A multi-perspective service evaluation exploring tuberculosis contact screening attendance among adults at a North London hospital

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ABSTRACT

Background Non-attendance at TB contact screening clinics has been highlighted as a common phenomenon across a number of sites during recruitment to the PREDICT TB Study. This has obvious implications for the safety of patients, their communities and for NHS resources. The objective of this study was to explore why adults who have been in contact with TB do, and do not, attend their screening appointment, thereby allowing identification of interventions to reduce non-attendance.

Methods A multi-method approach was taken using 15 questionnaires with adults who attended for screening, 15 telephone questionnaires with adults who did not attend and in-depth interviews with 8 TB nurses. Interviews were coded to trace emerging descriptive themes, then refined through an iterative process of interpretation and recoding.

Results Findings from the questionnaires and interviews were categorized into three principle themes following analysis: awareness, hospital factors and leadership. These themes deconstruct the complex phenomena of patients’ lack of attendance at this TB contact screening service.

Conclusion Recommendations related to issues of leadership, outreach services, flexibility of clinic timing and awareness amongst both the local community and GPs were made.

Keywords communicable diseases, public health, quality

Background

In an effort to combat the rising incidence of TB in the UK, national guidelines outline a range of interventions, including active and passive case finding in the community, to investigate contacts of cases and those in high risk groups. Case finding is challenging due to the high non-attendance rate in these groups. Case finding is challenging due to the high non-attendance rate in these groups. Anecdotal reports from clinic staff collaborating on the NIHR funded UK PREDICT study (NIHR 39607) indicated non-attendance at 20–60% in London, a variable rate reflected at the NPH clinic, though there was no published data or formal elucidation of reasons why the rates were so high. Added to the NHS cost of non-attendance is the possibility that infected individuals remain undetected, untreated and a potential source of onward infection.

There are several factors that may underlie non-attendance. Generally contacts are well at the time they are invited and unaware of their exposure. The identity of the active case is not usually revealed and this can affect risk perception. Furthermore, there can be stigma preventing foreign born
index cases from naming their contacts, which may be further exacerbated by contacts’ visa status. Research in gastroenterology outpatients, and primary care reported patient non-attendance was largely because they forget appointments. Other reasons included fear, anxiety, perceived disrespect and lack of understanding of the scheduling system.

Recruitment of adult TB contacts to the PREDICT study provided the opportunity to try to understand the observed high non-attendance to facilitate service improvements. Northwick Park Hospital’s (NPH) TB service saw 325 cases in 2013, the highest annual TB case burden in London. A nested qualitative evaluation of their contact screening service was conducted to make actionable recommendations that may improve attendance by exploring why contacts did or did not attend for TB screening.

Methods
A multi-method qualitative approach was undertaken to generate data addressing reasons for attendance and non-attendance at TB screening for patients at the hospital. The methods consisted of questionnaires with adult attenders; telephone questionnaires with non-attenders; and in-depth interviews with TB nurses.

The questionnaire was developed to gather basic demographic data, and address each domain of the conceptual model developed from the preliminary literature review (Fig. 1). The profile of respondents is summarized into Table 1. The In-depth interviews were conducted with a purposive sample of all seven specialist TB nurses from NPH and with one nurse from the Health Protection Unit (HPU). Through a constant comparative method, concepts and categories were revisited and refined following each interview. The patient and nurse responses were analysed separately with the results synthesized in the findings. Further method detail is recorded in the ‘Supplementary Methods’ file, with copies of the attender and non-attender questionnaires also included as supplementary files (see Supplementary data).

Results
A total of 30 questionnaires were completed, 15 from each of the attender and non-attender groups, in person and by telephone respectively. The three principle categories identified from all the data were; awareness, hospital factors and leadership.

Awareness
Most respondents attended for screening because they worried about having TB, which they considered a serious disease. Concern for family members, especially young children, and vulnerable clients at work also motivated attendance.

Most non-attenders knew TB could spread among people from ‘spending time together’ or ‘close contact’. The majority of attenders knew common symptoms of TB, with links made to bad hygiene, overcrowding, and poor living conditions. One young male attender shared this view, about when his mother was diagnosed with TB:

Our home, it’s not that kind of environment...
I was quite shocked, surprised.

