

Targeting TB

Sociocultural factors affecting tuberculosis treatment and prevention in Aboriginal and immigrant populations in Alberta

Nancy Gibson, Andrew Cave and
Diane Doering, principle investigators

A multimethod collaborative study

January 2002

FINAL REPORT
to research partners
and funders for the
period October 1998
to December 2001

Targeting TB

Sociocultural factors affecting tuberculosis treatment and prevention in Aboriginal and immigrant populations in Alberta

Final report to research partners and funders for the period October 1998 to December 2001

Prepared by Nancy Gibson, with assistance from Andrew Cave, Diane Doering, Paul Harms, Lucenia Marquez, Insaf Hag-Mousa, Coleen Kato, Hélène O'Connor and Marion Saffran.

Coordinated by the Community-Based TB Research Project Community Advisory Committee.

Prepared for Alberta Heritage Foundation for Medical Research • Alberta Health and Wellness • Canadian Heritage • Capital Health Regional Public Health • Capital Health Authority TB Clinic • Changing Together: Centre for Immigrant Women • Medical Services Branch / First Nations and Inuit Health Branch • Métis Nation of Alberta • Nechi Training, Research and Health Promotions Institute.

January 2002

Acknowledgements

Without the support and guidance of many people and organizations, this project would not have been possible. There are many individuals to whom we would like to express our sincere appreciation. A few of our friends include: Lana Benjamin • Ian Coleman • Kay Half • Sarah Li • Dr. Richard Long • Dr. Lyle Melenka • Ann Raftery • Nadene Rehnby • Dr. David Strong • Val Wood

Special thanks to Sonia Bitar and the staff at Changing Together: The Centre for Immigrant Women in Edmonton.

Primary funding for this project was provided by the Alberta Heritage Foundation for Medical Research. We are also grateful for additional funding from Canadian Heritage • First Nations and Inuit Health Branch, Government of Canada • Grey Nuns Family Medicine Centre Research and Education Fund • University of Alberta Endowment Fund for Small Faculties • University of Alberta departments of Family Medicine and Human Ecology.



University of Alberta

For information about this study, or to obtain further copies, please contact:

Nancy Gibson, Chair
Department of Human Ecology
Room 302 Human Ecology Building
University of Alberta, Edmonton, AB, Canada, T6G 2N1
t: (780)492-3883 • e: nancy.gibson@ualberta.ca

This study can be downloaded from the Internet at www.hecol.ualberta.ca/ngibson.html

Contents

Summary	6
Introduction	7
Structure of the study	8
Study genesis	8
Study objectives	9
Study design and methods	9
Managing the literature review	9
Theoretical framework	11
Study participants and personnel	12
Community participants	12
Community advisory committee	13
<i>Establishing the foundation principles</i>	14
Community research associates	15
Coordinators	15
Project mentors	15
Orientation / training	16
The interview process	17
Development of the guidelines	17
Support for CAs	18
Interview participants	18
Evaluation of CAs	19
Challenges encountered by CAs	19
Data analysis and interpretation	21
NUD*IST training, data entry and preliminary coding	21
Participant profiles	21
Time lived in Canada	23
Housing	23
Results organized by themes	24
Experiences with TB healthcare	24
Impressions of healthcare staff	25
How healthcare workers provide good service	27
Answers to questions about how people get TB	28
Social stigmatization due to TB	32
The initial diagnosis	36
Medication and treatments	37
Directly observed treatment	41
Reasons for stopping or refusing prophylaxis	42
The legacy of sanatoriums for Aboriginal people	43
Use of traditional healers or medicines	44
TB education	45
The relationship between perception and knowledge of TB	47
Preferred methods of learning about TB and TB healthcare	51

Evaluation strategies	52
Interim evaluation	52
Community group interviews	52
The wrap-up weekend, March 2001	52
Unanticipated challenges and strategies	53
Conclusions	54
Practice	54
Process	55
Recommendations	56
Dissemination and follow-on activities	58
Bibliography	60
Appendices	
Appendix 1: Original grant proposal summary (1997)	62
Appendix 2: Project personnel	63
Appendix 3: Community research associates recruitment	64
Appendix 4: Sample of interview guidelines	66
Appendix 5: Sample newsletter	69
Appendix 6: Sample posters	71
Appendix 7: Papers in progress	72
Appendix 8: CAC evaluation questionnaire	73
Appendix 9: CA evaluation questionnaire	78
Appendix 10: Publications related to the project	82
Appendix 11: TB information sheets	86

List of tables

Table 1: Interviewees by country of origin	21
Table 2: Interviewees by age	22
Table 3: Interviewees by gender	22
Table 4: Facility with English	22
Table 5: Sources of assistance for TB patients	24
Table 6: Impressions of staff at healthcare facilities	25
Table 7: Perceptions of causes of TB	28
Table 8: Issues related to social stigmatization	32
Table 9: How people learned they had contracted TB	36
Table 10: How people felt when they learned they had TB or tested positive	36
Table 11: Problems experienced with the medication	38
Table 12: Perceptions of quality of TB information	47
Table 13: Learning about TB	51

Case studies

From one drug to another	26
No side effects, please	29
Strictly for personal reasons	31
Trust your family doctor I	34
Mother knows best	40
Trust your family doctor II	46

Acronyms

AHFMR	Alberta Heritage Foundation for Medical Research
CA	Community research associate
CAC	Community Advisory Committee
CHA	Capital Health Authority (Edmonton)
CHR	Community health representative (First Nations)
DOT	Directly Observed Treatment
FNIHB	First Nations / Inuit Health Board
MSB	Medical Services Branch (Government of Canada)
NAPCPRG	North American Primary Care Program Research Group
NUD*IST	Non-numerical Unstructured Data Indexing Searching and Theorizing
PAR	Participatory Action Research
the TB Clinic	The Regional Public Health Tuberculosis Clinic in Edmonton, Alberta

Summary

ALTHOUGH TUBERCULOSIS IS NO LONGER A MAJOR THREAT IN CANADA, IMMIGRANT AND Aboriginal populations still have high rates of prevalence.

This multi-method study began with an epidemiological review of TB patient files at the Capital Health TB Clinic in Edmonton, Alberta, then used a participatory approach to examine the complex net of sociocultural factors that influenced behaviour related to TB prevention and treatment in 12 population groups in the province.

Trained community research associates collected qualitative interview data from the highest risk ethnic groups and helped with interpretation and evaluation. A Community Advisory Committee established foundation principles and monitored the ethical and cultural appropriateness of the research process.

A key finding is that although patients with active disease learn about TB from health professionals, time pressures limit their learning. To diagnose TB early and prevent spread, people in high-risk populations need to learn about TB transmission and prevention prior to contact. The study confirmed that health behaviour is person specific and that generalizations related to economic issues are more valid than those related to ethnicity. The study results underline the need for accessible and appropriate health education about TB in affected groups, and that this can be effectively accomplished with minimal training by lay people, particularly those who have recovered from active TB, their family members and community health workers.

The study also illustrates the unique challenges that arise with participatory action research (PAR) when the research team includes community agency representation, health professionals and funders. PAR creates a collaborative learning environment in which community members learn about health issues and strategies that affect their lives, and academics and health professionals learn about the context of the communities in which TB is a problem. PAR enriched the data and the research experience for all.

Introduction

ALTHOUGH TUBERCULOSIS IN CANADA IS NO LONGER REGARDED AS A MAJOR THREAT (Grzybowski and Allen 1999), there is a high prevalence in immigrant and Aboriginal populations. It is estimated that 40 to 50 per cent of new arrivals in Canada are already infected with TB. Many migrants to Canada test positive for TB infection because of exposure to TB even though they have not developed active disease. Tuberculosis is five times more common among Aboriginal people than among most other Canadians, according to Fitzgerald, Wang and Elwood (1999:351), while Fanning (1999:837) suggests the rate of TB in the Aboriginal population may be 10 times the Canadian norm. On the global scene, TB is one of the three infectious disease priorities identified by the G8 in its July 2001 summit agreement to which Canada was a signatory. TB remains a key priority for the World Health Organization.

This study underlines the need for accessible and appropriate information about TB in affected groups in Alberta and offers some insights and strategies. The study also addresses the unique challenges that arise with the participatory action research (PAR) approach. PAR involves collaboration between academics, local community members and funders in establishing research goals, selecting research methods, collecting and analysing data, and applying and disseminating results. The approach prioritizes reciprocal education between academics and community members, creating an exchange in which community members can learn about relevant social theory and policy formation processes that affect their lives. Likewise, academics learn about contextual factors as they affect the health of the people in the study communities (Green et al 1995:3, Traverse 1997:349).

This study assumes a complex net of sociocultural factors that influence behaviour related to TB prevention and treatment. The results confirm that behaviour is person-specific and that generalizations related to economic issues are more valid than those related to ethnicity.

The project had two themes: *practice* and *process* (Smith et al 1997). The first theme centred around a set of practice-related objectives focusing on tuberculosis in Aboriginal and immigrant populations in Alberta. The second theme followed the experiences of the research team as it learned about the challenges inherent in a community-based research process. It was often necessary to separate these interwoven themes to ensure that ethical issues such as confidentiality, anonymity, stigma, capacity building, commitment and support could be monitored and evaluated.

This study underlines the need for accessible and appropriate information about TB in affected groups in Alberta and offers some insights and strategies.

Structure of the study

Study genesis

THE STUDY BEGAN IN 1997 WHEN THE NURSE MANAGER OF THE CAPITAL HEALTH AUTHORITY Tuberculosis Clinic, Diane Doering, voiced concerns about TB among immigrant and Aboriginal people. They seemed to differ from the usual public health profile for immunity and exposure to disease. Conditions such as HIV, Hepatitis B and TB were being missed occasionally by health professionals, and the unique sociocultural health needs of immigrants and refugees were not being met consistently within the existing health services framework. Doering was seeking a model for the appropriate delivery of healthcare to immigrant patients that was inclusive of their physical, mental and emotional needs; a model that could help to guide training programs for health professionals in many settings. (See *Appendix 1: Original grant proposal summary*.)

Doering approached Yvonne Chiu, a community health worker who has championed immigrant health initiatives in Edmonton for some years. She also approached Nancy Gibson, then a professor in the Department of Public Health Sciences at the University of Alberta. Application was made to the Alberta Heritage Foundation for Medical Research (AHFMR) for a grant to support a study of immigrant and Aboriginal people, those who have the highest rates of tuberculosis in the province of Alberta. The resultant funding included one mixed Aboriginal community (in consultation with the Métis Nation of Alberta) and six immigrant groups in the study. The funding was supplied from July 1998 to December 2001.

Conditions such as HIV, Hepatitis B and TB were being missed occasionally by health professionals, and the unique sociocultural health needs of immigrants and refugees were not being met consistently within the existing health services framework.

The project also attracted funding from other sources, including a grant from the Medical Services Branch / First Nations and Inuit Health Branch that permitted the addition to the project of three First Nations communities. The University of Alberta Endowment Fund for Small Faculties, the Gray Nuns Foundation, the University of Alberta departments of Human Ecology and Family Medicine, and Canadian Heritage provided additional funding during the

subsequent three years. The composite community-based TB research project was designed to seek a better understanding of the sociocultural dynamics surrounding TB among Aboriginal and foreign-born Canadians.

As the study developed, it had many components and served as a training ground for graduate students and summer and rotational medical and public health science students, as well as many people from the study communities. The project included Chinese, Hong Kong, East Indian, Vietnamese, Filipino, and Eastern European communities in Edmonton as well as one rural, mixed Aboriginal community, expanding to include three First Nations Communities – Cree, Blackfoot and Peigan.

Study objectives

This was a multi-method project, painted with a broad brush. Commencing with an epidemiological review of patient medical records at the Capital Health TB Clinic in Edmonton (the TB Clinic), the project expanded to the collection of qualitative interview data by lay research associates selected from among the most affected ethnic populations (Cave et al forthcoming). As the highest incidence of tuberculosis in Canada is in immigrant and Aboriginal populations, an obvious question was whether there are cultural barriers to TB prevention. Consequently, the study's primary objective included identifying and understanding sociocultural factors surrounding the prevention and treatment of TB among the participating communities. Such understanding could then guide program delivery and training programs within those communities.

The second objective of the project was to build research capacity within the participating communities by orienting members of these communities to research methods, providing the communities with an experiential base and a network of partners to initiate and carry out future health research projects. A third objective was for community members, as well as academics, to gain experience with collaborative health research and in studying sensitive health issues in diverse communities. A fourth objective was to heighten public awareness of the prevalence, prevention and treatment of TB.

Study design and methods

The main source of data for this study included semi-structured interviews with individuals selected from immigrant and Aboriginal communities in Alberta. Historical documents and TB Clinic files were reviewed and several literature reviews were conducted. Group interviews with community health personnel and evaluation sessions with the various project groups were also used as sources of data. The design was like a spiral, in that each lesson learned from the research process itself affected the subsequent project design and management processes.

Managing the literature review

Reference databases were maintained throughout the project. Several databases were created using ProCite.

- *The Gray Literature Project* – a collection of articles and reports developed in conjunction with the University of Alberta John Scott Health Sciences Library and funded by the Faculty of Medicine. It established a collection of research documents and reports relating to health in immigrant and Aboriginal populations in Alberta, Western Canada, and Canada in that order.
- *The Participatory Action Research Database* – a critical literature review funded by the North American Primary Care Research Group.
- *Sociocultural Factors* – an overall database, complete with abstracts, on sociocultural issues relating to tuberculosis.



CULTURAL FACTORS IN TB PREVENTION AND TREATMENT: A MULTIMETHOD COLLABORATIVE STUDY

Nancy Gibson, Andrew Cave, Diane Doering, Chandra Magill, Yvonne Chiu
Departments of Family Medicine and Public Health Sciences, University of Alberta,
Capital Health Authority TB Clinic, Edmonton, Alberta, Canada



University of Alberta

Capital Health Authority

The tubercle bacillus can be killed, but TB has not been eliminated.
The highest incidence in Canada is in immigrant and Aboriginal populations.
What are the cultural barriers to TB prevention?

