

of malaria case management; however, such an evaluation is beyond the scope of this Guide and requires separate protocols developed for that purpose.<sup>3</sup> This Guide must, however, take into account two important aspects of the quality of care. The first is community *perceptions* of care. If caregivers perceive, for example, that health facility staff are rude or ineffective, caregivers may delay or avoid going to the facility. The second aspect involves any element of *actual* care that affects a caregiver's treatment behaviors.

Standards of care will vary across settings, but certain basic elements are essential. Although some of these fall into the realm of clinical skill, they also affect the caregiver's ability to proceed with optimal treatment. For example, if the clinician prescribes a given dose of an antimalarial, but the person dispensing it gives the mother an incomplete dose or incorrect information on dosage, then the mother will not be able to administer the drug correctly.

### ***Research and Program Implications of Step 3***

A fundamental element of optimal care is getting a child to an appropriate health facility in a timely manner. Without information on internal and external obstacles to service utilization, program planners will have an incomplete picture of why some children arrive at a health facility late or not at all. Where specific access barriers are identified in the research, planners can devise means for overcoming them. By learning the extent to which community perceptions of quality of care affect the use of health services and by obtaining basic information on quality of care provided at health facilities, intervention planners will know the degree to which they need to focus on improving the technical and interpersonal skills of providers.

### ***Modules that Address Step 3***

The illness narratives collected according to the guidelines in Module 2 are the primary source of information about the different provider options that caregivers pursue and how they choose among them. The Health Facility module (Module 4) focuses on the caregiver's experience in the health facility and how it affects her care patterns.

#### Elements of Optimal Care for Malaria Cases

##### Provider...

- Asks about history of fever, other symptoms
- Takes temperature
- Asks about treatments (especially antimalarials) given prior to visit
- Conducts lab work (if supplies and facilities are available)
- Diagnoses malaria
- Communicates diagnosis to caregiver
- Prescribes correct antimalarial
- Prescribes correct dose of antimalarial
- Has adequate supply of antimalarial
- Dispenses correct antimalarial
- Dispenses correct and full dose
- Clearly communicates correct drug regimen to caregiver
- Ensures that caregiver understands correct regime
- Gives advice about feeding
- Explains circumstances that require a follow-up visit

3. See Murray, J., and S. Manoncourt. 1998. *Integrated Health Facility Assessment Manual*. Arlington, Virginia: BASICS for USAID; also Varkevisser, C. M., I. Pathmanathan, and A. Brownlee. 1991. *Designing and Conducting Health Systems Research Projects*. Ottawa: International Development Research Centre.

## Step 4 – Compliance and Monitoring for Treatment Failure

Once the child has been seen at a health facility, optimal treatment can continue only if the caregiver complies with the recommendations of the health provider and recognizes the signs of treatment failure.

### ***Compliance***

A caregiver's willingness and ability to comply with the provider's recommendations depends on internal and external factors. For successful compliance, a caregiver must (1) fully understand the treatment recommendations; (2) believe that following them will cure the child; (3) be able to obtain and administer the required medication; and (4) have the means to take the child to another facility, if the provider recommended it.

### ***Understanding treatment recommendations.***

Where chloroquine (CQ) or other multidose drugs are prescribed, the caregiver must understand the dosing amount and schedule as well as the importance of completing the full course of medication. Whether the caregiver administers the drugs correctly or not is affected by how well providers explain what to do, discuss potential side effects, tell the caregiver what effects to expect (for example, in reducing a child's fever), and check that the caregiver has understood.

***Belief in the treatment recommended.*** Even if a caregiver understands a recommended treatment regimen, compliance may depend on her beliefs and expectations about the efficacy of the prescribed treatment. For example, CQ has been standard treatment in most African countries for many years, and many mothers are familiar with the drug and its effects. Because resistance of malaria parasites to CQ is growing, some countries are making Fansidar™ (sulphadoxine-pyrimethamine, or SP) the first-line drug. However, Fansidar™ does not reduce fever as rapidly as CQ. If a mother has experienced treatment failure with CQ, she may be reluctant to use it again. If Fansidar™ is prescribed, a mother may expect it to reduce fever quickly and conclude that it is not working. If she believes Fansidar™ to be too strong for a child, she is unlikely to administer it. If the child's condition is perceived to have spiritual causes, as convulsions sometimes are, then modern treatments may be considered ineffective.