Both groups reported TB was kept a secret and people with TB were avoided, because people felt afraid of the risk of death.

Awareness and education of health professionals, GPs, and the local community about TB emerged as a key factor from the nurse interviews. Working relationships with GPs were identified as key resources to prompt non-attenders to be screened. However, many people have no GP, and these are perhaps more likely to be the harder to reach populations at high risk of infection. Interviewees also described an apparently high threshold for patient referral by GPs with later presentation of cases creating more contacts. Raised awareness in healthcare professionals was highlighted by all staff interviewees as a way to overcome perceived hierarchy issues:

I think sometimes if you are coming from a Health Protection hat then it might be better received... and also HPA are considered an educational... sometimes received a bit better.

Staff suggested that raising community awareness would impact TB understanding and thus contact clinic attendance, disease progression and onward transmission:

I think it’s about working with the community, getting out there, doing the talks, and the education, allaying the fear, allaying the stigma, promoting TB as such...
Another described the level of fear and stigma as:

I’ve had a couple of people actually turn round and say they would rather have a diagnosis of cancer than TB...

We’ve had a young bride put back on a plane and sent home because of her diagnosis of TB.

Multiple occupancy housing was common in the area with frequent change and little interaction between tenants. Disclosure of the need for contact screening to house mates caused a fear of eviction in some instances, compromising the accuracy of contacts’ details. The TB nurses sometimes stepped outside of protocol to gain the trust of the index case:

what I’ve done lots of times is I do send a screening letter to the person with TB as well, so they all have their letters.

**Hospital factors**

Most attendees received a screening invitation from the hospital, but most non-attendees did not, so were unaware of the appointment that they missed. This may be an excuse, but could reflect the frequently inaccurate contact details supplied by the index case because of fear of disclosure, or postal service issues. For example, one respondent described living above a betting shop in a multiple occupancy property with all mail sent to the shop and left in a pile for people to check periodically. It is understandable that some people do not receive screening invitations in this context. For this study, non-attendees were contacted by the researcher through housemates who did attend and through managers in workplace incidents. A lot of time was spent on the telephone to find the contact and arrange a new appointment.

Four non-attendees from a workplace screening had the wrong contact information on their file, as submitted by the index case to the nurses. After numerous phone calls and explanations from the researcher to their supervisor, all four were reached and attended screening. Four more non-attendees were also able to attend after understanding the need for screening, following discussion with the researcher. The remaining three non-attendees, who were contacted, were unable to arrange time off work and felt there was no option open for them to attend. Signs and symptoms of active TB were explained with an emphasis on seeking help if there were any concerns. These examples illustrate the impact of personal contact on screening attendance. The need for outreach workers to trace contacts through home visits and telephone calls was frequently raised by the nurse interviewees, as the time required for these activities was not available in the team.

There was a lack of awareness among patients of who to contact to check if an appointment had been sent. Non-attendees who received the invitation had encountered issues getting time off work, reducing the priority of screening since they were feeling well. Nurse interviewees also felt attendance was a low priority as contacts felt well. Disease risk was weighed against child care and work issues:

If you are well, and you think school or work is more important... you’re not going to turn up.

Most attenders reported no issues arranging time off work. The screening clinic day and time were not flexible for any respondents which was a source of frustration.

No specific appointment times were given as clinics ran on a ‘first come first served’ basis. Waiting times varied from ‘no wait’ to up to an hour on the first screening day. Two said they rushed from work thinking they would miss their appointment to find a ‘walk-in’ style system operating. Mornings and different days were the most popular hospital screening options given with two people requesting weekend clinic times. Although clinic times were inflexible, some nurses tried to see patients outside of these. However, this was neither sustainable nor possible for significant numbers of patients.

I’ve seen someone in the carpark because they were told basically by their workplace, you’ve only got 15 minutes lunch so don’t come back late.

No reminders for appointments were sent, though non-attendees unanimously supported SMS reminders as already used in GP surgeries and other NHS services. All nurse
interviewees agreed, particularly with the younger generation and patients with limited English:

Patients are good with texts. We also find, as [the hospital] is a withheld number, they won't respond, but with a text, it's better.

