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APPENDIX 1

Original grant proposal summary (1997)

A Study of the Sociocultural Factors Affecting Tuberculosis Prevention and Treatment in Immigrant and Aboriginal Populations in Alberta

PRINCIPLE INVESTIGATOR: NANCY GIBSON, PH.D. DURATION OF STUDY: 3 YEARS

Summary: This is an investigation of the sociocultural factors that influence tuberculosis diagnosis and treatment in two high-risk populations in Alberta: the foreign born and the Aboriginal. The proposed study is founded upon collaborative principles with a community-based design that will achieve academic research goals while contributing to the research capability of participating groups. It builds on the foundation of an initial chart review and an interview survey of health professionals conducted in 1998-97 in collaboration with the Capital Health Authority TB Clinic and the Department of Family Medicine. The literature review and the results of the above study indicate those sociocultural factors among high-risk groups at the TB Clinic, as well as among non-attendees, merit further investigation.

Relevance: Given that the World Health Organization has declared TB to be a global epidemic despite the biomedical capability of prevention and treatment, it is reasonable to suspect that sociocultural and epidemiological factors as well as pathological factors play an important role in perpetuating this disease. Variability in health behaviour and healthcare utilization among ethnic communities is a poorly understood phenomenon and one that is highly relevant to current government policy directed toward shifting healthcare responsibility to communities.

Aims and Objectives: To identify sociocultural indicators that establish standards of cultural appropriateness for TB prevention and treatment programs, increase effectiveness of prevention, prophylaxis and treatment in high-risk populations, and can be used to design and evaluate TB programs.

Theoretical Framework: The starting point for this study is the Health Belief Model (HESM), which has been adapted by various scholars to explain and predict health-related behaviour. The innovative element in the proposed project is the application of this model to community-driven research methods to identify sociocultural indicators. The HRM will be tested in eight cultural / linguistic sub-groups in Alberta (six Asian and two Aboriginal) with high susceptibility to TB. Based on the findings, the HBM will be adapted to produce an alternative set of culture-specific and cross-cultural indicators that can be used to improve the effectiveness of TB research, program design and evaluation.

Rationale: Many previous studies have failed to elicit the information that will improve adherence to treatment regimens and service delivery in high-risk populations. Cultural barriers such as language, power differential and political factors often mitigate against collection of rich data from which culturally appropriate programs may be designed. The literature indicates that community-based and -directed research can be more effective in collecting and interpreting such data, and in ensuring sustainable follow-up projects.

Study Design: Sixteen community associates will be trained to conduct ethnographic interviews within their own cultural-linguistic groups. The initial group of interviewees will be selected from the patient population at the TB Clinic, including those who adhered to the prescribed regimen, and those who did not. Additional participation will be recruited in conjunction with the Aboriginal TB Committee of Alberta, the M4Us Nation of Alberta and immigrant settlement agencies. Interview data will be subjected to contextual analysis and electronic qualitative data analysis. The findings will be measured against the HBM to produce an alternative framework inclusive of sociocultural factors.

Expected Outcomes: A model for culturally appropriate tuberculosis treatment and service design that includes (a) a set of sociocultural indicators to guide systematic planning and evaluation and (b) a tested collaborative community-based research design.

APPENDIX 2

Project personnel

The Community Advisory Committee (CAC)

Yvonne Chiu	Multicultural Health Brokers Cooperative
Surinder Dhaliwal	Multicultural Health Brokers Cooperative
Virginia Cawagas	University of Alberta
Terese Szlamp-Fryga	Norquest College, Edmonton
Sonia Bitar	Changing Together: A Centre for Immigrant Women
Laurie Dokis	Hinton Health Unit
Jordan Head	Treaty 7 Health
Kay Half	First Nations and Inuit Health Branch

The Community Research Associates (CAs)

Irene Beaverbones	Margaret Biernacki	Thelma Chua
Mildred Dacog	Nha Le Diep	Darshanpal Gill
Ravi Gill	Marie Janvier	Deepak Kainth
Phu Van Le	Ray-Mei Liu	Lam Thi Phan
Denise Potts	Monica Red Crow	Jodi Tse
Heather Warrior	Jackie Whitford	Marion Xie

The Academic Research Team

Nancy Gibson, Chair, Department of Human Ecology, University of Alberta
Andrew Cave, Associate Professor, Family Medicine, University of Alberta
Diane Doering, Manager, The Regional Public Health Tuberculosis Clinic in Edmonton

Research Staff

Project Manager – administration of project (full-time)	Coleen Kato
Project Coordinator – data manager/writer (full-time)	Hélène O'Connor, Paul Harms, Insaf Hag-Mousa
Aboriginal Coordinator (part-time, advisory capacity)	Jeanette Sinclair, Susan Hulme
Immigrant Coordinator (part-time, advisory capacity)	Lucenia Marquez Ortiz
Technical Support and Data Management	Arif Alibhai, Errol Billing

Medical / Public Health Sciences Students on Elective Rotation

Chandra Magill	Usha Maharaj	Kate Hibbard
Parminder Thiara	Donna Neufeld	

Summer Students

Alex Hull	Rhonda Breitkreuz (Research Assistant)
Carey Kinjerski	Clifford Cardinal (Research Assistant)
	Pieter de Vos (Research Assistant)

Project Mentors

Ann Macaulay, Department of Family Medicine, McGill University
Milton Freeman, Department of Anthropology, University of Alberta

APPENDIX 3

Community research associates recruitment

Community Associates needed for a Community-based TB Research Project

The Community-based TB Research Project of the Department of Human Ecology, University of Alberta, is looking for individuals who are interested in working as Community Associates (CAs) in immigrant communities in Edmonton. The CAs will work with the TB Research Project team in providing understanding of their own culture and how research in their community should be conducted in a sensitive and responsive way.

Community Associates (CAs) will be asked to help in:

- contacting participants in the research;
- developing interview guidelines in a culturally sensitive way;
- conducting interviews and facilitating focus group discussions;
- interpreting research findings;
- sharing research results in the community; and
- assisting the community in benefiting from the research.

A Community Associate will be someone who:

- enjoys working with people;
- is interested and concerned about issues in their cultural community;
- is willing to learn and work as part of a team;
- enjoys the trust and confidence of their community;
- participates in social and cultural activities in their community;
- is an active member or participant in community / cultural groups, organizations or networks in their community; and
- can speak, read and write in English and one other language, i.e. Chinese, Vietnamese, Tagalog, Polish, and any East Indian language.

The estimated period of paid involvement is 75 hours over 12 months starting June 21, 1999, with a possibility of further work. Training in community research will be provided and no medical knowledge is required. There is no risk of becoming infected with TB through involvement in this research.

see Draft Letter of Agreement, next page

Draft Letter of Agreement

April 22, 1999

Thank you for agreeing to become a Community Associate with the Research Program: *Cultural Factors Influencing Prevention and Screening of Tuberculosis in Immigrant and Aboriginal Populations.* Below you will find the terms and conditions of this research relationship. If you find this letter satisfactory, please sign both copies, and return one to the research office, retaining the other for your files.

Community Associates will attend the training programs set out below, recognising that there may be scheduling changes in response to the availability of trainers and other personnel.

An initial five days of training will include:

- an overview of the project;
- research interviewing skills;
- review of ethical principles;
- development of question guidelines for community interviews;
- practice sessions; and
- related informational issues.

Research expectations include:

- completion of 16 interviews in your home community, each taking one to two hours, supervised by the Aboriginal Project Coordinator, and in conjunction with the research team and advisory committee, by April 1, 2000;
- a further training session for one to two days on analysing interview data and conducting focus group sessions;
- approximately five days (self-scheduled) analysing data from two interviews; and
- facilitation of a focus group in your community to test the results of the research.

You will receive an honorarium for your services:

- $250 upon completion of the initial training session;
- upon completion of the first 8 interviews (Phase 1);
- upon completion of the last 8 interviews (Phase 2); and
- upon completion of the focus group session.

You will participate in planning a strategy for circulating the results of this research. Your contribution will be acknowledged in any print material.

This project will be conducted in keeping with the principles attached to this letter. If you have any questions at any time, please contact the research office at (780) 492-1827.

Your participation in this project is greatly appreciated. We hope to learn about how families and communities think about TB, how they cope, and their perceptions of the screening and treatment process, in order to make improvements in the way TB is addressed in our communities.

I agree to participate as a Community Associate in this research project.

(Signature)

APPENDIX 4

Sample interview guidelines

To: XXX

From: Coleen Kato, Administrative Assistant, Community-based TB Research Project

Re: Interview Packages

Please see enclosed the following information:

- *Script for Initial Phone Call* – the initial telephone call to the participant will be made by you. Enclosed is the script the nurse from the TB Clinic and the research team developed together.
- *Interview Guide* – revised edition with labels for each participant to be interviewed. The purple copy is for taped interviews. The white copy is for interviews conducted over the telephone.
- *Consent Forms* – two copies for participant's signature (leave one copy with them). If needed, please translate the body of the consent form onto the back of the consent form that the participant signs. You must get the participant to sign the English version.
- *Fact Sheet* – questions the participant may ask about the study (leave a copy with them).
- *Tapes.*
- *Thank you note and honoraria* from the research team (for the participants). A receipt is enclosed with the envelope. Please sign on behalf of the participant and include it back with the returned package.

