

INTEGRATED MANAGEMENT OF CHILDHOOD ILLNESS

IMCI ADAPTATION GUIDE

*A guide to identifying necessary adaptations of clinical policies
and guidelines, and to adapting the charts and modules
for the WHO/UNICEF course*

PART 3 The Study Protocols

E. Protocol for Identifying and Validating Local Terms

June 2002



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The 2002 working draft of the IMCI Adaptation Guide consists of the following sections:

- Section A.** The Adaptation Process
- Section B.** Procedures for Adapting the Charts and Modules
- Section C.** Technical Basis for Adapting the Clinical Guidelines, Feeding Recommendations and Local Terms
- Section D.** Protocol for Adapting the Feeding Recommendations
- Section E.** Protocol for Identifying and Validating Local Terms
- Section F.** Protocol for Designing and Pretesting an Adapted Mother's Card
- Section H.** Modifying the Generic Chart Booklet: Using Microsoft Publisher®

Please provide comments and further input to WHO/CAH, Geneva, Switzerland.

This protocol is based on guidelines first developed in 1995
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E. Protocol for Identifying and Validating local Terms

OBJECTIVES OF IDENTIFYING LOCAL TERMS

The materials to support the integrated management of childhood illness need to be adapted to include local terminology. Using local terms permits the health worker to:

- **Assess the child correctly.** Health workers must ask the caretaker several questions in order to assess the child's illness. They cannot assume that caretakers will volunteer this important information. Some of the questions, however, require health workers to use local terms for illness or symptoms in order for the caretaker to understand the question. These assessment questions are:
 - Has the child had *convulsions*?
 - Does the child have cough or *difficult breathing*?
 - Does the child have *diarrhoea*?
 - Is there *blood in the stool*?
 - Has the child had *fever*?
 - Has the child had *measles*?
- **Advise the mother.** Health workers must advise the caretaker to return immediately if the child has these signs:
 - *Fast breathing*
 - *Difficult breathing*
 - *Blood in the stool*
 - *Not able to drink or breastfeed*
 - *Drinking poorly or breastfeeding poorly*
 - *Becomes sicker*
 - *Develops fever*

Teaching the caretaker these signs in terms she can understand may determine whether the child gets treatment in time to save his life. A caretaker may not understand, for example, what the health worker means by fast or difficult breathing, but may learn to return when she sees what is locally recognized as a "tight chest" or "rib pain". As cultural concepts of fever often include a cluster of symptoms, the health worker must also describe this symptom in a way that the caretaker can understand that she should return with her young infant if the infant has a "hot body", regardless of other accompanying symptoms. (See Annex E-3, page 53, for examples of the use of these and other local terms to adapt case management guidelines.)

The steps for identifying and validating the terms health workers can use to communicate more effectively with families are shaded (under column Section E) in the following chart, **Steps in Adaptation**. A key component of these activities are interviews with caretakers. These interviews should be conducted in the local language or dialect. If you do not speak the local language, you will need to get assistance from someone who does. Most important

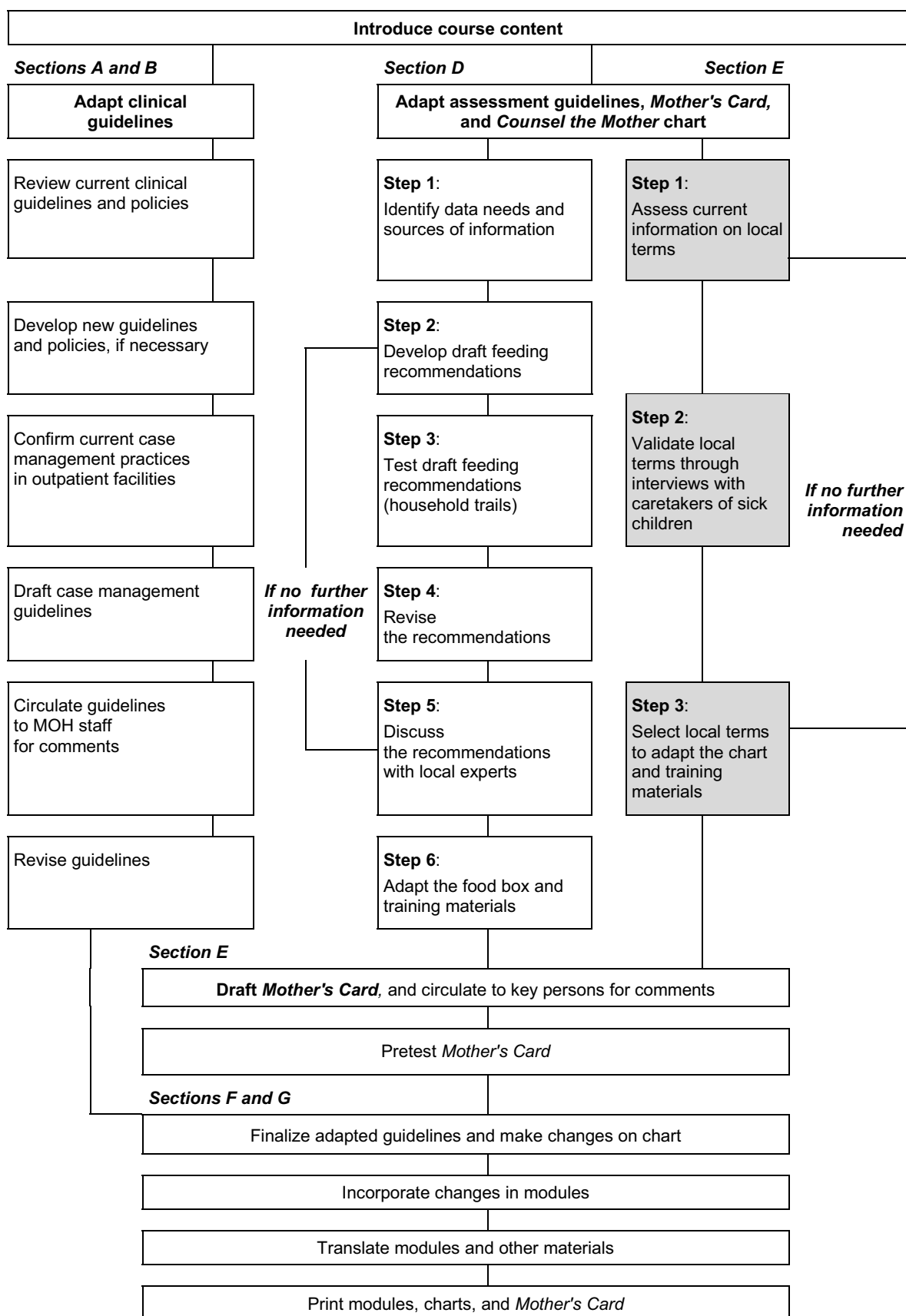
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is to emphasize that the objective is *to identify the terms families use*, not *a translation into the local language of the terms health workers use*.

