TUBERCULOSIS COMMUNITY ENGAGEMENT PROJECT

WITH SOUTH ASIAN COMMUNITIES

IN BLACKBURN WITH DARWEN

FINAL REPORT March 2015

Executive Summary

1. Background (p.4-6)

This report focuses on recent community-led research work in Blackburn with Darwen (BwD), responding to the fact that in BwD the majority of new TB cases are occurring within the South Asian heritage communities. BwD Public Health wanted to understand how TB is perceived within the South Asian communities, to help them to develop effective awareness-raising within the South Asian population. The Report is a starting point for action to be co-produced by agencies and communities, and will be used for to bringing people together to discuss the findings and take action on the recommendations for change. It will be presented to North West TB Summit in March 2015

2. Aim (p.6)

This project is designed to help inform effective prevention and treatment services, and increase the awareness and involvement of the South Asian heritage communities in tackling TB. The commissioned project sought to develop the services' and communities' understanding and effectiveness, through:

- Increased awareness amongst the South Asian Community in BwD of TB (symptoms, diagnosis, treatment and available local services)
- Up- to- date understanding of levels of community awareness and barriers created by stigma in relation to TB
- Improved awareness- raising campaigns on TB

3. Methodology (p. 7-10)

Our Life have been developing an innovatory community research approach , "community explorers". This approach harnesses residents' unique abilities to relate to each other in an informal exchange about issues which matter deeply to them. Our Life were commissioned to work alongside the voluntary network One Voice to recruit, train and mentor 6 residents from the South Asian communities to interview their peers about TB awareness and ideas for improving agency and community responses to TB.

4. Results (p.11-24)

The explorers completed 327 interviews from November 2014 to January 2015, reaching all age-groups within South Asian communities. The results revealed a huge diversity in awareness, regardless of age, gender or ethnicity, so it is impossible to generalise. Highest levels of awareness were apparent amongst people who had personal experience of TB or had received education in schools and colleges. Very few people knew the whole picture about TB symptoms, diagnosis or treatment, with 15% of respondents knowing nothing at all (p.10-13).

Social attitudes towards TB polarised according to knowledge of TB (p.13-18). Lack of awareness of TB transmission and of TB being curable had a marked impact on social attitudes and stigma, with myths from abroad and media leading many to fear TB patients and to ostracise them to avoid infection. Positive attitudes towards TB patients were expressed by respondents who had knowledge about TB being curable.

Communities suggested a variety of improvements in Health Services, including basic awareness sessions in GP surgeries and at community events. Mass leafleting was suggested as a method of tackling myths and stigma, so that people would focus their attention on detecting symptoms and seeking earlier treatment (p. 18-21).

The communities wanted to play an active role in promoting TB awareness, working closely with professionals. Schools and colleges were highlighted as key sites for raising young people's awareness, with sound information then spreading to others via young people. Self-education was possible if sound, easily digestible information reached communities. The role of community champions was celebrated by many respondents (p.21-24)

5. Recommendations (p.25-26)

The Report concludes with recommendations to adopt an empowerment approach to TB awareness through improved communication between professionals and communities and mobilising community assets. Face-to-face communication is a powerful means of reassuring people and delivering the education which helps de-stigmatise TB and point the way to treatment and prevention. Community champions and networks have a major role to play, alongside professionals. Schools and colleges provide access to young people, who can play a key role in spreading TB awareness throughout their communities

6. Acknowledgements (p.27)

7. Appendices (p.28)

Background:

Tuberculosis, commonly known as TB, is a bacterial infection that can spread through the lymph nodes and bloodstream to any organ in your body. It is most often found in the lungs. Most people who are exposed to TB never develop symptoms because the bacteria can live in an inactive form in the body. But if the immune system weakens, such as in people with HIV or elderly adults, TB bacteria can become active. In their active state, TB bacteria cause death of tissue in the organs they infect. Active TB disease can be fatal if left untreated. http://www.webmd.com/a-to-z-guides/understanding-tuberculosis-basics

Tuberculosis (TB) is a serious but treatable infectious disease. TB is spread from person- to-person by contact with anyone who has the infectious form of the disease; in effect, this means people suffering from lung TB. Left untreated, a person with TB of the lungs will infect around 10-15 other people every year, although this may be greater if there is very prolonged, intense contact or if the exposed people have lowered immunity.

It is therefore vital that TB is detected early and treated, to limit the spread of the infection throughout communities. Residents need to be aware of the symptoms, be encouraged to go to their GP for diagnosis and be reassured that it is curable through a free six-month course of anti-biotics. And, as always, prevention is better than cure.

TB can and does affect anybody. Despite the stories circulating in certain media, TB is not exclusive to any particular community and is found in many different communities throughout the UK. Nationwide there are numerous initiatives to promote TB awareness in diverse communities and seek to reduce the spread of TB.

This report focuses on recent community-led work in Blackburn with Darwen (BwD), responding to the fact that in BwD the majority of new TB cases are occurring within the South Asian heritage communities. The rate of new Tuberculosis (TB) cases in Blackburn with Darwen (BwD) are amongst the highest in the North West, with nearly 90% of cases being within the communities of South Asian heritage.