If you are interested in translating the tape, please translate word-for-word from the original tape onto other tape recorder and tape in English. Once completed, please submit the tapes of the interviews to our office; include the written notes and the interview guide for each participant with the signed consent forms and all receipts. Please call Coleen at (870) 492-1827 and courier service will be arranged.

If you have any questions or concerns, please contact either Lucenia or Coleen at (870) 492-1827.

Thank you. And good luck with the interviews!

Telephone Call

Hello, this is <first name> <second name> *and I am calling you about our study on TB. You may remember the telephone call from the public health nurse at the clinic asking you to participate?*

What language would you prefer to speak in?

I would like to make arrangements for a meeting with you to ask a few questions about your experience with TB. This meeting will take about one hour. I can meet you in your home or at Changing Together (for immigrants in Edmonton). *Or is there some place else that would be more convenient and/or comfortable for you?* (Set time and place.)

Thank you. Your participation in this study is very important. We are hoping to discover ways to do a better job of preventing and treating tuberculosis. I look forward to meeting with you.

* If you would like another CA to attend with you for the first interview, get permission from the participant first.

Confirmation

Telephone the participant to confirm time and location one day prior to the interview.

Beginning of the Interview

Establish a comfort level. *As you can see, I will be taping our talk today. The reason for this is to make sure that I have an accurate record of our conversation. The tapes will be transcribed into English, and your identity will be kept confidential. The tapes will be stored in a locked cabinet within the University of Alberta.*

As you may recall, we are hoping that the research will help us do a better job of treating and eventually preventing tuberculosis.

When we do a research project like this one, we always ask the participant to sign a release form so that the information from the interview can be used in the study. Here is a copy of the release form and an information sheet that you can keep that explains the reasons for the study.

Thank you. This release form will be filed in the research office within the University of Alberta.

- *Do you have any questions about this before we begin?*
- *Now for the record, my name is...*
- *We are in* (name the place, date and time)…
- *First I would like to talk about your own background.*

...Proceed to the Interview Guide.

Interview guide: active participants

Information sought	Question
A. Background profile of interviewee • Birthplace • Geographical history • Reasons for leaving	1. *How long have you lived here in (city/community)?* 2. *Why did you choose to live here?* 3. *How do you feel about living here?* 4. *What other places have you lived in?*
Cultural identity/ethnic identity Comfort in English and other languages	5. *What nation/cultural group do you belong to?* 6. *What is your first language?* 7. *What other languages do you speak?* 8. *Do you understand English?* 9. *Do you read and write in English?*
Marital status and family composition Sequence/pattern of movement	10. *Who else lives in your house?* 11. *Who else stays with you throughout the year?* 12. *Are there other places that you live as well?*
B. History of illness Time of initial diagnosis Emotional reaction First signs and symptoms the participant noticed How the participants were affected before they were diagnosed	1. *How long have you had TB?* 2. *How did you find out? (Who told you, and where?)* 3. *How did you feel when you first knew you had TB?* 4. *How has having TB affected your life?* 5. *How have you been able to deal with it?* 6. *Where in your body is the TB?* 7. *How do you think you got TB?* 8. *What changes did you notice in your body?* 9. *When did you first notice the changes?*

C. Treatment History of illness and treatment • More than one treatment? • More than one clinic? • More than one kind of healer?	1. *When did you first seek advice or help?* 2. *What kind of treatment have you been receiving?* 3. *Did you get help from traditional healers?* If yes, ask questions 4 & 5. 4. *How did this help you?* 5. *Did you tell your doctor or nurse about your traditional medicines?* 6. *When did you first get medical help?* 7. *How long have you been receiving your current treatment?*
Personal experience with medicine and treatments Experiences after the participants began to feel better Transportation/nutrition and other	8. *Please tell me about your experience with TB medicines.* 9. *Have you had any problems with taking the pills?* 10. *Have you been able to follow the advice that was given to you?* 11. *Do you have any suggestions about this?* 12. *Do you have any problems getting the care you need for your TB?*
D. Effects of TB Perceptions of tuberculosis in the family and community	1. *Who else did you tell that you had TB?* 2. *How did they act when you told them?* 3. *How has this affected your family?* 4. *What other members of your family have had TB?* 5. *When? Where were they treated? By whom?* 6. *Do you know anyone else who has had TB (please expand on this.)*
E. Service Nurses, Aboriginal liaison workers, doctors, acupuncture, traditional healers, etc. Strengths, weaknesses and problems (please note: names are not necessary)	1. *What people helped you with your TB?* 2. *Please tell me about your experience at the health centre/unit?* 3. *Are you comfortable with the staff/service at the health centre/unit? Please explain.* 4. *Do you have any suggestions for change?*
F. Prevention Level of knowledge/belief system Implications for improving prevention programs	1. *How do you think people get TB?* 2. *Did you get the information you needed when you were told you had TB?* 3. *What do people need to know about TB?* 4. *What other information do you think would be useful?* 5. *What are the best ways for people to learn about TB?*
G. Closing questions and comments	1. *Do you have any questions that you would like to ask me?* 2. *Do you have any comments or suggestions about this study?* 3. *Is there anyone else that you would like me to talk to about this study?* 4. *Would you like me to call you in a day or two in case you have some further thoughts or suggestions?*
Thank you very much for helping us with this study. As time goes by the research project will let you know what we have learned from this study.	

APPENDIX 5

Sample newsletter

Community-Based TB Project
A Little News About Ourselves

Fall 2000 Update

Some news to be proud of

The data for the part of the project that involves First Nations people have been collected, and the final report about it just needs to be checked over by the CAC and the CAs.

Did you know that a couple of members of our project have enjoyed their community research experience so well that they started another project of their own?

Some things to look forward to

We should have a pretty good idea by the middle of March what some results of the part of the project that involves immigrants will be.

Focus groups for CAs and CAC members will be held March 30 to April 1. We'll talk about the overall project, and also about our results and what we should do with them, and who we should tell. Attending the focus groups will give everyone another chance to have a say about the project.

Some statistics

The number of people who have given us interviews 111
Thanks to all of those people.

The number of interviews completed since mid-November 27
CAs have been doing a great job.

Interviews completed with people who had active TB 47

Interviews completed with people taking TB prophylaxis 39

Interviews conducted with people who refused prophylaxis 9

Interviews done with people who have had some experience with TB, or who know someone who had TB, or who had it themselves long ago 16
Most CAs are still working on their refused and history interviews.

The number of CAs who have finished all their interviews 4

The number of CAs with only a few interviews left to go 6

Total number of CAs who are completing the project 15

The whole project is really coming together now.

Here is a Short Summary of the Results and Recommendations from the Part of the Study that Involved First Nations People

The research results from each of the First Nations communities that participated in the project were very similar. TB healthcare in each of them must be similar, too.

CAs asked interviewees how they thought people get TB. Most people said they thought TB is contagious, but many people spoke as if they were not very confident about that. If people are not sure how they might get TB, it would be useful to spend some time teaching them about TB. Maybe some people answered that question with an uncertain tone because they felt uncomfortable telling a CHR about healthcare when it was already the CHR's business to know about healthcare. Sometimes it was hard to know exactly what the research results meant.

Most people felt badly when they found out they had TB, or had tested Mantoux positive, but some people said they weren't very bothered, and nobody was really shocked or overwhelmed by the news. Several people worried what others would think about them having TB. Some people with active TB felt like they got poor social treatment from their neighbours because they had TB, but hardly anyone who took prophylaxis said they felt that way.

It is better, and probably easier, to prevent TB than to cure people who have it. In order to be able to prevent TB effectively, people have to know a few important things about it. Almost everyone said they got enough information about TB and TB treatments when they needed it. On the other hand, nearly everyone who gave an interview for the project believed that people in their community generally did not know much about TB. The most common answers people gave when CAs asked them to suggest some good ways to learn about TB involved discussion. People said that, rather than read a pamphlet about TB, they would like to sit down for a while and talk to someone who knew a lot about it. The information about TB that interviewees suggested was most important for people to know was how people get it, and that the TB pills really can help cure TB. Maybe the project should recommend to FNIH that CHRs get more time to conduct informal health education.

People who gave interviews for this project generally had a good opinion of TB healthcare staff, and especially of the nurses who helped them. People said healthcare staff were at their best when they were helpful and informative. Even though they were glad they took the TB drugs and they were glad to be healthy, most people didn't really like the TB drugs. Half the people who took TB prophylaxis (4 of 8) reported having no problem with the TB medication, and only a quarter of the people who had active TB (2 of 8) said the pills caused them no problem. Only six people made special mention that DOT was a nuisance to them. People who had spent time in TB sanatoriums when they were younger had bad things to say about those places.

There were few differences between the comments made by men and women who gave interviews for the project. The same is true about people of different ages. Even though people who gave interviews were quite diverse, it seems like it would usually be difficult to make predictions about their attitudes regarding TB and healthcare based just on their age or gender.