The local terms, identified through these steps, are used in adapting the *Integrated Management of Childhood Illness* charts and training materials, and the *Mother's Card*.

STEPS IN ADAPTATION

(with references to sections in Adaptation Guide)



STEP 1: ASSESS CURRENT INFORMATION ON LOCAL TERMS

Ten terms used to describe childhood illness are to be identified. The first step is to assess the state of current information about them. This assessment is based on data from three sources: (i) written materials, (ii) interviews with members of the planning team and/or other clinicians, and (iii) interviews with caretakers. A comparison of the information from these sources will provide a means of assessing the extent of consensus about the most appropriate local terms to use and your confidence in their appropriateness. If there is consensus or near consensus, there is no need to complete Step 2, which is a procedure to validate the terms against observable signs with caretakers of sick children.

1. Gather information from written sources

- 1.1 There may be written sources that provide validated information on local terms. If ethnographic studies have been completed for the ethnic or linguistic groups in the area where the materials are being adapted, these will be a good source. Some countries may have identified and validated local terms for use in household surveys. Health education materials directed at the community and mother counselling cards will also be good sources, if they have been adapted for local use.
- 1.2 Review the written sources and highlight references to any of the ten terms or conditions that need to be locally adapted. Use **Recording Form 1a**. (at the end of this Step 1) to record this information. In the box labelled "Source" indicate the type of written material from which the information comes. Then fill in the information. For example, if a written source includes a local term for diarrhoea, write this in the box in the row for "diarrhoea".

Note: You may need to use additional pages of these forms, if you identify more potential local terms than spaces provided.

2. Gather information from members of the planning team and other clinicians

- 2.1 Interview individuals with clinical experience in the geographic area for which adaptation is being carried out. Use **Recording Form 1b**. Interview at least five clinicians. In the box labelled "Clinician", include information about the type of health worker (e.g. paediatrician, nurse), where he or she has practised (e.g. large hospital, community health centre), language or dialect, and ethnic group.

- 2.2 For each of the generic terms ask the clinician about the words or phrases caretakers in the area use. Encourage people to give more than one term or phrase if they believe there are several different terms that might be applicable. Record the answers in the appropriate boxes. Complete a column for each clinician interviewed.
- 2.3 After the interview, write notes and questions that can be clarified in the interviews with the caretakers. For example, if you find that several terms are used for difficult breathing, make a note to explore whether these words indicate different signs or whether individuals are using different words for the same sign.

3. Gather information from caretakers

- 3.1 Interview caretakers of young children. In Annex E-1, the **Guide for the interview with caretakers** provides instructions for conducting these interviews and an explanation for the purpose of each question. Use **Interview Form 1a: Information from Caretakers**, also in Annex E-1, to record the results of each interview.
- 3.2 Select a health centre to conduct the interview with the following characteristics: (1) serving a population that is typical of the area; (2) with a large enough patient load to obtain 15 interviews in a single morning; (3) with a physical layout that provides a quiet space to conduct the interviews. Interview at least 15 caretakers. If possible, interview a larger sample as this may resolve ambiguities and avoid the need to go on to Step 2.
- 3.3 Transfer the results from each of the individual interviews to **Recording Form 1c: Local Terms from Caretaker Interviews**. Use one column for each caretaker and begin by recording the name of the respondent in the box labelled "Caretaker name" and the "Language" used at home. Then fill in the boxes. For each generic word, write the word or phrase you have selected as the "best word" in Part 9 of the interview form.

4. Tabulate and compare results to assess whether further information is required for any of the terms

- 4.1 Tabulate the results of caretaker interviews on **Tabulation Form 1**.
 - a. Write in all the terms you have put on **Recording Form 1c**.
 - b. Count the number of times each term is used. Write the number of caretakers using the term in the appropriate column. (*Note that the maximum number you can have for any particular term is the total number of caretakers that you interviewed.*)
- 4.2 Compare the results of the caretaker interviews with results from the clinicians and the written materials.

- a. Take **Recording Form Ib**, which contains the terms suggested by the clinicians. Look for the caretaker terms you have listed on **Tabulation Form 1**. Each time you find the same term, make a tick mark (✓) in the appropriate box on **Tabulation Form 1**. in the column labelled "Number of clinicians using this term".
- b. Take **Recording Form Ia**. Refer to those written sources that provide validated local terms. For each term that was identified in the written materials, write a "yes" in the appropriate column on **Tabulation Form 1**.

If the term did not appear in any written materials, write a "no".

- 4.3 Assess the degree of consensus by comparing the terms used on **Tabulation 1**. First look at the results in the caretaker column: is there consensus or near consensus among caretakers? Then look at the column on clinician suggestions. How does this compare with the caretakers' responses? If there are differences, what might they be due to? Thirdly, compare the caretaker and clinician responses with the written materials. Do you find the most common words and phrases are described or used in these sources? If not, what is the likely explanation?

5. Decide whether to adapt materials on the basis of current information

- 5.1 The ability to select terms at this point depends on the level of consensus in the results on **Tabulation Form 1**.
 - a. *If there is consensus or near consensus among caretakers, clinicians, and other sources on local terms:* you do not need to gather additional information. This consensus is sufficient to select a term for use in adapting materials.

- b. *If consensus is high among caretakers but differs from the clinicians' suggestions and written sources:* decide whether this is because the latter sources are not sufficiently familiar with local terms and concepts. If so, you may decide that you do not need further information to select the caretakers' term.
 - c. *If caretaker' responses are split between two different terms:* an option is to include both terms in adapted materials. A split may be an indication that there are two subgroups of caretakers, such as two different ethnic or language groups. If the clinicians suggest only one of the terms, the split may instead mean that some caretakers have learned the words used by health workers. It would, therefore, be important to use both terms.
 - d. *If consensus is low among caretakers, and the clinician and written sources do not provide adequate information to determine why these variations occur:* then it is important to carry out **Step 2**. This step permits you to resolve ambiguities by validating terms against observable signs.
 - e. *If you are not confident from your interviews that you were getting the best local term:* you can use the procedures described in **Step 2**. The terms for *fast breathing* and *difficult breathing*, for example, may need to be validated. Experience has shown that interviewing caretakers about terms for breathing problems is difficult unless you can refer to a visual image.
- 5.2 If no further information is required, go to **Step 3**.
- 5.3 If further information is required for any of the generic terms, go on to **Step 2: Validate local terms through interviews with caretakers of sick children**. Use only those parts of the interview that are relevant for the terms you need to validate.

