

Political Ecology of TB in New Zealand

Full text of the original proposal

[Background](#)

[Research Design](#)

[References](#)

Background

TB is a major world health problem, estimated to cause over three million deaths per year, and to infect one third of the world's population. While NZ might seem relatively protected from the resurgence of this disease, this is an illusion. Well over half of those infected live in the South East Asia and Western Pacific regions in which NZ is located (Martin 2000). Although the incidence of TB in NZ is relatively low (about 10 in 100 000), the recent notification rates have been much higher than that of Australia (Harrison 2000, WHO 2001). In addition to TB among NZ-born people, NZ accepts as immigrants, visitors, students and refugees many people from countries with high incidence rates. It is inevitable that some of these people will have or develop active TB while they are here; indeed 46% of foreign-born cases develop within five years of arrival (Harrison 1999, citing MoH data).

TB is a disease of poverty and inequality. Studies overseas (e.g. Elender et al., 1998 Antunes and Waldman 2001) show that the highest rates are found in the most impoverished areas and are highly correlated with household crowding and with HIV infection. A recent study of two Auckland case populations, using NZDep scores, showed that residents in the least affluent parts of Auckland have rates of TB sixty times higher than those in the most affluent areas (Public Health Protection 2000). Similar correlations have been found in Wellington (Naing et al. 2000). Poverty and inequality is on the increase in NZ as it is in several OECD nations (Saunders 1997) and NZ has the greatest reported disparity between the richest and poorest 20% of the top 20 OECD countries (a ratio of 17.4, cf Australia 7.0; UNDP 1999:172). In 1998 of the 340 people notified with TB, almost one-third (109) were born in NZ. Thus TB is by no means confined to immigrants. Although Pakeha (2.7/100 000) rates are comparatively low and falling as are the considerably higher rates for Maori (10.5), nearly all active TB is theoretically preventable. Despite this, rates for Pacific people in NZ (27.1) and those of other ethnicities (82.1) are high and rising (Harrison 1999, Martin 2000). Nor is poverty associated with TB only in NZ-born people. Immigrants with TB are predominantly in the lowest socio-economic groups in NZ.

The second epidemic of stigma Farmer (1992) pointed out that with epidemics of certain infectious diseases comes a second epidemic of fear, prejudice and discrimination often compounding pre-existing prejudice against the most vulnerable sectors of societies. Even discussing such topics as TB or AIDS in the context of refugees and migrants can spark off this second epidemic. This research team is highly sensitised to this dilemma and is aware of the deeply felt shame which may accompany TB infection (see Worth et al, forthcoming, for a comparable example).

As a combined team we have had considerable experience of research and practice with some of the most stigmatised diseases (HIV, HCV and TB). We have developed research partnerships with mainstream and marginalised groups here and in Australia. We are acutely aware that the precarious social situation of recent migrants may be severely affected by this combination of prejudice and shame. Stigma may also affect New Zealand-born people with the disease, reducing the social support available to them (Hill and Calder, 2000).

Tuberculosis TB is most commonly caused by infections with the bacterium, *Mycobacterium tuberculosis*. Most people (90-95% according to Comstock and O'Brien 1991) infected have latent TB infection (LTBI). They are non-infectious, feel well but can be identified by Mantoux testing. Current practice is that all those with identified infection (defined by the combination of Mantoux test and risk for disease) are treated (MOH, 1996). In 5-10% of adults infection progresses to TB disease (TBD). This can occur within a short time, four to 12 weeks from infection to significant tuberculin reaction or later as the result of endogenous reactivation (MoH, 1998). The disease may then be transmitted by air-borne droplets produced by those with pulmonary TB (72.3% of cases of TBD have pulmonary disease in NZ, Carr et al. 2001). This transmission mode means that the physical and physiological environments people live significantly influence their risk of acquiring infection.

Most cases of active disease, if diagnosed early, can be successfully treated with combination therapy for at least six to nine months (MoH, 1996). However, an incomplete treatment can lead to clinical relapse or the emergence of drug-resistant infections requiring much longer periods of treatment.

Multi-drug resistant TB occurs when naturally occurring mutants become favoured during the course of intermittent and ineffective therapy. In the US, those who are infected with MDRTB tend to be the inner city poor. Farmer (2000) suggests this pattern is best understood as a socio-medical phenomenon as it is shaped by socio-political-economic forces summed up by the concept of "structural violence". In NZ, rates of MDRTB are low (less than 1%), but they are higher in non-NZ born. Cameron and Harrison (1997) found 9 MDR cases out of 838 confirmed cases. MDRTB does, however, occur in the Pacific (Mahmoudi & Abraham 1996).