APPENDIX 6

Sample posters

The following posters were generated during the project.

- Female Involvement in PAR
- Cultural Differences in Adherence to Preventive Tuberculosis Therapy in Alberta, Canada
- The Cost of TB: A Cost-Benefit Analysis of a Tuberculosis Control Program within Alberta's Aboriginal Population
- Developing the Foundational Principles for a Community-based TB Research Project
- The Ethics of Recruiting and Selecting Community Research Associates in a Participatory Research Project
- Training of Community Associates
- Tuberculosis: A Multi-Method Collaborative Approach to its Treatment
- Cultural factors in Attendance for Adherence at an Urban Tuberculosis Clinic – A Retrospective View
- Cultural Factors in TB Prevention and Treatment: A Multi-method Collaborative Study
- Complementary Strategies for Coping with Tuberculosis in Immigrant and Aboriginal Populations in Edmonton
- Cultural Differences in Adherence Rates for Tuberculosis Prophylaxis in Alberta

Study 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.

APPENDIX 7

Papers in progress

Cave, A.J. and N. Gibson and J. Sinclair and L. Melenka and P. Harms. Sociocultural Factors Influencing TB Prevention in First Nations People in Alberta.

Cave A., Melenka L., Doering D., Colman I., O'Connor H., Gibson N., Alibhai A. Cultural Differences in Adherence Rates for Tuberculosis Prophylaxis Treatment in Alberta.

Gibson, Nancy. A Framework for Integrating Diversity in Community-based Research.

Gibson, Nancy. Translating and Transcribing Interview Data: challenges and strategies.

Hibbard, Kate and Lucenia Marquez-Ortiz and Nancy Gibson and Diana Doering and Andrew Cave. The Experiences of Community Research Associates in the Community-Based Tuberculosis Research Project.

This paper explores the CAs perceptions of their involvement with the project.

Ibrahim, Insaf. Community Health Education for TB: A strategy/possibility for change.

Results/outcomes of a study investigating the sociocultural factors influencing TB prevention and treatment in immigrant populations in Alberta, Canada.

Ibrahim, Insaf. Literature Review on the Sociocultural Factors Affecting Tuberculosis Prevention and Treatment in Immigrant Populations.

Marquez-Ortiz, Lucenia. Towards Authentic Participatory Research in Health: A review of the literature.

The appeal of participatory research in health and healthcare practice stems from a critical awareness of the problems in the healthcare system that are rooted in systemic inequalities relating to class, age, gender, race and status.

Marquez-Ortiz, Lucenia. Understanding Decision-Making in TB Preventive Therapy: A cultural approach.

An account of the specific phase of the Study on Sociocultural Factors Affecting TB Treatment and Prevention in Aboriginal and Immigrant Populations in Alberta involving a small number of research participants from immigrant communities in Edmonton who opted out of preventive therapy for TB.

APPENDIX 8

CAC evaluation questionnaire

An Exercise in Evaluation

PART 1

To be filled out anonymously. DO NOT write your name.

This part is to be filled out by all Community Advisory Committee (CAC) members. Please answer the following questions and return this questionnaire in the self-addressed envelope included before ***May 17, 2000.***

Please read all the questions and the options carefully, and select the option which most closely reflects your thoughts or feelings.

At the end of the questionnaire we will ask you to estimate the time it took you to complete the questionnaire, so please make a note of the time now as you begin.

1. Are you employed? Yes ❒ No ❒
   If Yes: Full-time ❒ Part-time ❒ Self-employed ❒

2. Have you ever been involved in a community-based research project prior to the TB project? Yes ❒ No ❒

3a. When you were asked to join the CAC, how much of your time did you expect to dedicate to it?

_____

3b. Are you dedicating more or less time to this project than you expected? More ❒ Less ❒

4. Overall, do you feel that the expectations made of you by the project are appropriate/realistic? Yes ❒ No ❒

   Please comment: _____

   _____

5a. How productive are our CAC meetings?
   Not at all ❒ Somewhat productive ❒ Very productive ❒ Don't know ❒

5b. Do you think that meetings need to be (more/less/the same) frequent?
   More frequent ❒ Less frequent ❒ No change ❒

5c. How can we improve these meetings?

_____

_____

6. Your expertise and input into the research project are essential to its success.

How do you feel about how your expertise, skills, and contacts have been utilized?

Under-utilized ❒ Somewhat over-utilized ❒

Somewhat under-utilized ❒ Over-utilized ❒

Used adequately ❒ Taken advantage of ❒

Comments:

7a. In your view, your *overall* participation in the research project has been:

Non-existent ❒ Fairly substantial ❒

Very minor ❒ Substantial ❒

Minor ❒ Extensive ❒

7b. Would you like your participation in the final year of the project to be:

More ❒ Less ❒ No change ❒

Comments:

8a. By circling a number, please rank how you feel about your participation in the following steps of the research process:
(1 = not enough participation; 4 = satisfied with the level of your participation; 7 = too much participation)

Development of research question/issue	1	2	3	4	5	6	7
Development of Foundational Principles	1	2	3	4	5	6	7
Adoption of research approach and methods	1	2	3	4	5	6	7
Defining the research objectives and agenda	1	2	3	4	5	6	7
Recruitment/selection of Community Associates	1	2	3	4	5	6	7
Development of interview guides	1	2	3	4	5	6	7
Training of CAs	1	2	3	4	5	6	7
Support for CAs	1	2	3	4	5	6	7
Data collection	1	2	3	4	5	6	7
Dissemination of information (conferences, posters, etc.)	1	2	3	4	5	6	7
Data analysis (still in very early stages)	1	2	3	4	5	6	7
Overcoming challenges/troubleshooting	1	2	3	4	5	6	7
Recruitment/selection of new team members or partners	1	2	3	4	5	6	7
Funding sources	1	2	3	4	5	6	7

8b. Are there other aspects of the project you would like to comment on, with regards to your participation?

8c. Please describe some of the challenges/barriers to your participation in the project.

9a. From your perspective, how would you describe your contact with the Community Associates (those from your cultural group)?

Very little contact ❒ A fair amount of contact ❒

Some contact ❒ A lot of contact ❒

9b. Is this level of contact: Not enough ❒ Adequate ❒ Too much ❒

Comments: _____

_____

10a. How would you describe the communication between the different partners involved within the project (i.e. administrative research team members/communities/CAC/CAs).

Very poor ❒ Needs improvement ❒ Good ❒

Poor ❒ Satisfactory ❒ Excellent ❒ Don't know ❒

10b. Comments: _____

_____

11a. Overall, how would you describe the relationship between the participating communities and the research team?

Very poor ❒ Needs improvement ❒ Good ❒

Poor ❒ Satisfactory ❒ Excellent ❒ Don't know ❒

11b. Do you have any suggestions on how these relationships can be enhanced?

_____

_____

12a. Please evaluate the overall administration of this research project by ranking the following:

(1 = very poor; 2 = poor; 3 = somewhat poor; 4 = satisfactory; 5 = fair; 6 = good; 7 = excellent; 8 = Don't know)

Communication	1	2	3	4	5	6	7	8
Group dynamic	1	2	3	4	5	6	7	8
Teamwork	1	2	3	4	5	6	7	8
Motivation	1	2	3	4	5	6	7	8
Commitment	1	2	3	4	5	6	7	8
Setting and achieving goals	1	2	3	4	5	6	7	8
Overcoming challenges	1	2	3	4	5	6	7	8
Leadership	1	2	3	4	5	6	7	8

12b. Comments: _____

_____

13a. Rank how you feel the project has performed for the following aspects:

(1 = very poor; 2 = poor; 3 = somewhat poor; 4 = satisfactory; 5 = fair; 6 = good; 7 = excellent; 8 = Don't know)

Relevance of research question/issue	1	2	3	4	5	6	7	8
Foundational Principles / Guiding principles	1	2	3	4	5	6	7	8
Recruitment/selection of CAs	1	2	3	4	5	6	7	8
Dissemination of information and promotion of the project (conferences, posters, etc.)	1	2	3	4	5	6	7	8
Developing interview guides	1	2	3	4	5	6	7	8
Training of CAs	1	2	3	4	5	6	7	8
Support for CAs	1	2	3	4	5	6	7	8
Data collection	1	2	3	4	5	6	7	8
Administration	1	2	3	4	5	6	7	8
Data analysis	1	2	3	4	5	6	7	8
Funding sources	1	2	3	4	5	6	7	8
Evaluation	1	2	3	4	5	6	7	8
Overcoming challenges / trouble shooting	1	2	3	4	5	6	7	8

13b. Please elaborate on how we can improve, as well as what you feel the project has been doing well.

