

Healthwatch Evaluation of Patient Experience: Latent Tuberculosis (LTBI) in Newham March 2017

INTRODUCTION

Healthwatch Newham is an independent local organisation, and part of the national network led by Healthwatch England, established under the Health and Social Care Act 2012. Healthwatch Newham is the independent voice of local people and works to enable residents to contribute to the development of quality health and social care services, and to provide information on local services in Newham. Healthwatch Newham was formed in April 2013.

BACKGROUND

In October 2016, Newham Clinical Commissioning Group (CCG) commissioned Healthwatch Newham to learn about the patient experience and feedback on the Latent Tuberculosis Infection screening service (LTBI) in Newham, in order to identify the key factors that influence the uptake of screening and understand why patients decline the LTBI test.

Latent TBI is commonly described as 'sleeping' TB bacteria which can wake up and become active TB. Identifying and treating Latent TB will reduce the risk of it activating. As part of the national LTBI programme, Newham is offering screening to 16-35 years old, who were born or lived in a high-risk country. The offer was initially aimed at newly registered patients and the CCG has now started to offer patients that are registered on their list in the last 5 years.

The aims of the project were

- to carry out research amongst Newham service users of the LTBI screening primary care service currently provided by Newham CCG
- to engage with service users to obtain their feedback on the service, how it has worked for them and what improvements can be made with specific attention to the following areas
 - Feedback and information from patients who have taken the test
 - Feedback and information from patients who have declined the test
 - Feedback and information from patients who are eligible for the test

The objectives were to

- understand the intricacies of test decline
- understand the intricacies of test uptake
- improve the patient experience with the LTBI screening service

OUTCOME SUMMARY

Feedback from patients suggests that the client's level of engagement with their GP, and their awareness of Tuberculosis or Latent Tuberculosis, tends to have an impact on their uptake of the test.

Patients who have accepted the test suggest that their GP directly offers the test, part of a general check-up, explains the nature of Latent TB and the benefit of having the test, and provides reassurance to the patient. These act as the main reason for take-up.

Patients who have declined the test, usually do so because they think it is not relevant or not helpful as they think that they do not meet the eligibility criteria that are sent to them by their GP via a text message or a letter (eg having entered the UK in the past 5 years). Another reason is that they have already had the test in the past as an entry requirement to the UK.

Overall, patients suggest that the best way to encourage people to take the test is by offering it as part of a general check-up, and raising awareness of TB or Latent TB, by direct contact, the benefits of testing for Latent TB, the risks associated of catching TB, and the availability and feasibility of treatment.

METHODOLOGY

Placement in GP practices:

Newham CCG wrote to 19 selected GP practices. Six GP practices agreed to take part in this review. The Healthwatch Newham researcher carried out 12 visits to the following:

- Bolyen Medical Centre
- Claremont Clinic
- East End Medical Centre
- The Project Surgery
- Sangam Surgery
- The Transitional Practice

Phone interviews were carried out with patients in 6 GP practices. Patients were selected from a pre-defined list of eligible patients on EMIS system. Once a patient agreed to complete the interview/survey, they were briefed about the survey, how long it will take, and that it is going to be used to improve the service. All answers were confidential.

FINDINGS

Patient's background

- Calls were made to 299 patients; 60 patients provided feedback, from 6 GP practices
- 85% aged 26-36; 15% aged 16-25 years old
- 69% are Asian, 17% are Other (Philippines..etc), 12% are Black, 2% are White Other (East European)

Survey responses

Patient take up

- Patients are usually offered the test by an invitation letter, SMS text message, a phone call or a direct GP invitation
- 22% have declined the test, or were offered the test but did not take it up
- 22% accepted or took the test
- 56% were eligible but have not been offered the test yet
- Women are more likely to take the test
- Men are less likely to be offered the test
- Bangladeshi patients are more likely to take the test compared, to other Asian patients
- Indian patients are more likely to be offered the test, but did not take it or decline it
- Pakistani patients are more likely to decline the test

Reasons for taking the test

- The main reason to take the test is:
 - o Test has been offered directly by their GP or nurse
 - o Test has been part of a general check-up
 - o To enter the UK or for a visa application

