accompany her and she could not afford a taxi to ferry everyone to the hospital.

The TB specialist nurses followed up patients in the community. All TB patients received an initial visit to discuss the diagnosis and general health and social situation and to initiate contact tracing. Thereafter, patients who were experiencing difficulties completing treatment received more targeted support. Whereas the nurses' role was primarily to support patients through their treatment it was recognised that the illness could not be viewed in isolation as one of the nurses explained:

*The remit (of the TB nurse specialist) is to educate patients about TB, screen their contacts, help them through their treatment course, help them with treatment compliance, but it is also to oil the wheels if you like and make sure that there is nothing to stop them getting better. So if they can't afford to eat, then we need to look at that because it will not help them get better. If they are not sleeping because they are so stressed out because someone may take their kids away, or if they are so cold they can't sleep, then it is our responsibility to put them in contact with people who can help sort out these problems. We can put them in contact with the citizen's advice, or the council, or whoever, write letters of support to employers, the council, just generally try to keep them going until they have completed their course medication. When someone does not have anyone else and they are not able to access the services, they are not comfortable accessing services, then we do that little bit more for them.*

Although it was not in the official remit of the TB specialist nurses to provide additional social support, it was highly valued by patients and by other healthcare practitioners. With a shortage of social work support and a fear amongst some Somalis of the role of social workers, concern was expressed that vulnerable patients might otherwise 'slip through the net'.

### **Barriers to Somali people accessing treatment for TB**

Somali participants identified a number of barriers to seeking treatment for TB.

#### ***Lack of knowledge about the disease and treatment***

Lack of knowledge about the nature of the disease and its treatment was seen as a major obstacle to people receiving treatment for TB. Patients may not recognise the significance of their symptoms and seek appropriate medical advice. Additionally, the perceived stigma associated with TB may mean that people may be reluctant to come forward for fear of being diagnosed with the disease. Moreover, if patients held the belief that TB cannot be cured it may lead to them not seeing the value of completing the treatment regime.

#### ***Lack of trust in general practitioners***

Most participants held high expectations of primary care services. Whereas a number of participants were very satisfied with the care provided by their GP, others were less so. Some participants thought that some GPs did not have sufficient understanding of TB and its implications for Somali people. They feared that these GPs were not skilled in diagnosing TB and may prescribe the inappropriate treatment rather than refer the patient for further investigations. The lack of trust and confidence that a few participants expressed in their general practitioner was seen to be an obstacle to them seeking help.

#### ***Lack of confidentiality***

Several community participants expressed the view that because TB was regarded with stigma within the Somali community, patients would wish to hide their illness from others. Some concern was expressed that healthcare practitioners or interpreters may share information with family members, employers or the community at large.

#### ***Language barriers***

Language barriers were seen to be a major impediment for many Somali people to access health care services in general. This was especially problematic for women who were most likely not to speak English. It was difficult for patients to explain their symptoms to the GP, even when using an interpreter. Some general practices were able to provide interpreting services as a member of staff spoke Somali or use telephone interpreting services. However, many participants relied on family members to interpret on their behalf even though it compromised confidentiality. It was also recognised that many people who spoke Somali were not literate in the language and were therefore unable to read health-related information prepared in Somali.

Healthcare practitioners also highlighted the difficulties they experienced in communicating effectively with Somali patients who were not fluent in English.

*Even with an interpreter it is quite difficult to build up a relationship with someone where they trust you through an interpreter. You have no idea what they are saying, or how they are saying it. And how you say something has such an impact on how you build up rapport. I am not saying it doesn't ever work but there is just a feeling that you don't*

*quite know whether they fully understand you or not, something may have got lost in translation ... There is no continuity with interpreters unless we work very hard at it.*

### ***Social stigma***

The social stigma associated with TB was seen to be a significant deterrent in people presenting with TB and completing treatment. Fear about social isolation, loss of standing in the community, and future prospects meant that some people were reluctant to seek help if they thought they had TB or to complete treatment.