_____

14a. One of the challenges of doing research is to stay 'on course' and not lose focus. Rank how you feel the project is doing when it comes to staying focused for the following:

(1 = completely off course, and going in the wrong direction – i.e. the titanic heading for an iceberg!; 2 = off course, but can fix it; 3 = off course, but in a good way; 4 = somewhat on course; 5 = on course and everything is fine; 6 = don't know)

The research question	1	2	3	4	5	6
The Foundational Principles	1	2	3	4	5	6
The principles of participatory research	1	2	3	4	5	6
Responsiveness to the community	1	2	3	4	5	6
Transfer/sharing of skills and knowledge	1	2	3	4	5	6
Breaking down barriers (between communities and institutions)	1	2	3	4	5	6
Overall objectives	1	2	3	4	5	6

14b. Comments:

_____

_____

15a. Is being a CAC member what you expected it would be? Yes ❒ No ❒

15b. How does this role differ from your expectation? Better ❒ Worse ❒

Comments:

_____

_____

16a. Meeting all the different goals of the partners involved is very important to this research. Please rank how well you feel the project is meeting these goals.

(1 = not at all; 2 = not very well; 3 = have met some; 4 = are working to meeting goals; 5 = have met goals well; 6 = don't know)

Your personal goals as a CAC member	1	2	3	4	5	6
Your professional goals	1	2	3	4	5	6
The goals of the organization you represent	1	2	3	4	5	6
The goals of the cultural group you represent	1	2	3	4	5	6

16b. Please give examples of how the project is serving these goals as well as suggestions as to how the project can better serve these goals.

_____

_____

Estimated time it took you to complete the questionnaire _____

THANK YOU VERY MUCH!!!

PART 2

Please review these questions carefully. We will be discussing these questions together during the CAC meeting on May 24, 2000.

If you are NOT attending the meeting, please take the time to answer these questions and send us your responses, separately from Part 1 of the questionnaire since we want to keep Part 1 responses anonymous.

Name _____

1. Please state your own personal objectives for becoming involved in the project as a CAC member.
2. How do you feel about the role of the CAC in this research project?
3. Where do you think the overall ownership of this project lies?
4. What, do you feel, have been the major problems / challenges encountered by this research project?
5. What are some of the challenges that you anticipate / foresee that we should address in the final year of the project?
6. What do you feel we should have done differently?
7. What are our major successes so far?
8. What will be our major successes in the future?
9. What do you feel is the most important contribution that a CAC member could make to a community-based project such as the TB research project?
10. What kind of insights have you acquired, as a result of your participation in this project, that you feel you can bring back to your community?
11. Are there other areas that you feel should be covered in the evaluation?

Thank you very much!

APPENDIX 9

CA evaluation questionnaire

Community Associate Questionnaire

Date of interview _____

Time at start _____ Time at end _____

Location _____

Name of CA _____

Name of interviewer(s) _____

Others present _____

Background Information

1. Were you born in Canada? Yes ❒ No ❒

2. If 'No', for how many years have you been living in Canada? _____ *Years*

3. What cultural group do you identify with? _____

4. Is English your first language? Yes ❒ No ❒
   Do you read and write English?
   Other languages spoken / written?

5. What level of education you have completed?
   secondary/high school ❒ university ❒ college/technical training ❒
   Other *(please specify the field of study)*:

6. Are you currently a student? Where? In what?

7. Are you currently employed (not including work as CA)? Where? As what?
   Full-time ❒ Part-time ❒ Self-employed ❒

8. Can you tell me a bit about your daily life?
   – family?
   – type of work?
   – activities?
   – community involvement?

9. Before working as a CA, did you have any research experience? Yes ❒ No ❒

   Please specify:

   (if no)

10. Before working as a CA, did you have any interests in doing research? Yes ❒ No ❒

    Comments:

Becoming a CA

11. Before hearing about this research project, did you think TB was a health issue within your community?

    Yes ❒ No ❒

    Comments:

12. How did you find out about the opening for a Community Associate (CA) for this research project?

13. Why did you want to become a CA?

14. What did you hope to gain from your experience as a CA?

15. How were you selected to be a CA? Please explain:

16. Do you feel the training provided for you at the University of Alberta prepared you adequately for your duties as a CA? Please explain:

17. Looking back, now that you have completed your interviews, please suggest how the training sessions can be improved:

Conducting the interviews

18. Were you able to complete all your interviews? Yes ❒ No ❒

19. Let's talk about some of the problems you may have encountered. Here are some of the challenges you might have encountered while doing the interviews. Please tell us how they relate to you.

    ❒ Lack of patients/participants: _____

    ❒ Lack of willing participants (refusals): _____

    ❒ Lack of time: _____

    ❒ Difficulties with interview guide: _____

    ❒ Nervousness or anxiety: _____

    ❒ One-word answers (participants not responsive): _____

    ❒ Language barriers: _____

    ❒ Lack of support: _____

    ❒ Difficulties with the recording equipment: _____

    ❒ Perception of research project within community: _____

    ❒ Others: _____

20. Please describe the resources and strategies you used to help you overcome some of these challenges.

21. How did members of the research team (at the University of Alberta) help you during the interviewing process? What else could they do?

22. How could the Community Advisory Committee (CAC) members have helped you during the interviewing process?

23. Was your CAC member easy to get in touch with when you needed them? Were they responsive to your needs?

24. Did you get help or support from other people (i.e. friends, family or co-workers) who are not formally involved with this research project? Who?

25. Are you satisfied with the information obtained in your interviews?

26. What part of the interview process did you most enjoy?

The CA Experience

27. How did your experience as a CA meet your expectations?
    Personally / Professionally / Other: _____

28. Do you feel the compensation/honoraria you received for your training and your work as a CA was adequate? Please comment.

29. How has your experience as a CA made a difference in your life?

30. What have you learned and what will you take away from your experience as a CA?

    How do you think you will be able to apply the skills and experience you've gained as a CA to other aspects of your life?

31. How will your skills and experience as a CA benefit your career?

32. Are you interested in continuing to work in research? What opportunities are there for you to pursue in your community?

33. How do you feel your work as a CA has done something to improve life in your community as far as: (please comment on the following aspects)
    - ❒ Helping to improve services offered to TB patients from your community.
    - ❒ Helping to understand and reduce TB in your community.
    - ❒ Reducing the stigma associated with TB (improving the perception of TB) within your community.
    - ❒ Improving the general health status of your community.
    - ❒ Empowering people within your community to initiate future research projects.

34. Do you feel the research project has had any negative consequences? What are they?

35. What was the most rewarding part of being a CA?

36. What was the least rewarding / hardest part of being a CA?

Your Community

37. Do you feel the TB research project was and is responsive to the needs of your community?

38. Who do you think will benefit the most from this research?

39. What do you hope to see come out of this research?

40. What, do you feel, are the biggest health issues in your community (including and other than TB)?

41. How do you feel these health issues should be addressed?

42. With your experience as a researcher, how can research help address these health issues within your community?

43. Based on your experience with this project, do you think community-based research is an effective way of understanding and improving health issues?

44. What actions / steps can you recommend that would reduce TB in your community?

45. What actions / steps can you recommend that would improve the general/overall health of your community?

46. Would you be interested in being involved in a similar project again?

APPENDIX 10

Publications related to the project

Books and Chapters in Books

Gibson N., Gibson G., Macaulay A.C. 2001. Community-based research: Negotiating agendas and evaluating outcomes. In Morse J., Swanson J., Kuzel A.J. [Eds.], *The Nature of Qualitative Evidence*. Thousand Oaks: Sage: 161-182.

Refereed Journal Articles and Conference Proceedings

Macaulay A.C., Commanda L., Freeman W.L., Gibson N., McCabe M.L., Robbins C.R., Twohig P.L. Responsible research with communities: Participatory research in primary care. **British Medical Journal**. September, 1999; 319: 774-778.

Gibson N., Gibson G. Articulating the agendas: Negotiating a collaborative model for public health research. The Canadian Circumpolar Institute, Edmonton AB. In Wall D., Ed. **Securing Northern Futures: Developing research partnerships**. Occasional Publication (45). Edmonton: The Canadian Circumpolar Institute, 1999; 109-114.

Refereed Conference Presentations

Submitted

Cave A.J., Gibson N., Sinclair J., Harms P., for the Community Tuberculosis Project. Beliefs around Tuberculosis in First Nations Communities in Rural Alberta. NAPCRG 2001 – 29th Annual Meeting. Halifax, Nova Scotia. October 13-16, 2001.

Also submitted to CFPC Family Medicine Forum 2001. Vancouver, BC. October 25-27, 2001.

Presented

Gibson, N. TB Here and There: Alberta, Canada and Sierra Leone. Social Aspects & the Peoples' Participation in Tuberculosis Cure & Prevention. The UK TB Network Association. London, England, Imperial College. March 23, 2001. (Invited keynote address)

Marquez L., Sinclair J., Cave A., Doering D., Gibson N., the Community Advisory Committee. The ethics and process of selecting community research associates in a participatory research project. Qualitative Health Research 2000 Conference, Banff, AB. April 6-8, 2000.

Marquez L., Gibson N., Cave A., Doering D., the Community Advisory Committee. Developing the foundation principles for a community-based TB research project. Qualitative Health Research 2000 Conference, Banff, AB. April 6-8, 2000.

Kinjerski C., Marquez L., Sinclair J., Gibson N., Cave A., Melenka L., Doering D., Community Associates. Training and Participation of Community Research Associates in a Community-based TB Research Project. Qualitative Health Research 2000 Conference, Banff, AB. April 6-8, 2000.

