To cite this output:
Newell, James et al (2009). Stigma and discrimination associated with TB in Asia: Non-Technical Summary (Research summary)
ESRC End of Award Report, RES-167-25-0142. Swindon: ESRC
REFERENCE No. **RES-167-25-0142**

ACTIVITIES AND ACHIEVEMENTS QUESTIONNAIRE

1. Non-Technical Summary

A 1000 word (maximum) summary of the main research results, in non-technical language, should be provided below. The summary might be used by ESRC to publicise the research. It should cover the aims and objectives of the project, main research results and significant academic achievements, dissemination activities and potential or actual impacts on policy and practice and highlight where the project has been successful in building capacity.

Many people affected by TB suffer both from the disease and from the stigma associated with it. The overall objective of the study was to develop further understanding of the mechanisms of stigma associated with TB in and across Pakistan, Nepal and Bangladesh. This may lead to better strategies to reduce TB-related stigma.

The study involved qualitative research methods (in-depth interviews and focus group discussions) and applied the grounded theory approach to develop theory. Data was collected in urban and rural sites in three countries: Pakistan, Nepal and Bangladesh.

Very similar results were found in all sites, independent of country or urban/rural site.

- **Perceived hatred towards TB patients.** Self-protective behaviours arising from a fear of infection are both seen as justified or natural and as signs of hatred towards a TB patient because precautions against TB transmission (increased separation) are in direct contrast to caring behaviours. Confusion as to what precautions are necessary to prevent the transmission of TB is common.

- **Concealment of a TB diagnosis.** Most of the patients interviewed disclosed their TB diagnosis to their immediate family members. Beyond the immediate family, patients tended to be more selective about who they disclosed to. An important reason for non-disclosure was the anticipation of being avoided by others because of their knowledge and fear of TB's transmissibility.

- **Anticipated avoidance/separation of TB patients.** In Bangladesh, some TB patients interviewed intentionally did not disclose their TB to people or avoided people that they thought might be fearful and avoid interacting with them. Whether others fear TB is influenced by perceptions of its curability and transmissibility, and how evident symptoms were. Health workers sometimes harness people's fears of transmission to encourage healthy behaviours, such as treatment adherence.

- **Reduced marriage prospects.** Incapacitating and lengthy illness or treatment is likely to impact on the marriage prospects of those hoping or planning to marry soon. This is further compounded if the illness is perceived to be transmissible. However, this can be outweighed by highly desired characteristics, such as being a cousin in areas where cousin-marriage is favoured.

- **Family tension and (the threat of) divorce.** While divorce as a result of a TB diagnosis does not appear to be common and is unlikely to occur as a result of the TB diagnosis alone, it may occur, be threatened or advised if the marriage was recent

and not wholeheartedly approved of by the family, and in particular the husband's family. More common than divorce is exacerbation of tension within a family by TB.

- **Financial disruptiveness of TB.** TB disease is greatly feared because it can be financially crippling. Although TB drugs are provided free of charge, TB can still have a substantial financial impact because TB can make it difficult to continue working, treatment is lengthy and requires regular visits to a health facility, and expensive nutritious food or supplementary vitamins are thought to be needed to ensure full recovery.

- **Worry about fulfilling responsibilities and being a burden.** Some TB patients felt worried about being a burden to their families and about not fulfilling their responsibilities, impacting on their self-esteem. This depends, in part, on what responsibilities he or she has. For example, the perceived heightened susceptibility of babies and young children can make fulfilling parental responsibilities difficult.

- **Blame and guilt for TB infection.** The view that TB is transmissible from one person to another implies for some that one person gives TB to another and is therefore responsible for doing so. Likewise, some of the TB patients interviewed blamed themselves or felt guilty at the prospect of transmitting the disease to others: this issue arose primarily in Pakistan and Nepal.

The broad policy implications of this work largely relate to improving communication between health workers, patients and patients' families. This includes

- Increasing clarity on what constitutes necessary precautions.
- Increasing knowledge that TB ceases to be transmissible after two weeks of treatment.
- Considering the 'side-effects' of harnessing people's fears of TB infection to promote treatment adherence or other health-related behaviours, and particularly how this approach might fuel TB stigma.
- Considering how increasing knowledge of and emphasis on TB's transmissibility and patients' ability to prevent transmission by taking precautions may increase blame and guilt.

Other issues include:

- TB-related stigma is not just fuelled by knowledge and attitudes, but also by the disruptiveness of TB to people's lives. Measures to reduce the cost and disruptiveness of treatment provision need to be considered (such as incorporating flexibility and outreach into DOTS). Private and alternative practitioners need to be able and willing to refer TB suspects to Government and NGO services where treatment is free.
- The later the diagnosis or the more severe the TB, the more debilitating the illness and potentially the lengthier its treatment. Therefore, earlier diagnosis and treatment is needed.

We have held dissemination and strategy development workshops in each of the three countries. All National (and in Pakistan Provincial) TB Programme Managers were active participants. The research findings and broad strategy arising from the workshops has been endorsed by the Managers.

To cite this output:
Newell, James et al (2009). Stigma and discrimination associated with TB in Asia: Non-Technical Summary (Research summary)
ESRC End of Award Report, RES-167-25-0142. Swindon: ESRC

We are in the process of helping the Programmes to refine the broad strategy into specific actions and messages, and incorporate this into guidelines and training materials. This process dovetails with other work we are doing to update guidelines and training materials and methods to incorporate changes in national policies informed by other research we have been involved in.

We intend to present the results to the next annual SAARC (South Asian Association for Regional Cooperation) meeting of TB Programme Managers. We intend to present the findings of the work at the next World Lung Conference.

The project has developed not only capacity in qualitative research methods in the three countries, but more importantly, a much greater understanding of the role, process and importance of qualitative research within the three research institutions and National Tuberculosis Programmes involved.