



## **A Guide to Research on Care-seeking for Childhood Malaria**



*USAID, Bureau for Africa, Office of Sustainable Development and  
Bureau for Global Health, Office of Health and Nutrition*

# A Guide to Research on Care-seeking for Childhood Malaria

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## Abstract

The Guide is a manual for researchers who will plan and implement a study on care-seeking for childhood malaria. It provides a care-seeking model and research protocol (set of field guides) and offers guidance on implementing the research, adapting the protocol to different settings, planning logistical aspects of the study, conducting data analysis, and writing the research report.

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## Credit


Cover photo: WHO/TDR/Crump Caption: An infant child who is being treated in the hospital for severe malaria sweating markedly. The child has traditional antimalarial medicine scars around the breast.

## SARA Project

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## Web Accessibility

The full document of *A Guide to Research on Care-seeking for Childhood Malaria* can be downloaded from the publications section of the BASICS II Website, [www.basics.org](http://www.basics.org) and the SARA project, [www.aed.org/sara](http://www.aed.org/sara). All recording forms, coding sheets, and grids are available in Microsoft Word format for use in field research, and the implementation guides and modules are presented as PDFs.

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This Guide was written by Dr. Carol Baume of the Academy for Educational Development. The initial research protocol was drafted by Dr. Baume in collaboration with Dr. Deborah Helitzer of the University of New Mexico. Dr. Baume then field-tested and revised the protocol, and carried out research with local teams in Zambia and Kenya. In Zambia, Dr. Mubiana Macwan'gi collaborated closely in the instrument testing and revision process, and served as field supervisor as the research team (listed below) collected the data for the Zambia care-seeking study. In Kenya, the research protocol was adapted for the Kenyan context and further refined in collaboration with the team listed below. Dr. S. Patrick Kachur of the Centers for Disease Control and Prevention served as an ever-willing and always helpful technical resource during the development of the research protocol, and the Treatment Comparison Module in this Guide is adapted from his work in looking at local perceptions of medications in Malawi and Zambia. Dr. Nancy Nachbar of AED made substantive contributions to the model of optimal care-seeking, carefully reviewed the entire draft, and contributed many insightful comments to make this document especially useful in the field. Through the breadth of her knowledge and depth of commitment, Dr. Mary Ettling of USAID provided many forms of valuable support right from the beginning.

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## Acronyms

|        |   |
|--------|---|
| AED    | Academy for Educational Development                                     |
| BASICS | Basic Support for Institutionalizing Child Survival                     |
| CHW    | community health worker   |
| CQ     | chloroquine (an antimalarial drug)                                      |
| DHMT   | district health management team   |
| HF     | health facility   |
| IEC    | information-education-communication                                     |
| IMCI   | Integrated Management of Childhood Illness                              |
| ITN    | insecticide-treated (mosquito) net                                      |
| MOH    | Ministry of Health  |
| ORS    | oral rehydration salts  |
| SP     | sulphadoxine-pyrimethamine (trade name Fansidar™, an antimalarial drug) |
| TH     | traditional healer  |
| USAID  | United States Agency for International Development                      |



# Introduction

## Purpose

**M**alaria kills more than one million children every year. Most of these deaths could be averted if families recognized the symptoms of malaria and provided appropriate treatment as soon as possible. Early diagnosis and correct treatment of malaria is a key strategy for malaria control in endemic countries worldwide. But this strategy requires an understanding of community care-seeking practices: how caregivers recognize and respond to childhood malaria symptoms, what factors shape their care-seeking behavior, and how they choose among available treatment options. Program planners must understand the barriers to optimal care so that interventions can be designed to reduce those barriers. Sound behavioral research on the management of malaria in the community can provide this information.<sup>1</sup>

This Guide is a manual for conducting such research. It is written for investigators who will plan and implement a qualitative study on how people seek care for young children who have fever or convulsions—key symptoms of malaria. It provides a systematic yet efficient research protocol for researchers to use in the field, and also suggests ways to organize the research, analyze the findings, and write preliminary and final reports.

This Guide is intended for researchers who already have experience with qualitative data collection, recording, and analysis, but who may not have field expertise in investigating care-seeking for malaria. Therefore, the Guide does *not* provide training in research or qualitative methods. For example, it does not include instruction in interviewing techniques or focus group moderation. It assumes that the principal researcher has those skills and that any less experienced team members will be trained in field methods and the use of the research protocol before the fieldwork begins.

In addition to providing a research protocol, this Guide offers researchers guidance on:

- **Using a care-seeking model** to organize the research, make sure that all important topics are covered, and structure the analysis
- **Implementing the research protocol** in the field, with discussion of the purpose, method, sample, and data recording of each part of the protocol
- **Adapting the research protocol** to time or resource constraints, to the national drug policy, to the local health infrastructure, and to specialized research questions
- **Planning logistical aspects** of the research, such as timing and duration, team size and composition, and organization of the fieldwork
- **Conducting data analysis** by planning ahead to organize findings as fieldwork progresses, and using the model as an organizing tool to facilitate final analysis
- **Writing the summary and full research reports**

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1. There are numerous examples of the importance of social science research in formulating malaria policies and interventions in Baume, C. and Kachur, S. P. 1999. *Improving Community Case Management of Childhood Malaria: How Behavioral Research Can Help*. Washington, D.C.: Academy for Educational Development: SARA Project.

## The Nature of Formative Research

The research described here is formative research—research whose purpose is to guide or “form” programs and policies. Therefore, this research is usually conducted prior to planning interventions or making policy decisions. It can, however, be conducted at any point when information is needed to guide decisions about the project. For example, it can be used to monitor perceptions about a new antimalarial drug or get an early indication as to whether messages are having their intended effect. The focus is on *practical* research that will answer programmatic questions. Formative research is meant to provide timely information at a level of precision suited to its fundamental purpose: providing the information necessary to tailor interventions to the local setting.

Formative research draws from a number of social science disciplines: anthropology, psychology, sociology, and communications. Often traditional methods from these disciplines are adapted so that results can be obtained in a fairly rapid manner. Formative research involves mostly qualitative approaches, but can include a combination of quantitative and qualitative methods.

The research proposed here aims to understand *behavior*, since its primary objective is to guide the

design of programs to induce more healthful behaviors in the household and community. Changing behavior requires more than giving people information. It requires addressing the many factors that influence how people act. Behavioral research can help decision makers address both “internal” factors, such as perceived norms or beliefs, and “external” factors, such as access or cost that affect care-seeking patterns. Since case management involves the interrelationship of the individual and the health infrastructure, it is important to take a systems approach and look at both elements to gain a full understanding of treatment decisions and actions.

The research proposed in this Guide also seeks information on *communication* topics that intervention planners need in order to work effectively with communities. For example, it is important to know who is seen by families as a reliable source of information about treating febrile illness (illnesses with fever), who enters into the decision process and who influences those persons, what local values and views can be used as motivations for more healthful practices, and what the best forms and means of communication are.

It is also important to understand what this research does not do. It is not meant to produce accurate population statistics for the variables under study. Generally, samples will be non-random and rather small (20 to 100 interviews) so that topics can be investigated in depth. Percentages may be calculated, but the purpose principally is to indicate trends, rankings, and orders of magnitude. This level of precision is suited to the types of questions the research is meant to answer. For example, in planning an intervention, it would not matter whether the percentage of mothers giving incorrect doses of antimalarials was 70% or 79%; percentages in this range would indicate a severe problem that would need to be addressed by the intervention.

*Care-seeking, treatment-seeking, and community case management* are used interchangeably. These terms refer to all treatment actions undertaken in response to illness. They include home treatment behaviors as well as consultation with any health providers, whether traditional or modern.

## Overview of the Research Protocol

There are now a number of research tools available that look at care-seeking for malaria.<sup>2</sup> Each has a somewhat different emphasis and approach. This research protocol does the following:

- Uses a *model* and systems approach to tie together all elements-individual, community, and institutional-in the case management process
- Offers a *modular format* with the flexibility of designing very rapid studies when little field time is available, or designing comprehensive studies when more time and resources are available
- Puts emphasis on individual interviews in the form of illness narratives that ask about *actual behavior* in a recent case in order to document the factors that enter into each decision in the treatment sequence, rather than on group methods that elicit more general and normative information about treatment practices
- Builds initial basic *analysis* into the research protocol and provides guidance for overall analysis
- Uses a *community sample* rather than a health facility sample in order to look at all cases of illness with fever, including those *not* taken to the health facility- which may be the most important cases to understand
- Structures qualitative information in a way that can be coded to yield *counts* (quantitative data) for key variables where appropriate
- Includes, in addition to care-seeking topics, information about *communication issues* that are important to the design of effective interventions

This protocol takes a *symptom-based* rather than illness-based approach, concentrating on the treatment of fever and convulsions rather than on malaria. There are three reasons for taking this approach:

- 1) When an illness term such as “malaria” is used, even in translation, one cannot be sure that all parties understand the term to mean the same thing. Ethnographic studies from various parts of the world show that local people may use the term to cover a wider range of illnesses than clinical malaria (thereby calling something malaria when it is not), or they may interpret some signs of malaria, especially convulsions, as something else (thereby *not* calling something malaria when it is). Talking about symptoms makes it more likely that both researchers and respondents are talking about the same phenomenon, thus improving the validity of the data.
- 2) Few health facilities in developing countries have the laboratory equipment and staff to confirm suspected cases of malaria. Under these circumstances, fever is treated presumptively as malaria unless there are specific indications that it has other causes.

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2. See World Health Organization/Special Programme for Research and Training in Tropical Diseases. *Rapid Assessment of Health Seeking Behavior for Severe and Complicated Malaria*. 1998. Geneva: World Health Organization. The focus of that protocol is on severe cases admitted to hospital. See also Agyepong, A. et al. 1995. *The Malaria Manual*: Geneva: World Health Organization, produced by the Special Programme for Research and Training in Tropical Diseases and sponsored by UNDP/World Bank/WHO. This manual provides some basic instruction in research and supplies a variety of tools that can be used for looking at treatment-seeking and bednet use.

- 3) By focusing on fever and convulsions as symptoms, the research can directly support Integrated Management of Childhood Illness (IMCI) by providing information that has implications for health worker training as well as for community aspects of IMCI. IMCI is a symptom-based approach to case management. It is structured around danger signs, including high fever and convulsions. Furthermore, the model and the research protocol can easily be adapted to look at care-seeking in response to other illness symptoms.

#### About IMCI: Integrated Management of Childhood Illness

WHO and UNICEF developed the IMCI approach in the early 1990s. The IMCI strategy promotes integrated case management of the five most important causes of childhood deaths—acute respiratory infections, diarrhea, measles, malaria, and malnutrition—both in health facilities and in the community.

There are three components of the IMCI strategy:

- (1) Improvements in the case management skills of health providers
- (2) Improvements in the required health system for effective management of childhood illness, and
- (3) Improvements in family and community practices

Within the third component, improving care-seeking practices and treatment options within the community are key approaches for the reduction of morbidity and mortality. Additional information on IMCI can be obtained from UNICEF ([www.unicef.org](http://www.unicef.org)), WHO ([www.who.int/child-adolescent-health/integr.htm](http://www.who.int/child-adolescent-health/integr.htm)), the CORE Group ([www.coregroup.org](http://www.coregroup.org)), and the BASICS II Project ([www.basics.org](http://www.basics.org)).

Although this Guide describes an approach for documenting care-seeking patterns for fever and convulsions, much of the methodology is applicable for acute respiratory infections, diarrheal disease, and other childhood illnesses.

The research protocol in this Guide was tested and refined in Zambia and Kenya, and the examples are drawn from field experience and research findings in those countries. The countries have different health infrastructures and drug policies, and the research protocol was found to be easily adaptable to the differing contexts.

The research protocol consists of six modules:

|                                    |   |
|------------------------------------|---|
| Module 1: Community Introduction   | Set-up and community background information |
| Module 2: Illness Narratives       | CORE MODULE                                 |
| Module 3: Terminology and Taxonomy | Supplementary Module                        |
| Module 4: Health Facility          | Supplementary Module                        |
| Module 5: Other Providers          | Supplementary Module                        |
| Module 6: Treatment Comparison     | Supplementary Module                        |

The Community Introduction and Illness Narratives modules are the essential parts of the research protocol. The other modules are highly recommended, to be conducted as resources permit.

## Model of Optimal Care-seeking

### The Importance of Using a Model

Optimal case management involves a sequence of steps leading to the resolution of the illness. These steps can be depicted in a care-seeking model. If the purpose of your research is to understand the overall care-seeking process, it is advisable to explore each step in the model. Why is a model important? It will help you:

- *Plan the research*, by providing a structure for organizing the study in a systematic manner
- *Analyze the findings*, by helping to organize the discussion and analysis of findings
- *Organize the report*, by offering a complete and logical sequence of topics
- *Focus the intervention*, by serving as a diagnostic tool that will show the weak points in the care-seeking process and indicate where program efforts should be directed

Therefore, the care-seeking model will be referred to in subsequent sections of this Guide that cover planning the research, analyzing the findings, and organizing the report.

### The Model

In this section, the care-seeking model is described in detail to stress the importance of the topics to be included in the research. This section provides the research team with a basic background in the elements of care-seeking. In addition to covering the topics or substance of each step in the model, this section discusses methodological issues (where relevant) and reviews program implications of the topics. The general model is depicted in Figure 1 and includes the following steps:

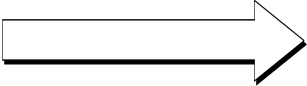
- Step 1 — Recognition of symptoms
- Step 2 — Appropriate home care and monitoring
- Step 3 — Treatment at a health facility
- Step 4 — Compliance and monitoring for treatment failure
- Step 5 — Return visit to health facility for treatment failure

The steps in the model represent critical points at which performance of optimal behavior maximizes the likelihood that the illness will be resolved. For example, if a caregiver gives the correct antimalarial in the correct dose at home, the child is likely to recover, and it is not necessary to proceed with the other steps in the model. Conversely, the inability or failure to perform optimal behaviors at a given step can have serious consequences. To illustrate: A caregiver's inability to pay for medical services or obtain transportation to a health facility (inadequate access) may mean that a severely ill child never receives needed treatment or that a follow-up visit for treatment failure never occurs.



Figure 1: General Model of Optimal Care-seeking for Malaria

| <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 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 |

*(Continued)*


| <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             | 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 |

## Step 1 –Recognition of Symptoms

In order for malaria to be treated in a timely manner, families must be able to *recognize* the symptoms and they must do so *at the time the symptoms occur*. Timely recognition is important since, especially in young children, malaria can progress from a mild to severe case in as little as 24 hours.

Once the symptoms are noticed, caregivers take action only if they perceive the symptoms as *abnormal*. In some settings, mothers recognize diarrhea but perceive it as normal if the child is teething. Teething children commonly put things in their mouths and get diarrhea; as a result, teething is seen as the cause and the condition is considered normal.

Caregivers must also see the symptoms as *amenable to modern treatment*. Some people believe that convulsions have supernatural causes and require the services of a spiritualist, not treatment at a health facility.

Proper case management can occur only if symptoms are recognized at the time they occur, are seen as abnormal, and are considered amenable to modern medical treatment.

### **Research and Program Implications of Step 1**

It is important to distinguish between awareness and recognition, especially of subtle indications of illness. Recognition at the time of occurrence—not just general awareness or knowledge of symptoms—is a prerequisite to ensuring that a child receives appropriate care. Not all research methodologies capture recognition. Terminology and taxonomy focus groups that ask caregivers to list the symptoms of an illness elicit knowledge or awareness, but do not necessarily indicate recognition. For example, mothers in a focus group may mention anemia in association with malaria. One cannot conclude from this method, however, that mothers actually recognize anemia when it occurs. In fact, anemia is seldom recognized until it becomes severe, and even then may go unnoticed. Even health providers have difficulty detecting anemia from external signs. The extent to which caregivers giving illness narratives cite anemia as a condition that prompted them to take action gives a better indication of actual recognition than the mention of anemia in terminology and taxonomy focus groups does.

Timely recognition is difficult to ascertain via retrospective methodologies. Even if a caregiver cites symptoms indicative of illness, it is difficult to know whether she noticed them at the time of occurrence. The model (and therefore the protocol) asks about “early signs” as well as illness symptoms in order to help determine the extent to which mothers are attuned to the condition of their children. If most caregivers notice subtle early warning signs such as irritability or diminished appetite or activity, it is likely they will notice the more definitive symptoms when they occur. The term “early signs” is used here to refer to indications that a child may be about to become ill. They are not illness

### Malaria Symptoms

The key symptoms of malaria are fever/chills/sweating, headache, and joint pain, often accompanied by vomiting and diarrhea. More severe malaria includes convulsions, which may be preceded by twitching movements. Anemia also results from severe or repeated cases of malaria.

Not all instances of fever and body aches are caused by malaria, but any time these signs or symptoms appear, families in endemic areas should be aware that their child may have malaria and promptly should seek appropriate treatment. Where adequate diagnostic equipment is lacking, health providers presumptively treat febrile illness as malaria.

symptoms per se, but “warning signs” such as irritability, tiredness, diminished activity, or lack of appetite. Early signs are more subtle than illness symptoms and can alert the caregiver that the child is becoming ill.

It is important to explore topics related to recognition to help intervention planners decide the extent to which strategies should include education on the symptoms of malaria and how to recognize them. In some places, recognition is not a problem; in others, it may be. To develop effective communication materials, planners also need accurate information on local terms for the illness symptoms associated with malaria.

### ***Modules that Address Step 1***

Information about caregiver recognition and interpretation of symptoms is gathered from the illness narratives, terminology and taxonomy focus groups, and Health Facility module preconsultation interviews with caregivers.

## **Step 2 – Appropriate Home Care and Monitoring**

Home care encompasses all treatments that the family decides to give the sick child, in contrast to treatments given on the recommendation of a provider. Home care includes palliative measures such as tepid sponging, traditional remedies such as herbs, and pharmaceuticals on supply in the home or obtained from community sources, including pharmacies when drugs are obtained without a prescription.

After families recognize illness symptoms, they need to take suitable action. Not all cases of fever persist or become serious; simple cases can be treated at home. Even if fever is caused by malaria, home administration of the correct drugs in the correct amounts can cure most cases of the disease. What constitutes “suitable action” may depend on the context. For example, in some countries the ministry of health (MOH) may be developing community sources of antimalarials (for example, community health workers), but in others the MOH may encourage mothers to take all cases of febrile illness for treatment at a health facility.

During home care it is critical that the family monitor the child for signs that he or she needs to be seen immediately by a clinician. These danger signs include high fever, persistent fever following administration of an antimalarial, stupor or lethargy, and twitching or convulsions.

When a child develops a potentially serious febrile illness, families make decisions about what to do and when to do it. To understand why some treatments are chosen and others are not, it is important to explore how such decisions are made. Decision making often involves several participants who may consider multiple factors as they decide what actions to take. The decision to seek care from an outside provider is intertwined with issues of access and quality of care, which are explored further in Step 3.

### **Appropriate Home Care and Monitoring**

#### **Appropriate home treatments**

- Timely and proper administration of correct antimalarial
- Administration of antipyretic (optional)
- Tepid sponging (optional)

#### **Danger signs indicating illness is severe and child needs prompt medical attention at a health facility**

- High or persistent fever
- Stupor, lethargy, loss of consciousness
- Vomiting all intake
- Twitching or convulsions

### ***Research and Program Implications of Step 2***

Information on home care will show intervention planners which actions in the home should be reinforced and which should be changed because they are ineffective or harmful. It will also indicate the need to address delays in taking suitable home actions or in seeking care at a health facility. Researchers should also pay close attention to how, when, and by whom decisions are made, so that intervention planners can design effective activities and messages, and direct them to the right people.

### ***Modules that Address Step 2***

Illness narratives are the primary source of information about the range, sequence, and timing of home actions that families take as a response to an episode of childhood febrile illness. The narratives also permit exploration of the decision-making process around those treatment elements.

## **Step 3 – Treatment at a Health Facility**

If home care fails to resolve the illness within 36 hours or so, or if at *any time* a danger sign appears, the child should be seen by a provider trained in modern medicine. In reality, caregivers do not always choose this optimal course of action; some may continue treating at home or consult a traditional healer. Practitioners of “Western” medicine may be found in a variety of settings: in the community (e.g., community health workers); in a government clinic or hospital; in a private clinic or hospital with religious affiliation; or in a small private clinic set up by an independent practitioner. The range of options and the suitability of each will need to be defined in each research setting, and the corresponding adaptations need to be made in the research protocol.

### Potential Barriers to Access to a Health Facility

- Distance; lack of transportation; cost of transportation
- Lack of time necessary to travel and wait for service
- Restricted hours of facility operation; strikes
- Perceived or actual cost of services and medication
- Need for childcare for other children
- Need for permission from others (husband, mother-in-law)
- Facility gatekeepers or guards, intake personnel

The decision whether to take the child to an appropriate facility may involve several people and consideration of several factors, including whether access barriers can be overcome and whether the caregiver perceives that the facility can effectively treat the illness.

**Access to Health Facility.** External barriers to access can come in many forms, such as cost of services, medications, and transport; distance to the facility; lack of transport (particularly at odd hours); limited service hours (facilities are often closed at night or on weekends); limited availability of clinicians; strikes; need for childcare for children left at home; or caregiver’s need to obtain permission before leaving home. Some facilities have guards or gatekeepers who determine who can enter to receive care.