Any stressor, such as poor **nutrition**, that compromises immunocompetence may contribute to the conversion from dormant to active TB and may inhibit recovery (Heywood and Marks 1993). Food programs were part of some of the interventions surveyed by Sumartojo (1993). He wisely remarks that they, and other "inducements", may in fact have acted as enablers. Before the use of antibiotics, the importance of a good diet and sufficient food was a major component of some treatment regimens – along with "fresh air" (Bryder 1991).

Interaction with HIV. Overseas studies show that there is a close association between HIV and TB, each impacting on the other. The areas that have been most affected by the HIV epidemic also report the greatest increase in TB cases. The rate of

progression to clinical TB is 10-30 times higher among individuals with both HIV and TB. HIV is the single strongest health risk factor for the progression of TB from infection to disease (Rojanapithayakorn and Narain 1999). Fifteen million people are estimated to be infected with both HIV and M. tuberculosis. In the last 15 years there has been increasing incidence and prevalence of TB in the developed world, particularly in areas where there is considerable urban poverty and high risk populations such as IV drug users and homelessness and high rates of HIV infection. Since 1985 joint TB/ HIV infections have been registered in many European countries: Exner-Freisfield (1995) estimates that between 5-10% of all HIV-infected individuals in Germany also contract TB (cf. Demedts et al 1995).

In contrast, Thomas and Ellis-Pegler (1997) reviewed all the cases of co-infection seen at Auckland Hospital in the preceding 11 years. They demonstrate that co-infection is a minor feature of the epidemiology of TB in NZ at present. However, with the propagation of the HIV pandemic in Asia and parts of the Pacific (which have a high prevalence of TB infection), co-infected population groups may well become more numerous in NZ in the future. Issues of stigma and acceptance of diagnosis are acute for people with co-infection.

Rates in the Region The WHO report for the Western Pacific Region (2000) shows an overall rate of 49.2 per 100 000 though this covers major differences. Polynesian rates range from 102.9 (Niue) to 0 (Tokelau). In Melanesia, Papua New Guinea has a rate of 259, Fiji 23. Micronesian rates tend to be high (from 297.6 in Kiribati to 66 in the Marshall Islands). In E and SE Asia, the Phillipines' rate is 198 while the lowest rates are in China and Japan both in the 30s. These rates are, of course, dependant on accurate surveillance and reporting, and in very small nations, like Niue, the rate needs to be interpreted alongside the population size.

Current Rates in NZ The most recent TB surveillance data available for NZ is from May 2001 (ESR 2001). This shows a concentration of TB cases in the greater Auckland area. The annual rates per 100 000 are highest in the urban concentrations of Central /South Auckland and Wellington which all have over 20/100 000. North West Auckland, Eastern Bay of Plenty, Gisborne, Ruapehu, Hawkes Bay, Manawatu, and Hutt all have rates between 8 and 15/100 000. The West Coast of the South Island is the only Health District with a zero rate. The national provisional rate for the year including May 2001 was 10.2. This compares with 11.4 for the previous year, a small but significant drop (ESR 2001), and 12.6 for the previous year when there were two large outbreaks (de Zoysa et al., 2001).

In common with other high income countries, New Zealand experienced a rapid decline of TB after the second world war but the rate of notifications has not declined since 1987 and indeed has increased slightly (MOH 1998). This parallels developments elsewhere (Porter and Ogden 1998). It remains a common notifiable infectious disease in Auckland, in particular.

These recent increases are not solely attributable to immigration. The proportion of TB among New Zealand-born has also increased, particularly among the young. Recent studies of outbreaks demonstrate that infections pass along the lines of social networks in which people live, beyond the immediate family (Calder et al. 2000a, de Zoysa et al. 2000, Hill & Calder 2000, Public Health Protection 2000). These recent outbreaks show that infection can be transmitted even during relatively brief contacts e.g. during a tangi (de Zoysa 2001 cf. Klovdahl et al. 2000 in Houston). In all of these cases, the attitudes and beliefs of those infected, their families and their communities affected whether treatment-seeking. In addition, the socio-economic facts of their daily lives (e.g. mobility, unemployment) impacted upon their treatment seeking and their accessibility to control measures.