O'Connor H., Gibson N., Community Associates. The challenges and strategies of participatory action research: experience from a community-based TB research project.

Presented at:

- Canadian Indigenous/Native Studies Association Annual Meeting and Conference, Edmonton, AB. May 28-31, 2000.
- Canadian Anthropological Society 27th Congress, Calgary, AB. May 4-7, 2000.
- Qualitative Health Research 2000 Conference, Banff, AB. April 6-8, 2000.

O'Connor H., Gibson N., Community Associates. The challenges and strategies of participatory action research: experience from a community-based TB research project. Global and Local Histories: Applied Anthropology Across the Centuries. The Society for Applied Anthropology 2000 Annual Meeting, San Francisco, CA. March 21-26, 2000.

Gibson N. Qualitative research on/in/about with communities. International Institute for Qualitative Methodology Conference, Edmonton AB. February 18-20, 1999.

Macaulay A., Gibson N. The ethics of community-based research. International Institute for Qualitative Methodology Conference, Edmonton AB. February 18-20, 1999.

Gibson N., Turnbull M. A framework for addressing diversity in Aboriginal research communities. *Proceedings of the Sustainable Forest Management Conference*, Edmonton, AB. February 14-18, 1999.

Gibson N., Gibson G. Negotiating a collaborative model for public health. Canadian Conference on Multicultural Health, Regina SK. May 7-9, 1998.

Doering D., Cave A.J., Gibson N., Magill C. Cultural factors in prophylaxis at an urban TB clinic. Canadian Conference on Multicultural Health, Regina SK. May 7-9, 1998.

Cave A.J., Gibson N., Doering D., Magill C., Chiu Y. Cultural factors in TB prevention and treatment. Canadian Conference on Multicultural Health, Regina SK. May 7-9, 1998.

Reports and Background Papers

1999 *Responsible research with communities: Participatory research in primary care. A policy statement for the North American primary care research group.*
[WebPages] http://views.vcu.edu/views/fap/naprcrg98/exec.html

Cave, A.J. and P. Harms. 2001. Cultural issues in the presentation and management of tuberculosis in First Nations communities. Report to the FNIHB, Health Canada.

Refereed Posters/Oral Presentations

Melenka L., O'Connor H., Gibson N. The Cost of TB: A cost benefit analysis of a Tuberculosis control program within Alberta's Aboriginal population. IUATLD (North America) Conference, Vancouver, BC. February 24-26, 2000.

Cave A., Melenka L., Doering D., Colman I., O'Connor H., Gibson N., Alibhai A. Cultural Differences in Adherence Rates for Tuberculosis Prophylaxis Treatment in Alberta.
Presented at:

- The Canadian/American Thoracic Society 2000 Conference, Toronto, ON. May 5-10, 2000.
- IUATLD (North America) Conference, Vancouver, BC. February 24-26, 2000.

Marquez L., Sinclair J., Cave A., Doering D., Gibson N., the Community Advisory Committee. The ethics of recruiting and selecting community research associates in a participatory research project.
Presented at:

- 11th Annual Canadian Bioethics Society Conference, Edmonton, AB. October 28-31, 1999.
- Research Revelation-2000, University of Alberta, Edmonton, AB. February 5, 2000.

Marquez L., Gibson N., Cave A., Doering D., the Community Advisory Committee. Developing the foundation principles for a community-based TB research project.
Presented at:

- Margaret Scott Research Day, Walter C. Mackenzie Hall, University of Alberta. March 7, 2000.
- 11th Annual Canadian Bioethics Society Conference, Edmonton, AB. October 28-31, 1999.
- Research Revelation-2000, University of Alberta, Edmonton, AB. February 5, 2000.

Kinjerski C., Marquez L., Sinclair J., Gibson N., Cave A., Melenka L., Doering D., Community Associates. Training of Community Associates – A study of the sociocultural factors affecting tuberculosis treatment and prevention in immigrant and Aboriginal populations in Alberta.
Presented at:

- Thirty-second Annual Students' Research Day, Edmonton, AB. October 2, 1999.
- Research Revelation-2000, University of Alberta, Edmonton, AB. February 5, 2000.

Thiara P., Gibson N., Cave A., Marquez L., Sinclair J., Melenka L., Doering D., Community Associates. Female involvement in participatory action research. Thirty-second Annual Students' Research Day, Edmonton, AB. October 2, 1999.

Gibson N., Hull A., Neufeld D., Cave A.J. Complementary strategies for coping with tuberculosis in immigrant and Aboriginal populations in Edmonton.
Presented at:

- 1999 Tuberculosis Conference, Edmonton, AB. March 17-18, 1999
- Research Revelation '99, University of Alberta. February 6, 1999
- Tuberculosis, Progress Through Partnerships Conference, Toronto ON. November 16-17, 1998.

Cardinal C., Cave A.J., Gibson N. Semantic problems in cross-cultural communication between Aboriginal patients and their physicians.

Presented at:

- Research Revelation '99, University of Alberta. February 6, 1999.
- North American Primary Care Research Group Conference, Montreal PQ. November 4-7, 1998.

Cave A.J., Gibson N., Kinjerski K., Melenka L., Alibhai A., Doering D. Cultural differences in adherence rates for tuberculosis prophylaxis in Alberta.

Presented at:

- 1999 Tuberculosis Conference, Edmonton, AB. March 17-18, 1999
- Research Revelation '99, University of Alberta, Edmonton, AB. February 6, 1999.
- North American Primary Care Research Group Conference, Montreal PQ. November 4-7, 1998.

Gibson N., Cave A.J., Doering D., Magill C., Chiu Y. Cultural factors in TB prevention and treatment.

Presented at:

- Margaret Scott Research Day, Walter C. Mackenzie Hall, University of Alberta. March 7, 2000
- Research Revelation-2000, University of Alberta, Edmonton, AB. February 5, 2000
- Research Revelation '99, University of Alberta, Edmonton, AB. February 6, 1999.
- Tuberculosis, Progress Through Partnerships Conference, Toronto ON. November 16-17, 1998.
- North American Primary Care Research Group Conference, Montreal PQ. November 4-7, 1998.

Neufeld D., Hull A., Gibson N., Cave A.J. Strategies for tuberculosis treatment: complementary approaches. Progress Through Partnerships Conference, Toronto ON. November 16-17, 1998.

Cave A.J., Doering D., Gibson N., Magill C. Cultural factors in the attendance and adherence at an urban tuberculosis clinic – a retrospective view.

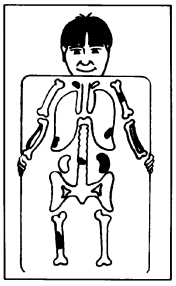
Presented at:

- Canadian Council on Multicultural Health Meeting and Conference, Regina SK. May 8, 1998.
- Scientific Assembly, Alberta Chapter, College of Family Physicians of Canada, Banff AB. March 6, 1998.
- International Union Against Tuberculosis and Lung Disease, North American Region Conference, Vancouver BC. February 26-28, 1998.
- Research Revelations '98 University of Alberta, Edmonton AB. February 7, 1998.
- College of Family Physicians of Canada Conference, Halifax NS. October 23-26, 1997.
- Alberta Lung Association Respiratory Disease Symposium, Banff AB. October 17-19, 1997.

APPENDIX 11

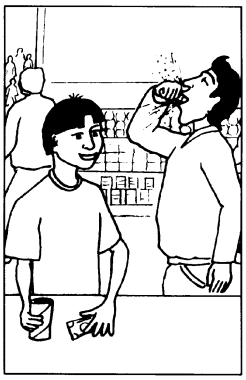
TB information sheets

Tuberculosis (TB) Fact Sheet



WHAT IS TB?

TB is a disease caused by the TB germ. TB is found mainly in the lungs, but the germ can travel to other parts of the body.



HOW IS TB SPREAD?

When a person who is sick with TB in his/her lungs coughs, sneezes, talks or sings, the TB germs spray into the air. You can breathe in the TB germs when you spend time with that person.

HOW WILL I KNOW IF I'VE BEEN INFECTED WITH THE TB GERM?

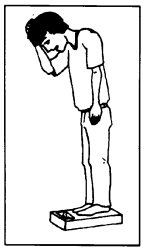
Ask your nurse for a TB skin test.

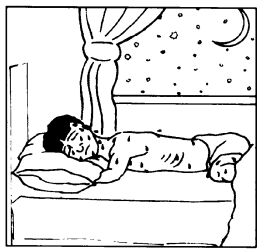
A drop of fluid is injected under the skin on your arm. If you have TB germs in your body, a red lump may appear on your arm.

CAN I GET RID OF THE TB GERMS? YES!

If your skin test is positive and your chest X-ray and sputum test don't show active TB, the doctor or nurse may offer you preventive medicine. You will need to take this medicine for about one year to kill all the TB germs.

HOW WILL I KNOW IF I HAVE TB DISEASE?

