

**Tuberculosis Epidemiologic Studies
Consortium (TBESC)**

**Preventing Tuberculosis in the
Foreign Born**

Instruction Guide for Adult Questionnaire

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I. GENERAL INSTRUCTIONS

A. When to use this questionnaire

Use this questionnaire:

- to interview all adult participants (18 years old and older)
- to directly interview adolescents age 15, 16, and 17.

DO NOT use this questionnaire to interview a parent or guardian about a child or adolescent who has TB; use the pediatric questionnaire for that.

Questionnaires (and consent forms) are available in English and ten other languages: Spanish, French, Haitian Creole, Tagalog, Chinese, Korean, Hindi, Somali, Ilocano, and Vietnamese.

II. PREPARATION

Because of the complexity of this questionnaire, interviewers must be VERY familiar with all the questions and skip instructions before the interview begins. We recommend that each interviewer practice the questionnaire several times alone and then with a friend or colleague who can act as a “dummy” participant.

Some of the questions are similar in wording but refer to different circumstances or different times. If you are familiar with and understand these questions, you will see the differences and be able to guide the participant better.

Do not review the participant’s medical records before the interview. The records should be reviewed only after the interview, and then only to obtain the information requested in the Health Department Record Abstraction Form at the back of the questionnaire booklet.

Items needed for Field Interview

- 1) Questionnaire booklet in the appropriate language
- 2) Four extra copies of the green questionnaires; 2 extra copies of the yellow, orange, and pink questionnaires.
- 3) Show cards (Tuberculin skin test, income groupings, BCG vaccination and TB medication)
- 4) Consent forms (2 copies) in the appropriate language: Note: when going to an interview that will be conducted in Haitian Creole, take a copy of the French consent form as well as the Haitian; some Haitians speak Haitian Creole but read only French.
- 5) HIPAA form (if your site requires one)
- 6) Large blank envelope, briefcase, or similar carryall to hold completed questionnaires and other documents.
- 7) Incentive
- 8) ID badge
- 9) Names and telephone numbers of local health department contacts and local suicide hotline
- 10) Interpreter (if needed)
- 11) Language Line contact numbers (if needed)
- 12) Driving directions
- 13) Personal ledger/appt. book to record mileage (if needed)

III. USING THE QUESTIONNAIRE

A. General questionnaire instructions

a. What the different typefaces mean

All information in **boldface type** (except for the section titles) should be **read out loud** to the participant. **Boldface** information includes (1) introductions to the different sections of the questionnaires, (2) the questions themselves, and (3) certain response options. Do not read the section titles out loud (Example: the words, “Section A: Demographic Information”, and “Part I, Immigration Status at First Entry to the United States or Canada,” should not be read out loud).

The “Don’t know” and “Refused to answer” options are in regular type, indicating that you should NOT read them aloud to the participants.

All information in *Italics* are instructions to the interviewer ONLY and should NOT be read to the participant.

b. Skip instructions

Some information in *italics* includes instructions on what question to go to next – skip instructions. We will ask participants different questions depending on their answers to previous questions. For example, if a participant tells us that he/she is homeless, we won’t ask how many rooms that person has. Please follow skip instructions accurately in order to ensure that the appropriate data is being collected.

Skip instructions are included ONLY for responses that require the interviewer to skip the next question. If a response option does not have skip instructions, **go to the next question.**

NEVER skip a question unless the skip instructions tell you to do so.

c. When can you check more than one answer to a question?

Most of the questions permit only one answer. If a question has no instructions next to it, mark only one answer. If more than one answer is permitted, the italic instructions next to the question will say, “*Mark all that apply*”

d. “Don’t know” and “Refused to answer.”

Select response option, “Don’t Know,” if the participant states that he/she does not know the response to the question, is unsure, or does not remember.

Select response option, “Refused to answer,” if the participant clearly refuses to answer a question or provide any information, or asks to go on to the next question.

e. US/Canada, state/province

For questions that say “US/Canada,” insert the country in which the interview is being conducted. For example, if you are in the United States, say only “US” when posing these questions. Similarly, for questions that say “state/province”, say “province” when you are referring to Canada or to countries that you know have provinces instead of states.

f. “Probe”

This manual and the questionnaire booklet sometimes instruct the interviewer to “probe” if the participant provides a certain response. This means that the interviewer should ask a follow-up question. For example, the instructions may say that if the person remembers only a year, the interviewer should “probe” for the month. That means you should ask, “Do you remember the month?”

g. Use of show cards

We use four show cards to help participants understand the questions:

1. An income card with a list of different ranges of income.
2. A card showing the placement of a tuberculin skin test.
3. A picture of a BCG vaccination compared to a smallpox vaccination.
4. A drug show card

Instructions boxes placed throughout the questionnaire indicate when to use each one.

Each card should be accompanied by a short introduction to explain what it is. The income show card, which is used with Question B10 (B9 in the pediatric questionnaire), already has a script associated with it: “Of all these income groups, can you tell me which one best represents your total family income...”

For the other cards, the interviewer should provide a short explanation the first time the card is used. Here are some suggestions for introducing each card the first time it is used:

The skin test show card: “Here is a drawing of a person getting a skin test.”

The TB drug card: “Here is a picture of some common TB medicines.”

The BCG card: “Here is a picture of a BCG and a smallpox vaccination mark.”

The TB drug card and the skin test card may be used more than once, depending on the skip patterns for each participant. When using a card a second time, do not use the same words you used the first time. We suggest you say something like, “Remember this picture I showed you before?”

B. Filling out the questionnaire

a. Timing (what to fill out prior to interview)

(1) Face sheet

a. Items to fill in before the interview

Fill in as much information as you can on the Face Sheet before the interview – name, address, phone numbers, state case number. **If the middle name is missing, ask the participant for this information at the time of the interview. The middle name may be important in locating information at the Division of Global Migration and Quarantine.**

b. Items to fill in after the interview

Some information on the Face Sheet will be filled out AFTER the interview, and will be based on information provided in the questionnaire: the alien registration number and the name used at entry to the U.S., if different from the name on the Face Sheet.

c. Item that may change

One item on the Face Sheet may change: whether or not the person is a source case. If a person is being interviewed only because he/she is a source case, then you will be able to definitively complete this item by marking “yes” before the interview. However, you may interview a participant and discover later that this person is also a source case. In this situation, you will have to go back to the Face Sheet, cross out and initial the “no” response, mark the “yes” response, and fill in the information about the pediatric case.

(2) General information

Fill in as many items as you can before the interview.

b. Errors and corrections

Use a pen to complete the questionnaire. If you make a mistake, cross out and initial the error, and select the correct answer.

If a participant changes his/her mind about a response, make the correction ONLY if the change occurs within one question. For example, if the participant answers Question A2, then answers Question A3, and then changes his/her mind about Question A2, the interviewer should go back, cross out and initial the error, and select the new response. However, if the change occurs more than one question later, the interviewer should not make

the change. This is because many of the questions are linked by complex skip patterns, and it would be too difficult to attempt to follow the corrections through all the skip instructions. Moreover, there is no guarantee that the new information is more “correct” than the old.

c. Making your mark

Select a response by placing an “x” or a check mark (√) in the box next to the response. Please make your mark entirely within the box, so the data entry person will not be confused about which option you have selected.

When a blank is provided to write in a response, please PRINT the response clearly. When a blank is paired with an “Other” option, please make sure that no other option provided is appropriate before you select the “Other” option. For example, Question D1 asks the participant to describe the main reason he/she went to the doctor who diagnosed the participant’s tuberculosis. If the participant says it was related to his/her diabetes, mark box #3, “Non-TB medical condition” and write “diabetes” in the blank. If the participant said he/she had a headache, mark box #2, “Symptoms.” Mark “Other” only if the participant mentions a reason that does not fit in any other box.

d. When to leave a blank

NEVER skip a question unless the skip instructions tell you to do so.

If you ask a question, you MUST fill in an answer. If the participant doesn’t know, is unsure, or refuses to answer, mark the appropriate box.

e. Source of information for the questionnaire

Use only the participant’s responses to fill out the questionnaire. Do not use information obtained from any other source (medical records, physicians, case managers, etc.), even if that information seems more “correct” than the participant’s responses.

f. Using previous responses in future questions

Some of the questions use information from previous responses (See eRoom file pathway Task Order #9/Materials for full rollout of study/Questionnaire manuals/Adult questionnaire manual/Responses used more than once in the questionnaire (Adult)) For example, the date of the participant’s TB diagnosis is requested early in the questionnaire, and then used to ask another question later in the questionnaire. We suggest that you carry a small dry erase board (like the one that we gave each interviewer at the first training) to jot down these items as they are asked, so you can easily refer to them later on.

Otherwise, you will have to flip back and forth in the questionnaire during the interview, and this can be distracting for both you and the participant.

We suggest the dry erase board rather than a pad of paper, because this is the easiest and most secure way to make sure that these jottings are not inadvertently retained. Also, the dry erase board can be used as a lap board in situations where you don't have a desk or other flat surface for the questionnaire. If you do take any notes on a separate sheet of paper, make sure the sheet does not contain the participant's name and that you destroy the sheet immediately after the interview.

C. Participant ID Number

The participant ID number is pre-printed on the questionnaire booklet in the upper right corner of the cover and in the upper right corner of the Face sheet and the first page of the General Information section. This is the number that you will enter into the data entry system (Data Management and Communications System, or DMACS). It is the only identifier in DMACS that we can use to link the participant back to the questionnaire booklet. Note that the only place where the participant's name and ID number appear together is on the questionnaire booklet's Face Sheet. This is part of our confidentiality system. Please do not create any other paper or computer document that has both the participant's name and ID number. Once we have entered all the data into DMACS, including the information from CDC Global Migration and Quarantine/Canadian equivalent, and the clinical data from the RVCT form/Canadian equivalent, we will notify the sites to destroy the face sheets. That will break the link between participant and questionnaire booklet, and the data will be anonymous - nobody will be able to trace a name on the consent form, Form 1, Form 2, or the tracking form, to a particular questionnaire or to the data in the database.

If you have to fill out colored questionnaires in addition to those in the booklet, please copy the participant ID number onto the upper right corner of each additional questionnaire that you use. Please also number it in the order in which it is used (see Section E for further information).

IV. WORKING WITH THE PARTICIPANT

A. Identifying the participant

Make sure you're talking to the right person before you identify the nature of the study or start asking questions. This protects both the study's integrity and the person's confidentiality. As a final mark, before you administer the questionnaire, make sure that the name the person signs on the consent form matches the name you have on the face sheet.

B. Asking the questions

a. Professionalism

As the interviewer, your job is to record what the participant says. Be careful not to make suggestions or comments that might indicate to a participant that one answer is "better" or more "correct" than another. This can best be done by asking the questions exactly as they are written, with no other comments or explanations.

If you know the participant, please find another interviewer to conduct the interview.

b. What to do if a participant doesn't understand a question

If the participant appears confused by the question or says "I don't understand," repeat the question.

If the participant still does not understand, offer an explanation **only if one has been provided in this questionnaire manual.**

For example, Question G5 asks the person his/her current visa status.

If the participant doesn't understand or doesn't know, the follow-up response is:

"Let me read you some of the different kinds of entry papers people might get. Some people enter with green cards if they are immigrants, refugees, or asylees. Temporary visitors have visas for business, work, pleasure, or school. Did you have any papers like these?"

If the participant says “permanent resident” or something similar, the follow-up response is:

“Thank you. Do you know if you are a refugee, an immigrant, an asylee, or some other type of resident?”

If the questionnaire manual does not have a standard explanation and the participant does not understand the question after you repeat it once, please **do not offer any other explanation**. Mark the “don’t know” box and go on to the next question as indicated by the skip instructions. Please do NOT tell the participant, “I can’t tell you anything else,” or “I’m not allowed to explain it,” or “they told me to ask the questions this way.” This implies to the participant that we are trying to hide something or that the questions have some hidden meaning that you’re not allowed to explain. A response like, “Let’s move on to the next question” is usually sufficient. If the participant wants information about a specific topic, like HIV or TB transmission, provide the name and telephone number of a health department contact at the end of the interview.

c. “How many?”

The questionnaire has four questions that ask participants how many months they took TB drugs (Section G, Questions 16b4 and 17f4 in the adult and 23b4 and 24f4 in the pediatric; Column H of the health screening questions in Section I; and Question J1c). If, in response to these questions, the participant answers “many,” please follow up with, “Can you tell me how many?” If the person does not know, write “don’t know” in the blank after the word “specify” on the questionnaire. When the data is entered, you will be prompted for the number of months. Enter 98, which is our code for “don’t know.”

d. How to respond to concerns about particular questions or the questionnaire in general

Some of the questions may be uncomfortable for the participant, or he/she may wonder why we are asking it. We have developed responses to Frequently Asked Questions (FAQs) that we hope will be helpful; see the document “Frequently asked questions for interviewers” in the eRoom (the file pathway is Task Order 9/Materials for full rollout of study/Questionnaire manuals/Frequently Asked Questions). Here are two examples:

I already told (the health department, my doctor, the nurse, etc.) all the answers to these questions. Why don’t you just get it from (him/her/them)?

Not every health department in the US and Canada asks patients for the same information. We need to ask some questions again to be sure the information we have is accurate. We hope you will be kind enough to answer them again.

Why are you asking me about my visa status?

The questions about visa status will give us information on who we should offer tuberculosis testing and other services. We would like to know if we should offer these services to other people aside from immigrants and refugees.

Some participants may become irritated at questions that they think they have answered before. For example, a participant may volunteer information that covers a future question and then be irritated when the interviewer asks that question later on. The participant may think that the interviewer did not pay attention earlier or did not believe the participant. Here is a suggested response to such a question:

I already told you the answer to this question. Why are you asking it again?

The questionnaire has been written so that everyone gets asked the same questions in the same way. But each person will respond to a question in his /her own way. So, we want to make sure we follow the same order of questions, even if this means asking you about something you have already mentioned.

C. Responding to requests for information or advice

In order to ensure the study's integrity and protect the participant's confidentiality, we must maintain a strict separation between the study and the participant's health care.

Your job as an interviewer is to record information, not to provide medical information, health education, or advice. Please do not answer any questions about tuberculosis or other diseases in general, or about the participant's treatment in particular. Refer the participant to the local health department or to his/her health care provider for all information and advice, no matter how simple the request.

For example, if the participant says he/she does not understand how tuberculosis is transmitted, provide a name and telephone number of someone at the local health department TB clinic or refer the participant to his/her physician.

In the unlikely event that a participant wants to give you information about a contact investigation or other related information, provide the name and telephone number of the local health department contact. In the extremely unlikely event that a participant expresses suicidal thoughts, provide the telephone number of the local suicide hotline.

V. USE OF INTERPRETERS AND FOREIGN LANGUAGE QUESTIONNAIRES

A. If an interpreter is present in person

The interviewer, not the interpreter, should always fill out the questionnaire. If an interpreter is present, the interviewer should provide the interpreter with a foreign-language questionnaire in the interpreter's language (if one is available) so the interpreter will know how to ask the questions and be able to follow along. But the **answers should be recorded in English in the interviewer's English-language questionnaire booklet.**

It is a good idea to provide the interpreter with the questionnaire in advance, if possible. The interviewer should meet with the interpreter at least briefly before the interview begins to explain how the interview will be conducted, go over the questionnaire, and answer any questions the interpreter may have. If the interview is being conducted in one of the ten languages for which a questionnaire translation is available, the interviewer should instruct the interpreter to ask the questions **exactly as written**, even if the interpreter thinks they could be worded better or are incorrect.

If the interpreter has not already signed a confidentiality agreement with his/her company, the interpreter should sign the same confidentiality agreement that all other members of the Task Order 9 research team have signed (the eRoom file pathway is Task Order 9/Materials for full rollout of study/Confidentiality guidelines and agreement).

Before the interview begins, the interviewer should explain to the participant how the interview will be conducted, and that the interpreter is there only to translate; if the participant has any questions, he/she should address the interviewer. The interviewer should explain to the participant that the only time the interviewer will address the interpreter is to provide skip instructions or to answer the interpreter's questions about a point of translation.

The interpreter should sit to one side and just behind the participant, so that the interviewer can maintain eye contact with the participant throughout the interview. The interpreter should not make any comments to the participant beyond translating the interviewer's words exactly as spoken (or as written, if the interview is in one of our 10 primary languages). If the interpreter needs to ask the interviewer a question, the interpreter should indicate to the participant that he/she is interrupting the interview to ask a question. The interviewer should give the interpreter skip instructions if necessary ("now we will skip to Question D1 on page 11." etc.)

The order of the interview when an interpreter is present is as follows:

1. The interviewer reads any introductory material, in English, pausing for the interpreter to translate.
2. The interviewer asks a question in English.
3. The interpreter translates the question as it is written in the foreign language questionnaire.
4. The participant responds, looking at the interviewer.
5. The interpreter translates the participant's response.
6. The interviewer marks the box that corresponds to the participant's response.
7. The interviewer asks the next question.

B. If an interpreter is present by telephone

In-person interpreters are preferred; use a telephone interpreter only as a last resort.