### ***Use of khat by some men***

Several community leaders, Somali participants, and healthcare practitioners, drew an association between the heavy use of khat, especially among men, and TB. The close proximity with which men socialised for long periods in khat houses meant that there was a higher risk of spread if someone in the group was in the infectious stage of the disease. The detrimental effects of khat were considered to be more widespread. These included:

- Physical effects of khat led to loss of appetite and difficulty sleeping which meant that people were more vulnerable to illness.
- Economic impact meant that if people were heavily dependent on the drug they were less likely to be economically active – they were often unable to hold down employment.
- Social consequences – women in particular were very vocal about the detrimental effects of heavy use of khat on family life. Men who were heavy consumers of khat were often seen to distance themselves from family responsibilities, placing an added burden on women to provide for the family and to care for children. There were reports that some women had divorced their husbands on account of their heavy dependence on khat. This in turn had led to some men becoming homeless and their ensuing economic and social hardship was seen to increase their vulnerability towards TB.

### **Facilitators to effective health promotion, diagnosis and management of TB**

Participants identified a number of factors that could facilitate effective health promotion focused the prevention of TB, timely diagnosis, and appropriate management of the disease among Somali people.

#### ***Raising awareness of TB within the Somali community***

Somali participants emphasised the need to raise awareness of TB among the community. More factual information on how TB is spread, presenting signs and symptoms, prevention, treatment and prognosis were considered important. Participants suggested that increasing people's understanding of the disease and its treatment would help to address stigma associated with the disease. The importance of delivering health messages in a culturally appropriate way was emphasised. Written information in the form of leaflets and posters in English and Somali for distribution through GP surgeries and community events were considered useful, however it was pointed out that a significant proportion of Somali people were not literate. Raising awareness through the spoken rather than the written word was proposed as a means of reaching a wider proportion of the community. One way of achieving this was to actively engage community leaders in this process.

*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. ... It would really help if some of the spiritual leaders in the community*

*could have some input and actually say to people 'you are not a bad person if you have TB' and perhaps say to people that 'you need to help friends and neighbours and other members of the community who have got TB, you are not going to catch it from them when they are no longer infectious, but they need your help and support, it is one of those things, TB is in our community, and we have to deal with it, we should unite against it, not divide'. I say particularly the spiritual leaders because I think that people look to their spiritual leaders, particularly in the Somali community for guidance. We need to target influential people in the community. It's about raising awareness – to reduce the stigma we need to normalise it, we need to get it so that people are very happy to say, 'I have a diagnosis of TB, I am a week into the treatment but give it another week, I am out of circulation for a week, I will be really happy to receive phone calls but then once I am out and about again we should get together to have a coffee'.*

Suggestions were made to have presentations at community gatherings such as luncheon clubs and to hold specific health events at local community centres, run by healthcare practitioners and Somali health workers. The need to raise awareness of TB among the younger population, for example through schools was also proposed. Different media were suggested including the radio, the internet and social media – however it was stressed that messages would need to be presented in a culturally appropriate way, for example through telling stories or through the poetry.

### ***Somali health workers***

The number of Somali health workers in Sheffield is very small. Many participants spoke highly of the contribution made by the part-time Somali health worker who worked with the TB specialist nursing team. This person had been appointed to work primarily as an interpreter but through developing an understanding of TB had assumed a more active role in supporting patients through treatment. A second Somali health worker with a broader remit across the PCT for Black and minority ethnic communities was seen to be highly influential within the Somali community in promoting positive health messages, including TB. However, bearing in mind the language barriers that many Somali people encounter in accessing and using health care services, this resource was considered insufficient to meet current needs. Many participants identified a need to increase the number of Somali health workers in order to raise the community's understanding of TB and to facilitate access to health care.

### ***Improved access to interpreting services***

TB patients who did not speak English normally had access to formal interpreting services when attending outpatient hospital clinics or visits from the TB specialist nursing service. However, for a number of patients communication with their GP prior to diagnosis had been hindered by language barriers. One GP practice employed a receptionist who spoke Somali and who was able to interpret for patients, but many patients found themselves relying on family members to assist or 'making do' with their limited understanding of English. There appeared to be fairly limited use of professional interpreting services provided by Sheffield Community Access and Interpreting Service (SCAIS) or telephone based language line service in primary care, with heavy reliance placed on patients identifying someone to interpret for them. Somali participants stressed the need for greater availability of interpreting services. However, this request was qualified by the need for interpreters to be known and trusted within the community in order to overcome the fear of breaches of confidence.