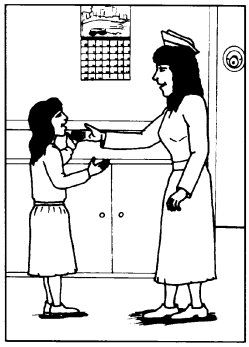




If you have

- a cough that lasts more than three to four weeks
- loss of weight
- tiredness
- night sweats
- fever

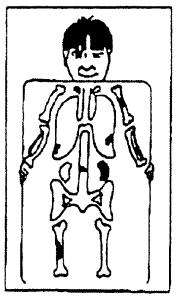
see your nurse or doctor and he/she will arrange the necessary tests.



CAN TB BE CURED? YES!

When TB disease is found and treatment taken, TB can be cured! The germs are tough. It takes six to nine months of three or four TB medicines to kill all the germs. It is important to continue to take the medicine even when you are feeling better. If the treatment is stopped early, you could get TB again.

Tuberculosis (TB) Hoja de Hechos

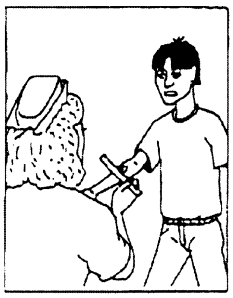


¿QUÉ ES TB?

TB es una enfermedad causada por el microbio TB. TB se encuentra pricipalmente en los pulmones, pero el microbio puede viajar a otras partes del cuerpo.

¿CÓMO SE PROPAGA TB?

Cuando una persona que está enferma de TB tose, estornuda, habla o canta, el microbio TB se rocia en el aire. Tu puedes inhalar el microbio TB cuando pasas tiempo con esa persona.



¿CÓMO SABRÉ SI HE SIDO CONTAGIADO CON EL MICROBIO TB?

Pide a la enfermera un examen de la piel para TB. Una gota de líquido es inyectada debajo de la piel de tu brazo. Si tienes el microbio de TB en tu cuerpo, aparecerá un bulto rojo en tu brazo.

¿PUEDO LIBRARME DEL MICROBIO TB? SÍ!

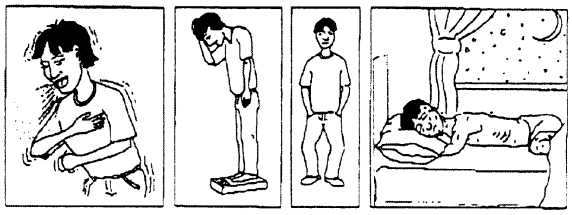
Si tu examen de la piel es positivo y los rayos X de tu pecho asi como el examen sputum no muestran TB activo, el doctor o la enfermera te pueden ofrecer medicina preventiva. Necesitarás tomar esta medicina por un año para matar al microbio TB.

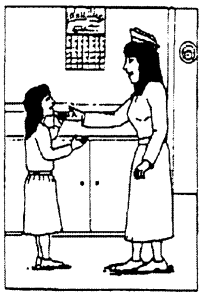
¿CÓMO SABRÉ SI TENGO LA ENFERMEDAD TB?

Si tienes:

- Tos que dura mas de tres o cuatro semanas
- Pérdida de peso
- Cansancio
- Sudor durante la noche
- Fiebre

visita a la enfermera o doctor y el (ella) realizará los exámenes necesarios.

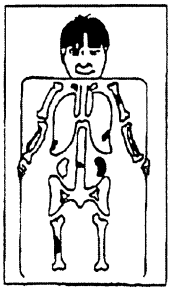




¿SE PUEDE CURAR EL TB? SÍ!

Cuando se detecta la efermedad TB y se toma el tratamiento, TB se puede curar! Los microbios son fuertes. Tarda entre seis y nueve meses con tres o cuatro medicinas de TB para matar a todos los microbios. Es importante continuar tomando la medicina aún cuando te sientas mejor. Si el tratamiento se suspende pronto, puedes contraer TB de nuevo.

Kaalaman Tungkol sa Tuberculosis (TB)

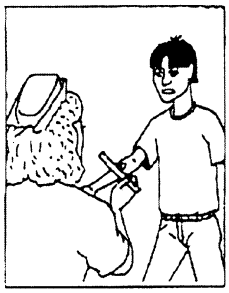


ANO ANG TB?

Ang TB ay sakit na galing din sa mikrobyo ng tb. Ang TB ay sakit na nakikita sa baga. Ito ay mikrobyo (TB) na kumakalat sa lahat ng parte ng katawan.

PAANO KUMAKALAT ANG SAKIT NA (TB) ?

Nakukuha ang TB kapag ang taong maysakit ay umubo, kumanta, bumahin o magsalita. Ang (TB) mikrobyo ay kumakalat sa hangin. Malalanghap mo ang mikrobyo (TB) kapag lagi mong kasama ang maysakit.



PAANO MO MALAMAN KUNG NAHAWAAN KA NG TB?

Magpatingin sa nurse para sa "TB skin test." Isang patak ng fluid ay iniiniksyon sa braso. Kung ikaw ay may mikrobyo (TB) sa katawan, may pulang bukol na makikita sa iyong braso.

PUWEDE BANG MAALIS ANG MIKROBYO NG TB?

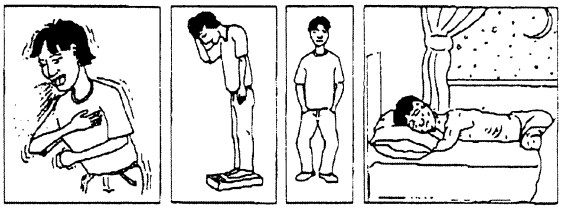
Oo! Kung walang nakita sa skin test at walang aktibong mikrobyo (TB) sa x-ray, sa baga at sa dura. Ang nurse o doctor ay magbibigay ng gamot para maiwasan ang sakit. Kinakailangan inumin itong gamot ng mga isang taon para mamatay ang mikrobyo (TB).

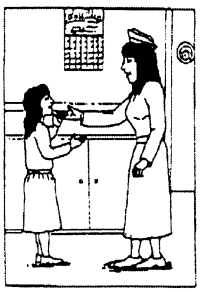
PAANO MO MALALAMAN KUNG MAYROON KANG SAKIT NA TB?

Kung meron kang ...

- ubo na tumatagal ng mahigit na sa tatlong linggo (coughing for more than three weeks)
- sobrang pagkapagod (fatigue)
- lagnat (fever)
- pamamayat (weight loss)
- pagpapawis (night sweats)

Magpatingin sa doctor o nurse at sila ang magaayos ng lyong test na kinakallangan.

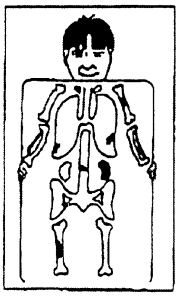




NAGAMOT BA ANG TB? Oo!

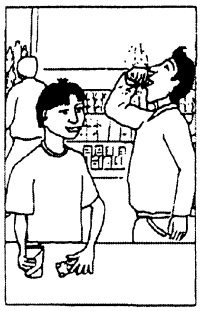
Kung ang sakit na TB ay naagapan agad, ito ay nagagamot! Malakas ang mikrobyo (TB). Inaabot ng anim o siyam na buwan na paggagamot, sa tatio o apat na gamot para puksain ang mikrobyo (TB). Importanteng tuloy-tuloy ang pag-inom ng gamot kahit na mabuti ang pakiramdam. Kung ang pag-inom ng gamot ay ihinto, ang mikrobyo ay muling babalik.

ਤਪਦਿਕ ਦੇ ਲੱਛਣ (ਟੀਬੀ)



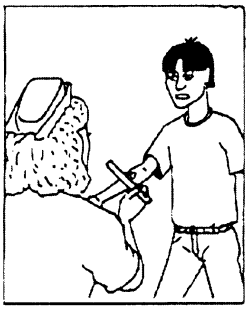
ਤਪਦਿਕ ਕੀ ਹੁੰਦੀ ਹੈ?

ਤਪਦਿਕ ਨੂੰ ਅੰਗਰੇਜ਼ੀ ਵਿੱਚ ਟੀਬੀ ਆਖਦੇ ਹਨ। ਟੀਬੀ ਦਾ ਰੋਗ ਟੀਬੀ ਦੇ ਕਿਟਾਣੂਆਂ ਤੋਂ ਲੱਗਦਾ ਹੈ। ਟੀਬੀ ਜ਼ਿਆਦਾਤਰ ਫੇਫੜਿਆਂ ਵਿੱਚ ਹੁੰਦੀ ਹੈ। ਪਰ ਕਿਟਾਣੂ ਸਰੀਰ ਦੇ ਦੂਜੇ ਹਿੱਸਆਂ ਵਿੱਚ ਵੀ ਹੋ ਸਕਦੇ ਹਨ।



ਟੀਬੀ ਕਿਸ ਤਰ੍ਹਾਂ ਫੈਲਦੀ ਹੈ?