All sites should use Language Line for telephone interpretation whenever possible. This is to make sure that interpretations are as consistent as possible from site to site, and also to save money because Language Line is providing a special rate. To sign up for the special rate, fill out the forms available in the eRoom and send them to the designated person at Language Line; the file pathway is Task Order 9/Language Line documents.

We have provided Language Line with electronic copies of the questionnaires in the study's ten official languages, and they have shared them with their senior interpreters. In order to access the senior interpreters, call the special telephone number that Language Line has provided: 877-205-2801. Because we are using a smaller group of interpreters, it may take longer to connect with one.

If you need an interpreter in an uncommon language that you think Language Line may have difficulty with (Mandingo, perhaps), call our Language Line contact, Frank Masin, toll free at 877 862 1816.

When using a Language Line interpreter, the same basic rules apply as in section "A" above: the interpreter is to provide an exact translation of the interviewer's words and the participant's responses, and should not add any comments or attempt to expand on the interviewer's words. If the interpreter has access to our electronic questionnaire in one of the 10 primary languages of our study, he/she should ask the questions exactly as written. Please report any problems with interpreters to Dolly Katz.

C. Using the interpreter as a witness

The interpreter can act as a witness if one is needed. A witness must sign the consent form(s) if the participant is illiterate or speaks a language for which we do not have a translated full consent form (see the Procedures Manual for further information on use of witnesses).

If you are using a Language Line interpreter, ask for the interpreter's full name and ID number, print them on the witness line, and add your initials.

D. If the interviewer is bilingual in the language of the interview and no interpreter is used

If the interviewer is bilingual, he/she should **use the questionnaire written in the language of the interview**, if one is available. For example, if the interviewer is conducting the interview in Spanish, he/she should fill out the Spanish-language questionnaire. If the interviewer is bilingual in a language for which we do not have a foreign-language questionnaire, the interviewer should fill out the English language questionnaire (see parts A, B, and C above).

Do not use more than one questionnaire for the interview. Do **not** read from one and fill in the other. For example, if the interviewer is bilingual in Spanish, he/she should use only the Spanish-language questionnaire, both to ask the questions and to record the responses.

Always record the participant's responses in English, regardless of the language of the interview.

VI. AFTER THE INTERVIEW

After completing the interview, briefly go through the questionnaire to make sure you have filled in all questions appropriately and that any handwritten items are readable. Thank the participant for his/her assistance with the study. Give the participant the \$30 payment in the form specified in the informed consent. Do not contact the participant again, even if you discover later that you are missing information.

THE QUESTIONNAIRE

Face Sheet

General Information

Section A: Demographic information

Section B: Socioeconomic status

Section C: Circumstances of tuberculosis diagnosis

Section D: Event that led to diagnosis

Section E: History of care sought for current tuberculosis illness

Questionnaire 2: Physicians and nurses

Questionnaire 3: Other health care provider

Questionnaire 4: Friend or family member

Questionnaire 5: Treated self

Section F: Health insurance

Section G: Immigration history

Section H: Household visitors and other contacts

Section I: Health screenings

Section J: Previous treatment for active disease

Section K: Other medical conditions

Section L: Tuberculosis knowledge and attitudes

Face Sheet

The face sheet contains identifying information. In accordance with confidentiality and policy regulations, it **MUST** be separated from the rest of the questionnaire as soon as possible after the questionnaire and data abstraction forms are completed. Place the face sheet in a separate envelope and store it in the designated locked cabinet at the site, along with the tracking form, consent forms, and any other papers (receipts, etc.) that contain the participant's name. The questionnaire booklet should be stored in a separate locked cabinet.

The Face Sheet is completed before the interview. The only items on the face sheet that will be completed from the interview questions are the "Alien Registration Number/Immigration Medical Services number", the "Name Used at Entry to US/Canada" (G6 and G4c respectively), and the participant's middle name (if the source database contains no middle name or only a middle initial).

NEVER HAND THE QUESTIONNAIRE TO THE DATA ENTRY PERSON WITH THE FACE SHEET STILL INCLUDED EVEN IF THE INFORMATION ON THE FACE SHEET IS INCOMPLETE.

Question

Explanation

Participant's name

Name of participant as it appears on the source documentation (for most sites, this will be the Tuberculosis Information Management System [TIMS] database). List participant's last name, then first name, then middle name as provided. If there is no middle name in the source documentation, **ASK** the participant his/her middle name at the time of the interview and write it on the face sheet. If you have only a middle initial from the source documentation, **ASK** the participant for the full middle name.

Participant's address

This is the mailing address of the participant as it appears on the source documentation including zip code (US) or postal code (Canada). Fill this in before the interview.

Question	Explanation
Participant's phone number(s)	Participant's phone number(s) as it appears on the source documentation. If no number is available, mark the box, "No Phone/Phone Number Not Available." Fill this in before the interview.
Participant's State Case Number	<i>For U.S. participants ONLY:</i> The state case number as reported in the source documentation. Fill this in before the interview.
Participant's Alien Registration Number	<i>For U.S. Participants ONLY:</i> This number is obtained from Section G, Question G6. Write the number here, NOT in Section G. If the alien registration number is not available, mark the box, "Alien Registration Number Not Available." Please do not attempt to subsequently contact the participant to obtain this number even if the participant is agreeable. The alien registration number has 8 or 9 digits. If the number has eight digits, please put a zero in front of the first digit (example: 090 999 999) Do not include any letter in front of the number.
Participant's Immigration Medical Services Number	<i>For Canadian participants ONLY:</i> This number is also obtained from Section G, Question G6. If the immigration medical services number is not available, mark the box, "Immigration Medical Services Number Not Available." Please do not attempt to subsequently contact the participant to obtain this number even if the participant is agreeable.

Question

Explanation

Name used at entry to US/Canada

The name is written here but obtained from Section G, Question G4c. Complete this field only if the name the participant now uses is different from the one used at entry to the US/Canada. Note that this name is not the same as the name on the source documentation and may not be officially documented anywhere. Record the name as reported by the participant.

Is Participant a source case?

Mark "Yes" if the participant is also a source case for an interviewed pediatric case less than five years old; otherwise mark "No". You may have to change this information later, if you discover that a previously-interviewed participant has been identified as a source case for a participant less than five years (60 months) old.

Pediatric Participant's name

If the participant is a source case, record the name of the pediatric participant.

Pediatric Participant number

If the participant is a source case, record the pediatric participant's study ID number. This is the preprinted number on the cover of the pediatric participant's questionnaire booklet.

General Information

Complete this section before the interview.

Question	Explanation
Participant's Zip Code	Obtain this information from the face sheet, not from the participant. If you do not have a zip code for the participant and you know the participant is homeless, mark the "homeless" box.
Date of interview	Record the date of the interview. The date of interview should be equal to or later than the Date Case Was Reported to Jurisdiction (see General Information, below).
Time interview started	Record the time you start to administer the questionnaire in hours and minutes. Also select A.M. or P.M. Do not use military time.(1300 hours, 1400 hours, etc.)
Time interview completed	Record the time the questionnaire was completed in hours and minutes. Also select A.M. or P.M. Do not use military time.
Interviewer number	Record the number the site has assigned to the interviewer. Each interviewer must have a different number. For example, if interviewer #1 leaves the project, the next interviewer should have a different number, NOT #1.
Interviewer initial	Record your initials
TBESC Consortium site	Record your site's TBESC consortium site name.
Date case was reported to jurisdiction	The date your jurisdiction (city, county, or state/provincial health department) became aware of the case. In the TIMS database, this is TIMS Variable #5. As noted above, this date can only be earlier than or equal to, the Date of Interview (above).

Question

Language of Interview

Explanation

Select the language in which the interview is being conducted. If an interpreter is present, the language is the one the interpreter is using. If the language of the interview is not listed, mark "Other" and record the language used.

How well does participant speak English?

Copy this information from the response provided on the Participant Tracking form; do not ask the participant again.

Interview conducted with

If the interview is not conducted in English, select the appropriate format of the interview from the response options: bilingual interviewer, telephone interpreter, etc. If the interview is being conducted in English, mark "Not applicable; interview conducted in English."

Foreign language (translated) questionnaire used.

Specify if a foreign language questionnaire is used for data entry. If an interpreter is used and the interviewer uses an English language questionnaire to record the answers, mark the "No" box.

Location of interview

Select the location where the interview took place; for example, health department clinic, hospital, etc. If the location is not listed, mark "Other" and specify the location.

Section A: Demographic Information

The purpose of this section is to gather demographic information on the participant. Data is collected on place of birth, date of birth, race, and gender. Ask all participants all the questions in Section A; the section has no skip instructions.

A1 What country were you born in?

We are interested in knowing the participant's country of birth. This may not be the same as the participant's country of citizenship/nationality, or the place the person lived in before coming to the US/Canada. If the participant names a city and you know the country, say the name of the country before writing it down. If the person names a country that you don't know how to spell, ask the correct spelling. If the participant does not know his/her birth country or refuses to answer, mark the appropriate box (box #98, "Don't know" or box #99, "Refused to answer") and go to Question A2.

Hong Kong is now a special administrative unit of China. If the person says he/she was born in Hong Kong, write that in the blank. DMACS has a country code for Hong Kong, which you should use in data entry ("Hong Kong (special administrative region of China)")

A2. What city or town were you born in?

If the participant names a place you don't know how to spell, ask for the correct spelling (this may be difficult if the person does not speak English and the language of the interview uses a different alphabet, but the interpreter will help you). For persons who were born in rural areas outside of any cities or towns, mark box #2, "Not applicable/was not born in a city or town". If the participant doesn't know his/her birth place or refuses to answer, mark the appropriate box and go to Question A3.

A person born in Hong Kong may give you the name of the island he/she was born on (Hong Kong consists of about 200 islands). If so, write that in the blank space provided. Since this is a text field in DMACS, you can also enter that name in the database. If the person says something like, "just Hong Kong" or something similar, enter "Not Applicable" on the blank and in the DMACS data field.

A3 What province or state were you born in?

If you aren't sure of the spelling, ask. In some countries, like Haiti, it is more appropriate to ask about the "department" the person was born in. If the participant doesn't know or refuses to answer, mark the appropriate box and go to Question A4.

For persons born in Hong Kong, do not ask this question, but write in "Not Applicable" on the blank, and the same in the database.

A4 What is your date of birth?

Please record this date using the month/day/year format as indicated in the questionnaire (mm/dd/yyyy). Probe for the full date if the person gives only a partial response. For example, if the person says only the year, ask if he/she remembers the month, and then the day. Record either (1) the full date of birth, (2) the month and year, or (3) the year only. Do not record only a month or only a day. If the person remembers only a month and/or day, mark box 98, "Don't know". Note: this date will not be retained in the central database. At data entry, it will be converted automatically into the person's age (to one decimal point) on the date of interview.

A5 Are you Hispanic or Latino?

We are interested in knowing if the participant identifies himself/herself as Hispanic/Latino or not. This is not a choice between being Hispanic or Latino; that is, the participant is not being asked to choose between the two ethnicities. This question is posed to imply that Latino is the same as Hispanic. If the person does not understand the question, repeat it once. If the participant still does not understand, or provides an inappropriate answer such as "I'm Caucasian," or "I'm Black," mark the "Don't know" box and move on to the next question. Do not attempt to define the terms.

A6 What is your race?

This is the racial group or groups that the participant most closely identifies with. There are response options for "Other Asian," "Other Pacific Islander," and "Other." When any of these responses is selected, specify the racial group the participant mentions in the blank provided. If you do not know whether a group mentioned is "Other Asian" or "Other Pacific Islander," write it in the blank next to "Other". Also use the "Other" to write in groups mentioned that are not races, for example if the person says "Hispanic". Select as many racial groups as the participant mentions – for example, "Chinese" and "Black". If the participant does not understand the question,

repeat it once. If the participant still does not understand, mark “Don’t know” and move to the next question. Do not attempt to define the terms.

A7 *And your sex is . . .*

Response options – “Male” and “Female” - are **bolded** to indicate that you should read aloud what you consider the participant’s sex to be. For example, if the participant appears to be female, the question should be read: “And your sex is female.” If the participant corrects you, mark whatever sex the participant indicates is the correct one. If you are unsure of the person’s sex, say, “And your sex is?” and let the participant supply the answer. If the person says he/she is trans-gendered or is undergoing a sex change operation, or if there is confusion, mark the “Don’t know” box and move to the next question.

Section B: Socioeconomic Status

The questions in this section ask about the participant's socioeconomic status: education, living arrangements, income, employment before and after entry to the US/Canada, and employment before and at the time of the tuberculosis diagnosis.

B1 I am going to read you a list. Please tell me the highest level of schooling you have completed.

Read the **boldface** options out loud to the participant. We are interested in the maximum level of education the participant has completed. If the participant mentions an option that does not fit in the first 6 options, mark the "Other" option (box #97) and record the participant's answer in the blank space. If the participant says "none" or otherwise indicates that the participant has not had any formal education, check the "Other" option and record "none" in the blank space. Do not read the "Don't know" and "Refused to answer" options out loud. After marking the appropriate response, continue to Question B2.

Questions B2 through B6c

The use of "work" and "job" in this section refer to employment where the participant earned money. This therefore does not include any volunteer, mandatory (such as court-ordered community service) or unpaid work.

The purpose of these questions is to assess the participant's socioeconomic status by determining job status (1) in the US/Canada and (2) in the country this person lived in before coming to the US/Canada. The reason we ask about jobs in another country is that many immigrants had higher-status jobs in the countries they came from. Someone who was a physician in India may be a research assistant in this country because he/she can't get licensed here. Knowing this person was a physician in India gives us a better picture of his/her socioeconomic status.

We ask the same questions about the person in the family who provides most of the family income. The participant may never have had a job, but may be married to someone with a high-paying job. Knowing the occupation of the principal wage earner gives us a better picture of the participant's socioeconomic status.

A person may have many jobs in a lifetime. We want to know about the US/Canadian job the participant had at the time of the TB diagnosis. If the person was unemployed at the time of diagnosis, we want to know about the last job before the TB diagnosis.

Please be very careful to follow the skip instructions in this section. For example, if the participant had a job at the time of diagnosis, we do NOT want to ask Question B3 about employment before diagnosis. Question B3 is only for

participants who say they were not working at the time of diagnosis. If the participant is a migrant worker, note this on the dry erase board or on a sticky note for later use in Section G, Part IV: Migration within the U.S. and Canada.

B2 *Were you working when you were told that you had tuberculosis?*

We want to know if the participant had a job at the time he/she was diagnosed with tuberculosis. If the participant was working at the time of diagnosis, mark Box #1 (“Yes”) and continue to Question B2a. If the participant was not working at the time of diagnosis, mark Box #2 (“No”) and follow the skip instruction to Question B3. If the participant says that he/she was a “volunteer” at the time of diagnosis, or uses other words to indicate he/she had an unpaid position, mark Box #2 (“No”) and follow the skip instruction to Question B3. If the participant does not understand the question, you may follow up with, “Did you have a job?”. If the participant still does not know or refuses to answer, mark the appropriate box and follow the skip instruction to Question B3.

B2a *What kind of work did you do?*

We are interested in the participant’s type of work or job title. Write the type of work or job title in the space provided. If the participant’s response is unclear to you or ambiguous, probe to get a more specific description. For example, if the person says “medical,” ask, “What kind of medical job did you have?” If the person says “technician,” ask “what kind of technician?” If the person says “bakery,” ask “what did you do in the bakery?” If the person says “chef,” ask, “what kind of place did you work it (for example, a Wendy’s chef is a much different occupation than a chef at Maxim’s in Paris). If the person gives you initials, like “PT,” ASK what the initials mean, don’t assume. Whenever possible, indicate the type of store, chain, etc., instead of providing the name (for example, say “supermarket chain” instead of “Publix”). Please do not use abbreviations or initials when writing down the participant’s occupation. Our goal is to have as specific a description of the person’s occupation as we can get.

If the participant has two or more jobs, write down all of them; since this is a text field, the data entry system will accept more than one job description.

If the participant’s job relates to seasonal work, follow the skip instruction to Question B2b.

Seasonal work is work that is available locally only during certain times of the year in different parts of the country. A person who wants to keep doing that job will either have to move from place to place or be unemployed for part of the year. Some examples of seasonal work include farming, construction work, fishing, and canning. If a person mentions any of these jobs, ask

Question B2b. Also ask Question B2b if you are unsure whether the participant's work is seasonal.

If the participant mentions a job that is clearly not seasonal, such as "nurse" or "teacher" DO NOT ask Question B2b. Follow the skip instruction to Question B5.

If the participant doesn't know what kind of work he/she was doing or chooses not to answer, mark the appropriate box and follow the skip instruction to Question B5.

B2b Did you move from place to place with the seasons?

The purpose of this question is to determine whether the participant was a migrant worker. (NOTE: the term "migrant worker" applies not only to agricultural work, but also to fishing, canning, and other seasonal work). You will need this information later in the questionnaire (see Box G1). Mark the participant's response and go to Question B5 for ALL responses.

Questions B3, B3a, B3b, and B4 are for people who said they were NOT working at the time they were diagnosed with tuberculosis. Participants who had jobs when they were diagnosed with tuberculosis do not answer these questions.