### ***Improved understanding of TB among General Practitioners***

Many patients felt that there had been delays in obtaining a diagnosis on account of their GP not referring them to the TB service soon enough. Patients perceived that GPs lacked an understanding of TB, especially when they did not present with classical symptoms. The specialist TB medical and nursing team acknowledged that the diagnosis of TB can be very difficult, especially when patients present with atypical symptoms. However, they also acknowledged that there were instances where patients could have been referred from general practice earlier. Some GPs had benefited from update seminars on TB provided by the TB specialist nurses for the group practice. These events had been well received and had raised GPs' understanding of TB. They had also made them aware of the support that the nurses could provide to GPs as well as patients. Further outreach work by the TB medical and nursing team to GP surgeries together with written or electronic resources to raise understanding of TB were proposed.

### ***Developing the cultural awareness of healthcare workers***

Whereas some Somali patients and community members reported positive experiences of their interactions with healthcare practitioners, this was not widespread. Patients were generally satisfied with the experience of hospital care, and the TB nursing service. However, patients' experience in primary care varied. Key issues of concern from the patient's perspective related to the importance of GPs listening to patients and giving more time to the consultation. Patients complained that consultations were often rushed and they came away dissatisfied because they did not feel that the GP had fully understood their health concerns. This was made all the more difficult when the patient could not speak English and there was no professional interpreter present. As a result, TB patients made many return visits to the GP in the lead up to a diagnosis being made in order to try to resolve their health problem.

The members of the TB specialist nursing team had worked with the Somali community for some years and also worked alongside the Somali health workers. This experience had given them considerable insight into the Somali community that they were able to apply in their practice. However, other healthcare practitioners who had less intense and prolonged contact with Somali patients indicated that they had limited understanding of the cultural norms of the Somali community and the implications this carried for how Somali patients managed health and ill-health. They expressed a need for greater understanding of Somali culture in order to inform their practice.

### ***Addressing issues of social exclusion and economic disadvantage***

Healthcare practitioners who worked closely with Somali TB patients drew attention to the social exclusion and poverty experienced by some members of the Somali community. As the brief profile of the Somali people presented earlier in this report highlights, many Somali people were unemployed, living in relative poverty, experienced poor housing and were reliant on state benefits as they had been unable to secure employment. Such social disadvantage inevitably had an impact on the physical and psychological health of the people concerned, as one healthcare practitioner explained.

*There's the psychological part of TB, people are more likely to get ill if they are depressed, if you feel isolated, feel disempowered, if you've lost status, if you feel disrespected, have poor housing and this is a common experience for many immigrants. People often start off with difficult circumstances, in overcrowded accommodation, they don't have a lot of money and if they're asylum seekers they might not be allowed to work. They're pushed into the worst housing in very cramped conditions, they've often left very traumatic things behind, they're often dreadfully homesick - so all these things*

*affect people's immune system and that makes people very vulnerable to any illness and TB is one of those illnesses.*

One participant summed up the importance of social cohesion and a sense of belonging: when asked about the main reasons for their sickness.

*I think if the family are bad to you or you don't have people you can trust or talk to, then you will get ill.*

Clearly, the difficult circumstances that many Somalis find themselves living in carry implications for the wider public health agenda of addressing social disadvantage and health inequalities.

### **Perceptions of primary health care services**

During the course of the interviews with Somali participants it became apparent that participants' experience of primary health care varied considerably. Whereas some people were very satisfied with the care provided by their general practice, the majority of participants expressed varying levels of dissatisfaction. Although the focus of the research was on Somali participants' experience of health care services in relation to TB, the broader concerns that participants raised are summarised below as they may have a bearing on the experiences of patients who present with early signs and symptoms of TB.

Somali participants were often able to compare and contrast health care systems as many had firsthand experience of health care in European and non-European countries. It was evident from the interviews with Somali participants that an individual's views had been shaped by their own experiences and those of other members of the community. The extensive social networks within the Somali community meant that news travelled fast, including news about other community members. Thus if an individual shared a negative experience of health care, others within the community quickly heard about it and it influenced their own views of the service even though they had not experienced it themselves. During the interviews and focus groups with a broad range of Somalis from across the city we were told about the negative experiences of particular individuals on several occasions as well as more general views of primary health care. The frequency with which participants raised issues about primary care and the intensity with which they voiced their concerns means that these are very real issues for the Somali community in Sheffield. The study did not set out to examine these broader issues, but they clearly have implications for the diagnosis of TB.