People ...don't know they have it
...don't always seek treatment
...don't always adhere to treatment

Step 1: Retrospective study chart review

Collaborators: University of Alberta Faculty of Medicine, Regional Health Authority, Provincial government TB Services

Findings: Epidemiological methods could not identify the barriers

Step 2: Semi-structured interviews with health professionals

Collaborators: University of Alberta Faculty of Medicine, Regional Health Authority, Aboriginal and immigrant community leaders and health workers

Findings: Cultural factors contribute to barriers

Step 3: Focus groups with health professionals, community leaders and tuberculosis patients

Collaborators: University of Alberta Faculty of Medicine, Regional Health Authority, Aboriginal and immigrant community representatives

Objective: To design and test a set of culturally appropriate questions for the six immigrant groups with the highest TB incidence in Alberta and two Aboriginal groups

Step 4: Training two community associates selected from each of the six immigrant groups with the highest TB incidence in Alberta and two Aboriginal groups

Collaborators: University of Alberta Faculty of Medicine, Regional Health Authority, Aboriginal and immigrant community leaders and health workers, advisory committee

Objective: To train 16 community associates to conduct semi-structured interviews within their own ethnic communities to identify cultural barriers to TB prevention and treatment

Step 5: Supervise the community associates as they conduct interviews within their own ethno-linguistic group

Each CA to hold interviews with:

- 4 people being treated for TB
- 4 people being given prophylaxis
- 4 people who have refused prophylaxis
- 4 people who have recovered from TB

246 interviews

Collaborators: University of Alberta Faculty of Medicine, Regional Health Authority, Aboriginal and immigrant community leaders and health workers

Objective: To collect data from within the cultural groups with the highest incidence of TB

Step 6: Analysis/interpretation of data by representatives from all partner organizations

Collaborators: All previous partners and community associates

Objective: To ensure validity and cultural appropriateness of interpretation

Anticipated findings:

- Cross-cultural factors influencing TB prevention and treatment
- Culture-specific factors influencing TB prevention and treatment
- Cross-cultural and culture-specific barriers to TB prevention and treatment

ANTICIPATED OUTCOMES

- Culturally appropriate strategies for reducing TB in high risk communities
- Increased awareness of TB within high risk communities
- Trained community associates improving sustainable local research capacity

...and the reduction of TB by using culturally appropriate strategies

Theoretical framework

As early assumptions by the research team anticipated considerable differences in health beliefs and practices among the cultural group being studied, the Health Belief Model (Strecher and Rosenstock 1997) was originally envisioned as a theoretical framework. It was soon learned that people's behaviour regarding TB was not primarily determined by their ethnicity; rather, other factors emerged as more influential than ethnic heritage. There was clearly more intercultural and cross-cultural community diversity than anticipated. The population categories used in the provincial clinical files, from which data were first drawn, such as "India," included people from places as diverse as Afghanistan and Pakistan. Early in the project it became apparent that the Health Belief Model could not be applied for the following reasons:

- the small size of the sample;
- the interpersonal differences within the communities used for this study; and
- the study design, which employed lay colleagues as interviewers.

Good (1994) has argued that beliefs do not stand outside the cultural context. The vast intercultural differences relating to other factors led to the search for other explanations. Thus, emphasis shifted from the influence of cultural beliefs or ethnic values on people's perceptions of and responses to TB healthcare (Strecher and Rosenstock 1997) to factors such as type of employment and income, family obligations, accessibility of service, and language. Kleinman's (1981) approach to understanding individual behaviour combines well with Triandis's (1994) approach to understanding sociocultural context. Explanatory models could thus identify overlapping personal and sociocultural factors that inhibit or enhance health behaviours.

The dual commitments to maximise community involvement and attempt capacity-building introduced a second theoretical consideration in which ethics became paramount.

It soon became clear that the experiment fell between traditional health research paradigms and ethnography. The dual commitments to maximise community involvement and attempt capacity-building introduced a second theoretical consideration in which ethics became paramount, driving revisions in study design as a result of formal and informal evaluations and day-to-day experiences with the community research associates. (Huxham (1996) describes this process as transformational collaboration.) Consequently, the theoretical framework was consistently guided by the ethics model set out in the foundation principles by the Community Advisory Committee at the beginning of the project (Macaulay et al 1998a). The importance of guiding principles is reflected in several publications (Gibson and Gibson 1999, Gibson et al 2001), the policy document developed for North American Primary Care Research Group (NAPCRG) on responsible research for communities (Macaulay et al 1998b), and the subsequent article in the *British Medical Journal* (Macaulay et al 1999).

Discussion papers and posters were presented at many conferences to take advantage of opportunities to exchange knowledge with people conducting other projects. Because nine languages were used for the interviews – Blackfoot, Cantonese, Dene, English, Filipino (Tagalog), Mandarin, Punjabi, Saulteaux, and Vietnamese – the interviews were primarily analysed as translated and transcribed texts. The process of identifying emergent theory was akin to grounded theory principles, whereby themes, once interpreted, identified what was being learned with relevance at various levels from the specific to the general.

Systems theory (Churchman 1983) was useful in many situations to identify the dynamics of the various communities. Empowerment theory (Fetterman 1996) was frequently invoked in the development, practice and evaluation of performance regarding the principles of equity and respect for complementary community skills (Macaulay et al 1997).

Study participants and personnel

Community participants

Project personnel
are identified in
Appendix 2.

The concept of “community” has been defined by many – it is important to indicate what it means in this report. Rhetoric about community participation abounds. LaBonte (1999) cautions against the uncritical use of the term, and Cooke and Kothari (2001) provide examples where the invocation of the term is artificial, misrepresenting the people involved in a project and/or their various constructions of community.

Community has been used in several ways in this report. First, the extensive research group that gathered around this project became an *intentional community* for the duration of the project, with a common task and focus, sharing and creating knowledge together. Second, the term was used rather loosely at the outset to refer to ethnic communities; however, the concept of *Aboriginal community* or *Chinese community*, for example, has little meaning in terms of shared culture or even language. The term is still used in the report to refer to the cultural groups included in the study, but readers are asked to bear in mind the caveat that the reality of inter-cultural diversity was recognized. Finally, *community* also refers to the groups of ethnically related persons upon whom the project was centred. In the case of Aboriginal groups, these were identifiable geographical places, but in the case of the immigrant groups, *geographic community* was not an appropriate concept, as the participants lived in many parts of Edmonton. It is important in this study to keep in mind that, “Community is a potent idea, but its reality is the more modest process of people organizing themselves, or being organized, into identity-forging, issue-solving groups” (LaBonte 1999:101).

DIVERSE CONTRIBUTIONS The research project brought together people working both inside and out of academic and public health institutions. Shown here are members of the research team, CAs and members of the CAC in March 2001.



Community advisory committee

Members of the Community Advisory Committee (CAC) were selected from existing organisations with a view to ethnic origin, networking experience, leadership skills and knowledge of community health in its broadest sense. CAC members were involved in planning and carrying out the study, guiding and contributing to the overall process. The CAC met two or three times each year. Individual members also provided advice and support to the academic staff and to the community associates (CAs) and participated in workshops and training sessions. Members of the CAC were also instrumental in the recruitment and selection of the CAs.

The research partnership between the communities and the academic team was negotiated at CAC meetings, bringing about mutual learning resulting from the research, and thus ensuring that the community perspective was always kept in mind. CAC members provided advice on how research in their own cultures should be conducted in a sensitive and appropriate manner. The functions of this committee were:

- To provide the linkage between the academic researchers and the community and to ensure that the immigrant and Aboriginal communities' interests were protected throughout the research process;
- To participate in the development of ethical principles for the research, design of research instruments, strategies for data collection in Aboriginal and immigrant communities, interpretation and analysis of data, and in the dissemination of results;
- To provide advice in the recruitment and training of CAs;
- To provide support and guidance to the CAs;
- To provide guidance on appropriateness of research methods throughout the project; and
- To facilitate the implementation of follow-up activities or action resulting from the research.

The CAC played a central role in developing the foundation principles, which articulate the project's commitment to fostering the development of research infrastructure within the various communities. These principles guided the project through ethical, methodological and theoretical challenges as they were encountered. (See *Establishing the foundation principles*, next page.)

THE FOUNDATION PRINCIPLES

1. Plan the code of ethics / foundational principles in conjunction with the Community Advisory Committee, community associates and cultural communities.
2. Honour the life circumstances of people we are working with and be guided by mutual respect and appropriate confidentiality.
3. Be sensitive and responsive to the values, culture and priorities of the individuals and communities.
4. Promote sustainability of community networks and research capability.
5. Research is to be responsive to identified community needs.
6. Research is to be educational.
7. Primary commitment should be to those who are at risk and to enhance possible coping strategies for those most challenged.
8. Advocate for equity to support those who have barriers / challenges.

ESTABLISHING THE FOUNDATION PRINCIPLES

The purpose of creating foundation principles was essentially to define the boundaries of power within the research relationship. The task of engaging community members in the research process and the sensitive nature of capturing the experience of people who had TB presented a major challenge. While the project was committed to traditional standards of responsible investigation, ethical questions arose that were unique to the participatory and collaborative research approach. These questions needed to be addressed not only by the professional academic researchers in the project but by everyone who would be affected by the processes and outcomes of the research. Some of these questions were:

- Who should participate in the research?
- Who should control the information generated in the research?
- When and how could the community best be included in the research?
- What strategy should be used to deal with findings that could have a negative impact?
- Who should take responsibility for ensuring collective consent for dissemination of findings?
- How might the dissemination and publication of the research findings be conducted to be of maximum benefit to the communities?

There was collective recognition of the diverse perspectives within the project from academic researchers, healthcare practitioners and community members with different cultural backgrounds. Thus, a defined set of values and principles was required that would reflect a philosophy about how people and their participation in research about their personal experiences would be valued. In a participatory and collaborative context, this power should reside with those who are active participants in the research process, including the people who have provided the information as well as those involved in the analysis and interpretation of the results. Framing the foundation principles was an iterative and dynamic process of defining participatory research, integrating cultural values and reaffirming personal philosophy among the three major participating groups in the project: the Community Advisory Committee, the professionals and academics, and the community research associates.

The foundation principles had two main components: the overall philosophy of the project and the ethical principles that guided the conduct of the research. The project philosophy was based on the assumption that all people have the inherent capacity to gather and develop knowledge to contribute to the improvement of their own health and quality of life.

The foundation principles exerted a profound influence in many decisions and actions throughout the research. Some examples include:

- participation of the CAC in critical decision-making and problem-solving of issues in the research;
- recruitment and selection of community research associates;
- application of a participatory training approach in the development of CA skills;
- development and finalization of interview guidelines;
- shared learning among the various Aboriginal and immigrant CA groups;
- introduction of qualitative methods to CAs;
- planning dissemination of results in discussion with both the CAC and CAs; and
- ongoing evaluation of research to improve participatory and collaborative process (Gibson et al 2001).

Throughout the research process, the foundation principles existed as a living document, constantly being tested and challenged as issues were brought forward to the CAC and research team for resolution.

Community research associates

The community research associates, or CAs, were the crucial link between the TB research project and the cultural communities involved in the study. They were recruited from the high incidence communities, providing the perspective of their own cultures and ensuring that the research was conducted in a sensitive and respectful way. The CAs were as much an integral part of the research project as were the CAC and the academic research team. With a project goal of building research capacity within the communities through training and participation of local CAs, the CAs became the heart of the research project because they could:

- articulate the experiences of the research participants;
- increase the project team's understanding of these experiences by providing the cultural lens to see beyond words;
- acquire additional knowledge about health and illness in their communities; and
- identify collective community interests beyond the research.

The community research associates were recruited in a variety of ways with the guidance of the Community Advisory Committee. To recruit CAs from the immigrant groups, advertisements were placed in ethnic newspapers in Edmonton, posted on bulletin boards at settlement agencies and circulated at meetings of groups such as the Indo-Canadian Women's Association. The Community Advisory Committee members circulated the ads in their various professional and cultural communities. The relevant coordinator and CAC member interviewed applicants. (See *Appendix 3: Community research associates recruitment*.)

In the Aboriginal communities, CAs were appointed from among the already existing community health representatives by the regional health directors.

Coordinators

Two part-time coordinators provided guidance and support to the community research associates. One coordinator, Jeanette Sinclair, was of Aboriginal heritage; the other, Lucenia Marquez Ortiz, had immigrated to Canada from the Philippines. Both had research experience and masters level education plus extensive networks that included many of the communities and organisations relevant to this study. Other research coordinators, Hélène O'Connor and Paul Harms, joined the project later on. Coleen Kato provided administrative support throughout the project.

STUDY COORDINATOR JEANETTE SINCLAIR Research staff worked closely with CAs before and during the interview process to maximize the quality of data collected.



Project mentors

Two project mentors were named in the application. Senior scholars Dr. Ann C. Macaulay of McGill University and Dr. Milton Freeman of the University of Alberta provided guidance on many ethical and procedural issues throughout the project.

Orientation / training

THE ORIENTATION / TRAINING SESSIONS (JULY AND OCTOBER 1999) WERE DESIGNED TO PROVIDE CAs with project information about TB, as well as interviewing and research skills. The sessions were also intended to foster a sense of team membership. The three-day sessions included:

- review / reworking of foundation principles;
- instruction from a physician on biomedical views regarding tuberculosis;
- a session with a public health nurse on the clinical treatment and prevention process;
- a “cultural iceberg” exercise that explored variations within cultural groups and what the expression of culture meant to participants;
- role playing exercises to develop interview skills;
- workshops on the principles of qualitative interviewing;
- technical training and rehearsal using tape recorders;
- intensive reworking of the interview questions guidelines;
- introduction to qualitative data analysis; and
- introduction to PAR principles with CAC members.

The training sessions for the community research associates were held at the University of Alberta. The second, three-day session in October brought together CAs who had not been able to attend the July session and included the Aboriginal CAs recruited under the MSB grant. Following the format of the original training session, the first two days included only the new CAs and gave them an overview of the project as well as an introduction to participatory and cross-cultural research methods, focusing on developing and practising interviewing skills. Shared meals encouraged interaction and formation of friendships at a personal level. Members of the CAC again participated in the training session both as facilitators and observers.

Adopting their new roles as mentors, the first group of CAs shared their interviewing experiences thus far. This session was one of the most valuable for both groups of CAs.

CAs from the July session were invited to the last day of training. Adopting their new roles as mentors, the first group of CAs shared their interviewing experiences thus far. This session was one of the most valuable for both groups of CAs, as it affirmed the first group’s progress and made the research experience much more real and achievable for the new group of CAs.

Following this session, both groups took part in an introduction to qualitative data analysis. This analysis orientation session was particularly effective in improving the CAs’ understanding of and familiarity with the interview questions. As well, this exercise clarified the kind of information sought from the interviews and increased CAs’ confidence and comfort level with the interview guidelines. Data in subsequent interviews seemed to be richer, as the CAs came to understand more clearly how the interview data would be processed to produce results.

In future, including an orientation to the analysis process after three or four interviews would be an important addition to the training process. An evaluation of the training sessions by the CAs revealed them to be a fulfilling experience on both a personal and an educational level.

