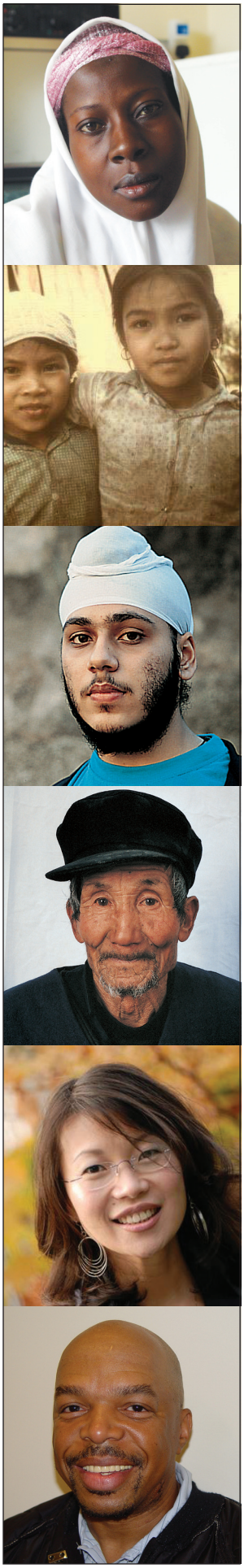

TB & CULTURAL COMPETENCY

Notes from the Field

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Understanding Cultural Differences

This article was written by Dr. Veronica White, a consultant respiratory physician with a specialist interest in tuberculosis (TB). She undertook her undergraduate studies at the London Hospital Medical College, Whitechapel, London, UK, which is in the heart of London's 'East End'. During her postgraduate training she studied for a fulltime Masters degree in Medical Anthropology and wrote her Doctorate thesis on Cultural Barrier to the treatment of tuberculosis (TB) in the Bangladeshi Community of East London, UK. She is now clinical lead for the TB service at Barts Health NHS[1] Trust, which serves a community of one million in East London. The service treats 650 cases of active TB per year and is one of the largest TB services in Western Europe. A large number of patients (>60%) have non-pulmonary TB, including brain, spinal and multi-site disease. This article describes Dr. White's research exploring cultural barriers to TB treatment and some of the lessons learned. Her research may be useful in other settings and can serve as a reminder to ask questions and try to gain a deeper understanding of the populations we work with.

Members of the multitalented TB team, including nurses, administrators, and advocates; their combined heritage reaches from Nigeria, Mauritius, Bangladesh, and Jamaica to East London and in total they speak at least 7 languages.

East London, UK

East London is just adjacent to the City of London and its financial hub. For centuries, it has been a predominately working class area and by the Victorian era (19th century), contained the docks where shipping from all around the world brought their cargos to the capital. This also made the area the point of entry for migrants arriving by sea and many, at least initially, made East London their home: French Huguenots in the 17th and 18th centuries, escaping persecution in mainland Europe; Eastern European Jews in the 18th and 19th centuries, also escaping discrimination. Cosmopolitan, overcrowded and working class, it was also a place where many infectious diseases where spread, child mortality was high and life expectancy short.

More recently, migrants from Bangladesh, initially lascars (seamen), after the 2nd World War were followed by economic migrants in the 1960s and 1970s. East London now has

Continued on page 2

1 National Health Service – founded in 1948. UK system of healthcare that is free at the point of care for residents of the UK and is funded through taxation. Services can essentially be divided into community (physiotherapy, health visitors, community matrons), primary care (family practitioners) and secondary care (general and specialist hospitals).

Continued from page 1

the largest Bangladeshi community anywhere in the world outside Bangladesh, with many second and third generation British Bangladeshis. In the 2011 UK census, 32% of the population of Tower Hamlets, one of East London's Boroughs, was of Bangladeshi heritage (just over 80,000 people). The community has high rates of heart disease, cerebral vascular disease and diabetes and also has a high burden of tuberculosis, particularly in those who are first generation migrants (in 2013, the rate of TB in UK-born population of Bangladeshi ethnicity (18/100,000) and the rate in the non-UK born of Bangladeshi ethnicity (139/100,000); in the same year rates of TB in Bangladesh were 193/100,000).