***Ability to obtain needed medications.*** Even if a caregiver understands the treatment recommendations and wishes to comply, external barriers may prevent her from doing so. External barriers to compliance include the cost and availability of drugs. Treatment and its associated costs (such as for transportation), even when minimal, can place a great burden on already impoverished families, making it difficult for them to act on provider recommendations. Even where costs are affordable, the needed drugs may not be readily available. Community perceptions of the cost and availability of antimalarials are as important as actual costs and accessibility. When families perceive costs as high or drugs as unavailable, these factors become barriers to compliance.

The studies in Kenya and Zambia found that caregivers are often given two or three drugs to administer to a child, each with multiple doses. During exit interviews, many caregivers could not recall accurately how to administer these drugs. Some were given packets with symbols to indicate dosage, but were not able to interpret the symbols.

The studies also showed that a central problem in the treatment process was the practice of giving incomplete doses of antimalarials. Few caregivers were told that it is essential to give the complete course of medication even if the child appears to recover before the medication is finished.

**Compliance with referrals.** A special kind of compliance issue is referral. Children who are referred by a trained provider to another health facility represent the most severe or problematic cases, yet because of the human and external factors already discussed, many such children are not taken to the recommended institution. Formative behavioral research can identify both perceptual and physical obstacles to acting on referrals.

### ***Monitoring for Treatment Failure***

As resistance to some antimalarials is growing, it is important to find out how caregivers define treatment success or failure and whether they know the symptoms of failure. Inability to recognize signs of treatment failure is likely to lead to delays in obtaining critical follow-up care.

### ***Research and Program Implications of Step 4***

Researchers need to understand why some families comply with treatment recommendations and others do not. Once the internal and external factors are identified, interventions can be planned accordingly. Where families do not understand treatment guidelines, planners can implement measures to improve communication or develop simple reference or reminder materials for caregivers. Where caregivers have erroneous beliefs or perceptions about treatment regimes, planners can develop activities and messages to dispel such ideas. Where the cost and availability of drugs prevent compliance, program managers can work at the national and district level to improve distribution and reduce costs. If caregivers do not discern treatment failure when it occurs, the research can help identify messages to improve recognition.

### ***Modules that Address Step 4***

Issues of compliance and recognition of treatment failure can be examined in the Illness Narratives that will be collected in Module 2. If compliance is a priority topic of your research, be sure to conduct the Health Facility module (Module 4), which gives special attention to follow-up interviews to find out what caregivers did after visiting the health facility and why provider recommendations were or were not followed. Although such follow-up interviews are resource-intensive, they are methodologically preferable to the illness narratives for examining compliance. The illness narratives rely on retrospective reporting on both provider treatment recommendations and caregiver treatment actions. The Health Facility module, on the other hand, records recommendations when the provider makes them and follows up at the time that compliance should be taking place.

## **Step 5 – Return Visit to Health Facility for Treatment Failure**

When a caregiver perceives that a child is not responding to treatment, she must start the decision-making process anew. Some families return to the same health facility. Others consult a different one, seek traditional sources of care, or pursue home remedies. Once again, a variety of internal and external factors affect their decisions. If an antimalarial is perceived to have failed, caregivers may be reluctant to return to the institutional health system. If cost and transportation were obstacles to a first visit, they may be even greater obstacles to a second.

If the child does not respond to treatment and is taken back to the health facility, the clinician must recognize the problem as treatment failure and prescribe or administer the correct second-line drug. If the same drug is prescribed and the child does not recover, a family may lose confidence in the provider.

### ***Research and Program Implications of Step 5***

Program planners will want to understand all of the factors that encourage or discourage return visits when the child fails to recover: internal factors, such as caregivers' expectations for recovery; external barriers, such as cost or transport; and health facility factors, such as provider reactions to return visits (whether the mother is praised or scolded) and decisions about using second-line drugs.