The interview process

Development of the guidelines

Unique guidelines were developed for four interview categories within each cultural group:

- Those with active TB (active group);
- Those taking preventive therapy (prophylaxis group);
- Those who refused or discontinued therapy (refused group); and
- Those with personal and/or professional experience related to TB (history group).¹

In keeping with the collaborative philosophy of the project, the process of developing the interview guidelines followed a participatory approach. The project leaders drafted an initial working version of the questionnaire. The immigrant and Aboriginal coordinators reworked this draft into four different interview guidelines that were then reviewed and workshopped during a CAC meeting. Finally, the community research associates revised the questions during the first and the second training sessions to better suit the cultural preferences and values of the people they expected to interview (See *Appendix 4: Sample of interview guidelines*).

Cross-cultural consistency in question format and data collection was a procedural concern. A balance had to be negotiated between open and flowing interviews and the CAs' need for structure, given their lack of experience in conducting research interviews. During the training sessions, CA groups reworked the interview guidelines to make them more culturally appropriate. When both Aboriginal and immigrant groups reconvened, everyone was pleased to discover that they had independently developed comparable questionnaires that included the core questions in their basic form, despite adaptations for cultural values, protocols and language conventions. While the interview guidelines maintained a semi-structured format, a written list of supporting questions, probes and follow-up options for each main question helped obtain richer data.

The interview guidelines in each of the four interview groups followed the same basic format. Each guide had four general sections for data collection:

- The background and profile of the participant;
- The participant's experience with TB and TB treatment;
- What the participants and their families knew about TB; and
- The participant's opinion of services received through healthcare facilities.

PRINCIPAL RESEARCHER NANCY GIBSON Interview training and guidelines for CAs balanced structure with opportunities for free-flowing discussion.



¹ Many interviewees included in the history category were able to provide a different perspective because of the depth and variety of their experiences with TB far enough in the past for them to have gained a degree of objectivity about their experiences.

Support for CAs

Support for community research associates took various forms:

- regular telephone calls from the coordinators and the project manager;
- easy access to the coordinators and the project manager for calls from the CAs;
- occasional community visits from the coordinators, CAC members and members of the administrative team;
- periodic newsletters (See *Appendix 5: Sample newsletter*);
- formal and informal meetings of CAs with CAC members and academics;
- letters of acknowledgement / reference;
- certificates of achievement;
- payment of personal expenses related to interviewing (daycare for orientation / wrap-up sessions, mileage / bus fare for travel to interview sites); and
- honoraria.

Interview participants

Participants for the foreign-born interview groups were obtained through the TB Clinic using a variety of methods. For the “active” group, all case files active in the clinic for the five years preceding the study were sorted into the six immigrant communities that were the study focus. Beginning with the most recent clients, the clinic nurse who had been the primary healthcare provider for each person attempted to contact that individual by telephone to obtain agreement to participate in the study. This process was repeated until the desired number of participants in each population group had been reached, or until the available numbers were depleted. Participants in the “prophylaxis” group were chosen at random by the clinic manager from all currently active files. Clients under age 18 years were excluded.

For the “refused prophylaxis” group, a report was run from the Alberta Health TB database listing the people who had been recommended to take a course of preventative medication (prophylaxis) in the previous year but had refused. The TB Clinic manager again used a process of sequential selection,

going through the list and selecting all the persons who belonged to the six community groups. Again, those under age 18 were excluded.

Participants in the fourth group, called the “history” group, were selected on the suggestion of clinic nurses who were able to identify clients who had had TB in their home country in the past and would be willing to be interviewed. The CAs also gathered additional names from interview participants who knew of family members, friends or colleagues who had some previous experience with TB.

COMMUNITY RESEARCH ASSOCIATES Support for CAs included formal and informal meetings, visits and check-ins.



The Aboriginal interview participants were selected from the roster of the health clinic in each community. Because of the lack of cases in some of categories in the smaller communities, it was not always possible to include four interviews in each of the four interview categories. Rather than making a random selection, the sample often included everyone with TB, on prophylaxis or who had refused prophylaxis in each community.

Thus, although the original study design called for each CA to conduct four interviews in each category for a total of 16 interviews, this target was unrealistic. The goal was adjusted to accommodate the real time frame of the CAs and the availability of interviewees in the various categories and communities. In all, 133 interviews were conducted.

On average, each interview took 45 minutes. All participant interviewees were offered an honorarium of \$10 to \$25, presented by the CA at the end of the interview. The CAs also offered brochures providing information on TB and an invitation for the study participants to contact them if they had any concerns about TB or the research process.

Evaluation of CAs

The CAs took part in two process evaluation sessions. Each orientation session was also evaluated. At the end of the first year, an AHFMR summer student conducted interviews with each of the immigrant CAs. A presentation was made at an international conference in India, and posters were presented at several conferences in Canada (See *Appendix 6: Sample posters*). At the end of the project, a summer medical student conducted recorded telephone interviews with each of the CAs to assemble and present a composite summary of their experiences in the project.

Challenges encountered by CAs

Among those involved in the research project, the CAs were the most regularly challenged, for they held the primary responsibility for capturing the experience of the research participants, the core data for the project; thus, the credibility and success of the research rested on the rapport and trust the CAs were able to establish.

Foremost among the challenges was the difficulty of making the first phone call to book an appointment for an interview. Although patients contacted by the TB Clinic initially consented to an interview, almost all of the CAs experienced rejection in at least one phone call to a potential interview participant. Some patients declined outright, others refused to answer voice messages and still others offered excuses to avoid being interviewed, e.g. too busy, going away, etc. The CAs were relieved to discover that this reticence on the part of the candidates for interview was not uncommon with other CAs, nor, indeed, in other research projects. Reassurance about the possibility of refusal to be interviewed and strategies for dealing with refusal should be stressed in any similar CA training program.

Finding time for interviews was another challenge. Most CAs had families as well as full-time jobs, or they were enrolled in school. Appointments for



COMMUNITY RESEARCH ASSOCIATES CAs held primary responsibility for capturing the experience of participants.

interviews had to fit around other priorities. Two CAs withdrew halfway through the research because of their increasingly demanding schoolwork. Some CAs also encountered research participants who made unreasonable demands on their availability, such as demanding late evening interviews because of shift work. Occasionally the Aboriginal CAs were permitted to conduct some interviews during their working hours as community health representatives, but in practice most interviews took place in the evenings or on weekends.

Interview refusals to CAs resulted in occasional delays in obtaining the names and contact information for other potential interviewees because appropriate cases were not always readily available, or because new interviews were not to be assigned until the last category of interviews was completed. In hindsight,

CAs were relieved to discover that this reticence on the part of the candidates for interview was not uncommon with other CAs, nor, indeed, in other research projects.

overlap of the four interview categories and consistent provision of possible interview names to CAs might have maintained a continuum of interview activity that could have contributed to a more sustained level of CA commitment to the process. Similarly, and in retrospect, the order of the interview categories should have been different. Rather than beginning with a sensitive category – people with active TB – it would have been easier for CAs to start with those on prophylaxis, as there were more available participants in this category and less potential stigma than with the active cases.

The translation and transcription of completed interviews also slowed the data collection process. Translation and transcription had not been included in the CA job description but were offered as optional tasks. Some CAs chose to attempt these activities. The translation was a tedious process of transcribing the spoken interview into a written transcript in the native language and then translating it into English. The CAs found the work time-consuming because English was not generally their first language. An average transcription / translation of a one-hour interview took four to five hours. Since this extra time had not been anticipated on such a scale, a small additional grant was obtained to help pay a flat rate of \$50 per transcribed interview. Professionals who also provided back-translation expertise translated other interviews.

SKILLS TRAINING CAs found they could conduct more productive interviews after they received further training about how their data would be used to meet study objectives.



Data analysis and interpretation

THROUGHOUT THE DATA COLLECTION PHASE AND AFTER THE COMPLETION OF THE PROJECT, the interviews were coded and analyzed using the qualitative analysis software NUD*IST (Non-numerical Unstructured Data Indexing Searching and Theorizing). Multi-rater analysis was used occasionally to ensure validity in the data coding and analysis. Once the initial stage of data analysis was completed, both the CAC and the CAs were consulted on aspects of the analysis and interpretation of data. They also advised on appropriate strategies for dissemination and use of the findings within the communities.

NUD*IST training, data entry and preliminary coding

In January 2000, project research staff attended a one-day training session on using NUD*IST software offered through the International Institute of Qualitative Methodology. When the interviews were complete and the resultant recordings transcribed and coded to ensure interviewee confidentiality, the transcripts were entered into the NUD*IST template. The software allowed the texts to be analyzed for recurring ideas, meanings and words that could be grouped and collapsed into themes that together compose the results section of this report and lead to the conclusions and recommendations.

Participant profiles

The project results are based on 133 interviews conducted between July 1999 and March 2001.

Table 1: Interviewees by country of origin					
	active	prophylaxis	refused	history	total
Hong Kong	8	8	4	5	25
China	5	6	0	4	15
Philippines	6	5	1	4	16
Vietnam	6	6	1	2	15
Hinton / Edson	6	1	1	2	10
East India	8	4	4	1	17
Eastern Europe	1	2	1	1	5
First Nations community A	2	2	0	2	6
First Nations community B	4	4	4	4	16
First Nations community C	2	2	2	2	8
total completed	48	40	18	27	133

Table 2: Interviewees by age					
	active	prophylaxis	refused	history	total
under 18	1	1	1	0	3
18 – 35	15	27	11	4	57
36 – 50	9	5	3	13	30
over 50	23	6	3	10	42

The age of one person in the prophylaxis group was unknown. There were five interviewees for whom only approximate age was known. The average age of the foreign born urban participants who were offered TB prophylaxis was 36.7 years, while the average age of Aboriginal people living in rural Alberta to whom TB prophylaxis was offered was 28.8 years, almost eight years younger. The average age of people with active TB in both rural and urban areas was 49.6 years. In the history category, people in the rural communities averaged seven years older than those in the city.

Table 3: Interviewees by gender					
	active	prophylaxis	refused	history	total
female	25	23	12	17	77
male	23	17	6	10	56

Among the Aboriginal participants, more males were interviewed (21 males, 15 females); among the immigrant participants, more women were interviewed (35 males, 62 females).

Table 4: Facility with English					
	First language		Ease with English		
	English	Other language	English well	Some English	No English
China	0	11	8	3	0
East Europe	0	4	4	0	0
East India	0	15	6	2	6
First Nations community A	2	2	4	0	0
First Nations community B	11	3	12	0	0
First Nations community C	2	5	6	0	0
Hinton / Edson	4	5	5	3	0
Hong Kong	0	20	9	5	6
Philippines	0	12	10	2	0
Vietnam	0	13	4	7	2
Total	19	90	68	22	14

Note: This table excludes interviewees in the history category where an individual's level of English was not pertinent to the results. Three people indicated they had two first languages, thereby making the number of first languages reported greater than the number of people reporting.

The right side of Table 4 is based on people's unelaborated reports of their own ability with English. Some CAs indicated that these results are distorted, because some people they interviewed did not speak or comprehend English as well as they had indicated. Actual facility with English by the participants can only be assumed, in many cases, as the example exchanges below indicate.

Participant (P): How can I say which information would be useful? I went to the TB Clinic and I saw the poster on the wall but it was in English. I was too lazy to read it because it was too hard for me.

CA: You looked at the picture and it explained some of it to you?

P: That is correct.



CA: Can you follow when someone speaks to you in English?

P: No, not much. Only a little.

Of the 10 people who said they didn't speak English at all, nine were women. The average age of the 10 was 65.8 years, their median age was 66.5 years and they had lived in Canada an average of 11 years.

Time lived in Canada

On average, immigrant interviewees had lived in Canada for 8.5 years. The actual time ranged from two months to 30 years. Of the 48 with active TB, one arrived in Canada as an infant 30 years ago.

Housing

Since TB is transmitted by close human contact, such as that maintained by crowded living conditions (Ruggiero 2000:2), the interview guides included questions about the number of people with whom interviewees shared their homes. The Canadian census of 1996 shows that the average household in Alberta consisted of 2.8 people. The participants in this study reported that an average of 3.4 people lived in their homes, mostly members of a nuclear family. The range was from one person living alone to a household of seven persons. (This number is likely lower than the actual average number of people it should represent. Some interviewees just said they lived with their children, not saying how many children there were. In those cases, the number of children was estimated as two.)

AN OPEN PROCESS Community research associates revised interview questions during the first and the second training sessions to better suit the cultural preferences and values of the people they expected to interview.



Results organized by themes

The following section presents the data, sorted by themes, relevant to the research question. It provides an overview of the characteristics of participants and their experiences with TB.

Experiences with TB healthcare

People reported receiving help from different kinds of healthcare professionals during their treatments for tuberculosis. Comments in the interviews generally reflect people's impressions of who helped the most or whose help was most important. Both doctors and nurses must have been involved in every case, but many people mentioned only one or the other.

	active	prophylaxis	refused	history	total
nurse	31	24	10	5	70
doctor	28	12	6	9	55
hospital	31	1	2	18	52
family	16	7	4	6	33
TB Clinic	7	14	3	1	25
medical professional abroad	1	1	1	12	15
other medical clinics	2	2	9	0	13
sanatorium	0	0	1	9	10
CHR	4	4	2	0	10
alternative medical practitioner	3	0	0	2	5
friends	1	1	0	1	3
non-medical staff at TB Clinic	2	0	0	0	2
Indian agent	0	0	0	1	1
don't say	0	2	1	0	3

"TB Clinic" means interviewees didn't mention anyone in particular at the clinic. Only one immigrant participant spoke of a sanatorium, although several mentioned the existence of TB hospitals or TB wards. The remaining references to TB sanatoriums were made by Aboriginal participants. One person in the 'refused' category spoke about having been in a sanatorium years ago and about it having been suggested that she take prophylaxis much more recently. Interviewees also often used the word *hospital* to refer to a medical clinic. Sample statements follow.

P: "One month after that, the doctor at the TB hospital called me and said they study the fluid in my lungs that have TB."



CA: About the services given to you, did the nurses or doctors help you?

P: Just nurses. But I did get a doctor at the university health clinic telling me to go to the TB Clinic. Basically, I only had nurses to help me.

Impressions of healthcare staff

Part of each interview dealt with people's impressions of their experiences with the TB treatment and with the staff at the healthcare facilities they attended. The interview questions were open rather than pointed. Some illustrations of impressions of healthcare staff are given below.