Reasons for declining the test

- Of those who declined, or were offered the test but did not take it up, 28% say that they were not offered the test. However, their GP notes show that they were offered the test and declined it or did not take it.
- The main reason is that they:
 - o Had the test before as part of an entry requirement to the UK and they felt it was not applicable to them.
 - o Did not feel it would be helpful, or the test does not apply to them (eg they have been in the UK for more than 5 years)
 - o Had a long time to wait to have the test, or too busy to have it

Awareness of the test

Of those who say they were not offered the test, they were asked questions to learn about the general awareness of TB or Latent TB. This is important as it may help understand as to why these patients may decline the test

- 83% think that there is no medicine to prevent TB, or do not know if there is any
- 66% think that people cannot have inactive TB germs in their body, or they do not know if people can have Latent TB
- 58% do not think or do not know if people, with HIV have Latent TB, are more likely to develop active TB
- 37% think that TB cannot be passed on to another person through the air, or do not know if so
- 35% do not think or know if doctors, generally, in the UK know how to treat TB or Latent TB
- 17% think that people can be deported from the UK for having Latent TB

Specific feedback

Across all patient groups, TB or Latent TB is seen as a lung disease, usually accompanied by coughing. Blood test for TB or Latent TB is seen as a way to find out if someone is ill or not. However, some patients expressed their anxiety when they are invited to have a TB or Latent TB blood test.

Reasons as to why patients decline:

- Previous test done for immigration purposes: An entry requirement to the UK
- Awareness: Patient does not know much about TB or LTBI, and they think it is not relevant to them
- Anxiety: patient does not want to know if they already have TB

Reasons of not responding to a Tuberculosis invitation letter/SMS text:

- Eligibility criteria: Patients think that they have been in the UK for more than 5 years, therefore, they feel that the test does not apply to them
- Awareness: As mentioned earlier, patient does not know much about TB or LTBI, and they think it is not relevant to them
- Inconvenience of appointments: Patients find the location and time of tests not convenient

Reasons as to why patients accept or take the test:

- General GP offer: the test is directly offered to patients as part of a general/regular GP check-up
- GP reassurance: Patients claim that they receive limited or no information on LTBI from their GP. When offered the test, they felt anxious about having the test. However, patient tends to take up the test when offered reassurance by GP. Those who were informed by their GP,

they were provided with an explanation of the benefit of having an LTBI test, and the risk of developing active TB, with reassurance offered to the patient

- An entry requirement to the UK
- Anxiety to know if they have TB or Latent TB

Patient's views on why some individuals from their community decline to have the test

- Not taking it seriously and lack of awareness of what TB or Latent TB is
- Anxiety to know if they have TB or Latent TB
- Too busy to take the test

Patient's suggestions on how to encourage individuals from their community to take the test

- Raising awareness of:
 - o What TB or Latent TB is
 - o How it affects the person
 - o How it affects vulnerable groups such as pregnant women and babies
 - o Risks of TB and Latent TB
 - o That cure is available
- Offering the test as part of a general GP check-up or a registration requirement at a GP practice

OBSERVATIONS

- GP practices that invite patients by phone to take the test, are more likely to have the patient take up the test, compared to practices that send letters or SMS only
- Although patients at-risk are pre-identified on EMIS in each GP practice, there is not necessarily a reminder on EMIS that helps GP 'remember' if a patient is at risk
- Patients think that TB or Latent TB test does not apply to them, due to patient's lack of awareness of what TB is. For example, one patient thinks that TB is a sexual disease, and therefore, people decline to take the test due to the stigma attached to this sexual disease. Other patients say that people who are frequent travellers or heavy smokers can develop TB, and therefore, the test does not apply to them.
- Many patients think that TB has no cure or medicine, which may cause anxiety to get tested for TB.

RECOMMENDATIONS

- To commission and to develop a community engagement scheme to raise awareness of TB and Latent TB among at-risk communities, working closely with the voluntary sector, including mothers' groups and children's centres
- To commission a dedicated TB community development worker, based in GP practices to engage with at-risk patients, and to ensure their uptake of test
- To ensure that the LTBI test is being offered to existing and new GP patients as part of a general GP check-up
- To ensure that information disseminated to individuals and communities about TB and Latent TB is reassuring and to include information that covers the following: what is TB and Latent TB, how it can be passed onto others, risks, and that the disease is curable and that treatment is available.
- To consider commissioning and developing a peer support scheme to raise awareness of TB among communities