The Report is a starting point for action to be co-produced by agencies and communities, and will be used for to bringing people together to discuss the findings and take action on the recommendations for change. It will be presented to North West TB Summit in March 2015 to contribute to their ongoing mission to “guide TB prevention and control and ensure that the growing problem of TB in the region is appropriately managed and addressed” https://tbsummit.wordpress.com/about/

BwD Public Health wanted to understand how TB is perceived within the South Asian communities, to help them to develop effective awareness-raising within the South Asian population. National Institute For Health & Social Care Excellence (NICE) guidance emphasises the importance of awareness raising in vulnerable groups.

To find out about community perceptions and begin to generate community involvement in awareness-raising, BwD Public Health commissioned a Manchester-based social enterprise, Our Life, to support a community-led research project, based on Our Life's successful 'community explorers' methodology.

This Report describes how Our Life worked alongside BwD's One Voice community network organisation to recruit, train and mentor a team of six residents of South Asian heritage to lead their own consultations within their communities. These 308 community conversations explored the diversity of prevalent attitudes, awareness, myths and misunderstandings in relation to Tuberculosis, and asked residents to consider how the situation could be tackled by services and the community**.**

The findings and recommendations in this Report seek to inform service development and targeted awareness on TB within the South Asian heritage community.

The Evidence Base:

Despite yearly fluctuation, the rates of new TB cases in Blackburn with Darwen are amongst the highest in the North West; in 2011, the lowest rate for many years was third highest, behind Manchester and Preston. In 2012, the Blackburn with Darwen rate was in line with previous years but was the highest in the North West.

New TB cases	2011 Case Rate/100,000	2012 Case Rate/100,000
Blackburn with Darwen	28.4 (42)	37.9 (56)
Cumbria & Lancashire	10.9 (214)	11.0 (216)
North West	11.6 (819)	11.2 (794)

Over 90% of cases of active TB in BwD are in BME groups and most cases are in those born abroad. Nearly 90% of cases of active TB in Blackburn with Darwen are of South Asian heritage.

Our Life were also commissioned to provide a second project to help BwD Public Health to understand the various social factors which inter-act to influence both the spread of TB and the impact of the disease. This complementary project has been investigating the impact of housing/ overcrowding, diet and nutrition, drugs and alcohol issues, and co-morbidities . The communities of South Asian heritage may also be particularly vulnerable to TB through close contact with people arriving from countries in South Asia where untreated TB rates are high.

Aim:

This project is designed to help inform effective prevention and treatment services, and increase the awareness and involvement of the South Asian heritage communities in tackling TB.

The commissioned project sought to develop the services' and communities' understanding and effectiveness, through:

- Increased awareness amongst the South Asian Community in BwD of TB (symptoms, diagnosis, treatment and available local services)
- Up- to- date understanding of levels of community awareness and barriers created by stigma in relation to TB
- Improved awareness- raising campaigns on TB

Local authorities are ideally placed to support specialist clinical TB services and their patients through the provision of its housing and social care services and by raising awareness of TB amongst the community.

The findings will support both awareness raising activity and commissioning of TB services.

Our Life:

Our Life were commissioned to undertake this project following their highly-commended community research project on TB on behalf of NW TB Summit in 2012-13: this earlier project had interviewed local people to find out how residents perceive Tuberculosis (TB) within a North West England neighbourhood, and report back on ways to raise awareness of the illness and encourage people to take preventative action and seek treatment.

http://ourlife.org.uk/case-studies/tb-the-lightning-conductor

Our Life are a social enterprise, working across the North West since 2009 to develop resident-led engagement in health and wellbeing issues, and have been leading the field through developing an innovatory community research approach , "community explorers". This approach harnesses residents' unique abilities to relate to each other in an informal exchange about issues which matter deeply to them, and has been demonstrated to move beyond the gathering of information to become a catalyst for residents to take action on the issues.

The Project:

The BwD TB Awareness project utilised the Community Explorers approach. Our Life were commissioned to work through existing community organisations and groups to identify residents who wished to become community explorers, to be trained in TB awareness and participatory research techniques. Our Life would mentor and support them to carry out the enquiry within their community. The project budget included payment of £20 vouchers per week for each explorer, for three hours work per week. This incentive recognises the commitment and time devoted by the residents and helps to sustain a consistent attendance by all.

The desired outcomes of the project were for services, commissioners and communities to better understand levels of awareness and understanding of Tuberculosis (TB) in the BwD communities of South Asian heritage. In particular the engagement work would explore the wide range of beliefs in the diverse communities, relating to:

- How TB is caught and transmitted
- Who is at risk from TB
- How TB can be prevented

- How TB is treated
- What myths there are regarding TB
- What stigma exists around TB
- What assets in the community can help prevent TB

The project would examine differing attitudes amongst groups within the communities, reaching all age groups, ethnicities, genders, recent arrivals, and faith groups.

This Report tells the story of the work from November 2014-March 2015, bringing together the findings from the explorer's 308 interviews, and ends with a series of recommendations for services, commissioners, communities and the NW TB Summit. The findings from the research will feed into the design of community TB awareness raising campaigns to be carried out in BwD during 2014/15 within and alongside the South Asian heritage communities.