Table 6: Impressions of staff at healthcare facilities				
	active	prophylaxis	refused	total
positive	24	22	6	52
neutral / mixed	17	15	9	41
negative	4	0	0	4
unclear	3	3	3	9

Positive

CA: Please tell me about your experience at the health clinic.

P: In here? I see they are not racist, do not avoid being with a TB person, and [they are] very helpful.

CA: Are you comfortable with the staff and service at the health clinic? Please explain.

P: Yes, I feel comfortable.



CA: Were you comfortable about the advice that was given to you?

P: Yes. Obviously, they would tell me the right thing.

CA: What did you think the test result meant?

P: I was alarmed at first. But their explanation calmed me down.



CA: Please tell me about your experiences at the TB Clinic and/or Health Centre?

P: Oh it was wonderful, always best people, really caring.

CA: That's great. Are you comfortable with the staff at the TB Clinic or the Health Centre?

P: Yes, oh yes. Oh, when I go there the nurses are good, the doctor is always available to discuss your questions, and all that. Very nice, nice people. The hospital staff was also amazing.

Neutral / mixed

P: I wondered why did I take these kinds of medicines too much. The doctor told me I had to listen to him, because I wanted to treat my sickness. I didn't dare to stop taking TB medicines any time. Government gave me the TB medicines. So I had to take them in order to treat my illness. I tried to take TB medicines every day. I felt sick of taking TB medicines, but I had to take them.



CA: They repeatedly asked you to take the medicine? Did you feel pressured?

P: A little, because I have decided not to take the medicine, but it seemed that they were forcing me to take it.

CA: How did it feel?

P: Strange. I am not taking it, let me be. Why repeat so many times? Perhaps I was not quite clear why I was positive.

CA: In regards to their service, what do you think needs to improve?

P: In fact, nothing in particular to improve. It was quite good as a whole.



P: There was one thing which I didn't like. When they called my office, my co-workers knew that I had gotten a phone call from the TB Clinic. They might think something is wrong with my health. My boss, who is a pharmacist, would question how I could face patients at the pharmacy store. ... For friends, if I knew they had TB, it would be okay. But for a boss or co-workers to know that I had TB, they will think of infections, etc. They would say that I could not work in front of the public.



P: Timing wise. Because I need to book my time early in the morning otherwise if I come after work I couldn't make the appointment. They already closed after I get off my work.

CA: You mean the clinic should open longer hours.

P: Yes, there's no reason that I should specially take half day off to pick up the pills.

CASE STUDY FROM ONE DRUG TO ANOTHER

Mr. Chen arrived in Edmonton 21 years ago when he was 55 years old. He lived in Hong Kong before his son sponsored him to come here. He still speaks Cantonese and has not learned English very well.

Mr. Chen's wife was first diagnosed with TB and was hospitalized for two weeks. The whole family was recommended for TB testing. Everyone except the grandchildren tested positive and took medication. Mr. Chen experienced difficulties going to the TB Clinic every day to take his medication, especially during winter. *"We had to walk a few blocks after getting off from the bus, very time consuming and inconvenient, everybody had to go to work."* There was no one in the family who could bring him to the clinic, so his daughter-in-law arranged with the TB Clinic to have his medication delivered twice a week at home.

However, after two months of medication, his platelet count dropped and he was hospitalized for a week. *"In October, I tried good medication, after two months, there was a side effect. My platelet count was very low, not balanced (normal). So the person who was responsible felt it was very complicated, he had to change medication and tested my eyes. I wondered why I had to be on medication for so long, because this medication was not that effective when compared with the one before."* Mr. Chen had changed his medication twice but his platelet count continued to drop.

The doctor changed his medication but when Mr. Chen learned that the drug would make him lose his appetite, he refused to take it. *"Doctor told me the side effects of the medication was losing appetite, I did not want to take it. I was let go after the examinations were done and was fine. Despite I did not talk English, doctor could see my gestures and my voice sounded like I did not like medication. So doctor asked me to come back in June, half a year, to have an examination."* This alternative was much more acceptable to Mr. Chen.

REF/HK/ND/1

Negative

CA: *Did you have to stay in the hospital for some time?*

P: *Yes, they kept me there for some days .*

CA: *How did you feel about staying there?*

P: *It was like being put in a prison. I would just sit on my bed and cry.*

CA: *You did not like it there?*

P: *No. I did not understand the language. I just kept looking at their faces all the while. Now you and I are talking, if there is someone like that, then you don't mind it, but they were all white. I could not speak, so I would just sit and cry.*

CA: *What about the food?*

P: *I would get food from home. They used to give me food there as well, but I would give it to the girls who would get it for me.*

How healthcare workers provide good service

Sixty-seven people in the active, prophylaxis and refused categories offered the following characteristics reflecting a positive opinion of clinic staff.

Friendly / caring / nice

P: *Oh, they were very nice. They greeted you and as soon as you come in, they assist you right away and after two minutes, three minutes they already called you to get your weight, blood sample...*

CA: *So, if you are going to rate how comfortable you were.*

P: *It was very comfortable, yeah, and my nurse was always smiling at me.*

CA: *And a smile makes a big difference, doesn't it?*

P: *Oh, it makes a big difference, that's true. It means you are really welcomed.*

Flexible / accommodating

P: *The problem is that I moved from Halifax to Edmonton, but I don't think it's a big problem, my moving. I come here I contact with Alberta TB Clinic. Halifax TB Clinic gave me three months' medication, so I still had medicine when I came here.*

Informative

CA: *What did you think the test result meant?*

P: *I was alarmed at first. But their explanation calmed me down.*

Thorough

P: *In Westmount, actually, the nurses they're all nice. At Aberhart, too. There is one who really monitors you. She doesn't get tired calling you and following up trying to remind you about taking your medication. She is really okay because other people may easily say 'who cares if you don't want to come for your medicines'. But she calls and calls and calls, you know.*

Answers to questions about how people get TB

Knowing how TB is contracted is a fundamental part of effective prevention. If medical practitioners and patients agree on how TB can be contracted, professional advice is likely to be well received. Also, if medical practitioners are aware of the level of their patients' knowledge about TB, they can anticipate problems in the treatment process before they become serious.

Interviewees named a variety of means for contracting tuberculosis. Some of those answers were generally consistent with the way medical professionals think about tuberculosis; others were not. Arthur Rubel and Linda Garro (1992:627) maintain that TB healthcare services can be impeded when patients and healthcare professionals have different perceptions of the illness, and communication breakdowns ensue. Interviewees could give as many answers as they thought appropriate. For example, if someone answered the question "How do you think people get TB?" by saying, "Oh, I'm not sure. Breathing someone's air that has it," the answer fits only the 'contagious' category because, in that case, the "I'm not sure" was simply a qualifier or introduction.

	active	prophylaxis	refused	history	total
contagious	28	26	13	25	92
not taking care of yourself	8	5	1	7	21
environment	5	4	2	7	18
don't know	4	4	1	1	10
smoking	2	2	1	4	9
hereditary	5	0	1	2	8
"coughing" (unexplained)	0	2	0	0	2
topic didn't come up	2	5	3	0	10

Ten people supposed that TB was caused by a category that some referred to as "vice." Three of those 10 came from Vietnam, three from the Philippines, three from Hong Kong and one from Romania. Eight of the 10 had active TB and the other two had known many people who had had TB. These people believed it was an irresponsible lifestyle that caused TB, but none expanded their comment to say whether TB was due to divine retribution, or whether it was because the vices wore the body down. For example:

P: In the Philippines, I worked in a printing press. There are chemicals. Maybe, I don't know, I probably inhaled chemical fumes. Also I had vices before – I smoke and drink alcohol.

Other people thought they got TB from overwork or not taking care of themselves. Such a conclusion might be appropriate in an environment where almost everyone has been exposed to TB, but only some people get sick.

Four of the 11 interviewees who thought people got TB because they did not or were unable to take good care of their health also answered that TB is contagious. They believed people were more susceptible to catching TB when they let their health run down. Two of the seven people who suggested that TB was caused by living in an unhealthy environment generally saw that as the primary cause of TB. Most of those people did not believe TB was contagious.

The following are some examples of statements representing the categories in Table 7.

Contagious

P: *The air in the classroom is filthy. Some people coughed, some people were sick. I didn't feel sick, but I felt uncomfortable.*

CA: *What made you uncomfortable?*

P: *Air is filthy, it's hard to breathe.*



CA: *How do you think people get TB?*

P: *Don't know. I am not sure. It is from other people most of the time.*

CA: *They get it from other people, how?*

P: *Maybe, the person is sick, cough and the germs spread in the air.*



CA: *How do you think people get TB?*

P: *I think it is caused by the contagious bacteria, and it also depends on the person's health and immune system. ... I was not having a good nutrition and my stress was too high, and we didn't have such a high stress at home. We have support from family and face no change in life, but here we have to deal with work, study and financial problems alone.*



CA: *Why did people catch TB?*

P: *I think they catch it through personal contact or through work. Or they have virus; respiratory systems start to have problems. Overloaded at work, malnutrition, people spitted sputum on the floor and germs exposed to the air.*



CA: *How do people get TB, in your opinion?*

P: *The disease is passed on from other patient when you are weak, when you don't have the strength to fight the disease.*

CASE STUDY NO SIDE EFFECTS, PLEASE

Ollie has been in Edmonton for eight years. She was born in Poland and lived in Germany before coming to Canada. She is 36 years old and married with two children. She speaks fluent English and German, Russian and Ukrainian. She likes living in Edmonton and currently works in a hospital.

Ollie tested positive for a Mantoux test two years ago. She said her TB is not active because she does not show any clinical symptoms associated with TB. Her family and friends knew about this and did not have negative reactions. *"Their response was normal."* The reason for this, she said, was because there are many people who have TB in Europe. When she worked in Germany, she came in contact with a lot of sick people. Even here in Edmonton, she has patients with TB in the hospital *"... almost every week, someone is coming in with an active TB."* Except for an aunt who tested positive, no one in her immediate family has had TB.

The doctor advised Ollie to take prophylactic medication. She was told there would be side effects. From what she knows, there is no guarantee how one's body will react to a drug. *"From my experience I know if you are taking any kind of pill, there are going to be side effects. Plus I know that if they are testing for side effects, no one knows 100 per cent how you are going to react."* Ollie was frank about her decision not to take medication because of the risks involved.

REF/POL/EN/2

Not taking care of oneself

P: *I don't know. My illness did not come from infection. First, I don't smoke. I don't drink. Is difficult to have TB, could be the hemo-dialysis.*



P: *I think for people without vice – like me I don't have any vice – I think we get it from working too hard, as well.*



P: *Some people catch a cold. They would cough, and keep on coughing and not seeing a doctor. ... Chinese call that "Hundred Days Cough." If you cough for 100 days, it would be more difficult to treat, and it would turn into TB. This is what I heard. This is what I heard the elders say.*



P: *... as soon as I had the cough, I went to see the doctor. As the procedures took a long time, I had to wait for three weeks to see a specialist, then wait another three weeks for the specialist to refer me to the hospital for a CAT scan. It took more than one month all together. I doubt that because of the delay, my cold turned into the TB infection. I almost bought an air ticket, flying back to China for treatment. As in China, several penicillin injections will cure the flu and the cough. When the disease get delayed, it would turn into a much more serious one.*

I don't know

Some interviewees didn't know how to answer the question about how people get TB, but they did know how to identify someone who has TB by their symptoms.

CA: *How do you think TB is caused?*

P: *I don't know. In India anyone who keeps becoming weak is taken to the doctor and is diagnosed with TB. ... Anyone who had prolonged fever and cough and kept becoming weak was suspected to have TB.*



CA: *How do you think people get TB?*

P: *I don't know. Well, it's fever and cough and when the fever does not go away it's TB. Other than that I don't know.*

Hereditary

CA: *Do you know the reasons why people have TB?*

P: *I don't understand why. My family history doesn't have this kind of illness.*

Environment

CA: *How do they think you get TB?*

P: *Too much work, unattended perspiration, supposed to change wet shirts from perspiration. Smoking, unhealthy, polluted air, environment, exposure to people with TB.*



CA: *So they never think that you acquired the disease from anybody?*

P: *Never. Most of them believe that the fumes from the tobacco are really harmful.*

CA: *So, do you have any idea why people contract the disease other than through the inhalation of fumes you mentioned?*

P: *It is common knowledge that if you work in a tobacco industry you get that disease.*



P: *No, no idea. Might be because I used to go in the train in India and the trains are not that clean. Maybe that's from where I got it. I don't know.*



CA: *How do you think people get TB?*

P: *I think TB is an illness that causes from weak lungs, hard working in the polluted air. These factors destroy the lungs and lead to TB disease. I think the simple reasons causing TB is working very hard in a bad condition. This reason destroys the lungs. I think so.*

None of the interviewees who said that TB is hereditary made it completely clear what they meant. An argument has been put forward in the academic literature that genetics might affect one's susceptibility to tuberculosis. Grybowski and Allen (1999: 1026) say there is growing support for the role of Darwinian genetics in shaping a TB epidemic.

Two First Nations people said TB was caused by coughing, but did not expand their answers beyond that single word. The CAs in those cases did not ask for further explanations. It seems reasonable to assume that those people meant that TB is contagious and that it spreads when people cough. Another plausible interpretation of those two answers parallels a traditional Filipino belief that a cough left untended for too long will turn into TB (Matsunaga et al 1998:20).

CASE STUDY STRICTLY FOR PERSONAL REASONS

Suneeta is 28 years old, married, and has a one-year-old daughter. She came to Edmonton two years ago from India, where she was a nursing student. She speaks English well.

Suneeta had her first TB test in India three years ago and tested positive. She took medication and completed treatment. She was still single at that time. As a nursing student, she knew the medical importance of TB treatment not only for herself, but to protect others from getting the disease. She believed she had adequate knowledge of TB based mainly on what she learned from school. Suneeta was well aware of the fear and stigma that people feel about TB in her home country. *"They are scared that they will contract TB from them, they shun them. If they have TB, people do not tell everyone about it."* She was convinced that she got TB from exposure to people who had TB when she was a student nurse.

Suneeta knew that because of her previous illness, she would always test positive for TB. It was not a surprise for her that she was asked to report to the TB Clinic for prophylaxis. However, she is convinced that she has been completely cured and there is no problem. She made a special request of the CA to keep her interview strictly confidential. The CA noted *"She is married now and has a one-year-old daughter. She has never told her in-laws or her husband about her past TB condition and wishes it to remain so."*

Her main reasons for declining medication included her belief that she is not at risk of contracting TB again, that she would not affect others, and her obvious fear of her in-laws. To do so would reveal something she had guarded with care. For her, there was too much to lose if her family were to find out about her past illness.