ਟੀਬੀ ਦੇ ਮਰੀਜ਼ ਦੀ ਖੰਘ ਨਾਲ, ਛਿੱਕ ਮਾਰਨ ਨਾਲ, ਗੱਲਾਂ ਕਰਨ ਨਾਲ, ਗਾਣਾ ਗਾਉਣ ਨਾਲ, ਕਿਟਾਣੂ ਹਵਾ ਵਿੱਚ ਫੈਲਦੇ ਹਨ ਜਾਂ ਉਹ ਕਿਟਾਣੂ ਸਾਡੇ ਅੰਦਰ ਚਲੇ ਜਾਂਦੇ ਹਨ।



ਇਹ ਕਿਸ ਤਰ੍ਹਾਂ ਪਤਾ ਲੱਗ ਸਕਦਾ ਹੈ ਕਿ ਮੈਂ ਟੀਬੀ ਦਾ ਸ਼ਿਕਾਰ ਹੋ ਚੁੱਕਾ ਹਾਂ?

ਨਰਸ ਕੋਲੋਂ ਟੀਬੀ ਟੈਸਟ ਕਰਵਾਓ। ਦਵਾਈ ਦਾ ਇੱਕ ਤੁਪਕਾ ਟੀਕੇ ਰਾਹੀਂ ਬਾਂਹ ਵਿੱਚ ਚਮੜੀ ਦੇ ਥੱਲੇ ਭੇਜਿਆ ਜਾਵੇਗਾ। ਜੇ ਟੀਬੀ ਦੇ ਕਿਟਾਣੂ ਸਰੀਰ ਵਿੱਚ ਹੋਣਗੇ ਤਾਂ ਇਸ ਦਵਾਈ ਨਾਲ ਬਾਂਹ ਉੱਤੇ ਟੀਕੇ ਵਾਲੀ ਜਗ੍ਹਾ ਕਾਫ਼ੀ ਲਾਲ ਜਾਏਗੀ ਅਤੇ ਸੁੱਜ ਜਾਏਗੀ।

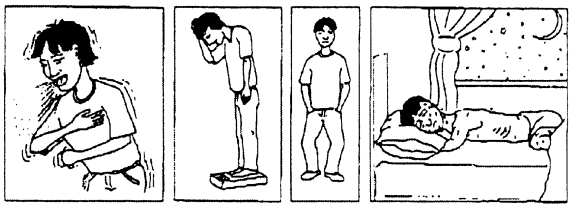
ਕੀ ਮੈਂ ਟੀਬੀ ਦੇ ਕਿਟਾਣੂਆਂ ਤੋਂ ਬੱਚ ਸਕਦਾ ਹਾਂ?
ਜੀ ਹਾਂ!

ਜੇ ਚਮੜੀ ਟੈਸਟ ਟੀਬੀ ਦਸਦਾ ਹੋਵੇ ਅਤੇ ਛਾਤੀ ਦੇ ਐਕਸਰੇ ਤੇ ਥੁੱਕ ਟੈਸਟ ਕੁੱਝ ਨਾ ਦਸਦੇ ਹੋਣ ਤਾਂ ਇਸ ਹਾਲਤ ਵਿੱਚ ਡਾਕਟਰ ਟੀਬੀ ਦੀ ਰੋਕਥਾਮ ਵਾਲੀ ਦਵਾਈ ਦੇਣੀ ਸ਼ੁਰੂ ਕਰ ਦਿੰਦੇ ਹਨ। ਟੀਬੀ ਦੇ ਕਿਟਾਣੂ ਖ਼ਤਮ ਕਰਨ ਵਾਲੀ ਦਵਾਈ ਇੱਕ ਸਾਲ ਖਾਣੀ ਪਵੇਗੀ।

ਇਸ ਬੀਮਾਰੀ ਦੇ ਲੱਛਣ ਕੀ ਹਨ?

- ਜੇ ਖੰਘ ਤਿੰਨ ਤੋਂ ਚਾਰ ਹਫ਼ਤੇ ਜਾਰੀ ਰਹੇ
- ਭਾਰ ਘੱਟ ਜਾਵੇ
- ਥਕਾਵਟ ਹੋਵੇ
- ਸੁੱਤਿਆਂ ਪਿਆ ਪਸੀਨੇ ਆਉਣ
- ਬੁਖ਼ਾਰ

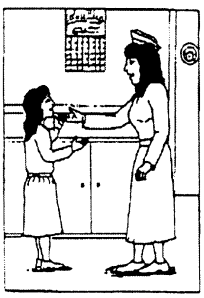
ਆਪਣੇ ਡਾਕਟਰ ਨੂੰ ਪੁੱਛੋ ਅਤੇ ਲੋੜੀਂਦੇ ਟੈਸਟ ਕਰਵਾਓ।



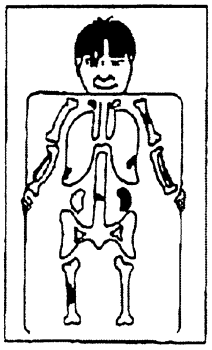
ਕੀ ਟੀਬੀ ਦਾ ਇਲਾਜ ਹੋ ਸਕਦਾ ਹੈ?
ਜੀ ਹਾਂ!

ਜੇ ਟੀਬੀ ਦੀ ਬੀਮਾਰੀ ਲੱਭ ਲਈ ਜਾਵੇ ਅਤੇ ਨਾਲ ਹੀ ਰੋਕਥਾਮ ਦੀ ਦਵਾਈ ਦਿੱਤੀ ਜਾਵੇ ਤਾਂ ਟੀਬੀ ਦੀ ਬੀਮਾਰੀ ਤੋਂ ਛੁਟਕਾਰਾ ਪਾਇਆ ਜਾ ਸਕਦਾ ਹੈ। ਟੀਬੀ ਦੇ ਕਿਟਾਣੂ ਬੜੇ ਹੀ ਤਾਕਤਵਰ ਹੁੰਦੇ ਹਨ। ਇਨ੍ਹਾਂ ਕਿਟਾਣੂਆਂ ਨੂੰ ਮਾਰਨ ਲਈ 6 ਤੋਂ 9 ਮਹੀਨੇ ਲਗਦੇ ਹਨ ਅਤੇ 3 ਜਾਂ 4 ਟੀਬੀ ਦੀਆਂ ਦਵਾਈਆਂ ਲੈਣੀਆਂ ਪੈਂਦੀਆਂ ਹਨ।

ਇਹ ਜ਼ਰੂਰੀ ਹੈ ਕਿ ਦਵਾਈ ਲਗਾਤਾਰ ਲਈ ਜਾਵੇ ਭਾਵੇਂ ਠੀਕ ਵੀ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋਵੋਂ। ਜੇ ਇਲਾਜ ਛੇਤੀ ਬੰਦ ਕਰ ਦਿਤਾ ਜਾਵੇ ਤਾਂ ਬੀਮਾਰੀ ਫਿਰ ਹਮਲਾ ਕਰ ਸਕਦੀ ਹੈ।



肺結核病《俗稱肺癆》的因由

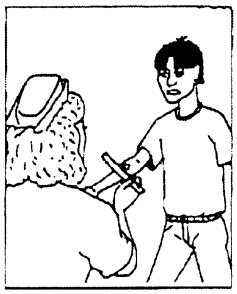


何謂［肺結核］?

肺結核是一種疾病由肺結核細菌引起。通常，肺結核是主要集中在肺部。但細菌則會轉移到身體其他部分。

肺結核怎樣傳染？

當一個有肺疾病的人咳嗽，談話，唱歌或噴嚏，他/她的肺結核細菌就會噴到空氣中。若你當時與他/她在一起時，你就有可能吸入肺結核細菌。

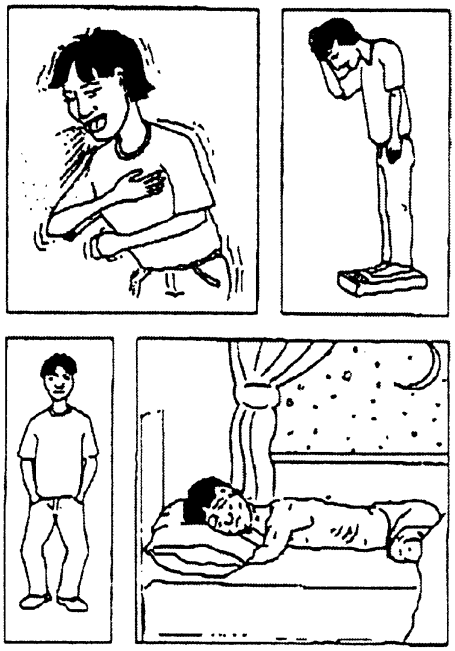


我怎樣知道已被肺結核細菌感染？

可向護士要求《肺結核皮膚》測試。方法是將少許液體作皮下注射到手臂上，若該部分出現《紅腫》則表示你身體內含有《肺結核細菌》。

可否將《肺結核細菌》消滅？

可以！如果你皮下測試出現《紅腫》呈《陽性反應》，但照肺的X光片和抽痰測試證實體內細菌並不活躍，醫生或護士會建議只需服食《預防性》的藥。這些藥要連續性服食大約一年時間，使體內細菌全部被消滅爲止。



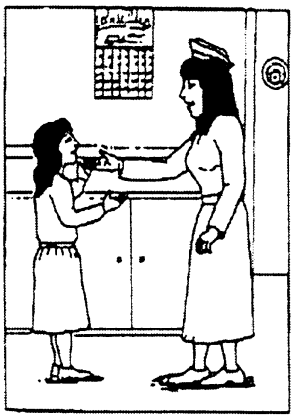
我怎樣知道有《肺結核》病？

如果你有下列情形：

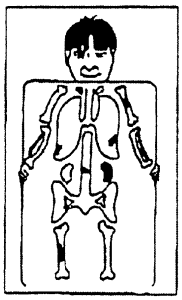
- 已咳嗽了三至四星期仍未痊癒；
- 體重減輕；
- 疲倦；
- 流夜汗；
- 發燒

應盡快往見醫生或護士，他們會爲你作出一切必要測試的安排。

肺結核病是可以完全復原的。當發現有肺結核病後及接受治療，這病是可以全面康復的。但要消滅細菌比較麻煩，要在六至九個月內服用多種藥物才可以。在治療過程中，緊記定時食藥至全面康復爲止；切勿見病情稍爲好轉就停止食藥。若過早停止食藥，則這病有再翻發可能。



NHỮNG VẤN-ĐỀ CẦN BIẾT VỀ BỆNH LAO (TB HAY TUBERCULOSIS)

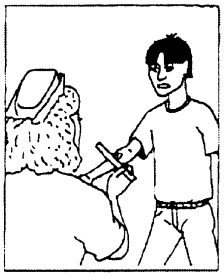


BỆNH LAO LÀ GÌ?