**Quality of care.** Optimal case management requires good care from health providers. A formal evaluation of provider technical skills should be conducted as part of any comprehensive assessment

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:

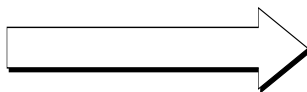
- The overall structure of the health system; health facility options; other provider options
- First-line and second-line drugs, and how each is to be administered
- Recommendations for home care treatments, such as tepid sponging
- In the absence of danger signs, the maximum amount of time that the 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)**

| <b>Step 1<br/>RECOGNITION<br/>OF SYMPTOMS</b>               |  | <b>Step 2<br/>APPROPRIATE<br/>HOME CARE<br/>AND MONITORING</b>  | <b>Step 3<br/>TREATMENT AT<br/>HEALTH FACILITY (HF)<br/>[Quality of Care]</b>             |  |  |  |
|---|--|---|---|--|--|--|
| 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<br><br>Appetite loss<br><br>Less active | Fever<br><br>Chills/sweating<br><br>Vomiting<br><br>Symptoms perceived as abnormal | Do tepid sponging<br><br>Give antipyretic (e.g., Panadol, aspirin)<br><br>Give correct dose of CQ<br><br>Watch for signals to go to HF right away:<br>– fever persists after CQ<br>– stupor/lethargy<br>– twitching/convulsions | HF open<br><br>Distance not excessive<br><br>Permission not needed<br><br>Cost affordable | Ask history of fever<br><br>Ask prior treatments, especially CQ<br><br>Take temperature<br><br>Laboratory work, if available<br><br>Diagnose malaria<br><br>Communicate diagnosis to caregiver | Correct antimalarial prescribed (CQ or SP)<br><br>Correct dose prescribed<br><br>Feeding advice given<br><br>Return visit explained: in 3 days for review or immediately if no improvement | Correct drug dispensed<br><br>Full, correct dose dispensed<br><br>Correct regimen clearly communicated<br><br>Correct regimen understood by mother |



| <b>Step 4<br/>COMPLIANCE AND MONITORING<br/>FOR TREATMENT FAILURE</b> |  | <b>Step 5<br/>RETURN VISIT TO<br/>HF FOR TREATMENT FAILURE</b>                            |   |
|---|--|---|---|
| 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<br><br>Follows feeding recommendations             | Watches for signals to return immediately to HF:<br>– fever persists<br>– stupor/lethargy<br>– twitching/convulsions | HF open<br><br>Distance not excessive<br><br>Permission not needed<br><br>Cost affordable | SP given (or quinine, if necessary)   |



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

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



## Module 1: Community Introduction - *Recording Form*

Community/District: \_\_\_\_\_ Date: \_\_\_\_\_

Ethnicity/Language: \_\_\_\_\_ Facilitator(s): \_\_\_\_\_

Method used (circle):            social mapping            group interview            both

# of participants:        \_\_\_\_\_ men        \_\_\_\_\_ women

Environment (e.g., urban, peri-urban, rural; located in valley, plateau): \_\_\_\_\_

### 1. General descriptive information

- Size
  
  
  
- Main forms of livelihood
  
  
  
- Other characteristics

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

- Hospital(s):
  
  
  
  
- Health facility:
  
  
  
  
- Private providers/clinics:
  
  
  
  
- CHWs:
  
  
  
  
- Traditional healers:
  
  
  
  
- Kiosks, stalls, stores, and pharmacies selling medication:
  
  
  
  
- Other:

### 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



some children will not exhibit any early signs of illness. The question is intended to find out how well caregivers are attuned to the condition of the child. If many caregivers cite these somewhat subtle early signs, it can be reasoned that they are likely to notice fever or other distinct illness symptoms soon after they occur. Figure 4 gives examples of responses.

**Figure 4: Recognition of Early Signs of Illness**  
*Excerpts from Zambia*

When asked how the child was the day before becoming ill, over 80 percent of the 146 respondents gave answers such as those cited here; the rest said the child seemed okay the day before. We concluded that, although mothers are busy and have many demands on their time and attention, they are well attuned to the condition of their children, and it is likely that they notice fever and other illness soon after they are manifest in the child.

*On Sunday the child was quiet, not happy, not playing. I knew my child was going to be sick. ♦*

*She refused to eat breakfast, she became less playful and became continuously thirsty. ♦*

*The child was playing but he did not eat enough of the rice I boiled for him. At 12 hours he did not even eat at all the nshima I cooked for him, but he was still playing. ♦*

*The child was fine and was eating in the morning and was playing as usual, but in the evening I noticed the baby was crying and less active. ♦*

*. . . around 16:00 hours the child stopped playing. Then I noticed something quite unusual: a short while later, around 17:00 hours, he went to sleep. I have never known him to sleep that early. . . ♦*

*The child was playing but irritable and crying frequently. You give him this and he throws it away and says "I want something else." You give him that and he throws it away again and says "I don't want this" and cries. ♦*

*He was crying a lot. If I put him on his back, he wanted to be on his front. He was quite irritable. If I left him alone, he would cry. He only wanted to be with me. He was less active, I would say. I was observing him and I just kept him on my back. ♦*

*During the day and the afternoon she was feeling well and playing about, but she changed in the evening. Supper was prepared but she did not eat. Her body was weak. ♦*

*The baby was fine in the morning. However she started behaving strangely in the afternoon—crying and then she stopped breastfeeding. ♦*

*The child was fine the whole morning and afternoon but changed in the evening when she started crying, drinking a lot of water, and then she went to bed very early. ♦*

You then ask what happened day by day for the course of the illness. Interviewers need to be familiar with the critical care-seeking issues described in the model in Section 2 so that they can probe appropriately. As a reminder, the Illness Narrative module contains a list of probe topics.

The length of the interview will vary considerably from case to case. Where the duration of symptoms was short and few treatment actions were taken, the interview may be as short as 15 minutes. For more extended cases involving multiple actions, it may last an hour. When issues of special interest and relevant to the research questions appear, you will want to probe. For example, if most caregivers stop giving

multidose medication as soon as the child shows signs of recovering and you encounter a mother who gave a complete dose, it will be important to find out why she did so. If few mothers consult a traditional healer, spend additional time with each mother who did consult a healer to find out all the factors leading to that decision, what the healer recommended, and any other information that contributes to an understanding of the circumstances under which traditional healers are consulted. The ability to accommodate these variations in cases is one of the strengths of the illness narrative method proposed in this protocol.

## Special Issues When Implementing the Narratives

***The caregivers' perception of how severe the illness was.*** The literature on care-seeking shows a link between perception of severity and treatment decisions. The greater the perceived severity, the more likely that action will be taken. There are, however, methodological problems in learning about perceived severity. Perception of severity is likely to change over the course of the illness and to correspond to the child's overt response to treatment. If you ask about the child's initial symptoms and how severe the child's condition was, you may miss a later assessment of greater severity as new symptoms appear. If, on the other hand, you ask the caregiver to think about the episode as a whole and how serious it was, you capture a retrospective assessment that may be based in large part on whether the child recovered. This retrospective assessment does not tell you the extent to which severity is a cue to action; it is more a reflection of outcome. Furthermore, the idea of "severity" and "treatability" may become melded. For example, mothers may say that malaria is not severe since it is common and treatable, yet if they almost always respond quickly with antimalarials and/or a visit to a health provider, this suggests that they do consider it a potentially severe illness.

There is no simple solution to this problem. It is probably best to ask at critical junctures how severe the caregiver thought the child's illness was. For example, if a mother says that the child started twitching, you could ask whether she thought the condition was serious. If she says she decided to take the child to the health facility, you could ask how serious the child's condition was at that point, to get an idea of what level of perceived severity led to that decision. If there are no definite markers, you can ask at the end how serious the illness episode was. When coding, the severity level should be the most serious assessment at any point in the illness.

In addition to the caregiver's assessment as to whether the case was mild, moderate, or severe, gather qualitative information to understand how "severe" or "serious" is defined locally. Figure 5 shows some examples. An examination of these comments will demonstrate the kinds of symptoms that do or do not prompt action.

***Accurate information about antimalarial drugs and dosages.*** Ascertaining whether multidose antimalarials have been administered correctly is very important and very difficult (see Figure 6 for correct dosages). Difficulties may arise because:

- At health facilities, caregivers are often given multiple drugs to take home but not told what drugs they have been given. It is not always certain that the caregiver is reporting on the antimalarial rather than on another drug she was given.
- Antimalarials come in different strengths and dosage schedules. Because few mothers know the strength of a medication, you will have trouble determining whether it was correctly administered.
- Dose and administration regime differ according to the age of the child.
- There may be different forms of the drug, for example, tablet and syrup.

Figure 5: How Mothers Define “Serious”  
*Excerpts from Zambia*

- Q: At the time you took the child to the clinic, how did you consider the condition of the child—very serious, a bit serious, or not serious at all?**  
A: He was quite sick, but I can't say he was serious. [Child had had high temperature and cough]
- Q: What symptoms would you have seen if you were to have considered your child as serious?**  
A: Very fast breathing, very weak, and moving the neck backwards. ♦
- Q: How serious was your child's condition?** [Mother had noticed fever and given leftover CQ and Panadol, and the fever had subsided.]  
A: I did not think it was very serious. That is why I decided to give him medication at home. [She lives about 150 meters from the health center.]
- Q: What would you call a serious condition?**  
A: When the body gets very hot and the child starts breathing fast. I would have taken him to the health center if he had become worse. ♦
- Q: At the time you took the child to the health center how would you describe the condition of the child— not serious, somewhat serious, or very serious?**  
A: Not serious.
- Q: What condition would you have seen if you were to describe your child to be very serious?**  
A: The child would be extremely weak and fail even to talk. The eyes would be rolling upwards. ♦
- Q: How was the child's condition?**  
A: My child's condition was not serious, since he was eating and was not very weak.
- Q: How does a child who is serious become?**  
A: It stops eating, does not talk and is very weak. ♦
- Q: What do you consider serious?**  
A: When the child is not talking and has extreme body weakness and is also grunting. ♦
- Q: At the time you took the child to the clinic, how was its condition?**  
A: I wouldn't say the child was very serious because amid spells of the illness he could still play once in a while.
- Q: What symptoms would you have needed to see to describe the child as serious?**  
A: Well a serious child will be known from the way it breathes and grunts and has severe weakness like the child I found at the clinic.
- Q: What then made you decide to take the child to the clinic on that day?**  
A: Because there was not any improvement in the child's body temperature. ♦

There are some ways to help with this problem. You will find it useful to have samples of antimalarials to show the mother and ask if she can identify which, if any, were given. If she has any of the drug left over, ask to see it. To assist interviewers in determining whether the child was given the correct dose, an underdose, or an overdose, give them a reference chart based on locally available antimalarials. In all cases, however, instead of recording whether a correct dose was given, record what the caregiver says the child was given: the medication, the amount given, and the frequency. Then someone who is medically trained can determine whether the amount given constitutes a correct dose, an underdose, or an overdose.

**Avoiding under-reporting of consultations with traditional healers.** Sometimes people are reluctant to report that they have consulted a traditional healer, fearing that they will be regarded as backward by those in the “modern” world, particularly health providers. There are several ways to reduce such inhibitions, making it more likely that your data will be accurate:

Figure 6: Instructions for Giving an Oral Antimalarial

► **Give an Oral Antimalarial**

RST-LINE ANTIMALARIAL: \_\_\_\_\_  
COND-LINE ANTIMALARIAL: \_\_\_\_\_

► **F CHLOROQUINE:**  
explain to the mother that she should watch her child carefully for 30 minutes after giving a dose of chloroquine. If the child vomits within 30 minutes, she should repeat the dose and return to the clinic or additional tablets.  
explain that itching is a possible side effect of the drug, but is not dangerous.

► **F SULFADOXINE + PYRIMETHAMINE:** give single dose in clinic.

| AGE or WEIGHT                             | CHLOROQUINE<br>give for 3 days |     |                        |     |                               |     | SULFADOXINE + PYRIMETHAMINE<br>give single dose in clinic |        |       |   |
|---|--------------------------------|-----|------------------------|-----|-------------------------------|-----|---|--------|-------|---|
|   | ABLET<br>(150 mg base)         |     | ABLET<br>(100 mg base) |     | YRUP<br>(50 mg base per 5 ml) |     | ABLET<br>500 mg sulfadoxine<br>25 mg pyrimethamine        |        |       |   |
|   | 1                              | 2   | 1                      | 2   | 1                             | 2   | 1   | 2      | 3     |   |
| Children up to 12 months<br>(4 - < 10 kg) | 1/2                            | 1/2 | 1/2                    |     |                               | 1/2 | .5 ml   | .5 ml  | .0 ml | 1 |
| 2 - 12 years up to 10 - < 14 kg           |                                |     | 1/2                    | 1/2 | 1/2                           | 1/2 | 5.0 ml  | 5.0 ml | .0 ml |   |
| 13 years up to 14 - 19 kg                 | 1/2                            | 1/2 | 1/2                    |     |                               |     |   |        |       |   |

Source: World Health Organization and UNICEF. *Integrated Management of Childhood Illness* (Chart book).

- In the Community Introduction module, you will have discussed traditional healers as a treatment option, thereby breaking the ice and showing that you are not judgmental about them. You will also have asked who the traditional healers are and how to contact them, thereby communicating that traditional healers are part of your study.
- Do not use health facility staff to help you identify households with sick children. Identify respondents at the introductory community discussion, or find them by going door to door.
- When obtaining consent for an interview, be sure to mention traditional healers as a treatment option, as explained in the section on implementing the narratives, above. The Illness Narrative module suggests wording.
- If it seems helpful, remind your respondent that the discussion is confidential and that you are not from the health facility or hospital.
- When training interviewers, keep reminding them that they must ask questions in a neutral way and must avoid any appearance of disapproval when caregivers talk about traditional healers.

If you interview traditional healers using the Other Providers module, you can triangulate your findings by comparing what healers and mothers say. In both the Kenya and Zambia studies, for example, few caregivers reported taking the child to a traditional healer for febrile illness. Traditional healers corroborated this, saying they seldom treated young children for fever.

**Asking “Why not?” as well as “Why?”** You will be asking why various treatment decisions were made, but sometimes it is just as important to ask why something was *not* done. For example, if a mother did not seek care at a health facility, you will want to find out why not. When training interviewers, it is important to discuss how they can do this in a neutral way that does not imply that the action *should* have been done. One way is to ask the caregiver to tell you the reasons she did X or did not do X. Figure 7 shows mothers’ responses when asked why they did not go to a health facility.

A related question is why one provider or treatment was selected instead of another. Figure 8 shows examples that indicate some of the factors that affect mothers’ decisions about provider options. In this case, mothers who said they took the child to a private clinic were asked why they took them there rather than to the government or NGO health facility.

**Figure 7: Why Caregivers Did Not Go to the Health Facility  
Excerpts from Zambia**

*I heard from someone who had gone to the health center that there were no medicines so I decided not to go there and decided to give her the Cafenol at home. ♦*

*I didn't go to the clinic because most of the time they say they have no drugs. When they have, they usually only give 1/2 a tablet and you just take it at the clinic. They never give you something to carry home. So they don't give enough. And those people at the clinic never really examine our children. They just write what we tell them. If you ask questions, they would just shout at you that "There is nothing that you can tell us. This is not your relative's clinic." ♦*

*I hate standing on long queues for hours. You arrive as soon as they open the clinic, but you can still be there even after lunch. I thought of trying treatments at home since I had an idea what was wrong with her. ♦*

*I have got no money. They charge K200 for a card (registration) and K300 for medicine. All together I will have to pay K500. I don't really like going to the clinic because the nurses there always scold us over very little things. They do not attend to our children when we don't have money and they send us away. ♦*

*During the time the child was sick, I was also sick. The other thing is that it is very far to the health center. Unless I had a bicycle, I could not have taken her there. ♦*

*No reason in particular. I saw that he had recovered so I didn't go. Besides I had drugs which I had kept so there was no need to go to clinic. ♦*

*It is far. We take about 2 hours on foot. ♦*

**Figure 8: Why Caregivers Prefer Going to a Private Clinic Rather than a Health Facility  
Excerpts from Kenya final report**

**Q: Why did you go to [small private clinic]?**

A: We believe in injections. If we go to the hospital and they don't give an injection, we get disappointed. The small clinics give injections. ♦

**Q: What made you decide to go to Moding [private clinic] and not Korosiandeti?**

A: Their cost is reasonable and there is no shortage of drugs. ♦

**Q: Why did you decide to take the child to the private clinic and not to any other health facility?**

A: Because the clinic is nearer and each time I take the convulsing child to the clinic, the child recovers. ♦

**Q: Why did you decide on going to this clinic and not another?**

A: I prefer it to others because that is where we have been going. If you don't have enough money, they will still treat you and you can take the money later.

**Q: How much do they usually charge?**

A: For children it's 180 shillings, but the man is also good with children.

**Q: Were you satisfied with the treatment given?**

A: I was because the vomiting, diarrhea, and fever were reduced. The only problem is that the baby is still not eating. ♦

**Q: Why did you decide to go to [private clinic] and not anywhere else?**

A: Because, though expensive . . . this clinic is good also because one can pay in installments.

**Q: How far is the clinic?**

A: It is walking distance and one does not need public transport. ♦

## Standardizing and Quantifying Basic Treatment Information

The illness narrative interview allows open-ended exploration of issues but also includes some standard information that should be collected in each interview. Coding of that standard close-ended information and entry into a simple spreadsheet, database, or statistical program will be extremely helpful to your analysis. Many qualitative researchers are averse to quantifying information (even though they labor over hand tallies!). For many methods and circumstances, quantification is inappropriate. In this case, quantification of selected information will help you enormously. It will make your analysis more efficient by avoiding the time-consuming and error-prone task of hand tallies and by allowing you to focus your time on truly qualitative questions. You will immediately be able to identify key trends that you can then explain with the qualitative information your team gathers. For example, you may see immediately that almost everyone tries to treat at home first, that the average amount of time between onset of symptoms and seeking help at the local health facility is too long, or that few mothers give the correct treatment regimen for CQ. These basic facts help set the frame for your main conclusions, which you can fill in with a more nuanced understanding of treatment decisions garnered from the illness narratives. Thus, the interviews produce a small quantitative data set plus a qualitative data set consisting of transcripts or detailed notes on each narrative.

The standard information that should be gathered from each narrative and entered on the coding sheet is shown in Figure 9. You can of course add variables, but the number of coded variables has deliberately been kept to the minimum essential to describe treatment patterns.

### Sample

How many narrative interviews should be conducted? For some studies, 20 narratives may be sufficient; for others, 100 may be ideal. The number depends on the diversity of types of health facilities and heterogeneity of the population in your study area. Care-seeking patterns are affected by characteristics of the health facility (perceived skill of providers, availability of drugs, cost, distance, and so on), so you will want to include different types and locations of facilities in your sample. Within the catchment area of each facility, you may want to select one community located close to the facility and one far, and in each community you would conduct 6–10 narratives.

Children under 5 years who have had fever and/or convulsions in the preceding 2 weeks can be identified in the introductory discussion with the community (Community Introduction module). Alternatively, interviewers can walk systematically from house to house looking for cases. Do not use health facility personnel to identify cases. You want to avoid the impression that you are associated with the health facility, because if mothers fear that you will pass information on to the facility, they will be reluctant to discuss all the treatment actions they have taken—especially those involving traditional healers.

In selecting cases:

- (1) You will need to define the specific recall period. In general, look for cases of fever and/or convulsions that have occurred in the preceding 2 weeks. If this does not allow you to capture enough cases, extend the period to 3 weeks. It is not advisable to extend beyond three weeks, because recall is likely to be faulty. You are likely to find more cases during or immediately after the rainy season, and may wish to time your research accordingly.
- (2) You need to decide whether to limit the sample to completed cases. The advantage is that each narrative will describe all the treatment actions taken in a given case. If you will be calculating treatment sequences, it may be best to look at completed cases only since ongoing cases may

Figure 9: Variables to Code from the Illness Narrative Interview

**ID#** (should correspond to ID# on the narrative interview)

**BACKGROUND INFORMATION**

Community

Date

Interviewer

Child's age

Child's sex

Caregiver relation to child

Caregiver age

Caregiver education

Symptoms besides fever (fever is assumed since it is a criterion for selecting respondents)

Perceived illness

Perceived cause

Perceived severity

# of days since onset of fever

**TREATMENT**

Type and sequence of providers consulted

- home care
- pharmacist (code this if child was taken to pharmacist for diagnosis; do not use this code if caregiver went to pharmacy to buy medication but not to seek diagnosis or fill prescription)
- formal provider (the coding sheet has space to fill in information for two formal providers)
- community health worker
- traditional healer

When each provider was consulted (# of days after onset of fever)

Treatments recommended by formal providers

- Antimalarial
  - type of antimalarial recommended (adapt coding sheet to local antimalarials)
  - amount of antimalarial recommended
  - amount of antimalarial given
  - correct dose, underdose, or overdose given
- Injection
  - # of injections given
  - type (antimalarial, antibiotic)
- Other drugs given
- Whether referral to another provider/facility was made
- Whether referral was followed
- Whether child was admitted

**STATUS OF CHILD** (recovered, still ill, deceased)

receive further treatment after the interview. Alternatively, you can code for whether a case is ongoing or completed and only include completed cases in the descriptions of treatment sequences. This, of course, reduces sample size for calculating treatment sequences.

The disadvantage of limiting the sample to completed cases is that you will miss prolonged cases. Often these cases result from repeated insufficient doses of antimalarials, which abate symptoms but do not cure the disease. These are important cases to understand.

You may also want to seek out caregivers of children currently in hospital for malaria and of children who died from malaria. These adjunct interviews may help to uncover some of the structural and behavioral reasons for severe illness and death. You could, for example, visit the hospital and interview several caregivers whose children have been diagnosed with malaria. In the cases of children who died, it would not be necessary for the case to have started within the preceding 2 weeks. The interview would attempt to recapture the sequence of key events, but it would not be necessary to conduct a day-by-day narrative.

## Note Taking and Recording

The narratives will yield two kinds of recorded information: a near-verbatim transcript and a sheet with key information coded on it.

**Transcript:** Sections of the narratives should be recorded virtually verbatim by detailed note taking, possibly supplemented by tape recording. It takes skill to record verbatim notes (be sure to include verbatim note taking in training!), but at the end of the day the notes can be handed to a secretary, whereas transcription of tapes takes an enormous amount of time. It is not necessary to note basic facts or standard questions verbatim, such as day the child become ill or what the symptoms were. Use as close to verbatim as possible for explanations, interpretations, or opinions, where knowing exactly how the caregiver expressed something may be useful. Work in pairs so that one person can take notes while the other person conducts the interview.

It is important to organize the notes well for ease of analysis. Label the day that fever started as Day 1. It is helpful to record which day it was, for example, "Day 1/Tuesday." Label your notes on how the child was the day before the illness as Day 0. After Day 1 and Day 0 have been described, proceed to Day 2 and so on, noting what was done and why for each day of the illness. This will help organize the information you collect and facilitate completion of the computer coding sheets. Figure 10 shows an excerpt from notes taken for a narrative.

At the end of each day of interviews, each interviewer and recorder pair should review the verbatim notes (and tape-recorded narrative, if available and necessary). The pair should fill in anything needed for the secretary to type as complete a transcript as possible on the following day.

**Coding Sheet for Computer:** *At the end of the day*, transfer information from the narratives onto the coding sheet. Do not wait until the end of fieldwork to code the narratives! The coding sheet is quite simple and has been put in small print so that everything fits on one page to minimize paper-shuffling in the field.<sup>4</sup> Once you know how to complete the coding sheet, it takes only about five minutes to fill out from the interview notes or transcripts. Figure 11 shows a sample of a completed Coding Sheet for Computer.

4. This type of compressed coding sheet with small print and abbreviations would not be suitable for larger quantitative studies or for large teams. This coding sheet assumes a small and well-trained team familiar with the topics and the layout of the coding sheet. Note that adding a second page doubles the amount of paper to keep track of and requires stapling.



Figure 10: Illness Narrative Excerpt

Lutaso Village

4/3/98 / Interviewer: Elizabeth

Recorder: Wambui

Child: 2 yrs 1 mo, F (Mercy)

Caregiver: mother, aged 21, finished Std 3

**DAY 1 / Sun****Q. When did you notice that Mercy was not well?**

A. Sunday in the afternoon [March 22]

**Q. What did you notice that made you think that Mercy was not well?**

A. Symptoms: Hot body, runny nose na kushituka shituka [twitching]

**Q. What illness did you think it was?**

A. I thought it was malaria and this is common because people say that the child of an expectant mother normally gets sick as the unborn baby “feeds” on the child.