History of Tuberculosis in New Zealand It is unlikely that TB existed in New Zealand before the arrival of Europeans in the nineteenth century (Miles 1997), but it was indisputably endemic within both European and Maori populations by the second half of the nineteenth century. Indeed many settlers suffering from TB had come from Britain to the colony specifically in the hope that the latter's climate would cure them. Once it was established that TB was an infectious disease (1882), attempts were made by the government to restrict the entry of those suffering from it, although this was implemented in a relatively haphazard way. Early twentieth century measures to combat TB followed overseas models, particularly Britain. The measures were based on the belief that fresh air, good food, exercise and rest were effective preventive and curative agents against the disease. BCG vaccination was discovered in France in 1921, but like Britain, New Zealand did not adopt it until after the Second World War (Bryder 1991).

Following the Second World War more interventionist methods became available to treat and prevent TB. These included mass miniature radiography for early detection, BCG vaccination, and effective drugs, starting with streptomycin, discovered in 1943. The Department of Health set up a Division of Tuberculosis in 1943, indicating a more proactive approach. In the 1950s and 1960s TB was declining among Pakeha and Maori, and it was believed the problem would soon be 'conquered'. In the 1970s the Director-General of Health identified a new problem, the undue proportion of cases occurring in the immigrant Polynesian population. In 1969, 44 per cent of all notifications of TB in New Zealand were among Polynesians, an ethnic group comprising 9 per cent of the population. Much debate followed as to whether they brought the disease with them, or contracted it here because of their poor living conditions. TB has long been known as a disease of poverty, and with the downturn in the economy in the latter part of the twentieth century, the incidence increased, particularly among lower socio-economic groups, notably Maori and Pacific Islanders. There is a need for a more detailed historical analysis of the post-Second World War period, in order to contextualise the current problems and policies.

Pathways to treatment and adherence to medication Knowledge, attitudes, beliefs and behaviours of the patient have a profound impact on their responses to the symptoms and treatment of TB (Mata 1985, Jenkins 1996, Westaway 1989, 1990,

1994, Carey et al. 1997, Nichter 1994, Bakhshi 1995, Rubel and Garro 1992, Asch et al. 1994).

Culture is often cited in studies of TB as one of the determinants of successful treatment. It is indeed useful to know, as Ito (1999) discovered for Vietnamese refugees in the US with TBI, that one reason why certain among them discontinued their medication was because of the “hot” side effects, referring to an imbalance between heat and cold. Balance is necessary for health in this humoral health knowledge system, therefore if “hot” side effects such as rashes or irritability are experienced, the patient will try and attain equilibrium by eliminating the cause of the excessive heat; namely the medication. Similar, research-based information about other health knowledges and practices of groups represented in NZ would be useful background for TB control workers. A considerable amount of such information is already available in published form for groups represented already in New Zealand (e.g. Barnhoorn and Adriaanse 1992 for India (Wardha), Liefoghe et al 1995 for Pakistan, Vecchiato 1997 for Ethiopia, Nair et al 1997 for India (Bombay)). In addition to these TB specific studies, broader works on “cultures of health” (Rubel and Garro 1992) are available for many Pacific groups (e.g. Parsons 1985). However, there are two main cautions. One is that this can serve only as background information, providing health workers with a context for understanding what patients tell them and what they observe themselves, and prompting them to ask appropriate questions and offer relevant guidance and support. Because there is enormous variety within cultures it can never be assumed that an individual will embody a general cultural description. The second caution is the relative importance of cultural knowledge and practice relative to the other determinants of health, or of adherence. Jenkins et al (1996), for example, acknowledge that Vietnamese explanatory models for health are very different from mainstream US ones, yet this difference did not appear to inhibit their access to health services. Rather it was their health insurance status and having a regular doctor which were the most important determinants of access (cited in Ito 1999). Thus while understanding the explanatory models of people with TBI and TBD may be extraordinarily helpful for health workers, enabling them to build better rapport and mutual understanding, those models appear to have variable effects on treatment seeking and treatment completion.

Some more micro level socio-cultural factors have also been reported to be important. These include the quality of the relationship between the person with TB and his or her health workers, the presence of social support, the level of fear and stigma which infection with TB incurs, and, especially if there is stigma associated, whether the medication can be taken in private, the atmosphere of the clinic and its surroundings. Micro-level economic factors include the opportunity costs of taking medication and attending clinics, waiting times, transportation costs (Sumartojo 1993, Farmer 1997, Ito 1999).