Recording Form 1a: Local terms from WRITTEN MATERIALS

Generic term	Source:	Source:	Source:	Source:	Source:
1. DIARRHOEA					
2. BLOOD IN THE STOOL					
3. FEVER (elevated body temperature)					
4. FAST BREATHING					
5. DIFFICULT BREATHING					
6. MEASLES					
7a. NOT ABLE TO DRINK					
7b. DRINKING POORLY					
8a. NOT ABLE TO BREASTFEED					
8b. BREAST-FEEDING POORLY					
9. BECOMES SICKER					
10. CONVULSIONS					

Recording Form 1b: Local terms from CLINICIANS

Generic term	Clinician:	Clinician:	Clinician:	Clinician:	Clinician:
1. DIARRHOEA					
2. BLOOD IN THE STOOL					
3. FEVER (elevated body temperature)					
4. FAST BREATHING					
5. DIFFICULT BREATHING					
6. MEASLES					
7a. NOT ABLE TO DRINK					
7b. DRINKING POORLY					
8a. NOT ABLE TO BREASTFEED					
8b. BREAST-FEEDING POORLY					
9. BECOMES SICKER					
10. CONVULSIONS					

Recording Form 1c: Local terms from CARETAKER INTERVIEWS

Generic term	Caretaker name:	Caretaker name:	Caretaker name:	Caretaker name:	Caretaker name:
	Language:	Language:	Language:	Language:	Language:
1. DIARRHOEA					
2. BLOOD IN THE STOOL					
3. FEVER (elevated body temperature)					
4. FAST BREATHING					
5. DIFFICULT BREATHING					
6. MEASLES					
7a. NOT ABLE TO DRINK					
7b. DRINKING POORLY					
8a. NOT ABLE TO BREASTFEED					
8b. BREAST-FEEDING POORLY					
9. BECOMES SICKER					
10. CONVULSIONS					

Tabulation Form 1: Comparison of Terms

Generic term	Local term (word or phrase used by caretakers)	Number of caretakers using this term (selected as best)	Number of clinicians using this term	Identified in written materials? YES/NO
1. DIARRHOEA				
2. BLOOD IN THE STOOL				
3. FEVER (elevated body temperature)				
4. FAST BREATHING				
5. DIFFICULT BREATHING				
6. MEASLES				
7a. NOT ABLE TO DRINK				
7b. DRINKING POORLY				
8a. NOT ABLE TO BREASTFEED				
8b. BREAST- FEEDING POORLY				
9. BECOMES SICKER				
10. CONVULSIONS				

STEP 2: VALIDATE LOCAL TERMS THROUGH INTERVIEWS WITH CARETAKERS OF SICK CHILDREN

To validate the meaning and use of local terms for signs of childhood illness it is best to assess the terms in relation to physically observable signs. This requires that data be collected in a setting (hospital ward or busy outpatient clinic) where children with these signs are available. For signs that are physically observable at the time of the interview (e.g. fast breathing), the words caretakers use can be compared to the physical signs. Asking about other, less observable signs (e.g. diarrhoea, convulsions) through interviewing caretakers who have brought children with these symptoms for care is also a way to validate the appropriateness of specific terms.

1. Select individuals to conduct the interviews

Since the validation requires a comparison of caretakers' terms with visible signs, and the procedure includes a short examination, the individual conducting the interview must be able to assess clinical signs. A clinician is therefore a good choice to conduct the interviews. However, as the purpose is to validate local terms, great care must be taken to avoid giving the caretaker any signal to use "medical language". The interviewer must be capable of using informal, simple language. He or she should *not* wear a white coat or give any other clues of professional identity. In some settings a youthful appearance may also be an advantage, if caretakers expect health workers to be older.

2. Identify an appropriate site for the interviews

To ensure that cases with the signs that need to be validated are available, it will be necessary to conduct the interviews in a facility where the children who are brought for care are quite sick. The type of facility to select for the interviews might be a hospital with an active outpatient department, as well as an inpatient ward. It is important that the facility be used by a cross-section of the population to be served by health workers being trained with the adapted materials.

3. Prepare the interview forms and pretest the interview

In addition to translation, you may want to modify the interview forms to record only those terms that you need to validate or that can be easily included in the interview. For example, if you need to validate the terms for *fast breathing* and *difficult breathing*, you may also use the interviews with caretakers of children with respiratory signs to validate the selected local term for *fever*. With the sicker children, you may also hear terms that the caretakers who were interviewed in Step 1 used for "*becomes sicker*". Retain a place to record this on the interview form.

As with all interview protocols, it is important to pretest the questions and procedures before you begin collecting data. Pretest the protocol with two or three caretakers. Use this experience to become familiar with the facility setting and familiar with ways caretakers are likely to respond to your questions.

4. Identify caretakers of children with cough or difficult breathing and/or diarrhoea, and/or fever, depending on the terms you need to validate

To identify caretakers to be interviewed, look for children with cough or who appear to have difficult breathing. Ask whether there are any children with diarrhoea or fever. For each of the terms or phrases you need to validate, you should have responses from at least 15 caretakers. If cases are difficult to find, you may interview several caretakers about the same child, provided the child's caretaker and other present family members do not object. If you do this, be sure that you interview the other caretakers one at a time in order to avoid the problem of influencing the perceptions and answers of individual caretakers.

5. Conduct the interviews

To conduct the interviews, see the instructions in the **Guide for the Validation Interview with Caretakers of sick Children** in Annex B. Use the **Interview Form 2: Validation Interview with Caretakers of sick Children** at the end of Annex E-2 to record the responses.

Interview the caretaker and record the words the caretaker uses to describe the condition of the child in Part 1 of the interview form. (See the next step, the examination of the child, for instructions on completing the column "Corresponding clinical sign".)

6. Examine the child

In order to avoid directing the caretaker's attention to specific signs, conduct the brief examination *after* asking the questions in Part 1 on the interview form.

- Examine the child, and record the results of your examination in Part 2 of the interview form. Then go back and fill in the section in Part 1 labelled "Corresponding clinical sign" before continuing with the rest of the interview questions in Part 3.

7. Ask the caretaker the follow-up questions

Interview the caretaker about the signs you identified during the examination of the child. Use the basic follow-up questions in Part 3 on the interview form. Ask additional probing questions, if necessary to identify conditionals associated with the caretaker's terms and confirm the words and phrases used. (See the caretaker interview in Step 1 to remind you of the structure of probing questions.)

8. Analyse the results of the validation interviews

Use **Tabulation Form 2: Results of Validation Interviews with Caretakers of sick Children** to collect the results of the interviews.

- 8.1 The first task is to identify all the cases with a particular sign. Starting with *diarrhoea*, use the signs identified in Part 2 (the physical examination) to do the first sort. For signs not found during the examination, refer to the caretaker's responses to Question 1 or 2 to help you sort.
- 8.2 Review Part 3 (the follow-up, confirmation questions) on all the forms you have selected. List all the terms (words and phrases) that caretakers used in referring to the problem in the column **Caretakers' Term**.