**Q. So what advice are you given to prevent this?**

A. One is advised not to sleep with the child and not kumbebabeba [not to carry her all the time].

**Q. How serious did you think her condition was?**

A. It was serious.

**Q. Did you do anything to treat?**

A. Tepid sponging at night.

**DAY 0 / Sat****Q. Let us go back to the day before, on Saturday; how was she?**

A. She was not playing so much but she was ok.

**DAY 2 / Mon****Q. How was her condition on second day? That would be Monday.**

A. I bought some Panadols and would give her 2 tablet when she would get hot. I had some Septrin in the house, so I started to give her 1 teaspoonful 3 times [she had learned from providers that Panadol, Septrin treats fever and coughs respectively].

**DAY 3 / Tues**

The fever persisted. I noticed her eyes were white and that the color of the body was also turning white, she normally has blood problems. There was a time she was taken to Webuye Hospital (about 65km) for the same symptoms, so I knew it was serious.

**Q. So what did you do?**

A. As her condition worsened in the evening when the chemists were closed, I went to the health clinic to look for drugs. I wanted to buy Fansidar because by then I had realised she was suffering from malaria. I didn't want my child injected with CQ as I had been told that this injection “eats” blood and as I said my child was already having blood problems.

**Q. What happened at the clinic? . . .**

At the top of the sheet is basic background information: identifying information (ID, community name, etc.), demographic information (age and gender of child, age and education of caregiver, etc.), and information about the characteristics of the illness (symptoms, perceived cause, etc.).

The rest of the sheet records essential codable treatment information. The sheet allows you to capture the major sources of care or treatment actions, the order in which they were taken, and when (number of days after onset) they were taken. Recall that the narrative was conducted and notes were taken and labeled in a day-by-day sequence. Therefore, as you skim the narrative to complete the code sheet, you should be able to see each treatment source in sequence. In the bolded blank line along the left of the code sheet, put in the sequence number for each major source of care. For example, if on Day 1 the mother gave something at home, on Day 2 waited to see if the child would get better, on Day 3 took the child to the health facility, and on Day 5 returned to the facility because the child was still ill, then put a “1” before “Gave home care,” a “2” next to “Consulted Formal Provider 1,” and a “3” next to “Consulted Formal Provider 2.” The number along the left column indicates the sequence of treatment actions, not the day of the action. There is, however, a space to put in the number of days after onset of fever that each action was taken, so that timing of actions can be calculated.

Within each treatment source section, there is an indented column of blank lines corresponding to main actions taken by the treatment source. Tick (✓) each action taken. For example, if the home treatment the mother gave consisted of tepid sponging and two CQ tablets on one day and one tablet on the next, then in the “Gave home care” section tick “tepid sponging or bathing” and “Antimalarial given.” Then circle “CQ” to indicate that the antimalarial was chloroquine and write in that mother gave two tablets of *X* milligrams on one day and one tablet of *X* milligrams on the next. Then circle “u-dose” to indicate that this was an underdose. Note that the antimalarials listed on the coding sheet may have to be changed to correspond to those given in your research area.

The category “Took child to pharmacist” refers only to situations where a pharmacy staff person is used as a kind of health provider. In some countries, caregivers may bring in a child and ask the pharmacist to diagnose the illness and recommend medication or even, in some cases, give an injection. To plan the study and adapt the coding sheet, check whether pharmacists are used this way in your study area. In the rural areas of Zambia where the BASICS care-seeking study took place, this was not practiced, and the “Took child to pharmacist” treatment source was not included on the form. The category “Took child to pharmacist” should *not* be ticked if, for example, the mother decided to go to a pharmacy to buy CQ to give to the child. Since the locus of decision making was with the mother, the action would be coded as “Gave home care” and the category “Antimalarial given” would be ticked. Adapt the coding sheet to accommodate the main types of treatment sources found in your area of study.

To save space, the coding sheets for the Illness Narrative and Health Facility modules use abbreviations, which are explained in Figure 12.

Figure 11: Sample Filled in Coding Sheet for Computer

## Module 2: Illness Narratives – Coding Sheet for Computer

Community: Masaba Date / Interviewer: Aug 3, Rena ID#: 2203  
 Child's age: 0 yrs 10 mos Sex: F  M  
 Caregiver relation to child:  mother other: \_\_\_\_\_ Age: 24 Education: 2 years  
 Symptoms besides fever:  vomiting diarrhea chills/sweating cough  twitching/convulsions other: \_\_\_\_\_  
 Perceived illness: DK  malaria other: \_\_\_\_\_ Perceived cause: DK cold weather  
 Perceived severity: not very serious somewhat serious  very serious # days since fever began: 7

TREATMENT (Put sequence number in left-hand bold column for each care source used. Then for each care source used, tick in the vertical column the treatments given and fill in further information as indicated)

**1** Gave home care ( all home treatments given): # days after onset of fever: 1  
 Tepid sponging or bathing  
 Home remedies/herbs  
 Antimalarial given: CQ SP Other: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose  
 Other drugs:  Antipyretic Antibiotic Other: \_\_\_\_\_

**—** Took child to pharmacist # days after onset of fever: \_\_\_\_\_  
(tick only if pharmacist was asked to diagnose and recommend treatment)  
 Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # & type: \_\_\_\_\_  
 Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose  
 Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

**3** Consulted formal provider 1 (type): private clinic # days after onset of fever: 4  
 Antimalarial given:  CQ SP Other: \_\_\_\_\_ Injection: # & type: 1-DK  
 Amt recommended: can't recall Amt given: 1/2, 1/2 c-dose  u-dose o-dose  
 Other drugs:  Antipyretic  Antibiotic Other: \_\_\_\_\_  
 Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes  
 Admitted

**—** Consulted formal provider 2 (type): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_  
 Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # & type: \_\_\_\_\_  
 Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose  
 Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_  
 Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes  
 Admitted

**—** Consulted CHW # days after onset of fever: \_\_\_\_\_  
 Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # & type: \_\_\_\_\_  
 Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose  
 Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_  
 Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

**2** Consulted traditional healer # days after onset of fever: 3

STATUS OF CHILD: \_\_\_\_\_ recovered \_\_\_\_\_ still ill \_\_\_\_\_ deceased

Figure 12: Abbreviations on Coding Sheets for Illness Narratives and Health Facility Modules

|               |   |
|---------------|---|
| <b>amt</b>    | amount  |
| <b>med</b>    | medication  |
| <b>ORS</b>    | oral rehydration salts                            |
| <b>CQ</b>     | chloroquine                                       |
| <b>SP</b>     | sulphadoxine-pyrimethamine (trade name Fansidar™) |
| <b>c-dose</b> | correct dose                                      |
| <b>u-dose</b> | underdose   |
| <b>o-dose</b> | overdose  |
| <b>CHW</b>    | community health worker                           |
| <b>DK</b>     | don't know  |
| <b>HF</b>     | health facility                                   |
| <b>HP</b>     | health provider                                   |
| <b>#</b>      | number  |



## Module 2: Illness Narratives

### 1. Select respondent and obtain consent

- 1.1 Screen for children under 5 years who have had fever or convulsions in past 2 weeks.
  - *Are there any children 5 years and under in this house?*
  - *In the past 2 weeks, has that child [have any of those children] had any illness involving fever [“hot body”]?*
  - *In the past 2 weeks, has that child [have any of those children] had any convulsions?*
  - *[If you are calculating treatment sequences and want only completed cases ask: Is the child still ill today?]*
- 1.2 Select someone familiar with what happened during the illness as an interviewee.
  - *Who has been the primary person caring for the child during the illness?*
- 1.3 Explain your mission, assure confidentiality, and obtain consent.
  - *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 facility 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?*
- 1.4 In a conversational manner, gather demographic information: age and sex of the child; age and educational level of the caregiver; and relationship to the child.

### 2. Conduct illness narrative

- 2.1 Ascertain the day and time the mother first noticed illness symptoms, since you will want to calculate how long afterwards various treatments were given. Note taker: label this “Day 1.”
  - *Please tell me what happened, starting from the beginning.*
  - *First, I would like you to think back to the day you noticed the child was ill. What day was that? About what time of day was it?*
- 2.2 Find out symptoms, or why mother defined the child as “ill.”
  - *What did you notice that made you think the child was ill? Anything else?*
- 2.3 Ask the caregiver how the child was the day before he or she got ill. Note taker: label this “Day 0.”
  - *Now what about the day before—do you remember how the child was the day before?*
- 2.4 Go back to Day 1 and find out what mother thought illness was, the cause, and how serious it was.
  - *Okay, so let’s go back to that first day when the child was ill, [“Saturday”].*
    - *What did you think the illness was?*
    - *What do you think caused this illness/problem?*
    - *How serious did you think the illness was on that first day?*

## 2.5 Ask about treatment.

- *Did you do anything that day to help the child get better?*  
[Get details of treatment. See probes below.]

Then ask her about the next day and the next in the same manner.

- *Then what happened the next day?*

### ***Treatment-seeking probes***

Within this chronological structure, probe to make sure that topics are explored as appropriate. Below is a list of topics to ask about. From the Narrative Coding Sheet for Computer, learn which topics or variables that must be a standard part of every interview.

Your overall objective is to find out what treatment actions were taken, when, and why:

- What did caregiver do?  
[Note especially if an antimalarial was given and how much was given.]
- Why was each step taken? What was the trigger to take each step?
- Who was involved in treatment decisions? [Listen especially for role of fathers.]

The following are specific probes for each source of care mentioned:

#### **a) Home care**

- What measures were taken? Why?
- If antimalarial given: Why did caregiver decide to give that drug? How much was given? How did she decide how much to give? Where was drug obtained? What does the drug do?
- What other drugs were given?
- Did caregiver seek advice from family or neighbors? Other sources?

#### **b) Health facility**

- What prompted caregiver to seek help from a health facility?
- What advice was given? Was this considered good advice?
- Did caregiver get what she needed? What was she happy with? Unhappy with?
- How far does the caregiver live from the facility? How long does it take to get there from home?
- Was permission needed to go to the facility?
- What did it cost to get to the facility? What did treatment and/or drugs at the facility cost?

#### **c) Compliance with advice from facility providers**

- Was advice followed? Why or why not?
- If antimalarials were recommended, what did she give, and how much?  
[Pay attention to *dose* and probe to understand why or why not the correct dose was given.]
- Did treatment help? What happened?
- Did the health facility ask the caregiver to return? Did the caregiver return? What happened?
- Was a referral made to another provider/facility? Was referral acted upon?  
Why/why not? What happened?

**d) Community providers (CHWs, traditional healers)**

- Why did caregiver decide to seek help from this provider?
- What advice was given? Was advice was followed? Why or why not?
- Did treatment help? What happened?
- What did treatment cost?

**e) Knowledge of antimalarial administration**

- Although the focus of this module is on *behavior*, it is important to ascertain caregiver's *knowledge* about administration of antimalarials, since this directly affects her behavior. At some natural point in the narrative, ask questions such as, "*Why did you give [X amount]?*" "*In your opinion, how much CQ/Fansidar™ do you think should be given?*" "*What is the dosage?*" Also find out whether anyone ever explained to her how to give the drug, and ask who—for example, neighbor, pharmacist, clinic staff.

***Other topics that can be explored*****f) Prior experience**

- It may be useful to find out if this child or other children in caregiver's charge have had this illness before. Did the caregiver treat this episode differently from other episodes? How? Why?

**g) Definitions and perceptions of treatment success and treatment failure**

- Listen for opportunities to define treatment success and failure. For example, if caregiver says child got worse, better, or well, you can ask how she knew.

**h) Comparison of perception of SP/Fansidar™ with CQ**

- Comparisons are important where drug policies are in transition and acceptability of the new drug may be an issue. SP/Fansidar™ and CQ have different dosage regimes and characteristics. Explore the impact of those differences on preferences and perceptions. See the Treatment Comparison module (Module 6) for suggestions on how to do this.

**i) Communication**

- During the course of the narrative, you can learn much about whom the caregiver consults for various types of information and decisions. If she indicates she made decisions herself, you can ask where she learned how to treat malaria (or local term caregiver used for illness). It is especially important to ask about how she learned what drugs to administer and how much to give. If your research is to be used in planning ways to improve support for treatment in the community, try to find out how caregivers in the community get information about health—ask whether the respondent belongs to any organizations, attends talks at the health facility, listens to health programs on the radio, and so on.









## Module 2: Illness Narratives - Coding Sheet for Computer

ID#: \_\_\_\_\_

Community: \_\_\_\_\_ Date / Interviewer: \_\_\_\_\_ / \_\_\_\_\_

Child's age: \_\_\_\_\_ yrs \_\_\_\_\_ mos Sex: F M

Caregiver relation to child: mother other: \_\_\_\_\_ Age: \_\_\_\_\_ Education: \_\_\_\_\_

Symptoms besides fever: vomiting diarrhea chills/sweating cough twitching/convulsions other: \_\_\_\_\_

Perceived illness: DK malaria other: \_\_\_\_\_ Perceived cause: DK \_\_\_\_\_

Perceived severity: not very serious somewhat serious very serious # days since fever began: \_\_\_\_\_

**TREATMENT** (Put sequence number in left-hand bold column for each care source used. Then for each care source used, tick in the vertical column the treatments given and fill in further information as indicated)

\_\_\_ **Gave home care** (✓ all home treatments given): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Tepid sponging or bathing

\_\_\_ Home remedies/herbs

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ **Took child to pharmacist** \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

*(tick only if pharmacist was asked to diagnose and recommend treatment)*

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ **Consulted formal provider 1** (type): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

\_\_\_ Admitted

\_\_\_ **Consulted formal provider 2** (type): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

\_\_\_ Admitted

\_\_\_ **Consulted CHW** \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

\_\_\_ **Consulted traditional healer** \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

**STATUS OF CHILD:** \_\_\_\_\_ recovered \_\_\_\_\_ still ill \_\_\_\_\_ deceased



## Module 3: Terminology and Taxonomy - *Implementation Guide*

### ***Purpose***

- Elicit terminology for fever, convulsions, malaria
- Construct local taxonomy of illnesses involving fever and/or convulsions
- Obtain normative information on treatment of childhood febrile illnesses
- Determine local knowledge of the causes, symptoms, and treatment of malaria

### ***Method***

Group interview with free listing and semi-structured questioning to fill in matrix

### ***Sample***

Principally women, but men may participate also

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

Terminology and taxonomy grid

Detailed notes, some verbatim

Tape of session (optional, but recommended)

## **Purpose**

The purpose of this module<sup>5</sup> is to identify local terms for illnesses involving fever and/or convulsions, and to understand local taxonomies (classifications) of those illnesses. By identifying local terminology and illness classifications, you can ensure that you and the respondents are talking about the same thing. This module can help you to determine the extent to which local terms correspond to the clinical definition of malaria. You may discover that participants call some symptoms and illnesses “malaria” that are not clinical malaria, and that they are not calling other symptoms and illnesses “malaria” that are part of the definition of clinical malaria. If you elect to use this module, conduct the terminology and taxonomy interviews after the Community Introduction module but before all other modules. This sensitizes your team to terms and classifications that local people may use when you are carrying out other modules.

## **Method**

The module first elicits a list of child illnesses involving fever, and then, for each of those illnesses, asks about the cause, prevention, and treatment. Then the same procedure is followed for convulsions. The questions in this module should not be asked in a rote fashion. To do this module well, the researcher must listen actively and probe to differentiate illnesses with similar symptoms.

5. This module was adapted from Helitzer-Allen, D. L., and H. A. Allen, Jr. 1994. *Targeted Intervention Research on Sexually Transmitted Illnesses with Community Members*. Washington, D.C.: USAID and Family Health International AIDS Control and Prevention Project.

Although detailed probing is essential, it is important not to force participants into making clear-cut classifications if none exist. *It is also essential that in the discussion as well as in your notes you use only the actual terms the participants use for any symptoms and illnesses, not your translation of those terms.* For example, only say or write the term “malaria” if that is the actual local word used, not if another term is used that you think means malaria.

This module yields information on terminology and illness classifications, and general normative information on how those illnesses are treated. This module should not be the primary source of information about how those illnesses are actually treated. That information is best gathered via the illness narratives, which ask about actual febrile illness cases.

You will note that this module has been labeled “supplementary” rather than “core.” Some researchers may consider this exercise essential, and indeed it can yield important information. You are strongly encouraged to conduct this module if your team has sufficient time and expertise to do so. There are several reasons why this module has been made optional:

- The exercise looks simple but is hard to do well. Unless you are fluent in the local language, you must rely on local researchers. Few researchers have strong experience in doing this research, and they need a high degree of skill to do it correctly. At a minimum, they must understand the concept of taxonomies and explanatory models of illness. The terminology portion is much more than just getting a translation; it involves active listening and on-the-spot construction of a probing sequence that elicits accurate categories.
- The module is time-consuming and participants often find it tedious. At least four and as many as a dozen illnesses may be named in the initial free listing, each of which must be discussed using the same sequence of questions. Then the procedure is repeated for convulsions.
- If more than one language is spoken in your study area, you will need to develop a taxonomy for each. This requires a minimum of two but preferably more groups per language, which can take up a disproportionate amount of your research time and result in long tables explaining local terms that may be of limited use in the development of regional or national interventions.
- You can usually reach a mutual understanding of terms during data collection by talking about symptoms rather than illnesses—for example, by talking about a child being ill with fever rather than with malaria. Then you can listen for and ask about any other terms the mother introduces. For example, if a mother says her child had fever and she thought it was malaria, ask more about how she knew it was malaria and then use the term malaria from that point on in the interview.

### Convulsions Taxonomies

There are several important objectives in constructing a local taxonomy of convulsions. One is to learn whether convulsions in the presence of high fever are seen as linked to the fever or are seen as a separate condition. If caregivers perceive these convulsions to be a separate illness with a separate cause, they are likely to seek a different course of treatment. It is important to learn whether caregivers think that a child with convulsions and fever should be taken to a health facility immediately. Another objective is to find out whether community members distinguish between convulsions related to high fever/malaria and those caused by epilepsy, which occur without fever.

Biomedically, there is a distinction between febrile convulsions and cerebral malaria. Febrile convulsions can result from any condition that causes high fever, and are treated by reducing the fever. Convulsions associated with cerebral malaria, a severe form of the illness, require treatment with antimalarials and intravenous fluids. From a care-seeking standpoint, it is not important that community members know this distinction. What is important is that they know that a child with convulsions and fever needs to be seen at the health facility as soon as possible.

Similarly, if the objective is to learn whether treatment varies by how an illness is classified, then it is better to ask about a specific episode, including what the mother thought the illness was and what she did to treat it.

How much time you decide to spend on the Terminology and Taxonomy module will depend on how much the results of your research will be used to develop local, as opposed to national or regional, IEC materials or programs. For NGOs that will be working long term in a particular district, it is worth taking the time to understand all the terms that local people use. If the program encompasses more than one language or ethnic group, then the strategy should be based on finding a common rather than local way of talking about malaria.

From the standpoint of communication strategy, it is desirable to use a single term for malaria, and link that term to a common, accurate understanding of symptoms and treatment. One aim of the research, therefore, is to find out how well people understand a common term, and how their understanding could be improved. Fortunately for communication efforts, the English term *malaria* or its equivalent in the dominant language (e.g., *paludisme* or *palu* in French) is becoming more and more widely used, even in rural Africa.

## Sample

The sample should consist mainly of mothers and grandmothers of children under 5 years of age, but fathers may also participate. No health providers should be included in the group.

## Note Taking and Recording

The products of this module are (1) a verbatim or near-verbatim transcript of the discussion and (2) a taxonomy grid that organizes the information into symptoms, causes, prevention, and treatment, as in the recording form in the following pages.

- (1) Because the intent of the module is to capture local terms and subtle differences in illness classifications, you may wish to tape-record these sessions as well as take detailed notes. Make sure that the note taker can take notes quickly and accurately.
- (2) The taxonomy grid organizes the information for analysis. To save time and to give you a basis for end-of-day discussion and analysis, use an additional note taker to fill in basic information in the grid during the discussion session. The person filling in the grid should write each illness mentioned by free listing (Step 2 in the module) down the left-hand column, and then fill in information about the illness—symptoms, causes, and so on—across the grid as each is discussed. The information in the grid can be reviewed and refined when the complete transcripts are typed.

It is worth repeating that whenever discussions are recorded or transcribed, you should record the *actual local terms used, rather than translations*.





## Module 3: Terminology and Taxonomy

### Fever

1. **Terms for fever:** Find out the term(s) for fever.  
*When a child's head or body gets hot, what is this called?*  
Confirm: *So if my child's head or body is hot, I say, "My child has [term]?"*
2. **Illness list:** Obtain a free list of illnesses with fever as a symptom.  
*Can you tell me all of the illnesses that children get that cause [term]*
3. **Symptoms:** For the first illness with fever, elicit a free list of other symptoms associated with the illness. You may also want to ask if symptoms usually appear in any sequence.  
*How do you know when a child has X [illness]? What is it like when a child has X? Do these symptoms appear at once, or do some appear before the others?*
4. **Causes:** For that same illness, ask what causes the illness.  
*How does a child get X?*
5. **Prevention:** Ask if there is any way to prevent the illness.  
*Is there any way to prevent a child from getting X? How? Why do some children get X and some don't?*
6. **Treatment:** Ask how X is treated.  
*How do you treat a child who has X?*  
*Where do you go for treatment (home, shop, clinic)?*  
*Who has the most information about this illness?*  
*Are there any medicines for X? How do you decide which one to give?*

**Repeat Steps 3–6 for each febrile illness with symptoms that overlap with malaria.**

### Convulsions

1. **Terms for convulsions:** Find out the term(s) for convulsions.  
*When a child gets like this [imitate], what is this called?*
2. **Types of convulsions:** Find out if there are different types of convulsions. Get a description of each.  
*Are there different types of convulsions? How do you know which type of convulsion a child is having? What is each like?*
3. **Causes of each:** Find out what causes each type of convulsion.
4. **Treatment for convulsions:** Find out how each type of convulsion is treated.







### Module 3: Terminology and Taxonomy: Taxonomy Grid

Community:

Language:

Date:

Facilitator/Note taker:

| Illness Name | Symptoms | Causes | Prevention Methods | Treatments |
|--------------|----------|--------|--------------------|------------|
|              |          |        |                    |            |
|              |          |        |                    |            |
|              |          |        |                    |            |
|              |          |        |                    |            |

*[Use as many sheets of grids as necessary.]*



## Module 4: Health Facility - *Implementation Guide*

### **Purpose**

To investigate:

*The history of the illness and the triggers to care-seeking, including:*

- treatments tried and providers/facilities consulted prior to the health facility visit
- illness symptoms or other factors that prompted the caregiver to bring the child to the facility
- the time between the onset of fever and the visit to the health facility (if first visit)

*The provider's interaction with the caregiver, including:*

- the provider's understanding of the history of the illness and of what treatment has been tried
- the provider's advice to caregiver regarding treatment and prevention
- the provider's explanation and whether it is sufficient to enable the caregiver to comply with the advice
- duration of consultation

*Caregiver's satisfaction and ability to comply with the provider's advice, including:*

- the caregiver's confidence in the diagnosis, advice, and treatment
- what the caregiver liked and disliked about the experience
- the caregiver's ability to understand and recall the provider's advice
- other factors that facilitate or hinder caregiver's compliance

*Caregiver's compliance with treatment advice*

### **Method**

- Interviews with caregivers when they arrive at the health facility, as they exit, and 2 or 3 days later
- Interviews with providers
- Observation of the interactions of caregivers and providers at the facility

### **Sample**

- Caregivers at the health facility who brought children under 5 years with fever and/or convulsions or perceived malaria
- A subset of this sample, interviewed 2 or 3 days later
- Providers at the health facility

### **Note Taking and Recording**

This module consists of six sub-modules that use different methods, and the recording technique for each sub-module is specified. The close-ended questions in this module can be coded and entered into a data set.