B3 Were you working before you were told you had tuberculosis?

We are interested in the last paying job the participant had before he/she was diagnosed with tuberculosis. If the participant had a job before the TB diagnosis, mark Box #1 ("Yes") and continue to Question B3a. If the person did not have a job before the TB diagnosis or doesn't know or chooses not to answer, mark the appropriate box and follow the skip instruction to Question B6.

B3a What kind of work did you do in the last job you had?

We are interested in the participant's type of work or job title. Write the type of work or job title in the space provided. Encourage the participant to be as specific as possible; if you don't understand what the person says, probe ("what kind of technician were you?"). See response to B2a for more information.

If the participant's job relates to seasonal work, follow the skip instruction to Question B3b. Seasonal work is available locally only during certain times of the year. A person who wants to keep doing that job will either have to move from place to place or be unemployed for part of the year. Some examples of

seasonal work include farming, construction work, fishing, and canning. If a person mentions any of these jobs, ask Question B3b. Also ask Question B3b if you are unsure whether the response relates to seasonal work.

If the participant mentions a job that is clearly not seasonal, such as “nurse” or “teacher,” DO NOT ask Question B3b. Follow the skip instruction to Question B4.

If the participant doesn’t know what kind of work he/she was doing or chooses not to answer, mark the appropriate box and follow the skip instruction to Question B4.

B3b *Did you move from place to place with the seasons?*

The purpose of this question is to determine whether the participant was a migrant worker. (NOTE: the term “migrant worker” applies not only to agricultural work, but also to fishing, canning, and other seasonal work). You will need this information later in the questionnaire (see Box G1). Mark the participant’s response and go to Question B4 for ALL responses.

B4 *What country was this job in?*

Since the participant had this job before being diagnosed with tuberculosis, it could have been before the participant came to this country. If the participant says this job was in the US or Canada, mark box #1 and continue to Question B5 to find out what job the participant had before coming to the US/Canada. If the participant says the job was in a country outside the US/Canada, mark box #2 (we will not collect the name of the country) and follow the skip instruction to Question B6. For “Don’t know” and “Refused to answer” responses, follow the skip instruction to Question B6.

B5 *What kind of work did you do before you came to the US/Canada?*

We are interested in the participant’s occupation prior to coming to the US/Canada. Write the type of work or job title in the space provided. Encourage the participant to be as specific as possible; if you don’t understand what the person says, probe (“what kind of technician were you?”). See instructions for Question B2a for more detail.

If the participant did not have a job before coming to the US/Canada, mark Box #2 (“Did not work before I came to the US/Canada”) and continue to Question B6. If the participant doesn’t know or chooses not to respond, mark the appropriate box and continue to Question B6.

B6 *Now I am going to ask you some questions about your family's income. Who provides most of your family's income? Is it you or somebody else?*

This question refers to the primary money earner in the family. We do not ask the participant's relationship to this person, only whether the primary earner is the participant or somebody else. If it's somebody else, mark box #4 and continue to Question B6a to ask about that person's job history. For all other responses (the participant is the primary wage earner, the participant and somebody else provide equally, nobody in the family provides any income, the participant doesn't know or refuses to answer), mark the appropriate box and follow the skip instruction to Question B7.

Questions B6a, B6b, and B6c refer to the person in the family who provides the most income. Ask these questions ONLY if the primary provider is someone other than the participant – in other words, if you checked response #4 ("somebody else") in Question B6.

B6a *What kind of work does this person do now?*

This question has the same meaning as in Questions B2a, B3a, and B5. We are interested only in paid employment, not in volunteer or any other kind of unpaid work. Write the name of the job or job title in the blank provided. Encourage the participant to be as specific as possible; if you don't understand what the person says, probe ("what kind of technician was he?").

It may be that the person who provides most of the family income does not have a job, but is supporting the family with savings or some other way. In that case, mark Box #2 (Doesn't have a job). Regardless of how this question is answered, go on to Question B6b after selecting the appropriate response.

B6b *What country was this other person living in before coming to the U.S./Canada?*

We are interested in the country this person was living in before moving to the US or Canada. This is not necessarily the person's country of birth or country of citizenship. Write the name of the country in the space provided. If this person has always lived in the US or Canada, mark box #2 and follow the skip instruction to Question B7.

If the person is not living in the U.S., write the name of the country where the person is currently living and add a note that the person is currently living there. Then SKIP the next question and go to Question B7.

For any other answer, mark the appropriate box and go to Question B6c.

B6c *What kind of work did this person do before coming to the U.S./Canada?*

We are interested in the occupation of the primary family provider before this provider moved to the US or Canada. This question has the same meaning as in Questions B2a, B3a, B5, and B6a. We are interested only in paid employment, not in volunteer or any other kind of unpaid work. Write the job or job title in the space provided. Encourage the participant to be as specific as possible; if you don't understand what the person says, probe ("what kind of technician was he?").

If the person didn't have a job before coming to the US/Canada, mark Box #2 and go to Question B7. For any other answer, mark the appropriate box and go to Question B7.

Questions B7, B7a, B8, B9, and B10 are about the participant's household. Note that household can include people who are not family members.

B7 *How many people live in your household, including yourself?*

This is the number of people who live in the same dwelling unit as the participant, whether they are related to the participant or not. In an apartment building, this means the number of people living in the same unit as the participant. A dwelling unit can be a trailer, a room in a boarding house, a tent, or any other structure the participant considers his/her current home.

If the participant provides the number of people, continue to Question B7a. If the participant lives alone, mark Box #2 ("Live alone") and follow the skip instruction to Question B8. If the participant doesn't know or chooses not to answer, mark the appropriate box and follow the skip instruction to Question B8.

If the participant says he/she is homeless, mark Box #3 ("Homeless") and follow the skip instruction to Question B9.

B7a *How many of them are children under the age of 18 years?*

Write in the blank the number of children under the age of 18 years. This does not include those who are 18 years old. If the answer is "none," write the numeral 0 in the space. Proceed to Question B8. If the person doesn't know or chooses not to respond, mark the appropriate box and continue to Question B8.

B8 *How many rooms do you have, not counting bathrooms?*

We are interested in the number of rooms in participant's dwelling unit. An enclosed porch is a room if it is suitable for year-round use (this will vary by climate). A recreation room is a room, as is a loft bedroom and a kitchen. Utility rooms, laundry rooms, unimproved basements, unenclosed porches, and bathrooms do not count as rooms. A dining room, to be counted, must be a separate room; a "dining area" is not a room. Write the number in the space provided, or select the "Don't know" or "Refused to answer" box and continue to Question B9.

Questions B9 and B10 both ask about family income. Income is a sensitive question for some people. We are asking two questions because research shows that people are more likely to answer a general question about whether they earn "more or less" than a certain amount (in this case, \$20,000) than they are to pick a specific category of earnings (as is requested in B10). Therefore, we expect that most people will answer Question B9, so we will have at least some information about income for most people.

B9 *In the 12 months before you were told you had tuberculosis, would you say your total family income was less than \$20,000 or \$20,000 and above?*

This is the total family income, NOT the participant's income only. It does not include income of unrelated persons sharing living quarters, unless these persons pool their income. If the family income was in a currency other than the US dollar, please ask the participant to estimate the amount in US currency. Mark the appropriate box and continue to Question B10.

B10 *Of all these income groups, can you tell me which one best represents your total family income in the 12 months before you were told that you had tuberculosis?*

Show the participant the Income show card to select the income letter that is closest to the participant's family income. Record in the blank space the letter corresponding to the income range; do not record the actual income range. If the participant does not know the family income or chooses not to respond, mark the appropriate box and continue to Question C1.

Section C: Circumstances of Tuberculosis Diagnosis

The questions in this section all refer to the participant's current tuberculosis diagnosis. We are interested in knowing the circumstances relevant to the current diagnosis ONLY. These questions do not relate to any previous tuberculosis screening, diagnosis or treatment that the participant may have received.

C1 When did a doctor or nurse first tell you that you had tuberculosis? I am talking about your current tuberculosis illness.

This refers to the date that the participant learned of the current TB infection for which he/she is being treated. If the participant provides an ambiguous response, like "April," confirm the year ("You mean April of 2004?"). If the participant provides a vague response, like "six months ago," or "about a year ago," calculate the approximate date and confirm it ("So would that be December 2004?" If the participant agrees, then record 122004; otherwise mark "Don't Know"). If the participant provides only the year, probe for the month. Do not record only a month. If the participant cannot provide a year, or chooses not to, mark the "Don't know" or "Refused to answer" box and continue to Question C2.

If the participant provides a date that is clearly too long ago (1972, for example), remind the participant that if he/she has been sick more than once with TB, we are asking only about the **current** illness.

In addition to the questionnaire, record the diagnosis date in another place that can be easily accessed such as a dry erase board or sticky note. You will need to recall this date for subsequent questions [D2, E1, and F2].

C2 What city and state/province were you living in at that time?

We are interested in the city and the state or province the participant was living in when he/she was diagnosed with tuberculosis. These locations may be the same as where they are now or may be different. Record the location as reported by the participant. In the U.S. pose the question as, "What state and city were you . . ." and in Canada pose the question as, "What province and city were you . . ." Mark the appropriate response and continue to Question C3.

If the participant mentions a place that is outside the US/Canada, **this is a clue to you that the participant is thinking about a previous diagnosis, NOT** about the current diagnosis. In order for the participant to be a RVCT (Reported, Verified, Case of Tuberculosis) or Canadian equivalent, he/she has to have been diagnosed in the US/Canada and reported as a new case (states and counties may follow cases that were diagnosed in another

country, but they do not report them as RVCTs). Remind the person that we want information about the current diagnosis (“I’m sorry if I have confused you. My question is about your current tuberculosis diagnosis here in the US/Canada”). Go back to the previous question and clarify the date that the person was diagnosed in the US/Canada, then ask again what city and state/province the person was living in.

C3 *Which of the following best describes where you lived at the time you were told you had tuberculosis?*

This is the type of housing the participant lived in when he/she was diagnosed with tuberculosis. Read the **boldface** choices out loud for the participant to select one. Do not read the “Don’t know” or “Refused to answer” choices. If the participant says he/she lived in a house or an apartment, mark Box #1 and continue to Question C3a. For all other responses, mark the appropriate box and follow the skip instruction to Question C4. If a type of housing is mentioned aside from those provided, mark box #5, “another kind of place,” and record what the participant says – a trailer, tent, warehouse, the beach, a vacant lot, homeless, etc., and follow the skip instruction to Question C4.

C3a *Was this:*

We are interested in knowing who owned or paid the rent on the house or apartment the participant lived in when he/she was diagnosed with tuberculosis. Read the **boldface** selections out loud (do not read the “Don’t know” or “Refused to answer” options) If a person is mentioned other than a family member, relative or friend, select ‘other’ and specify the person mentioned. After marking an appropriate box, continue to Question C4.

C4 *Where did you find out that you had tuberculosis? Was it at a...*

We are interested in knowing what type of health care facility the participant went to when he/she was diagnosed with tuberculosis. Read the **boldface** options out loud (do not read the “Don’t know” and “Refused to answer” options). If any facility is mentioned besides a private doctor’s office, ask the participant the name of the facility and write it in the blank next to the box. If the person mentions “emergency room,” write that in Box #3 (Hospital) and ask the participant the name of the hospital; write that in the blank next to box #3.

If a participant mentions a facility that is a combination of the options provided – for example, “A TB clinic at the health department,” pick the first option that is listed in the booklet – in this case, box #1, “health department”, and record the name of the health department in the blank. If the participant says “A hospital TB clinic,” select box #2, “tuberculosis clinic,” and record the name of

the clinic in the blank. If the participant remembers the type of facility but not the name, check the box for the facility and write “Don’t know” in the blank.

Questions C5, C5a, C5a.1 are asked only if the interview is NOT being conducted in English. If the interview is being conducted in English skip to Question D1 in Section D: Event That Led to Diagnosis.

The purpose of the following questions is to find out whether the participant learned of his/her TB diagnosis in a language the participant could understand. For example, if a person speaks only Spanish but was told the diagnosis in English, with no interpreter present, it is unlikely this person understood the diagnosis.

C5 What language did the doctor or nurse use when he or she told you that you had tuberculosis?

1. Write down on the blank line for Question C5 the language that the doctor or nurse used to tell the participant he/she had tuberculosis (Spanish, English, French, etc.). We are interested in the language the doctor or nurse spoke, regardless of whether an interpreter was present.

2. Compare the language the doctor or nurse used with the language in which you are conducting the interview.

3. **If the languages are the same**, skip the rest of section C and go to Section D. For example, if the doctor or nurse spoke Spanish and the interview is being conducted in Spanish, skip to section D. If the doctor or nurse spoke Haitian and the interview is being conducted in Haitian, skip to section D. This is because study interview is in a language the participant understands. If the doctor or nurse spoke to the participant in the same language, we know the participant understood that language.

If the languages are different, go to Question C5a. For example, if the doctor or nurse spoke English but you are conducting the interview in Spanish, go to Question C5a. The next questions will determine whether an interpreter was available when the participant learned he/she had TB.

C5a Did somebody translate the doctor or nurse’s words into your language?

If the answer is “Yes”, mark Box #1 and continue to Question C5a.1. If not, or if the participant does not know or does not remember, then mark the appropriate box and follow the skip instructions to Section D: Event That Led to Diagnosis.

C5a.1 Who translated the doctor or nurse's words into your language? Was it...

Read the **boldface** choices out loud. Do not read the "Don't know" or "Refused to answer" choices. Mark the appropriate response and continue to Question D1 in Section D - Event That Led to Diagnosis.

Section D: Event That Led to Diagnosis

D1. What was the main reason for your visit to the doctor or nurse who told you that you had tuberculosis?

We are interested in the reason the participant went to the doctor or facility where he/she was diagnosed with tuberculosis. Select the option that best matches the participant's response. For example, if the participant says that someone from the health department told him/her to get tested because a relative tested positive for tuberculosis, then we know that the participant is referring to a contact investigation, and you should mark box #10. Some participants may tell you that they went to the doctor who diagnosed them because they were referred there by another doctor or health care worker. In that case, mark box #1 ("Referred by another doctor") and go on to Question D1a. If any other box is marked, follow the skip instructions to Question D2.

If the participant went to the doctor for a routine TB screening, select the particular type from boxes 5-9 ("employment," "immigration," "pregnancy," etc.)

Please do not mark the "Other" box (box #97) unless the participant's response will not fit in any of the other boxes. For example, if a person mentions diabetes, high blood pressure, angina, or any other non-TB health condition, you should check box #3 and specify the condition. If a person mentions a symptom, like a cough, headache, cold, or just says "I didn't feel well," you should check box #2, "symptoms."

D1a Why did you go to the doctor/health care worker who referred you?

Ask this question ONLY if you marked box #1 in Question D1, "Referred by another doctor/health care worker." Here, we are interested in the reason the participant went to the doctor who referred him/her to the place where he/she was diagnosed with TB. For example, a participant may have gone to the first doctor because he/she had a chronic cough. The doctor, apparently suspecting TB, referred the participant to the physician who made the TB diagnosis. In that case, you would mark box #1, "Symptoms," under Question D1.a. Regardless of the box marked, continue to Question D2.

Questions D2a through D2h all refer to the symptoms the participant had in the 12 months before he/she was diagnosed with tuberculosis. To make sure that the participant keeps focused on the correct time period, begin the first question with, “In the 12 months before [insert diagnosis date], did you ...” It may be awkward to repeat that phrase before each question. However, you should insert the phrase again at questions D2a1 (if you ask it), D2c and D2h.

Note that this question refers to a response provided earlier in the questionnaire – Question C1, the date the participant was diagnosed with TB. For this reason, we suggest that you carry with you a dry erase board (which can double as a lap board for filling out the questionnaire) or separate sheet of paper on which you can note the date of diagnosis and the date of the earliest symptom. Then you won’t have to be flipping back and forth through the questionnaire to find that information when you need it again. Make sure you erase or shred these notes immediately after the interview.

If you don’t know the participant’s diagnosis date (i.e., the participant responded “Don’t know” or “Refused to answer” to Question C1), ask the question without the specific date: “In the 12 months before you were told you had tuberculosis, did you...?”

D2a. In the 12 months before [diagnosis date], did you have a cough that lasted at least 3 weeks?

If you don’t know the participant’s diagnosis date, ask the question without the specific date: “In the 12 months before you were told you had tuberculosis, did you...?” If a person has had a chronic cough (like a smoker’s cough, etc.) for years, he/she may respond by saying, “Oh, I’ve always had a cough,” or “I’ve had a cough for years.” In that case, mark the box for “always coughed,” and ask Question D2a1. If any other box is marked, including “Don’t know” and “Refused to answer”, follow the skip instruction to Question D2b.

D2a1 “In the 12 months before [diagnosis date], did you notice a change in your cough?”

Ask this question ONLY if you marked the box, “always coughed” in D2a. In a person with a chronic cough, the onset of active TB may be accompanied by a noticeable change in the person’s cough (more frequent, more bothersome, more productive of mucus, etc). This question may allow us to identify the onset of TB symptoms in persons with chronic coughs.