In the 21st century East London is an area of dichotomy: it still contains areas of mass overcrowding, whilst the dockland area has been transformed into luxury apartments and office blocks housing London's second financial hub at Canary Wharf. Migrants seen in TB clinics are not just from Bangladesh, but may be management graduates from, for example, China, arriving for internships at the international banks.

Cultural Barriers to the Management of TB

I was working in the Borough of Tower Hamlets, East London at the end of the 1990s. There was concern in the local TB clinic at that time that patients from different ethnic and cultural backgrounds were not presenting to their family practitioners or TB clinic for treatment because they were seeking medical advice elsewhere in the community, possibly with traditional healers. I was interested to learn more and started a full time MSc in Medical Anthropology at University College, University of London. My Masters dissertation looked at healthcare beliefs amongst the Bangladeshi Community of East London.

The following year, I started my TB-specific research. Its aim was to look at the cultural health beliefs in our local East London Bangladeshi community in relation to TB and to understand if there were any traditional beliefs or cultural myths that either prevented people presenting with the disease or inhibited them from taking medication. Patients from Bangladeshi heritage made up and continue to make up the majority of TB patients in our local TB clinic.

The research used predominately qualitative methodology; semi-structured interviews were held with patients who had been recently diagnosed with TB. It explored four main themes: 1) recognition of common signs and symptoms of TB, together with the perceived origins or causes of the disease; 2) stigma attached to the disease and patients' 'images' of the illness; 3) use of traditional or 'alternative' healers; and 4), patients' attitudes and adherence to medication and its acceptability.

The research included 41 patients from the Bangladeshi community, who were recruited over a 14-month period. Each patient was interviewed twice, using a Bengali advocate, or translator, where necessary. Demographic information such as education, literacy levels, housing and employment were also collected. The research also included 5 focus groups of local residents from the Bangladeshi community who had no known link to the TB clinic as well as 22 health professionals with varying experience of treating and interacting with TB patients. The interviews were analysed using a software program, NVivo, which helps organise the data in to themes, or 'nodes', which can then be analysed independently.

Bangladeshi community in East London

The East End of London has been a destination for émigrés for many centuries. The Bangladeshi community of East London is the largest outside Bangladesh and most of its members' heritage can be traced back to the Sylhet province of Bangladesh in the North East of the country. Part of the Borough of Tower Hamlets, is now known as 'Bangla Town' where Bangladeshi supermarkets, corner shops and cafes predominate; there is also a large mosque and Islamic centre in Whitechapel which is a focus of worship and community life.

The community is in general a settled one, with many second and third generation British born members, although particularly in the older generations travel between the UK and Bangladeshi is frequent, with older people staying in Bangladesh for several months in the UK winter. Large families with extending families living together are still the norm. This has led to marked overcrowding, where it is not unusual to find two or three young families living in, for example, a two-bedroom apartment meant for only one. Whilst educational and employment opportunities 20 years ago were relatively poor, the standards of local schools has recently risen dramatically leading to a rise in career aspirations and university education, some schools staying open during the holidays to allow pupils a quiet place to study for exams.