REF/EI/DG/RV/I

Social stigmatization due to TB

Evidence of social stigma attached to having tuberculosis appeared to be more prevalent among the Aboriginal participants (14 per cent) than among the immigrant participants (3 per cent) in this study. However, some CAs conducting interviews with immigrants believed there was a stigma attached to having TB that influences people's attitudes to prevention and treatment. In a wrap-up session, one CA reported:

The reaction from the community workers was, 'Don't make it such a big fuss, it's going to bring negative stereotyping to the clients. Don't splash all over the mainstream media that immigrants have TB: it will just make the discrimination that might exist, even higher.' So their reaction, when we first brought them together, was interesting. But later, when we worked in the Chinese community itself, I think because so many people in the local Chinese community had some interaction with TB Services or TB, they understood the need to help others [eliminate] unnecessary fears or myths about TB.

	active	prophylaxis	refused	history	total
No problem with stigmatization	11	19	4	12	46
Feared being stigmatized	7	3	3	5	18
Didn't tell people they had TB	9	5	2	1	17
Reported being stigmatized	4	3	0	2	9
Issue not raised in the interview	17	11	8	5	41

Note: The numbers in the history category are somewhat distorted because the people in that category were talking about TB from considerably diverse perspectives.

There is a gray area between social stigmatization and behaviour that indicates people's desire not to catch TB, as in this example:

P: People stayed away from each other, not sharing cigarettes and stuff like that. Just really kept to themselves.

Two interviewees reported no stigmatization from their neighbours, but felt that healthcare professionals treated them less well because of their TB. One Aboriginal interviewee said she felt little stigmatization within her own community, but felt there was a stigma against Aboriginal people as a group in their interaction with non-Aboriginal people.

How people are affected depends on their philosophical interpretation of their illness (McGrath 1999:484; Matsunaga et al 1998:4). They could simultaneously consider tuberculosis as a germ infestation and as a personal situation. For example, according to Clifford Cardinal (2000:18), some Aboriginal people in Alberta believe that personal health is influenced not only by their physical state, but by an integrated combination of their physical, spiritual and social states and by the quality of their physical, spiritual and social interactions with others. Illness can be a reflection of an imbalance in the whole person caused by a lack of synchronicity between the physical, spiritual and social self. Part of the stigma attached to tuberculosis, then, could come from people's fear that their serious illness will be a poor reflection on them in the opinion of others. Although no one expressed this philosophy outright in the interviews, some comments seem consistent with Cardinal's explanation.

It was sometimes unclear why some did not tell others they had TB. One reason might be that they were worried how other people would respond. Some may have felt there was simply no reason to tell anyone.

No problem

CA: *How has this affected your family?*

P: *Not much influence. If everybody knows, be open. Doesn't matter.*



CA: *Whom else did you tell that you had TB?*

P: *All my family knows it, and some of my friends and classmates.*

CA: *How did they act when you told them?*

P: *At first they were surprised, after that I think they treat me just the same.*



CA: *How did they act when you told them?*

P: *Ah, they've also been positive anyway, so they're aware and it's not a big deal.*

CA: *Not something scary or things like that?*

P: *No.*



P: *You know, it just happens. It's not like it's something you bring on yourself. It's not like you'd been leading a crazy sex life and then you get something...*

CA: *Did people treat her like it was a "dirty" disease?*

P: *No, not really.*



P: *In the past, TB illness was a terrible disease. People didn't keep too close to these people due to infection. But TB is under control. As long as you don't keep too close from them, be careful in personal hygiene, then TB illness is not a terrible illness. I didn't see anybody cough up blood before, I don't know what the reaction can be, there is a cure, the TB patients are approachable, the illness can be under control as long as the patients are on treatments.*

Fearful

CA: *Like you said earlier, you did not want to tell others, some people are afraid. What do you think their attitude will be, how will they treat these sick people?*

P: *Keeping a distance, would not sit so close together having a conversation.*



CA: *Did you disclose to anyone about your TB?*

P: *No, no, no, not to anyone, I just say that my chest got black. Otherwise everyone will think that I got TB.*



CA: *How did they react when you told your wife?*

P: *She was worried as well, worried there might be some changes in our life. Like our occupation, I am an engineer, not a labourer. I am supervising many people, healthy people. We didn't know what might happen after this.*



CA: *Whom else did you tell that you had a positive TB test?*

P: *Nobody, because I am not an open-minded person, so I did not tell anyone that I can not pass my illness to anyone. It just makes them scared of me more.*

CA: *Did you tell your family members that you had a positive TB test?*

P: *Yes, only my family members.*



CASE STUDY TRUST YOUR FAMILY DOCTOR I

Born in Shanghai, Mr. Chiang was sponsored by his son to come to Edmonton in 1993. He speaks three Chinese languages: Cantonese, Mandarin and Shanghai. Even before he came to Edmonton, Mr. Chiang spoke a bit of English, but he is still not comfortable speaking in the new language. He worked for a while at a Chinese seniors centre, but retired a few years ago.

Mr. Chiang still remembers the history of his illness back to 1958, during the Cultural Revolution in China. At that time he was working hard, sometimes three to four days without sleep, which he felt weakened his body. He coughed up blood and was sent for several tests, including sputum, urine and blood. According to him, the tests did not reveal anything. After a year, the same thing happened and he went to the TB hospital. The test result for sputum was negative, so he was sent for a bronchiogram examination. He was diagnosed with bronchiectasis, a chronic dilatation or enlargement of the bronchial tubes. He had lung surgery twice, in 1958 and in 1960. After his surgery, he had annual checkups; each time, his sputum test were negative. When he applied for immigration to Canada in 1992, his previous medical records could not be found. He underwent a complete medical examination and, according to him, his tests were okay, and that could be why he was approved for immigration.

When he arrived in Edmonton, he applied for work at the Chinese seniors centre. Because he would be interacting with seniors, he was asked to have a medical checkup. He went to the Public Health Centre, where he was told that his legs were swollen and his kidney might have fluid ("effusion"). He was also told that they would give him another test – a "needle" test – at the health centre. Then a nurse from the TB Clinic phoned him about taking medication. He consulted his family doctor about his kidney condition and also asked about the TB medication. His doctor told him to take care of the kidney first and deal with TB later. *"The doctor told me not to take drug. He asked me the condition of my lung, I said that I had surgery, but it was not a big problem. When I worked in the factory of China, I had checkups every half a year, no problems."*

His family doctor's advice was the principal reason for Mr. Chiang's refusal. He also firmly believes that he does not have, and never had, TB. *"They told me to have needles and take medication. I said I didn't need to because my lung was okay. My lung tissues are normal even though I have bronchiectasis."*

Mr. Chiang and his son, who later joined the interview, maintain that their family does not have a history of TB. Yet towards the end of the interview, his son told the CA that his mother (Mr. Chiang's wife) reacted more quickly than his father. When asked to go for a test, she went immediately for a blood test and X-ray at the TB Clinic. She was advised to see a specialist the following month.

REF/HK/ND/2

CA: *What was your reaction when you heard that someone had TB?*

P: *Some people avoided those TB people, but I don't mind. It doesn't matter to me, so I don't have TB.*

CA: *Some people are afraid of hearing that somebody has a TB infection?*

P: *They were so afraid that they didn't want to get close to the patients and chat with them. They would run away. Didn't tell anyone*

CA: *Whom else did you tell that you had TB?*

P: *Nobody, I just told my youngest son. My oldest son, he doesn't know. If he had come I would have told him.*



CA: *Did you mention about your condition to anyone outside your family?*

P: *No, I did not talk to anyone about it, not at all.*



CA: *Besides them, have you talked to others about TB?*

P: *No, there's no particular reason to mention about it.*

CA: *If you talked about it, normally what do you think their reaction would be?*

P: *There shouldn't be anything special because lots of people knew about TB, there shouldn't be a big problem.*

Felt / aware of stigma

CA: *What do people in your community feel towards people who have TB?*

P: *They try to avoid people who have TB. They won't say anything, but one knows when they do not want to visit you, sit with you or talk to you. They try to get away from you, without looking rude.*



CA: *What did the people in the community think about TB?*

P: *They are very sensitive. They think TB is life-threatening disease. A few months ago, a lady had a bad cold; she coughed a lot and lost her voice. My boss looked for this information about TB in the Internet and posted it on the board. See how sensitive he was?*

CA: *So your boss must take preventative measure against TB disease.*

P: *They won't communicate too close with the people who have TB germs.*

CA: *Besides gossip, how about in action?*

P: *They kept a distance with these ladies.*

CA: *Did they discriminate about your TB germs?*

P: *I didn't let them know that I had TB germs, because I saw the results with those two ladies.*



CA: *How did TB affect people you knew?*

P: *People in my community, it worried them a lot. People in the community who are known to have TB are being avoided by other members of the community.*

The initial diagnosis

People were asked how they first learned they were sick with TB or tested positive for TB and about their response to this news. The following two tables and quotations summarise the responses.

Table 9: How people learned they had contracted TB				
	active	prophylaxis	refused	total
checkup due to ill health	35	3	0	38
test after contact with active case	2	12	6	20
routine screening for a job or volunteer position	0	6	4	10
in part of immigration process	2	6	1	9
in regular health checkup	2	3	3	8
routine test on entering remand centre	0	1	0	1
test after hearing a talk by a public health nurse	0	1	0	1
not TB+, just wanted prophylaxis	0	1	0	1
unclear from interview	7	7	3	17

Table 10: How people felt when they learned they had TB or tested positive				
	active	prophylaxis	refused	total
okay / no reaction	12	17	4	33
upset / stressed	10	7	0	17
bad / awful	11	3	2	16
surprised	7	6	1	14
scared	4	5	4	13
confused	2	1	0	3
embarrassed	3	0	0	3
sad	3	0	0	3
relieved it was just TB	2	0	0	2
relieved it was not TB	0	1	0	1
don't say	6	3	7	16

Examples of replies summarized in Table 10 follow.

CA: *How did you feel when you knew you were TB positive?*

P: *Nothing, because at the time the doctor explained it very clearly. He said that in Canadian population, a large portion have the same signs, not to worry. That's why I did not worry.*



P: *I don't know, it really didn't affect me in a negative way, because my mom's positive too and she knew that because she works. She's a nurse, so she had to get tested before she started working, and like, you know, from seeing my mom, it's not like it's scary or anything like that, like it's not gross or whatever, it's not active, that's the thing .*



P: *I did not feel sad because I cannot do anything to make things different. It's God's act. If you are sick and it's time for you to go, then I might as well go.*



CA: *How did you feel when you first knew you had TB?*

P: *Well I felt pretty bad about that, because my oldest brother had TB when he was small, when he was, I don't know how old he was. They brought him to Cardston Hospital and he stayed there for awhile, I think three months.*



CA: *How do you feel when you first had or when you first knew you had TB?*

P: *I wanted to go home to the Philippines because I know I will be stuck here at the hospital.*



CA: *This was your first time to take x-ray, then they said that you had a scar.*

P: *I was told, then I was so afraid that, I went to see my family doctor, I had another x-ray again, but the result was okay.*

CA: *You said that you were afraid, can you tell me what you were afraid of?*

P: *I was afraid that I really had TB. Sometimes I never knew I contacted the carrier. I want to protect my health, don't want to get sick.*

Medication and treatments

People's experience with TB treatments in the past is likely to influence their reception of TB and TB treatments. People who had taken TB medication were asked what it was like for them. Most reported having had trouble with side effects. People talked about directly observed treatment (DOT) and the advantages and disadvantages of that treatment strategy.

Problems taking the medication

All of the people interviewed for this project – with the obvious exception of the people in the refused and history categories – reported completing their treatment despite possibly having had problems taking the medication. This is a higher level of adherence to the TB medication regime than in much of the literature. For example, Hoepfner and Marciniuk (2000:145), and Matsunaga et al (1998) found that TB patients were often less likely than others to begin or complete prescribed drug therapies.

The TB project had considerable difficulty in securing interviews with people who had declined TB prophylaxis. In 1998, of the 3,828 individuals in Alberta testing Mantoux positive, 1,273 or 69.6 per cent actually took the preventative medication (Alberta Health and Wellness 1998:50). One of the reasons people reported not finishing the TB prophylaxis once they had begun was that the problems caused by the pills did not seem worth the potential benefit. (See the case studies.)

Table 11: Problems experienced with the medication				
	active	prophylaxis	refused	total
nuisance / inconvenience	23	12	1	36
nausea / achiness	20	9	1	30
none	13	16	0	29
tiredness	9	6	0	15
high liver toxicity	2	2	3	7
headaches	3	1	1	5
harmed eyesight	4	0	1	5
itchy skin	4	0	0	4
offended by pills	3	0	0	3
weight loss	1	2	0	3
harmed kidneys	2	0	0	2
tingly fingers / cold feet	0	2	0	2
feeling like drunkenness / slurred speech	2	0	0	2
harmed hearing	1	0	0	1
weight gain	0	1	0	1
nosebleeds	0	1	0	1
causes forgetfulness	0	1	0	1
topic not raised	2	1	0	3

The following quotations concern problems interviewees had with taking TB medication.

None

P: But the nurse does ask me every time I go there whether the medicines bother me or anything. But everything is okay.

Nuisance / inconvenience

P: Every time I had to go to the centre to take the medicine. It may be done for the purpose of making sure that the patient takes the medicine according to the time schedule. I'd like to suggest some flexibility about it. If the nurse knows the patient would take medicines strictly according to time schedule, it would be very helpful giving the patients medicines for one month or two months. I was quite busy at that time, and I didn't have a car. It brought me many inconveniences to go there regularly. I do understand why they make such requirements, many people will forget to take the medications as required, which will postpone the cure. However, I did remember to take medication strictly according to the time schedule. I understand from their point of view, but from my point of view, I wish they would allow such flexibility.



CA: Please tell me about your experience with the TB medicines.

P: I am frightened. It's a whole bunch of pills, and the nurse watches you. What can you do? Just take them.

CA: Anything else?

P: The pills are big, some seem to stick in my throat. Tomorrow's Friday, I have to take the medicine. I am afraid even when I talk about it, but I have to face it, because it won't work otherwise.



CA: Please tell me about your experience with the TB medicines.

P: I felt very scared at first. I look at many pills, First time I took about six or seven pills, now I take seven pills at a time. Every time taking the TB pills, I am very scared and worry for some side effects in the future. I took many TB pills for about six months continuously, so I worried too. In the other hand, I think I have that illness so I have to try to take the medicines to kill this disease. I only try very hard; otherwise I am very scared at looking at the pills.