Occasionally a term might appear frequently in responses to Questions 1 and 2 in Part 1, but does not appear in the confirmation section, Part 3. Use your judgement about whether the term is sufficiently common that it should be added to this tabulation list. If so, you will need to identify the number of times it appeared in Questions 1 and 2, not just in Part 3, in order to complete this tabulation.

- 8.3 Go through the Interview Forms a second time, and for each term (e.g. each term caretakers used for *diarrhoea*), put a tick ✓ in the column **Caretakers using this term**.
- 8.4 When you have completed the tabulation, count the number of ticks marked for each term. Write the **Total** number of caretakers in the last column.
- 8.5 Repeat 8.1 to 8.4 (above) for each of the terms you are validating.

STEP 3: SELECT LOCAL TERMS TO ADAPT THE CHART AND TRAINING MATERIALS

Selecting the terms to include in adapting the *Integrated Management of Childhood Illness* charts requires a synthesis of what you have learned from Step 1 and, if it was carried out, Step 2. In this step, therefore, select what appear to be the most commonly used and understood terms that relate most clearly to the clinical signs.

1. Begin with **Tabulation Form 1**. Record the terms you are confident were the best terms to use in talking with caretakers. These are the terms for which there is relative consensus.
2. If you have completed Step 2 for one or more terms, then refer to **Tabulation Form 2**. Select the terms for which there is relatively high consensus among the caretakers who were interviewed. If there is a disagreement between the terms obtained in Step 1 and Step 2, use the terms identified through the validation interviews in Step 2.

Complete the table on the next page to organize the terms you select, and to relate these terms to the task of adapting the *Integrated Management of Childhood Illness* charts. After the charts have been adapted to include these local terms, use the charts to adapt the *Mother's Card* and other training materials.

**Local Terms to Use in
the *Integrated Management of Childhood Illness* Charts**

For the generic term:	Use the local term (word or phrase):	Literal translation of local term into English:	Located in the BOX on the IMCI charts:
1. DIARRHOEA			Assess
2. BLOOD IN THE STOOL			Assess When to return
3. FEVER (elevated body temperature)			Assess When to return
4. FAST BREATHING			When to return
5. DIFFICULT BREATHING			When to return
6. MEASLES			Assess
7. BECOMES SICKER			When to return
8a. NOT ABLE TO DRINK			When to return
8b. DRINKING POORLY			When to return
9a. NOT ABLE TO BREASTFEED			Assess When to return Counsel the mother
9b. BREASTFEEDING POORLY			Assess When to return Counsel the mother
10. CONVULSIONS			Assess

Section E

ANNEXES

Annex E-1	Guide for the interview with caretakers
Annex E-2	Guide for the validation interview with caretakers of sick children
Annex E-3	Sample local Terms

Annex E-1

Guide for the interview with caretakers

1. INTRODUCTION

This guide provides instructions on how to ask the questions on **Interview Form 1** in order to obtain good information from caretakers on local terms. (See the form at the end of this Annex E-1.) It also gives the rationale or explanation for why these questioning procedures help you to get better information. The guide contains detailed suggestions for *opening questions* and *probing follow-up questions*. It also has suggestions for ways of restating questions in order to *confirm* that you have understood what the caretaker is telling you.

Interview Form 1 itself does *not* contain all of the introductory statements, opening questions, probing questions, and confirming questions. It contains only the opening questions and spaces for recording conclusions. You will need to study this guide, and then practice asking the opening, probing, and confirming questions. When you become familiar with this sequence and the Interview Form, you will not need the guide when you conduct the interviews. But it is important to use these questioning procedures in a systematic way to obtain good information from caretakers.

2. INSTRUCTIONS FOR INTERVIEWING CARETAKERS

Instructions

Introduce yourself and describe the purpose of the interview. Obtain the caretaker's name.

To describe the purpose of the interview, you may say:

"We want to learn about the way people here in [community] talk about children's illnesses - not the language the doctors use, but the language that families use".

Before you ask the "opening question", determine what language the caretaker speaks or prefers to speak at home.

Ask the opening question:

"What kinds of illnesses or problems do children in this community commonly experience?"

Encourage the caretaker by asking:

"Is there anything else?"

Record the answers on the Interview Form C.1.

1. Ask about DIARRHOEA and BLOOD IN THE STOOL

Rationale

The introduction should stress the need to find out about local language, rather than medical language.

The goal of the interview is to obtain the local terms only for the ten generic terms. However, ask this question first because:

- *The question orients the caretaker to focus on children's illnesses.*
- *The question signals to the caretaker that you regard her/him as someone who can tell you something you do not already know. By writing down the answers you reinforce the message that you take what caretakers say seriously.*

Note that the first phrases or answers people give are often the most salient or most common.

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Record the information about diarrhoea and blood in stool on the Interview Form, in Part 1.

a. Pick out the diarrhoea words in the reply to the opening question

Tick ✓ all items that refer to diarrhoea and stomach (GI) problems. If you are not sure what some words refer to, ask the caretaker to describe the problem.

Explain your intention to talk about diarrhoea first:

"You have mentioned _____, _____, and _____. I would like to ask some questions about these first."

b. Obtain the terms for stool

Ask:

"What is the most common word people here use for stool? Is there any other word?"

If there is more than one word, ask:

"What is the difference between _____ and _____?"

c. Identify characteristics of the most common word for diarrhoea

Ask:

"If a child has [first diarrhoea word], what does the stool look like?"

Answers may refer to consistency, colour, presence of mucus or blood; and caretaker may also mention frequency.

If the caretaker DOES NOT mention blood, ask:

"If there was blood in the stool, would you say that the child has [same diarrhoea word]?"

If the answer is YES, confirm the appropriate term by rephrasing the question. Ask:

"So, if I want to talk about the problem of stool with blood, can I say [(diarrhoea term) with blood]?"

Note that you are adding the word, "blood" as a modifier with the general term.

The first terms to obtain are those for "diarrhoea" and "blood in the stool" because they are relatively unambiguous compared to words and concepts for other signs of illness.

Nevertheless, cultural interpretations of diarrhoea are often fairly elaborate, and there may be a number of different words pertaining to different kinds of diarrhoea. You need to ask several different questions to be sure that you have the correct meaning of terms in order to determine:

- Is there more than one word for diarrhoea?*
- Do different words refer to different conditions or do these words mean the same?*
- Is there a specific and separate word for bloody diarrhoea, or do people use the general word for diarrhoea and an adjective or modifier to refer to it as diarrhoea with blood?*

Identify the word for stool here so that it can be used when you discuss "blood in the stool".

Then ask:

"Is there any other way or any other words you would use to talk about [(diarrhoea term) with blood?]"