Themes and Findings of Research

1. Signs and Symptoms; causes of TB

Most patients understood that cough, weight loss and coughing up blood (haemoptysis) were symptoms of TB. However, few realised that TB could occur in the body outside the lungs and a diagnosis of extra pulmonary TB was often greeted with both surprise and scepticism. Statement made by participants included: *"I was surprised [that I had TB], because I had no cough and I was not coughing up blood." "I still think that it's just a boil, 'boron' [a case of lymph node TB]. TB is only in the chest."*

Fevers and night sweats had more general implications and were often linked to 'having 'flu', being too hot or to diabetes: *"I thought that I had 'flu", "I thought that they were symptoms of diabetes", "Lots of people in Bangladesh get unwell with symptoms like fever, sweats and flu; they tend to be ill all the time. So getting night sweats is not unusual."*

When asked about the origins or causes of TB, there were a variety of responses from patients and laymen. Some thought that TB was an inherited disease, either through the blood or the genes, although when asked to be more specific, patients were unsure. These beliefs, however, have interesting implications for the TB clinic: by asking families and household members to attend TB clinics for contact tracing, we realised that we were inadvertently perpetuating the myth that TB 'ran in families.' The community saw it as an inherited disease, caused by the 'bad blood' that ran in that family, rather than the fact that it was a transmittable infection. For example, imagine a scenario in which Mr. Ali has TB and his family are invited to attend the TB contact clinic for screening. The neighbours might be looking through their curtains and thinking, 'Ahh, Mr. Ali's family are all going up to the hospital together; he's got TB! There must be bad blood in that family; we're not going to marry our daughters to one of their sons!'

TB was often seen as a disease of poor people, a dirty disease. *"I'm clean, I'm middle class; I've led a good life; I can't possibly get TB!"* Some patients thought that they might have got TB from the dust in the factories where they had worked; for example, garment factories were very common in East London. Others put TB down to smoking. Black magic, associated with witchcraft was also blamed, although it should be emphasised that this is a traditional folk belief, not an Islamic belief. Others put TB down to bad jinn, or Islamic spirits. Others were much more pragmatic, "*Allah sends disease, but he also sends us the cure." "I've told people. I'm not worried. It's a God-given disease."*

2. Stigma and Tuberculosis

One of the most striking results of the research was the depth of stigma that surrounded the diagnosis of TB. The fear in some cases was palpable. TB was seen as a dirty disease, a disease of the poor and destitute, a disease that came to 'bad' people, not to good, clean, wholesome individuals.

As outlined above, the fear of contagion was mixed with the mythology surrounding the disease. Many people know that it is contagious, but not in what form or how.

One of the more middle class patients, who was studying in the UK, would not tell us who he was living with and was determined not to return to Bangladesh until he had finished his TB treatment. According to this patient, *"There is a superstition in Bangladesh that TB is inherited. When it comes to getting married, the bride's family will think that I will pass TB on to their daughter and will refuse to let the wedding take place."* His concern went as far as saying that he did not want to go back to Bangladesh on treatment as when he used a public toilet, particularly a male urinal, other men would see that his urine was red and know that he was on TB treatment.

We asked patients about their images of TB: if they were to close their eyes and think about TB, what would they see?

Other patients also expressed their concern that the older generation still feared TB and that, *"If a young boy or girl gets TB then their marriage prospects are almost zero."*

One area that we wished we had explored in more detail was that of employment. Certainly one of the female patients working in a call centre here in England was asked to leave when she told her manager that she had lymph node TB, which is non-infectious. Many of our male patients worked as chefs or waiters in Indian/Bangladeshi restaurants in and around London. Many stopped working when they became unwell. In hindsight, we are not sure whether they stopped due to ill health or because they had been asked to leave when their employers discovered they had TB. One of them reported *"Some of the restaurants that I've worked in wouldn't take me back."* Comments from other participants included: *"I've not told them because I think they will be scared of the TB."* or *"I haven't told anyone as they might hate me, 'ginnaba,' [disgust, repel]"*

We asked patients about their images of TB: if they were to close their eyes and think about TB, what would they see? In general they were frightening images: Descriptions

Continued on page 4

included: *"It is dark, serious and sinister." "The patient is rotten inside." "I think of a skeleton face." "In my imagination, someone coughed and coughed and coughed, and had to be kept away from."*