Starting the work

In September 2014, Our Life's Community Engagement Specialist met with One Voice, the community network organisation for South Asian communities in BwD, to discuss the project and how we could collaborate. One Voice provided great support from the beginning, publicising the project within the communities and helping to recruit potential explorers. One Voice organised a meeting with six South Asian residents, who immediately expressed interest in the roles.

Our Life developed and delivered a three session training package for the residents, which focussed on:

a) Awareness of TB (using a shorter, adapted version of TB Alert's awareness training, and input from Donald Read, Consultant for Public Health, on the local TB data)

b) Sharing the trainee's own perceptions of TB

c) Understanding Community Engagement principles and methods (see Appendix Two: The training Programme)

The group deliberated over the sensitive issues which would need to be carefully handled, and agreed to minimise alarm about TB by reassuring people that it was not at epidemic

proportions and that our aim was to help prevent its further spread by gathering insights into what might help the communities to access health services and protect their own health. The group also recognised the dilemmas in trying to answer clinical questions about TB, as it is a very complex and specialist topic, so they decided that they would only convey basic messages about the importance of seeing a GP if anyone had fears that they might have TB, and that it is curable and treated without cost to the patient.

At the end of the third evening session at Pleckgate High School library, the Explorers devised a questionnaire which they would use for their interviews in the community:

THE TB AWARENESS QUESTIONNAIRE

Date..... Gender..... Age ..... Ethnicity .....

1.What do you know about TB? Eg Symptoms? Cure? How it can be caught? What to do? Who gets it? Where is it from?]

2.How did you learn what you know about TB? Eg experience, newspaper story, study,etc

3.How do you think someone with TB would be viewed by the community?

4.What might help improve the situation?

a) **what could Health services do better?**
b) **what could communities do themselves?**

5. Any comments?

The pro-forma asked people to give their gender, age and ethnicity, but ensured anonymity by not recording names or addresses. The group agreed that it would be potentially intimidating to ask people about their nationality status, as many refugees are facing insecure futures and are understandably very wary of such questions.

NOVEMBER 2014: Beginning the research

From November 2014 the Explorers began testing their questionnaire with friends and family to see if it worked well. Once they were pleased with the outcome, their confidence soared and they began meeting residents in community settings to interview them. They agreed to set themselves a target of six interviews by individual Explorers each week. Every fortnight the team of explorers met with Our Life's Community Engagement Specialist at the Kashmiri Association Community Centre in Whalley Range to analyse the results and decide which sections of the community needed to be prioritised next. The Explorers were intrigued by the views they were hearing from their peers, and continuously discussed how their own perceptions were affected by the emerging picture. By the end of January 2015, the Explorers had conducted 327 interviews!

Results:

Profile of those interviewed

Profile	Number of interviews
Pakistani Male up to age 21	**25**
Pakistani Male aged 22-55	**44**
Pakistani Male aged 55+	**7**
Pakistani Female aged up to 21	**38**
Pakistani Female aged 22-55	**38**
Pakistani Female aged 55+	**13**
Indian Male up to age 21	**16**
Indian Male aged 22-55	**31**
Indian Male aged 55+	**9**
Indian Female aged up to 21	**25**
Indian Female aged 22-55	**29**
Indian Female aged 55+	**1**
Asian male under 17	**9**
Asian female under 17	**10**
Other heritages	**26**

Findings:

TB Medical knowledge within the communities:

1. The interviews revealed a huge diversity in awareness levels about TB.

2. It is impossible to generalise about higher or lower levels of awareness amongst any particular heritage group – there are 'experts' and 'novices' in all age groups, ethnicities, and both genders.

3. The highest levels of awareness of TB symptoms, diagnosis and treatment were found in people who had studied TB in school or college (46 people) and/or who had experienced TB personally (16 people) , within their family (20 people), close friends (13 people) and neighbours (3 people).

"TB is short for tuberculosis, a disease of the respiratory system. It is caught through other sufferers or from travelling to hot countries such as Africa and the Far East. TB affects people of all ages but is common in elderly and young people. TB was also known as consumption" (Male Pakistani heritage,35)

"TB is a very serious disease. It can sometimes be dormant in the body but if the person is hit with a sudden severe illness it can return due to a weakened immune system..symptoms include fever, cough, sore throat I think" (Female Pakistani heritage,17)

"Did an 8 hours long course at NHS and TB was at the end so wasn't really listening" (Female White Asian heritage,19)

Even among the most knowledgeable, there are significant gaps in their awareness: very few knew about the importance of completing the full 6 month treatment course to prevent antibiotic resistance (2 people).

"I had TB when I was younger, was given antibiotics for 6 months" (Male Pakistani heritage,43)

Some knew a lot about many aspects of TB but also had some misinformation:

"Smoking can cause it and makes it worse" (Female Pakistani heritage,17)

"I think that the germs of this disease are infectious just for a period of time - when that period has gone he is alright" (Male Pakistani heritage,42)

4. Very few of the remaining respondents knew more than three symptoms, with coughing, sneezing and fever being mentioned most often (30 people).

5. Over a quarter of the respondents had some degree of awareness about the serious nature of TB (80 people) but most knew very little about symptoms, diagnosis, or treatment. 30 people knew two symptoms. 28 people knew only one symptom (generally, coughing was mentioned).