Bệnh lao là chứng bệnh gây ra bởi vi-trùng lao. Bệnh lao phát-sinh từ phổi nhưng vi-trùng có thể lan ra các bộ-phận khác trong cơ-thể.

BỆNH LAO TRUYỀN-NHIỄM NHƯ THẾ NÀO?

Khi một người mắc bệnh lao phổi ho, hắt hơi, nói chuyện hay ca hát, vi-trùng lao có thể truyền qua không-khí. Chúng ta có thể hít vào vi-trùng lao khi chúng ta ở gần người có bệnh lao phổi.



LÀM THẾ NÀO ĐỂ BIẾT ĐƯỢC VI-TRÙNG LAO ĐÃ XÂM-NHẬP VÀO CƠ-THỂ?

Bạn có thể yêu-cầu được thử-nghiệm nếu bạn nghi ngờ là bạn đã bị nhiễm vi-trùng lao.

Y-tá sẽ tiêm một loại thuốc thử trùng vào dưới da trên tay bạn. Nếu bạn quả thực đã bị nhiễm bệnh, tay bạn, ngay chỗ thuốc tiêm vào, sẽ có một vết sưng đỏ.

VI-TRÙNG LAO CÓ THỂ BỊ TIÊU-DIỆT KHÔNG?

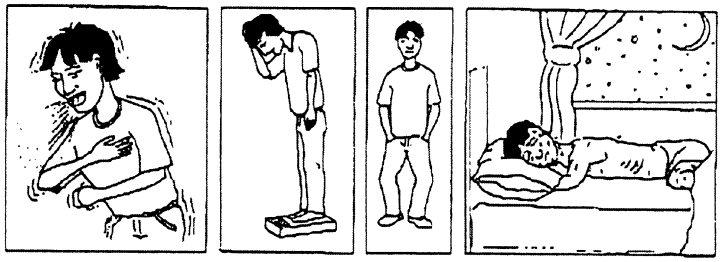
Nếu kết-quả từ sự thử-nghiệm chứng-tỏ cơ-thể bạn đã có vi-trùng lao, nhưng hình chụp phổi và nước bọt không có dấu vết của vi-trùng, bác-sĩ hay y-tá sẽ cho bạn dùng thuốc để ngăn ngừa sự phát-triển của vi-trùng lao. Bạn sẽ phải uống thuốc ngừa trong vòng một năm mới có thể diệt được hoàn-toàn vi-trùng lao trong cơ-thể bạn.

LÀM THẾ NÀO ĐỂ BIẾT ĐƯỢC TÔI ĐÃ BỊ NHIỄM VI-TRÙNG LAO?

Nếu bạn bị:

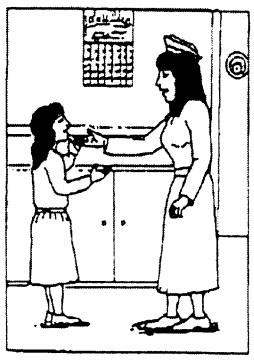
- ho kéo dài hơn ba hay bốn tuần-lễ
- sụt cân
- mệt mỏi
- đổ mồ hôi ban đêm
- nóng sốt

nếu bạn có những triệu-chứng trên, bạn nên đi khám bác-sĩ hay gặp y-tá để yêu-cầu được thử-nghiệm.

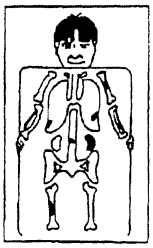


BỆNH LAO CÓ THỂ ĐƯỢC CHỮA KHỎI KHÔNG? VÂNG!

Khi tìm được vi-trùng lao và đã được chữa trị, bệnh lao có thể được chữa khỏi! Vi-trùng lao khó diệt. Phải cần một thời-gian từ sáu đến chín tháng, với ba hay bốn loại thuốc khác nhau để tiêu-diệt hoàn-toàn vi-trùng lao trong cơ-thể. Bạn vẫn phải tiếp-tục uống cho hết thuốc ngay cả khi bạn đã cảm thấy đã phục-hồi phần nào sức khỏe. Nếu không tiếp-tục điều-trị cho đến khi hoàn-toàn bình-phục, bạn có thể sẽ bị lao trở lại.



معلـــومات تهمك عن مرض الســـل



ما هو السل ؟

السل هو مرض تسببه جرثومة السل .
السل عادة ما يصيب الرئة ولكن جرثومته قد تنتقل لتصيب أعضاء أخرى في الجسم .

كيف ينتشر السل ؟

عندما يكح ، يعطس ، يتحدث أو يغني الشخص المصاب بالسل الرئوي فإن جرثومة السل تنتشر في الهواء . يمكنك أن تستنشق جرثومة السل إذا قضيت وقتا مع هذا الشخص .

كيف يمكنني معرفة ما إذا كنت مصابا بجرثومة السل ؟

قم بسؤال الممرضة لإجراء اختبار جلدي للسل .
قطرة من سائل سوف تحقن تحت الجلد في ساعدك . إذا كنت مصابا بجرثومة السل في جسمك فإن تورم أحمر اللون سوف يظهر مكان الحقن في نفس الساعد .

هل يمكنني التخلص من جرثومة السل ؟ نعم !

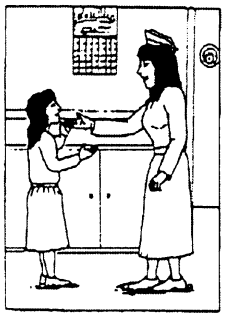
إذا كان اختبارك الجلدي موجبا ولكن أشعة الصدر واختبار واختبار البصاق لا يظهران علامة سل نشط في هذه الحالة فإن الطبيب أو الممرضة قد يعطيك علاج وقائي . سوف تحتاج إلى أخذ هذا الدواء لمدة سنة تقريبا حتى يتم القضاء على كل جراثيم السل في الجسم .

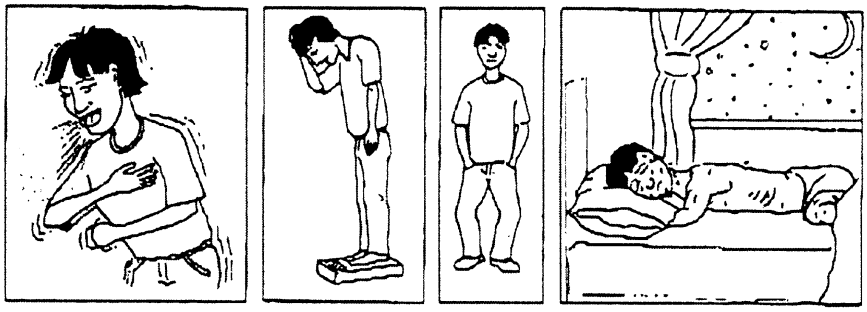
كيف يمكنني معرفة ما إذا كنت مصابا بالسل ؟

إذا كان لديك :

- كحة لمدة تزيد عن ٣ — ٤ أسابيع .
- نقصان في الوزن .
- إحساس بالتعب .
- عرق أثناء الليل .
- حمى .

إذا ظهرت عليك أي هذه الأعراض يجب أن تراجع
الممرضة أو الطبيب لترتيب إجراء الفحوصات اللازمة .





هل يمكنني معالجة السل ؟ نعم !

إذا اكتشف السل وتم اخذ العلاج اللازم له ففي هذه الحالة يمكن
معالجة المرض .

جرثومة السل تعتبر جرثومة قوية لذا فهي تحتاج من ٦-٩ أشهر من
العلاج المتواصل بثلاثة إلى
أربعة أدوية لمعالجة السل وذلك حتى يتم القضاء على المرض.

إنه من الضرورى الاستمرار فى تعاطى الدواء حتى وإذا شعرت بالتحسن .

إيقاف العلاج مبكرا قبل إتمام الجرعة اللازمة قد يؤدي إلى معاودة الإصابة
بالمرض.