Some non-attenders had a preference to be screened near their workplace or at their GP surgery, for ease of location and flexible timings, as opposed to attending the hospital clinic which ran in the middle of the day. One commented:

you can’t work, not work, then work again.

Nurse interviewees supported these findings:

One that I certainly see is the hospital [itself]. It is much less threatening to go to your GP surgery or something.

Parking costs at the hospital at the minimum of £4 for 2 h were mentioned as a barrier by patients, and although this did not stop attenders from coming, creative solutions were sometimes necessary. Examples given included; parking in the town and walking 15 min to the hospital, getting a taxi, and being screened in shifts where one family member remained in the car to avoid the parking charge.

**Leadership**

The issue of leadership permeated the nurse interviews as a major barrier to the provision of user-oriented services. The need to advocate for more resources in administration, community outreach and core nursing staff was clear but they did not have time, or did not feel mandated to advocate for change.

The working relationship with the HPU in relation to the contact screening process appeared to be a source of frustration in the TB nursing team as their expectations were not always met in practice. All discussions of resource constraints and screening issues were mentioned in relation to the HPU rather than the hospital hierarchy.

It’s the HPA, they are the ones who are supposed to look at this and say right, do you know what, put pressure on the board.

The nurse manager for the TB nurses was responsible for all specialist nurses at the hospital and had only limited time for TB services. Nurses acknowledged she did the best she could, but more visible leadership was requested. A visit from the chief executive of the hospital to the department prompted his comment that he did not realize TB was that serious and on the rise. While this clearly dampened morale it also underlined the need for the TB service to raise its profile.

**Discussion**

**Main findings of this study**

There were three key categories that arose from interviews with nurses and contacts of TB cases, which resulted in potentially implementable changes to clinics which could improve attendance. These broadly encompassed increasing staffing levels skill mix, improving TB education in the community and among healthcare professionals, and introducing more flexibility in appointment times. These findings supplement the original conceptual model designed from the literature (Fig. 1) and reflect the more hierarchical connections found in practice (Fig. 2).

**What is already known on this topic**

These findings are consistent with the local implementation plans of the Collaborative TB Strategy 2015–2020. The proposed development of TB control boards will provide the accountability and leadership sought by the interviewees of this study. They have a responsibility to ensure appropriate staff skill mix and numbers. This will support the principal recommendation of this evaluation. Namely, to appoint a full time TB nurse lead to provide leadership, co-ordination and advocacy for the NPH nursing team and service users.

**What this study adds**

As NPH makes the transition to a specialist centre for TB, there is a lot of expectation of staff roles and workload. Interviewees identified the need for an advocate to support these structural changes in practice. Implementation of the recommendation to increase nurse staffing levels in line with the NICE guidelines would require
significant resource review. The nurse/patient ratio, reflecting the caseload of each member of the NPH team, was quoted by the interviewees at 1 nurse per 70 ‘notified cases’. NICE guidelines recommend a ratio of 1:40, or 1:20 if cases are complicated, such as in multi-drug-resistant TB. Reducing case loads to the recommended levels would allow more time for contact tracing activities.

As part of the Collaborative TB Strategy 2015–2020, TB control boards are given responsibility to ensure delivery of service specifications at the local level. This includes community outreach and focus on the overlap between clinical and public health domains. A significant recommendation from the NPH evaluation was for the appointment of a full time outreach worker to support contact tracing and follow-up. This would enable nurses to focus on their clinical caseload more effectively, while implementation of a strategic campaign to raise community TB awareness in collaboration with local groups and employers would strengthen the public health and clinical links.