   "Lungs can be damaged, or you could die from it. You can catch it from others like a virus" (Male Indian heritage, 21)

6. 50 respondents knew nothing or very little about TB.

7. Some respondents thought TB was no longer in existence in Britain (8 people):

   "It's a thing of past, it doesn't exist anymore" (Female Pakistani heritage,17)

   "It doesn't exist anymore as cures found", (Female Arabian heritage,22)

"It was in the past and doesn't exist anymore" (Male Pakistani heritage,17)

"It only affects people in third world countries, (Female Pakistani heritage,34)

"This is supposed to be a TB-free country" (Male Pakistani heritage,56)

8. TB symptoms and diagnosis are complex and many respondents confused TB with other illnesses: flu was mentioned by 7 people. People who saw TB as an incurable killer (19 people) made associations with cancer, HIV and Ebola.

   "Cough, sore throat, runny nose, feeling faint, muscle pains, migraines - similar to flu symptoms" (Female Indian heritage, 17)

   "it's like cancer, and can kill you" (Male Pakistani heritage, 32)

   "TB means you're dead - it has no cure whatsoever" (Male Indian heritage, 21)

   "it kills you instantly – there's no cure" (Male Indian heritage, 18)

   "Is it like Ebola? Don't scare me!" " (Male Indian heritage, 18)

9. TB was perceived as incurable by 19 people. 25 people knew about anti-biotic treatment, and 2 people said that the 6 month course had to be completed. 14 people though vaccination was the cure (rather than a preventative measure) and 4 people mentioned isolation as a treatment.

   "There is a cure but it has side effects which can be just as bad" (Male Pakistani heritage,47)

   "They would be segregated - that's what they do in hospital" (Female Pakistani heritage,17)

   "It can be cured through an injection" (Female Asian,15)

10. The transmission of TB was understood by 30 people (who cited that it is airborne, a droplet infection, spread by coughs and sneezes from infected people). 6 people mentioned dusty and dirty environments (cotton mills in particular), 4 people saw smoking as the cause, and 4 people believed that shared plates and utensils are a danger, allied to the 3 people who mentioned spit. Other perceived causes were poverty (6 people), cows (4 people), poor hygiene (3 people), touch (3 people), food

allergies (2 people), chemicals ((2 people), drug use (2 people), and a single mention insects.

"Seen posters about TB. Usually have injections on them so assume TB has something to do with the bloodstream" (Female Indian heritage,17)

"It is spread through sharing spoons and plates of an infected person" (Female Pakistani heritage,58)

"I don't know anything but I'm going to guess it is caused from touching someone or having some form of intercourse" (Male White/Pakistani heritage,16)

"I'd feel sorry for them, and think they were living a low standard life" (Female Pakistani heritage,34)

"Look down on them as they probably haven't been looked after" (Female Pakistani heritage,46)

"The badgers gave it to cows who gave it to humans" (three Male Asians, aged 16)

11. When asked where TB comes from, 19 people said Asia, 19 people said Third World countries, 4 said from immigrants, 3 cited the Middle East and 3 said Africa.

"In this country we are immunised but people from third world countries such as India are affected" (Female Indian heritage,38)

Social attitudes in the communities

12. There was a general fear of contagion. This prompted 85 respondents to say that the communities would stay away from TB sufferers to avoid catching TB, although these respondents were not antagonistic towards people with TB.

"People in the community would probably not go close to the person with TB for fear they would catch it. Someone with TB may get sympathy" (Female Pakistani heritage,14)

"They may feel isolated and alone because people will leave them out more" (Female African/Indian heritage,16)

"We don't allow people to share utensils with TB person. Keep our distance from infected people" (Male Pakistani heritage,33)

"*My mom told me to run away from that person and do not touch them" (Male Pakistani heritage,35)*

“When a person gets TB it's gonna be a risky situation so we should stay away from that person” (Female Pakistani heritage,36)

“Catchable - stay away. We can't eat with that person” (Female Indian heritage, 50)

“Don't go near or you will catch TB!” 10 (Male Indian heritage, 45)

“*Stay away - Scared of being contaminated.” (Female Pakistani heritage,38)*

13. Hostile views of TB sufferers were expressed by 58 interviewees. The hostile reactions were related to extreme fears of contagion, where people saw TB as incurable and a killer due to their experiences of health services abroad and from stories heard from others.

“Viewed in bad way by some because they don't have enough awareness” (Female Pakistani heritage, 15)

“In India where I grew up not many people survived the illness, and whole families were treated and sometimes whole villages were quarantined” (Male Indian heritage, 55)

“Back in Pakistan you were told about TB through old wives tales. Can't read English so haven't read anything about it” (Male Pakistani heritage,35)

“Back in India many years ago it was taboo: people were disowned and here in the UK we behave similarly towards them due to fear of catching TB” (Male Indian heritage,67)

“I know it is curable now but people still have memories from the past and deal with it based on past views” (Male Indian heritage,55)

“*I hope that they would be supported but I suspect some people will be quite fearful” Female Black British heritage,47)*

“People in my neighbourhood in Pakistan had it. We were told to stay away from that address and people who lived near them” (Male Pakistani heritage,68)

“The community would try to stay away from someone with TB and whisper about them rather than talk to them” (Male Pakistani heritage,47)