D2b Cough up blood?

Mark a box and continue to Question D2c.

D2c In the 12 months before [diagnosis date,] did you have night sweats so bad that your clothes were wet?

Mark a box and continue to Question D2d.

D2d Have a fever that lasted more than a few weeks on and off?

Mark a box and continue to Question D2d.

D2e Lose 10 pounds (or about 5 kilograms) or more without dieting?

This question refers to rapid, unintended weight loss. Mark a response and continue to Question D2f.

D2f Have swollen glands (lumps in your neck) that did not get better?

Mark a response and continue to Question D2g.

D2g Have pain in your chest when you coughed or took a deep breath?

Mark a response and follow the skip instructions.

D2h In the 12 months before [diagnosis date], did you have any other symptoms that you think were caused by tuberculosis?

Participants with extrapulmonary tuberculosis may have had a great variety of symptoms that the questionnaire does not mention. This question is intended to capture those symptoms.

If the participant mentions ANY additional symptom mark box #1 and write the symptom(s) in the blank(s) provided. If the participant mentions a symptom that you already asked about, and that the participant denied having, do NOT go back and change the answer. Instead, write the symptom in the blank provided. For example, if the participant says “No” to Question D2a (have a cough that lasted at least 3 weeks?), and then mentions a cough in response to Question D2h, write the word “cough” in the appropriate blank next to box #1. Do not change the original response.

If the participant answers “yes” to more than one of the questions from D2a through D2h, go to D2i to identify which symptom started first. If the participant answers “yes” to only one of the questions, skip to D2i1 to identify when that symptom started.

If the participant does not report any symptoms in the year before diagnosis – that is, the participant answers No, Don’t Know, or Refused to ALL questions

D2a through D2h – then skip D2i, D2i1, and Section E; go to Question F2 in section F, “Health Insurance”. The reason is that section E asks about the different ways the participant sought help for his/her symptoms before diagnosis. If the participant had no symptoms, then these questions are not relevant.

If a person reports that he/she “always coughed,” and answers No, Don’t Know, or Refused to all other questions from D2a through D2g, follow the skip instruction to Question F2.

D2i Which of the symptoms you mentioned started first?

If the participant names one symptom that started first, mark the box that corresponds to the symptom and continue to Question D2i1. If the symptom mentioned is not listed as one of the options for D2i, mark box #97, “Other,” and write the symptom in the blank space next to the box. **Also write this symptom on your dry erase board or pad of paper, because you will need it for Question F1.** If the participant says more than one symptom started first, or all symptoms started around the same time, mark box #7 (all symptoms started at the same time), and continue to Question D2i1. If the participant does not remember which symptom started first or chooses not to respond, mark the appropriate box and follow the skip instruction to Section E, “History of Care Sought for Current Tuberculosis Illness.”

D2i1 When did you first notice this [name of symptom]/ these symptoms?

When you ask this question, insert in the brackets the symptom that started first. If more than one started first, say “When did you first notice these symptoms?”

If the participant provides only the year, probe for the month. If the participant remembers only the year, record the year.

Record this date on your dry erase board or notepad. You will need it for Question F1.

If the participant does not know or does not remember the date when symptom(s) started, or refuses to answer, mark the appropriate box and continue to Section E: History of Care Sought for Current Tuberculosis Illness.

Section E: History of Care Sought for Current Tuberculosis Illness

This section is only for participants who said “yes” to at least one symptom in Questions D2a through D2h. If the person reported no symptoms in the year before diagnosis, skip this section and go to Question F2 in Section F.

This section includes Questions E1 and E2 on a white page and Questionnaires 2 through 5: the green, yellow, orange, and pink questionnaires in the middle of the booklet. The purpose of this section is to track all the places the participant went for help from the time he/she noticed the symptoms reported in D2a through D2h, until either (1) the participant was diagnosed with TB, or (2) the participant stopped seeking help.

Different kinds of care are recorded in different colored questionnaires:

- green for physicians, nurses, and facilities where TB is diagnosed and treated;
- yellow for other health care providers such as pharmacists, chiropractors, and herbalists who are not licensed to diagnose or treat TB;
- orange for friends or family members; and
- pink for self-treatment.

Each of these questionnaires ends by asking the participant where he/she went next for help.

The number of colored questionnaires you fill out and the order in which you complete them are based on the care sought. Fill out a separate colored questionnaire for each time the participant sought care for his/her symptoms. So, for example, a participant may have gone first to an herbalist for a cough remedy, then to a chiropractor, then to an emergency room, and finally to the health department where the diagnosis was made. In that case, you would fill out two yellow questionnaires and two green ones. At the end of the second green questionnaire, you would mark box #17, “This is where the participant was diagnosed with tuberculosis.” In another case, a participant may have tried a home remedy, then gone to an herbalist, then to an emergency room where he left before being seen, and then stopped seeking care. This participant was then identified and diagnosed as part of a contact investigation. In that case, you would fill out a pink questionnaire, then a yellow one, and finally a green one, in that order. At the bottom of the second green questionnaire, you would mark box #16, “Did not do anything else before diagnosis.”

Note that each colored questionnaire has, in the upper right corner, a space to enter the order in which the questionnaire was used and the total number of questionnaires used. As you add each colored questionnaire, number it in this space. For example, the first questionnaire you use will be “Number 1,” the second “Number 2,” and so on. When you have finished the interview, go back to each colored questionnaire you have filled out and fill in the second

blank, which asks for the total number of colored questionnaires used. So, for example, if you used first a pink, then a green, then another green, the pink one would be “Number 1 of 3 colored questionnaires,” the first green one would be “Number 2 of 3 colored questionnaires,” and the second green one would be “Number 3 of 3 colored questionnaires.”

There are three copies of the green questionnaire and one each of the yellow, orange, and pink questionnaires in each questionnaire booklet. It is possible that you may need more, particularly of the green questionnaires. It is a good idea to make extra copies of the colored questionnaires to take with you.

Introduction

Read the **boldface** introduction to the participant.

E1 Before your current diagnosis in [diagnosis date], did you do any of those things I mentioned to get help for any of your symptoms?

When you come to the brackets, say the diagnosis date from Question C1. If the participant did not know the diagnosis date, say, “Before your current diagnosis, did you do any of those things I mentioned to get help for any of your symptoms?”

If the participant says “No”, “Don’t know,” or refuses to answer, mark the appropriate box and follow the skip instruction to Question F1 in Section F, Health Insurance. If the participant says he/she did seek help before the current tuberculosis diagnosis, mark box #1 and continue to Question E2.

E2 What was the first thing you did to get help?

Mark the box that most closely describes the participant’s response. There are 15 boxes; mark only one. Some of the responses refer to **persons** (doctor, pharmacist, friend), and some refer to **places** (hospital, health department, emergency room). That’s because some participants may describe the places they went to, while others might mention the persons they saw. For our purposes, either is acceptable.

If the participant says “a doctor,” or names a particular doctor, we need to make sure that the participant is referring to a licensed M.D. or D.O., and not to a chiropractor or other type of professional. Therefore, before you mark box #1 (“doctor,”), **probe** by asking, “what kind of doctor was this?” If the participant’s response indicates this was a medical doctor – for example, if the participant says medical doctor, family doctor, osteopath, surgeon, my regular doctor, etc. – then mark box #1. If the participant’s response indicates the person was a pharmacist (box #7), traditional healer (#8), herbalist (#10), etc., mark the appropriate box. If the participant says he/she doesn’t know

what kind of doctor the person was, **probe** again by asking, “Was this a medical doctor?” If the participant still doesn’t know, fill out a yellow questionnaire (“Other health care provider.”).

If the participant says a place, like a hospital, mark the appropriate box (#5 for “hospital,” #2 for “emergency room,” etc.,) and ask for the name. Write the name of the facility in the blank. If the participant doesn’t remember the name, write “Don’t know” in the blank.

The skip instructions next to the box you have marked will tell you what colored questionnaire to go to.

- If the participant sought help from a physician, nurse, nurse practitioner, physician’s assistant, hospital, emergency room, clinic, or health department, go next to **Questionnaire 2, printed in green.**
- If the participant went to a pharmacist, healer, acupuncturist, herbalist, or chiropractor, go to **Questionnaire 3, printed in yellow.**
- If the participant mentions a profession that is not listed, write it next to the group of boxes you think it belongs to, and go to the questionnaire for that group. For example, if the participant says he/she went to an astrologer, write that next to the group of boxes that includes “spiritual healer,” and go to **Questionnaire 3, in yellow.**
- If a participant says he/she asked a friend or family member for advice, go to **Questionnaire 4, printed in orange.** If the participant says he/she asked a friend who is a doctor, use the orange questionnaire, because the person was being consulted as a friend. If the participant says he/she prepared a home remedy, go to **Questionnaire 5, printed in pink.**

THE COLORED QUESTIONNAIRES

Questionnaire 2 (green): Physicians and nurses (NP/PA)

Fill out one of these questionnaires each time a participant mentions that he/she went to a physician, a nurse, nurse practitioner, physician's assistant, hospital, emergency room, clinic, or health department.

E2a. When did you go to [person or place]?

Insert in the brackets the person or place the participant went to for help.

If the participant mentions only a year, probe for a month. If only a year is available, write in the year. If the participant mentions only a month, probe for the year, even if you think you are sure you know what year it was. For example, if the participant says, "I went in June," ask, "Was that June 2003 or June 2004?" If you have already completed more than one colored questionnaire for this participant, and it is clear that all these visits occurred in the same year, just name the year as you write it down, so the participant can correct it if it is wrong.

For all responses, including "Don't know," and "refused to answer," continue to Question E2a1.

E2a1. What country were you in?

Write in the blank US, or Canada, or whatever other country the participant mentions and continue to Question E2a2.

Sometimes a participant may telephone a physician in another country. If the participant says he/she did this, mark box #96, "called doctor or nurse in another country", and specify the name of the country on the blank line next to the box. Continue to Question E2a2.

If the participant answers "Don't know" or "Refused to answer", mark the appropriate box and follow the skip instruction to Question E2a3.

E2a2. What city and state/province were you in?

Write the city and state/province in the blank spaces provided and continue to Question E2a3. If the participant says "Don't know" or chooses not to answer either question, mark the appropriate box and continue to Question E2a3.

E2a3. Did you see a doctor or nurse?

We are asking this question because some participants may have gone to a hospital, clinic, doctor's office, etc., and then left before they were seen. By "seen," we mean that some kind of service was rendered: the participant was examined, or had an x-ray, a skin test, or some other kind of service. If the participant says he/she was seen, mark Box #1("Yes") and follow the skip instruction to Question E2a4. If the participant says he/she was not seen, mark Box #2 ("No") and continue to Question E2a3a. If the participant answers "Don't know" or refuses to answer, mark the appropriate box and follow the skip instructions to Question E2a10.

E2a-3a. Why were you not seen for your problem?

This question is only for participants who indicated in E2a3 that they were not seen for their problem. We would like to find out why the participant was not seen. Mark the box next to the explanation that comes closest to the participant's response. For example, if the participant says, "Nobody spoke Spanish and I was very confused," mark the "Language issue" box. If the participant provides more than one answer, use the FIRST answer that the participant provides. If the participant provides a response that does not match boxes 1,2, or 3, mark box #97, "Other," and briefly summarize the participant's response in the space provided.

For all responses, follow the skip instruction to Question E2a-12, which asks where the person sought help next.

E2a4. How did the doctor or nurse communicate with you? Did the doctor or nurse:

The purpose of this question is to identify any language barriers. Read the **boldface** answers out loud until the person selects one. If the person provides a different response, mark Box #97, "Other," and write the person's response in the blank.

For all responses, continue to Question E2a5.

E2a5. Did you get a chest x-ray?

Mark the participant's response, and continue to Question E2a6.

E2a6. Did you get a skin test for tuberculosis [SHOW TST PICTURE]?

To make sure that the participant understands what a skin test is, show the participant the laminated card that shows a skin test being applied. Mark the participant's response, and continue to Question E2a7.

E2a7. Did you get a test where you were you asked to spit or cough into a cup?

Mark the participant's response and continue to Question E2a8.

E2a8. What did the doctor or nurse who saw you say was causing your symptoms?

If the word "tuberculosis" or any local word for tuberculosis is mentioned, mark Box #1 ("any mention of tuberculosis") and follow the skip instruction to Question E2a10. If the participant says anything else, mark Box #97, "Other," and go to Question E2a9. We are not interested in a description of the other causes the doctor or nurse might have mentioned. If the participant says "Don't know" or refuses to answer, mark the appropriate box and continue to question E2a9.

E2a9. Was tuberculosis mentioned?

This question is for participants who did not mention tuberculosis in Question E2a8. We are asking this question because the doctor or nurse might have stressed some other cause for the participant's symptoms, but may also have mentioned tuberculosis, and we want to capture that. Mark the participant's response and continue to question E2a10.

E2a10. Did you get medicine or a prescription to buy medicine?

We are asking this question to get a better understanding of the reasons for delays in diagnosis. If a doctor prescribes medication, this may delay the true diagnosis, because the participant may wait for the medicine to work before seeking care again. If the participant indicates that any kind of medicine was given, prescribed or recommended, mark Box #1, "Yes", and go on to Question E2a10-a. If the participant gives any other response, mark the correct box and follow the skip instruction to E2a11.

E2a10-a. Do you remember what kind of medicine? [Mark all that apply]

For this question, mark as many boxes as necessary to record all the participant's responses. For example, if the participant says, "the doctor prescribed an antibiotic and told me to buy some Robitussin," mark Box #1, "Antibiotic," and Box #2, "Cough medicine," and continue to E2a11. If the participant mentions receiving a certain number of drugs but doesn't know what kind, select "Other," and then write "three medicines" in the blank. If the person remembers the name of one but not the others, indicate the name of the known drug, and then write "three others." If the participant says "No," or "Don't know," mark Box #98 (Don't know), and continue to Question E2a11. If the participant refuses to answer, mark the appropriate box and continue to Question E2a11.

E2a11. Did you spend at least one night in a hospital room?

We are interested in whether the participant was admitted to the hospital. We used this phrasing to try to distinguish between participants who may have been held overnight in the emergency room but not admitted and those who were actually admitted. Do not attempt to explain this distinction to the participant; simply record the participant's response ("Yes", "No", "Don't know," or refused to answer) and continue to Question E2a12.

E2a12. After you went to the [clinic/hospital/doctor], what was the next thing you did to get help for your symptoms?

You will ask this question at the end of each colored questionnaire, and the participant's response will tell you whether to (1) go on to another colored questionnaire or (2) go on to Section F. In the brackets, put the name of the facility or person that the participant has just finished talking about. For example, if the person has just finished answering questions about a visit to an emergency room, you would say, "After you went to the emergency room, what was the next thing you did to get help for your symptoms?"

Note that the responses to this question are exactly the same as the responses to Question E2. Follow the same instructions as in Question E2. Continue to go to new colored questionnaires until the participant tells you either (1) he/she did not do anything else before diagnosis, or (2) this is where the participant was diagnosed with tuberculosis (this second answer is possible only on a green questionnaire).

If the participant tells you that he/she did not seek care anywhere else before diagnosis, then mark Box #16, "Did not do anything else before diagnosis," and follow the skip instruction to Section F, Question F1. The participant might say this for two reasons: (1) the participant stopped seeking care, and was diagnosed as a result of a contact investigation or a visit to a doctor for some other reason. (2) The participant's next source of care was the place where he/she was diagnosed [mentioned in Question C4], so the participant assumes you do not want to hear about that visit. Either reason is acceptable.

If the participant tells you that the visit he/she has just described is the one where he/she was diagnosed with TB, then mark Box #17, "This is where the participant was diagnosed with tuberculosis," and follow the skip instructions to Section F, Question F1.

NOTE: We do not want to count as separate visits the different places a person may have gone for tests after seeing a physician. For example, if a participant went to a physician who ordered an x-ray, and the person had to go to a radiologist for that x-ray, we do not want to count that as a separate visit or fill out another green questionnaire for that.

Questionnaire 3 (yellow) Other health care provider:

Fill out a separate one of these questionnaires for each time a participant mentions that he/she went to a pharmacist, spiritual healer, acupuncturist, herbalist, chiropractor, or any other professional who provides advice but is not licensed to diagnose or treat tuberculosis.

E2b. When did you go to see the [healer, herbalist, etc]?

Insert in the brackets the type of person the participant went to for help.

If the participant mentions only a year, probe for a month. If only a year is available, write in the year. If the participant mentions only a month, probe for the year, even if you think you are sure you know what year it was. For example, if the participant says, "I went in June," ask, "Was that June 2003 or June 2004?" If you have already completed more than one colored questionnaire for this participant, and it is clear that all these visits occurred in the same year, just name the year as you write it down, so the participant can correct it if it is wrong.

For all responses, including "No" and "Don't know," continue to Question E2b1.

E2b1. What country was this in?

Write down US, or Canada, or whatever other country the participant mentions. For all responses, continue to Question E2b2.