Medical staff also recognised that there was a significant stigma surrounding TB. Some of the comments made by medical staff included: *"It still frightens." "It's considered low class and dirty."* Some medical staff were also concerned that they perpetuated some of the stigma, particularly the use of masks and isolation of patients in negative pressure rooms. Statements included *"The use of the mask is something that haunts me in this job." "[Patients'] meals are left on bins outside the rooms" "There is so little social interaction – they do what they [the staff] have to and are out ASAP."*

3. Use of traditional healers

Islam is the major religion of East London's Bangladeshi community. There are a number of mosques, including the large East London mosque in Whitechapel. Asking about religious practices around illness needed to be handled with care: when I first started my research, most people denied visiting any form of traditional healer. I realised that questions needed to be carefully phrased. Rather than asking, "Did you go to see your mullah when you became unwell?" to which most people responded with an emphatic, "No," I would ask, "I'm interested in the community's use of traditional medicine, do you know anyone who has visited their imam or mullah or local herbalist when they are sick?" This would often lead to a description of a cousin or friend visiting a local religious leader and, for example, receiving a blessing or a tabiz to help with their symptoms. I would then ask if they, the patient, had ever done the same. Of the 41 patients in my study, only 4 stated that they visited an indigenous healer in relation to the symptoms caused by TB, whilst a further 6 had been for previous illnesses and 2 took blessed water or seeds that they had been given by relatives who themselves had visited mullahs. There are likely to have been some patients who did not want to admit to me that they had sought 'alternative' treatment; one very candid patient pointed out: *"Ah, [laughing], at least 50% of people [go to the mullah], but they will not always admit it to you!"*

Tabiz, which may be tied around the neck, upper arm or waist and contains a verse from the Koran.

From previous work I knew that Islamic religious leaders would give their followers a variety of support. For example, special 'Sura,' or prayers, taken from the Koran, are used to give help and support in times of illness. Tabiz are small metal lockets that could be bought locally. An imam would give the client a verse from the Koran written on a small piece of paper which was then placed inside the tabiz and closed with sealing wax. On some occasions, blessed oil, water or seeds were given either to be rubbed on the affected part of the body or to be ingested.

There were also individuals in the community who produced traditional herbal remedies. Some of them felt that it was their 'calling' to make the remedies and gave them to clients in return for donation to the mosque or to charity. However, I was also told that there were other individuals who set themselves up in the community, claiming to produce traditional healing remedies yet had no credentials and were only out to make money; they were often perceived as 'false' healers who were embezzling from a community that was already quite poor. It has been reported that some families would spend several thousand dollars on traditional remedies.

4. Medication

At the beginning of the research, we theorized that patients from the Indian sub-continent preferred injections to tablets and this method of delivery was perceived as more efficacious. However, we realized our theory was wrong as we talked to patients. The patients we talked to were pragmatic: they wanted the best treatment for the problem. Their main complaints about TB treatment were the same as for most patients, too many large tablets for too long. They also continued to take 'conventional' medicines with any 'traditional' remedies that they had been given. What was important to adherence was their social infrastructure and the medical support they received. Once they told family or friends their diagnosis, they found *"My friends have been very helpful and encourage me to take them [tablets] everyday."* Patients recognised that it was 'tempting to stop when feeling better.' The pivotal role of the TB nurses and advocates during treatment was also highlighted.

A number of our older patients were illiterate, but this did not appear to affect adherence. If anything, they were inversely proportional to each other: older illiterate patients were grateful that TB treatment was free and for the regular visits of the TB team. Younger, British-educated, patients, who were working or studying, were described as working on a 'hierarchy of needs,' once they felt better, TB drifted to the bottom of their list of priorities and some would stop their treatment.

Side effects of treatment were highlighted as an issue

and 'demanded lots of time and energy.' Ensuring that the medical team addressed the problems and supported the patient was essential to compliance. An important consideration for treatment completion with this community is Ramadan.

Veronica working with Shurma, one of our Bengali-speaking advocates, discussing symptoms with a male patient.