## Purpose

The purpose of the Health Facility module is to understand the caregiver's experience in the health facility and how it bears on the overall treatment that a child receives. It should be emphasized that the purpose is *not* to assess the quality of health services or the clinical skills of health providers, but rather to understand the clinic experience from the caregiver's perspective and to identify those factors that encourage or discourage the caregiver being able to proceed with optimal treatment. (There are other research protocols designed to assess health service quality—see footnote 4.) It is worth referring to Step 3 in the care-seeking model described in Section 2 for a review of issues relevant to this module.

To perform the module, the research team “follows” caregivers through their health facility visit: interviewing them on arrival, observing their consultations with the provider and in the treatment room, and interviewing them as they leave. At least one provider from each facility should be interviewed. You may also interview some of the caregivers again a few days after the visit, to see how well they have understood, remembered, and complied with treatment recommended by the health facility staff.

## Sample

Your overall sampling plan will probably include 5 to 10 health facilities, and you should aim to interview from 6 to 10 caregivers at each. Depending on the size of the facility, you should interview one or two providers. The number of follow-up home interviews, if any, depends on how important the issue of caregiver compliance is to your research. As a general guide, you would conduct follow-up interviews with one-third to one-half the caregivers interviewed at the facility, but if your study is focused solely on compliance, you will want to conduct follow-up interviews with all of them.

## The Components of the Module

**Basic information about the health facility.** Assemble (on one page) basic descriptive information about the facility (such as name and location, size, and type) and collect other information you deem relevant to your study (such as current stock of antimalarials, regularity of supply, special mechanisms for making insecticide-treated nets (ITNs) available, and so on). You will already know the basic descriptive information but will want to keep track of it for describing the health facility sample in your report. Other information can be collected informally during your initial conversation with staff when you are explaining your purpose and gaining permission to collect data.

- 4-I. *Preconsultation interview with the caregiver* to elicit a brief history of the illness; treatments already tried and/or providers consulted; symptoms or factors that prompted the decision to bring the child to the facility; and time between this visit and onset of fever.
- 4-II. *Observation of the caregiver's consultation with the provider* to note how well the provider and caregiver communicate about the history of the illness and treatments already tried; the provider's diagnosis; and the provider's advice about medication, feeding, return visits, referral to other facilities, and prevention.
- 4-III. *Observation of the treatment room* to note medication regimes prescribed, whether medication is identified to the caregiver, and quality of communication of dosages.
- 4-IV. *Exit interview with the caregiver* to assess caregiver's ability to understand and recall treatments, caregiver's confidence in diagnosis and treatment advice, and satisfaction with the visit.
- 4-V. *Interview with the provider* to obtain provider's perspective on caregivers' treatment practices.

4-VI. *Follow-up home interview with the caregiver* after 2 or 3 days, to find out how well caregivers are complying with the treatment recommended at the health facility.

It may not be feasible to conduct all six components of the Health Facility module. The follow-up interviews (4-VI), in particular, require finding caregivers several days after they visit the health facility, and may be difficult to arrange. However, if compliance issues are of high importance in your research, this component is worth the effort. Compliance issues can also be explored in the illness narratives, but this approach is not as reliable as the follow-up interview because you will have to depend on the caregiver's report of what the provider recommended. The caregiver's recollection may be faulty, or she may not mention provider recommendations that she did not act on.

## Approaching the Health Facility

Check the facility schedule and try to visit on a typical day. Do not go, for example, on a day designated for prenatal visits only. Find out the facility hours and begin, ideally, at opening time. Whether or not you need to pre-arrange your visit depends on the facility. If it is possible to arrive at opening time and gain permission to work that same day, that is preferable to giving advance notice since you want to minimize the opportunity for the staff to prepare for the visit and change normal operations to make a good impression. Emphasize to the staff that you are looking at the *caregivers'* perceptions of illness and treatment; be careful not to give the impression that you are checking up on or assessing the health providers. Stress that you do not want to impose on the staff or disrupt their work, and that the main purpose is to talk to the caregivers in the facility and look at their experience there and the kinds of things they do to seek help for children who are ill with fever. Tell staff what you will want to do—that some team members will want to talk to caregivers before and after their consultation and that others will want to observe the consultation and talk with the health provider afterwards.

If members of your team are from the Ministry of Health and known to facility staff, do not use them in this module. The presence of someone known to be an MOH official is almost certain to influence, if not intimidate, the staff.

## Organizing Your Team

Divide the team up to conduct preconsultation interviews, consultation observations, treatment room observations, and exit interviews simultaneously. To plan this, find out in advance about the size and organization of the health facility. Depending on your sample, "health facility" can mean a rural health post or a large urban hospital outpatient clinic, so the organization of services will vary. In many facilities, the clinician performs the examination and gives the diagnosis and another staff member administers treatments such as injections and drugs. Figure 13 provides an example of an organizational approach for a team to conduct the components of the Health Facility module simultaneously in a mid-sized facility.

Figure 13: How to Organize the Team to Follow Caregivers in a Typical Mid-sized Health Facility

| <i>Component</i>  | <i># of team members</i> | <i>Team members' tasks</i>  |
|---|--------------------------|---|
| 4-I. Preconsultation interview with the caregiver                   | 1 or 2                   | One interviews, the other takes notes; if patient flow is high, both interview so as not to keep caregivers waiting.<br><i>Average time: 10 minutes per interview</i>   |
| 4-II. Observation of the caregiver's consultation with the provider | 1                        | Sit through all consultations, whether patient is in sample or not (unless there are privacy considerations), but fill out observation sheets only when a patient in the sample is being seen.<br><i>Average time: 10 minutes per patient</i> |
| 4-III. Observation of the treatment room                            | 1                        | Sit through all patients, record only when a patient in the sample is being seen.<br><i>Average time: 10 minutes per patient</i>  |
| 4-IV. Exit interview with the caregiver                             | 1 or 2                   | One interviews, the other takes notes; if patient flow is high, both interview so as not to keep patients waiting.<br><i>Average time: 10 minutes per interview</i>   |

## Keeping Track of Your Interviewees and Records

To make sure that records from different caregivers do not get mixed up, give each caregiver an identity (ID) number and ensure that it is written on all records from all components with that caregiver. This must be done systematically:

- 1) At the start of each preconsultation interview, the interviewer assigns the caregiver an ID number and writes it on the preconsultation recording forms. At the end of the interview, the interviewer gives the caregiver a card with the ID number on it and asks her to give it to the team member in the consultation room. If this is the first health facility and the first caregiver, the ID could be 11; for the second caregiver, the ID could be 12; for the third, 13; and so on. If you are giving incentives,<sup>6</sup> you could tell caregivers that they will receive a small gift when they exit the facility, to increase chances that they will complete the exit interview.
- 2) The observer in the consultation room will know that a caregiver who presents a card is part of the sample. The observer writes the ID number on the recording form for the caregiver's consultation with the provider, hands the card back to the caregiver, and asks her to give it to the team member in the treatment room.
- 3) The observer in the treatment room writes the ID number on the recording form for the treatment room and asks the caregiver to hand the card to someone who would like to interview her upon exit.
- 4) Immediately after the interviews, the IDs should be matched, and the recording forms from all components for a given caregiver should be stapled together.

6. Whether or not incentives or small gifts are given to the respondent depends on the setting. In some countries or under some projects, incentives are highly discouraged or prohibited. In others, they are seen as an appropriate means of giving a small compensation to the respondent for her time. In most cases, an incentive is a small item, such as a bar of soap.

## Implementing the Preconsultation Interview with the Caregiver (4-I)

Researchers conducting preconsultation interviews should post themselves where patients enter the facility and select respondents who meet the following criteria:

- (1) Child is under 5 years
- (2) Illness involves fever or convulsions, or caregiver perceives the illness to be malaria

In most facilities, there are (sometimes long) waits before the patient can be seen by the provider; this waiting period is usually a convenient time to conduct the preconsultation interview. Interviewers should, however, be careful to minimize any inconvenience to the caregiver and sick child. Some caregivers may be bringing in very sick children who need prompt care, and, although the entry interview takes only about 10 minutes, in no case should the interview delay the receipt of care or the flow of services. If necessary, the initial interview can be conducted after the child has been treated, so that the entry and exit interview are combined. There may be some cases where the caregiver is too worried or hurried or the child is too upset or uncomfortable to take any time at all for interviews.

The preconsultation interview is similar to the illness narrative in Module 2, but shorter, to avoid inconveniencing the caregiver whose primary interest is to get treatment for a sick child. The main objective of this interview is to document prior treatment and what prompted the caregiver to bring the child to the facility. There may be little time to ask details of how and why treatment decisions were made. Of course, if the caregiver is willing, you should explore issues in as much detail as time permits.

Briefly explain the purpose of the research, assure the caregiver that responses are confidential and will not be communicated to the health facility staff, and obtain permission to continue.

The key information to gather is:

- age and sex of child
- caregiver relationship to child
- whether this is the first, second, or third visit to this facility for this illness
- illness symptoms besides fever (fever is a criterion for inclusion in sample)
- perceived illness, cause, and severity
- number of days since the onset of fever
- prior treatments given, including antimalarial type and amount; whether the amount of antimalarial given was the correct dose, an underdose, or an overdose; formal providers, CHWs, and traditional healers consulted
- what prompted caregiver to bring in child to the health facility
- information on access to the health facility, including what form of transportation was used, how long it took to get to the facility, and how much it cost

Note the arrival time if you want to calculate waiting times. (The observer in the consultation room will note the time the consultation starts.) After the interview, hand the caregiver a card with her ID number and ask her to give it to the team member in the consultation room when she is called to see the provider.

**Note taking and recording.** This is a mini-narrative, but concentrate on documenting the main treatment events, but with less detail on the reasons for them. Record responses directly on the coding sheet, and take additional notes as appropriate, including any noteworthy verbatim statements. The coding sheet is

like that used in the Illness Narrative module; to use it, follow the instructions under “Note taking and recording: (2) Coding Sheet for Computer” in the implementation guide for Module 2. The close-ended information can be taken directly from the coding sheet and entered into a database. This health facility sample constitutes a separate data set from the narratives sample.

## Implementing the Observation of the Caregiver’s Consultation with the Provider (4-II)

Only record consultations with caregivers who have ID cards from the preconsultation interview. Write the ID number on the coding sheet immediately to ensure that records from different caregivers do not get mixed up.

It is particularly important to record the following:

- 1) Medication: what drugs the provider recommended
- 2) Feeding: what advice the provider gave about feeding the child
- 3) Return visit: whether the provider asked the caregiver to return to this facility
- 4) Referral: whether the provider told the caregiver to go to other facilities
- 5) Prevention: whether the provider recommended use of an ITN

Your record of this information will be compared with what the caregiver recalls in the exit interview. The comparison will indicate how well the caregiver recalls advice, as incomplete recall would clearly influence the ability to comply. If this caregiver is given a follow-up interview to look at actual compliance, her treatment actions will again be compared with the treatment recommendations recorded here.

Also note:

- Whether the provider obtained information about the history of the illness—especially history of fever and presence of convulsions—either by asking whether specific symptoms were present or by giving the caregiver the chance to describe the illness problem
- Whether the provider obtained information on what the caregiver has already done to treat the child, either by asking whether specific treatment actions were taken or by giving the caregiver the chance to describe what she did
- What diagnosis the provider made, and whether the provider communicates it to the caregiver (if not, ask the provider for the diagnosis after the caregiver leaves)
- Your qualitative assessment of the interaction between the provider and the caregiver
- Time consultation begins and ends

Observers should note their qualitative assessment of the interaction, and the team should discuss beforehand the interaction criteria—e.g., provider interest, empathy, and attempts to make the caregiver comfortable. Observers are encouraged to note other aspects of the caregiver’s experience with the provider, such as how the provider handled the child during the exam, whether there was privacy for the consultation, whether the caregiver was scolded, permitted to ask questions, and so on.

Usually a clinician carries out the consultation and another staff member dispenses the treatment. In a facility where one staff member does both, combine the observation of the treatment room with the observation of the caregiver’s consultation with the provider.

**Note taking and recording.** The observation guide includes space for recording and coding. Note items to be observed and mark as indicated. It is not necessary to take verbatim notes on the interaction unless something is said that you want to recall. For example, if the provider scolds the caregiver, you may wish to record what was said. Write other notes about the session, as relevant.

## Implementing the Observation of the Treatment Room (4-III)

In many facilities, the caregiver goes from the consultation with the provider to a “treatment room,” where injections may be given, medication dispensed, or prescriptions written. The purpose of this component is to observe the treatment given and the provider communication with the caregiver regarding medications or other treatments recommended for the child. To administer treatments correctly at home, the caregiver must receive the correct medications in the correct amounts and understand how they are to be given. On the form, the observer will note what happens in the treatment room that might affect the caregiver’s ability to comply with the provider’s instructions. For example, there is space for recording whether the dispensing provider said what medication was being given (if caregiver did not know already) and explained how to complete the administration of any multidose medications at home. The form should be adapted to reflect the first-line and second-line antimalarial for the country in which you are working, as well as any special issues related to those drugs. For example, if the first-line drug has recently been changed from CQ to Fansidar™, then the provider ideally would explain to the caregiver some key differences between the drugs, such as that Fansidar™ may take longer to show effect.

Note any other factors that might affect the caregiver’s understanding of how to administer medications, such as the speed or tone of the instructions given or the clarity of written instructions. In the Zambia study, researchers noted that in some clinics the staff person who was filling the prescription had her back turned as she was giving instructions on how to give the medication. This made it difficult for the mother to hear the instructions and discouraged her from asking questions. Note any other pertinent circumstances, such as whether caregivers are expected to provide their own empty bottles or other containers for carrying the medication, whether special symbols are used to indicate dosage, and so on.

Even when doses were accurately prescribed, dosage instructions were usually given in a quick, inaudible, unclear manner. Sometimes two, three, and four different medications were handed to the mother with very rapid instructions on each. The name or purpose of the drug was rarely stated. Even when written instructions were given, labels and written instructions were confusing, especially those written on bottles containing liquid medications. The persons doing the dispensing did not check to see whether the mother understood the dosage, and some seemed annoyed if a mother asked a question.

—excerpt of health facility observations from the Zambia report

The observer will record only sessions for caregivers who have ID numbers from the preconsultation interview, and will immediately write the ID number at the top of the observation form. When the card is handed back to the caregiver, she should be asked to give the card to a team member posted outside the facility who will talk to her briefly when she is finished.

**Note taking and recording.** As in the observation of the caregiver's consultation with the provider, the recording form serves both as an observation guide and recording device. Note the items to be observed and mark accordingly, but write other notes on the session, as relevant.

## Implementing the Exit Interview with the Caregiver (4-IV)

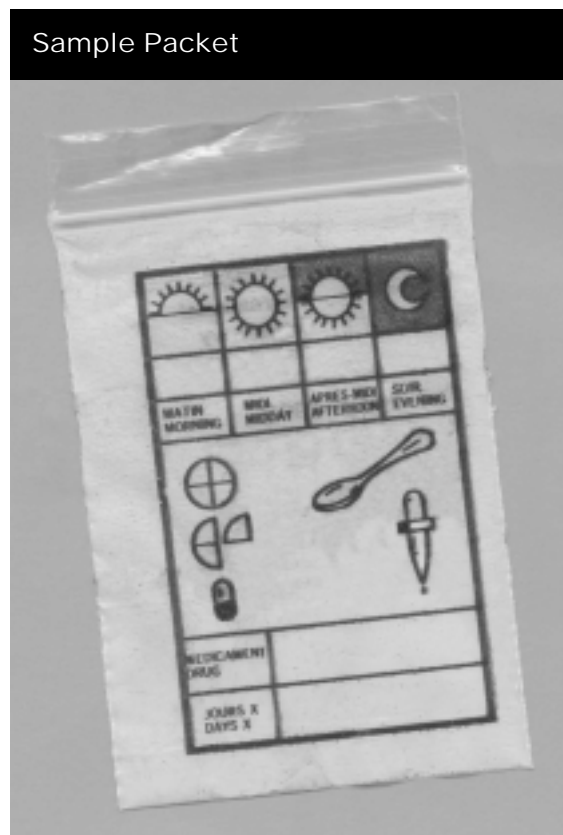
The main purpose of the exit interview is to ascertain recall of treatment advice, satisfaction with services, and cost of services. The following topics should be covered:

- Recall of treatment: A primary purpose of the exit interview is to ascertain recall of the provider's main recommendations on medication, feeding, return visits, referrals, and prevention. You may want to obtain both unprompted and prompted recall. For unprompted recall, start with an open-ended question on what the provider recommended to help the child get better. Then, for any action not mentioned, prompt: "Did [the provider] say anything about X?" In the analysis phase, the caregiver's recall will be compared with what the providers actually recommended.
- Understanding of antimalarial dosage: If a multidose antimalarial has been prescribed, correct understanding of how to administer it is essential. Interviewers must be sufficiently trained to recognize the various antimalarials and ideally also should know the administration regimen of each. At a minimum, one person on the team must know the dosing regimens and be responsible for coding whether the instructions and the recall are correct.

If interviewers have the skill and the time, they can ask how each of the drugs the caregiver was given is to be administered. (If you do this, adapt the module and recording form accordingly; currently it asks only about administering the antimalarial.) In Zambia, caregivers were routinely given two or three drugs, and about half the caregivers could not recall on exit how the drugs should be administered. Further, some caregivers misinterpreted symbols used on medication packets. The round sun, intended to mean that a dose was to be given in the morning, was taken to mean "give a whole tablet," and a symbol showing the lower half of the sun, intended to mean that a dose was to be given in the afternoon, was taken to mean "give half a tablet."

After all research questions about dosage have been asked and if the caregiver has misunderstood how to administer the drugs,

Sample Packet



explain the correct administration to her. If she has misunderstood symbols, explain those to her. For your records, note what has been explained to her, especially if she may be included in follow-up home interviews looking at compliance.

- Confidence in treatment recommended and satisfaction with the overall visit: The perceived efficacy of the treatment recommendations will affect whether the caregiver feels that it is worth carrying them out. Find out whether the caregiver thinks that the provider has recommended the right treatment. Often, caregivers are hesitant to question the authority of a health provider. Interviewers will have to ask questions in an open and neutral way. The module suggests asking, “*Do you think this is the right treatment for this child?*” and “*What about the recommendation/ treatment makes you think it is right?*”

Find out the caregiver’s level of satisfaction with the visit. Again, a caregiver may be hesitant to say that she was not happy with her experience, and the module suggests neutral language for asking about satisfaction: “*Did you get what you need today?*” “*Was there anything else you would have wanted to happen?*” “*Was there anything that you were unhappy with?*” “*Was there anything you were particularly happy with?*” Some respondents may be worried that you will pass on what they say to the provider; reassure them their opinions are confidential.

- Cost of services and medications: Cost is known to influence utilization of services. Sometimes services are supposed to be free, but in fact fees are charged. You may also wish to find out whether the caregiver considers what she paid to be reasonable or expensive.
- Caregiver age and level of education, for purposes of analysis.

If you are doing follow-up home interviews, let the caregiver know that some mothers will be visited by a team member in a few days. Obtain detailed instructions on how to locate potential interviewees.

**Note taking and recording.** The interview guide is on a separate sheet from the recording form, as the exit interviews will most likely be conducted by an interviewer and note taker team. Some questions are close-ended and responses are set up for coding on the recording form, but some questions are open-ended and space is provided for noting the exact wording. For example, note what the caregiver says about satisfaction; do not just record “satisfied.” The close-ended information can be coded and entered into the Health Facility data set, and the open-ended information provides more detail about the coded responses.

## Implementing the Interview with the Provider (4-V)

The interview can be done after all the caregivers in the sample have had consultations, or whenever it is most convenient for the provider(s). Your main purpose is to compare provider perceptions of caregiver treatment practices with what actually occurs. In introducing the purpose of the interview, emphasize that you are interested in learning what mothers do to treat febrile illness. You are not testing the provider’s competence, and be sure to avoid giving that impression.

**Note taking and recording.** This is a standard semi-structured interview. Answers can be written directly on the combined questionnaire and recording form. Take a combination of summary and verbatim notes.



## Implementing the Follow-up Home Interview with the Caregiver (4-VI)

The follow-up home interview seeks detailed information on the factors that encourage the caregiver to comply with the treatment recommendations and the factors that discourage her from doing so. It also seeks information on any additional treatments given or any other providers consulted since the visit to the health facility.

This component can be logistically complicated, as it involves returning to the communities 2 or 3 days after the health facility visit, finding caregivers in their homes, and comparing recommended treatments with actual treatment. If the Health Facility module is conducted on the first day in a community, then two researchers can do follow-up interviews on the last day of work in the community, possibly when other team members are writing up findings from the other modules.

In preparation for the follow-up interview, interviewers should review the completed health facility forms for the caregivers to be visited to know the background and recommended treatments for each case. The forms will indicate whether the provider recommended that the caregiver:

- Give medication at home
- Follow feeding recommendations
- Return to the facility for a follow-up visit
- Go to another facility (i.e., the caregiver was referred)
- Use an ITN

For any of these that the providers did *not* recommend, circle “NA” on the form.

Start the interview with an open question, letting the caregiver tell you what she has done: “*How is the child doing?*” “*Has the child been given any treatment since visiting [facility]?*” Note that you are asking about actions taken since the health facility visit. Actions prior to the visit have already been recorded in the preconsultation interview.

For each treatment action that was recommended by the provider but not mentioned by the caregiver (actions A–E on the form), ask whether the caregiver carried it out and find out what helped or hindered her. Do not ask about actions that the provider did not recommend. For example, if the caregiver was not given feeding advice or referred to another facility, it is not necessary to ask if she did those things.

If the caregiver was to give an antimalarial at home, it is especially important to ask her what doses she gave the child each day and to determine whether she administered it correctly. Ask also whether any other drugs were given; whether you want to ascertain if those drugs were correctly administered depends on your research objectives and on the technical knowledge of the interviewer.

Then ask about *other things* that she may have done, specifically whether she gave any herbal remedies and whether she consulted various types of providers since she was interviewed in the health facility.

**Note taking and recording.** The combined interview and recording form includes some questions that are close-ended and easily coded and others that are open-ended with space for notes and exact wording where relevant. The close-ended information can be added to the Health Facility data set. If data are entered into the computer, only the “**no/yes**” responses in the right-hand margin need be coded. The qualitative information can be typed and analyzed as any other qualitative information.

## Module 4: Health Facility - 4-I. Preconsultation Interview with the Caregiver

### A. Identify suitable respondents

As caregivers enter the clinic and register, introduce yourself and screen for two criteria.