E2b2. What did [healer, herbalist, etc.] say was causing your symptoms? [Specify]

Briefly summarize here whatever the participant says, or mark "Don't know" or "refused to answer." For example, the participant might say, "the pharmacist said she couldn't diagnose my symptoms, and suggested I see a doctor," and you would write "pharmacist said she didn't know" in the blank spaces. Do not include the information about seeing a doctor; that should go in Question E2b4. After you have marked a response, continue to Question E2b3.

E2b3. Was tuberculosis mentioned?

Mark the participant's response and continue to Question E2b4.

E2b4. What did the [healer, herbalist, etc.] recommend?

Mark the appropriate box. For example, in response to Question E2b2, the participant might say, "The pharmacist told me she couldn't diagnose my symptoms, and suggested I see a doctor." The suggestion to see a doctor should be noted by marking Box #3, "Go to a physician." It is important to mark it in this space and not in the space for Question E2b2 so we can analyze it with all the other responses to this question. It is okay to ask the participant this question even if the participant appears to have already answered it in Question E2b2. If the participant appears impatient and points out that he/she has already answered the question, you can respond:

"The language of the questionnaire has been standardized so everyone gets asked the same questions in the same way. That means I will follow the same order of questions even if this means asking you about something you have already mentioned. This is so we make sure we ask everybody the same questions."

If the participant says the person recommended any kind of medicine, mark Box #1 ("medicine") and write the particular kind of medicine (cough medicine, aspirin, Robitussin, etc.) in the blank space. If the participant mentions something that is not included in Boxes 1, 2, or 3, mark Box #97 ("Other") and briefly summarize the recommendation, then go on to Question E2b5. If the participant doesn't remember or refuses to answer, mark the appropriate box and go on to Question E2b5.

E2b5. After you went to the [herbalist, healer, etc.] what was the next thing you did to get help for your symptoms?

This is the question that you will ask at the end of each of the colored questionnaires, and the participant's response will tell you whether to (1) go on to another colored questionnaire or (2) go on to Section F. In the brackets, put the kind of professional that the participant has just finished talking about. For example, if the person has just finished talking about a visit to a pharmacist, you would say, "After you went to the pharmacist, what was the next thing you did to get help for your symptoms?"

Notice that the responses to this question are exactly the same as the responses to Question E2. Follow the same instructions as in Question E2. Continue to go on to new colored questionnaires until the participant tells you either (1) he/she did not do anything else before diagnosis, or (2) this is where the participant was diagnosed with tuberculosis (this second answer is possible only on a green questionnaire).

If the participant tells you that he/she did not seek care anywhere else before diagnosis, then mark Box #16, "Did not do anything else before diagnosis," and follow the skip instructions to Section F, Question F1. The participant might say this for two reasons: (1) the participant stopped seeking care, and was diagnosed as a result of a contact investigation or a visit to a doctor for some other reason. (2) The participant's next source of care was the place where he/she was diagnosed [mentioned in Question C4], so the participant assumes you do not want to hear about that visit. Either reason is acceptable.

Questionnaire 4 (orange): Friend, family member, or clergy

Fill out a separate one of these questionnaires for each time a participant mentions that he/she went to a friend or family member for help. If a participant mentions that he/she went to a friend who is a doctor/nurse/pharmacist/etc, fill out an orange questionnaire.

E2c. When did you talk to your [friend/family member/clergy]?

Insert in the brackets the kind of person the participant went to for help.

If the participant mentions only a year, probe for a month. If only a year is available, write in the year. If the participant mentions only a month, probe for the year, even if you think you are sure you know what year it was. For example, if the participant says, "I went in June," ask, "Was that June 2003 or June 2004?" If you have already completed more than one colored questionnaire for this participant, and it is clear that all these events occurred in the same year, just name the year as you write it down, so the participant can correct it if it is wrong.

For all responses, including "No" and "Don't know," continue to E2c1.

E2c1. What country was this in?

Write down US, or Canada, or whatever other country the participant mentions. For all responses, continue to Question E2c2.

E2c2. What did he/she say was causing your symptoms? [Specify]

Briefly summarize here whatever the participant says, or mark "Don't know" or "refused to answer." After you have marked a response, continue to Question E2c3.

E2c3. Did he/she mention tuberculosis?

Note the participant's response and continue to Question E2c4.

E2c4. After you talked to your [friend/family member/clergy], what was the next thing you did to get help for your symptoms?

This is the question that you will ask at the end of each of the colored questionnaires, and the participant's response will tell you whether to (1) go on to another colored questionnaire or (2) go on to Section F.

Note that the responses to this question are exactly the same as the responses to Question E2. Follow the same instructions as in Question E2. Continue to go to new colored questionnaires until the participant tells you either (1) he/she did not do anything else before diagnosis, or (2) this is where the participant was diagnosed with tuberculosis (this second answer is possible only on a green questionnaire).

If the participant tells you that he/she did not seek care anywhere else before diagnosis, then mark Box #16, "Did not do anything else before diagnosis," and follow the skip instructions to Section F, Question F1. The participant might say this for two reasons: (1) the participant stopped seeking care, and was diagnosed as a result of a contact investigation or a visit to a doctor for some other reason. (2) The participant's next source of care was the place where he/she was diagnosed [mentioned in Question C4], so the participant assumes you do not want to hear about that visit. Either reason is acceptable.

Questionnaire 5 (pink): Treated self

Fill out a separate one of these questionnaires for each time a participant treated himself/herself. For example, you would use this questionnaire if a participant said he/she went to the store and bought a health tonic.

E2d. What did you use/do to help your symptoms? [Specify].

Briefly summarize whatever the participant says he/she did, or mark “Don’t know” or “refused to answer.” For all responses, continue to Question E2d-1.

E2d1. When did you first use [insert item from E2d] for your symptoms?

Insert in the brackets whatever the person mentioned in question E2d – for example, “When did you first use the health tonic?”.

If the participant mentions only a year, probe for a month. If only a year is available, write in the year. If the participant mentions only a month, probe for the year, even if you think you are sure you know what year it was. For example, if the participant says, “I went in June,” ask, “Was that June 2003 or June 2004?” If you have already completed more than one colored questionnaire for this participant, and it is clear that all these events occurred in the same year, just name the year as you write it down, so the participant can correct it if it is wrong.

For all responses, including “No” and “Don’t know,” continue to Question E2d2.

E2d2. What country were you living in at the time?

Write down US, or Canada, or whatever other country the participant mentions. For all responses, continue to Question E2d3.

E2d3. After you used [insert item from E2d], what was the next thing you did to get help for your symptoms?

This is the question that you will ask at the end of each of the colored questionnaires, and the participant's response will tell you whether to (1) go on to another colored questionnaire or (2) go on to Section F.

Note that the responses to this question are exactly the same as the responses to Question E2. Follow the same instructions as in Question E2. Continue to go to new colored questionnaires until the participant tells you either (1) he/she did not do anything else before diagnosis, or (2) this is where the participant was diagnosed with tuberculosis (this second answer is possible only on a green questionnaire).

If the participant tells you that he/she did not seek care anywhere else before diagnosis, then mark Box #16, "Did not do anything else before diagnosis," and follow the skip instructions to Section F, Question F1. The participant might say this for two reasons: (1) the participant stopped seeking care, and was diagnosed as a result of a contact investigation or a visit to a doctor for some other reason. (2) The participant's next source of care was the place where he/she was diagnosed [mentioned in Question C4], so the participant assumes you do not want to hear about that visit. Either reason is acceptable.

Section F: Health Insurance

The questions in this section are designed to determine whether the participant had health insurance either (1) at the time of symptom onset, or (2) at the time the participant was diagnosed with tuberculosis. Follow the skip instructions carefully. **Note that Question F1 should be asked ONLY of persons who reported any symptoms in Question D2.** If a person did not have symptoms, you cannot ask if he/she had health insurance when symptoms began. Instead, for persons who reported no symptoms, use Question F2, which asks if the person had health insurance when he/she was diagnosed.

F1. *I would like you to think about the time when you began to have [name symptoms]. That was [date]. Were you living in the U.S./Canada at that time?*

Insert in the brackets the symptoms mentioned in Question D2i and the symptom onset date mentioned in D2i1. We are interested in where the participant was living during the period of time when he/she began having the symptoms mentioned.

If the participant did not provide the date when he/she began to have symptoms, pose the question as, 'I would like you to think about the time when you began to have symptoms. Were you living in the U.S./Canada at that time?'

If the participant did live in the US or Canada at that time, mark box #1 ("Yes") and **continue to Question F1a**. If the participant did not live in the US or Canada at the time, mark Box #2 ("No") and follow the skip instruction to **Question F1b**. For all other responses ("Don't know," refused to answer), mark the appropriate box and **follow the skip instruction to Question F3**.

F1a. *At that time, did you have health insurance?*

If the participant did have health insurance, mark Box #1 ("Yes") and follow the skip instruction to Question F1c. If the participant did not have health insurance, or if the participant does not know or refuses to answer, mark the appropriate box and follow the skip instruction to Question F3.

F1b. *When you arrived in this country, did you have health insurance?*

This question is ONLY for participants who were not living in the US or Canada at the time when their symptoms began (participants who answered "no" to Question F1). If the participant answers "yes," mark Box #1 and go to Question F1c. For any other answer, mark the appropriate box and follow the skip instruction to Question F3.

F1c. What kind of health insurance did you have at that time? [Mark all that apply]

We are interested in the kind of health insurance the participant had when his/her symptoms began. Note that a person can have more than one kind of health insurance. Please mark all types of health insurance that the participant reports. If the participant mentions private health insurance, mark box #1, ask for the name of the health insurance plan, and write it in the space next to Box #1. For all answers, mark the appropriate box(es) and **follow the skip instruction to Question F3.**

F2. I would like you to think about the time when you were told you had tuberculosis, on [diagnosis date]. Did you have health insurance when you were told you had tuberculosis?

This question is ONLY for persons who did not mention any symptoms in Question D2, and thus skipped Section E. Because they had no symptoms, we cannot ask them if they had health insurance when their symptoms started. Instead, we will ask them whether they had health insurance when they were diagnosed with tuberculosis.

Insert in the brackets the diagnosis date the participant provided in Question C1. If the participant did not remember his/her diagnosis date, then just say, "I would like you to think about the time when you were told you had tuberculosis." If the participant did have health insurance, mark Box #1 and **proceed to Question F2a.** For all other responses, mark the appropriate box and **follow the skip instruction to Question F3.**

F2a. What kind of health insurance did you have? [Mark all that apply]

For the participants who had health insurance when they were diagnosed with tuberculosis, we are interested in knowing the types of health insurance they had at that time. Please mark all types of health insurance mentioned. If the participant mentions private health insurance, mark box #1, ask for the name of the health insurance plan, and write it in the space next to box #1. After marking the appropriate boxes and continue to Question F3.

F3. When you need to see a doctor, where do you usually go?

All participants are asked Question F3. We are interested in knowing where the participant is most likely to go when he/she needs to see a doctor. If a participant has only recently arrived in this country and says he/she has not had the chance to go to a doctor yet, mark Box #97 (Other), and write a brief explanation on the blank line. Also use Box #97 for other responses that do not fit the other boxes, and briefly summarize what the participant says.

For all responses, go on to Section G, "Immigration History".

Section G: Immigration History

Section G has five parts. The first two ask about the participant's immigration status when he/she first came to this country, and the participant's current immigration status. The third and fourth parts ask about travel history in this country and elsewhere. The last part asks about any medical tests the person may have had to obtain a visa or to change his/her visa status.

The questions about immigration and visa status in particular may be sensitive. If the participant hesitates or is reluctant to answer questions, remind him/her that all responses are confidential and will not be shared with anyone outside the study. But if the person still is reluctant, then mark the question as "Refused to answer" and move on. Please remain pleasant and cordial if the person refuses to answer; a refusal is a perfectly acceptable response.

Part I: Immigration Status at First Entry to the United States or Canada

G1. What country did you live in right before you came to the United States/Canada for the FIRST TIME?

This is the last country the participant lived in before coming to the US/Canada for the first time. This is the country the participant actually lived in, not the country he/she visited last before coming to the US/Canada. Write the name of the country in the blank, or mark "Don't know" or "Refused to answer" and continue to Question G2.

G2. When did you come to the United States/Canada for the FIRST TIME?

This question refers to the very first time the participant came to this country, regardless of whether the participant came here as a tourist, student, etc., and regardless of how long or short the visit. Record this information using the month and year format - mm/yyyy. If the participant provides only a year, probe for the month; if only the month, probe for the year. Do not record only a month. If the participant remembers only a month and not a year, even after probing, mark the "Don't know" box.

G3. How old were you when you FIRST came to the United States/Canada?

This refers to the person's age on the date mentioned in Question G2. Please record this as reported by the participant regardless of whether the age provided seems incorrect in relation to the age reported in Question A4. If the person was an infant (less than a year old), mark Box #1 and go to Question G4. If the person was a year old or older, mark the "Years" box (response option 2) and record the age in years in the blank next to this box. For all responses, go on to Question G4.

G4. When you first came to the U.S./Canada, did you have a visa or other entry papers?

This refers to the time in G2 when the person first entered the US/Canada. If the person says he/she had entry papers, mark box #1 (“Yes”) and go to Question G4a.

If the participant says no, mark box #2 and follow the skip instruction to Question G5 in Part II, Immigration Status Today. Do NOT ask Question G4a, because the participant has already said he/she did not have a visa, so it is not logical to ask what kind of visa he/she had.

If the participant appears confused or does not understand the question, repeat the question. If the participant still does not understand, mark the “Don’t know” box and follow the skip instructions to Question G5.

If the participant refuses to answer, mark the “Refused to answer” box and follow the skip instructions to Question G5.

G4.a. What kind of visa or other papers did you have?

There are two columns of responses for this question. The left column is for participants residing in the U.S., and the right column is for participants residing in Canada. **Place a response in only one column.**

Please mark only one box. We have tried to be comprehensive in listing all possible visas and responses, but if a participant mentions something that is not listed, mark Box #97 (“Other,”) and write the participant’s response in the space provided.

If you are curious or confused about the different visa types, we have a document, “Explanation of U.S. Visa Types,” in the eRoom (the file pathway is Task Order #9: Materials for full rollout of study/Questionnaire manuals) that describes and explains each type of U.S. visa. We do not have a similar document for Canadian sites, but the Canadian visa system seems to be simpler and easier to understand.

Possible answers for U.S. residents:

Green card. If, in response to your question, the participant says “I had a green card,” **probe** for the participant’s actual visa status: “Thank you. Were you a refugee, an immigrant, or an asylee?” and mark Box #1 (refugee), #2 (immigrant) or #3 (asylee), depending on the response (note that we are asking the person to pick one of the three). If the participant who had a green card does not know or remember the specific status, or repeats “green card,” mark Box #97 (“Other,”) and write “green card” in the blank space provided. Go to Question G4.b.

Permanent resident. Although “permanent resident” is often used as a synonym for immigrant, If the participant responds that he/she entered this country as a “permanent resident,” probe for the type. Say, “Thank you. Do you remember whether you came as a refugee, an immigrant, an asylee, or some other visa type?” If the participant does not know, or repeats “permanent resident,” mark Box #2, “Immigrant/permanent resident,” and Go to Question G4.b.

Citizen. If the participant says he/she first entered this country as a US or Canadian citizen, mark Box #4 and follow the skip instruction to Part III, “Travel/residence outside the US/Canada”.

Visas A-V. Some participants might be very knowledgeable about visas and might give you the formal letter designation – “visa type F,” for example. We have provided the letter designations in parentheses next to the informal name. If a participant mentions a letter designation, speak the name of the visa to confirm it before you mark the box. For example, if a participant says “Type F,” you should say, “That would be a student visa?” before marking Box #6. Go to Question G4.b.

Visitor. If the participant says he/she had a visitor’s visa, ask if it was a visa for business (visa type B2, Box #11) or pleasure (visa type B1, Box #10). If the participant doesn’t know, mark Box #15 (Temporary resident/visitor but specific visa type unknown) and go to Question G4.b.

Other. If the participant mentions something that is not listed, Mark Box #97 (“Other”) and write the response in the blank provided. Go to Question G4.b.

Don't know. If the participant says he/she does not know or does not remember, **probe** for a response by describing the types of visas. For example, you could say, "Let me read you the different kinds of entry papers people might get. Some people enter with green cards if they are immigrants, refugees or asylees. Temporary visitors have visas for business, work, pleasure, or school. Did you have any papers like these?" If the participant still does not remember, mark Box #98 (Don't know), and go to Question G4.b.

Employment authorization card. This is a temporary work permit that a person receives from immigration after he/she has been approved for a green card, but before the card is actually issued (which can take up to a year). Some participants refer to it as a "work permit." If the participant mentions this, mark Box #97 ("Other,") and write the response in the blank provided. NOTE: This card also contains the participant's alien registration number. If the participant shows you the card, copy the alien registration number onto the face sheet in the spot provided and go to Question G4.b.

For all responses except "US/Canadian citizen" (#4), go to Question G4.b. after you mark a response. For US/Canadian citizen,, follow the skip instruction to Part III.