Advocacy and Translation

Good medical translation is the key to many of the consultations that take place in our TB clinic. From obtaining a reliable medical history to explaining the complexities of antituberculous therapy, our translators, or advocates as they are known, often discover the intricacies of a problem that would otherwise remain uncovered.

The Advocacy department in our hospital was set up in early 1990s. The name comes from the need not just to provide accurate medical translation but for translators to 'advocate' on behalf of the patient to allow medical staff to understand, not just their words, but their feelings, concerns and in some cases cultural sensitivities around a medical problem. The advocates can also 'advocate' for the medical staff. For example, a patient may decline to take treatment during Ramadan. However, the advocate can use their cultural understanding of Islam as well as the importance of taking uninterrupted TB treatment to discuss both the religious and medical implications of the problem. Advocates are a key component of our program.

Sensitivities and Ramadan

Islam asks that all fit and healthy adults fast from sunrise to sunset during the month of Ramadan. Nothing should be taken by mouth and smoking is not permitted. It is a challenging time for many, particularly during the long, sometimes hot, days of a British summer. In 2014, fasting started as early as 4:45am and finished at 9:25pm, with temperatures soaring to 32 degrees centigrade (or 89.6 degrees Farenheight) on some days. The Koran states that pregnant women, children, the elderly and those who are unwell are exempt from fasting. Fasting can either be undertaken at another time or a charitable gift can be given instead. However, Ramadan is such an important tradition, as well as a religious obligation, that unwell patients often need to be gently reminded that they also have an obligation to look after their health. For many with 'straight forward' TB, we simply discuss taking medication at different times of the day, either as they wake up to eat in the morning or as they break their fast at sunset. For those whose who are more frail or elderly, we politely suggest that fasting is not a good idea this year.

Heterogeneity within homogeneity

We all make snap judgements. It can be very easy to pigeonhole people, particularly when they come from different social or religious cultures to our own. Whether someone sports a Mohican {Mohawk}, widespread tattoos, a burka or a white cane many of us have an instantaneous, almost subconscious reaction that creates a story around them. However, this is our story about them, not theirs.

One of the biggest lessons I learned during my research is the obvious: everyone is different; Yes, everyone. Just because a patient was born in Bangladesh, only speaks Syleti and is illiterate, does not mean that he or she is the same as his next door neighbour with similar credentials. He may not necessarily be a Muslim. If he is, he may have a secret (or not so secret) alcohol problem, or his daughter may

Continued on page 6

Ramadan

Fasting for Ramadan is one of the five pillars (fundamental religious duties) of Islam. Many Muslims fast during daylight hours, having one meal just before sunrise, *suhoor*, and an evening meal just after sunset, *iftar*. It is often a time of increased religious devotion, reading the Koran and prayer, as well as giving monies to charity. The United Kingdom's Department of Health produced a guide to healthy fasting during Ramadan, which aims to help people avoid health complications when they fast. Many Muslims fast during Ramadan despite having some underlying health problems; the tradition of Ramadan is multifaceted combining an important religious duty, cultural tradition together with a strong sense of solidarity within the community.

be one of my colleagues. Both of these factors may change the dynamics of my consultation with him. A woman may present to the TB clinic wearing a burka, but the person who sits beneath may be an elderly non-English speaking women or a British born PhD student with a love of jazz music. We also know that some of our female patients only wear a burka to the TB clinic so that they cannot be recognised. Beware our own cultural assumptions! It is important to know your patient as an individual. Use open-ended questions and talk with your client.