Nausea

CA: Please tell me about your experience with TB medicine.

P: First three months I was quite sick, I was not able to hold down the food. Getting nausea, no appetite, very sick until they stopped one of the medications.

CA: So it was that one?

P: It seems like it was that one that was causing the problems, once that was stopped I had much better time and this time they hadn't put me on that one because they are not sure how it affects the baby.

Fatigue

CA: Can you tell me some experiences in taking medication, nausea or the reactions?

P: I felt tired every day, but when I took medication, it was fine, no big problem.



P: First I took TB medicines, I felt tired. When I took the pills that are long and red, I got fever and headache. I couldn't raise my head, tired. First I took TB medicines, I felt tired. After that, I didn't have any problems like that.



Offended by pills

P: I didn't feel anything, I didn't feel any good. When I was at Rocky, they came and gave me the pills. Look at these pills, these are the ones that are causing this, I just grabbed the pills and threw them into the bushes. I just stopped eating them. They didn't help me.

CASE STUDY MOTHER KNOWS BEST

Kim came to Canada in 1995 from Hong Kong. Age 12 at the time, she says she was too young to note any difference between her home country and Edmonton. She says she feels she has been here all her life. She speaks Cantonese and Mandarin and admits that her fluency in English is “50/50.” She lives with her mom and dad and two sisters and is a high school student.

When Kim volunteered at the University Hospital, she was required to take a skin test for TB. Her skin became red and swollen; she was told that the swelling was bigger than 10 mm. She tested positive and was recommended for an x-ray exam and referred to the TB Clinic. Although it surprised her, she knew it was a common belief in Hong Kong that if you had BCG vaccination, you would always get a positive result in the skin test. At the TB Clinic, the doctor advised her to take medication. Kim and her mother, who went with her to the clinic, were overwhelmed with the information they got from the doctor. He presented figures and statistics: “... *actually there were many numbers, but we don't remember, how many per cent will come back and so many per cent and so on, but we just don't remember, but I remember that they have listed a lot of numbers...*” The conversation was in English, even though “... *in the beginning we told him that our English level, listening ability is not high enough...*” The doctor recommended that Kim take prophylactic medication. They were also told that the medication might affect her liver.

“My mom decided for me.”

Kim's mother made the decision, primarily because Kim was a minor, but also because her mother had experienced the side effects of a prophylactic medication. As a teenager in Hong Kong, her mother had a shadow in her lungs. When she came to Canada, it was recommended that she take medication to protect her from TB in case her body weakened. She took the medication for over a year, but stopped every time her liver test indicated it was above normal values. There were also physical signs, such as feeling tired and her hair turning dry and yellow. However, she also mentioned that she was taking thyroid pills and had just finished radiation. Even the doctors could not say whether the side effects were due to the TB medication. “*They have not given me a concrete answer. They just said there is no conflict, in other words, taking thyroid medication on one hand and taking the other has no effect.*”

Kim is convinced her BCG vaccination caused the positive test result. Since she does not show any signs or symptoms of TB and is feeling well, she feels she does not need medication. Besides, there was too much risk involved in taking the drug as experienced by her mother. “*Mainly it affects the liver, that is, the BCG vaccine will affect this and they said that BCG vaccine does in fact affect the TB result, even though it has the chance to re-occur, the chance is very slim. I didn't feel it was necessary to take the medicine.*” After Kim declined prophylaxis, the nurse offered an option they felt more comfortable with – a yearly checkup, including x-ray.

Volunteer work

Kim was accepted as a volunteer at the hospital and was assigned to the TB ward, where she pushed carts and sold treats to patients. Working on the TB ward made her realize how much stigma is attached to TB. She recalled that many volunteers avoided the TB ward, even if protective masks were given to them. She did not ask why, but assumed the other volunteers were afraid they would catch the disease. Kim was not affected so much by it because she does not stay long in the TB ward and has no close contact with patients.

Family history

Kim's mother recalled how she got TB – by sharing the same bed with her sister who was diagnosed with TB. She was about 17 or 18 years old at the time. The whole family took x-ray tests and all had scars in their lungs. Kim's mother remembered that she took medication for only two weeks. She had x-ray tests every year for five years, but because the scar did not become larger, she did not take medication. When the family migrated to Canada, she was asked to report to the TB Clinic. She took medication for nine months.

Directly observed treatment

Directly observed treatment (DOT) is the recommended method of managing drug treatments for tuberculosis by the World Health Organization (WHO 1999). It is also the protocol in Alberta (Alberta Health TB Control Manual 2000). In DOT protocol, a healthcare professional must observe each person taking pills every day or twice weekly, depending on the stage of treatment for active TB. The advantage of this supervision is that it ensures consistency and avoids gaps in the treatment process. People were asked about DOT and their feelings about the treatment strategy. Only two people made particular reference to having a problem getting their pills every day. Some reported that having to take the pills was a nuisance. Time conflicts seemed to be a bigger issue for the immigrant populations in Edmonton than for the Aboriginal people in rural areas. Several Aboriginal people said that a nurse brought pills to them at home. Everyone interviewed in the city had to visit a clinic to obtain their pills. That alone may account for the difference. Comments about DOT follow.

P: The clinic itself is good, the doctors and nurses are good. The only thing I had problems with is that I had to go on the medication protocol, that I have to be observed taking the medication and I just find that quite insulting, they say it is a protocol and they can't change it. I have to do this that way; I found it quite a nuisance. In the beginning that I have to leave my work, go to the clinic, wait there, take pills, come back to work and it was going to take quite a bit of time of my work days. If we arrange it so that I would have someone at work observe, since I am surrounded by nurses, OTs, physios, that one of them would observe me, I don't try to take it personally, but still I don't really like that part of it.



CA: Please tell me about your experience with the TB medicines.

P: I am frightened. It's a whole bunch of pills, and the nurse watches you. What can you do? Just take them.



Experience at the TB Clinic

Kim appreciated the diligence and effort of staff at the TB Clinic to convince her and her mother to take prophylaxis. *"I don't quite remember, they told me that I tested positive, but the lung x-ray was clear. The best was for you to take the medicine, then they kept on explaining why you needed to take the medicine, what are the advantages and what are the disadvantages, so many percentage this, so many percentage that."* They received a lot of information, but would have preferred some to be in print. *"They did not give me any written information to read. Then perhaps I was not quite clear why I was positive, but they have said it was because of the BCG vaccine, I would conclude that because the BCG vaccination, I was tested TB positive."* Without the chance to read something at home, with time to understand it, they did not know what questions to ask and felt that something was missing. *"Missing, don't know, not knowing clearly and completely how TB came about. Perhaps they have said it, but at the time, I couldn't quite get it."* She did not ask questions to find out more. *"I was too lazy to ask other people, so even though I couldn't quite understand, after they said it, I just let pass."*

Although Kim felt a bit pressured by TB staff following up with her to take medication, she understood that it was necessary. *"It was their responsibility, they were doing it for the benefit of the patients; therefore, they needed to say it so many times, to make sure that you take the medicine."*

REF/HK/JT/2

P: *It's very troublesome to take the medicine every day. Why don't they give me the medicines to take at home? I don't understand why I need to take the medicines for months if my test is negative.*



P: *My husband used to say, "You don't have to watch me. It's my skin. I want to get better." We believe in medication. If you know it's for your own good. We don't need supervision. We would take it anyway. I don't know if this can be changed. I guess some people wouldn't take the medication. I know we could be trusted to take it. When I know I have to take a pill at 5 p.m., I take it right at 5 p.m. Not before or after. Some people are against medications.*



P: *... they wanted me to be on [prophylaxis] for nine months ... At that time, I had to go back frequently to the TB Clinic to pick up medication, and to have the blood work. With my work as well as my schooling, it made it very difficult for me to go ... all the way there. Every single time it was, every two weeks, and then monthly, but still I found it difficult. I would have preferred that they allow me to take the medication home with me, and ... go for my blood work wherever I wanted to, because there are other labs that open on the weekend as well as evening times and all that. Anyway, that is one thing that I find ... is such a difficulty in ... taking the medication. ... I feel, in a way, that it prevented me from wanting to go on to take the medication.*

Reasons for stopping or refusing prophylaxis

People refused to take, or prematurely quit taking, prophylaxis for a number of reasons: concern about side effects, pregnancy, perceived toxicity of the medication, the advice of a medical professional, distrust of medical professionals, inconvenience or because they believed they were not ill.

P: *I have taken the medicine before and I found that it was harmful to the body quite a bit. I insisted that it was because the BCG vaccine, the picture of the lung was clear; therefore I did not agree. [This quotation is from the mother of a 17-year-old interviewee. She told her daughter not to take the prophylactic drugs.]*



P: *If I knew that I needed to be on treatments definitely, I would remember to take it. But if I am fine, I don't think I can remember to take medication.*

CA: *Did you make the decision by yourself or did somebody help you?*

P: *By myself, after seeing the family doctor. My family doctor knew my health for long years. And I don't think the clinic knew about me. They can't make decision just based on one x-ray result. I trust myself. If I coughed for a long period of time, I would suspect, maybe I had TB. But I never did.*



CA: *Did you try to take the pills, the prophylaxis?*

P: *No.*

CA: *What were your reasons for deciding not to take medication?*

P: *Too long and side effects.*

The legacy of sanatoriums for Aboriginal people

One might expect the history of sanatorium isolation (Rothman 1992) to influence people's perceptions of TB treatment in the present. Jenkins (1977:546) reports that Natives in British Columbia in the 1970s feared that when people got TB they would be sent to die, away from family and friends. Case finding and treatment were therefore difficult, particularly in B.C., during that time.

Because this project dealt with current TB treatment, no questions were asked directly about sanatoriums. Eleven people, however, did refer to sanatoriums in their responses. Of those, five had spent time in a sanatorium. One person did not know that TB sanatoriums no longer exist. A few people suggested that stories about the old sanatoriums still influence people's thoughts about TB today. As the following comments show, sanatorium experiences were negative.

P: It was not a good time for me. I had to stay in the hospital ... for nine months. I was lonesome for my parents, my mom, the kids, my sisters. I missed them a lot.



P: I lived in a sanatorium in Calgary for four years, two years of age to six years.

CA: So did you ever go home?

P: You mean during the treatments? I don't recall, but I was told I was there for the longest time. I never came home. That's why when I did get home, everybody sort of treated me as an outsider.



P: I told you about how long I was hospitalized for, how I suffered for a long time. I never even received any mail. No mail, no TV. That's how it was: very lonely.



IMMIGRANT COORDINATOR
LUCENIA MARQUEZ ORTIZ
Project staff addressed language challenges through wide consultation, CA expertise, and occasionally using interpreters and translation services.

Use of traditional healers or medicines

Each interview included at least one question concerning the use of traditional medicine and traditional healers so as to describe the full range of treatment strategies (McGrath 1999:484, Matsunaga et al 1998:4). The project hoped to determine what effect traditional healing methods had on people's perceptions and use of TB healthcare services in Alberta. However, relatively few people gave affirmative answers to questions about traditional medicine or traditional healers. This may be because of the sacred nature of such information and treatment, or because biomedical healthcare is usually covered by insurance, while other kinds of treatment may not be. The following are typical responses.

CA: *Did you see a herbalist doctor and try herbalist medication?*

P: *Kind of trying. There are not too many herbalist doctors here. Alberta Health Care doesn't cover the costs of seeing a herbalist doctor and herbalist medication which I cannot afford – the medication costs around \$10 to \$20 daily and I have to take it for awhile, so I tried it one or two times, then I stopped.*

CA: *So you were seeing a general medical doctor and taking western medication?*

P: *Actually, I didn't take much medication, when my family doctor told me that I had inflammation, he prescribed four to five kinds of antibiotics for me. I stopped when the stomach was bleeding. Later, there was no improvement in taking the antibiotics, he sent me to the hospital.*



CA: *Among the friends you knew in Vietnam, what kinds of treatments did they use for TB illness?*

P: *They caught a four-legged reptile, broiled and ate it. If they had TB, they ate raw lizard etc. Some people ate crocodile meat. But I am not too sure whether it cured or not.*

CA: *... did they take western medication?*

P: *They can't afford to buy medication. They can only eat the animal that they catch and feel better as people told them to do so.*

CA: *You meant the drug is expensive.*

P: *The drug is expensive, snake is free to catch.*



CA: *This time when you took medication, did you take with those medicinal foods like before?*

P: *Yes, I use American ginseng to make soup, as it was so cheap. I made soup almost every day with different ingredients.*

CA: *Made soup every day?*

P: *Like today I used American ginseng, the next day I used apple, the third day I used different kind of medicinal food, anyway every day I make soup.*

CA: *Did you feel these medicinal foodd helping you?*

P: *I think so. I drink milk in the morning, but I felt uncomfortable in my tummy. And people told me that as I am getting older, I need to drink milk with more calcium intake in my body, so I drink milk every day.*

TB education

Because the World Health Organization promotes directly observed treatment as the best strategy to stop tuberculosis globally (WHO Report 1999), a wide range of educational and training materials are available. John Grange (1997:294), however, argues that patients' non-adherence to drug treatments is only part of the problem in eliminating TB around the world. If it were the answer, he reasons, DOT would have solved humanity's TB problem. Early diagnoses are too rarely made, and too often no appropriate measures are taken to counteract a TB infection until the disease has become quite contagious (Gibson et al 1998).

Grange advocates health education as the best way to improve the situation. If people recognize the symptoms of tuberculosis and understand how to counteract the disease's negative potential, they can take timely measures to cure the disease before they infect others. San Sebastian and Bothamley (2000:652), who conducted a study of TB prevention strategies, found that people who knew more about TB were more likely to complete prophylaxis. People who knew less about it were more likely to believe TB was not a health risk with which they need concern themselves. The need for public health education about TB was confirmed in the present study.

This study asked people if they thought they knew enough about TB when that knowledge was most needed. They were also asked what they thought people in their communities should learn about TB and in what manner. There was obvious concern among the interviewees about the lack of understanding in their communities about tuberculosis, its spread and its treatment.

P: They knew that TB was infection, they had to be careful. But I still felt that our Chinese community lacked information on TB. They thought about infection and didn't know much about TB disease.



CA: Now, talk about the community. How is TB known in the community?

P: There is a whole lot, perhaps know a little, not quite clear what the disease is.

CA: Know a little, can you tell me more about that, what is knowing a little?

P: Not completely knowing it, perhaps they only know the name, knowing there is something wrong in the lungs, but not knowing the consequence or the effects it has.