Possible answers for Canadian residents:

Permanent resident. Canada has several classes of permanent resident. If the participant says only that he/she came as a permanent resident, probe for the type (landed immigrant, refugee, etc.) and mark the appropriate box.

Citizen. If the participant says he/she first entered this country as a US or Canadian citizen, mark Box #4 and follow the skip instruction to Part III, "Travel/residence outside the US/Canada".

Visitor. If the participant says he/she came as a temporary resident or visitor, probe for the specific type (work, student, etc.) If the participant does not remember, mark Box #15 (Temporary resident/visitor but specific visa type unknown).

Other. If the participant mentions something that is not listed, Mark Box #97 ("Other") and write the response in the blank provided.

Don't know. If the participant says he/she does not know or does not remember, probe for a response by reading off the types of visas. For example, you could say, "Let me read you the different kinds of entry papers people might get. Some people who plan to stay here enter as refugees or immigrants. Visitors might get visas for work, study, or pleasure. Did you have any papers like these?" If the participant still does not remember, mark Box #98 (Don't know), and go to Question G4.b.

For all responses except "US/Canadian citizen" (Box #4) go to Question G4.b. after you mark a response. For US/Canadian citizen, follow the skip instruction to Part III.

G4.b. Did you use a different name when you first entered this country?

Some people change names after they enter this country, either because of marriage or for other reasons. We would like to know the participant's name when he/she entered this country, if it is different from the participant's current name.

If the participant says no, or doesn't remember, or refuses to answer the question, mark the appropriate box and follow the skip instruction to Question G5.

If the participant says yes, mark Box #1 and ask Question G4.c.

G4.c. Do you remember what that name was?

If the participant provides a name, mark Box #1 ("Yes"), but DO NOT RECORD the name here; record this name on the Face Sheet ONLY. This is in order to maintain confidentiality throughout the study. If the participant says "No," "Don't know," or refuses to answer, mark the appropriate box and continue on to "Part II: Immigration Status Today."

PART II: Immigration Status Today

The questions in Part II refer to the participant's immigration status **TODAY - the day of the interview.**

G5. *What is your status TODAY?*

NOTE: For all responses **except refugee, immigrant, and asylee**, mark the appropriate response and skip to Part III, "Travel /Residence Outside the US/Canada." If the participant responds "refugee," "immigrant/permanent resident," or "asylee," mark the appropriate response and follow the skip instruction to Question G6. If the participant says only that he/she has a "green card," go to Question G6 after marking Box #97 (Other) and writing "green card" in the blank.

There are two columns of responses for this question. The left column is for participants residing in the U.S., and the right column is for participants residing in Canada. **Place a response in only one column.**

Please mark only one box. We have tried to be comprehensive in listing all possible visas and responses, but if a participant mentions something that is not listed, mark Box #97 ("Other,") and write in the participant's response in the space provided.

If you are curious or confused about the different visa types, we have attached a document, "Explanation of U.S. Visa Types," that describes and explains each type of U.S. visa. We do not have a similar document for Canadian sites, but the Canadian visa system seems to be simpler and easier to understand.

Possible answers for U.S. residents:

Green card. If, in response to your question, the participant says "I have a green card" say, "Thank you. Are you a refugee, an immigrant, or an asylee?" and mark Box #1 (refugee), #2 (immigrant) or #3 (asylee), depending on the response. If the participant who has a green card does not know or remember the specific status, mark Box #97 ("Other,") and write "green card" in the blank space provided. Go to Question G6.

Permanent resident. Although "permanent resident" is often used as a synonym for immigrant, If the participant responds that he/she is now a "permanent resident," probe for the type. Say, "Thank you. Do you know if you are a refugee, an immigrant, an asylee, or some other visa type?" If the participant does not know, or repeats "permanent resident," mark Box #2, "Immigrant/permanent resident," and Go to Question G6.

Changing status. If the participant responds that he/she has applied to change status, say, “Thank you. For our study, we would like to know the kind of visa you have today.” We are not interested in the type of visa the participant has applied for; only what he/she has today.

Citizen. If the participant says he/she is a US or Canadian citizen, mark Box #4 and go to Part III, “Travel/Residence outside the US/Canada”.

Visas A-V. Some participants might be very knowledgeable about visas and might give you the formal letter designation – “visa type F,” for example. We have provided the letter designations in parentheses next to the informal name. If a participant mentions a letter designation, speak the name of the visa to confirm it before you mark the box. For example, if a participant says “Type F,” you should say, “That would be a student visa?” before marking Box #6. Go to Part III, “Travel/Residence outside the US/Canada”.

Visitor. If the participant says he/she has a visitor’s visa, ask if it is a visa for business (visa type B2, Box #11) or pleasure (visa type B1, Box #10). If the participant doesn’t know, mark Box #15 (Temporary resident/visitor but specific visa type unknown). Go to Part III, “Travel/Residence outside the US/Canada”.

None required. It is possible that some participants came for a visit from countries for which the US does not require a visa. If the participant says he/she does not have a visa because none is required, mark Box #16 (no visa required). Go to Part III, “Travel/Residence outside the US/Canada”.

Mark the option, “No visa required” only if this is what the participant says. Do not select this option if the participant mentions a visa that is not listed, does not know or does not remember.

Undocumented. Note the difference between “no visa required” and “undocumented.” The first describes persons who are here legally. The second describes persons who should have visas or other entry papers, but do not. Go to Part III, “Travel/Residence outside the US/Canada”.

Visa expired. Some participants may have entered this country on temporary visas and remained here after their visas expired. If the participant tells you that, mark Box #18, “Visa expired.” Go to Part III, “Travel/Residence outside the US/Canada”.

Other. If the participant mentions something that is not listed, Mark Box #19 (“Other”) and write the response in the blank provided. Go to Part III, “Travel/Residence outside the US/Canada”, on Page 20.

Don't know. If the participant says he/she does not know or does not remember, probe for a response by reading off some of the types of visas. For example, you could say, "Let me read you some of the different kinds of entry papers people might get. Some people enter with green cards if they are immigrants, refugees or asylees. Temporary visitors have visas for business, work, pleasure, or school. Did you have any papers like these?" If the participant still does not remember, mark Box #98 (Don't know). Go to Part III: Travel/Residence outside the US/Canada.

Employment authorization card. This is a temporary work permit that a person receives from immigration after he/she has been approved for a green card, but before the card is actually issued (which can take up to a year). Some participants refer to it as a "work permit." If the participant mentions this, mark Box #18 ("Other,") and write the response in the blank provided. NOTE: This card also contains the participant's alien registration number. If the participant shows you the card, copy the alien registration number onto the face sheet in the spot provided and go to Part III, "Travel/Residence Outside the US/Canada".

Matricula consular. Mexican consulates sometimes issue these documents to persons who use them to get drivers licenses, etc. These are not true visas, but we provide a box for them (Box #19) in case some participants mention them. Go to Part III, "Travel/Residence outside the US/Canada".

For all responses except refugee, immigrant/permanent resident or asylee, follow the skip instruction to Part III, "Travel/Residence outside the US/Canada. For refugee, immigrant/permanent resident, or asylee, go to Question G6. If the participant says only that he/she has a "green card," go to Question G6 after marking Box #97 (Other) and writing "green card" in the blank.

Possible answers for Canadian residents:

Permanent resident. Canada has several classes of permanent resident. If the participant says only that he/she is a permanent resident, probe for the type (landed immigrant, refugee, etc.) and mark the appropriate box. Go to Question G6.

Changing status. If the participant responds that he/she has applied to change status, say, "Thank you. For our study, we would like to know the kind of visa you have today." We are not interested in the type of visa the participant has applied for; only what he/she has today.

Citizen. If the participant says he/she is a Canadian or US citizen, mark Box #4. Go to Part III, "Travel/Residence outside the US/Canada".

Visitor. If the participant says he/she is a temporary resident or visitor, probe for the specific type (work, student). If the participant does not remember, mark Box #15 (Temporary resident/visitor but specific visa type unknown). Go to Part III, "Travel/Residence outside the US/Canada".

None required. It is possible that some participants came for a visit from countries for which Canada does not require a visa. If the participant says he/she did not have a visa because none was required, mark Box #17 (no visa required). Go to Part III, "Travel/Residence outside the US/Canada".

Mark the option, "No visa required" only if this is what the participant says. Do not select this option if the participant mentions a visa that is not listed, does not know or does not remember.

Undocumented. Note the difference between "no visa required" and "undocumented." The first describes persons who are here legally. The second describes persons who should have visas or other entry papers, but do not. Go to Part III, "Travel/Residence outside the US/Canada".

Visa expired. Some participants may have entered this country on temporary visas and remained here after their visas expired. If the participant tells you that mark Box #19, "Visa expired." Go to Part III, "Travel/Residence outside the US/Canada".

Other. If the participant mentions something that is not listed, Mark Box #97 ("Other") and write the response in the blank provided. Go to Part III, "Travel/Residence outside the US/Canada".

Don't know. If the participant says he/she doesn't know or doesn't remember, probe for a response by reading off some of the types of visas. For example, you could say, "Let me read you some of the different kinds of entry papers people might get. Some people who plan to stay here enter as refugees or landed immigrants. Visitors might get visas for work, study, or pleasure. Did you have any papers like these?" If the participant still does not remember, mark Box #98 (Don't know). Go to Part III, "Travel/Residence outside the US/Canada".

For all responses except refugee, landed immigrant/permanent resident or asylee, skip to Part III, "Travel/Residence outside the US/Canada. For refugee, landed immigrant, permanent resident, or refugee, follow the skip instruction to Question G6.

G6. *May I see your green card or another document with the number on it so I can copy down the alien registration number/immigration medical services number?*

This question is asked ONLY of those who have permanent residency status (refugee, immigrant, asylee) in the U.S. or Canada.

In the US, the alien registration number is an 8 or 9 digit number preceded by the letter "A" (that's why it is often called the "A-number"), which can be found on a participant's green card or employment authorization card (note: green cards are no longer green).

If the participant asks why we need to have this information, repeat that having the number will help us get information about the medical exam the participant had when he/she applied for permanent residency. If the participant is reluctant to give it, or seems troubled, say that we can skip the question if he/she prefers.

If the participant provides this number, DO NOT record the number on the page. Mark box #1, ("number recorded on face sheet") and record the number in the appropriate spot on the face sheet. Go to Question G7.

If the participant does not have the number or does not want to provide the number, mark box #99 ("refused") and go to Question G7.

PART III: Travel/Residence Outside the U.S./Canada

- G7. *Starting with your country of birth, I would like you to tell me all the countries you lived in for three months or longer.*

The first country recorded should be where the participant was born even if this is not the participant's country of citizenship. Write the name of the birth country on the blank line under "Let's start with your country of birth," and ask how long the participant lived there. Record the answer in the "years" or "months" blanks. Do not use both the "years" and "months" blanks. For example, if a participant says he/she lived in the birth country for two years and six months, round up to 3 years and enter a "3" in the "years" blank only. Use the "months" blank only if the participant says he/she lived there for 11 months or less.

After you ask about the birth country, ask the participant where he/she lived next, and write the name of that country on the blank line under the first "Where did you live next?". Ask the participant how long he/she lived there, and record the information in the appropriate blank.

Continue asking the participant where he/she lived next until you arrive at the participant's current country of residence, which should be the US/Canada. Ask the participant how long he/she has lived in the US/Canada, and record the information. Record this information even if the participant has been in the US/Canada for less than 3 months.

If the participant does not remember each country, record the countries that the participant does remember. If the participant does not remember how long he/she lived in a country, ask if it was for at least three months. If the participant says no, do not record that country. If the participant says yes but does not remember exactly how long, enter the name of the country on the appropriate line, mark the "Don't know" box for the length of time, and ask about the next country. When you arrive at the current country (US/Canada), record the amount of time lived here and go to Question G8.

Use the "Don't know" or "Refused to answer" boxes that are located just outside and below the chart only if the participant does not remember **any** countries he/she lived in other than the country of birth. For example, if a participant says he/she lived in four countries besides the country of birth, but remembers only three of them, record the three countries; do NOT check the "Don't know" or "Refused to answer" boxes.

G8. Have you ever lived in a refugee camp?

We are interested in knowing if the participant has ever lived in any refugee camp at any time in his/her life. If the participant has lived in a refugee camp, mark Box #1 and go to Question G8a. If the participant has never lived in a refugee camp, or if he/she doesn't know or refuses to answer, mark the appropriate box and follow the skip instruction to Question G9. Do not attempt to define the term if a participant does not understand.

G8a. Where was the camp located?

Record in the blanks the region or province, and country where the refugee camp was located. First ask the participant for the region or province and then ask for the country. The region may not necessarily be an urban area, it may be a rural area such as a village or small town. If the participant has lived in several refugee camps, we are interested in the last one he/she lived in. If the participant does not remember the location, or chooses not to answer, mark the appropriate boxes for both region and country. For all responses, continue to Question G8b.

G8b. How long did you live there?

If the participant lived there less than a year, mark Box #1. If the participant lived there for a year or more, mark Box #2 and record the number of years in the blank to the right of Box #2. Regardless of the participant's answer, go to Question G9.

G9. In the last two years, have you traveled from the United States/Canada to other countries?

If the participant says he/she has lived in the US/Canada for less than two years, ask, "Have you traveled to other countries since you arrived in this country?" If the answer is yes, mark Box #1 and go to Question G9a. If the participant has not traveled, does not know or does not remember, or chooses not to answer, mark the appropriate box and follow the skip instruction to Part IV: Migration within US/Canada.

G9a. Please tell me which countries you visited and how many times you went there.

For each country named, ask the participant how many times he/she visited there either in the last two years or (for persons who have been in the U.S./Canada less than two years) since coming to the US/Canada. If the participant does not know the number of times he/she has visited, ask for the participant's best estimate. Then ask the participant the length of the most recent visit to this country. If the participant does not know or does not remember the length of the visit, or refuses to answer, mark the appropriate box and ask about the next country.

Use the "Don't know" or "Refused to answer" boxes that are located just outside and below the chart only if the participant does not remember **any** countries he/she visited. If a participant visited many countries but remembers only some of them, record the countries the participant remembers.

If the participant has visited more than four countries in the past two years, ask about the four most recently visited.

Go to Part IV, "Migration within the US/Canada".

PART IV: Migration within the U.S./Canada

Part IV refers to all places the participant has lived while in the US/Canada. If the participant had previously traveled in and out of the US/Canada, we are referring to the most recent stay in the US/Canada, which is this visit/stay. If the participant's answers to B2b or B3b indicate that he/she is a migrant worker (a seasonal worker in agriculture, fishing, canning, etc.), skip this section and follow the skip instruction to Part V: "Tuberculosis Screening Related to Immigration/Visa Process".

G10. What city are you living in now?

Question G10 asks where the participant is living now. This may seem obvious, because the interviewer knows where the interview is taking place. But in some cases, the interview may take place in a big city clinic, while the participant may live 20 miles away in another city.

If the participant provides this information, write it in the blank and also write in the second blank the name of the state/province where the city is located. If you don't know, ask. Continue to Question G10a. If the participant does not know what city he/she is living in now, or refuses to answer, mark the appropriate answer and follow the skip instruction to Question G12.

G10a. Have you always lived in this city since you came to the US/Canada?

If the participant answers "yes," mark Box #1 and follow the skip instruction to Question G14. For all other answers, mark the appropriate response and continue to Question G11.

G11. When did you come to [name of the city in G10]?

When asking this question, insert the name of the city you wrote in the blank in Question G10. for example, if the participant said he/she currently lives in Newark, say, "When did you come to Newark?" Record this date using the month and year format (mm/yyyy). If the participant provides only a year, prompt for the month. If the participant doesn't remember the month, record the year and continue to Question G12. If the participant remembers only a month, mark the "Don't know" box and continue to Question G12.

G12. What was the first city you lived in when you came to the U.S./Canada?

This is the city where the person actually lived, not the port of entry. Write the participant's answer in the blank if it is **different** from the city named in Question G10, and write the name of the state/province on the second blank line. If you don't know the state/province, ask. Continue to Question G12.a.

If the participant does not know or does not remember what city he/she first lived in, mark the appropriate box and follow the skip instruction to Question G14.

G12.a. How long did you live there?

If the participant lived in this city for more than one year, mark the "Years" box (response option 3) and record the number of years in the space provided. Please round to the nearest whole year. For example, if the participant lived in the city less than 18 months, mark the "six months to one year" box. If the participant lived in the city for 18-24 months, mark the "Years" box and enter the number 2 in the blank. And so on. After recording the response, continue to Question G13.

G13. What was the main reason you moved from [name of the city in G12]?

Mark only one response. If the participant mentions two reasons, ask, "Which of those is the **main** reason?" Select the response that is closest to what the participant says. If the reason the participant mentions is not one of the responses listed, mark box #97, "Other", and then specify the participant's reason in the blank provided. Continue to Question G14.

G14. How many different addresses have you had since you have been in the U.S./Canada?

This question is a measure of the participant's mobility. We are interested in the number of times the participant has moved, including moves within the same city. Enter the number of addresses in the blank. So, for example, if the participant has lived in Seattle since his/her arrival in the U.S., and has lived in six different places in Seattle, enter the number 6 in the blank.