The main concerns expressed by Somali participants related to:

- Language barriers and the poor availability of interpreters in many practices made it difficult for Somali people to access services. There was also a lack of trust in the skills of interpreters and concern that they may make errors in interpretation.
- The perception that GPs often prescribed medication without having taken a detailed history and come to a firm diagnosis. Some participants complained that the GP reached for a prescription pad as soon as they entered the consulting room. They voiced concern about being prescribed pain killers or antibiotics unnecessarily.
- A lack of trust in the medical skills of some general practitioners and the delays in reaching a diagnosis led some Somalis to seek a second opinion. People reported using private general practitioners in other cities, especially London, and several participants referred to family and friends seeking medical treatment outside the UK. The German health care system was especially attractive. Somalis were reported to have accessed polyclinics where investigations were undertaken over a period of 2-3 days and patients received the results and diagnosis

before returning to the UK. Somali contacts in Germany helped patients to arrange appointments and secure accommodation for their stay. Social networks also functioned effectively in identifying alternative health care; information about specific private doctors, including those in Germany was readily shared amongst community members as well as with the research team.

- A number of participants complained of negative attitudes expressed by some GPs towards them. They felt that they were not treated with respect and their concerns were not listened to. They also suspected that they received a poorer service than the white British population, for example they felt that they had to wait longer to secure an appointment.
- Women expressed concern that they found it difficult to talk to male doctors about their medical problems and were not always able to see a female doctor.
- Several people perceived that GPs were reluctant to refer them to hospital for further investigations and indicated that on occasions they had attend the A&E department at the local hospital when they perceived that they were not receiving appropriate care from their GP.
- Reports in the media also influenced people's perceptions. Lack of trust in GPs was often reinforced with reference to Harold Shipman, fear that patients may be subject to the wrong treatment was put in the context of media reports of surgical errors.

One Somali participant summed up some of the above concerns.

*Some of the doctors who work at the surgery are very good, they will treat you good, they listen to you, they give you the treatment that you need. But there are other GPs who people complain about. People complain about how these GPs treat them, 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 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.*

Whereas many of the primary care experiences that participants shared with us were negative, the social networks also functioned effectively in sharing positive experiences. There was shared knowledge across the community about which GP practices provided a good service for Somali patients, even when participants were not registered with that particular practice. Interpersonal skills, cultural understanding as well as medical skill were considered important. Somalis regarded very highly GPs whom they felt listened to their concerns, actively sought to overcome communication barriers, did not rush the consultation and had some understanding of the Somali culture and context in which people lived.

We interviewed four GPs as part of the study. These GPs worked in group practices with a relatively high Somali practice population and cannot be considered to be representative of the GPs in Sheffield, or indeed of GPs within their particular practice. Neither should it be assumed that any of the above concerns voiced by Somali participants related to the services provided by the GPs who participated in the study. The GPs who were interviewed showed considerable insight into the health needs of the Somali population and the influence of culture on a patient's response to health and ill-health. However, the GPs also shared some of the challenges they faced in seeking to provide appropriate health care to Somali patients and families.

GPs perceived a lack of understanding of the British health care system among some Somalis. They considered that those who were new migrants from countries where there was no comprehensive primary health care system were more likely to present at A&E departments with minor ailments rather than attend general practice. This was particularly so for common childhood ailments. GPs recognised that mothers might associate a child's fever with more serious illnesses encountered in Somalia and respond as they would in Somalia by taking the child to hospital when it could have been managed effectively in primary care. GPs therefore identified a need to educate mothers about how to manage some common illnesses which infants and children encountered in the UK. Additionally, because people migrating from Somalia were most likely to have relied on hospital services when they needed medical attention, GP felt that Somali patients did not always appreciate the breadth of medical expertise available in general practice.

GPs also perceived that Somali people had different expectations regarding the outcomes of a medical consultation. In particular, older people often found it difficult to accept that many of the symptoms they experienced related to long term conditions such as arthritis which could not be cured. Somali patients were perceived to place emphasis on cure rather than long term treatment and this meant that some patients were reluctant to continue with medication when they began to feel better, for example the need to continue with medication once their blood pressure had returned to normal. Although some very positive accounts of primary health care were reported, the summary of participants' views of primary care services outlined above identifies some tensions between the views of Somali people and those of the general practitioners interviewed. These tensions are reflected in the recommendations arising from the study.

