

**Tuberculosis Epidemiologic Studies  
Consortium (TBESC)**

**Preventing Tuberculosis in the  
Foreign Born**

**Pediatric Questionnaire Instruction Guide**

## **GENERAL INSTRUCTIONS**

### **A. When to use the pediatric questionnaire**

Use the pediatric questionnaire only to interview participants' **parents/legal guardians**. Therefore, you should use this questionnaire to obtain information about:

- ALL participants less than 15 years old (age 0 through 14)
- participants 15 through 17 years old whose parents will not permit them to be interviewed directly (NOTE that participants 15 through 17 years old who are interviewed directly are interviewed with the adult questionnaire).

The pediatric questionnaire is available in English and ten other languages (Spanish, French, Haitian Creole, Tagalog, Chinese, Korean, Hindi, Somali, Ilocano, and Vietnamese).

### **B. How to use the pediatric questionnaire**

The general instructions and explanations of questions provided in the Instruction Guide for the Adult Questionnaire should be followed for the pediatric questionnaire except for a few questions. Explanations for these questions are provided in this instruction guide.

### **C. Definitions**

**Informant:** the parent or guardian who is interviewed to obtain information about a pediatric participant.

**Participant:** a person diagnosed with TB who is enrolled in the study.

**Source case:** a person diagnosed with TB who has been identified as the source of infection for a case of TB in a child less than five years (60 months) old.

## 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 interview is completed. Place the Face Sheet in a separate envelope and store it in the designated locked cabinet at the site. The Face Sheet **SHOULD NOT** be stored in the same cabinet as the completed questionnaire.

The only items on the face sheet that will be completed from the interview questions are: "Alien Registration Number (US)," "Immigration Medical Services Number (Canada)," and "Name Used at Entry to U.S./Canada" (G13 and G6a respectively). For any other missing information, particularly the participant's middle name, please ask the informant before you begin administering the questionnaire. The source case information is completed after the Health Department Record Abstraction Form (at the back of the questionnaire booklet) is completed.

**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**

Name of Informant

### **Explanation**

Name of the person being interviewed. The informant must be the child's parent or legal guardian, and the one who signs the parental consent form. List the parent/legal guardian's last name, then first name, then middle name or initial as provided.

Has a source case been identified for this child?

Mark "Yes" (Box #1) and go on to the next question **ONLY** if (1) the child is less than five years (60 months) old **AND** (2) the health department has identified a source case for the child [i.e., you marked "Yes (Box #1) to Question 2 of the Health Department Record Abstraction Form for Pediatric Participants

If the health department has not identified a source case for this child, or if the child is five years old or older, mark Box #2 ("No") and follow the skip instruction to the "General Information" section

**Question**

Has the source case agreed to participate?

**Explanation**

Mark "Yes" (Box #1) if the identified has been enrolled in the study, and enter the source case's full name and participant number in the spaces provided

Mark "No" (Box #2) if the source case has refused to participate in the study or could not be reached or turned out to be ineligible for enrollment (See Source Case recruitment and questionnaire guide in the eRoom; the file pathway is Task Order 9/materials for full rollout of study/Source Case recruitment). Continue to the General Information section.

Number of Source Case

Name of the source case as it appears on the Face Sheet of the source case's questionnaire booklet. List the last name, then the first name, then the middle name or initial, if available.

Source Case Participant Number

The number preprinted on the source case's questionnaire booklet

## **Section A: Demographic Information**

*A8 Are you the child's birth mother/birth father?*

If the informant says he/she is the participant's birth mother or father, mark the correct box [Box #1 ("Yes, birth mother) or Box #2 ("Yes, birth father")] and follow the skip instruction to Section B, Question B1. For all other responses, mark the appropriate box and continue to Question A8a.

*A8a Is this child adopted?*

Ask this question if the informant indicates he/she is not the birth parent or has responded "Don't know" (Box #98) or "Refused to answer" (Box #99) to Question A8. If the informant says the child is adopted, mark Box #1 ("Yes") and continue to Question A8b. If the informant says the child is not adopted, mark Box #2 ("No") and ask the informant to specify his/her relationship to the child (for example, the informant might be the child's legal guardian). Write the informant's response in the blank space next to Box #2. For "Don't know" or "Refused to answer" responses, mark the appropriate box and follow the skip instruction to Section B, Question B1.

*A8b. When did you become this child's parent/guardian?*

Ask this question only if the informant is not the child's birth parent. WE want to know when the child was adopted or – if the child is not adopted – when the informant became the guardian. When asking Question A8, use whatever term the informant has used to describe his/her relationship to the participant. Record the date using the specified format mm/yyyy. If the informant provides only a year, prompt for the month. Do not record only a month. If the informant does not know the year or chooses not to answer, mark the appropriate box and continue to Question B1.