If the answer is NO, ask:

"What words would you use to talk about the problem of blood in the child's stool?"

If the caretaker DOES refer to blood in the description of stool, confirm by asking:

"So, I can use the word [diarrhoea] when the stool is [_____, _____] (whatever words the caretaker used to refer to consistency and frequency)] and when there is blood, is that correct?"

Then ask:

"If there is no blood in the stool and it is only [watery], is there any other word to use, besides [diarrhoea]?"

d. Identify characteristics of other words for diarrhoea

Ask about other terms mentioned in the opening question:

"You also mentioned [_____]. Is [_____] the same or different than [first diarrhoea word]?"

If the caretaker says that it is different:

"How is it different?"

In response to your opening question, the caretaker may have given you other words that refer to intestinal problems or other words for "diarrhoea". Before you decide that you have identified the correct word for "diarrhoea" and for "blood in the stool", you need to ask about these other terms.

2. Ask about FEVER

Record the information about fever on the Interview Form, in Part 2.

a. Identify words or phrases that refer to elevated body temperature or hot body

Explain your intention:

"Sometimes when children are sick their skin feels hot when you touch them."

Then ask:

"What words would you use to describe this?"

Confirm the appropriateness of term for an infant or child.

Ask:

"So, if I feel my child's face or body and it feels hotter than normal, I can say 'My child is or has [fever term]'?"

In many cultures, the word that translates into English as "fever" refers to a complex of signs and symptoms, not just elevated body temperature. Families may use the word "fever" as an illness term or diagnostic category. A child may be described as "having fever" when he or she has signs indicative of flu, respiratory infection, or even a GI infection.

The purposes of the questions are to determine:

- *What words or phrases are used to refer to elevated body temperature or skin that is hot to the touch?*
- *Is there more than one word for this condition?*
- *Do these words mean the same?*

b. Identify characteristics of words or phrases for elevated body temperature

Ask:

"When a child has [fever term], is there anything else wrong that you can see or feel?"

The purpose of these questions is to determine whether the fever term is conditional on the occurrence of other signs or symptoms.

Probe for relationship of these other characteristics as conditionals for fever:

"If a child has [fever term] but does not have [other term mentioned in answer to previous question], would you still say that he has [fever term]?"

If answer is NO, ask:

"Then what word or words should I use if I want to tell you that the child feels hot to the touch?"

c. Confirm the terms for fever

If there are NO conditionals, and the term can be used without regard for the presence or absence of other signs, confirm by asking:

"So, whenever a child's skin feels hot to the touch, I can say, 'This child has [fever term].' Is this correct?"

If there ARE conditionals, and the term or phrase can only be applied when selected other signs are present, then ask:

"So, if a child's skin feels hot, but he does not have [name of conditional sign], then I cannot say that the child has [fever term]. Is this correct?"

"But I can say, 'This child is or has [words or phrase suggested by caretaker in answer to previous question].' Is that correct?"

3. Ask about FAST and DIFFICULT BREATHING

Record the information on the Interview Form, Part 3.

a. Identify words or phrases that refer to fast or difficult breathing

Explain your intention:

"Sometimes when children are sick they have difficulty in breathing because they have a blocked nose. But sometimes the problem is in the chest [*show location*]. I would like to find out what words to use to talk about breathing problems in the chest."

Then ask:

"What words would you use to describe this?"

b. Identify differences among words

Ask:

"What is the difference between [first word] and [second word]?"

If there is no difference, confirm by asking:

"So, if a child is having trouble breathing because of a problem in the chest, I can say either [] or []; is that correct?"

Ask about other words:

"You also said [third word]. Is there any difference between [third word] and [first word] and [second word]?"

c. Identify characteristics of the most common words.

Ask:

"When a child has [breathing term], is there usually anything else wrong that you can see or feel?"

Probe for relationship of these other characteristics as conditionals for difficult breathing:

"If a child has [breathing term] but does not have [other term mentioned in answer to previous question], would you still say that he has [breathing term]?"

If answer is NO, ask:

"Then what word or words should I use to talk about difficult breathing if [other term mentioned] or [the child's body is not hot to touch]?"

In most cultures, there are many different words and phrases to talk about respiratory signs and symptoms. The problem is to identify the words that refer specifically to the signs of fast and difficult breathing that are indicative of pneumonia rather than words that are used for breathing problems associated with upper respiratory infections.

When the caretaker describes the differences between words she uses, listen for the words that relate to quickness of breath, and those that relate to other stressful breathing (e.g. struggling for breath, very slow or hard or laboured breathing). These differences may help to distinguish fast from difficult breathing.

*Also, in some cultures the chest indrawing that occurs with severe pneumonia is seen as a problem in the abdomen, not in the chest. It is difficult to find this out through interviewing about terms for breathing problems. It is therefore particularly important to confirm the terms through the interviews of caretakers with children who exhibit these signs. The answers to these questions will give you some words to confirm in the clinic study in **Step C2**.*

The purpose of these questions is to determine whether the terms for fast and difficult breathing are conditional on the occurrence of other signs or symptoms, particularly fever. This is an important step because in many cultures breathing difficulties are regarded as a symptom of "fever", and, if the child does not have markedly elevated body temperature, the terms you have been given may not apply.

4. Ask about MEASLES

Record the information on measles on the Interview Form, Part 4.

a. Identify the illness name for measles

Explain your intention:

"Earlier, when you told me about the kinds of illnesses or problems children have, you (did) (did not) mention [term for measles you think is locally used]. I would like to ask you more about that."

As measles is a very distinctive disease, there is usually a specific term for it in most cultures. You can confirm the local term with caretakers by asking for the signs that are associated with the illness term.

b. Confirm skin rash as a sign of the local term

Ask:

"When a child has [measles term], does he have anything wrong with his skin?"

If YES, ask:

"How would you describe it?" *(This should give you the local term or phrase for generalized rash.)*

If NO, this is not the correct word for measles, ask:

"What do you call the illness when children have [a rash] on their skin?"

c. Confirm other measles signs

Ask:

"When a child has [measles term], with [rash], are there any other problems that they sometimes have?"

If caretaker does not mention one of the following: cough, runny nose, or red or sore eyes, ask:

"Do children with [measles] sometimes have [cough], [runny nose], or [red or sore eyes]?"

If caretaker answers NO to all three, the term she is referring to is probably not measles.

5. Ask about NOT ABLE TO DRINK or DRINKING POORLY

Record the information on the Interview Form, Part 5.

a. Identify words or phrases for "not able to drink" and "drinking poorly"

Explain your intention:

"Sometimes a sick child is so ill that they are not able to drink. I would like to know how to talk about this problem."

Ask:

"How would you describe a child who cannot drink? Are there any other words you would use?"