“I think someone with TB would be treated with caution. They may be viewed as 'untouchables' by most of the community” (Female Asian heritage,11)

“W*e should look after the patient but the community think they'll catch it easily and will stay away from that person” (Female Pakistani heritage,43)*

"They would be viewed negatively: they would be labelled as a person who has a contagious disease. People would avoid the sufferer" (Female Indian heritage,17)

"People would talk and stare as if there is something wrong with an ill person" (Female Africa/Indian heritage,48)

"OMG, it's contagious. A boy in my class had TB and everyone stayed away from him: OMG, that TB guy" (Female Indian heritage,17)

"They would be viewed like the plague" (Male Pakistani heritage,40)

"Many of us born abroad still hold the view of keeping people with TB at home and not mixing with others" (Male Pakistani heritage,59)

14. The impact of this hostility on TB patients is to isolate them further:

"People tend to go undercover and the community tend to find out after someone has recovered from it" (Male Pakistani heritage,35)

"People will be scared they might get TB so they will stay away from that person and they will feel lonely" (Female Pakistani heritage, 13)

"They may feel isolated and alone because people will leave them out more" (Female African/Indian heritage,16)

"They would be a social pariah. People are afraid they might catch it" (Male Pakistani heritage,18)

"*They don't let people know they have TB -embarrassment!" (Female Pakistani heritage, 48)*

15. The stigmatising myths included stories about TB being the result of the sufferer's lifestyle (smoking, poor hygiene, diet). In response to the question about who is at risk of TB, 4 people said it was prevalent in developing countries but eradicated here. 6 people linked TB to homelessness

"I used to hear about cases in Pakistan when I was young but very rarely hear about it here" (Male Pakistani heritage, 59)

"It came from Arabs being unclean and not washing their feet" (Male White/Asian heritage, 16)

"Auntie in Pakistan had it. She never used to eat properly so got TB" (Female Pakistani heritage, 64)

"I know about TB from India-didn't think it occurs here" (Male Indian heritage, 42)

16. The source of most people's negative information was word-of-mouth from family, friends or overheard conversations (82 people). 7 people mentioned stories they had been told as children in South Asian countries. 20 people had read newspaper stories, 17 people had seen TV programmes which mentioned TB, and 14 people had read about TB on the internet.

"An extended family member had it many years ago and I heard my parents talking about it, and from what I remember we did not visit the family for a long time" (Male Indian heritage,21)

"Resources on TB and how it can be caught are widely available on the web. These include newspaper stories, case-studies, real life examples" (Male Pakistani heritage,35)

17. Sympathetic views of TB sufferers were expressed by 52 respondents across all ethnicities, age groups and both genders, prompting a call for more caring and support for TB sufferers and their families. 11 people said that attitudes nowadays were much better than in the past because TB is now known to be curable. People who knew TB is curable were much more relaxed about TB and more supportive of TB patients and their families (32 people said that they knew enough about TB to feel 'okay' about people with TB, and 13 people said that it was just an illness, to be treated carefully but without added anxiety..

"Nowadays people have more knowledge about the illness. 15 + years ago it was regarded as an illness that once caught would kill them. Keep away from them" (Female Pakistani heritage, 45)

"It's different nowadays due to improvements in NHS services. People know that they can get treated. Not as much of a taboo as before" (Male Pakistani heritage,35)

"TB has stigma surrounding it and people shun those with TB but this is improving now due to better understanding" (Male Pakistani heritage,36)

"We help people and give them positive ideas" (Male Indian heritage,51)

"Don't leave them alone - spend time with that person and give them their meds on time" (Female Indian heritage,31)

"We should look after that person, spend time with them so that he doesn't feel he's got a very serious illness" (Female Pakistani heritage,70)

"Treat him as a normal person as it's not infectious" (Female Indian heritage,21)

"I don't think there is a stigma - it is something that South Asian communities accept" (Female Indian heritage,38)

"I think that the germs of this disease are infectious just for a period of time - when that period has gone he is alright" (Male Pakistani heritage,42)

"It can't be spread from sharing cups or cutlery - so after doctor's advice we should treat him like a normal person" (Female Pakistani heritage, 30)

"It's not that sort of disease that we should keep away from that person. According to me he'll be alright in the community" (Female Indian heritage,35)

"*People stay away because they think they'll get TB easily. I think we should give more awareness to people so they change their attitude" (Female Pakistani heritage,47)*

"I thank all the people looking after TB and trying to cure them. People with TB: hang in there" (male Asian, 15)

"Make sure people with TB are treated equally and are not bullied" (Male Asian,16)

18. The sympathetic reactions were prompted by personal experience of TB (52 people said personal experience had affected their perception of TB).

"Dad used to have it. When you cough, blood comes out. Dad's experience made me aware, but never seen it on the news. Learnt a little in AS level Biology at college" (Female Indian heritage,17)

19. Other positive views were expressed by people who had received education about TB being curable (41 people had learnt about TB in school biology classes, 5 had college inputs, 14 had undertaken person study, and 5 had medical training. 7 had learnt from their GP, and 9 had read NHS leaflets or brochures. 14 had learnt about TB from having the BCG vaccination.