Pluralistic health beliefs

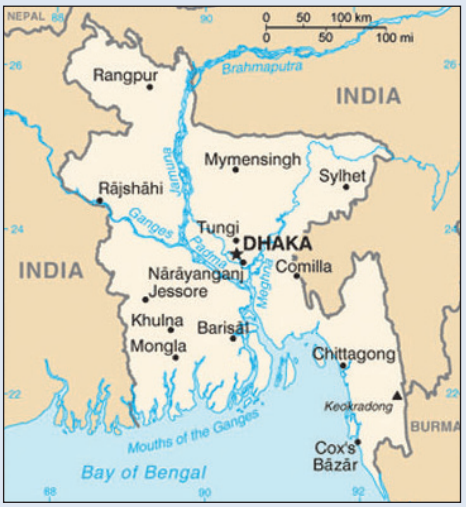
One of our biggest concerns was that our patients' cultural and/or religious beliefs were delaying them from seeking medical attention. Prior to my research, there has been at least one patient who believed his medical symptoms were due to 'bad' jinn (Islamic spirits) and he refused to take TB medication. He disappeared and we believe that he went home to Bangladesh.

However, the research showed that patients have a strong Islamic religious identity, although it varies from individual to individual. Some patients and their families believed that bad jinn may have sent their illness and turned to their imams and mullahs for religious instruction and comfort. However, this did not stop then consulting their Western trained doctors or taking prescribed medication. It had been a rather patronising assumption of ours that people only used one 'style' of medical treatment. Just as someone might seek help from an acupuncturist for his back pain as well as an orthopaedic surgeon, our patients also consulted with and are treated by more than one medium of medical practitioners. As one of the community members put it, *"Medical treatment and mullahs' treatment can work side by side."*

What these stories highlight is the importance of understanding patients' cultural and religious beliefs in relation to health problems whilst not fearing the effect they might have on their reaction and interaction with Western medical care. Yes, in some cases, a strong cultural belief, for example in Ayurvedic[2] or herbal medication, may stop someone from seeking medical care, but for others, religious beliefs can sit side by side with medical care explained in a culturally sensitive way.

2 Ayurvedic medicine (Ayurvedic meaning 'knowledge of life): traditional Indian medical practice which includes use of herbal remedies, regulation of diet and adherence to a strong moral code.

Bangladesh



From the middle of 18th century, Bangladesh was part of the British-ruled Indian subcontinent. Known at this time as Bengal, it was renowned, together with its geographical neighbour Assam, for its tea and rice growing. Many tea plantations set up by the British colonialists continue to this day. After Partition in 1947, Bengal became part of the Muslim nation of Pakistan and was known as East Pakistan. However, the Islamic nation was not harmonious with the Western province becoming industrialised and wealthier whilst the Eastern province remained economically and culturally suppressed.

West Pakistan also tried to impose the state language of Urdu on all of its people. This led to demonstrations in many major cities, including Dhaka, in East Pakistan (now capital city of Bangladesh). Many unarmed protestors, particularly students, were shot dead by soldiers loyal to West Pakistan. The anniversary of the killings in 1952 continues to be remembered in Bangladesh on 21st February, otherwise known as Martyrs' Day. The struggle for regional autonomy culminated in the bloody War of Liberation which ended in the formation of the new independent state of the People's Republic of Bangladesh in 1971.

Bangladesh continues to be a predominately Muslim country with a population of approximately 160 million. It is one of the most densely populated countries in the world as well as being amongst the poorest. One of the aims of the young country was to provide healthcare for the whole community and to ensure that each Thana (district) had its own health complex. In 1993, a National TB Programme was implemented based on WHO guidelines which provides free medical care and treatment for TB.

The emergence of cupping

One form of traditional medicine that has become more popular within the Bangladeshi community in East London over the last decade is cupping. Cupping is the technique of placing hot glass cups or jars on an individual's back with a view to drawing out any impurities in the body. Sometimes a small cut is made in the skin under the area where the cup is placed in order to draw out impurities in the blood. In my practice, I had noticed that a number of younger Bangladeshi patients had had the technique applied (I had noticed the marks left by the cups when I examined them). I was curious to know more and spoke to members of the community. Cupping is discussed in the Hadith (word of the Prophet) and is a tradition of the Prophet Mohammed who is recoded as having cupping done on himself on a regular basis and recommended it for health and religious purposes. The practice appears to have become more popular over the last decade amongst younger people, not necessarily for health issues, but as a form of purification or detoxification and heighten sense of spiritualization. Use of the practice and where to have it performed is spread by word of mouth; in theory, as a religious practice, it should be offer for free with individuals making a gift to the practitioner in return for procedure, although in reality some pay $150-$300.

