

## **Subject: Tackling Tuberculosis (TB) in Newham**

**Source:** 'Have your Say' TB Information and Workshop event by Healthwatch Newham in association with Barts Health NHS Trust and TB Alert

**Purpose of Report:** This report seeks to highlight the concerns of residents and service providers in Newham.

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### **Recommendations for Health and Wellbeing Board, Newham CCG and London borough of Newham Council**

7<sup>th</sup> July, 2014 is the next Health and Wellbeing Board meeting and is asked to note:

The recommendations presented by residents and key service users on tackling the problems associated with TB specifically, access to services and service delivery.

### **Purpose of Recommendations**

Newham is the Tuberculosis capital of Western Europe with the highest rates of TB in London and in the UK.

### **Background**

Each year, worldwide, approximately 9 million people become unwell with TB and last year there were 1.3 million deaths.

In 2012, 366 residents were diagnosed with TB in Newham, a staggering rate of 117 per 100,000 of the population. Treatment completion rates in Newham are below the London average with 1 in 10 patients being lost to follow-up. Levels of drug resistance are also higher in Newham than the London average. The role of Healthwatch Newham is to advocate for health and social care services across Newham and in doing so, improve the quality of services. Healthwatch Newham held a 'Have your say on TB' workshop and information event on 28<sup>th</sup> March 2014 in association with Barts Health NHS Trust and the UK national TB charity, TB Alert. The event was well attended by residents, local healthcare workers, and representatives from Barts Health NHS Trust TB Service, Newham Council, Public Health England and Newham's Clinical Commissioning Group (CCG).

The user engagement event was marketed heavily within Healthwatch Newham, Barts TB service and TB Alert networks. This included posters and flyers displayed at the Newham University Hospital TB clinic. Healthwatch Newham provided a lengthy editorial in the Newham Recorder.

The aim of the event was to educate attendees on what is Tuberculosis, and to seek feedback on issues relating to TB in Newham. The attendees were informed that Healthwatch Newham would give their recommendations to the Health and Wellbeing Board and the Newham CCG. Two workshops were arranged looking at the following aspects in relation to Tuberculosis:

### **Workshop 1**

- What is TB?
- What concerns you about TB?

### **Workshop 2**

- How can we tackle the high incidence of TB in Newham?

**Concerns raised by attendees during Workshop 1 relating to TB in Newham:**

#### **1. Poor understanding and awareness of TB**

Attendees felt that there was poor awareness of the problem of TB in Newham and a lack of understanding of what TB is, who gets TB, how it is passed from one person to the other, what the treatment involves and that it is a curable disease.

Also, the public were concerned that they did not understand why Newham has the highest rates of TB in the UK. Is it due to the high immigrant population within Newham or, due to the social deprivation within the Borough?

#### **2. Stigma attached to TB**

Attendees felt that there was no focus on tackling the stigma which is associated with TB, especially as the majority of people contracting tuberculosis in Newham come from backgrounds where TB is shunned publically.

There was a general understanding that there is a stigma attached to TB amongst many different cultures. Some communities believe the disease to be incurable, African communities often associate it with HIV. Many people believe it is always highly contagious, even if it is TB outside of the lungs. Attendees felt that tackling the stigma associated with TB was an important issue for the board to address.

It was also highlighted that information on TB in multiple languages is not readily available across Newham which impacts on TB awareness amongst migrant populations.

### **3. Access to healthcare**

Attendees felt that TB services were focused within local GPs and hospitals and were not reaching people that do not always access GPs, especially women, young adults and adolescents. The point was made that the people most affected by TB (young men) often were working and struggled to access services within the normal working day.

### **4. BCG vaccination**

Concerns were raised that children who move into Newham may have come from regions where they would not have been offered a BCG at birth. These children are then never offered a BCG as there is no teenage BCG vaccination programme and no other time when they are screened for BCG status.

### **5. TB screening**

Current screening programmes were not 100% effective in picking up new active TB cases. Specifically, concerns were raised about children migrating to the UK from European Union who are not subject to any screening programme. Furthermore, screening for new-entrants was not readily known about nor clear. There was a concern that despite new pre-entry screening that some people would enter the UK having not been screened for active TB (for example holiday-makers and undocumented migrants).

Attendees had no prior understanding of latent TB infection. After the introductory educational lectures, they understood that treating latent TB infection could prevent someone from becoming unwell and therefore infectious with TB. They felt there should be screening and treatment for latent TB infection as well as for active TB infection.

## **Ideas generated by attendees during Workshop 2: How to tackle TB in Newham**

### **1. TB awareness**

It was voiced that schools, crèche facilities, NCT classes, places where outreach could be important, were not targeted by current TB services.

Faith groups, homeless shelters and shopping centres were other places suggested as good targets for awareness raising campaigns and education. The use of local magazines, newspapers and radio were highlighted as potential tools which could be better used to improve TB awareness and education. A Newham based TB awareness text messages and the use of social media were other ideas.

## **2. Reducing the stigma associated with TB**

Raising awareness in itself was felt to help reduce stigma associated with TB but it was also appreciated that more targeted ‘myth-dispelling’ information events would be useful.

It was suggested that community groups or advocacy groups for people with TB would be helpful to support and educate both patients and their families.

Attendees thought that a ‘TB Champion’ who was famous and could openly discuss their own experiences would help reduce stigma. A local campaign similar to the ‘I survived cancer’ campaign was also suggested as this could help raise awareness and break down stigma.

## **3. Improve healthcare access**

Provision of TB services which were local and accessible was an important point for attendees. Walk-in clinics were suggested, alongside adequate access to translators and educational materials written in different languages.

Attendees also suggested that the most vulnerable TB patients should be supported financially throughout their treatment. There should also be a strong element of education for newly diagnosed TB patients. It was felt both these points would improve treatment completion.

It was emphasised that TB services within the borough should be protected from political and financial pressures.

## **4. BCG vaccination**

It was suggested that all children that had moved into Newham, having been born elsewhere, should be offered the BCG vaccine.

## 5. TB screening

This was addressed by Margaret Chirgwin, Director of Primary Care Strategy, and Newham CCG, who outlined the new screening programme for latent TB, set to go live in April 2014. Currently the plan is to screen all people registering with their GP who have come from a country of high incidence of TB for latent TB infection.

## 6. Key Recommendations

### *Targeted TB awareness at:*

- Schools
- Mother & baby groups
- Birthing classes
- Faith groups
- Homeless shelters
- Community centres
- Sports clubs

### *Reduce the language barrier:*

- Educational materials in a variety of languages
- Improve access to translators for patients

### *Improve access to healthcare*

- Walk-in, locally based TB clinics
- Outreach clinics to educational facilities to target students' aged between 16 and 25years old.

### *Financial support for vulnerable TB patients throughout treatment*

- Housing
- Food
- Travel to clinic

### *Improved use of technology and media to raise awareness and break down stigma*

- SMS awareness texts
- TB screen savers
- Social media
- Radio, local TV and local newspapers and magazines

### *Funding*

Increase funding for TB services and ring-fence the budget, to ensure that services remain consistent, despite changes in local or national Government.

***Housing***

Address issues around overcrowded living conditions within the borough.

***School children***

Screen all children who newly enrol at a school or at a new GP surgery for a BCG vaccination status and ensure they are offered the BCG vaccination if they have not had it.

***At-risk groups***

Screen at-risk groups for latent and active TB at GP registration.

## **7. Conclusion**

We hope the decision-makers on TB service provision and support take on board our recommendations and work in partnership to take the serious public health issue of TB in Newham.

Report completed 23/04/2014.

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