20. As a result of receiving education about TB, people were more aware of risk factors: 14 people mentioned weak immune systems, 2 mentioned diet, 6 mentioned homelessness, and 2 mentioned unvaccinated people. In contrast to the perceptions that TB is now ethnic-specific, 20 people stated that anyone can catch TB if they are in contact with an infected person.

21. Ironically, lack of awareness of TB as a danger can sometimes have positive effects on social attitudes:

"Most people wouldn't know and would treat them as a regular person. A minority are aware of the condition and may be cautious in coming into contact. Many are not informed of the disease and are oblivious to the dangers" 160 (Female Pakistani heritage,14)

"If they had a lot of knowledge they would be scared to come into close contact" Male Pakistani heritage,18)

"*I doubt it would stop me working with anyone but I don't know all the facts" (Male Indian heritage,54)*

Suggested improvements in Health Services from the communities' perspectives

22. The majority of respondents (184 people) suggest the need for a basic awareness campaign for all communities, focussing on symptoms, treatment, prevention, and reinforcing the message that TB is curable.

"There needs to be much more awareness - we need more info!"(Female Pakistani heritage, 16)

"Make more people aware so you're able to catch it early. Set up support groups" (Female Indian heritage,18)

"Make symptoms clearer: how do they differentiate from normal flu symptoms?" (Female Indian heritage,17)

"Tell people that TB's treatment is free so that when a person knows he's got TB he'll go to the GP immediately" (Female Pakistani heritage,70)

"Health services could educate people about TB, how it is caught and how to spot an infection. Leaflets, community events" (Female Indian heritage,17)

"Increase awareness that it can be cured, it's not deadly" (Female Pakistani heritage,17)

"The truth behind TB needs to be told to us to dispel any lies" (Female Pakistani heritage,43)

23. GPs were cited as key players in transmitting better information about TB. 54 people mentioned the GP as their first contact if they were concerned about having TB. Local check-ups for TB were recommended by 53 people, to ensure that early diagnosis helped to prevent the spread of TB. Screening and vaccination was mentioned by 20 people.

"Go to the GP asap because if not caught early it can lead to death" (Male Pakistani heritage,45)

"We need annual GP check-ups at mobile walk-in centres" (Female Pakistani heritage,46)

24.Opinion was divided on the best methods of communicating messages about TB: leaflets and posters in GP surgeries or hospitals were suggested by 36 people, with 10 people emphasising the need for information in community languages.

"Raise awareness - posters in better viewed places, milk cartons etc so people WILL read it
Regular full Health Checks should include TB. Advertise on social media groups, push youngsters to get involved" (Male Pakistani heritage,18)

"The Health services could send leaflets to homes to help introduce TB" (Female Indian heritage,17)

"*Advertise health messages rather than promote businesses" (Male Pakistani heritage,25)*

"Clearer details advertised by NHS and GPs to explain TB better" (*Male Pakistani heritage,47)*

"More people need to be aware so you're able to catch it early. Set up support groups (Female Indian heritage,18)

A community focus group on February 18th 2015 brought together the six Explorers and six South Asian residents to discuss these findings. The focus group felt that leafleting should be in as many community languages as possible, using existing communication networks such as schools and surgeries, and focus on challenging myths about TB so that sound information about treatment and prevention would be heeded. Community awareness events would need to be incorporated into Fun Events as people wouldn't be attracted to TB information days alone. Professionals

would need to be alongside community leaders to ensure accurate information about TB was shared.

24. TV advertisements were suggested by 23 people

25. Information has to be delivered with reassurance, because there are heightened fears about TB. Accordingly, face-to-face methods of communication were recommended to ensure the human touch helped people to explore the facts and myths about TB. There was warm support for professionals to engage in community-based events to raise awareness about TB (14 people), alongside community leaders and speakers with TB experience.

"Create groups for people to learn more and make people feel better" (Female African/Indian heritage,16)

"They could do group counselling which can raise awareness and allow people to discuss their feelings about people who have TB and about support they can get if they have more questions" (Female Pakistani heritage,17)

"Raising awareness may help people to identify the symptoms quicker eg charity events, and urge them to get looked at by a doctor. More medical support may also help in curing quicker" (Female Indian heritage,18)

26. Many respondents called on Health professionals to work closely with other agencies, particularly schools and colleges, to raise awareness of TB amongst young people (26 people). The interviews with under-21 year olds revealed a wide diversity of awareness: those who had attended biology classes had a lot of information, while many others knew nothing or quoted stories they had heard from elders. People over 40 remembered the BCG vaccination in schools and felt that younger people today needed opportunities to find out about TB.

"Target more age groups in a wider area. Tell people regardless of an existing risk. Inform schools and colleges. Target people who have a large impact on others" (Female Pakistani heritage,15)

"Not enough people know what it is. I only know about it through A level biology.
Talks in college for students would help. Leaflets are not very effective.
Can use youtube as way to get word across to teens" (Female Pakistani heritage,17)

"Advertise better to youngsters, using foreign languages for those who don't speak English" (Female Pakistani heritage,46)

"The NHS could educate people through increased use of partner organisations, such as clinics, pharmacies, community-led partnerships, faith organisations" (Male Pakistani heritage, 25)

27. Some respondents had negative personal experiences of TB health services (6 people) and called for improvements in support, including families feeling more included in the process and better information about side-effects of medication. More TB nurses were seen as the answer to reduced waiting times by two people who had experienced frustrations in having TB treated. 6 people praised the NHS TB services.