*A group of us is here from [organization] studying some illnesses in this region and how they are treated. We are not part of [health facility] and all your answers would be confidential. Would it be all right if I spoke with you for a few minutes about your child's illness?*

1. Child must be under 5 years  
*How old is this child? Ask years and months, for example 3 years and 2 months.*
2. Illness must involve fever or convulsions, or caregiver must mention malaria unprompted.  
*What brings you to the clinic? What is wrong with this child? Ask about symptoms to see if fever or convulsions mentioned. Record all symptoms using caregiver's actual terms. Any other symptoms?*  
If caregiver has not mentioned illness name, ask: *What do you think this illness is?*

Continue if both criteria are met. Let the caregiver know that someone else from the team will be in the consultation with the provider, and ask if that is okay. Write an ID number on a card, and ask the caregiver to hand the card to observer when she goes into the consultation room. Make sure the ID number is written on all pages of the coding sheet.

### B. Gather further background information

*Is this a first visit here for this illness or a follow-up visit?*

*What do you think caused this illness?*

*How serious is the child's condition now? Would you say: not very serious, somewhat serious, or very serious?*

### C. Obtain a brief history of the illness

Find out:

- When illness began.  
*When did this problem/illness begin? When was the very first time that you noticed the child had [symptom(s)]? What day was that?*
- What prior treatments (home treatments, medications given, and other providers consulted) were given. Get the sequence of treatment actions.  
*Have you done anything to make the child feel better? Start with the first thing you did. What did you do? When did you do this? Why did you decide to do this? Did you do anything else?*  
*Did you take this child to see anyone else or ask advice of anyone? What did he/she recommend?*  
*[If antimalarial given:] How much did you give?*
- What prompted caregiver to bring in child today.  
*What made you decide to bring the child in to the clinic today?*

### D. Obtain information on access to clinic

If not obvious, ask: *What time did you arrive here?*

*How long did it take you to get here? How did you get here? (e.g., foot, bicycle)*

*Did you have to pay for transportation? How much?*

*Did you have to get permission from anyone to come to the HF? Who?*



## Module 4: Health Facility - Coding Sheet for Preconsultation Interview with the Caregiver

ID#: \_\_\_\_\_

Health facility: \_\_\_\_\_ Date / Interviewer: \_\_\_\_\_ / \_\_\_\_\_

Child's age: \_\_\_\_\_ yrs \_\_\_\_\_ mos Sex: F M

Caregiver relation to child: mother other: \_\_\_\_\_

Visit # to this facility for this illness: 1<sup>st</sup> 2<sup>nd</sup> 3<sup>rd</sup> Arrival time: \_\_\_\_\_

Symptoms besides fever: vomiting diarrhea chills/sweating cough twitching/convulsions other: \_\_\_\_\_

Perceived illness: DK malaria other: \_\_\_\_\_ Perceived cause: DK \_\_\_\_\_

Perceived severity: not very serious somewhat serious very serious # days after onset of fever: \_\_\_\_\_

NOTES: \_\_\_\_\_

-----

**TREATMENT (Put sequence number in left hand bold column for each care source used. Then for each care source used, tick in the vertical column the treatments given and fill in further information as indicated.)**

**\_\_\_ Gave home care** (✓ all home treatments given): # days after onset of fever: \_\_\_\_\_

\_\_\_ tepid sponging or bathing

\_\_\_ home remedies/herbs

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

NOTES: \_\_\_\_\_

**\_\_\_ Took child to pharmacist** # days after onset of fever: \_\_\_\_\_

*(tick only if pharmacist was asked to diagnose and recommend treatment)*

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

NOTES: \_\_\_\_\_

**\_\_\_ Consulted formal provider 1** (type): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # &amp; type: \_\_\_\_\_

Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

\_\_\_ Admitted

NOTES: \_\_\_\_\_

\_\_\_ **Consulted formal provider 2** (type): \_\_\_\_\_ # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # & type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

\_\_\_ Admitted

NOTES: \_\_\_\_\_

\_\_\_\_\_

\_\_\_ **Consulted CHW** # days after onset of fever: \_\_\_\_\_

\_\_\_ Antimalarial given: CQ SP Other: \_\_\_\_\_ Injection: # & type: \_\_\_\_\_

\_\_\_ Amt recommended: \_\_\_\_\_ Amt given: \_\_\_\_\_ c-dose u-dose o-dose

\_\_\_ Other drugs: Antipyretic Antibiotic Other: \_\_\_\_\_

\_\_\_ Referred to other provider/facility (specify): \_\_\_\_\_ Referral followed? No Yes

NOTES: \_\_\_\_\_

\_\_\_\_\_

\_\_\_ **Consulted traditional healer**

NOTES: \_\_\_\_\_

\_\_\_\_\_

**Prompt to seek care from HF / Why caregiver brought child in today:**

\_\_\_\_\_

**Access to HF:**

Amount of time to reach HF: \_\_\_\_\_ Mode of transport: \_\_\_\_\_ Transport cost: \_\_\_\_\_

NOTES: \_\_\_\_\_

\_\_\_\_\_

OTHER NOTES: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Module 4: Health Facility - 4-II. Observation Guide and Recording Form for Caregiver's Consultation with the Provider

ID#: \_\_\_\_\_

Health facility: \_\_\_\_\_ Time session begins: \_\_\_\_\_

Observer: \_\_\_\_\_

Type of provider (*circle*):    doctor    nurse    clinical officer    other: \_\_\_\_\_

### A. Information gathering

|                                  |    |                               |
|----------------------------------|----|-------------------------------|
| Asked about history of fever     | No | Yes                           |
| Asked about convulsions          | No | Yes                           |
| Asked about appetite             | No | Yes                           |
| Asked about lethargy/weakness    | No | Yes                           |
| Asked about prior treatment/meds | No | Yes                           |
| Asked about other                | No | Yes ( <i>specify</i> ): _____ |

### B. Diagnosis and advice

|   |     |   |
|---|-----|---|
| Stated diagnosis to caregiver                         | No* | Yes ( <i>state verbatim</i> ): _____      |
| Medication: recommended                               | No  | Yes                                       |
| Specified meds to caregiver                           | No  | Yes: _____                                |
| Feeding: advice given                                 | No  | Yes: _____                                |
| Return visit: requested                               | No  | Yes, for review    Yes, if no improvement |
| Checked feasibility of return                         | No  | Yes                                       |
| Referral: recommended                                 | No  | Yes                                       |
| Checked feasibility of referral                       | No  | Yes                                       |
| Prevention: ITN recommended                           | No  | Yes                                       |
| Other notes regarding the consultation session: _____ |     |   |
| _____   |     |   |
| _____   |     |   |
| _____   |     |   |

(Continue on back as necessary)

\*If diagnosis was not stated, after the consultation ask provider what it was: \_\_\_\_\_

\_\_\_\_\_

### C. Quality of interaction with caregiver

(Consider provider interest, patience, empathy, attempt to make mother comfortable; not clinical assessment)

Overall assessment:    very poor    somewhat poor    somewhat good    very good

Comments: \_\_\_\_\_

Time session ends: \_\_\_\_\_



## Module 4: Health Facility - 4-III. Observation Guide and Recording Form for Observation of the Treatment Room

ID#: \_\_\_\_\_

Health Facility: \_\_\_\_\_

Observer: \_\_\_\_\_

| <b>CQ/Amodiaquine given</b>                | <b>No</b>      | <b>Yes</b>   | <b>Prescription only</b> |
|--|----------------|--------------|--------------------------|
| Form                                       | <b>Tablets</b> | <b>Syrup</b> | <b>Injection</b>         |
| Identified med to caregiver                | No             | Yes          |                          |
| Explained how to administer                | No             | Yes: _____   |                          |
| Gave full course to take home              | No             | Yes          |                          |
| Explained importance of giving full course | No             | Yes          |                          |
| Checked if caregiver understood dosage     | No             | Yes          |                          |

| <b>SP given</b>             | <b>No</b> | <b>Yes</b> | <b>Prescription only</b> |
|-----------------------------|-----------|------------|--------------------------|
| Identified med to caregiver | No        | Yes        |                          |
| Explained single dose       | No        | Yes        |                          |

**Other medication prescribed**                      **No**                      **Yes**

Check as many as apply:

\_\_\_ Antipyretic (e.g., Panadol, aspirin)

\_\_\_ Septrin or other antibiotic

\_\_\_ ORS

\_\_\_ cough medicine

\_\_\_ eye ointment

\_\_\_ other

Total number of medications given: \_\_\_\_\_

NOTES: \_\_\_\_\_

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## Module 4: Health Facility - 4-IV. Exit Interview with the Caregiver

### A. Recall of treatment, and ability to comply

Ascertain whether caregiver recalls advice or action plan.

*What did [provider] recommend that you do [to treat]? Anything else?*

Record the unprompted recall, and then prompt for (if the caregiver has not mentioned) recommended medication, feeding advice, return visit, referral, and ITN use.

Medication:

*Did [provider] recommend any medications?*

Feeding:

*Did [provider] give any feeding advice?*

Return visit:

*Did [provider] tell you to come back to [facility]?*

[If return visit recommended:] *Do you think you will be able to return or will it be difficult to return?*

Referral:

*Did [provider] tell you to go to another provider? Do you think you will go? What would make it difficult for you to go?*

Prevention:

*Did [provider] recommend that the child sleep under an ITN? Do you think you will be able to put the child under an ITN when he/she sleeps? What would make it difficult to have the child sleep under an ITN?*

### B. Understanding of dosage

If antimalarial was dispensed, check whether the caregiver

- knows *what drug* she was given, and
- knows how to administer it, including *amount to be given* and *at what times* or *how often*.

If mother has written or symbolic instructions, check her interpretation of those instructions.

If antimalarial was prescribed only or if full course was not given, find out where the caregiver will get the medication, whether there will be any problems getting it, whether the caregiver received an explanation how to administer it, and whether she knows what the correct dosage is.

*Where will you get this medication? Will you have any problems getting this medication?*

*Did anyone here explain how much to give? How much [antimalarial] should be given?*

NOTE: After all research questions about dosage have been asked and if mother has misunderstood, explain to her the correct dosage. If she has misunderstood symbols, explain them to her.

**C. Confidence in advice and satisfaction with the visit**

Find out the caregiver's confidence in the treatment given.

*Do you think this is the right treatment for this child?*

*What about the recommendation/treatment makes you think it is right?*

Find out the caregiver's satisfaction with the clinic experience.

*Did you get what you need today? Was there anything else you would have wanted to happen?*

*Was there anything that happened you were unhappy with? Happy with?*

**D. Cost of facility services**

Find out whether the caregiver had to pay for services or medication.

*Did you have to pay anything for the services you received today?*

[If she received medication] *Did you have to pay anything for the medication you received?*

**E. Demographic information**

Ask the caregiver's age, and years of education.

**F. Follow-up**

Find out where the caregiver is from, so that if the village is in the sample you can arrange a follow-up home visit to look at compliance issues. Confirm the name of the caregiver and get good directions as to how to find her.

## Module 4: Health Facility - *Recording Form for Exit Interview with the Caregiver*

ID#: \_\_\_\_\_

HF: \_\_\_\_\_ Interviewer / Note taker: \_\_\_\_\_ / \_\_\_\_\_

### A. Unprompted and prompted recall of treatment, and ability to comply

[Tick **Unprompted** mentions in 1st column and **Prompted** mentions in 2nd column. Fill in additional info as specified.]

**U**      **P**

\_\_\_\_\_    \_\_\_\_\_ Medication: drugs to be given at home (complete section B)

\_\_\_\_\_    \_\_\_\_\_ Feeding advice given (specify): \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_ Return visit requested: **After** \_\_\_\_\_ **days**    **If no improvement**    **To get more drugs/injections**  
*Do you think you will return?*                      *What would make it difficult to return?*

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_ Referral to another provider (detail): \_\_\_\_\_  
*Do you think you will be able to go to [referral]?*                      *What would make it difficult?*

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_ Prevention recommended using an ITN  
*What did [provider] say about using an ITN?*  
*Do you think child will now sleep under an ITN?*                      *What would make it difficult?*

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

### B. Understanding of dosage of drugs to be administered at home

\_\_\_\_\_ Tick if drugs *prescribed* only (mother must buy)

Where will caregiver get the medication? Any obstacles to buying?

[Researcher: write in what antimalarial was given/prescribed: \_\_\_\_\_ ]

What mother thinks the drug is: \_\_\_\_\_                      **Knows drug?**    **No**    **Yes**

What mother thinks dosage is: \_\_\_\_\_                      **Knows dose?**    **No**    **Yes**

NOTES: \_\_\_\_\_

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**C. Confidence in advice and satisfaction with visit**

*Do you think this is the right treatment for this child?*

*What about the recommendation/treatment makes you think it is right?*

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*Did you get what you need today? Was there anything else you would have wanted to happen?*

*Was there anything that happened you were unhappy with? Happy with?*

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**D. Cost**

Pay for the services received?      **No**      **Yes** (amount): \_\_\_\_\_

Pay for the medication received?      **No**      **Yes** (amount): \_\_\_\_\_      **NA** (no meds rec'd)

**E. Demographic information**

Caregiver age: \_\_\_\_\_      Years of education: \_\_\_\_\_

**F. Follow-up**

If caregiver resides in sample village, directions for finding her for follow-up interview:

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## Module 4: Health Facility - 4-V. Provider Interview and Recording Form

Health Facility: \_\_\_\_\_ Provider type: \_\_\_\_\_

Date / Interviewer: \_\_\_\_\_ / \_\_\_\_\_

Ask if you can speak with the provider about how mothers care for young children who have malaria. Continue notes on back or use additional sheets as necessary.

- A. Do you feel that mothers give you sufficient information about their child's symptoms for you to make an accurate diagnosis? Do mothers recognize when a child's condition is becoming dangerous?

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- B. Do you feel that mothers give you sufficient information about the treatment actions they take before coming to the clinic? What kinds of things do they do before bringing in a child to the clinic?

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- C. Do you think mothers should do anything differently in how they care for a child becoming sick with malaria?

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- D. When children have malaria, at what point in the illness do mothers bring them in? Fairly early on or rather late? What makes them decide to come to the clinic for treatment at a particular time?

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- E. Do you think mothers understand your advice? What makes you think they do or do not understand?

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- F. Do you think mothers follow your treatment advice? What makes you think they follow your advice? What are some of the reasons that mothers don't follow treatment advice?

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- G. Do you have any suggestions for improving the care for children with malaria are cared for?

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## Module 4: Health Facility - 4-VI. Interview Guide and Recording Form for Follow-Up Interview with the Caregiver

Community: \_\_\_\_\_ ID#: \_\_\_\_\_  
Date / Interviewer: \_\_\_\_\_ / \_\_\_\_\_

Preparation: From the records of the interviews and observations at the health facility, note which of actions A–E below were recommended. Code whether each was carried out or not. For any not recommended, circle NA.

Without prompting her, ask the caregiver:

*How is the child doing? Has the child been given any treatment since visiting [facility]?*

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If she fails to mention any action A–E that was recommended, ask whether she carried it out. Do not ask about actions (A–E) that were not recommended.

### A. Medication

Look on HF forms and enter which antimalarial drug(s) the child was prescribed. If an antimalarial was to be administered at home, record amount of antimalarial given each day; then code if the dose was correct. Day 1 is the day the caregiver was at the HF. Circle which day you are doing this interview.

| antimalarial prescribed | Day 1 (HF) | Day 2 | Day 3 | Day 4 |
|-------------------------|------------|-------|-------|-------|
|                         |            |       |       |       |

Code if antimalarial was correctly administered: **No** **Yes** **NA**

Other drugs given: \_\_\_\_\_

NOTES: \_\_\_\_\_

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### B. Feeding

Was any feeding advice given during your visit to [the HF]? If so, what? **No** **Yes** **NA**

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Were you able to do that? [Probe]

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**C. Return visit** **No** **Yes** **NA**

*Were you able to return to [the HF]? [If she returned, find out what happened. If she did not return, find out why not.]*

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**D. Referral** **No** **Yes** **NA**

*Have you been able to go to [referral provider/facility]? [Find out in detail what happened.]*

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**E. ITN** **No** **Yes** **NA**

*Has the child been sleeping under a mosquito net since you visited [the HF]? [Find out why or why not.]*

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[If family has a net] *Has the net ever had insecticide on it?* **No** **Yes** **NA**  
 [Find out if net was pretreated or treated after purchase; where and how treatment was obtained, etc.]

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**F. Other treatments: herbal remedies** **No** **Yes**

*Have you given any herbal remedies since you visited [the HF]? What was given/why/what happened?*

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**G. Other providers consulted**

Ask about, and then get details of, any other providers consulted.

*Since your visit to [facility], have you consulted*

*... any other health facility?* **No** **Yes**

*... a community health worker?* **No** **Yes**

*... a traditional healer?* **No** **Yes**

*... anyone else?* **No** **Yes**

NOTES: \_\_\_\_\_

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## Module 5: Other Providers - *Implementation Guide*

### Private Clinics and Private Doctors

#### **Purpose**

*To determine*

- Role of provider in treating illnesses with fever, especially cases likely to be malaria
- Provider's knowledge of causes of malaria
- Provider's diagnostic criteria for malaria
- Provider's treatment recommendations for malaria
- Whether provider knows that convulsions can be caused by malaria
- Provider's treatment for convulsions
- Cost of service

#### **Method**

Semi-structured interview

#### **Sample**

Small private clinics that serve the area around the sample village

### Traditional Healers or Community Health Workers

#### **Purpose**

*To determine*

- Role of provider in treating illnesses with fever, especially cases likely to be malaria
- Provider's knowledge of causes of malaria
- Provider's diagnostic criteria for malaria
- Provider's treatment recommendations for malaria
- Role of provider in treating illnesses with convulsions
- Provider's perception of causes of convulsions
- Provider's treatment for convulsions
- Cost of service

#### **Method**

Semi-structured interview

#### **Sample**

Health providers consulted by the community who are not based in a facility

*[continued]*

## Pharmacists and Drug Vendors

### *Purpose*

*To determine*

- Types of antimalarials sold and cost of each; consistency of supply
- Role of vendor in treating malaria in children
- Vendor's recommendations for treating malaria in children
- If caregivers seek advice from vendor on which drug to purchase for treatment of malaria in children
- If caregivers seek advice from vendor on dosage
- Amount of dose caregivers generally purchase (full or partial)

### *Method*

Semi-structured interviews and observation

### *Sample*

Pharmacists, shop sellers, market and street vendors

### *Note Taking and Recording*

No special recording forms were developed for this module, as the interview guides list topics rather than offer set lines of questioning. Use a combination of open notes and verbatim notes, as appropriate.

The Other Providers module offers suggested topics to investigate for several types of providers not covered in the Health Facility module: private doctors or small, private clinics; community health workers (CHWs); traditional healers; pharmacists; and drug vendors. (The Health Facility module includes an interview with formal providers working in government or NGO health facilities.) The Other Providers module comprises a subset of modules; implement interviews only with providers relevant to the research setting. These modules can be adapted for other types of providers, such as injectionists or ayurvedic practitioners, as necessary.

The methodology used is the standard semi-structured interview, supplemented by observation where appropriate. The number of interviews for each type of provider depends on how much of a role each plays in treating childhood febrile illness. In Zambia, there are very few private clinicians or pharmacists in the rural areas, so they were not included in the study there. In Kenya, the private sector is well developed, and families often seek the advice of pharmacists and clinicians outside the government system. Therefore, it was important to include these types of providers in the Kenya study.

## Module 5: Other Providers - *Private Clinics and Private Doctors*

### Suggested Topics

- Overall size and staffing
  
- Volume of young children with probable malaria  
(if volume is quite small, then interview can be cut short)
  
- Perception of causes of malaria
  
- How diagnosis of malaria is made
  
- Treatment and advice for malaria
  
- Treatment and advice for convulsions
  
- Perception of causes of convulsions
  
- Under what conditions the provider refers caregivers to another provider
  
- Cost of services

## Module 5: Other Providers - *Traditional Healers or Community Health Workers*

### Suggested Topics

- Types of conditions this provider treats; main patients (adults, children, infertile women, etc.)
  
- Number of young children provider sees with malaria and/or convulsions (if volume is quite small, then interview can be cut short)
  
- Provider's idea of
  - symptoms associated with malaria
  
  - cause of malaria
  
  - treatment of malaria (if antimalarial drugs are given or advised, find out what dosage is recommended)
  
- [If not covered above] Provider's idea of
  - types of convulsions
  
  - cause of convulsions
  
  - treatment for convulsions
  
- Referral to other providers: whether provider ever advises patient to consult another provider; if so, which ones and under what circumstances
  
- Cost of services and method of payment

## Module 5: Other Providers - *Pharmacists and Drug Vendors*

### Suggested Topics

- What antimalarials are sold; cost of each
  
- Consistency of supply of various antimalarials; periodic difficulties in getting supplies
  
- Approximate number of people who buy malaria drugs from them per day; variation by season
  
- [For pharmacists only] Whether customers can obtain CQ or Fansidar™ without prescription
  
- Which antimalarials mothers most commonly ask for to treat young children; whether mothers ask for advice on what to buy and dose, or whether they just come to purchase
  
- What advice is given for treating malaria in young children (including dosage recommended, where learned about dosage, if there are written instructions that can be referred to, etc.)
  
- How much of the antimalarials the mothers buy at one time (partial or full dose)
  
- Where possible, *observe*:
  - Storage and selling conditions
  
  - Expiration dates of drugs being sold



## Module 6: Treatment Comparison - *Implementation Guide*

### **Purpose**

- To determine what factors influence caregivers' choice of medications (depending on your research questions, traditional as well as modern remedies can be included)
- To learn how participants interpret treatment efficacy—how they judge whether or not a treatment is working
- To determine whether participants know the difference between antipyretics (drugs that reduce fever) and antimalarials (drugs to kill malaria parasites) and how they use these classes of drugs
- To identify barriers to acceptance of a new drug, and to identify counseling guidance that will facilitate acceptance and proper use of the drug

### **Method**

Open-ended individual or group interview; pile sorts and ranking with locally available medications

### **Sample**

Individuals or a group of up to six persons; can be conducted with caregivers, drug vendors, chemists, facility-based health providers, or community-based health workers

## Exploring Beliefs About Drugs

This module<sup>7</sup> is especially useful if you wish to explore local beliefs about malaria-related drugs. If you conduct the other five modules, you will have already covered all of the major topics in the care-seeking model. This module seeks in-depth information about local perceptions of the medications themselves, such as whether physical characteristics of medications affect beliefs about efficacy, how the drug's biological actions affect caregiver perceptions and use, and how caregivers choose drugs.

Exploration of these topics can be especially useful just before or after a change in drug policy, particularly where the drugs involved have different properties and act on the body differently. For example, the Ministry of Health in Kenya is recommending a change from CQ to Fansidar™ as the first-line drug for treatment of uncomplicated malaria. In Kenya, CQ-resistant malaria is spreading, and Fansidar™ is more effective against malaria parasites. But mothers are used to CQ, which has different properties from Fansidar™. CQ acts quickly and reduces fever, so the patient feels rapid relief, even though ultimately all parasites may not be killed. Fansidar™ takes longer to act and does not reduce fever, so must be taken with an antipyretic. CQ is given in multiple doses; Fansidar™ is given in one. Fansidar™ is also more expensive than CQ.