Diagnostic delays: A recent Auckland study, Calder et al. (2000b) based on interviews with 100 people with TB reported that there was some delay on the patients’ part in seeking treatment but that more delay was attributed to the doctors involved. Fear of what would be found, a belief that the problem would go away by

itself and being a current smoker were all associated with longer delays, as well as reporting a cough as opposed to having no cough among their symptoms.. These delays were compounded by doctor delays, especially failure to investigate TB history at the first appointment. In the school-associated outbreak (Calder et al 2000a: 42) reported that shame and stigmatisation of people with the disease and their families inhibited contact screening, while Hill et al (2000) report that denial and stigma were major obstacles to rapid investigation in the tight-knit church community in which an outbreak occurred. In the latter instance, the pastor of the church hindered access for screening and “resisted any attempts to involve Pacific Island health workers because of perceived shame”. Members of the church were fearful of the social repercussions of revealing contact details. Both these outbreaks occurred among Pacific Islands people but there is no reported information on which to base cultural interpretations.

Delays to diagnosis not only allow the infected person to develop more advanced TB, but they promote the spread of the infection through the person’s own contacts. Clearly, any knowledge that can be applied to decrease delay to diagnosis is of great assistance in the reduction of TB cases.

The second main area of intervention is that of increasing **adherence to medication regimens**. All the information presented suggests that this is a highly complex problem for which there is no one answer. Many answers, each incrementally adding to completion of treatment rates, are the best that we can hope for. Our approach, following the definition of health noted (see below), concentrates on assessing the material and non-material resources which will allow people with TBI and TBD to complete their chemotherapy and recover. The specific foci include the material aspects, e.g. adequacy of income, which promote or inhibit adherence and the health and well-being of the affected persons, as well as those non-material resources, e.g. health cultures, social networks, degree of stigma. While these aspects are attributes of individuals and families, they will be understood in terms of the community to which individuals and families belong, or are assigned, by the wider society.

Social networks are a set of people connected together by social relationships: kinship, work, neighbours, church etc (Scott 1992). Along the lines of such networks flow information of various kinds, influence, and infection. Studies of infectious disease have concentrated on the links of transmission (e.g. Parker 1999). However social and geographical networks do not only involve the pathogens, people exist with networks of the physical environment (access to employment, to transport, to health care), networks of information flow, and networks of social support, medical support (Barnhoorn & Adriaanse 1992). These impact upon the ability and desire to seek treatment and to adhere to a treatment programme. It has been reported elsewhere that patients felt that their family and friends avoided and shunned them and that their social networks contracted. The result was patients isolating themselves and becoming secretive about their illness (Kelly 1999). This contraction of networks during treatment is also potentially significant as a disincentive to adherence.

An often neglected aspect of networks are the social relationships around treatment which impact upon adherence and the success of treatment. For TB this includes the

hospital-based clinicians, community based GPs and protection teams plus ancillary health professionals (e.g. pharmacists). We will explore the various dimensions of these networks from the perspective of the patients and these perspectives will be contextualised through information gained from interviews with stakeholders involved in the above networks.

Analysis of these overlapping networks needs to take account of the myriad ways in which socio-economic factors (such as transport, health care access) serve to interact (e.g. Beyers et al 1999 on TB distribution in S Africa). A useful way of combining this information is to overlay the location of those infected with a range of indicators, NZDepI as well as transport, location of health care professionals, housing type etc. GIS is a useful visual tool with which to explore the overlay and coalescence of particular factors such as transport distance and availability to health care (e.g. analysis of DOT programs, Tanser and Wilkinson 1999). This gives a data-rich background to the factors that interviewees identify as interacting and affecting their take up and continuation of treatment (Koch and Denike 2001).

In addition the mobility of those infected has been seen in some cases as a barrier to both tracing and maintaining care for some individuals (Calder 2001). Again these movements serve to link particular areas or places into a network of transmission and network of care. The networks of treatment are equally important, e.g. transport incentives have been identified as significant enablers of treatment (Calder 2001). Using GIS in combination with ethnographic interview allows for these factors to be translated into space.

[Top of Page/Home](#)

Research Design and Methods

Theoretical framework. In her magisterial paper exploring the reasons for the failure of TB treatment world wide, despite the availability of effective medication, Sumartojo (1993:1318) of the Centres for Disease Control, called for a theory-based approach.

The value of a theoretical approach is that it guides systematic and programmatic research. Research that is not theory-based tends toward trial and error, one-shot studies that describe behavior in very specific situations but provide no basis for generalization to other situations.