## **Conclusions**

The impetus for this study arose from a shared concern among members of the Somali community and healthcare practitioners working in the field of TB of the need to provide more culturally appropriate services for Somali people. The project set out to gain insight into socio-cultural influences on the prevention, diagnosis and treatment of TB within the Somali community by engaging with Somali people with personal experience of TB, community leaders and the wider Somali population. The study also sought to understand how healthcare practitioners viewed TB within the Somali community and their experiences of providing TB services to Somalis.

The participatory research approach involved university researchers working in partnership with Somali community researchers and a TB specialist nurse. This approach was successful in facilitating access to the community and the active engagement of Somali participants in the study. The community leaders' endorsement of the value of the project to addressing an important health concern meant that the Somali community soon became aware of the study through their social networks. As a research team we were both surprised and delighted when several people, including TB patients, approached us to participate in the study without us making an initial approach. The TB nursing team and Somali health workers fed back to us that in their opinion the very act of undertaking the research and engaging community researchers in the process had contributed towards TB being more openly discussed in the Somali community at the end of the study than when it commenced. Training for Somali community researchers included increasing their understanding of TB and the community researchers used this knowledge in their on-going interactions with members of their community. The community researchers' primary motivation to participate in the study was based on a concern to influence how TB was perceived by the community. Although the effect of the research on raising the profile of TB within the Somali community cannot be quantified, it provides some evidence of immediate benefits of the study which can be built upon in subsequent dissemination activities



involving the community. The role that community researchers played highlighted the potential for training lay health educators who would be perceived as credible within the community.

The study's findings identified a general awareness of TB among the Somali community in terms of the signs and symptoms of pulmonary TB, its treatment and prognosis. There was less understanding of non-pulmonary TB among Somali participants and some healthcare practitioners. Many Somalis lacked understanding of how the disease was spread and people became infected. Established community beliefs were difficult for healthcare practitioners to challenge. For example, assumptions that TB was a hereditary disease, or that it could be acquired by sharing eating utensils with someone who had TB in the past were prevalent, even among some patients who had been treated successfully.

Somali people spoke of how TB was perceived to be stigmatised within the Somali community and this was seen to originate from how the disease had been viewed in Somalia before treatment became readily available. Despite an acknowledgement that TB could now be treated effectively, the disease remained stigmatised by many of the participants because of how they perceived others may view TB. Whereas a person suffering from TB would generally share their diagnosis with their immediate family concerns remained that they may become ostracised by members of the wider community if knowledge of the disease became more widespread. We interviewed a range of age groups and we did not notice any trends in differences of opinion held by those educated in the UK or who had lived here a long time, compared to more recent migrants from Somalia. Indeed, young men who had been educated in the UK voiced some of the strongest negative views regarding the stigma associated with TB. However, attitudes towards TB were changing. Community leaders emphasised that as people became more knowledgeable about TB then the stigma would diminish but it is acknowledged that deeply held beliefs about the causes and consequences of TB will take time to change.

A number of barriers that hinder Somali people accessing TB services were identified. Some, like stigma, are embedded in cultural beliefs or are linked to socio-cultural activities such as chewing khat. A lack of trust and confidence in healthcare providers, especially some GPs, arose from the protracted time it often took from when the patient first presented in primary care to reaching a diagnosis. This highlights the need for GPs to be knowledgeable about the various ways in which TB may manifest itself and to make timely referrals to the TB services. The study also identified the benefits of healthcare practitioners developing a greater understanding of the Somali community to assist them to provide more culturally sensitive care and to take steps to overcome language barriers. Several avenues through which culturally appropriate strategies targeted at reducing the spread of TB, early diagnosis and effective management of the disease were identified. These are captured in the recommendations arising from the study and suggest the need for a more proactive approach to raising awareness of TB within the Somali community and among primary care practitioners.

Interpretations of TB are culturally bound and in order for TB services to better meet the needs of the Somali community there is a need to develop greater awareness among healthcare practitioners of the needs of Somali patients and overcome linguistic barriers through improved access to interpreting services, especially in primary care. However, addressing the above concerns will not be sufficient in itself. There remains a need to address the social exclusion and economic disadvantage experienced by many members of the Somali community. Economic hardship, poor housing and unemployment all have a negative impact on health, and whereas many of the people we interviewed were self-reliant and resourceful, some patients were living in very difficult material and economic circumstances which made their engagement with healthcare services all the more difficult. The recommendations arising from this study, point therefore, to the need to address the wider public health agenda of social disadvantage in order to overcome health inequalities.