7. This module is based on a protocol by Dr. S. Patrick Kachur of the Centers for Disease Control and Prevention in his studies examining local perceptions of treatment options in Zambia. See Williams, H. A. et al. 1999. A Community Perspective on the Efficacy of Treatment Options for Children in Lundazi District, Zambia in *Tropical Medicine and International Health* 4(10) (October): 641–52.



A modified version of this module was carried out in the Kenya study to determine whether caregivers differentiate between antimalarials and antipyretics, to determine how they perceive CQ and Fansidar™, and to identify potential barriers to the acceptance of Fansidar™. These determinations supplemented the information from the Illness Narratives module. Figures 14 and 15 show caregivers' ideas about the role of commercially available antipyretics and antimalarials (traditional remedies were not included) and specifically about their perception of the difference between CQ and Fansidar™.

## Adapting this Module

This module can be administered as a “stand-alone” instrument or parts can be integrated into other instruments. For example, it could be appended to the Terminology and Taxonomy module, or certain questions from it could be incorporated systematically into the Illness Narratives module or into the drug vendor interview in the Other Providers module. The specific topics you will discuss and the groups you will sample (e.g., caregivers, drug vendors, or health providers) depend on your research questions.

## Preparing for this Module

This module requires that each interviewer have samples of four to eight commonly used local malaria or fever treatments. Depending on your research questions, these may include traditional treatments. To make it easier to record specific treatment options, number or letter each treatment, making certain that all interviewers use the same set of treatments and the same number or letter codes. A few other common medications, such as antibiotics and cough medicines, also can be included. The line of questioning around the topics can be left open, as long as the interviewer understands the intent of the questions so that he or she can probe appropriately.

**Figure 14: Mothers' Perceptions of the Role of Different Drugs**  
*Excerpts from Kenya final report*

**Q: Which of these have you used?**

A: I have used Malariaquine, dawaquine, Panadol, and Dawanol. Panadol reduces fever and Malariaquine treats malaria. ♦

**Q: What do the Panadol and Cafenol tablets do?**

A: Panadol lowers the body temperature and Cafenol reduces homa. ♦

**Q: What do CQ, Panadol, and Septrin treat?**

A: Septrin treats stomachaches and cough; CQ treats malaria; Panadol lowers the body temperature; and Pen-V adds more blood to the body. ♦

**Q: What do the drugs you gave do?**

A: Panadol lowers body temperature; Cofta and Actifed are for cough; Flagyl for the stomach; Geston and Good Morning also treat, but I don't know what exactly. ♦

**Q: Have you used any of these medicines?**

A: I have used Malariaquine and also Panadol.

**Q: What do these drugs do?**

A: I buy Malariaquine now since Panadol doesn't have much strength these days. ♦

**Figure 15: Mothers' Comparison of Chloroquine and Fansidar™**  
**Excerpts from Kenya final report**

[I gave CQ because] Fansidar™ takes a long time to make the child feel better, and it is more expensive. ♦

I didn't give CQ, as I had Amobin (Amodiaquine). As for Fansidar™, it is more expensive. A friend said Fansidar™ is not good for small children as it is too strong. ♦

Fansidar™ is good because it takes longer for the illness to re-occur. CQ sometimes itches. ♦

No [I have never used Fansidar™]. I usually give CQ and Amobin syrup from the chemist. My friend told me that she used Fansidar™ on her child and it stayed some months without falling sick. I was also thinking of using it . . . ♦

Panadol reduces temperature, Malariaquine tablets treat ordinary malaria, and Fansidar™ treats abrupt malaria. ♦

Fansidar™ is stronger than chloroquine. ♦



## Module 6: Treatment Comparison

- A. Treatment options:** Find out what different medicines are used to treat childhood illnesses with fever, including malaria. Use the term “malaria” or its local equivalent if you have determined that the local definitions correspond to the biomedical definitions.

*What are the different medicines used to treat young children when they have fever or malaria? Any others?*

**PROBES:**

- [If not mentioned and if appropriate to your research questions]  
*What about traditional medicines for fever/malaria?*
- *Where can you get [medicine]?*
- *How much would you give to an 8-month-old child and for how many days?*
- *How much would you give to a 2-year-old child and for how many days?*
- *How much does the dose cost for a 2-year-old child?*

- B. Treatment efficacy:** Find out how caregivers know that a treatment is or is not working.

*When your child is given medicine for malaria or fever, how do you know it is working?*

**PROBES:**

- *What changes do you look for to know the medicine is working?*
- *How soon should you see the first change?*
- *How long would you wait before trying another treatment?*
- *What would you conclude about the cause of the illness?*

- C. Features of medicines:** Find out the features of the best medicines for fever in children.

**PROBES:**

- *tablets, capsules, and/or syrups vs. injections*
- *one pill vs. many pills*
- *strength*
- *taste, color*
- *cost*

- D. Classifications of medicines (pile sort):** Find out local classifications of medicines. Show participants the collection of medicines. Ask them to sort the medicines according to which ones are most alike. They may make as many or as few piles as they wish. Then ask them to explain the reasons for their groups, how one group differs from the other, etc.

*Which of these are alike and which are different? Which go together and which should be in separate piles?*

*Why did you put these together? What are the medicines in this pile like?*

- E. Medicine preference (ranking):** Ask participants to look over the medicines again and rank them in terms of which ones work best for treating malaria in children. Record the rank order and the explanation for each of the medicines.

**PROBE:**

*Sometimes a medicine recommended by health worker is not the one you want. Can you think of a time when you wanted a different treatment than the one a health worker recommended? What did you do?*



# Module 6: Treatment Comparison - Recording Form

Date: \_\_\_\_\_

Community: \_\_\_\_\_ Interviewer / Note taker: \_\_\_\_\_ / \_\_\_\_\_

Type of Interview (tick one):  individual  group:  number of participants

Type of Participant (tick one):

mother(s) of children under 5 years

father(s) of children under 5 years

drug vendor(s)

traditional healer(s)

community health worker(s)

facility health worker(s)

## A. Treatment options

Construct a list of options in order of mention. Write additional notes beside the option as discussion progresses.

- 1) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_
- 2) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_
- 3) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_
- 4) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_
- 5) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_
- 6) \_\_\_\_\_ : \_\_\_\_\_  
\_\_\_\_\_

## B. Treatment efficacy

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**C. Features of medicines** [Write feature and note comments about it.]

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_
- 4) \_\_\_\_\_
- 5) \_\_\_\_\_
- 6) \_\_\_\_\_
- 7) \_\_\_\_\_
- 8) \_\_\_\_\_

**D. Classifications of medicines** (*pile sort*)

| Pile | Medicines in pile<br>(write #s) | Description of pile |
|------|---------------------------------|---------------------|
| 1    |                                 |                     |
| 2    |                                 |                     |
| 3    |                                 |                     |
| 4    |                                 |                     |
| 5    |                                 |                     |
| 6    |                                 |                     |

**E. Medicine preference** (*ranking*)

| Medicine      | Reason for ranking/Comments |
|---------------|-----------------------------|
| Rank 1. _____ | _____                       |
| Rank 2. _____ | _____                       |
| Rank 3. _____ | _____                       |
| Rank 4. _____ | _____                       |
| Rank 5. _____ | _____                       |
| Rank 6. _____ | _____                       |
| Rank 7. _____ | _____                       |
| Rank 8. _____ | _____                       |

*Additional discussion/Comments:*

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## Planning the Study

In planning the study, you will want to make adaptations in the protocol, determine your sampling strategy, and make decisions about logistical aspects such as the timing of the study and team composition and training.

### Adapting the Research Protocol

The research protocol included in this Guide can be adopted in its entirety for studies examining the entire case management process. However, some level of adaptation is likely to be needed, ranging from minor to moderate. Minor adaptations involve adjusting questions to the drug policy context or to the types of health institutions in your sample area. More extensive adaptations may be necessary when time and budget are very limited, and the study will need to focus on a few key questions. In other cases the purpose of the research may be to look at only one or two aspects of care-seeking, but to examine them in greater depth. The following are some suggestions for making these types of adaptations.

#### *Adapting to the Drug Policy Context*

Different countries have different first-line drugs for malaria. Some countries are in the midst of a transition to a new first-line drug. You will need to adjust your research questions accordingly. Because CQ is a multidose drug, in countries where it is or has recently been the first-line drug it will be important to assess how well caregivers understand the dosage, how much of the drug they buy or are dispensed, and how much they give the child. This information will determine if the full course was completed and if not, why not. Since the resistance of malaria parasites to CQ is common, it is also important to determine whether caregivers recognize the signs of treatment failure and what they and their providers do in the event of treatment failure.

In contrast, where Fansidar™ is the first-line drug and only a single dose is required, there is no issue of “completing the course.” However, there may be other issues related to the particular characteristics of this drug: the fact that it is not an antipyretic, that it takes longer to work, or that it may be perceived as too strong for children. In countries where the drug policy is in transition, it is especially important to explore the perceptions of both the “old” and the “new” drug to identify the type of information or counseling that will facilitate a smooth transition to the new policy. The care-seeking model (Figure 1) as well as the research modules and recording forms should be modified to reflect the specific drugs used for malaria treatment in the sample region.

#### *Adapting to Local Health Infrastructure*

Options for health care vary by setting. Most ministries of health provide three basic levels of health facility: health post or dispensary, clinic, and hospital. The MOH may also organize a network of community providers—community members who have been trained to manage simple, common health problems. Generally, religion-affiliated health facilities will fit into the MOH structure of health care. In addition to MOH and religion-affiliated providers, there are others to whom local people may turn for care: private doctors, pharmacists, and traditional healers. You will want to have an idea of what these options are when you plan the research, and you should adapt the lines of questioning and the recording sheets accordingly.



Zambia and Kenya provide contrasting examples of health care contexts. Zambia has a history of a centralized provision of public services; there are few private facilities and providers, and few commercial pharmacies or other drug outlets. In rural Zambia, most families have access to only one health facility and limited access to commercial medicines. In comparison, Kenya has a fairly well developed private sector. Caregivers can choose among many different types of providers and obtain a variety of medications at pharmacies and other drug outlets. Discussion of formal providers in Zambia was confined to the local health facility, whereas in the Kenya study the line of questioning and the recording sheets had to allow for multiple formal providers. In Zambia, if a health facility was visited twice in the course of an illness, it was the same health facility; in Kenya, care-seeking tended to be “nomadic” with caregivers going from one provider or facility to another.

### ***Adapting to Time or Resource Constraints***

A team of five or six people can carry out all the modules in a given community in 2 or 3 days. When time, money, or other resources are limited, there are two basic approaches to scaling down the research:

- 1) Limit the number of communities to visit. If the project area is fairly homogeneous, it may be acceptable to visit only three or four sites. If there are distinct cultures, however, it will be necessary to visit at least two communities from each major group. The section on sampling provides a fuller discussion of sampling issues.
- 2) Eliminate some of the modules. It is possible to eliminate some of the modules and still obtain a solid base of information on care-seeking practices. Some of the modules are meant to enhance information or provide triangulation, and some modules are more important to some research questions than others.

For any research looking at the overall care-seeking process, *it is essential to do the illness narratives*. If the scope of the research must be scaled down, center the research around a set of well-conducted illness narratives. In addition to narratives, you will want to first cover at least some topics in the Community Introduction module. This module helps you set up the research and gather some community-wide information on providers and communication topics. The combination of the introductory community discussion and illness narrative interviews can suffice for studies conducted in a very short amount of time. The community discussion can be expanded or adapted to gather some of the information contained in other modules that you may need. For example, it could include some discussion of the perceptions of different drugs that were drawn from the Treatment Comparison module.

In some cases you can also drop parts of modules. Each module starts with a list of its purposes, and if any are irrelevant to your research, you can eliminate the corresponding part of the module.

### ***Adapting to Specialized Topics***

Sometimes smaller specialized studies on a particular topic are needed. For example, a Ministry of Health is considering changing its drug policy and needs timely information about community factors that would enter into the decision, such as especially negative or positive perceptions of the new drug; or perhaps a focused study is needed to gain an in-depth understanding of why mothers are not acting on referrals.

In these cases, the specific modules dealing with the research topic can be selected as a starting point for the research. In the example about the drug policy change, one would use the Treatment Comparison module as a suggested method for approaching the topic and expand it to address additional research questions.

## Sampling

Since the research uses qualitative methodologies, you will be working with small, purposive samples. The primary consideration in determining sample size is the *heterogeneity* of the population under study. The more variation there is in the population, the larger the sample needs to be. If the area you study contains several ethnic groups or is both urban and rural, your sample must be larger than if the area were uniform. The intent of your sampling strategy is to gain a good understanding of the population that your project intends to serve.

Several stages of sampling will probably be involved:

- 1) *Sampling of large units:* You will want to select units that cover the probable variation in care-seeking practices. These large units may be administrative (e.g., provinces or districts), topographical (e.g., mountainous, plateau, or coastal), ethnic (e.g., Ibo or Yoruba), or religious (e.g., Muslim and Christian). In order to decide which units might be relevant, look at other research and talk to those with knowledge of local geography and cultures.
- 2) *Sampling among health facilities:* Care-seeking patterns may differ depending on the type of health facility to which families have access. Therefore, you may wish to stratify the sample by “level” of health facility: health post or dispensary, clinic, and hospital. You may also want to include both government and non-governmental facilities (such as religion-affiliated health institutions).
- 3) *Sampling among communities:* Once health facilities have been identified, you will need to select communities in the catchment area of those facilities. A recommended strategy is to choose two communities in each catchment area: one close to the facility and one far. In any event, select communities that are large enough to yield at least eight narratives each.

You generally will want to exclude atypical communities from the sample—for example, those that have been the focus of an intensive project, have had a recent influx of refugees, or recently experienced a natural disaster. You may also want to avoid communities that have already been the site of other studies, especially if a lot of interview time was involved.

- 4) *Selection of individuals:* You may decide to have a target number of interviews to conduct per community—say, ten—or you may decide to include *all* children under 5 years who had a recent case of fever in the community. If you opt for a target number, make some attempt at randomization. For example, two teams of interviewers could start at opposite ends of a village and go door to door asking whether there is a child under 5 years who has had fever or convulsions in the past 2 weeks.

The following Figures 16 and 17 are examples of sampling plans and show how health facilities were selected in the Kenyan and Zambian studies.

**Kenya.** In Kenya, the project—and therefore the research—took place in only one district. The population of Bungoma District was fairly homogeneous, but the District Health Management Team wanted to include

communities served by different levels of health facilities and to include some non-governmental institutions. It was decided that communities would be selected so as to include the three levels of facilities, both governmental and non-governmental.

Figure 16: Bungoma District, Kenya Sampling Plan

|                      | <i>Government HF</i>                       | <i>Non-governmental HF</i> |
|----------------------|--|----------------------------|
| <b>Hospital</b>      | Bungoma District Hospital                  | Misikhu Mission Hospital   |
| <b>Health Center</b> | Naitiri HC<br>Chwele HC                    | Khasoko HC                 |
| <b>Dispensary</b>    | Milo Dispensary<br>Korosiandeti Dispensary | Machwele Dispensary        |

Eight communities were included in the sample, and an average of 12 illness narrative interviews per community were conducted, yielding 97 narratives.

**Zambia.** The project in Zambia was to cover a larger and more diverse area than in Kenya, and three districts in the area were selected for the research. Typically, Zambian residents have access only to a health center, so only health centers were included in the study. Three health centers were selected in each district, for a total of nine health centers. Within the catchment area of each health center, two communities were sampled—one near the health center and one far—meaning that 18 communities were included in the study. An average of 8 illness narrative interviews were conducted in each community, which yielded 146 narratives.

## Logistics

### *Timing of the Study*

In some places malaria transmission occurs year-round, but in others it occurs only at certain times of the year. The illness narratives, which are the core of this research protocol, rely on the recall of febrile illness occurring within 2–3 weeks before the caregiver is interviewed. The research therefore should be conducted when malaria is prevalent.

Even where malaria occurs year-round, people may treat fevers differently at various times of the year, depending on what they perceive to be the cause and what resources they have available for treatment. Local officials and health providers may know whether this is likely to be the case and may help you to choose when to carry out the study. It is also important to learn from local colleagues what time of year and what time of day people would be available to take part in the interviews with minimum inconvenience.

### *Team Composition*

To implement all the modules, a team of five or six, including the field supervisor, is recommended. It may be difficult to organize and utilize a larger team efficiently, and it would be difficult to carry out all the modules in less than 4 days if the team were smaller.

Figure 17: The Zambia Sampling Plan

| <i>District</i>            | <i>Health Center</i>           | <i>Community</i>                    |
|----------------------------|--------------------------------|-------------------------------------|
| <b>Chipata</b>             | <b>Kapata</b> (urban)          | Kapata                              |
|                            |                                | Navutika Village                    |
|                            | <b>Rukuzye</b> (rural)         | Chanje Village                      |
|                            |                                | Padambo Village                     |
|                            | <b>Kakumbi</b> (rural)         | Kanyanta Village                    |
|                            |                                | Kapanzi Village                     |
| <b>Kitwe</b>               | <b>Ipusukilo</b> (urban)       | Ipusukilo Compound                  |
|                            |                                | Chipata Compound                    |
|                            | <b>Ndeke</b> (semi-urban)      | Ndeke Township                      |
|                            |                                | Mulenga Compound                    |
|                            | <b>Twibukishe</b> (semi-urban) | Two Twibukishe township communities |
|                            | <b>Lufwanyama</b>              | <b>St. Joseph Mission</b> (rural)   |
| Kashimoto Village          |                                |                                     |
| <b>Shimukunami</b> (rural) |                                | Katembula                           |
|                            |                                | Mpopo                               |
| <b>Mukumbo</b> (rural)     |                                | Mukumbo                             |
|                            |                                | Chifumpa                            |

Because of the skill involved in conducting qualitative research and the time involved in becoming familiar with care-seeking issues and the research protocol, it is better to have one team working together and moving from community to community than to have several teams working simultaneously in several communities. Team members will discuss their findings at the end of each day's work and conduct at least the preliminary analyses; therefore, they need to function as a team rather than as individual data collectors. (Because of local language requirements, however, it may be necessary to drop and add members in certain sites.)

Some characteristics that make a good team member are:

- Experience in formative, qualitative research
- Ability to work fluently in at least one local language
- Ability to establish good rapport with community members
- Technical background in malaria
- Flexibility and willingness to work in field conditions
- Some experience in intervention design

Of course, no one person is likely to have all these qualifications, but the team as a whole should have them. At least one member should have a medical background that is sufficient to identify local antimalarials and the treatment regimen for each.

The research also requires the services of someone who can manage the quantitative data. It is recommended that basic information from the illness narratives be entered into a spreadsheet, data base, or statistical program (see the implementation guide for the Illness Narratives module). If you are conducting the Health Facility module, the close-ended information from that module should be put in another data set. The team will need someone to set up the data programs and enter the data. The amount of quantitative data is small, however, and so are the samples, so it may not be necessary to have a full-time data manager in the field. It would be ideal to find a team member who had the skills to double as an interviewer and data manager. In any event, do not wait until the fieldwork is finished to have the quantitative analysis done. The data manager should be working closely with the team and enter data more or less as it comes in, so that the quantitative data is available as soon as the fieldwork finishes.

A secretary is another key team member. It is essential that a secretary, along with a computer and printer, accompany the team into the field. *It cannot be overemphasized how important the secretary is.* The secretary should be skilled in word processing (and ideally know how to enter information into a qualitative analysis software program) and be detail-oriented, organized, and flexible. He or she should type narratives and other notes each day and keep files of data organized by community and module. If your data and notes are well organized, you will be able to keep up with analysis in the field and find the documents you need when the final analysis is performed. The secretary can make or break the smooth functioning of the research. It is a good idea to invite the secretary to parts of the training, especially to the initial sessions that give an overview of the project, the research, and malaria. Make sure your team appreciates how important the secretary is and makes a special effort to thank him or her often!

### **Training**

Good qualitative research takes skill. Most qualitative data collection instruments are guides, not scripts. Their purpose is to ensure that the interviewer covers key topics and addresses pertinent issues. Therefore, the interviewer must pay careful attention to what the respondent says and to determine what kind of follow-up questions to ask, when to probe for more information, and how to sequence questions so that all the important topics are addressed. To do this, interviewers must have a solid understanding of the subject area, have the research objectives firmly in mind, establish a good rapport with the respondents to open up conversation, know how to elicit information, and be good listeners. The training should develop these skills and include the following topics:

- Overview of the project
- Overview of malaria
- Behavioral issues in care-seeking
- Research objectives
- Drugs used for malaria treatment and their administration regimen
- Discussion of and practice in the methods to be used
- Practice using the modules, both in the classroom and the field; practice in coding
- Note taking
- Analysis

Figure 18 shows the training schedule that was used in the Kenya study.

Figure 18: Training Schedule Used in the Kenya Study

| <i>DAY 1 (Monday)</i>  | <i>DAY 2 (Tuesday)</i>   | <i>DAY 3 (Wednesday)</i>  | <i>DAY 4 (Thursday)</i>   | <i>DAY 5 (Friday)</i>   | <i>DAY 6 (Saturday)</i>  | <i>DAY 7 (Monday)</i>   |
|--|--|---|---|---|--|---|
| <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Intros/icebreaker</li> <li>■ Malaria overview</li> <li>■ Research project overview</li> <li>■ Training overview</li> <li>■ Intro to qualitative research, participatory research</li> <li>■ Mapping exercise and discussion</li> </ul>  | <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Community Introduction module field practice</li> <li>■ Discuss field experience</li> <li>■ Complete Community Information Form</li> </ul>  | <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Terminology and taxonomy field practice</li> <li>■ Discussion of field experience; analysis</li> </ul>   | <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Clinic Module field practice</li> <li>■ Preconsultation interviews with caregivers</li> <li>■ Observation of screening</li> <li>■ Observation of treatment room</li> <li>■ Exit interview</li> <li>■ Interview with provider(s)</li> </ul> | <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Community provider interviews field practice</li> <li>■ Discussion of field experience; analysis</li> </ul>  | <p><b>Morning</b></p> <ul style="list-style-type: none"> <li>■ Illness narratives field practice</li> </ul>  | <ul style="list-style-type: none"> <li>■ Follow-up interviews field practice</li> <li>■ Complete illness narratives</li> <li>■ Write summaries</li> <li>■ Organize for continued fieldwork</li> </ul> |
| <p><b>Afternoon</b></p> <p>Preparation for Community Introduction module</p> <ul style="list-style-type: none"> <li>■ Discuss community entry and general behavior and attitudes</li> <li>■ Discussion techniques and asking questions</li> <li>■ IEC topics</li> <li>■ Review Community Introduction module</li> <li>■ Note taking</li> <li>■ Organize for field</li> </ul> | <p><b>Afternoon</b></p> <p>Preparation for Terminology and Taxonomy module</p> <ul style="list-style-type: none"> <li>■ Terminology</li> <li>■ Taxonomy</li> <li>■ Focus groups: free listing, taxonomy</li> <li>■ Note taking and use of tape recorder</li> <li>■ Organize for field</li> </ul> | <p><b>Afternoon</b></p> <p>Preparation for Health Facility module</p> <ul style="list-style-type: none"> <li>■ Malaria treatments</li> <li>■ Semi-structured interviewing</li> <li>■ Observation</li> <li>■ Practice administering modules</li> <li>■ Organize for field</li> </ul> | <p><b>Afternoon</b></p> <ul style="list-style-type: none"> <li>■ Discussion of field experience; analysis</li> <li>■ Completion of clinic notes and forms</li> <li>■ Preparation for Community Providers module</li> <li>■ Organize for field</li> </ul>  | <p><b>Afternoon</b></p> <p>Prepare for Illness Narratives module</p> <ul style="list-style-type: none"> <li>■ Open interviewing</li> <li>■ Role play practice</li> <li>■ Screening of candidates</li> <li>■ Organize for field</li> </ul> | <p><b>Afternoon</b></p> <ul style="list-style-type: none"> <li>■ Illness narratives—discussion of field experience; analysis</li> <li>■ Illness narratives coding</li> <li>■ Preparation for follow-up interviews</li> </ul> |   |

The amount of time necessary for training will depend on the team's experience in using qualitative approaches. Even a team composed of people who have used qualitative methodologies in other field studies will need about a week to become familiar with the data collection and recording instruments if all the modules are to be implemented. Because different modules investigate different issues and use different methodologies, the training should include field practice in each module. Further, it is advisable to continue coaching the team in field skills even when they start the data collection.