    23 people called for more staff and care for TB sufferers, to reassure patients and their families quickly, and create a service which destigmatises TB.

    "More workers in the hospitals, especially in the North as there are more in the South which is unfair. Pay more attention to the patients, proper checks. TV adverts" (Female Indian heritage,17)

    "Explain the tests better to the public as we were treated like sheep when tested" (*Male Pakistani heritage,77)*

    "Health services need to treat the families of TB sufferers better. My friend's brother had TB and she was made to wear gloves to see him. I understand it is a safety precaution but it reinforces the idea that we should stay away from TB sufferers" (Female Pakistani heritage,18)

    "*GP didn't refer a family member until it was set in him" (Male Indian heritage,41)*

    "Explain to non English speaking people with interpreters" (*Male Pakistani heritage,33)*

28. 11 people suggested vaccination and more research.

Community assets

29. The communities recognise that they can be active players in sharing awareness of TB, detecting symptoms early and urging people to see their GP, developing pro-active health activity (diet, exercise, smoking cessation) and offering care and support to TB sufferers and their families (helping people take their medication consistently,

befriending, and challenging any myths and antagonisms). There are already a significant number of people in the community who have very positive mindsets about supporting people with TB (36 people wanted to be involved in caring for TB patients within the community, and 20 people expressed sympathy for people with TB).

"Communities should not marginalise TB sufferers and should give them more support 72 (Female Pakistani heritage,17)

"Communities need to work with health services and not scare people"(Male White English heritage,17)

"We avoid people with TB but if we could be of help I would help. We are a selfish community ,too bothered about ourselves" (*Male Pakistani heritage,18)*

"Learn to help a person with TB, not neglect them and treat them as though they are a disease"(Female Pakistani heritage,15)

30. The communities want to generate their own self-help awareness-raising to complement and partner the input from professionals. 64 people mentioned self-education, supported by easy-to-understand information about symptoms and treatment.

"It's our own responsibility to do it better. In our communities people don't co-operate with NHS. When they send letters to attend Women's health check for breast cancer or smear tests, only one in ten goes there. So it's not the NHS - it's our own duty to look after ourselves" (Female Pakistani heritage,30)

"We should have a positive attitude towards this illness and help to combat TB" (*Male Pakistani heritage,33)*

"They could stop viewing people with TB as 'untouchables' and start helping them out a bit more. TB would be cleared a lot more quickly and they would be safe" (Female Asian heritage,11)

"Communities could hold stalls at events, promoting general good health and wellbeing - in return this would deter diseases and save NHS a lot of money!" (Female Pakistani heritage,48)

"Communities could have more interaction and communication through neighbourhood groups and discuss and find out about the issues, maybe distribute leaflets informing people about it"(Female Indian heritage,40)

"Communities could advise one another on TB - how it spreads etc, and ensure anyone who has been infected is seen to by a medical professional asap to prevent spread. They can also improve sanitation in their own homes" (Female Indian heritage,17)

"Look for symptoms in local community. Take care of one another" (*Male Pakistani heritage,18)*

"Teach one another, through word of mouth" (Female Indian heritage,52)

"Communities need to discuss and pass on info, and dispel wrongly-held beliefs" (Male Bangla Deshi heritage,44)

"Community to discuss more, volunteers to visit community centres and have posters to show helpline number and website address" (Male Indian heritage,32)

"Communities could discuss this problem to the public but make sure they don't make people feel excluded" (Female Indian heritage,17)

"Communities should take care of that person -make sure he goes to appointments, takes his meds on time and finishes the full antibiotic course of 6 months" (Female Pakistani heritage,42)

31. There is a vital role for community network organisations in making the community-agency partnership happen: One Voice played a huge part in facilitating the Explorers project at every stage. Community venues can be accessed through these networks so that TB can be discussed in settings where communities feel at home, and residents respond positively to invitations via the network organisation.

    "People with experience of TB should tell others about what it really is and what actually happens" (*Male Pakistani heritage,77)*

    "Communities could attend workshops and focus groups with the potential to generate increase in awareness of TB and its implications"(*Male Pakistani heritage,35)*

    "Charity events where there are professionals to explain" (Female Indian heritage,18)

32. Community leaders can be very effective champions in raising awareness of TB and allaying fears. 4 people suggested work with mosques and madrassas

    "Use influential people to talk about TB" (Female Pakistani heritage,17)

33. To some extent, the communities' awareness was developed by the TB Explorers as a bi-product of talking about TB in the course of interviews. Several residents thanked the Explorers for raising the issues with them and being committed to the communities' wellbeing. The six TB Explorers are now trained and confident community engagers and could continue to be very effective assets within their own communities in future.

Recommendations

1. Generally, the research endorses the approach to community empowerment outlined by AMPH:

   Empower people with TB and communities through partnership.

   - Pursue advocacy, communication, and social mobilization.
   - Foster community participation in TB care.