## **Recommendations**

The main recommendations arising from the study address the importance of increasing an understanding of TB within the Somali community and among healthcare practitioners working in primary care. In addition, healthcare services need to be responsive to cultural needs of Somali people and healthcare practitioners equipped with the knowledge and skills to provide culturally appropriate care. There is also a need to address the wider public health agenda of social disadvantage in order to overcome health inequalities experienced by many Somalis.

### ***TB prevention through education***

A community that is knowledgeable about TB is in a strong position to avoid contracting it. Thus a major recommendation arising from this study is to increase an understanding of TB among the Somali community. This will require strategies which challenge deeply held lay beliefs about how the disease is spread and the long term prognosis. Maximising the social capital of the community, for example, community leaders, patients who have personal experience of TB, may provide a highly credible and influential means of conveying important messages.

This could be achieved through the following strategies.

- Culturally appropriate materials should be developed in a variety of formats (written, spoken and pictorial) that are accessible to Somali people, especially those who do not speak English and are not literate in Somali or English. Communicating key messages in stories or poetry through oral media may be a more effective than factual leaflets. Social media may also present an avenue for dissemination.
- Maximise the potential of Somali community leaders, including religious leaders, to educate the wider community with support from healthcare practitioners, for example by supporting events that they may organise such as luncheon clubs, Somali dance classes. The TB specialist nursing team has an important role to play in strategies to empower the community to lead on delivering targeted messages about TB.
- Places of worship, community centres and schools should be used more to increase dissemination and coverage of TB information.
- Recruit and train Somali lay health educators to promote a greater understanding TB within the community. These people could work with community organisations to identify opportunities for health promotion.
- Increase the number of Somali health liaison workers to provide a more comprehensive service to the community and to healthcare practitioners.

### ***Effective management of TB***

Timely diagnosis of TB is essential in reducing the spread of the disease and in improving health outcomes for those affected by the disease. A recommendation of the study is that front-line primary care practitioners are knowledgeable about ways in which TB may present and avenues for referral for screening to the TB services. The TB nursing services has already initiated work in this area and this should be extended further.

- Frontline primary care providers (GPs, practice nurses, district nurses and health visitors) should receive training in the prevention, diagnosis and management of TB and how to utilise the local TB services effectively.

- Frontline primary care providers who work with the Somali community should receive training in the socio-cultural ramifications of TB and the causes and consequences of TB associated stigma.
- Information resources on TB and methods of control including available services and how to access them should be available in a variety of formats (written, spoke, pictorial) and disseminated through GP surgeries.
- Services to support the emotional and psychological needs of people suffering from TB should be developed further.

### *Provision of culturally appropriate services*

Effective TB control within the Somali community is dependent in part on healthcare services being responsive to the needs of Somali patients. In order to achieve this, healthcare practitioners should develop an understanding of socio-cultural factors which influence health beliefs and behaviours among Somalis and how to overcome language barriers.

- Continuing professional development for healthcare practitioners who work with the Somali community should provide opportunities to develop an understanding of socio-cultural factors that may influence health beliefs and behaviours of Somali people. The place of traditional and western medicines in managing ill-health should also be included. Somali community leaders should be involved in such training.
- Primary care and interpreting service providers should aim for a caseload rather than a random approach to ensure continuity, allocating interpreters to the same patients with whom they can establish an ongoing relationship. This is especially important when patients present repeatedly with the same symptoms.
- Healthcare providers involved in TB services should ensure ongoing dialogue with Somali community leaders in order to monitor progress with achieving the recommendations identified above and to identify any new concerns. A biennial meeting of key stakeholders is recommended.
- Training should be available for healthcare providers on how to communicate effectively with patients through the use of interpreters.
- Professional interpreters should make explicit ground rules relating to confidentiality in order to engender the trust of Somalis who are reliant on their services to access and make use of health care services.
- Information for Somali patients on how to derive maximum benefit from consultations with GPs should be made available in a variety of formats (written, spoken and pictorial) in Somali and English. General practices might consider hosting open days to promote the services they provide to Somalis and how best they might be utilised.
- The number of bi-lingual healthcare providers should be increased. Consideration should be given to promoting a broad range of healthcare careers among Somalis.
- Some community leaders were highly influential as health advocates in community. Their contribution represents valuable social capital which could be supported more effectively by healthcare and social care practitioners.

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