The skill of the team members will vary, particularly if part of your job is to build local capacity in qualitative research. If there are members with little experience, pair them in the field with more seasoned and skilled qualitative researchers. The less experienced member can begin by taking notes and gradually become an interviewer as his or her skills develop.

***A note on note taking.*** The implementation guide for each module specifies how note taking and recording are to be done and refers to two types of notes: verbatim and open. Some modules, such as the Illness Narratives module, require as close to verbatim recording as possible for certain types of information. Verbatim notes are appropriate for capturing respondents' opinions, feelings, and expressions. The team must write fast enough to get verbatim notes, and it helps to agree on a set of abbreviations for commonly used words such as "malaria." (In the studies in Kenya and Zambia, an M with a circle around it was used.) Open notes are notes that need not be written verbatim. These are usually statements of fact, where the *way* that someone conveyed the information is not important. In the Community Introduction module, when the community group lists what health facilities are available, it is not necessary to take down a long verbatim statement such as: "We have the dispensary which is close by—just over here—and there is a health center. But it takes an hour by bus to get to the health center, so we only go there if the child is serious." It is sufficient to write:

#### *Health Resources*

- 1) *dispensary: close to village*
- 2) *health center: an hour by bus. Used for serious cases.*

Usually some combination of open and verbatim notes is appropriate. Even in the illness narratives, a mix of open and verbatim notes can be used. Facts such as the child's age, caregiver's education, or date of onset of fever, need not be recorded verbatim. When the mother starts talking about symptoms and the treatment, however, the note taker should write verbatim notes for certain descriptions, explanations, and opinions. These can be interspersed with short notes on facts, such as how much medication was given. The training must teach the fieldworkers to know when something is worth capturing verbatim and when it is enough to write short notes. No matter how fabulous the interview or enlightening the focus group, if the information is not properly recorded, it is as good as lost.

#### ***Duration of Fieldwork***

The amount of time required for conducting the fieldwork is highly variable and depends on a number of factors, including:

- The nature and scope of the research questions
- The diversity of the population under study, which affects sample size
- The size of the area under study and the time required to travel from site to site
- The size and expertise of the team

Sometimes 1 or 2 weeks in the field can shed much light on a specific question, but sometimes 1 or 2 months are necessary. As a general rule, a team of five or six can cover one community in 2 or 3 days. The typical data collection period for a well-organized research project looking at care-seeking patterns will range from 2 to 6 weeks.

### **Cost**

The cost of the research will vary and mainly depend on how many communities need to be studied and the cost of personnel and transport. The larger the geographical area and the more diverse the population are, the greater the number of days will be required in the field. The following lists basic budget categories to help you estimate overall expenses. The term “per diem” includes both food and lodging.

- *1 research supervisor*  
    *fee*  
    *per diem*
- *4–6 data collectors*  
    *fee*  
    *per diem*
- *1 secretary*  
    *fee*  
    *per diem*
- *1 data manager*  
    *fee*  
    *per diem (only if data manager is in the field)*
- *1 driver*  
    *fee*  
    *per diem*
- *Vehicle and fuel*
- *Copying and supplies for training and fieldwork*
- *Laptop and printer rental (if necessary)*

### **Sample Implementation Plans and Fieldwork Log**

Fieldwork requires a high degree of both organization and flexibility. There is no single “right way” to schedule the modules in each community. The supervisor must continually assess the progress and pace of the research and plan each day accordingly.

Figures 19 and 20 are two possible schedules for implementing all the modules in a community. Note that a team of four to six is large enough to divide so that two modules can be implemented simultaneously.



Figure 19: Illustrative Field Work Schedule 1

|        |           |  |                                  |
|--------|-----------|--|----------------------------------|
| Day 1: | morning   | full team: Community Introduction module   | 1 group                          |
|        | afternoon | 2–3 team members: Terminology and Taxonomy module<br>2–3 team members: Other Providers module                  | 1 group<br>4–8 interviews        |
| Day 2: | morning   | 4–6 team members: Health Facility module   | 6–10 interviews/<br>observations |
|        | afternoon | 4–6 team members (2–3 pairs): Illness Narratives module  | 4–8 interviews                   |
| Day 3: | morning   | 4–6 team members (2–3 pairs): Illness Narratives module<br>1–2 team members: Treatment Comparison module       | 4–8 interviews<br>2 groups       |
|        | Day 4:    | 2–4 team members: Health Facility module:<br>Follow-up interviews<br>Rest of team: draft summaries of findings | 4–8 interviews                   |

Figure 20: Illustrative Field Work Schedule 2

|        |           |   |                                 |
|--------|-----------|---|---------------------------------|
| Day 1: | morning   | 4 team members: Health Facility module  | 6–8 interviews/<br>observations |
|        | afternoon | 2 team members: Community Introduction module<br>Health Facility team members complete notes and coding<br>2 team members: Other Providers module | 1 group<br>4–8 interviews       |
| Day 2: | morning   | 2 team members: Terminology and Taxonomy module<br>4 team members (2 pairs): Illness Narratives module  | 1 group<br>4–6 interviews       |
|        | afternoon | 4–6 team members (2–3 pairs): Illness Narratives module   | 4–8 interviews                  |
| Day 3: | morning   | 1–2 team members: Treatment Comparison module<br>4–6 team members: Health Facility module:<br>Follow-up interviews                                | 2 groups<br>4–8 interviews      |

Track the progress of the fieldwork by keeping a daily log of what was done. The Fieldwork Log includes the date and community, the modules implemented, and the numbers of interviews and observations carried out by each team member. The form can have simple columns, such as the following:

| FIELDWORK LOG |                  |               |                    |              |
|---------------|------------------|---------------|--------------------|--------------|
| <i>Date</i>   | <i>Community</i> | <i>Module</i> | <i># Completed</i> | <i>Notes</i> |
|               |                  |               |                    |              |
|               |                  |               |                    |              |
|               |                  |               |                    |              |

## Analysis

This section suggests ways to organize your analysis and is not meant to provide training on qualitative analysis. It is assumed that the research supervisor is highly skilled in qualitative analysis, and that most or all of the team members also have some experience in it. For the most part, the discussion here focuses on applying those skills to the specific modules and topics in this protocol.

Your overall objective is to deepen your understanding of all the steps in the model of optimal care-seeking in Section 2. Therefore, keep the model in mind as you conduct your analysis discussions. You may want to refer to the discussion of the model to remind yourself of the specific issues involved in each step.

It is important to have daily analysis sessions in the field—a “rolling analysis”—in addition to your site analysis and the final analysis at the end of all data collection. The following provides suggestions how to proceed with each.

### Daily Analysis

Each day, try to finish fieldwork early enough to return to base, complete the notes and forms, and discuss the day’s findings. For example, if narratives were conducted, the interviewer and note taker should fill in the field notes, code topics in the narratives, and then complete a Coding Sheet for Computer. Completed notes can be given to the secretary each day to type into a word processor or qualitative data analysis program.

For all interviews, especially the narratives, you will want to code the text that sheds light on particular aspects of the care-seeking process. Qualitative data analysis programs make this particularly easy. Your objective is to have “topic sheets” that contain all quotes from your fieldwork that pertain to a particular key topic. You will want to have, for example, a topic sheet on the barriers to going to the health center. During analysis these sheets will have information at hand to readily identify the major reasons (stated in the community’s own words) why a caregiver would decide not to consult the health center for the child’s illness. These topic sheets will also provide you with a collection of quotes that you can include in your final report.

#### Suggested Topics to Code

- Recognition of early signs (how the child was the day before becoming ill)
- Definition of illness (symptoms that made caregiver decide the child was ill)
- Definition of “severe”; why caregiver concluded that child was seriously ill
- Why caregiver sought advice at a pharmacy; what happened at the pharmacy
- What prompted caregiver to take child to health facility
- Why caregiver decided to consult a traditional healer
- Why caregiver went to a small private clinic rather than an official health facility
- Why caregiver gave a certain amount of antimalarial
- Perceptions of characteristics of different antimalarials
- Access to health information; preferred means of getting information

Your daily analysis discussions can be organized around the research topics or list of “purposes” at the start of each implementation guide. Generally, your daily discussion will cover:

- What you have learned about the topics covered in the module
- How your findings compare with what you found in other communities
- Emerging issues—topics that may warrant investigation but were not in the original research protocol

If new issues emerge, you may want to alter your fieldwork. You may see a need, for example, to shift emphasis among research topics or add a new question or topic. Perhaps you find that it is more important to talk to some types of people than others. For example, in the Zambia study, mothers fairly consistently reported that they did not seek treatment advice from drug vendors, as they felt that the vendors’ advice might be influenced by a profit motive. Therefore, once we verified from mothers in each new community that vendors played a small role in the treatment process, we considerably shortened the vendor interview. In Kenya, once it was clear that private pharmacies and drug sellers were playing a large role, we decided to explore more fully their role in diagnosis and treatment.

## Site Analysis

When you complete work in a site, you will want to step back and think about what is going on in the site as a whole. Again, the model of optimal care-seeking in Section 2 will help you to do this by breaking down a complex process into key steps. In particular, you will want to compare the site to those already covered, identifying similarities as well as differences. It can be especially instructive to look at differences and examine what factors account for them.

As you complete each site, make preliminary summaries of the information gathered to assist you in the final analysis. Figure 21 summarizes recording information and indicates how to prepare the information for analysis.

## Final Analysis

Since you have been conducting a rolling analysis in the field and if you have kept up with data entry, you should be set for final analysis after a brief post-fieldwork break. Final analysis should follow as closely on the heels of the fieldwork as possible, so that information is fresh and momentum is maintained. Most or all of the team should participate in at least the first stage of the analysis, when the main conclusions of the research are defined.

Ensure that all your information is organized before beginning the final analysis. This means that:

- 1) All forms have been completed, all notes have been put in final form and typed where appropriate, and everything has been filed for easy retrieval.
- 2) You have printed topic sheets.
- 3) You have a printout of the frequencies for the variables that you have quantified from the Illness Narratives or Health Facility modules. The quantitative data gives you an immediate overall picture for some of the treatment variables, which means you can quickly focus on in-depth examination of the qualitative data to explain patterns.

How can you begin to analyze the complex care-seeking picture? Again, you can organize your discussion around the model of optimal care-seeking (Section 2), discussing each step in the model in sequence.

The overall objective is to see how actual care-seeking practices compare with the ideal. What is working well in the process? Where are the weak points? What factors facilitate ideal case management, and what factors impede it? Are care-seeking patterns consistent among your sites, or are there variations? Where do those variations occur (i.e., ethnic group; type of health facility; urban or rural community)? What factors account for the variations?

Figure 21: Preparing Records from One Site for Analysis

| <i>Module</i>            | <i>Recording in the Field</i>  | <i>Preparation for Analysis</i>   |
|--------------------------|--|---|
| Community Introduction   | <ul style="list-style-type: none"> <li>■ Recording Form for Community Description</li> <li>■ open notes* on health resources</li> <li>■ open notes on communication</li> </ul>   | <ul style="list-style-type: none"> <li>■ Community Description Table</li> <li>■ typed** notes on health resources</li> <li>■ typed notes on IEC</li> </ul>  |
| Illness Narratives       | <ul style="list-style-type: none"> <li>■ verbatim notes</li> <li>■ Coding Sheet for Computer</li> </ul>  | <ul style="list-style-type: none"> <li>■ topic codes inserted in verbatim notes</li> <li>■ typed verbatim notes (with topic codes)</li> <li>■ frequencies for quantitative data</li> <li>■ site summary</li> </ul>  |
| Terminology and Taxonomy | <ul style="list-style-type: none"> <li>■ taped sessions</li> <li>■ verbatim notes</li> <li>■ terminology and taxonomy table</li> </ul>   | <ul style="list-style-type: none"> <li>■ list of illnesses with fever</li> <li>■ completed Taxonomy Grid</li> <li>■ typed verbatim notes or transcript</li> <li>■ site summary</li> </ul>   |
| Health Facility          | <ul style="list-style-type: none"> <li>■ recording forms, plus open notes for preconsultation illness histories</li> <li>■ coding sheets</li> </ul>  | <ul style="list-style-type: none"> <li>■ HF descriptions</li> <li>■ additional notes typed</li> <li>■ frequencies for quantitative data</li> <li>■ site summary</li> </ul>  |
| Other Providers          | <ul style="list-style-type: none"> <li>■ open notes for private clinics and doctors, traditional healers, CHWs, and pharmacists and drug vendors.</li> </ul>   | <ul style="list-style-type: none"> <li>■ typed notes</li> <li>■ site summary for each type of provider</li> </ul>   |
| Treatment Comparison     | <ul style="list-style-type: none"> <li>■ Treatment Comparison Form that includes: <ul style="list-style-type: none"> <li>– free lists of treatment options, treatment efficacies, and features of medicines</li> <li>– pile sort of medicines</li> <li>– ranking of medicine preference</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>■ site summary</li> </ul>  |
| SITE OVERVIEW            | (pull together from all of the above)  | <ul style="list-style-type: none"> <li>■ What are the “breakdown points” in the model of optimal care-seeking?</li> <li>■ What are the key factors that influence whether treatment is close to optimal or poor?</li> <li>■ What information or issues are emerging that you want to explore more fully as you continue?</li> </ul> |

\* “Open notes” means you do not have to record what happened word for word, although there may be some statements you will want to capture verbatim.

\*\* “Typed” means entered into a word processor or qualitative analysis program.

### Organizing Your Research Files

It is essential to organize your field notes, forms, transcripts, and other documents in a way that permits anyone on the team who needs information to find it. The organization system that worked best in the studies in Kenya and Zambia was to keep files by site. Each site file contained a folder for each module conducted in that site. All the files for one site were the same color, with a different color for each site. The color coding helped everyone find the right files and keep them in order.

It is best to use large folders and large standardized labels, for example:

*SITE A: COMMUNITY DESCRIPTION*

*SITE A: NARRATIVES*

*SITE A: HEALTH FACILITY*

After typing notes, the secretary should clip the typed version on top of the original and place in the appropriate file. It is important to have the originals on hand, as you may occasionally need to verify whether the secretary has deciphered handwriting correctly. *It is very important to label each handwritten and typed interview with module, community, date, interviewer and note taker, and ID number.*

Your team will need to refer to these files regularly. To ensure accessibility, the files can be put in a sturdy cardboard box in the middle of the table in your workroom. This low-tech, open-access system really facilitated our work!

Since your discussion is organized around the steps in the model, draw from all modules that shed light on each step. This is better than discussing the results module by module. It is vastly preferable to integrate and synthesize all information that you have on a given topic and have gathered from different methodologies. For example, when discussing recognition of symptoms, you can draw on information from the illness narratives, from the terminology and taxonomy focus groups, and the preconsultation interviews in the Health Facility module. When discussing caregivers' experience in the health center, draw on the illness narratives as well as the interviews and observations from the Health Facility module. You may also have some general information from the Community Introduction module, if it included a general discussion of health resources and perceptions of care. Drawing from all sources and methods helps you triangulate and validate your conclusions.

## Presentation of Key Findings

**Using quotes.** Most of your data is qualitative. Quotes not only support your conclusions, they also bring the information to life and give the reader a feel for the caregiver's perspective. Figures 4–7 are examples of collections of quotes showing local perceptions of important topics. You can also weave a single exemplary quote into your text, or pull together two or three short quotes to substantiate a point. Here are three examples from different sections of the Zambia report:

A major reason caregivers go to the health center is to obtain drugs. If a caregiver knows that the clinic is out of drugs, she will probably decide not to go there for treatment. From a focus group in Chipata/Kakumbi, which had the lowest proportion of children taken to the clinic for care: . . . *when we reach there we are always told that there are no medicines so we just stay at home and wait for fate.*

Once at home, caregivers sometimes stop giving the medication because the child vomits it repeatedly. Sometimes the child resists because the medication is bitter. *Sometimes the children refuse to take CQ. It is bitter and they vomit and it is also often itchy. But many of us force them.*

More often, caregivers give only as much as is needed to see signs of improvement in the child, thinking that no more is needed. Since CQ relieves symptoms quickly, it is not uncommon to find mothers stopping the medication after one day. Sometimes mothers want to have some medicine left over to use in a future illness.

*. . . sometimes just after administering two times you find the child recovers, starts playing. So you stop and keep the medicine, in case the child falls ill again. ♦*

**Q: Did you give the child all the medication?**

A: *No. She was recovering so there was no point in giving the rest. ♦*

**Q: Have you continued giving medication?**

A: *No, I think she has now recovered. ♦*

**Tabulating factors that encourage or discourage key behaviors.** It will be very useful to program planners if you synthesize the factors that encourage or discourage a desired behavior. Here are two tables from the Zambia study: Figure 22 on seeking care at the health facility, and Figure 23 on giving the correct dose of CQ.

Figure 22: Factors that Encourage or Discourage Seeking Care at the Health Center

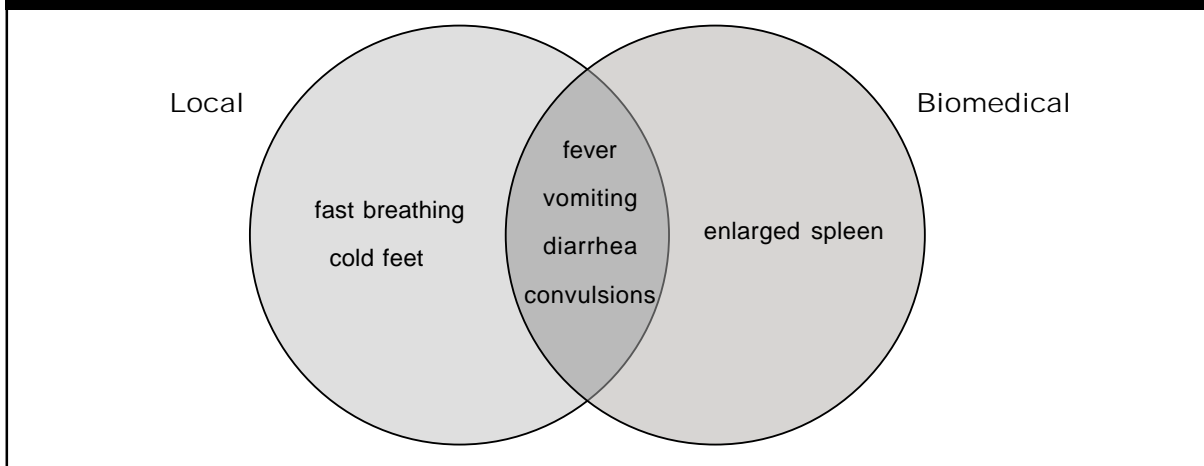
| <i>Encourage</i>  | <i>Discourage</i>  |
|---|--|
| <ul style="list-style-type: none"> <li>■ Recognition of a severe or worsening condition</li> <li>■ Proximity to health center</li> <li>■ Free service and medication</li> <li>■ Competence of health provider perceived to be high</li> <li>■ Provider thoroughly examines child</li> <li>■ Attitude of staff is friendly and empathetic</li> <li>■ Confidence that the illness is treatable by modern medicine</li> <li>■ Drug availability</li> <li>■ Convenient hours (one health center was open 24 hours)</li> <li>■ Lack of external constraints such as need for transport, childcare for other children, permission from someone else</li> <li>■ Child recovered on previous visit</li> </ul> | <ul style="list-style-type: none"> <li>■ Child's symptoms are abating</li> <li>■ Treatment available at home, e.g., drugs accessible at home, whether purchased or left over</li> <li>■ Absence of trained staff at facility or perceived low level of competence of trained staff</li> <li>■ Lack of drugs, or being prescribed partial doses</li> <li>■ Lack of effective drugs—when child did not respond to CQ and caregiver knows child will be given CQ again</li> <li>■ Long travel distances</li> <li>■ Cost—user fees for children who are under 5 years (St. Joseph's). Some caregivers said they do not go because they cannot afford it, although the staff said they do treat on credit.</li> <li>■ Long waits/congestion at facilities, leading to long queues and waiting time of over 1 hour</li> <li>■ Fear of being scolded—for such things as prior treatments given or losing the under-5 clinic card</li> <li>■ Perceived cause of illness is not biomedical—where witchcraft is suspected, caregivers tend to seek services of a traditional healer rather than of a health center</li> <li>■ Measles—waiting to see if fever is due to measles (i.e. if rash appears), which many believe should not be treated in the health center</li> </ul> |

Figure 23: Factors that Encourage or Discourage Giving Correct Dose of Chloroquine

| <i>Encourage</i>  | <i>Discourage</i>   |
|---|---|
| <ul style="list-style-type: none"> <li>■ Full course of drugs available and dispensed for caregiver to take home</li> <li>■ Clear verbal and written instructions on drug administration</li> <li>■ Ability to interpret packet symbols</li> <li>■ Ability to read written instructions</li> <li>■ Breaking of tablet medication in halves and quarters by health providers to facilitate administration of correct dosage at home</li> <li>■ Having a health provider instruct the caregiver as to the importance of giving a complete course</li> </ul> | <ul style="list-style-type: none"> <li>■ Incorrect dose or regime prescribed by health provider</li> <li>■ Untrained staff; incorrect dose given to caregiver</li> <li>■ Partial doses dispensed to take home; daily return visits for subsequent doses required; inability to purchase if prescribed</li> <li>■ Unclear verbal and written instructions; inability to interpret packet symbols</li> <li>■ Poor or hurried staff attitude; discouraging questions from caregivers</li> <li>■ Lack of emphasis from health provider on importance of completing a course</li> <li>■ Inability of caregivers to recall instructions</li> <li>■ Idea that medication is needed only until child shows recovery signs</li> <li>■ Wanting to save medication for future illness</li> <li>■ Child vomits the medication and caregiver does not have replacement dose</li> </ul> |

**Venn Diagrams.** If you conduct illness taxonomies, you may wish to illustrate the extent to which local concepts of malaria correspond to biomedical definitions of the illness by using a Venn diagram (see Figure 24). In the common area of overlapping circles, you would indicate those symptoms common to both local and biomedical definitions. In the external part of one circle you would list those biomedical symptoms that are not part of local concepts, and in the external portion of the other circle you would indicate any local symptoms that are not part of biomedically defined malaria.