Political ecology is an approach developed in two of the more interdisciplinary social sciences: anthropology and geography, both of which include socio-cultural and bio-physical sciences in their ambit. Political ecology combines the historical political economy and world systems theory of scholars like Wallerstein, Wolf and Roseberry (see Roseberry 1998) who analyse the production of inequality through the operation of world systems in local contexts, with a bio-social approach which focusses on the interaction of societal forces, biology and environment in the persons of human beings in communities at different times and places, and with an interpretative approach based on cultural anthropology's insistence that humans impose their realities on the world, although, as Marx observed, not always in circumstances of

their own choosing. This approach sees health as dynamic, as “access to and control over the basic material and nonmaterial resources that sustain and promote life at a high level of satisfaction” (Baer et al 1997:5). Our research design is developed within this general theoretical framework to provide the basis for meeting the objectives specified.

Research Goal: To produce culturally specific information on the pathways to diagnosis and adherence to treatment of TB (Obj.1 & 2), taking into account relevant socio-economic factors, that can contribute to services and policy directed at TB control and treatment in New Zealand.

Research Design. To achieve these objectives the project will have an advisory group and a design which includes research in five ethnic groups, stakeholder interviews, media analysis, GIS analysis and historical research from 1945 to the present.

Research Methods

Data collection

The project will employ multi-level research methods: **in depth interviews** with members of the ethnic groups (both with and without TB) and participant observation where appropriate; **stakeholder interviews** with agencies involved, eg. Housing NZ, Immigration, Refugee and Migrant Services, health care providers and community workers involved in the control and treatment of TB, **media analysis** of press coverage of TB and the participating recently arrived ethnic groups, **historical research** on TB in New Zealand since 1945 and **GIS analysis** in order to identify clusters of cases and the relationship of patients to markers of socioeconomic status, social and treatment networks. All fieldwork methods will be piloted at the beginning of each study and tailored to the specific group.

Research with five language/ethnic/cultural groups addresses Objectives 1,2,3 & 5.

TB oriented interviews Five to 15 interviews per group is estimated, depending on the rate in the particular group and its size, with people (and their families if consent is given) with TBI and TBD, including people who have recently recovered from these infections. Invitations to participate will be issued by health care providers. The interviews will focus upon the patients’ view of the experience, the pathways to diagnosis, their knowledge of the disease/infection and its treatment, the likely outcome for them, the politico-social effects of the infection (such as discrimination or immigration issues), the nature and development of their relationships with health professionals and health services in hospitals and clinics as well as in the community. The interviews will also collect socio economic and demographic information, including housing, household size and structure, food availability, and delineate social networks. Up to three interviews with people still undergoing treatment are envisaged. Where interviewees are mobile or transient, efforts will be made to contact at least a few as they move, including into rural areas.

Community interviews with a cross section of approximately 20 community members, using Kleinman’s (1980) explanatory models and Ito’s (1999) “cultures of

health” frameworks will investigate health knowledges in general, and specifically about TB. Recruitment will be through community networks matching as far as possible characteristics of the TB group. In addition, available published information relating to the particular cultural group’s health knowledge and practices will be compiled, along with a brief history of each group which, in the case of recent migrants, will include the circumstances of their settlement in New Zealand, as well as a review of the group’s socio-economic situation.

Stakeholder interviews (Objectives 1-4) will gather the perspectives and concerns of up to 20 key people; namely their perspectives on barriers and facilitating factors to patients’ rapid presentation and diagnosis, successful adherence to TB control programs, and inter-agency communication. These interviews will also ensure that the study is relevant to the needs of both stakeholders and people with TB.

Media An assemblage will be collected of items on TB and on the African and Asian migrant groups from newspapers and internet sources.

Historical research will on the period since WWII (the earlier period has already been documented by Dr Bryder). This will be based on archival research, other published research and interviews, as necessary. A brief overview of TB in the Pacific since colonization will also be compiled (e.g. Kunitz 1994).

GIS will be used to record routines of patients and their health care and social networks (factors such as transport distance, location of health care facilities, centers of social life). This information will be overlaid with NZ census data and socio-economic determinants e.g. NZDepI. This will allow us to look at particular factors identified by participants as affecting uptake and continuation of treatment (Objectives 1 and 2).

Data Analysis

Interview and background data from each “ethnic” group will be analysed in its own terms, as will the historical research and stakeholder interviews. These independent reports will provide the basis for an overview. The presence of separate lines of evidence adds strength and validity to the analysis. The analysis will be guided by the research objectives, but also open to new and developing themes. This openness is a desirable characteristic of social science research and a means of allowing participants’ perceptions to shape the research.