### ***Modules that Address Step 5***

Information about return visits is gathered from the Illness Narratives and Health Facility modules (Modules 2 and 4). In the narratives, caregivers can explain what they did when the child did not recover as expected. Some caregivers interviewed in the Health Facility module will be there for repeat visits, and can describe what happened and their decision to return to the facility.

## **Elaborating the Model for Your Research Setting**

It is useful to elaborate the care-seeking model and make it specific to the setting in which you are working. Some elements of the model are universal—for example, early signs and illness symptoms. Other elements are context-specific—such as the first-line antimalarial or MOH recommendations for home care actions. Ask MOH personnel to identify the elements of each step that are “local.” *The MOH needs to define exactly what it is asking caregivers to do.* Health officials often assume there is consensus on this, but when you ask for it to be specified, you may find that there are, in fact, differing opinions. For example, some staff may feel that as soon as a mother detects fever in her child, she should take the child to a health facility. Others reason that fever among children is common and may be transient, and that the health system would be overwhelmed if every case were seen at a health facility. In this latter case, the emphasis would be on home care and monitoring for symptoms that indicate the child needs to be taken promptly to a health facility. If differing opinions exist, the MOH should begin a process of coming to consensus about them. When messages to caregivers are designed as part of an intervention, it is important that they do not conflict with MOH policy.

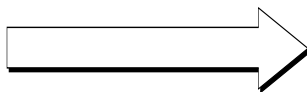
The following are some of the things that you will want to determine for the setting in which you are working:

- The overall structure of the health system; health facility options; other provider options
- First-line and second-line drugs, and how each is to be administered
- Recommendations for home care treatments, such as tepid sponging
- In the absence of danger signs, the maximum amount of time that the MOH recommends treating low-grade fever at home before a caregiver takes the child to the health facility. (Of course, as soon as any danger sign appears, the child should receive modern care immediately.)
- Health facility policies for review and return visits
- How health facilities are organized for provision of service. In some places, the clinician examines and decides what treatment should be given, but the caregiver actually receives medications and instructions from a different staff person. The Health Facility module will need to be adapted to reflect the internal organization of the institution.
- The fee policy for service or medication

The elaborated model used in Zambia is shown in Figure 2 and includes some of the particular elements of the Zambian context. For example, in Zambia, health centers promote tepid sponging at home, CQ is the first-line drug, and mothers who have visited a health facility are asked to return in 3 days for a “review visit” or come back sooner if the child shows no improvement. All of these elements were included in the Zambian model and examined in the research. The specifics of the model will differ by country and have implications for topics to explore in the research. For example, where Fansidar™ is the first-line drug and only a single dose is required, the issue of “completing the course of medication”—so important if CQ is the first-line drug—becomes irrelevant.

**Figure 2: Sample Elaborated Model of Optimal Care-seeking for Malaria  
(Model of ideal treatment in Zambia, where CQ is the first-line drug)**

| <i>Step 1<br/>RECOGNITION<br/>OF SYMPTOMS</i> |                                       | <i>Step 2<br/>APPROPRIATE<br/>HOME CARE<br/>AND MONITORING</i>   | <i>Step 3<br/>TREATMENT AT<br/>HEALTH FACILITY (HF)<br/>[Quality of Care]</i> |   |   |   |
|---|---------------------------------------|--|---|---|---|---|
| Caregiver recognizes early signs              | Caregiver recognizes illness symptoms | Caregiver gives appropriate home care and decides to go to the health facility when symptoms warrant                   | [HF is accessible]  | Staff takes adequate history, gives adequate exam and correct diagnosis | Staff prescribes correct treatment  | Staff dispenses and explains correct treatment and follow-up; refers when necessary |
| Crying/irritability                           | Fever                                 | Do tepid sponging  | HF open   | Ask history of fever  | Correct antimalarial prescribed (CQ or SP)                                    | Correct drug dispensed  |
| Appetite loss                                 | Chills/sweating                       | Give antipyretic (e.g., Panadol, aspirin)  | Distance not excessive  | Ask prior treatments, especially CQ                                     | Correct dose prescribed   | Full, correct dose dispensed  |
| Less active                                   | Vomiting                              | Give correct dose of CQ  | Permission not needed   | Take temperature  | Feeding advice given  | Correct regimen clearly communicated  |
|   | Symptoms perceived as abnormal        | Watch for signals to go to HF right away:<br>– fever persists after CQ<br>– stupor/lethargy<br>– twitching/convulsions | Cost affordable   | Laboratory work, if available   | Return visit explained: in 3 days for review or immediately if no improvement | Correct regimen understood by mother  |
|   |                                       |  |   | Diagnose malaria  |   |   |
|   |                                       |  |   | Communicate diagnosis to caregiver                                      |   |   |