## **Section B: Socioeconomic Status**

The questions in this section relate to the family's socioeconomic status. We ask the same questions as in the adult questionnaire. The difference is that we ask these questions about different people.

### *Question B1:*

In the **adult** questionnaire, Question B1 asks about the **participant's** education. In the **pediatric** questionnaire, Question B1 asks about the educational level of the **person in the child's family who has the most education**. This may be the informant or it may be somebody else. We do not ask who this person is, just his/her educational level.

### *Questions B2 to B5a:*

In the **adult** questionnaire, we ask these questions about the participant **and** about the person in the family who provides most of the family's income. In the **pediatric** questionnaire, we ask these questions **only** about the person in the family who provides most of the family income.

## **Section D: Event That Led to Diagnosis**

*D1. What was the main reason your child went to the doctor or nurse who told you he/she had tuberculosis?*

The pediatric questionnaire has two options that are not in the adult questionnaire. These options are:

1. Option 4: Regular or well-baby checkup
2. Option 10: Screening for post-adoption checkup

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

Ask this question ONLY if you checked box #1 in Question D1, "Referred by another doctor/health care worker. The pediatric questionnaire has two options that are not in the adult questionnaire. These options are:

1. Option 4: Regular or well-baby checkup
2. Option 10: Screening for post-adoption checkup

**Questions D2a through D2h are the same as in the adult questionnaire except for Question D2e.**

*D2e Lose weight without dieting, failed to gain weight normally, or lose his/her appetite?*

This question refers to rapid, unintended weight loss. In the adult questionnaire a weight loss of 10 pounds is specified. We do not specify a particular amount in the pediatric questionnaire because for very young children, a weight loss of 2 to 3 pounds would be significant, while for older children, weight loss would not be noticeable until it reached 5 to 10 pounds.

Mark a response and continue to Question D2f.

## **Section E: History of Care Sought for Current Tuberculosis Illness**

### **The colored questionnaires**

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

Fill out one of these questionnaires each time the parent/guardian mentions a visit to a physician, a nurse, nurse practitioner, physician's assistant, hospital, emergency room, clinic, or health department. The pediatric questionnaire has three additional questions in the green questionnaire.

#### *E2a-8 Were any other tests ordered?*

If the parent/guardian says "Yes" or mentions any test(s), mark box #1 ("yes") and continue to Question E2a8a. For all other responses, mark the appropriate box and follow the skip instruction to Question E2a9.

#### *E2a8a Did the doctor put a tube into your child's lung to get some fluid?*

This question is asked only of those parents/guardians who say additional tests were ordered for their child. Mark the appropriate response and continue to Question E2a8b.

#### *E2a8b Did the doctor put a tube into your child's stomach to get some fluid?*

This question is asked only of those parents/guardians who say additional tests were ordered for their child. Mark the appropriate response and continue to Question E2a9.

## **Section G: Immigration and Travel History**

The pediatric questionnaire asks some additional questions. In addition to questions about the participant's visa status, the pediatric questionnaire also asks about the parents'/guardians' visa status, birth country, and date of entry to the US/Canada. Please pay careful attention to the italic skip instructions; for children born in the U.S., many of these questions are inappropriate and should be skipped.

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

Questions G4 through G6a are about the **child's** immigration status. Questions G7 to G11c are about the **parents'/guardians'** immigration status.

If the child was born in the US or Canada, **skip** the first six questions and begin with Question G7 about the parent/guardian's visa status. The reason is that the first six questions assume the child was born in another country.

G11a. When did this person first arrive in the US/Canada?

This questions asks about the child's other parent or guardian. In some cases, the other parent or guardian may not be living in the US/Canada. If this is the case, the interviewer should write "Person did not come to the US/CANada next to the response boxes for Question G11a, check the "don't know" box in Question G11b, and follow the skip instruction to Part II, Immigration Status Today, on page 24.

### **PART II: Immigration status Today**

This part asks only about the **child's** current immigration status. If the child was born in the U.S./Canada, **skip this section and follow the skip instruction to Part III.**

### **PART IV: Migration within the US/Canada**

Some of the questions in this section should be asked a little differently if the child was born in the US/Canada.

*G17a. Has your child always lived in this city since he/she came to the US/Canada?*

If the child was born in the US/Canada, do not ask the question this way. Instead, ask, "Was your child born in this city?"

*G19. What was the first city your child lived in when he/she came to the US/Canada?*

If the child was born in the US/Canada, do not ask the last part of the sentence. Just say, "What was the first city your child lived in?"