The purpose of these questions is to determine what is the best way to alert caretakers to the danger signs of "not able to drink" and "drinking poorly".

b. Determine whether there is a distinction between "not able to drink" and "drinking poorly"

It is likely that caretakers make a distinction between "not able to drink" and "drinking poorly". The follow-up questions permit you to determine this.

Ask:

"Can I say [phrase], if the child is drinking poorly but still drinking something?"

If not, ask:

"What would you say to describe a child who is drinking poorly?"

6. Ask about NOT ABLE TO BREASTFEED OR BREASTFEEDING POORLY

Record the information on the Interview Form, Part 6.

a. Identify the words for "not able to breastfeed"

Ask:

"What word do you use for drinking from the breast (or nursing)?"

The purpose of these questions is to determine what is the best way to alert caretakers to the danger signs of "not able to breastfeed" and "breastfeeding poorly".

Ask:

"Sometimes a baby is too sick to [nursing term]. Would you say that the baby is [negative form of nursing term]?"

Then ask:

"Are there any other words you would use or any way you would describe this?"

- b. **Determine whether there is a distinction between "not able to breastfeed" and "breastfeeding poorly"**

It is likely that caretakers make a distinction between "not able to breastfeed" and "breastfeeding poorly". The follow-up questions permit you to determine this.

Ask:

"Can I say [phrase], if the child is [nursing] poorly but is still sucking from the breast?"

If not, ask:

"What would you say to describe a child who is [nursing] poorly?"

7. Ask about "BECOMES SICKER"

Record the information on "becomes sicker" on the Interview Form, Part 7.

- a. **Identify words or phrases that refer to "becomes sicker"**

Explain your intention:

"When babies and small children are sick, they have specific problems, such as fast breathing, diarrhoea, or a rash. But you also know they are sick because of the way they look and act. I would like to know how caretakers here talk about these problems."

Then, ask:

"How do you know that a child is becoming sicker? What words would you use to describe this?"

- b. **Identify differences among words to determine the characteristics of the words**

Ask:

"What is the difference between [first phrase] and [second phrase]?"

If there is no difference, confirm by asking:

"So if a child is very sick, I can say either [_____] or [_____]. Is that correct?"

Ask about other words:

"You also said [_____]. Is there any difference between [third word] and [second word]?"

Caretakers need to be able to recognize that the condition of the child is worsening and they therefore should return immediately with the child to the health worker. It may be helpful to translate "becomes sicker" to include local terms that are the equivalent of "lethargic", "very weak," etc. The purpose of these questions is to identify local terms for generalized signs of worsening sickness. In contrast with other terms that must refer to more specific signs, the terms identified for "becomes sicker" should be able to apply to several clinical conditions.

8. Ask about CONVULSIONS

Record the information on convulsions on the Interview Form, Part 8.

a. Identify the word for convulsions

Explain your intention:

"Earlier, when you told me about the kinds of illnesses or problems children have, you (did) (did not) mention [convulsions term that you think is locally used]. I would like to ask you more about that."

Then, ask:

"How would you describe [convulsions term]?"

Ask:

"Is there any other way or any other words you would use to talk about [convulsions term]?"

b. Identify characteristics of words or phrases for convulsions

Ask:

"When a child has [convulsions term], are there any other problems that they sometimes have?"

Probe for the relationship of these other characteristics as conditionals for convulsions:

"If a child has [convulsions term]. But does not have [other terms mentioned in answer to previous question], would you still say that he has [convulsions term]?"

If answer is NO, ask:

"Then what word or words should I use to talk about [convulsions term] if the child does not have [other term mentioned]?"

The local term that translates into English as "convulsions" may refer in some cultures to a complex of signs and symptoms (e.g. the word for "fever" may be related to "convulsions"). The term may also mix the believed illness category or its etiology with its description (e.g. bad spirit). It is, therefore, important to ask the caretaker to describe what she means by the local term for "convulsions" so that it is distinct from "fever" and other terms.

9. Summarize the responses of this caretaker

Complete the summary section (Part 9) immediately, so that you can select the best word or phrase for the caretaker you have just interviewed.

Interview Form 1
Information from Caretakers

1 of 8

Caretaker's name: _____

Language used at home: _____

Ask the opening question: "What kinds of illnesses or problems do children in this community commonly experience?"

Record the answers below:

Tick ✓ the words above that appear to relate to diarrhoea.

Part 1. Ask about DIARRHOEA and BLOOD IN THE STOOL

1. Ask: "What is the most common word people here use for stool? Is there any other word?"

Word(s) for stool: _____

2. "If a child has _____ [first diarrhoea word ticked ✓ above] what does the [stool term] look like?"

Characteristics: _____

Blood in the stools? ____ **Yes** ____ **No**

3. "If a child has _____ [second diarrhoea word ticked ✓ above] what does the [stool term] look like?"

Characteristics (how it is different from the second):

Blood in the stools? ____ **Yes** ____ **No**

4. "If a child has _____ [third diarrhoea word ticked ✓ above] what does the [stool term] look like?"

Characteristics (how it is different from the second):

Blood in the stools? ____ **Yes** ____ **No**

5. "Is there any other way to talk about the problem of stools with blood?"

Other words or phrases to describe stools with blood: _____

Part 2. Ask about FEVER

1. *Ask: "Sometimes when children are sick their skin feels hot when you touch them. What words would you use to describe this?"*

Word(s) for hot body: _____

2. "When a child has _____ [first hot body word], do they have anything else wrong that you can see or feel?"

Conditions: _____

Conditionals? ☐ **Yes** ☐ **No**

3. "When a child has _____ [second hot body word], do they have anything else wrong that you can see or feel?"

Conditions: _____

Conditionals? ☐ **Yes** ☐ **No**

4. "When a child has _____ [third hot body word], do they have anything else wrong that you can see or feel?"

Conditions: _____

Conditionals? ☐ **Yes** ☐ **No**

5. "If a child does not have [conditionals from above], but she is hot to the touch, can I still say she has _____ [likely best fever term]?"

☐ **Yes** ☐ **No**

Part 3. Ask about FAST AND DIFFICULT BREATHING

1. *Ask about words to describe difficulty in breathing, caused by a problem in the chest.*

Word(s) or phrases for fast and difficult breathing: _____

2. *Word or phrase that relates most to FAST BREATHING:* _____

3. *Word or phrase that relates most to DIFFICULT BREATHING:* _____

4. "When a child has _____ [fast breathing term], what else is wrong?"

Conditions: _____

Conditionals? ☐ **Yes** ☐ **No**

5. "When a child has _____ [difficult breathing term], what else is wrong?"

Conditions: _____

Conditionals? ☐ **Yes** ☐ **No**

Part 4. Ask about MEASLES

1. Likely words for measles (from opening question above, offered by caretaker, or earlier interviews):

Word(s) for measles: _____

2. "When a child has _____ [measles term] does he have anything wrong with his skin?" ___Yes ___No

If yes, characteristics of skin problem:

Measles rash? ___Yes ___No ___Not sure

3. "When a child has _____ [measles term], with _____ [rash], are there other problems they sometimes have?"