If the participant says he/she is homeless, ask, "How many addresses have you had where people can find you?" If the participant provides a number, record it in the blank and do NOT mark box #2, "Participant is homeless". Mark the "homeless" box only if the participant says he/she has had no addresses where people could find him/her, or if the participant repeats that he/she is homeless. Continue to Part V: Tuberculosis Screening Related to Immigration/Visa Process.

PART V: Tuberculosis Screening Related to Immigration/Visa Process

The questions in Part V all refer to any type of medical exam or health screening the participant may have had to change his/her immigration status. The change in immigration status may be (1) in order to enter the US/Canada or (2) to change visa status once in the US/Canada. The first set of questions asks about exams done before arrival in the US/Canada, and the second set asks about exams done while resident in the US/Canada. Please ask these questions of everyone, including the undocumented, because it is possible that a person who is undocumented had one of these exams and, for whatever reason, did not follow through.

G15. Did you ever have a medical test outside the United States/Canada to get a visa to enter the United States/Canada?

If the participant says yes, mark Box #1 and continue to Question G15a; otherwise mark the appropriate box and follow the skip instruction to Question G17.

G15a. In what country did you get the medical test?

If the participant provides the name of the country, write it in the blank; otherwise mark the "Don't know" or "Refused to answer" box and continue to Question G15b.

G15b. When did you get the medical test?

If the participant reports more than one time, ask for the date of the most recent test. If the participant provides only a year, probe for the month; if only a month, probe for the year. If the participant does not remember the month, record the year. Do not record only a month. Mark the appropriate response and continue to Question G15c.

G15c. Did you get a chest x-ray?

We are interested only in a chest x-ray associated with the exam for a visa. Mark the appropriate response and continue to Question G15d.

G15d. Did you have a test where you were asked to cough or spit into a cup?

If the participant does not understand the question, repeat it. Please do not provide any additional explanation. Mark the appropriate response and continue to Question G16.

G16. After the medical test, were you told or given a letter or note recommending that you go to the health department or health clinic when you arrived in the city you were going to live in?

If the participant says yes, mark Box #1 and continue to Question G16a; otherwise mark the appropriate box and follow the skip instruction to Question G17.

G16a. Did you visit the health department/clinic?

We want to know if the participant visited the health department/clinic when he/she arrived in the place he/she planned to live. If the answer is yes, mark Box #1 and follow the skip instruction to Question G16b. If the answer is no, mark Box #2 and continue to Question G16a.1. If the participant does not remember or refuses to answer, mark the appropriate box and follow the skip instruction to Question G17.

G16a.1. What was the main reason you did not go to the health department/clinic?

Mark the box that best matches the participant's response. Do not read the list to the participant. Mark only one response. If the participant provides more than one reason, ask, "Which of the reasons you mentioned is the main reason you did not go to the health department/clinic?" If the participant's response does not match any of the listed response options, select Box #97, "Other," and record the participant's response as close to his/her own words as possible. After marking the appropriate box, follow the skip instructions to Question G17.

G16b. At the health department/clinic, did they recommend that you take medicine for tuberculosis?

Mark Box #1, "Yes", if the participant says he/she was given medicine, was told to take some medicine, or was given a prescription, and continue to Question G16b.1. If the participant says no, does not remember, or refuses to answer, mark the appropriate box and follow the skip instruction to Question G17.

G16b.1. Did you take the medicine?

If the participant says yes, mark Box #1 and, continue to Question G16b.2; otherwise mark the appropriate box and follow the skip instructions to Question G17.

G16b.2. Do you recall how many different medicines you took every day at the beginning of your treatment?

We are interested only in the number taken at the beginning of the treatment. Note that we are interested in the number of different medicines, not the number of pills. Mark the appropriate box and continue to Question G16b.3.

G16b.3. Do you remember what medicines you took?

Show the participant the 'Medicines' show card to select the type of medication(s) that the participant took at the start of treatment. Mark all the medicines that the participant points to. If the participant mentions a medicine that is not on the show card, mark Box #97, "Other," and specify the name of the medicine. For all responses, including "Don't know" and "Refused to answer", continue to Question G16b.4.

G16b.4. How many months did you take the medicine(s)?

Mark Box #1 if the participant mentions any length of time less than one month. If the participant mentions a number equal to one month or longer, round to the nearest month and enter the number in the blank space provided next to Box #2. If the participant says he/she is still taking medicine, mark Box #3 and ask how long he/she has been on medication; record the number of months in the blank space on the same line as response option 3.

If the participant answers "many" when asked how many months, please follow up with, "can you tell me how many months?" If the participant does not know, enter 98 in the space provided at Box #2, which is DMACS code for "don't know."

After recording the response, continue to Question G17.

All sub-questions of G17 refer to any medical examination the participant may have had in order to change his/her visa status while in the US/Canada. This is the difference between the sub-questions in G15/16 and the sub-questions in G17. If the participant asks why you are asking the same question, explain that:

"The previous question(s) asked about medical tests before you entered the US/Canada; the current questions ask about medical tests done after you arrived in the US/Canada."

G17. Did you ever have a medical test in this country to change your visa status?

If the participant says yes, mark Box #1 and continue to Question G17a; otherwise mark the appropriate box and follow the skip instruction to Section H: Household Visitors and Other Contacts.

G17a. When did you get the test?

If the participant mentions more than one examination, ask about the most recent. If the participant provides only a year, probe for the month; if only a month, probe for the year. If the participant does not remember the month, record the year. Do not record only a month. Mark the appropriate response, including 'Don't know' and "Refused to answer", and continue to Question G17b.

G17b. Did you get a chest x-ray?

Mark the appropriate response and continue to Question G17c.

G17c. Did you get a test where you were asked to cough or spit into a cup?

If the participant does not understand the question, repeat it. Please do not provide any additional explanation. Mark the appropriate response and continue to Question G17d.

G17d. Did you receive a tuberculosis skin test on your arm?

Show the participant the 'TST' show card while asking this question. Please do not offer any other explanation of a skin test or its purpose. Mark the appropriate box and continue to Question G17e.

G17e. After the medical test(s), were you told or given a letter or note recommending that you go to the health department or health clinic in the city you were living in?

If the participant says yes, mark Box #1 and continue to Question G17e.1a; otherwise mark the appropriate box and follow the skip instruction to Section H: Household Visitors and Other Contacts.

G17e.1. Did you visit the health department/clinic?

If the answer is yes, mark Box #1 and follow the skip instructions to Question G17f. If the answer is no, mark Box #2 and follow the skip instruction to Question G17e.1a. If the participant does not remember or refuses to answer, mark the appropriate box and follow the skip instruction to Section H: Household Visitors and Other Contacts.

G17e.1a. What was the main reason you did not go to the health department/clinic?

Mark the box that best matches the participant's response. Do not read the list of possible responses to the participant. Mark only one response. If the participant provides more than one reason, ask, "Which of the reasons you mentioned is the main reason you did not go to the health department/clinic?" If the participant's response does not match any of the listed response options, select Box #97, "Other," and record the participant's response as close to his/her own words as possible. After marking the appropriate box, follow the skip instructions to Section H: Household Visitors and Other Contacts.

G17f. At the health department/clinic, did they recommend that you take medicine for tuberculosis?

Mark Box #1, "Yes", if the participant says he/she was given medicine, was told to take some medicine, or was given a prescription, and continue to Question G17f.1. If the participant says no, does not remember, or refuses to answer, mark the appropriate box and follow the skip instructions to Section H: Household Visitors and Other Contacts.

G17f.1. Did you take the medicine?

If the participant says yes, mark Box #1 and, continue to Question G17f.2; otherwise mark the appropriate box and follow the skip instructions to Section H: Household Visitors and Other Contacts.

G17f.2. Do you recall how many different medicines you took every day at the beginning of your treatment?

We are interested only in the number taken at the beginning of the treatment. Note that we are interested in the number of different medicines, not the number of pills. Mark the appropriate box and continue to Question G17f.3.

G17f.3. Do you remember which medicines you took?

Show the participant the 'Medicines' show card to select the type of medication(s) that the participant took at the start of treatment. Select all the medicines that the participant points to. If the participant mentions a medicine that is not on the show card, mark Box #97, "Other," and specify the name of the medicine. For all responses, including "Don't know" and "Refused to answer", continue to Question G17f.4.

G17f.4. How many months did you take the medicine(s)?

Mark Box #1 if the participant mentions any length of time less than one month. If the participant mentions a number equal to one month or longer, round to the nearest month and enter the number in the blank space provided next to Box #2. If the participant says he/she is still taking medicine, mark Box #3 and ask how long he/she has been on medication; record the number of months in the blank space on the same line as response option 3.

If the participant answers “many” when asked how many months, please follow up with, “can you tell me how many months?” If the participant does not know, enter 98 in the space provided at Box #2, which is DMACS code for “don’t know.”

After recording the response, continue to Section H: Household Visitors and Other Contacts.

Section H: Household Visitors and Other Contacts

The purpose of this section is to ask about two particular situations – household visitors and consumption of unpasteurized dairy products – that could have exposed the participant to tuberculosis.

H1. In the 12 months before a doctor or nurse told you that you had tuberculosis, did you have any visitors in the US/Canada who came from countries outside of the US/Canada and stayed for at least one week in your household?

If the participant says yes, mark box #1 and continue to Question H1a. For any other response, mark the appropriate box and follow the skip instruction to Question H2. If the participant has not lived in this country for 12 months, ask about the period he/she has lived here. For example, if the participant is a visitor who has been in this country only 10 months, then ask about visitors over the past 10 months. Note that we are interested only in persons who visited the participant in the US/Canada. Some people who travel frequently may have visitors while they are staying in other countries; we do not want information about those visitors.

H1a. For each visit, please tell me the country the visitor or visitors came from.

Note that we are interested here in **visits**, not **visitors**. For example, if a family of three people from Guatemala came to visit, that counts as a single visit. If a participant received visitors from two countries at the same time, fill in two country blanks. If the participant has had more than six visits, ask about the most recent six.

H2. In the 12 months before a doctor or nurse told you that you had tuberculosis, did you eat raw (unpasteurized) dairy products [milk, cheese, etc.]?

When you read this sentence to the participant, include the words in parentheses. (“In the 12 months before a doctor or nurse told you that you had tuberculosis, did you eat raw, or unpasteurized, dairy products, like unpasteurized milk or cheese?”). Mark the appropriate box and continue to Section I, Health Screenings.

Section I: Health Screenings

The purpose of this section is to identify any times in the past, **before** the participant's current diagnosis, when the TB infection could have been picked up through screening. **NOTE** that we are not asking about recent TB screenings done as part of the diagnostic workup for the current diagnosis. We are asking about screenings done in the **PAST**.

The questions in Section I ask about TB screenings the participant had in the US/Canada **except** for (1) overseas medical examinations required to obtain a visa (already asked in sub-questions G16); and (2) examinations to change visa status (already asked in sub-questions G17).

Each of the nine questions in Section I asks if the participant was ever screened for TB in a particular setting (like a jail) or for a particular reason (like starting a new job or a new school).

Each of the questions starts by asking if the participant was ever in the particular situation or setting. If the answer is no, the interviewer skips down to the next question (for example, from I1 to I2). If the answer is yes, the interviewer moves across the row for that question, asking a series of sub-questions: whether the participant received a skin test, the results of the test, whether the participant had a chest x-ray, received medications, etc. Depending on the answer to each sub-question, the interviewer moves either across to the next sub-question, or down to the next question about a different situation. Next to each response box is a letter in parentheses that indicates where the interviewer should go next. In addition, most response boxes have arrows pointing to the next sub-question the interviewer should ask. **Always follow the arrows to move through this section.**

Abbreviations used in Section I:

DK: Don't know
RF: Refused to answer
INH: Isoniazid
RIF: Rifampin
PZA: Pyrazinamide
EMB: Ethambutol

The introduction

The section starts with the introductory sentence, "Now I am going to name other places and times where tuberculosis testing is often done in the US/Canada. I am interested in whether you were ever tested at any of these times or places before your current diagnosis of tuberculosis."

The main questions

When asking questions I1 through I6, begin each question with, “Before your current diagnosis, did you ever....” and then the question. For example, Question I1 will be posed as, “Before your current diagnosis of tuberculosis, did you ever have a job in a hospital, clinic, nursing home, or other health care facility in the US/Canada?”

Questions I7-I9 are asked a little differently; they begin, “Have you ever...” For example, Question I7 asks, “Have you ever been pregnant since you have been in the US/Canada?”

- I1. (Before your current diagnosis, did you ever) have a job in a hospital, clinic, nursing home, or other health care facility in the US/Canada?*

This question asks about any job the participant has had in any health care setting. If the participant responds “yes,” mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question I2.

- I2. (Before your current diagnosis, did you ever) start any other job in the US/Canada where you were required to have a health screening first?*

This question refers to any other job in the US/Canada (besides a health-related job) that required the participant to have any kind of health screening before he/she began working. If the answer is “yes,” mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question I3.

- I3. (Before your current diagnosis, did you ever) enroll in a school or college in the US/Canada?*

We are interested in knowing if the participant ever enrolled in any type of school. This could be a high school, vocational/technical school, college, or university in the US/Canada. If the answer is “yes,” mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question I4.

14. *(Before your current diagnosis, did you ever) Serve time or work in a jail or prison in the US/Canada?*

This question refers to (1) any type of work the participant may have had at a jail or prison, or (2) anytime the participant may have been incarcerated while in the US/Canada. Note that we do not distinguish between the two; we are interested only in whether the participant was ever in a prison environment. This may be a sensitive question for some participants; if the participant appears uncomfortable, remind him/her that all answers are confidential and he/she may choose not to answer any question. If the participant says he/she did work or serve time in a jail or prison, mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question 15.

NOTE: Some participants may mention that they were detained by immigration officials at entry to this country. If a participant mentions any kind of immigration detention, mark this question as a “yes”.

15. *(Before your current diagnosis, did you ever) work or participate in a program for persons with alcohol or drug problems in the U.S./Canada?*

This question refers to any association (work, volunteer work, or participation) the participant had with persons in an alcohol and/or drug program in the US/Canada. If the participant appears uncomfortable with this question, remind him/her that all answers are confidential and he/she may choose not to answer any question. If the participant worked or participated in a program for persons with alcohol or drug problems while in the US/Canada, mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question 16.

16. *(Before your current diagnosis, did you ever) work in or spend the night in a shelter for homeless persons in the U.S./Canada?*

If the participant worked or volunteered at or spent at least one night in a homeless shelter while in the US/Canada, mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question 17.

17. *(Before your current diagnosis, have you ever) been pregnant since you have been in the US/Canada?*

Ask this question only of females. If the participant says “yes”, mark Box #1 and continue across to Column a. For any other response, mark the correct box and follow the skip instructions down to Question 18.

- I8. (Before your current diagnosis, were you ever) told that you had been close to a person in the US/Canada who had active tuberculosis disease?*

If the participant says “yes”, mark Box #1 and continue down to Question I8.1. For any other response, mark the correct box and follow the skip instructions down to Question I9. **Note that Question I8 is the only question in Section I that has no sub-questions.**

- I8.1. How did you know this person?*

This question is asked only of participants who report that they have been close to someone with active tuberculosis as defined in I8. If the participant does not understand the question, the interviewer should repeat the question. If the participant still does not understand, the interviewer may say, “What I mean is, was this person a family member or friend, or did you know this person through work or school or some other way?” Mark the box under Question I8.1 that fits closest with the person’s response. If the person’s response does not match any of the boxes, mark Box #97, “Other,” and summarize the response in the blank line next to the box. For all responses, continue to Column a.

- I9. Before your current diagnosis was there any other time when you were tested for tuberculosis in the US/Canada?*

The purpose of this question is to identify any other situation, besides those mentioned in I1 through I9, where the participant was tested for TB while in the US/Canada. We are not interested in a description of the specific circumstances. If the participant says “yes,” mark box #1 and continue to Column a. For any other response, mark the appropriate box and follow the skip instructions to Question I10.

The sub-questions

The sub-questions in columns a through h are the same for each main question. As you move across the page, ask the question at the top of each column. For example, if the participant answers “yes” to I1, “Before your current diagnosis, did you ever have a job in a hospital, clinic...” then ask the question at the top of Column a: “At that time, were you tested for tuberculosis with a skin test on your arm?”

When moving from one column to the next, it is useful to periodically remind the participant of the situation/event you are referring to, to keep the focus on that particular situation. For example, in question I1, Column d, you might say, “what was the result of the skin test you had at the nursing home?”

Column a: *At that time, were you tested for tuberculosis with a skin test on your arm?: [SHOW TST CARD]*

We are referring to any TB skin test the participant may have had at any time during the specific situation. So, for example, in I1, we want to know about any TB skin test the participant may have had that was associated with a job at a hospital, clinic, or other health care facility. When you ask this question the first time, show the participant the 'TST' show card. Use your judgment about showing the card again when you ask the Column 'a' sub-question for another Section I question.