| <i>Step 4<br/>COMPLIANCE AND MONITORING<br/>FOR TREATMENT FAILURE</i> |  | <i>Step 5<br/>RETURN VISIT TO<br/>HF FOR TREATMENT FAILURE</i> |   |
|---|--|--|---|
| Caregiver gives correct treatment and/or goes to referral, or both    | Caregiver recognizes treatment failure and decides to go to health facility  | [HF is accessible]   | Staff takes history, examines and diagnoses; prescribes, dispenses, explains correct treatment; refers when necessary |
| Gives correct dose  | Watches for signals to return immediately to HF:<br>– fever persists<br>– stupor/lethargy<br>– twitching/convulsions | HF open  | SP given (or quinine, if necessary)   |
| Follows feeding recommendations                                       |  | Distance not excessive   |   |
|   |  | Permission not needed  |   |
|   |  | Cost affordable  |   |



## The Research Protocol and Implementation Guides

The six modules in this section make up the research protocol. Each module consists of a set of questions to be asked or observations to be made, and all except one provide formatted pages on which to record the answers and results. Unlike the questions in a survey, the questions and observations provided here are not to be followed rigidly—they cover the essential topics, but are meant to be a starting point from which the researcher can work in whatever way seems best to get the desired information. On key topics, interviewers should probe particularly thoroughly until the topic has been adequately covered.

Each module is preceded by an implementation guide, which summarizes the module's purpose, method, sample, and recording techniques, and explains how to implement the module and address issues that arise. *It is important to read the implementation guide!*

The research protocol covers all the elements of the model of optimal care-seeking described in Section 2. If all modules are used, the protocol comprises a comprehensive study of care-seeking for febrile illness. Although comprehensive, the protocol is not time-consuming: the entire set of modules can be completed in each community in 2 to 3 days by a team of four to six people.

The research protocol's modular structure makes it adaptable. Modules can be altered, omitted, or implemented in different sequences, depending on the available resources and the questions the research is meant to answer. For very rapid studies, researchers can use just the first two modules (Community Introduction and Illness Narratives) and still obtain a very solid basis of information on care-seeking. Section 4 of this Guide, Planning the Study, discusses how to adapt the protocol and modules.

This research looks at the care-seeking process and focuses on community aspects of treatment. One of the modules, however, consists of interviews and observations at the health facility. Caregivers' decisions are very much interrelated with the quality of care they receive at the health facility, both perceived and actual. The Health Facility module gives the researcher the option of examining caregivers' experience in the health facility—not for purposes of assessing clinical skill, but for understanding what features of the experience encourage and discourage appropriate community care.

| The Modules in the Research Protocol |                            |                                       |
|--------------------------------------|----------------------------|---------------------------------------|
| <i>Type of Module</i>                | <i>Name of Module</i>      | <i>Methodology</i>                    |
| Set-up and General Background        | 1 Community Introduction   | Group interview and/or social mapping |
| Core                                 | 2 Illness Narratives       | Individual narrative interview        |
| Supplementary                        | 3 Terminology and Taxonomy | Focus group                           |
| Supplementary                        | 4 Health Facility          | Interview and observation             |
| Supplementary                        | 5 Other Providers          | Individual interview                  |
| Supplementary                        | 6 Treatment Comparison     | Pile sorts and rankings               |