Photo courtesy of Dr. Veronica White

DOT – Health worker in Bangladesh overseeing a patient taking her TB tablets.

Visit to Bangladesh

As part of my research, I spent a month visiting Bangladesh. I visited Dhaka, the capital city, Dinajpor, in the North-west and Sylhet, in the North East, where many of our patients in London originated. I also visited the national TB programme, both in the central TB hospital in Dhaka and 'in the field' in rural Bangladesh. At the time the programme was well set up to look after pulmonary TB and treatment was free. Health education programmes emphasised the importance of recognising the symptoms of more than 3 weeks of cough, fever, night sweats and weigh loss.

Cultural and Health Education

So what has been the benefit of this research? Locally it has shown us the importance of discussing cultural and religious issues with patients. As one of our Bangladeshi TB health advocate put it, *"I had no idea that patients from our community worried so much about marriage. I shall definitely bear that in mind when talking to patients."* It has also decreased our frustration at perceived lack of understanding about the disease and concerns about adherence to therapy.

Dr. Veronica White

Our team also ensure that we take the message in a culturally sensitive manner into the community. In recent years, we have given talks at local mosques, including to a large groups of local imams, and community centres; World TB day events have included appearances on British Bangladesh and British Somalian television shows together with articles in local newspapers. At a professional level, there are regular meetings of the local TB services, lectures to Family Practitioners and trainee doctors as well as visiting American sociology students and British High school teachers. Overall, though this work required significant effort, it provided us with insights into the community and helped us explore and improve our communication with the patients and communities we serve. —*Submitted by Dr. Veronica White*

Continued on page 8

Migrants, migration and health

Individuals migrate for different reasons and this can affect their 'status' in their destination country. In the UK there are four main types of migrants: workers, students, family members and asylum seekers. More than half of these migrants are non-European nationals. Most students are given fixed term student visas, as may some workers and relatives visiting loved ones, others maybe longer term migrants. The term 'undocumented migrant' is now used to describe those who arrive without appropriate documentation such as a visa and are living illegally in the country.

So where do people go when they feel unwell? For most people who have been born and bred in the UK, their local family practitioner tends to be their first port of call. However, where do you go if you are new to the UK? How do you navigate the health system? If you do not speak English making an appointment, or even working out how you make an appointment, may be your first challenge.

It can therefore be easier to choose another alternative: simply showing up at the local Emergency Department maybe an option, but is not always well received if the health problem is not acute. Thus some people will attend doctors in their community who speak their language, even though they may not be registered in the UK system or indeed properly trained. Others will book appointments at local private hospitals only to find that they do not have the funds to continue in the private system. Still others may go to private registered practitioners via company health schemes and then be referred on to the NHS system. Others will simply fly home and seek help in a system they understand with the support of both family and local finances. In East London there is now a clinic set up by the international organization Doctors of the World, which provides health care to clients who are not entitled to NHS care, including undocumented migrants (doctorsoftheworld.org.uk/pages/london-clinic). Additionally, one of the local family practitioner practices also is funded to look after homeless patients.

The current situation is likely to be made more complicated by the recent introduction of the Immigration Act 2014 which plans to bring in financial charges for recent and irregular migrants for certain primary care and emergency medicine services. This is likely to deter migrants from accessing healthcare services, although the full impact will not become clear until the final implementation plans have been published.

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Public Health England: www.phe.org.uk

TB Alert, UK national TB charity: www.tbalert.org

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