The building of descriptions of living with TB and its treatment and the attitudes of others (including the media) to people with TB will be a vital part of the analysis. Specific questions, developed out of NZ and overseas studies (e.g., Barnhoorn 2000) which this research will illuminate are:

Recognition of infection: how are symptoms (and other bodily signs such as side effects) of TB perceived, evaluated and acted upon by patients and their families?

How does one respond when physical symptoms disappear in the course of the treatment? How is co-infection, especially with HIV, experienced?

Ideas about tuberculosis: which perceptions and ideas about TB (etiology, course, prognosis), its consequences and treatment opportunities are prevalent among patients and their families. How are these related to the health behaviour of patients?

Experience of treatment: Which feelings, thoughts, situations lead to more or less self-efficacy among patients in relation to the requirements of TB treatment? When and why are these beliefs of self-efficacy constrained or raised among TB patients?

Community attitudes: Are there cultural or social norms that can be linked to a shared set of ideas and explanations of health and disease, and specifically TB, by the community e.g. symptom interpretation, health seeking behaviour, and follow-up care. What fears and misunderstandings are present regarding TB?

Relationship with health professionals: How is the cultural knowledge of TB patients, their family and community dealt with by local health workers? What knowledge do patients and their families need in order to seek medical help and to stay in treatment long enough? What knowledge do households and communities need in order to increase awareness and health finding? What are useful metaphors to convey concepts of TB infection and treatment?

Access to support: Which sources of social and health support are available to patients and in what ways do they influence the health behaviour of patients? Do such networks change during treatment? Are they limited as a result of treatment? What barriers exist in people's lives both as objective reality and perceptions to accessing health care and help?

Socioeconomic factors: Which demographic and socio-economic factors characterise TB patients and their families? How do these features influence patients' health seeking and adherence behaviour?

Interviews with stakeholders will be analysed as above and for information about services and policies, their perceptions of issues and problems relating to TB and their ideas about any improvements, including in inter-agency communication.

Analysis of qualitative data will be assisted by NUDIST4. The interviews will be analysed both for their content and as texts, the construction of which carries information in its own right. The language, imagery, and structure of the interview transcripts will be attended to closely. The analytic approach described by Anderson and Jack (1991) as 'listening for meaning' will be employed. In brief, this includes listening for 'moral language' or evaluative statements listening for 'meta-statements' or spontaneous reflections, and listening to the 'logic of the narrative', or the consistencies and contradictions in themes and the relationship between themes. GIS analysis will use ArcInfo with ArcView as the visual front-end and SPSS for additional statistical work. Least cost analysis and similar analytical GIS tools will be used to search for specific pattern in those spatial relationships of social networks, socio-economic determinants, and health care access. .

The historical analysis will assess changes over time in the ways in which the problem of TB has been framed and approached, as an aid to the understanding of present-day policies and the present day distribution of the infection.

Ethics

Our method of contacting potential participants is in accordance with ethical and legal guidelines relating to privacy. All participants will be given a code so that research documents relating to them may be linked but individuals will not be identified. Any person who wishes to be identified will be given that option. Informed consent will be obtained at each stage of the project. Before finalising reports, the advisory group will have the opportunity to comment, and we will work on recommendations in conjunction with this group and other key persons. All participants will be given a brief summary of the research findings, and will have access to the research reports.

In the course of the interviews, we may find that participants become distressed while discussing their concerns, experiences or fears for the future. All the researchers have had experience with sensitive research, and in this instance we will be able to call on the experience of the advisory group. Should a person experience more distress than we feel our own or the advisory group's resources can cope with we will ensure that s/he has access to appropriate counselling.

The research as a whole is designed to benefit people with TB and their communities and those who care for them by producing information that can be used in service provision, provision of support, lobbying for resources, and in educating both those with TB and the wider society about TB. We are aware of the possibility of re-stigmatisation.

Dissemination of Results

- Workshops for each ethnic group following completion of the specific analysis to present the main findings, and seminars for health professionals and policy and service stakeholders in the area of TB control and treatment,
- A fact sheet outlining the main research findings will be produced for wide dissemination among providers of services, community groups, and support organisations,
- Theses and dissertations on specific aspects of the research,
- Research monographs for each specific group and summaries in English and mother-tongue
- Papers in refereed journals dealing with all aspects of the studies
- Presentation at health-related and academic conferences.

[Top of Page/Home](#)

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[Top of Page/Home](#)