Figure 24: Venn Diagram Showing Local and Biomedical Definitions of Malaria



## Quantitative Data

Although the protocol is principally qualitative in nature, ideally you will have quantified some key variables from the illness narratives and the health facility modules. The amount of quantitative data you will have is limited. As with most qualitative studies where the primary aim is to gather in-depth information on a topic, the samples are rather small. For example, you will probably have between 20 and 100 illness narratives. In your report, be careful not to present a lot of data as if this were a quantitative study.

What is appropriate use of quantitative data in this kind of study? There are three basic uses for quantitative data in your report:

- 1) Describing the sample: You will want to present frequencies that describe your sample. For example, Figure 25 is the description of the illness narratives sample from the Kenya study.
- 2) Giving frequencies of key events: You can also report some basic frequencies, primarily to indicate orders of magnitude and support assertions about care-seeking patterns. In this excerpt from the Kenya study, note that the frequencies were rounded to avoid the impression that they are intended as precise population estimates.

*Childhood febrile illness is almost always treated first at home: over 90 percent of mothers reported treating fever at home. Home treatment is dominated by modern pharmaceuticals. Caregivers either “know” what drugs to give, or describe symptoms and obtain recommendations at a pharmacy. Of those giving treatment at home, about 80 percent give an antipyretic; over 50 percent give an antimalarial; about 20 percent give an antibiotic; and about 25 percent give at least one other type of drug. Most children treated at home receive 2–3 drugs, but it is not uncommon to give more.*

It is not appropriate to have many data tables. One that is appropriate is a table of frequencies on resorts to care that establishes overall patterns. Figure 26 is from the data on Zambia.

These data provide a “frame” that describes some basic features of treatment and provide clear evidence of the overall patterns. For example, it is immediately clear from this table that a great

**Figure 25: Characteristics of Illness Narratives Sample in Kenya study (n=97)**

|                                   |                 |
|-----------------------------------|-----------------|
| Mother is caregiver (interviewee) | 96%             |
| Caregiver's median age            | 26 years        |
| Caregiver's level of education    |                 |
| None                              | 11%             |
| Primary                           | 60%             |
| Secondary                         | 27%             |
| Post-Secondary                    | 2%              |
| Child's median age                | 1 year 8 months |
| Gender of child                   |                 |
| Female                            | 55%             |
| Male                              | 45%             |

**Figure 26: Resorts to Care  
Number and percentages of cases involving a given resort to care in the Zambia study (n=154)**

| Resort                         | N   | %   |
|--------------------------------|-----|-----|
| Gave home treatment            | 124 | 80% |
| Consulted clinic at least once | 109 | 71% |
| Consulted clinic twice or more | 16  | 10% |
| Consulted CHW                  | 2   | 1%  |
| Consulted traditional healer   | 5   | 2%  |



deal of care takes place at home, but at the same time most caregivers do consult a health facility when their young child has a febrile illness. It is also clear that community providers such as the CHW and traditional healer are playing a small role in treating childhood febrile illness. Your qualitative data will allow you to explain these quantitative patterns.

- 3) Treatment sequences: It is very useful to construct treatment sequences from your data. Treatment sequences are analyses that indicate the *sequence* in which treatment was sought from each resort to care. Each narrative will be characterized by a particular sequence. Figure 27 shows the frequency of each of the most common treatment sequences from Zambia. This table shows immediately that the most common care-seeking pattern is initial treatment at home followed by care by a formal provider. At the same time, a sizable proportion of cases (about a quarter) are treated solely at home.

**Figure 27: Sequence of Treatment-seeking  
Number and percentages of cases following a given  
treatment sequence in the Zambia study**

| Sequence                | n          | %           |
|-------------------------|------------|-------------|
| Home → Clinic           | 60         | 39%         |
| Home {end}              | 41         | 27%         |
| Clinic {end}            | 25         | 16%         |
| Home → Clinic → Clinic* | 14         | 9%          |
| Other sequences         | 14         | 9%          |
| <b>Total</b>            | <b>154</b> | <b>100%</b> |

\*This sequence includes those who visited the clinic *twice or more* for the same illness.

## Writing the Report

The results of formative research are meant to serve as a basis for making program decisions. The sooner results are available, the better. It is advisable for the team to write a summary report immediately after the fieldwork, while the information is fresh in their minds. Because the members of the team have been discussing and summarizing their findings in the field, they should be able to generate quickly a summary of key findings. These findings can be in the form of bulleted paragraphs organized by major topic and can be produced within a week. The Annex contains the summary report from the Zambia study.

The final report is a complete and formal research report containing a full documentation of the methodology and further details on the findings cited in the summary report. It also contains further analyses, such as tabulations on resorts to care or treatment sequences, and collections of quotes that illustrate key points.<sup>8</sup> Ordinarily, this final version is prepared by the principal researcher. Figure 28 shows a suggested format for the table of contents of the final research report.

Once again, the model can be used as an organizing tool for reporting your findings regarding the care-seeking process. For example, you will want a section covering recognition of signs, one on home treatment, one on decisions whether to seek care at a health facility and/or consult other providers, and so on.

Keep in mind that the purpose of the research is to provide information for making programmatic decisions. Therefore keep your descriptions of findings focused on practical information. If you have a communication or program design background, state what the implications of the findings are for the intervention, particularly its communication strategy. An example of intervention implications can be found as part of the summary report in the Annex.

In the annex of your report, you can include several narratives that exemplify different situations and bring the data to life in the body of the report.

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8. See Baume, C. 2002. *Comparing Care-seeking for Childhood Malaria: Lessons from Zambia and Kenya*. Arlington, Va: SARA Project and BASICS II, for USAID.

Figure 28: Suggested Table of Contents for a Full Research Report

**Acronyms****Executive Summary****I. Introduction****Purpose****Malaria in [Country]****Research Design and Methodology**

Research Sites

Methods

**II. Terminology and Illness Concepts****III. Treatment of Febrile Illness****Recognition of Illness Symptoms****Treatment for Fever**

Home Treatment

Treatment at Health Facilities

Community Providers

**Treatment for Convulsions****Overall Treatment Patterns****IV. Drug Perceptions****V. Target Audiences and Channels of Communication****Annexes**

Annex A: Description of Study Sites

Annex B: Overview of Research Modules

Annex C: Narratives of Care-seeking: Case Examples

Narrative 1: Case Example of...

Narrative 2: Case Example of...

Narrative 3: Case Example of...

Narrative 4: Case Example of...

Narrative 5: Case Example of...

## References for the Kenya and Zambia Care-seeking Studies

This Guide grew out of the experience of conducting care-seeking studies in Zambia and Kenya. The research reports were originally available from the BASICS I project and are now published together by BASICS II; the citations are shown below. Research results from the Zambia study were further elaborated in a journal article, also cited below.

Baume, C. 2002. *Comparing Care-seeking for Childhood Malaria: Lesson from Zambia and Kenya*. Arlington, Va.: BASICS II, for USAID.

Baume, C. 1998. *Care-seeking for Fever in Kenya: Implications for Malaria Programs*. Washington, D.C.: USAID/BASICS Project.

Baume, C., and M. Macwan'gi. 1998. *Care-seeking for Illnesses with Fever or Convulsions in Zambia*. Washington, D.C.: USAID/BASICS Project.

Baume, C., D. Helitzer, and P. Kachur. 2000. Patterns of Care for Childhood Malaria in Zambia in *Social Science & Medicine*. 51(10):1491–1503.



## Annex

# Example of Summary Report from Zambia Study

The following is the summary report that was produced shortly after the field research in Zambia. The team spent about a week writing this summary, and then presented results to the Ministry of Health and other interested organizations so that the information would be available as soon as possible to program planners. The summary includes major findings plus implications for an intervention to improve care-seeking for febrile illness.

## Zambia Study on Care-seeking for Fever and Convulsions

### *Summary of Major Findings and Implications for Programs*

The following is a summary of findings from formative research undertaken to provide detailed understanding of care-seeking for children under 5 years who have fever and/or convulsions, two key symptoms of malaria. Implications for information-education-communication (IEC), Integrated Management of Childhood Illness (IMCI) health worker training, malaria interventions, drug policy, and community partnerships are delineated.

The research used qualitative methods, but key variables were quantified. One of the main methods used was illness narratives—interviews with 154 caregivers (almost all mothers) who gave chronological descriptions of the actions taken and decisions made in treating a child under 5 years that had suffered fever and/or convulsions within the 3 weeks prior to the interview. Another 89 caregivers with children under 5 years presenting with fever were interviewed and observed in 9 health centers. The research took place in three districts in Zambia: Chipata (Eastern Province), Kitwe (Copperbelt), and Lufwanyama (Copperbelt). Within each district, three health centers and two villages/communities within the catchment area of each were selected as research sites.

The overall recommendation emanating from the study is that care for uncomplicated malaria be located within the community, to provide prompt access to appropriate medication and monitoring of dosages. The following are the main findings and their implications.

### **Mothers recognize the signs of febrile illness.**

In spite of the many demands on their time and attention, mothers are very attuned to the condition of their children. Almost all reported noticing changes in a child even before illness manifested itself, citing crying or irritability, diminished activity, and decreased appetite as early warning signs. Thus, their “intuitions” are peaked, possibly leading them to early recognition of a worsening condition.

Fever is a defining indicator of illness. Mothers appear to be keenly aware of when fever starts and can describe its course—when it worsened or abated over a period of time—in detail.

The term for fever in all local languages is “body hotness.” Although there are a number of perceived causes of fever, malaria is the predominant one. When asked what childhood illnesses can cause fever, all groups mentioned the English term “malaria” as well as local terms that correspond to a large degree with malaria. Malaria is recognized as a distinct illness, but just as often, being sick is thought of in terms of signs/symptoms rather than an illness. For example, in answer to the question, “What illness did your child have?” a mother might say, “Hot body and vomiting.”

Mothers have good general knowledge of the signs of malaria, associating it with high or intermittent fever, vomiting “yellow stuff,” chills, and sweating. Many also know that anemia can result from frequent or prolonged attacks. Almost all know that convulsions can result from high fever and that they are dangerous. Twitching is recognized as a precursor to convulsing, and it is therefore considered a danger sign in itself.

#### Implications

- The IMCI orientation around danger signs is well suited to local concepts of illness.
- IEC does not have to emphasize teaching caregivers to recognize fever or febrile convulsions; mothers already know these illness signs and are keenly aware of when they appear.

#### **Fever is promptly attended to; both traditional and modern treatments are given, but uncomplicated malaria most often is thought of as an illness suited to modern pharmaceuticals.**

Fever is considered something that warrants attention; no case of fever encountered was left unattended. At the same time, fever is extremely common and is not immediately considered serious. The initial response typically is to treat it at home, often with a mix of traditional and modern remedies, and to monitor the child’s condition. Common home responses are:

- Sponging with tepid to cold water to lower the fever
- Herbal remedies, which are either ingested, inhaled in steam, or rubbed on the body
- Commercial medications, usually antipyretics (e.g., example, Panadol, Cafenol, or aspirin) and/or CQ that is usually left over from a prior illness

It is also extremely common to take the child to the health center for fever, whether the episode is perceived as serious or not. About two-thirds of cases detailed in the illness narratives were taken to the health center, the majority of them 1 or 2 days after the onset of fever. Key factors related to whether a child was taken to the health center were:

- Whether the child’s condition was worsening
- Whether there were drugs in the home or otherwise readily available
- Perceived quality of care at the health center, including availability of drugs
- Distance from the health center

This combination of factors meant that a different proportion of febrile children was taken to a health center for treatment in each district studied: 80% in Kitwe, 70% in Chipata, and 58% in Lufwanyama. Kitwe is more urbanized than the other sites, and its health centers are more accessible and more likely to have drugs.

The vast majority of children brought to the health center with fever symptoms were given chloroquine (CQ) and Panadol/aspirin. Many children who were not taken to the health center received equivalent treatment. Mothers know that CQ is the remedy that they will be given at the health center, so if CQ is available in the home or at a nearby shop, they often administer it themselves. Thus, in the vast majority of cases, whether treated at home or at the health center, CQ is given for fever.

Both traditional and modern treatments are considered appropriate for fever. They often are given concurrently. Generally, giving herbal treatments does not seem to interfere with or delay giving modern medications.

Community health workers (CHWs) and traditional healers play a relatively minor role in treating fever cases in children. CHWs were not consulted if community members knew they were out of drugs. When the CHWs have drugs, they are visited. It appears that traditional healers are not commonly consulted for cases of uncomplicated malaria, although they are if convulsions develop. Drug vendors are not seen as sources of advice, but only as a source of drugs. They provide a convenient source of antipyretics, which are used as a first response to fever, but are less often a source of antimalarials, since drugs are free for children under 5 years (under-fives) in most health centers.

#### Implications

- Since mothers already know that CQ is the treatment for suspected malaria, and will obtain it from the most convenient location, CQ should be more accessible in the community, especially in communities located far from the health center.
- CHWs need to have a consistent drug supply.
- Health providers should emphasize that sponging/bathing should be done with tepid, not cold, water.

#### **The central problem is improper dosage.**

Although CQ is the usual treatment for fever, the proper full course of the drug is seldom administered by caregivers. Although partial doses usually are given, overdoses are not uncommon.

Both caregivers who had sought assistance at a health center and those who treated at home were administering incorrect doses. *There is little emphasis on this vital element of treatment at the health center or elsewhere.* It is not clear that health providers themselves understand how important it is. In any event, there is little communication with caregivers about the proper dosage.

There are many reasons why children are not receiving proper doses:

*Many health centers prescribe or dispense partial doses.* Many mothers ended up taking home a partial dose for a number of reasons: provider error in the amount prescribed; shortage of drugs; health center policy of monitoring doses by asking mothers to return each day (most mothers did not return since they had to walk for several hours to reach the health center); and mistakes made because the person dispensing did not have technical training to read prescriptions accurately. Also, some caregivers said that their children often vomit the medication, but they were reluctant to return to the health center for replacement doses for fear of being scolded by staff.

*Patient-provider communication is very poor.* Perhaps the greatest problem is communication of dosages to caregivers. Even when doses were accurately prescribed, dosage instructions were usually hurried, inaudible, and unclear. Sometimes two, three, or four different medications were handed to the mother with very rapid instructions on each. The name or purpose of the drug was rarely stated. When written instructions were given, labels and written instructions were confusing, especially those written on bottles containing liquid medications. The people dispensing the drugs did not check that the caregiver understood the dosage, and some seemed



annoyed if caregivers asked questions. Exit interviews conducted minutes after caregivers were handed medication found that about 40% had not understood how the medications were to be given to the child.

*Home administration of medication often is incomplete.* Once at home, caregivers sometimes stop giving the medication because the child repeatedly vomits it. More often, caregivers give only as much as is needed to see signs of improvement in the child, thinking that no more is needed. Another treatment pattern is particularly worrisome, both for the health of the child and for the development of drug-resistant strains of disease: giving small amounts of drugs for low-grade fever that persists over a period of weeks or months. In these situations the fever is attended to, symptomatically relieved by Panadol and kept in check by periodic inputs of CQ, but the illness is never cured.

#### Implications

- Health provider IMCI training on proper dosage is very important, since some providers are prescribing incorrect doses.
- One of the most critical messages is the importance of giving the full course of medication. This needs to be emphasized to health providers as well as mothers.
- Caregivers need to take the full course home with them and not be asked to return for daily doses. Accommodation should be made for children who are vomiting. Either more than the exact dose should be given, with a clear explanation to the caregiver that the extra should be given *only* if the child vomits, or caregivers should be asked to return for replacement doses and be praised for doing so. There needs to be better follow-up case management for cases where the child vomits repeatedly.
- The dosage chart should be copied and posted in screening and treatment rooms as a reference for health providers. A large, bold message reminding them to tell caregivers to give the full dose should accompany the chart. Caregivers who can read can also benefit from this message.
- All people dispensing drugs need to have adequate training so that they can interpret prescriptions correctly.
- Very basic communication skills and attitude changes on the part of the dispensing staff are likely to improve caregivers' understanding of dosage greatly. If the staff looked at the caregiver when speaking, pointed to the written instructions as they spoke, and allowed questions to be asked, it is likely that many more mothers would know how to administer the drugs correctly.
- An IEC specialist should develop a simple and clear dosage card for illiterate caregivers. The reference card needs to indicate the dose as well as the importance of completing it.
- The importance of completing the dose can be explained in under-five clinic talks. Caregivers seem to accept information given in under-five clinics.

#### **Modern treatment for convulsions needs to be more prompt.**

Most caregivers link twitching/convulsions with malaria, but caregivers (especially older ones) often suspect witchcraft as a cause. Therefore, traditional treatments are more likely to be sought if these signs appear. Herbal remedies are considered especially appropriate. In four of the ten cases that had reached the convulsion stage, a traditional healer was consulted. However, in eight of these

cases the child was also seen at a health center. In none of the cases was a child seen only by a traditional healer. Unlike treatment for uncomplicated malaria, there appears to be some reservation about modern treatments for convulsions. A number of the focus groups expressed the idea that a child with convulsions could die if it got an injection.

Giving traditional treatments appears to cause only a short delay in seeking modern treatment for convulsions, but since a child's condition is very serious at this point, any delay should be discouraged.

**The official policy of giving Fansidar™ in cases of CQ failure is not being implemented.**

In spite of official policy, Fansidar™ is not being given in cases of CQ failure. Among the 21 children brought back to the clinic because malaria-like symptoms persisted despite treatment with CQ, *none* was given Fansidar™. Eleven caregivers clearly had given a full dose of CQ and the child had not responded; the rest were probable cases of CQ failure but some of the details, such as whether a replacement dose was given if the child vomited, were not clear. Among the 154 illness narrative interviews, only 2 children had been given Fansidar™. Two of the health centers did not have the drug in stock; in the others, CQ was prescribed even though Fansidar™ was available.

**IMCI is critically needed and is working.**

Dramatic differences were noted in health providers who had been trained in IMCI and those who had not. In most health centers with no IMCI training, providers did not ask much about the characteristics of the illness or what prior treatments had been given; they hardly touched or looked at the child; they communicated little or nothing about the child's condition or about recommended treatment to the caregiver; and they often did not show empathy for the patients. IMCI appears to have remedied these shortcomings, and the trained providers

Implications

- One IEC message should be that febrile convulsions should be treated immediately at a health center.
- Consideration should be given to training traditional healers to make an immediate referral to a health center in the case of fever-related convulsions.

Implications

- All health centers must have Fansidar™ available.
- The criteria for and importance of administering Fansidar™ needs to be communicated to health providers.
- A small qualitative study could be conducted of providers' perception of Fansidar™ to help understand their reluctance to use it.

Implications

- Extend IMCI training to as many health workers as possible.
- Develop effective follow-up supervision at the district level to reinforce new knowledge and skills.
- During IMCI training in Zambia, share some of the results from this study to give health providers an understanding for how poor reception at the health center discourages good care-seeking.

observed were clearly of a higher caliber in terms of skills, attitude, and communication with caregivers. The increased time spent with patients slowed patient throughput, but some of the providers were newly trained and had not yet become efficient at the procedures.

**People want information, and there are good opportunities for providing it.**

Even though the purpose of focus group discussions was not to teach, people enjoyed the sessions and wanted further discussion and visits. They were quite willing to spend 1½ hours in discussion and were even reluctant to have the group disperse.

Mothers are open to new treatment behaviors. The vast majority reported learning from the under-five clinics the treatment of tepid sponging/bathing to reduce fever, and this is now one of the first things they do to treat fever. In the few health centers where correct and complete dose messages were communicated, mothers accepted the instructions and complied. They also have adopted other new health practices taught by the health center, such as using oral rehydration solution (ORS) for diarrhea and boiling avocado leaves to make a drink for anemic children.

There are many means of communicating with caregivers: via under-five clinics, CHWs, neighborhood health committees (NHCs), the radio, women's groups, church groups, and posters. Most caregivers prefer communication in person so that they can ask questions. Most mothers obtain health information from under-five clinics, which many attend fairly regularly, especially in urban areas. When presentations at these clinics are interesting and questions are welcomed, mothers like to attend. The other communication channels are underused.

Malaria information should focus on (1) the amount of medication to give, (2) the importance of completing the course of medication, (3) looking for signs of failure to respond, and (4) seeking immediate treatment at the health center if a child begins to twitch or convulse.

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#### Implications

- An IEC strategy needs to be developed that is based on interpersonal communication, but also draws on other channels as appropriate.
  - The potential of existing structures such as under-five clinics, neighborhood health committees (NHCs), and community health workers (CHWs) should be tapped. These groups should receive integrated technical information and be assisted in developing their educative role.
  - The results of this study could be disseminated and discussed in communities, especially those that participated in the study.
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**Community partnerships and community-based care should be strengthened. Serious consideration should be given to using community health workers for education and front-line treatment for uncomplicated malaria.**

Current policies in Zambia call for presumptive treatment of high fever as malaria and for CQ to be used as the first-line drug. Children seen at health centers for uncomplicated malaria are not necessarily getting better treatment than children treated at home. Treatment is already taking place in the community, and there are a number of positive elements in place that are required for adequate home care. Mothers know the signs of malaria, and they quickly respond by giving antipyretics and CQ.

The basic elements lacking from the treatment picture are ready access to a complete dose and actual administration of the complete dose. These elements could be provided in the community if the potential of community providers and networks (CHWs, NHC members, traditional healers, and drug vendors) was exploited. Simple training would emphasize the correct dose, the importance of giving the complete dose, the recognition of when the illness does not respond, and the need to refer to the health center immediately if that happens.

Moving basic care to community providers has a number of advantages. It would allow more timely treatment by eliminating travel time to and waiting time at the health center. It would also eliminate the discomfort and possible aggravation of illness a sick child must endure on the trip to a health center. Higher rates of compliance might be achieved because community providers have more time to explain dosages to caregivers and may be able to monitor dosages. Congestion at health centers would be relieved, and staff would be free to attend to other illnesses that cannot be treated in the home. Moving basic care to community providers has a number of advantages. It would allow more timely treatment, by eliminating travel time to, and waiting time at, the health center. It would also eliminate the discomfort and possible aggravation of illness a sick child must endure on the trip to a health center. Higher rates of compliance might be achieved because community providers have more time to explain dosages to caregivers, and may be able to monitor dosages. Congestion at health centers would be relieved and staff would be freed to attend to other things that cannot be treated in the home.



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## **BASICS II**

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