## Module 1: Community Introduction - *Implementation Guide*

### ***Purpose***

- Introduce the team and community
- Gather basic descriptive information about the community relevant to the research
- Find out what modern and traditional health care providers and other health resources, such as drug vendors, are available and create a comfortable atmosphere for talking about all providers, including traditional healers
- Obtain information on experiences with health facilities and providers
- Obtain information on communication topics for women and men
- Set up the rest of the research: identify potential interviewees and organize focus groups

### ***Method***

Group interview and/or social mapping

### ***Sample***

A cross-section of community residents

### ***Note Taking and Recording***

Recording Form for Community Description and open notes

## **Purpose**

This module helps you set up the research and obtain some basic community information. Holding a community discussion upon arrival at each site allows the team and community members to introduce themselves. The team can obtain permission to do the research and make arrangements to carry it out. The team should put the community at ease about the activities that will take place and should allow participants to ask questions.

Gather the basic descriptive information that you consider relevant, such as general size and type of community, source of water, main forms of livelihood, and organization of households. Also gather substantive information on selected community-wide topics, such as perceptions of various providers and IEC (information-education-communication). This general information will help set a framework for more detailed information that will come out of other modules. For example, the IEC information from the community interview can be supplemented by information from the illness narratives or elsewhere. The community discussion will give you an overview of topics, such as access to media, level of literacy, and types of community organizations. In the individual narrative, the interviewer may explore individual-level communication information, such as who entered into a particular decision or what information a health worker gave a caregiver regarding treatment.

The IEC questions should be adapted to your setting and to what you need to know for planning the intervention. If no households have electricity, you will not, of course, ask about television viewing.

Before asking about interpersonal communication, find out from your MOH colleagues what organized community provider groups there are (e.g., community health workers), how these groups are supposed to be organized, what conditions they are to treat, what drugs they have, and so on. Compare that information with what community members say about how these groups function.

Another important role of the introductory discussion is to reduce the inhibitions community members may have about mentioning traditional healers. If you discuss all the health resources available, the topic of traditional healers will probably come up. If not, the discussion leader should ask about it in a neutral way. If the team members show that they are open and nonjudgmental, it is more likely that, during later individual interviews, caregivers will feel free to say if they have sought the advice of a traditional healer.

The last task of the discussion is to set up some logistical aspects of the research. Depending on which modules you will be implementing, you can set up a time and place for the Terminology and Taxonomy focus group, find out how to locate private practitioners or traditional healers, or arrange a meeting with a community health worker. You may wish to recruit some caregivers for narratives, although in some settings it is easier to go house to house. In identifying your subjects, follow the criteria for selecting samples in each of the modules that you are using.

## Method

There is a lot of flexibility in how the information listed in the Community Introduction module is obtained. Decide whether mapping, group interview, or a combination of both is the most appropriate means of becoming acquainted with the community and preparing for the research. Sometimes the descriptive questions can be most easily answered by asking two or three people to draw a map on a piece of paper, then discussing the other issues with the community at large. Some communities may already have drawn maps for other purposes; these can be used as points of departure. Sometimes discussion suffices and no map is necessary. In urban areas, it may be difficult for community members to draw a map, as they may not know all their neighbors or be able to identify homes where children have been ill. Feel free to add participatory activities around the topics that you particularly wish to emphasize. For example, in discussing provider options you could conduct a listing and ranking exercise. Most of the information in this module is descriptive and should be gathered in the most comfortable and efficient way for all concerned. In modules involving more perceptions or opinions, it will be more important to follow a specific method.

## Note Taking and Recording

A Recording Form for the Community Description is provided for easy recording of basic descriptive information. Someone on the team can fill it in during the discussion. It is not necessary to tape the discussion as long as a note taker captures the facts and points of discussion. From this form, a chart can be easily compiled that describes the communities studied. Figure 3 is an example of such a chart for one of the three districts in the Zambia study.