The London TB service review reported in the Model of Care document,12 recommended the identification of functions currently undertaken by specialist staff that could be managed by less specialist staff. The nurse interviewees of this project identified contact tracing activities as a function that would be appropriate for an outreach team member. This is because of their access to the community, their remit to conduct house visits and the success of personal contact in attendance. The value of outreach workers has been shown in London by the decrease in TB rates in boroughs that invested in such personnel.12 Furthermore, there was a statistically significant increase in the number of TB contacts traced among the immigrant population of Barcelona where community health workers recruited from the target populations (CHWs) were operating in the team.13 An analysis of the TB prevention strategy in the USA before and after the significant funding increase into TB services in 1993 revealed identified outreach workers as one of the most important interventions to combat the observed rise of TB in the USA at the time.14 The expansion of the outreach service to meet the needs of the under-served population in London has been recommended as a new area for investment in the Collaborative TB Strategy for England 2015–2020.8

The increase of TB awareness among health professionals and in the community has been recommended previously.12,15 In other screening contexts, the decision to take up screening was influenced by the individual’s perception of their susceptibility to the particular illness, in conjunction with their perception of severity of the illness. This leads to the recommendation of community-based education for residents and health professionals that was sensitive to underlying health and cultural beliefs.16 Furthermore, in a randomized controlled trial of an educational intervention among primary care staff to promote TB screening of new GP practice registrants, it was found that TB screening, diagnosis of active TB, diagnosis of latent TB and BCG coverage were all measured significantly higher in the intervention practices.17

A strong recommendation following analysis of the patient questionnaire data was to increase the flexibility of contact clinic times and location to include different days and morning sessions or GP based screening. This would require additional nursing and administration support along with the allocation of appropriate outpatient clinic space. The team has since created three flexible appointment slots a day for contact screening in discussion with the business manager. Logging outpatient attendance in non-clinic time will generate revenue for the service as well as formally providing a more flexible service for patients. GP screening requires high level discussions with commissioners.

Feedback from the nurse interviews revealed frustration at apparently shifting responsibilities and extended action timelines from the HPU. This emerged from looking to the HPU as a source of resource support, for which they also did not have capacity. The perception of the TB nurses interviewed was often to move quicker than the HPU, or to take a more practical approach to risk assessment and planning the logistics of outbreak screenings in line with service capacity. A re-establishment of lines of communication and review of the protocols could alleviate this tension. However, the establishment of TB boards with a clear accountability structure as proposed in the new TB strategy could overcome some of these frustrations.

No patients received any reminders for their appointment, though there was unanimous support for this when offered in the questionnaire. Despite SMS reminders not being official NHS policy, numerous studies have found them to be acceptable and non-intrusive, while increasing attendance by 5–10%. This has resulted in their widespread implementation (http://www.institute.nhs.uk/building_capability/technology_and_product_innovation/text_messaging.html).18,19 Within the TB context, care should be taken as some contacts may not have control of their phones and would be made potentially vulnerable through an SMS alert.

Limitations of this study
The perspective of 30 questionnaire respondents is only a snapshot view of TB contacts at NPH. However, with the nurse interviews they give a sense of the complexity of the phenomena of non-attendance in this population. Furthermore, self-selection in participation, for example with around 50% of non-attenders uncontactable by telephone, may have introduced bias to the study findings. Nevertheless,
successfully contacting 50% of individuals who failed to attend provides an insight into a pool of patients that might have attended if appropriate supportive measures were put in place. It should also be noted that the socio-demographic profile of the NPH catchment population means that one hospital community may not be representative of the needs of others. It would therefore be important to conduct similar exercises in other trusts before assessing whether results from the current project were generalizable.

**Conclusion**

The aim of this project was to explore reasons behind non-attendance at the TB contact screening clinic of NPH and make actionable recommendations for change. Multi-level recommendations have been made and the conceptual model of non-attendance revised. The complexity of non-attendance and the requirement for context-specific approaches to improve screening attendance is revealed. A follow-up evaluation at NPH is recommended for 1 year to assess the impact on screening attendance following implementation of the recommendations.

**Supplementary data**

Supplementary data are available at the *Journal of Public Health* online.

**Conflict of interest**

None declared.

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**Authors' contributions**

J.M. and K.W. designed the data collection tools, collected the data, completed the analysis and write up. E.V. supervised the analysis and write up. R.D. and J.R. co-ordinated site access and approvals. I.A. provided input on project design and write up. J.S. conceived the project and maintained overall supervision including input on manuscript drafts. All authors approved the final draft for submission.

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