P: Many people in the local Chinese community ... understood the need to help others [eliminate] maybe unnecessary fears or myths about TB. And it was very interesting, when we talked to community members, people were mixing TB up with lung cancer, asthma, so the term, particularly the formal term of TB is not very well understood. It's sort of lumped in with other lung conditions. When TB actually could affect any other parts of your body and so there is a lot of miscommunication within the community. Not only some fears about this, but a whole lot of muddle around the condition.

CASE STUDY TRUST YOUR FAMILY DOCTOR II

Mrs. Li came to Edmonton from Hong Kong in 1975 with her husband and daughter. She said her daughter had more choices here in Canada for education than in her own country. A teacher in Hong Kong, she took a course in Early Childhood Development at Grant MacEwan Community College, worked at a daycare, and taught playschool for more than 10 years. At present, Mrs. Li is a part-time interpreter on an on-call basis. She is comfortable in Edmonton.

When Mrs. Li applied as a volunteer at St. Joseph's Hospital in September, 2000, she was required to have an X-ray exam. She was told that her X-ray showed a scar in her lungs. Mrs. Li was scared about the results so she decided to consult her family doctor who told her that it was fine, that there was nothing wrong with her. Her family doctor also told her he would inform the TB Clinic that she was fine.

She was confused, then, when the TB Clinic phoned her several times. *"No, they said the report showed that I had a scar, I had to take drug. Maybe I just exposed to that kind of people, but not necessary I am a carrier or I have TB. Nobody told me that I has scars, so I was surprised, my family doctor never says that I have a problem with my lung. I never cough or anything, I don't often have flu or cold, even though I work with children, my respiratory system is in good condition. If I am sick, of course, I want to be on medication, I don't want to infect others or get sick. So I go to see a family doctor right away to make sure whether it is true or not. After all the tests, I am okay."*

Mrs. Li was very frustrated. She could not understand why the TB Clinic would push her to take medication when she did not feel sick and her family doctor had already informed the clinic about her health status. *"I felt frustrated. I felt people bother me for nothing... If I told myself I am fine, of course, that is not right, because I am not a professional, I can't tell. But my family doctor who knew for many years and told me that I am fine, no need to be on treatments, why they still keep on pushing me? I have a feeling that they want to experiment everybody, anything on treatment, just to try out. I don't like medicine, if I need medicine, I will have it. But I don't need it. Why do I have to put it in my body? Why they keep pushing me, I know what I am doing, and why they don't trust the opinion of my family doctor, and keep on bugging me?"*

Although Mrs. Li felt that the TB Clinic staff were very persistent, she considered it part of their job. She said they tried to explain to her the risk involved if she did not take the medication, not only to herself, but also to others. *"She also called me two to three times at least. I can't remember well, it happened long time ago. She was not rude; she's just doing her job; just kind of nonsense for me. She can get professional opinion from my family doctor, and I trust him because he has been with me for more than 20 years. I trust myself because I know my respiratory system is good, even though I walked up the stairs, I seldom short of breath, that's why I don't trust them."*

When she told the TB Clinic her decision, the nurse, unable to convince her to seek treatment, advised that she go for an annual x-ray and checkup. Mrs. Li promised to follow the nurse's advice.

Mrs. Li said her husband supports her decision. He had a scar and received treatment in Hong Kong. He also took medication when he arrived in Canada. Mrs. Li said she does not see that her husband is different from other people in Hong Kong, where she said many had scars.

Mrs. Li could say for sure whether she has TB, despite the scar in her x-ray result. She demonstrated some basic knowledge about TB, such as poor health (malnutrition) as a cause of TB, coughing and blood in sputum as a symptom, and that TB can be transmitted by people who have TB.

REF/HK/JT/1

The relationship between perception and knowledge of TB

Information obtained regarding personal knowledge about TB supported the view that one's knowledge about TB and attitude toward it are related. Those who said they did not know enough about TB had a more negative attitude about it and a worse experience with the disease than did people who said they had been able to learn enough about it. This information strongly reinforces the view concerning the importance of TB education.

Table 12 indicates whether participants believe they got the information they needed when they were told they had TB.

Table 12: Perceptions of quality of TB information				
	active	prophylaxis	refused	total
yes	29	26	10	65
no	8	5	6	19
wanted more	1	2	0	3
didn't say	9	7	2	18
don't want to know	1	0	0	1

The following comments relate to knowledge and perception about TB.

Yes

P: *In Vietnam there were many campaigns about TB, so I know it too. When I came to Canada and knew I had TB, I just took the TB pills. All other things I know already.*



CA: *Did you get the information you needed when you were told you had TB?*

P: *Yes, on the shelves there are many documents that are in Vietnamese and in English. On the table there are some pamphlets from which people can consult. I took some of them home to read too.*



CA: *During your treatment, did they give you enough information?*

P: *Not much information, but I knew how to handle TB illness. In China, if there was TB, things had to be sterilized and boiled with hot water.*



CA: *Did you get the information you needed when you were told you had TB?*

P: *Yes, they gave me, they translated many ways to treat TB into Vietnamese, also they shown me those papers that have many kinds of TB pills and their reactions.*

No

CA: *Did the doctor or nurse explain to you?*

P: *No, they spoke English. I often asked my children how come the doctor says so much to you and you only tell me two sentences. They say you are okay, nothing serious.*

CA: *Your children didn't explain much to you?*

P: *No.*



CA: *Did you get the information you needed when you were told you had TB?*

P: *No, because I did not understand how the treatment works. For example, they started the operation then sent me to take medicines. I do not know anything else.*



CA: *Even though they haven't given you any written information to take home to read, do you feel that the verbal information provided to you was sufficient?*

P: *Something is missing.*

CA: *What is missing?*

P: *Missing, don't know, not knowing clearly and completely how TB came about. Perhaps they have said it, but at the time, I couldn't quite get it.*

CA: *When you couldn't get what they were saying, did you ask them, or write down the questions to ask other people, or just accept what they said?*

P: *I was too lazy to ask other people, so even though I couldn't quite understand, after they said it, I just let pass. I did not seek the root cause.*



P: *The doctor said the virus in my body was still sleeping and I have not got sick yet. Therefore, he just gave me the medicines to prevent and kill the TB virus. That is all I know. I just follow what they told me, I did not find out anything.*

Did not want to know

CA: *During the time of your illness, did you get enough detailed information to help you?*

P: *I don't want to know.*

A COLLABORATIVE STUDY Principle researchers Nancy Gibson and Diane Doering drew from experiences learned by CAs during interviews.



Wanted more

CA: *Did they provide enough information to you for TB illness?*

P: *Their information is not totally enough. I want to know more about the causes of TB and the prevention of this disease.*

CA: *You want to get more information for post-medication?*

P: *There is a chart posted in the clinic in English saying that Chinese people are easy to infect TB. It would be nice if it is in Chinese or other different languages because not everyone can read English.*

CA: *It would be helpful if there were Chinese brochures and forms.*

P: *If the explanation about the causes is in Chinese, it will be easy to understand more and to take preventative measures to make sure I don't infect others, etc. That's important.*

Of the 22 people who thought they did not get enough information about TB when they needed it, seven had a generally good impression of TB healthcare professionals, and four had a mostly negative impression. (This includes both of the people who said they had a lot of information, but wanted more.) The remaining 11 were ambivalent.

Of the people who thought they did not get enough information when they first learned they had TB or that they were TB positive, their stated knowledge about how tuberculosis is transmitted varied:

- 13 said it is contagious;
- four said they did not know how TB could be spread;
- four said people get TB when they do not, or are not able to, take care of their health;
- two said TB comes from living in a dirty or unhealthy environment;
- two said TB is hereditary;
- one said smoking causes TB; and
- one said it is caused by “not following the rules.”

In this study, a large number of respondents had known someone who had had TB. Knowing people who have, or have had, TB seems to ease people's own experience with it. Interviewees commonly suggested that a good way to learn about TB was to speak with someone who had previously had it. Indeed, knowing someone who had had TB (most often a close relative) did seem to correspond positively with people's level of knowledge about TB. Of the four people who had known no one with TB, three gave no answer when asked how people contract TB, and one made an uncertain guess. Likewise, they avoided telling anyone they had TB or felt stigmatized because of their TB. Knowing someone who had TB in the past positively influenced people's attitudes about TB, again supporting the hypothesis that knowing more about TB will help people develop attitudes that will eventually decrease TB. This supports the possible use of recovered TB patients and/or family members as community health educators.

When asked what they thought people should know about TB, the following responses were given:

- how people get TB;
- how to prevent TB;
- the symptoms of TB;
- the treatment of TB;
- the consequences of having TB;
- the importance of maintaining good health;
- the importance of trusting doctors and seeing them when you're sick;
- the importance of finishing all the medication; and
- the side effects of TB medicines.

The following are typical responses to questions about what people should know.

CA: What do you feel people ought to know about TB? What other information do you think would be useful?

P: Something that will make you realize faster that you have some problem, if you know at the first stage.

CA: So, do you think if you knew more what the symptoms were like you would have reacted faster?

P: Yes.

P: People always think TB can be passed on through air, by cough, but when I got TB, maybe mine was not contagious. At that time, my husband, who was my boyfriend at that time, he was with me, he didn't keep a distance from me, but he didn't get TB. I was separated from my family, but it was not very complete. Sometimes we may use the [same] cups by mistake. My Mum only worried that my nephew might get it, but he didn't. Actually none of them got it, ever since 1992 until now. I wonder when TB is contagious, when it's not.

CA: Is there anything else you would like to know about TB?

P: Nothing else. Nothing else. Mainly, why is there TB? I just don't understand, why is there TB?

One-page TB information sheets were translated into six languages – Arabic, Chinese, Filipino, Punjabi, Spanish, Vietnamese – for circulation to CAs, members of the CAC, TB health personnel and agencies, and others. (See Appendix 11: TB information sheets.)



Preferred methods of learning about TB and TB healthcare

The project asked participants how they preferred to learn and how they believed others in their communities could learn more about TB. Several people noted the importance of the availability of the information in languages other than English.

Table 13: Learning about TB					
	active	prophylaxis	refused	history	total
pamphlet	9	8	7	4	28
workshops	6	9	3	4	22
TV	8	7	2	0	17
talk to healthcare professionals	4	3	2	3	12
don't know	6	1	1	1	9
newspaper	2	6	0	0	8
the media (undifferentiated)	3	1	1	2	7
Internet	2	4	0	1	7
information in schools	0	2	2	3	7
radio	2	3	0	0	5
posters	0	3	1	1	5
talk to medical professionals	1	2	0	1	4
talk to people who have had TB	1	2	0	1	4
reading (unqualified)	3	0	1	0	4
video	0	1	1	1	3
books	0	3	0	0	3
listening (unqualified)	0	0	2	0	2
no answer	15	10	5	10	40

The 40 people in the 'no answer' category were either not asked about this topic or gave no clear answer. The eight people who thought they had not been given enough information about TB together provided 12 suggestions for ways that people could learn about TB. However, one woman pointed out that some people would always be unwilling to learn, no matter how information is presented to them.

CA: Do you think people close their ears to TB? ... Do you feel it's low priority or do you think they're eager to learn?

P: It works both ways: some are eager to learn; others will turn a deaf ear. They're going to turn a deaf ear on it, and [say] "It's never going to happen to me." And that's the ones that we have to fear for.

TB education is most likely to be successful in helping people learn if the character of the education is consistent with the manner in which the people in the target audience prefer to learn.

Evaluation strategies

Interim evaluation

THE RESEARCH PROJECT ADOPTED AN AGENDA-BASED EVALUATION STRATEGY FOUNDED ON THE belief that the research process is as important as the results (Gibson et al 2001). The evaluation process, therefore, included measuring the means through which the different goals and agendas of all partners were articulated, how these goals were being met, and how people thought the dynamics of the collaboration were working. In keeping with the principles of Participatory Action Research, the evaluation process was as inclusive as possible and ongoing throughout the duration of the project.

In April 2000, members of the CAC received a questionnaire seeking their perspectives on the research process, the project's successes and challenges, and what they perceived to be future challenges (See

Appendix 8: CAC evaluation questionnaire). In general, CAC members gave positive and constructive feedback. They were satisfied with the research process and methodology. They were positive about the linkages between the various research partners and satisfied with the communication between them. It was clear that even though roles and objectives were negotiated and defined at the outset of the project, these changed as the project moved

The evaluation strategy was founded on the belief that the research process is as important as the results. Evaluation was as inclusive as possible and ongoing throughout the project.

from one phase to another. CAC members re-emphasized the importance of maintaining close contact with the various research partners and communities, as well as other community groups and leaders not directly involved with the project. The interim evaluation of the project by the CAC was a worthwhile and essential step in the participatory research process.

Community group interviews

Kate Hibbard, a medical student, spoke with CAs near the end of the project, taping telephone sessions with them. Their comments were incorporated into an article (in process) about the CA experience, and are also reflected in the conclusions and recommendations. Small discussion groups were also held in several Aboriginal communities with CAs and the health professionals with whom they worked. The sessions were also audio taped and analyzed for implications for the evaluation and reporting of the project.

The wrap-up weekend, March 2001

As the research project came to a close, a weekend gathering was held for the CAs, the CAC and the research team. The 24 people in attendance formed small discussion groups to evaluate the project as it related to the foundation principles. Together the participants:

- heard the experiences of those who contributed to the project;
- celebrated the work of members of the research team;
- took a preliminary look at the data so that CAs, CAC members and the research team could contribute additional context for the data; and
- developed a dissemination / follow-up plan for the findings of the project.

Unanticipated challenges and strategies

As in any research project, it is generally difficult to foresee all the potential challenges and problems. In the case of this TB research project, dealing with the unanticipated was both educational and productive.

While many of the interviewees had some level of English, a greater number than anticipated preferred conducting the interviews in their native languages. For those CAs fluent in their native language, this was not a problem, but for those no longer fluent, an interpreter was required to assist the CA with the interview. As a result, the project increased in time and cost.

Other challenges arose from barriers caused by the distance of some of the participating communities from each other and from Edmonton, which often made it difficult to maintain the kind of contact that would allow all research partners to remain aware of circumstances in the distant communities. Consequently, the academic researchers made several site visits to the more distant communities to maintain personal contact with and to offer support to the CAs. In addition, communication and rapport with the more proximal CAs (within Edmonton) were enhanced by having personal or small group meetings with the CAs to discuss the progress of the interviews.

BREAKING THE ISOLATION In addition to large group meetings in Edmonton, Dr. Andrew Cave and the other academic researchers also made several site visits to maintain personal contact and offer support to CAs in the more distant communities.