Other measles signs mentioned:

___Cough ___Runny nose ___Red or sore eyes Other: _____

At least one measles sign? ___Yes ___No

Part 5. Ask about NOT ABLE TO DRINK OR DRINKING POORLY

1. "How would you describe a child who cannot drink?"

Phrase(s) for not able to drink: _____

Differences between phrases: _____

2. "What would you say to describe a child who is drinking poorly?"

Phrase(s) for drinking poorly: _____

Differences between phrases: _____

Part 6. Ask about NOT ABLE TO BREASTFEED OR BREASTFEEDING POORLY

1. "What word do you use for drinking from the breast (or nursing)?

Word(s) for nursing: _____

2. "Sometimes a baby is too sick to [nursing term]. Would you say that the baby is

_____ [negative form of first nursing term]?" ☐ **Yes** ☐ **No**

3. Sometimes a baby is too sick to [nursing term]. Would you say that the baby is

_____ [negative form of second nursing term]?" ☐ **Yes** ☐ **No**

Differences between first and second phrases: _____

Part 7. Ask about "BECOMES SICKER"

1. "How do you know that a child is becoming sicker?"

Phrases for "becomes sicker": _____

2. Characteristics of first phrase:

Characteristics of second phrase:

Characteristics of third phrase:

Part 8. Ask about CONVULSIONS

1. "Is there any other way than _____ [convulsions term you think is locally used] you would use to talk about [convulsions term]?"

Word(s) for convulsions: _____

2. Characteristics of first word:

Conditionals? ☐ **Yes** ☐ **No**

3. *Characteristics of second word:*

Conditionals? ___Yes ___No

4. *Characteristics of third word:*

Conditionals? ___Yes ___No

Part 9. Summarize the responses of this caretaker

1-2. List the DIARRHOEA and BLOOD IN THE STOOL terms:

Word or phrase	Includes blood in the stool?	
	Yes	No

For this caretaker, best word or phrase to use for DIARRHOEA is: _____

For this caretaker, best word or phrase to use
for BLOOD IN THE STOOL is: _____

3. List FEVER terms:

Word or phrase	Conditional on other signs?	
	Yes	No

For this caretaker, best word or phrase to use for FEVER is: _____

4. List FAST BREATHING terms:

Word or phrase	Includes blocked nose?		Conditional on high fever?	
	Yes	No	Yes	No

For this caretaker, best word or phrase to use for FAST BREATHING (not due to blocked nose) is: _____

5. List DIFFICULT BREATHING terms:

Word or phrase	Includes blocked nose?		Conditional on high fever?	
	Yes	No	Yes	No

For this caretaker, best word or phrase to use for DIFFICULT BREATHING (not due to blocked nose) is: _____

6. List MEASLES terms:

Word or phrase	Includes at least one other measles sign?	
	Yes	No

For this caretaker, the best word or phrase for MEASLES is: _____

7. List terms for NOT ABLE TO DRINK and DRINKING POORLY:

	Word or phrase
Not able to drink	
Drinking poorly	

For this caretaker, the best word or phrases to use
for NOT ABLE TO DRINK is: _____

For this caretaker, the best word or phrases to use
for DRINKING POORLY is: _____

8. List terms for NOT ABLE TO BREASTFEED and BREASTFEEDING POORLY:

	Word or phrase
Not able to breastfeed	
Breastfeeding poorly	

For this caretaker, the best word or phrase to use
for NOT ABLE TO BREASTFEED is: _____

For this caretaker, the best word or phrase to use
for BREASTFEEDING POORLY is: _____

9. List terms for "BECOMES SICKER":

Word or phrase	Characteristics	

For this caretaker, the best word or phrase to use for "BECOMES SICKER" is (the one that refers most generally to becoming sicker): _____

10. List terms for CONVULSIONS:

Word or phrase	Conditional on other signs?	
	Yes	No

For this caretaker, best word or phrase to use for CONVULSIONS is: _____

Annex E-2

Guide for the validation interview with caretakers of sick children

INSTRUCTIONS FOR INTERVIEWING CARETAKERS OF SICK CHILDREN

Instructions

1. Introduce the purpose of the interview

Approach the caretaker, and ask whether you can speak to her briefly about her child's problem. You should make it clear that this interview is voluntary.

Explain:

"We want to learn about the way people here in [community] talk about children's illnesses - not the language the doctors use, but the language that families use."

Rationale

The introduction should stress the need to find out about local language, rather than medical language.

When possible, it is best to complete the interview before the caretakers see the health worker so that their answers are not influenced by the medical diagnosis. For children on hospital wards this will not, of course, be possible. In either setting, arrange the interviews so that you do not delay the child's treatment.

2. Ask questions a, b, and c on the Interview Form 2, Part 1

Ask:

- a. "What problem does your child have?"

Write down all the words the caretaker gives you in the space below Question 1.

Note that some caretakers will respond to this question by telling you what signs the child has. For example: "She has a cough", or "He has diarrhoea and vomiting". Others will answer by giving you the name of an illness they think the child has. For example: "He has a bad cold", or "He has [local name for pneumonia]".

Ask:

- b. "Are there any particular signs or symptoms you are worried about?"

Write down all the words the caretaker gives you and probe for additional terms.

Ask:

- c. "Can you show me [sign 1]; [sign 2]; etc.?"

Some of the signs the caretaker is worried about will be present and visible, but others will not. For visible signs - e.g., respiratory signs, fever, rash - ask the caretaker to show you these signs. Write the words she gives these signs in the left-hand column labelled "Caretaker's Terms". Write in the corresponding clinical signs on the right hand side.

3. Examine the child

Observe the child and record the physical signs and symptoms in Part 2 of the Interview Form.

After the examination, go back to Part 1. Fill in the "corresponding clinical sign" next to the appropriate caretaker's term.

Use the information from the examination:

- a. *To confirm the physical signs to which the caretaker has referred. For example, confirm that there was fast breathing by counting the breaths or look and listen for other signs of difficult breathing.*
- b. *To identify which signs and symptoms to ask the caretaker about during the follow-up questions in Part 3.*

4. Ask the follow-up questions to confirm the caretaker's terms

Ask the follow-up questions (Part 3 on the Interview Form) for each sign the child exhibits at the time of the interview. These are the signs that you found during the examination of the child.

It is particularly important to ask the follow-up questions for children with fast breathing, difficult breathing, and blood in the stool. These local terms are used when counselling mothers to alert them about danger signs that require them to return immediately.

1 of 2

Age of child: _____

Inpatient
Outpatient

Ask, and record the answers.