If the participant says "yes," mark Box #1 and follow the arrow to Column b. If the participant says "No", mark Box #2 and follow the arrow and skip instruction to Column e. A participant may volunteer that he/she did not have a skin test because he/she had a history of a previous positive skin test ; in this case, mark Box #3 and follow the arrow and skip instruction to Column e. If the participant does not know or does not remember whether he/she had a skin test, mark the appropriate box and follow the skip instruction in the parentheses down to the next question.

Column b: *When did this happen?*

If the participant reports more than one skin test associated with this particular situation, ask about the date of the most recent skin test. **NOTE: do not read the words in parentheses out loud ("If more than once, when was the last time this happened?"). These are instructions to the interviewer.**

Record the date using the month and year format (mm/yyyy). If the participant provides only a year, probe for the month; if only a month, probe for the year. If the participant does not remember the month, record the year. Do not record only a month. Continue to Column c.

Column c: *Did you go back to have the test read?:*

Ask the question in Column c only of participants who had a skin test. If the participant says "yes," mark Box #1 and follow the arrow to Column d. If the participant says "No", "Don't know," or refuses to answer, mark the appropriate box and follow the skip instruction to Column e.

Column d: *What was the result of the skin test?:*

Mark the appropriate response and continue to Column e.

If the participant does not understand the question, repeat it. If the participant still does not understand, the interviewer may say, "By results, I mean whether the skin test was positive or negative." If the participant still does not understand, mark Box #98 ("Don't know") and continue to Column e.

Column e: *Did you have a chest x-ray?:*

We would like to know if the participant had a chest x-ray done in association with the particular situation (a new job, new school, etc.) regardless of the result of their skin test. This question is asked of all participants even if they did not have a skin test or if the skin test was negative.

Pay close attention to the skip instructions in Column e; they will depend on the responses to BOTH Column a and Column e; follow the arrows carefully:

For participants who had a skin test (answered "yes" in Column a): Mark the appropriate response to the Column e question about a chest x-ray. Regardless of whether the participant did or did not have a chest x-ray; or if he/she does not know or does not remember, continue to Column f.

For participants who did not have a skin test (answered "no" in Column a): If the participant reports that he/she had a chest x-ray, mark box #1 (:yes:) and follow the arrow across to Column f. For any other answer ("No", "Don't know," refused to answer), mark the appropriate box and follow the skip instruction down to the next question.

For participants who did not have a skin test because a previous skin test was already positive (box #3 in Column a): If the participant reports he/she had a chest x-ray, mark box #1 ("Yes") and follow the arrow across to Column f. If the participant did not have a chest x-ray, mark box #2 ("No") and follow the arrow across to Column f. If the participant does not know or refuses to answer if he/she had an x-ray, mark the appropriate box and follow the skip instruction down to the next question.

Column f: *Were you given medicines to stop tuberculosis?*

If the participant reports getting medicine more than once in association with the particular situation, ask about the most recent time he/she was given medicine. For example, a participant who had jobs in the health care field might respond in Question I1 that (s)he received medicine during jobs at two different health facilities. In that case, ask about the most recent time.

Follow the arrows carefully. Note that there are three sets of boxes in Column f, depending on the participant's responses in previous Columns. Mark only one box. If the participant says he/she received medicines to prevent tuberculosis, mark the appropriate box ("Yes") and follow the arrow across to Column g. If the participant provides any other answer, mark the appropriate box ("No", "Don't know," refused to answer) and follow the skip instruction down to the next question.

Column g: *Do you remember which medicines you got? [SHOW CARD. MARK ALL THAT APPLY]*

Show the participant the 'Medicine' show card and ask the participant to point to the medicines he/she got. Mark as many boxes as necessary to indicate all the different medicines taken. If the participant mentions a medicine that is not listed, mark box #97 (other) and write the name of the medicine on the blank line next to the box. Note that the abbreviated names listed in Column G include the same formulations listed in the responses to Questions G16b.3 and G17f.3:

INH: Isoniazid or Isotamine

RIF: Rifampin, Rifadin, Rifamate, Rifater, Rifabutin, e-Rofact

PZA: Pyrazinamide, Tebrazid

EMB: Ethambutol, Myambutol, Etibi

Response box 5 (Total #__) is used in two situations:

1. When the participant says "I don't remember, but I took 3 drugs," mark Box #5 and put the number mentioned in this blank. 2. When the participant names some drugs, and then says he/she took another drug but doesn't remember the name or picture, then select the named drugs and Box #5 and write the total number of drugs taken. For example, if the person says "I took Rifampin and Isoniazid, and something else, but I don't remember what," mark "INH," "RIF," Box #5 (total #), and in the blank for "total number," put 3. If the person mentions INH and Rifampin and another drug that is not listed, select INH and RIF and Box #97 (other) and write the name of the third drug in the blank next to box #97; don't put a "3" in the blank next to Box #5.

After marking the appropriate box(es) in Column g, follow the instruction across to Column h.

Column h: *Approximately how many months did you take the medicines?:*

If the participant took medicine for less than one month, mark box #1 and follow the skip instruction down to the next question. If the participant took the medicine(s) for a month or longer, Mark box #2 (≥ 1 month) and record the number of months in the space provided; record only whole months and round up or down as appropriate.

If the participant answers “many” when asked how many months, please follow up with, “can you tell me how many months?” If the participant does not know, enter 98 in the space provided at Box #2, which is DMACS code for “don’t know.”

If the participant took different medications for different amounts of time, record the longest time mentioned (for example, if the participant took Isoniazid for three months and Rifampin for six months, record 6 months). If the participant did not take any medicine, mark the “Did not take” box. After marking the appropriate response, follow the instruction down to the next question.

I10. Have you ever received the BCG vaccine? [SHOW BCG VACCINE CARD]

Show the participant the BCG vaccine show card with a picture of both a BCG vaccine scar and a smallpox vaccine scar. If the participant does not read or does not read English, the interviewer may point to the different scars and explain that one shows a BCG vaccine scar and the other a smallpox scar. If the participant does not understand, repeat the question. If the participant still does not understand, mark box #98 (“Don’t know”) and continue to Section J. Do not offer any other explanation about either vaccine.

After marking the appropriate response, continue to Section J: Previous Treatment for Active Disease.

Section J: Previous Treatment for Active Disease

The questions in this section refer to any other time when the participant was diagnosed with tuberculosis. We want to know if the participant started treatment, what country the participant lived in at the time, and if the participant was told he/she had completed treatment.

J1. Before your current tuberculosis illness, was there another time when you were told that you had tuberculosis?

The intent of this question is to find out if the participant had been diagnosed with active tuberculosis before the diagnosis date reported in C1. If the participant says he/she was previously diagnosed with tuberculosis, mark Box #1 ("Yes") and continue to Question J1a. Accept whatever the participant says at face value. Do not attempt to explain the difference between active and latent tuberculosis. If the participant mentions that he/she was previously diagnosed with **latent** tuberculosis infection, mark Box #2 ("No"). If the participant was not previously diagnosed with tuberculosis or does not know, or refuses to answer, mark the appropriate box and follow the skip instruction to Section K: Other Medical Conditions.

J1a. Can you tell me approximately when you started treatment?

We are asking only for the year(s) of the participant's previous tuberculosis diagnosis. If the participant reports starting treatment more than once, record up to 3 previous start dates, beginning with the most recent. After recording the treatment date(s), follow the skip instruction to Question J1b.

If the participant reports that he/she was not ever treated, mark box #2 ("did not start treatment") and follow the skip instructions to Section K: Other Medical Conditions.

If the participant says he/she does not know or remember when he/she started treatment, mark box #98 and follow the skip instruction to Question J1a.1.

If the participant refuses to answer, mark box #99 (Refused to answer) and follow the skip instructions to Question J1b.

J1a.1. Was it:

Ask this follow-up to J1a only of participants who do not remember when they started treatment after a previous diagnosis of tuberculosis. Read aloud the responses: "Was it: Less than 2 years ago?, More than 10 years ago?, 2 to 4 years ago?, 5 to 10 years ago?."

If the participant selects one of the responses that is read aloud, mark the appropriate box and continue to Question J1b. If the participant does not remember or refuses to answer, mark the appropriate box and continue to Question J1b.

J1b. What city and country were you treated in?

Write the names of the city and the country in the appropriate blanks, or mark the "Don't know" or "Refused to answer" boxes and continue to Question J1c.

If the participant reported in J1a that he/she had started treatment more than once, ask about the city and country of the most recent treatment.

J1c. How many months did you take the treatment?

Mark box #1 if the participant took the treatment for less than 1 month. If the participant took the medication for 1 month or longer, write the number of whole months in the blank.

If the participant answers "many" when asked how many months, please follow up with, "can you tell me how many months?" If the participant does not know, enter 98 in the space provided at Box #2, which is DMACS code for "don't know."

After recording the appropriate response, continue to Question J1d.

J1d. Did you usually take the medicine by yourself, or was there usually a health care worker present?

For participants who started treatment, we are interested in knowing if they took the medicine by themselves (mark Box #1, "Usually by myself"); if they took the medicine with a health care worker present, for example through directed observed therapy (mark Box #2, "Usually with health care worker present"); or if they took the medicines sometimes by themselves or sometimes with a health care worker present (mark Box #3, "Sometimes by myself, sometimes with health care worker present"). After marking the appropriate box, continue to Question J1e.

J1e. Were you told you had completed treatment?

Mark the appropriate box and continue to Section K: Other Medical Conditions.

Section K: Other Medical Conditions

The following questions refer to other medical conditions that may increase the participant's risk of contracting tuberculosis. Some of these may be sensitive questions, particularly Questions K6, K6a, K6b, and K6b.1 about HIV/AIDS. It is therefore important to emphasize to the participant that all the information is confidential.

Some participants may not be familiar with some or all of the terms used in this section. Please do not offer any explanations beyond what is provided in the questions. If a participant does not understand any question, repeat it once and then select the "Don't know" box (Box #98) if the participant still does not understand.

- K1. Has a doctor ever told you that you have . . .*
- a. Diabetes or sugar diabetes?*
 - b. Silicosis or coal miner's lung disease?*
 - c. Cancer?*

The possible responses to each question are: "Yes," (Box #1), "No," (Box #2), "Don't know" (Box #98), and "Refused" (Box #99). If a participant does not understand a question, repeat the question. If the participant still does not understand, mark Box #98 and continue to the next question. Do not attempt to explain the meaning of any of the words. If more than a few seconds elapse between questions (for example, if the person takes a long time to answer K1a or you have to repeat the question), start the next question as a full sentence (for example, "Has a doctor ever told you that you have silicosis or coal miner's lung disease?") After selecting an appropriate response to each of the questions, continue to Question K2.

- K2. Have you ever had an organ transplant?*

The possible responses to this question are Yes, No, Don't Know, or Refused to answer. Do not probe the participant for additional information (for example, the type of organ). If the participant does not understand the question, repeat the question. If the participant still does not understand, select "Don't Know" and continue to Question K3. Do not attempt to explain what an organ transplant is.

K3. Are you currently on kidney dialysis (that is the machine that takes poisons out of your blood when your kidneys have failed)?

Read the words in parentheses as part of the question. The possible responses to this question are Yes, No, Don't Know, or Refused to answer. Do not probe the participant for additional information. If the participant does not understand the question, repeat the question. If the participant still does not understand, select "Don't Know" and continue to Question K4. Beyond the explanation offered ("that is, the machine that takes poisons out of your blood...", do not attempt to explain kidney dialysis or when it is used.

K4. Are you taking any medicines that contain steroids, like prednisone or cortisone?

The possible responses to this question are Yes, No, Don't Know, or Refused to answer. Do not probe the participant for additional information. If the participant does not understand the question, repeat the question. If the participant still does not understand, select "Don't Know" and continue to Question K5. Do not attempt to explain what steroids are or when they are used.

K5. Have you smoked more than 100 cigarettes in your lifetime?

This is a standard question used to classify persons as smokers or nonsmokers. The possible responses to this question are Yes, No, Don't Know, or Refused to answer. Do not probe the participant for additional information. If the participant does not understand the question, repeat the question. If the participant still does not understand, select "Don't Know" and continue to Question K6.

Questions K6, K6a, K6b, and K6b.1 are about HIV/AIDS. Begin this section with the statement, "The next questions are about HIV/AIDS." If a participant appears uncomfortable answering any of these questions, remind him/her that all responses are confidential and will not be shared with anyone outside the study.

K6. Have you ever been told you have HIV or AIDS?

Some cultures/languages do not use the term "HIV" in everyday language. Nevertheless, please use both terms in the question. If the participant says "yes," mark Box #1 and continue to Question K6a. If the participant says "no", mark Box #2 and follow the skip instruction to K6b. If the participant doesn't know or doesn't understand or refuses to answer, mark the appropriate box and follow the skip instructions to Question K6b. Do not attempt to define HIV/AIDS

K6a. When was the first time you were told this?

Record the year and/or month. If the participant does not know or refuses to answer, select the appropriate response and follow the skip instruction to Section L: Tuberculosis Knowledge and Attitudes.

K6b. Have you ever been tested for HIV or AIDS?

If the participant says he/she has ever been tested, mark Box #1 and continue to Question K6b.1. Otherwise, select the appropriate response and follow the skip instruction to Section L: Tuberculosis Knowledge and Attitudes.

K6b.1. When was the last time you were tested?

If the participant provides only the year, probe for the month; if only the month, probe for the year. If the participant does not remember the month, record the year. Do not record only the month. After selecting the appropriate response, continue to Section L: Tuberculosis Knowledge and Attitudes.

Section L: Tuberculosis Knowledge and Attitudes

These questions ask about the participant's knowledge of tuberculosis and his/her attitude toward tuberculosis-related issues

Questions L1a-L1f.

For each of the statements, the participant is asked to respond yes or no. If the participant appears confused by a statement, repeat it. If the participant says something like, "it depends," or "sometimes yes, sometimes no," encourage him/her to respond yes or no by saying, "Overall, do you think that the answer is more yes or more no?" If the participant still does not understand or does not want to provide a yes/no answer, mark the "Don't know/No Opinion" box and continue to the next statement.

If the participant wants to know what you think of a particular question or wants more information about a subject, offer to provide the name of someone at the health department who can answer the participant's questions. Provide the name and telephone number at the end of the interview.

Questions L2a-L2n.

For each of these statements, the participant is asked to respond yes or no. If the participant appears confused by a statement, repeat it. If the participant wants more information or says "it depends", encourage a yes/no answer by saying, "We would like to know what you think about the question the way it is. Would you say yes or no?" and repeat the question. If the participant still does not know or does not understand, mark the "No Opinion" box and continue to the next statement.

Some of the questions may not be applicable to a particular participant. For example, a person might not have told friends and family about his/her TB, and then the person might respond to Question L2b, "**Do Your family and friends think it is important that you take your tuberculosis medicines?**", with "**I don't know; I haven't told anybody.**" In that case, mark the "Not applicable" box. Do not select the "Not applicable" box before you ask the question. Note that only some questions have a "Not applicable" option. That is because everybody should be able to answer all the other questions.

Question L2f.

Health Department Record Abstraction Form

This form has only two questions. Both refer to a form, known in the US as CDC 75.17, "Report of an Alien with Tuberculosis", that the CDC's Division of Global Migration and Quarantine sends to local health departments. The form is sent out when an immigrant, refugee, or asylee has suspicious findings on an entry exam but did not test smear positive. The form is sent to the health department in the jurisdiction where the alien has said he/she is going to live, and requests an evaluation and report. A copy of the form is attached below.

In some jurisdictions, the form is sent not to the local health department, but to the local Division of Refugee Health. Please determine where in your jurisdiction such forms are sent.

In Canada, immigrants and certain other persons arriving from foreign countries who have evidence of TB infection are placed under medical surveillance as a condition of entry. Such immigrants or visitors are then required to report, within 30 days of entry, to a public health authority in the province/territory (P/T) of destination. The form they fill out is known as an IMM535. Canadian sites should look in their participants' provincial health records for this or other evidence that the participant has been placed under medical surveillance as a condition of entry.

1. *Does the health department record contain a report (CDC 75.17) about this participant from the Division of Global Migration and Quarantine/Citizenship and Immigration Canada?*

This question asks whether the participant's health department record contains a notification from the CDC that the participant was examined at entry to the U.S. and may have TB. This is called a Class B form, or CDC 75.17 report. A blank copy of this form is at the end of this Instruction Guide. NOTE that different states keep this form in different places. Some keep it at the state health department; some send it to the county; some send it to their refugee health division, etc. Each site should identify where in their jurisdiction this form is located. Sometimes, the health department record will have, in addition or instead, a multi-page document from the CDC containing the results of the examination. This document has the number DS 3026 in the bottom left corner of each page. If either document is present, mark the "yes" response in the record abstraction form and proceed to Question 1.1; otherwise mark "no" and stop.

1.1 *Date DGMQ/CIC report was received*

This is the date the report was received at the first jurisdiction to which CDC sent it – the state health department, the city health department, etc. If more than one receipt date is noted, record the earliest one. Remember, the date requested for this project is the date the state or local public health jurisdiction received the CDC 75.17 and or DS 3026, so be careful not to record other dates that may be stamped on the form.