Figure 3: Extract from Site Description Chart in Zambia Report  
*Compiled from community description recording sheets and describing the communities in one district studied*

| <i>DISTRICT</i> | <i>HEALTH CENTER</i> | <i>COMMUNITY</i>              | <i>COMMUNITY DESCRIPTION</i>  |
|-----------------|----------------------|-------------------------------|---|
| Chipata         | Kapata (urban)       | Kapata near HF                | <p><b>Ethnic group/language:</b> Mixed: mostly Ngoni, Chewa, Nsenga/Nyanja</p> <p><b>Characteristics:</b> High density squatter compound</p>  |
|                 |                      | Navutika Village 8 km from HF | <p><b>Livelihood:</b> Low-income category civil servants</p> <p><b>Ethnic group/language:</b> Mixed: mostly Ngoni, Chewa, Nsenga/Nyanja</p> <p><b>Characteristics:</b> High density squatter compound</p> <p><b>Livelihood:</b> Most mothers not formally employed but some are marketeers; husbands employed in low-income jobs, such as servants and watchmen</p> |
|                 | Rukuzye (rural)      | Chanje Village 1 km from HF   | <p><b>Ethnic group/language:</b> Chewa/Chichewa</p> <p><b>Characteristics:</b> Plateau</p> <p><b>Livelihood:</b> Agriculture; main crops are maize, cotton, groundnuts, tobacco; also brewing</p>   |
|                 |                      | Padambo Village 4 km from HF  | <p><b>Ethnic group/language:</b> Chewa/Chichewa</p> <p><b>Characteristics:</b> Plateau; village is near a dam</p> <p><b>Livelihood:</b> Agriculture: main crops are maize, cotton, groundnuts; small-scale fishing, brewing, carpentry, and mat-making</p>  |

For descriptive information, such as village size, verbatim notes are unnecessary, but for some IEC and health resources information, you should take verbatim notes of people's attitudes and feelings. For example, you would want to capture some of the things said about caregivers' experiences in a health facility, or why a traditional healer would be preferred to a modern provider.

Notes for IEC can be kept on a separate sheet and, when integrated with other communication information obtained in the illness narratives, be compiled as a separate section of the report.



## Module 1: Community Introduction

Introduce yourselves and briefly discuss the purpose of your visit and the research. Explain that the work involves learning about childhood illnesses and how they are treated, and give an overview of what the team would like to do in the community in the next 2 or 3 days.

You do not necessarily have to ask about these topics in the order listed. Ask follow-up questions as appropriate.

### 1. General description of community

- Size
- Main forms of livelihood
- Other characteristics

### 2. Health facility/provider resources and experiences

*What health provider/facility options are available to people in the community? How far away are they? Why/when would you take/not take a child to each? What are the advantages/disadvantages of each? How are mothers with sick children received? How are fathers with sick children received?*

[Recall that detailed information on care-seeking will be collected in the illness narratives. At this point, you are gathering general background information.]

If no one mentions the following, ask about:

- |                                 |   |
|---------------------------------|---|
| ■ Hospitals                     | ■ Community health workers                                  |
| ■ Health facilities             | ■ Traditional healers                                       |
| ■ Private providers and clinics | ■ Kiosks, stalls, stores, and pharmacies selling medication |

### 3. IEC: actual and potential sources of health information

General: *Where do people seek information on how to care for a young child with fever?*

Radio/TV:

- General level of radio/TV ownership
- Whether women have access to the radio/TV; how often they listen/watch; programs they like; when they listen/watch
- Whether men have access to radio/TV; how often they listen/watch; programs they like; when they listen/watch
- Whether there are programs on health; which ones they like/don't like

Interpersonal:

- What community groups there are (e.g., church, men's, and women's groups)
- Informal gathering/communication points for women and for men
- Health talks at clinic: how often people attend, topics covered, interest level

Print:

- General literacy level: how far most men and women go in school
- Poster recall
- Newspaper readership

### 4. Preparation for implementing other modules: identification of potential respondents

- For illness narratives (Module 2): inform the community that the team will wish to interview some mothers
- For terminology and taxonomy (Module 3): set up place and time to meet
- For private clinic interviews (Module 5): obtain names and location
- For community health worker interviews (Module 5): obtain names and locations
- For traditional healer interviews (Module 5): obtain names and locations