Conclusions

Practice

THE MOST SIGNIFICANT FINDING OF THIS STUDY WAS THAT ALTHOUGH TREATMENT OF TB BY DOT can be successful, prevention in high-risk groups is equally, if not more, important. However, resources are less often applied to TB prevention. A higher level of awareness and knowledge is required in high-risk communities, but health professionals tend to meet patients only in the active stage of TB. This study suggests that novel use of lay resources – people recovered from TB, family members of recovered patients, lay health communicators – can be effective sources of information in fostering community awareness. A cadre of trained people in the community can provide a substantial prevention program.

The objectives set out in this study were met. Sociocultural factors surrounding the prevention and treatment of TB in the Aboriginal and immigrant communities studied were identified, and a basic level of understanding was achieved. Important factors included English language proficiency, level of TB-specific knowledge and stigma. Length of time in Canada and ethnicity were not significant. Furthermore,

some members of the communities studied were introduced to and trained in research methods as members of the CAC and as CAs. Both community members and academics gained experience with collaborative health research, and the contextual data thus gathered were important for the study. And, finally, through publications, kits, workshops, reports, the video produced and the process of the study itself, public awareness of the prevalence and treatment of TB was raised.

People with active TB or on prophylaxis interviewed in this project expressed confidence in TB healthcare services. Friendly,

informative and helpful staff enhanced their treatment experiences. Nearly all of the people who gave a reason for having taken TB medication said they took the pills because they believed the drugs would work. Thus, the imposition of inappropriate or unwelcome healthcare practices was not an issue for those people, nor was there any significant problem caused by the imposition of a potentially culturally alien medical philosophy.

The results indicate that people's attitudes to TB are shaped partly by their experiences with the medication and the treatment. Most of the participants' problems with medication were either physical side effects or the inconvenience of taking the medication and visiting the TB Clinic regularly. People taking larger doses of drugs for active TB reported more problems than people taking prophylaxis. Thirty-four per cent of participants said DOT caused them some inconvenience.

The interview data suggest that a proactive TB health education program is an important strategy for prevention. Although WHO has focused on successful treatment strategies, prevention receives much less attention and funding. People in high risk communities would like to learn more about TB causes and prevention but there are few opportunities to do so. Lack of knowledge about TB limits people's ability to prevent its spread and seek early treatment. This study shows that levels of patient knowledge also correlate with healthcare professionals' ability to provide effective treatment. These findings are consistent with academic literature on the subject (Grange 1997:294, San Sebastian and Bothamley 2000:652).

This study suggests that novel use of lay resources – people recovered from TB, family members of recovered patients, lay health communicators – can be effective sources of information in fostering community awareness. A cadre of trained people in the community can provide a substantial prevention program.

Answers to questions about perceptions show that many people have negative feelings about tuberculosis and feel uncomfortable or anxious with people who have it. People who had been sick with TB were more likely to report feeling stigmatized than those on prophylaxis. Most of those who reported that they felt distrusted because they had TB were Aboriginal. People who fear a stigma attached to TB are less likely to want to discuss it and consequently to learn about TB or to go for early treatment. This suggests an education program that could help to reduce the persistent stigma surrounding the disease.

Nearly everyone interviewed believed that people in their communities generally were not well-informed about TB, but most of those with active TB said they had received enough information about TB and its treatment following their diagnosis. The people who wished they had learned more about TB also generally had a less positive perception of TB and TB healthcare. Knowledge valued included how people get TB, how to prevent it, what the symptoms are, and how medication can cure TB.

Process

At least 18 people (and several others who attended part of the program) were trained in the interview process for the purpose of gathering qualitative data. CAs have applied their training skills and new knowledge in a variety of ways. Although two CAs were somewhat disappointed in their knowledge level, expecting that they would be prepared to conduct research independently, all are applying their knowledge and skills in the community, particularly their knowledge of the nature and treatment of TB, and their cross-cultural skills. Several are multicultural health brokers, and are using their skill in cross-cultural interviewing in their clinical settings. Some will be involved with the nurse / educator in the follow-on community education project. The CAs also agreed that the project had increased TB awareness in their communities (See *Appendix 9: CA evaluation questionnaire*).



CAs BRING SKILLS TO THE COMMUNITY
CAs and members of the CAC have applied their new knowledge in a variety of ways.

Recommendations

Recommendations fall into clusters relating to TB prevention through education and training, and collaboration with community researchers.

TB prevention through education

1. Recruit and train lay health educators in high-risk communities.

A general population that is knowledgeable about tuberculosis is in a good position to avoid contracting it. Thus, the major recommendation from this project is a well-planned program of TB education among the people in Alberta who are most likely to have TB (Aboriginals and people from countries with high TB rates).¹ Active and appropriate dissemination of educational information will promote health and encourage prevention of TB.

2. Recruit and train TB health liaison workers for clinical settings.

Public health TB clinics should recruit lay health educators (CAs, recovered TB patients and/or their family members) to work as mediators in clinics and in high-risk communities. The CAs in the study were a major source of TB information according to the participants. The Capital Health Authority funds the Multicultural Health Brokers Cooperative, a small pool of trained bicultural, bilingual workers already providing support to immigrant families in hospital and community settings. There are also Aboriginal health workers in several hospitals. These programs could serve as starting points for additional training regarding TB.

3. Develop appropriate training and public education support materials for lay educators, health liaison workers and health professionals in active treatment centres.

Provide basic information in appropriate and accessible formats and languages and distribute it widely and regularly in clinical and community settings.

Training / collaboration with community researchers

1. Ensure adequate resources (time, funding, and personnel) to build trust and a sound working relationship with collaborating communities.

The project affirmed the need to take the time to establish and maintain trusting relationships with potential participant communities before the commencement of the formal research process. This ongoing contact was essential to ensuring full and authentic participation in the research capacity building.

2. Negotiate a clear definition of roles and expectations for community participants in the research.

It is vital that there be a process for articulating roles and expectations of community participants in the research, whether at the advisory level or at the field research level. A mediation or conflict resolution process should also be in place. Issues of community representation and community perspectives should be addressed early in the research. In this project, members of the Community Advisory Committee clearly delineated their roles as people who would bring cultural and community perspectives into discussion of the research process. Their task was to ensure that community interests and benefits were considered in decisions and actions taken in the project. The clarity of these roles also defined power relationships in the research process and broadened ownership of the research process. CAs indicated

¹ Press release WHO/30 19 March 1998 lists the world's TB 'Trouble Spots' as Brazil, Indonesia, Iran, Mexico, Philippines, Russian Federation, South Africa, Thailand, Afghanistan, Ethiopia, India, Myanmar, Nigeria, Pakistan, Sudan and Uganda.

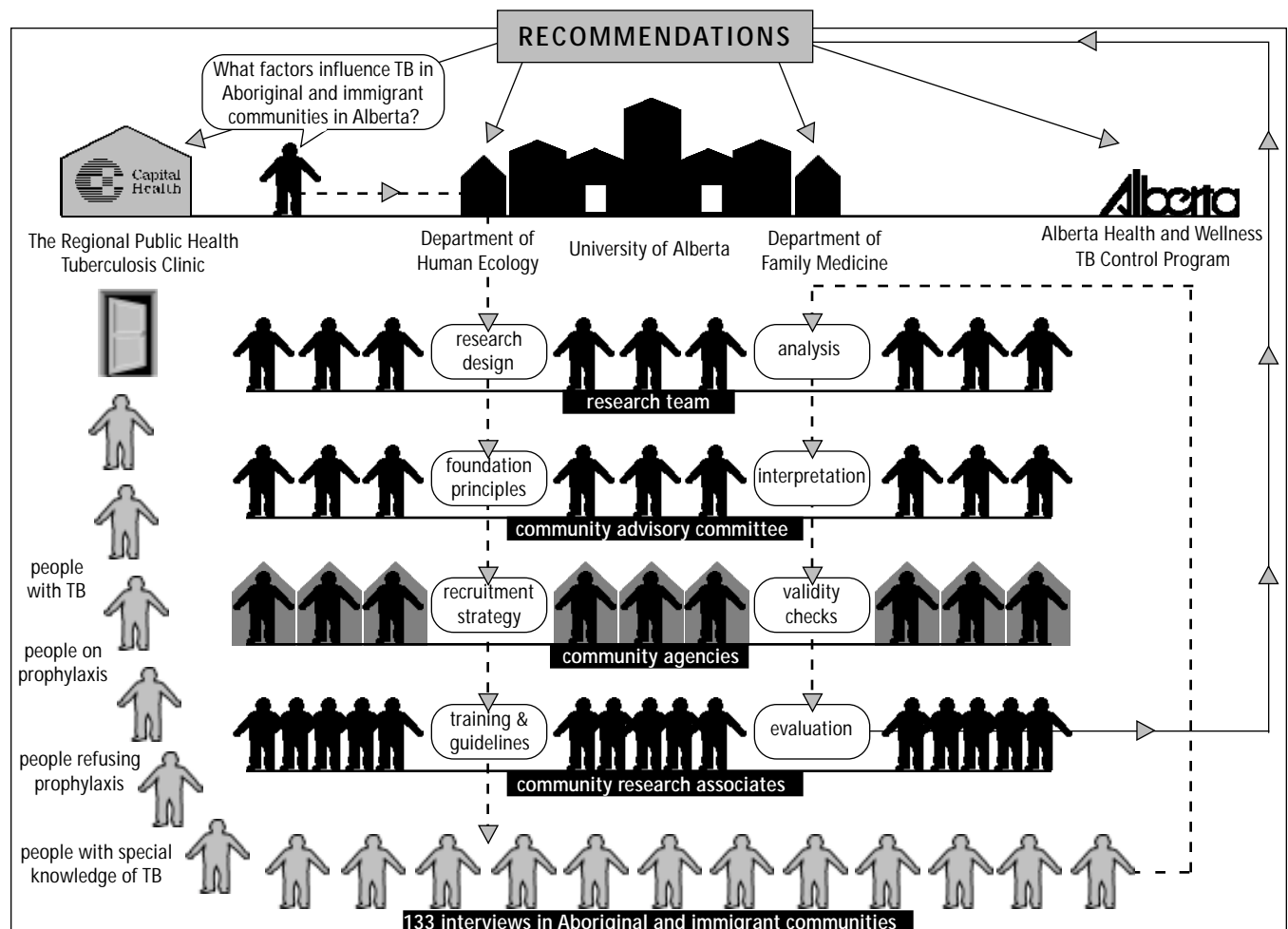
in the evaluation that they would have appreciated being involved in the CA training process. Thus, it was recommended that in similar programs student orientation training should be offered to all, including nurses in neighbourhood clinics where CAs work.

3. Evaluate CA training and progress throughout the research process and modify the design accordingly.

Although CAs were trained to collect project data through interviews with people in their home communities, they may not have been fully cognizant of how important their work was to the scope of the project. An orientation to analysis early in the data collection period would have helped clarify the kind of information being sought from the interviews. Support and reassurance should be stressed in any CA training program, particularly where the CAs come from geographically diverse communities and feel isolated from CA colleagues and project staff. Furthermore, rather than having the CAs begin interviews with the sensitive category of people with active TB, commencing interviews with those on prophylaxis would have been easier, as there were more available participants in the prophylaxis category and less potential stigma than with the active cases. CAs should progress from the easier to the more difficult interview categories.

4. Invest in the dissemination of research findings in relevant communities.

Dissemination occurs throughout a PAR project as the communities are actively involved and the project is discussed in many informal and formal venues. Relevant information in a suitable format (e.g. brief newsletters, interim reports, etc.), along with facilitation and informative community visits to CAs and their clinical coworkers, should be incorporated into the ongoing research process.



Dissemination and follow-on activities

FROM THE OUTSET, THE PROCESS OF CONDUCTING COMMUNITY-BASED RESEARCH YIELDED MANY interesting experiences and applicable findings. Some of these findings were presented over the course of the project as discussion papers or posters at a number of venues, ranging from academic conferences to community centres and health centres. The project was presented at international conferences in the USA, UK, Spain and India and has become the basis for invited half-day training sessions at international conferences (e.g. the International Institute for Qualitative Methods 2000, 2002). Information on the project was also made available to research partners, as well as other interested individuals and groups, through brochures, newsletters and poster handouts. (See *Appendix 10: Publications related to the project* for a list of papers, poster presentations at international conferences and published articles.)

Information dissemination

In participatory action research, the dissemination of information leading to community action and change is one of the most crucial parts of the process. Members of the research team appreciated the importance of designing a dissemination plan that was both sensitive to and responsive to the views of the different partners in the project and that would lead to an appropriate strategy for education and action within each of the communities involved. The dissemination strategy includes:

- CAC / CA final kits;
- final reports to granting agencies;
- reports to communities;
- community TB information workshops;
- TB information kits;
- an educational video on TB;
- academic papers; and
- discussion and reporting in ethnic media.

CAC / CA final kits

Each member of the Community Advisory Committee and each community research associate received a letter of thanks that could also serve as a reference letter, a set of TB information sheets, a summary of the project for submission / circulation, a copy of the video, and the completed formal report.

Final reports to granting agencies

The formal final report will be distributed to AHFMR and FNIHB, the University of Alberta, the Grey Nuns Family Medicine Centre Research and Education Fund, Canadian Heritage and others, as well as to CAs, CAC members and health directors in the four Aboriginal communities.

Follow-on activities

Community workshop facilitation

One suggestion that arose from the evaluation sessions was the possibility of a nurse-facilitator visiting the communities to provide further information about TB, its prevention and treatment. This follow-on project has been funded by Alberta Health and is being conducted by a Capital Health Authority TB Clinic nurse for a period of six months. The CAs and the participating communities in this research project comprise the starting point.

TB information sheets

As requested by several CAs in the evaluation sessions, a one-page information sheet about tuberculosis was translated into six languages (Arabic, Chinese, Filipino, Punjabi, Spanish and Vietnamese) for circulation to CAs, CAC members, TB health personnel and agencies, and others as appropriate (See *Appendix 11: TB information sheets*).

Educational video

Another request was that general information regarding tuberculosis be made available in video format. *Tuberculosis: It's Everyone's Responsibility* is a seven-minute video to be used in doctors' offices or health clinics, in communities, or for people to take home to view with families. It features an immigrant person raising the key questions about TB that arose from the study. Clear answers are provided at a language level accessible to those whose first language is not English. This follow-on project was funded by Alberta Health and coordinated by Diane Doering at the Capital Health TB Clinic.



EDUCATIONAL TOOLS Principal researcher Diane Doering coordinated the production of *Tuberculosis: It's Everyone's Responsibility*, a seven-minute video answering key participant questions in easily-accessible English.