(The Social Determinants of Tuberculosis: From Evidence to Action: James R. Hargreaves, PhD, MSc, Delia Boccia, PhD, Carlton A. Evans, MD, PhD, DTM&H, Michelle Adato, PhD,Mark Petticrew, PhD, and John D. H. Porter, MD, MPH, American Public Health Assn, April 2011)

2. The Explorers are trained in TB awareness, have strong relationships with others in their communities and have been instrumental in starting the conversations about TB. It is recommended that the Explorers continue to play a leading role in health awareness campaigns as a valuable resource.

3. The community-led research has proved to be very effective in reaching a relatively large cross-section of the South Asian communities. It is recommended that the 'explorer methodology' be utilised for other health issues.

4. The facts about TB are not widely known. Ignorance or myths from overheard stories breed fear, and this misinformation needs to be rectified to reduce stigma, anxiety and hostility. It is recommended that an awareness campaign focuses on simple key messages (how to detect symptoms; reassurance that it is curable with six months of antibiotics taken every day; go to your GP first; it is not virulently contagious; antibiotic stops spread within 2 weeks; you will receive emotional and medical support)

5. Professional and communities could consider how to include TB awareness activities within community-based events to develop more open discussion in the communities and reduce stigma. People who knew TB is curable were much more relaxed about TB and more supportive of TB patients and their families.

6. Young people have an important role in challenging past myths and cascading sound information throughout their communities. It is recommended that awareness raising is conducted within secondary schools and colleges, with teaching resources to help convey the facts and issues about TB.

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This project was made possible by the combined efforts and dedication of BwD's South Asian communities and BwD Public Health:

The Explorers: Danyaal Mahmud, Ehsan Raja, Farkhanda Fatima, Mariyah Mahmud, Shabnum Ahmed, Zaheer Mahmud

One Voice: Zaffer Khan

The Commissioners: Donald Read, Gifford Kerr and Kenneth Barnsley (BwD Public Health)

Appendix One: the training programme

SESSION ONE focussed on helping the Explorers become aware of TB. The group worked in pairs to create a Word Association spider which expressed their current perceptions about TB. This revealed associations with Death, Coughing, Serious illness, Needles and Poverty.

The group agreed the project timescale and were inducted into the basic facts about TB by working through an adapted version of TB Alert's slideshow, "The Truth About TB". This presentation gave them the data about TB globally, nationally and locally, and clarified the medical side of TB – different types of TB, how it spreads, symptoms, diagnosis, treatment and prevention. They were heartened to hear that TB is preventable and curable, and began to explore the social dimensions of TB: how TB is presented in the media, the myths which prevail and the stigma which increases TB sufferer's isolation. They discussed how these myths may affect communities, and how community specific stigma may delay that delay people from seeking healthcare if they have symptoms. They debated how to challenge myths effectively with real information about TB.

SESSION TWO introduced Donald Read, Consultant in Public Health for BwD. Donald presented the local data on TB, and facilitateded the group's discussions about the medical and social issues. They explored the social dimensions: TB isn't about identity – it's about risky situations and behaviours, some of which cannot be chosen, including spending time with someone with infectious TB, living where TB is more common eg.cities, having close

links to a country where TB is common, overcrowded living conditions, unventilated environments eg prisons, and having weak immunity systems. They discussed how the medical and social factors can combine and the positive factors which can help prevent TB eg. how maintaining a healthy immune system can generally kill off TB bacteria or hold it dormant.
The Explorers were also thinking about the sensitivities in raising awareness of TB without exacerbating fears. They decided that the medical complexity of TB meant that they wouldn't be drawn into clinical issues but would signpost anyone with anxiety about TB to contact their GP immediately. They developed a short list of important messages which they would mention after interviews with residents: that TB is curable, that someone with TB is isn't infectious after two weeks of antibiotic treatment, and that the full six month course of treatment is essential to prevent antibiotic resistance.

By the end of session two, the group were ready to plan how they would be communicating their aims and role to their communities, and a series of key questions which they would be using in future interviews:

What do people know about TB?
Where did they get that info from?
How do people think TB sufferers would be viewed by the community?
How can we improve the situation through the actions of agencies and communities?

These questions were turned into a questionnaire, which the Explorers took to their families after the session to test its effectiveness as a tool.

SESSION THREE focused on the engagement approach and methods. The group improved the Questionnaire and decided to reassure residents about anonymity by only asking for personal details about age, gender and ethnicity. The Explorers decided not to ask people about their nationality status as they felt this would be intimidating for refugees and asylum-seekers who may be facing very stressful situations.
They planned where and when they could locate all sections of the South Asian communities, including Women , Men ,Younger people , Older People , Refugees and Asylum seekers, and recent migrants to the UK. They decided to start with 'the lowest hanging fruit', the people they were already in close contact with. This strategy helped to build their confidence in interviewing before extending their reach to others.

Finally, the group practiced skills in interviewing: how to introduce our project, how to help people feel at ease when talking, ways of asking open questions and prompting, and how to record findings. They explored the safety issues and developed their own policy: they would avoid door-knocking or leafleting, as they had personally felt alienated by these experiences.

By the end of this session, the group felt confident in introducing and using the Questionnaire independently, and agreed to start the research phase. Their evaluation forms revealed 100% happiness with the training and their confidence in carrying-out their roles. They agreed to meet with Our Life fortnightly to review progress and plan the next stages based on lessons learnt from experience.