### 3. IEC: actual and potential sources of health information

**General:** *Where do people get information on how to care for a young child with fever?*

#### **Radio/TV:**

- General level of radio/TV ownership
  
- Women's access to radio/TV; how often they listen/watch; programs they like; when they listen/watch
  
- Men's access to radio/TV; how often they listen/watch; programs they like; when they listen/watch
  
- Whether there are programs on health; which ones they like/don't like

#### **Interpersonal:**

- What community groups there are (e.g., church, men's, and women's groups); how widely attended
  
- Informal gathering/communication points for women and for men
  
- Health talks at clinic: how often people attend, topics covered, interest level

#### **Print:**

- General literacy level: how far most men/women go in school
  
- Poster recall
  
- Newspaper readership

#### **Other:**

## Module 2: Illness Narratives - *Implementation Guide*

### ***Purpose***

- Identify care-seeking patterns—including types and sequence of treatment actions—and the factors that affect treatment decisions
- Learn how caregivers define the beginning of an illness: what symptoms make them define a child as “sick” and illness as “severe”
- Ascertain knowledge of correct dosage for antimalarial, actual dose given to child, and reasons why that dose was given
- Identify what prompts caregivers to seek help from various providers
- Determine the amount of time between the onset of a danger sign and treatment by a health worker
- Identify how caregivers define treatment success or failure
- Identify the factors that facilitate or impede appropriate care-seeking
- Identify obstacles to acting on referrals
- Obtain some specific further information for the development of IEC strategies

### ***Method***

Individual interviews using retrospective day-by-day descriptions of treatment actions for a recent febrile illness to elicit detailed information on the timing, content, and sequence of care giving, and factors that bear on decision making

### ***Sample***

Interview caregivers of children who have had fever and/or convulsions in the past 2 weeks. If you will be calculating treatment sequences (see Section 5 of this Guide: Analysis), you may wish to limit the sample to cases *completed* in the last 2 weeks. You may also want to obtain additional illness narratives for inpatient children and deceased children to help identify care-seeking factors associated with severe morbidity and mortality.

### ***Note Taking and Recording***

The interviews will yield two kinds of records: a near-verbatim record of what the respondent said and a sheet with key information coded on it.

Note: An illness narrative is a description of an illness episode and the response to it. The narratives are the “heart” of the research protocol. If you want to understand community care-seeking and you do no other module, do the illness narratives!

## **Advantages of the Structured Narrative Method**

Research conclusions about treatment should be based primarily on the narratives. For documenting treatment practices, illness narratives are far preferable to focus groups, interviews about general treatment patterns, and interviews with officials. There are a number of reasons:

- A narrative describes an *actual* illness and treatment behavior (“What did you do . . .”) rather than a hypothetical case (“What would you do if . . .”)
- Febrile illnesses cover a broad range of symptoms of varying severity; a narrative permits description of the characteristics of a given case, to which treatment can be linked
- “Treatment” for a given case usually consists of a sequence of actions requiring a sequence of decisions, each influenced by more than one factor; only individual interviews examining an actual case will allow you to document the sequence of events and the specific factors that entered at each decision point

Focus groups are an efficient and effective means for gathering certain types of information, such as provider options and general community perceptions about appropriate care. However, in focus groups, respondents generalize what people do when certain symptoms or illnesses occur and tend to give normative information. Actual behavior may deviate from normative descriptions. For example, during an illness taxonomy focus group in western Kenya, members strongly insisted that if the child has a particular febrile illness they called *embaha*, certain herbs must be given and the health facility should be avoided. The individual narratives, however, revealed that even when a family diagnosis of *embaha* was made, caregivers did seek care at the health facility and did not always give herbs. Had researchers relied on the focus group, they would have reached the wrong conclusions about care-seeking practices.