## **PART V: Tuberculosis Screening Related to Immigration/Visa Process**

If the child was born in the US/Canada, **skip** this section and go to Section H.

### **Section I: Health Screenings**

The purpose of this section is to identify any times in the past, **before the child's current diagnosis**, when TB infection could have been detected through screening.

*Questions I2 and I3:*

Questions I2 and I3 (I4 and I5 in adult questionnaire) are asked **only of children 12 years old and older**. In the adult questionnaire, these questions are asked of everyone.

*Other questions in section I:*

The adult questionnaire has two job related questions in this section (I1 and I2). The pediatric questionnaire does not ask about jobs.

### **Section K: Other Medical Conditions**

The questions in this section ask about other medical conditions that may increase the child's risk of contracting tuberculosis.

The only difference between the adult and pediatric questionnaire in this section is that the pediatric questionnaire does not ask about silicosis or coal miner's lung disease (Question K1b in the adult questionnaire).

## Health Department Record Abstraction Form

Complete this form after the interview with the informant is finished. The information recorded on this form should be obtained from the child's health department record, not from the informant.

In addition to the questions about CDC/Citizenship and Immigration Canada notification (Questions 1 and 1.1), which are the same as in the adult questionnaire, the pediatric questionnaire asks about **source cases for children less than 5 years (60 months) old**.

### *2 Has a source case been identified for this child?*

The information on source cases should be obtained from health department personnel. If the health department/clinic has identified a source case for the child, mark Box #1 ("Yes") and continue to question 2.1.

If the health department has not identified a source case, mark the appropriate box [Box #2 (Investigation not done), Box #3 (Investigation completed, source case not identified), Box #4 (Investigation ongoing), or Box #98 (Don't know)] and **STOP**. Data abstraction on this participant is complete; do **not** complete the Source Case Linkage Form.

#### *2.1 Where is the information documented?*

Record in the blank space where you found the information regarding the source case (for example, "contact investigation form" or "health department record"). If the information is not documented (for example, if the case manager tells you there is a source case but it isn't documented or the documentation can't be found), Mark Box #1, "Information not documented", and continue to Question 2.2.

#### *2.2 How was the source case identified?*

The options listed in Boxes 1 through 3 are the most common ways a source case is identified. For example, sometimes the child is diagnosed first, and the source case is identified as a result of the child's contact investigation (Box #3). Sometimes it's the other way around (Box #1 or #2). If the explanation the health department employee provides does not fit in Boxes 1, 2, or 3, mark Box #97 ("Other"), and record the information in the blank space. If you don't know how the source case was identified, mark box #98, "Don't know". For all responses, continue to Question 2.3.

### 2.3 *How is the source case related to the pediatric case?*

Select from the options provided the correct relationship between the child and the identified source case. If the type of relationship is not listed, mark Box #97 (“Other”) and record the type of relationship in the blank. If you do not know how the child is related to the source case, mark Box #98 (“Don’t Know”) and continue to the Source Case Linkage Form.

#### **Source Case Linkage Form**

Complete this form for each participant less than five years (60 months) old who has an identified source case.

##### 1 *Is the source case already a study participant?*

You may have already enrolled the source case as a participant in the study before you knew he/she is also a source case. To check, review Form 1 (the Excel spreadsheet) for the participant’s name. If the source case’s name is listed, review the Form 1 information to determine if the source case was approached for enrollment.

If the source case is already a study participant, mark Box #1 (“Yes”) in the Source Case Linkage Form, enter the source case’s participant ID number (the number pre-printed on the Face Sheet, NOT the state case ID number) in the space provided, and **STOP**. Do **not** continue to Question 2.

If Form 1 indicates that the source case was previously approached to be a participant and refused to participate, mark Box #3 (“No, refused to participate”) and **STOP**. Do **not** continue to Question 2 and do not attempt to contact the source case.

If the source case is not already listed on Form 1:

- a. Mark Box #2 (“No”)
- b. Add the source case’s name and other required information to Form 1,
- c. Attempt to enroll the source case if he/she meets eligibility requirements for a source case (see Source case recruitment and questionnaire guide; the file pathway is Task Order 9/Materials for full rollout of study/Source case recruitment); and
- d. Complete Question 2.

2. *Source case Participant ID#*

This question records the outcome of the attempt to enroll the source case in the study. Answer this question **only** if you marked Box #2 (“No”) in Question 1 of the Source Case Linkage Form (i.e., the source case had not been previously approached to participate in the study).

If the source case agreed to participate and completed the interview, record in this space the participant ID number pre-printed on the source case’s Face Sheet.

If the source case refused to participate when approached, mark Box #1, “Source case refused to participate.”