- Record the terms the caretaker mentions below. Confirm the clinical signs (when appropriate) that correspond to the caretaker's terms, as you examine the child in Part 2.*

Caretaker's term	Corresponding clinical sign

Record your findings in the box below.

1. Temperature:	_____ °C axillary or _____ °C rectal		
2. Respiratory rate (<i>count for 60 seconds in calm child</i>):	_____ breaths per minute		
Circle your findings:			
1. Fever (> 39.5°C)?	yes	no	cannot tell
2 a. Fast breathing?	yes	no	cannot tell
b. Difficult breathing (<i>specify if lower chest indrawing or other difficult breathing, such as grunting</i>): _____	yes	no	cannot tell
3. Measles (generalized rash)?	yes	no	cannot tell
4. <i>Circle one</i> : Not able to drink or drinking poorly?	yes	no	cannot tell
5. <i>Circle one</i> : Not able to breastfeed or breastfeeding poorly?	yes	no	cannot tell
6. Convulsions?	yes	no	cannot tell

Part 3. Ask follow-up questions to confirm the caretaker's terms

Ask the follow-up questions listed below that relate to the child's condition and signs of illness (identified during your examination in Part 2). If the caretaker uses the same term (word or phrase) she used in responding to Part 1 above, record the response in the box to the right of the question, indicating that the term has been confirmed.

If NO, it is a new term, ask additional follow-up questions to clarify which is the term she would use. For example: "When you described this before, you called this [first term]. How is [first term] different from [new term]?" When you confirm the term she would use, write it in the box.

<i>If child has:</i>	<i>Ask the follow-up question(s):</i>	<i>Write confirmed term:</i>
1. DIARRHOEA	"What do you call this problem when your child has frequent stool?"	
2. BLOOD IN THE STOOL	"Have you seen any blood in your child's stool?" <i>If there was some blood:</i> "Is there any particular name or word for this kind of diarrhoea?"	
3. FEVER	"When your child's skin is hot like this, what would you call this problem?"	
4. FAST BREATHING	<i>Point to the chest area:</i> "How would you describe your child's breathing? Is there any particular word you would use for this kind of breathing?"	
5. DIFFICULT BREATHING (visible chest indrawing)	"What would you call this problem?"	
6. MEASLES	<i>Point to the rash:</i> "What do you call this problem on the skin?" "What illness do you think your child has?" <i>If local term (identified in Step 1) is not used:</i> "Do you think your child may have [local term for measles]?"	<i>For rash:</i> <i>For measles:</i>
7. NOT ABLE TO DRINK OR DRINKING POORLY	"How would you describe your child's problem with drinking?"	
8. NOT ABLE TO BREASTFEED OR BREASTFEEDING POORLY	"How would you describe your child's problem with breastfeeding?" <i>If caretaker has not identified problem:</i> "How would you describe the way your child is breastfeeding?"	
9. APPEARS VERY SICK (for "becomes sicker")	"How does your child seem to you?" "How would you describe the way the child seems right now?"	
10. CONVULSIONS	"What would you call what is happening (or just happened)?" <i>If no convulsion is occurring, demonstrate the shaking movement:</i> "What would you call what is happening when the child does this?"	

Tabulation Form 2

Results of interviews with caretakers of sick children

Generic term	Caretaker's term (word or phrase)	✓ Caretakers using this term	Total
1. DIARRHOEA			
2. BLOOD IN THE STOOL			
3. FEVER			
4. FAST BREATHING			
5. DIFFICULT BREATHING			
6. MEASLES			

Generic term	Caretaker's term (word or phrase)	✓ Caretakers using this term	Total
7a. NOT ABLE TO DRINK			
7b. DRINKING POORLY			
8a. NOT ABLE TO BREASTFEED			
8b. BREASTFEEDING POORLY			
9. BECOMES SICKER (or child is very sick)			
10. CONVULSIONS			

Annex E-3

Sample local terms

Following are two samples of local terms identified by interviewing caretakers and other experts. Sample 1 was drafted from the results of a Focused Ethnographic Study, the tool which provided the background experience for developing this shortened protocol for identifying and validating local terms. The final decision on specific terms to select in adapting charts and other materials needs to be made by combining the results of these studies with technical information on clinical signs and appropriate local treatments.

Sample 1: Results of a focused ethnographic study in Ile-Ife, Nigeria

ARI Home Care Advice to Mothers (for children ages 2 months to 5 years)	
<p>If your child has <i>iko</i>, Sooth the throat and relieve the cough by doing the following:</p> <ul style="list-style-type: none"> • Keep the child warm. • Give <i>osan wewe</i> and <i>ovin</i>. • Or give a teaspoon of <i>epo pupa pelu ivo</i>, or a teaspoon of <i>epo pupa pelu sugar</i>. • Clear the child's nostrils if they are blocked. 	
<p>You can try to prevent <i>iko</i> from becoming <i>iko</i></p> <ul style="list-style-type: none"> • <i>otutu</i> • <i>iko tutu</i> • <i>otutu aya</i>, or • <i>iko otutu aya</i> 	<p>By doing these:</p> <ul style="list-style-type: none"> • Feed your child warm, soft foods like pap. • Coax your child to take warm fluids (like water, milk) • Keep your child warm • Watch for fast or difficulty in breathing (see below)
<p>Watch for these signs in your child:</p> <ul style="list-style-type: none"> • <i>emi lile</i> • <i>oun mi fulefule</i> • <i>iha a ma gbe soke sodo</i> • <i>ko no le jeun</i> • <i>ara gbigbona</i> • <i>ailagbara</i> 	<p>This child may have <i>iko otutu aya</i>!</p> <p>Don't self medicate. Immediately, take the child to the health worker.</p>

Sample 2: Local terms for fever, measles and blood in stool

1. In preparation for IMCI training in Uganda, a "local terms" study was conducted. Step 1 showed a lack of consensus for three terms: "fever", "measles" and "blood in the stool".
2. In the chart below, the alternative words for these items (from Step 2), with literal translation into English, are shown. Based on interview results, including both frequency of use and referents, the terms selected for IMCI use are indicated with an asterisk.

IMCI chart	Local term/phrase	Literal translation	Physical referent
Fever	Omusujja	"fever"	Elevated body temperature, with body aches and joint pain
	Omuliwo	"illness with fire"	Same as above
	Ayokya omubiri*	"hot skin"	Elevated body temperature
Measles	Olukusense*	"disease with rash"	Measles rash plus other characteristic findings
	Mulangira	"The Prince"	Same as above
	Oluseru	"The thing"	Same as above
Blood in stool	Okudukana omusayi*	Running bloody stool	Diarrhoea with blood
	Embiwo zomusayi*	Frequent bloody stool	Same as above
	Gerenge	Bloody diarrhoea	Diarrhoea/dysentery