Another example of differing conclusions resulting from focus groups and individual narratives is found in reported treatment for convulsions. In focus groups during the Kenya and Zambia studies, people said that convulsions were spiritually caused and must be remedied by a traditional healer. However, the narratives, which were based on actual behavior, showed that people usually consulted the health facility for convulsions, although some also consulted a healer. In reality, treatment decisions are more nuanced and complex than focus groups can capture, and people do many things that are different from the reported norm.

It is not advisable to base conclusions about community care-seeking on interviews with officials or health providers. Officials and providers may be able to describe some general patterns to give you an initial idea of what the issues are. They can give ideas as to what the problems are *from their perspective*, but their views are not necessarily an accurate description of what caregivers do or why. Sometimes it is useful to ask officials and providers what caregivers are doing (and why) to compare their perceptions with what you find is happening in the community. A divergence means there are probably misunderstandings and miscommunications that an intervention will need to address.

## The Approach to Conducting Illness Narratives in this Protocol

There are a number of ways to conduct illness narratives, from very open approaches to structured approaches implemented like a questionnaire. In this protocol, the illness narratives have been structured to elicit detailed chronological descriptions that contain all of the key information about care-seeking. *It is highly recommended that the specific methodology outlined in the module be followed.* By carrying out the narratives in the prescribed manner, you will be able to determine:

- frequencies of types of treatment
- sequence of treatment actions
- timing of each major treatment action
- detailed qualitative information around these points

The illness narratives are also structured so that key variables can be quantified. The approach tries to combine the best features of both qualitative and quantitative methodologies. It allows the respondent to tell a story but imposes enough structure to ensure that all key information is gathered in a way that facilitates analysis. In some of the other modules, major topic areas are listed and the interviewer can ask about them and probe in any way that gets at the information most relevant to the study. This is not the case for the Illness Narratives module; a specific procedure is outlined and should be followed.

Since the narratives are critical to the research, their implementation is discussed in detail here. The overall approach to these narratives is to gather day-by-day descriptions of treatment actions and the rationale for doing them. There is some standard and codable information that should be gathered in each narrative interview (e.g., demographic information, symptoms noticed) and also a list of probes to ask. Within this standard structure, the line of questioning is open and directed by the kinds of issues raised in the particular case. Although the overall concept is simple, getting good information from narratives takes skill. At this juncture, it would be useful for you to look at the Illness Narrative (Module 2) to review the method described for doing the interviews. Then the points discussed below will be more meaningful.

## Implementing the Narratives

After screening for the inclusion criteria (child under 5 years, fever and/or convulsions within recall period), explain your purpose in simple terms and obtain consent. In obtaining consent, give enough information so that the respondent understands the general nature of the study and what is being asked of her, let her know that the information she provides is confidential, and give her the opportunity to ask any questions that she may have. Some research sponsors may have more specific consent requirements. The module provides some suggested language:

*We are talking to people about what they do when their young children get ill with fever (“hot body”). Some mothers wait and watch the child; others may take them to a pharmacy; some give medicine or herbs at home; some go to a traditional healer; some go to a health facility. I would like to ask you about your child’s illness and all the things you did to help the child get better.*

*We are from [organization]. We are not part of the health center and everything you say will be confidential. You are free to stop the interview at any time. Do you have any questions before we start? May I go ahead?*

*Do not* say you are studying malaria; name the symptoms, not the disease, so that you do not influence responses. *Do* give the examples of types of treatment actions, including taking the child to a traditional healer. If this is included, a caregiver who has taken a child to a traditional healer is more likely to feel comfortable about telling you.

Once the respondent agrees to participate, ask the following:

- *When* the child became ill. This will be labeled by the note taker as Day 1.
- *How* the caregiver knew the child was ill. The symptoms noted constitute local definitions of “ill.”
- *What* the caregiver thought the illness was on the first day. This is the caregiver’s initial diagnosis—the illness name linked to the symptoms she noted. In some cases, however, the caregiver may simply reiterate the specific signs, or say, “I don’t know.” (This is okay.)

Also ask how the child was the day *before* becoming ill. Caregivers may respond that the child was crying or irritable, or had diminished appetite or activity. Some will say the child was fine, and indeed