

WHO Household Survey to Measure Access to and Use of Medicines

Long Version

Instructions for Data Collection in Jordan

July 26, 2009

It is important to know...

- *if people have access to essential medicines;*
- *if they are getting medicines that are safe, effective and of good quality; and*
 - *if these medicines are being properly used.*



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1 Introduction

Indicators to measure access to medicines are most often obtained at health care facilities and retail medicines outlets. Little information is available from end users of medicines. While indicators measured at health care facility/provider level are useful, the household survey is an important tool to obtain accurate information on how people obtain and use medicines.

WHO has developed a household survey that measures people's access to and use of medicines when faced with either acute illnesses or chronic diseases. The questionnaire covers health-seeking behavior, as well as source, availability, cost, affordability, and appropriate use of medicines. It gathers information on household practices, as well as beliefs and other factors that influence the decision to seek professional advice or to take medicines. Through this information, the questionnaire provides important data on access to medicines in the community.

It is recommended to complete the household survey at a regular 2-3 year interval. Reports should describe the reference population included in the sample. Details on household sampling are discussed in Section 2.

For practical and logistical reasons, the household survey is implemented in conjunction with the Level II indicator survey (see the *WHO Operational Package for Monitoring and Assessing Country Pharmaceutical Situations*).

2 Sampling

The household survey is intended to be carried out in conjunction with a Level II health facilities indicators survey. Reference health care facilities for the Level II survey are selected *by geographic area, and by level and capacity of health care facilities*. The household survey sample will consist of a certain number of households per reference health care facility. These households will be selected purposively, according to their distance from the facility.

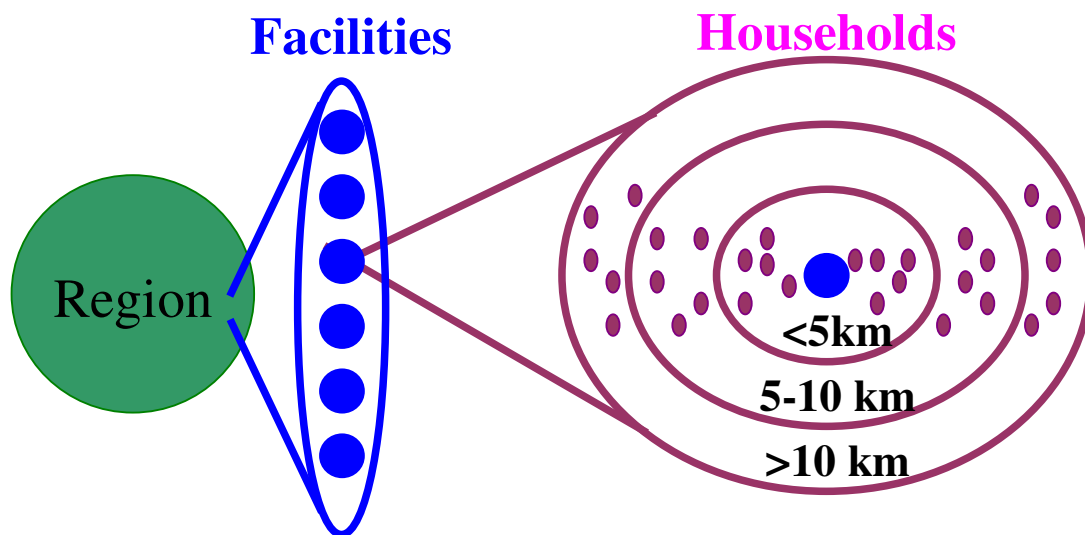
To simplify the logistics of the survey, households will not be selected randomly from a census list, tax list, or other formal listing. Instead, data collectors will select clusters of households at a given distance and in a given direction from the reference health facilities according to guidelines described below. It is important to select households that are reasonably representative of the geographic areas studied in order to obtain survey estimates close to true population values.

2.1 Selecting survey locations

The districts and reference public health care facilities that are included in the Level II survey should have been randomly selected within defined geographic areas. The appropriate methodology is described on pages 23-26 of the *WHO Operational Packages for Monitoring and Assessing Country Pharmaceutical Situations: Manual for Core Indicators on Country Pharmaceutical Situations*. The recommended sample of reference health facilities consists of 36 randomly selected public health care facilities distributed across 6 regions/districts.

Thirty households will be interviewed around each reference health care facility, a total of 1080 households. Assuming a design effect of 2.0 due to clustering (which would double the width of the confidence interval and halve sample efficiency), this size sample will estimate most percentage indicators in the entire survey sample with a 95% confidence interval of +/- approximately 6%.

The quota sample of 30 households per facility should be divided into 6 clusters: ten households (2 clusters of 5) should be selected within a 5 km radius from the facility, 10 households (2 clusters) between 5 and 10 km from the facility, and 10 households (2 clusters) more than 10 km from the facility. Selection of the location of each cluster can be purposive, since it would be impractical to randomly pick the location of individual clusters, especially in areas with low population density. Beginning with the health facility as a central reference point, the clusters should be divided such that they are in two opposite directions, as illustrated in the figure below.



2.2 Selecting households

Within each cluster, select a random starting household at the required distance from the health facility in one of the two opposite directions determined by spinning a bottle. Identify whether it is possible to interview an appropriate household informant (see section 2.3). Not every household will be able to participate in the survey; in such cases, the next household should be chosen as a replacement. After completing an interview (or scheduling one for a later time), skip 3 or 4 households before selecting another household in the cluster. This will minimize including too many households from the same extended family. If the sample is selected in this way, the confidence intervals around estimates in the three subgroups of households at each defined distance from the reference facilities (< 5 km, 5-10 km, >10 km) should be approximately +/-10%.

Interviewers should be trained to use judgment in selecting the households and respondents for the sample. General rules of thumb include:

- Households should not be next to each another;
- Households should not be excluded if respondents are not immediately present but an appointment can be scheduled to interview them later in the same day;

- Households should have an economic status that is generally representative of the area in terms of dwelling condition, size, organization of the household premises, and water supply.

2.3 Selecting an appropriate respondent

After introducing the survey in a given household, the interviewer should seek to identify the best household informant or an appropriate substitute who meets at least three of the following criteria:

- Main health care decision maker
- Most knowledgeable about health of household members
- Most knowledgeable about health expenditures of the household
- Most knowledgeable about health utilization by household members
- Designated care giver for sick household members

It is important to remember that the definition of respondent for the purpose of this household survey is not equivalent to that of household head. It is possible that the respondent meets three of the above criteria without being head of the household.

3 Survey logistics and training

3.1 Selecting data collectors

In general health care workers who deal with medicines can participate in data collection. In most settings, pharmacists, pharmacy assistants, nurses, community health workers, pharmacy or nursing students during periods when they are not in classes can serve as data collectors. Their familiarity with medicines will be very useful. When the household survey is conducted in conjunction with the Level II survey, it is possible to have a combined team composed of local data collectors from the community and national data collectors who are also engaged in the Level II survey.

It may not be advisable for local health care staff to serve as data collectors. First, their perspective as health system employees may consciously or unconsciously introduce bias into the data collection process. If respondents are aware that data collectors work for local health facility, they may tend to make more socially desirable responses. Methods to reduce possible bias should also be discussed during training.

Data collectors should be familiar with the community and local language as this will minimize cultural barriers, e.g. choice of words to explain certain concepts or mistrust of strangers asking questions about family situations. If necessary the household questionnaire should be translated into the local dialect. Safety and security are also better assured if data collectors know the area. They need to have patience and be sensitive to issues that may arise during the introduction and interview.

The best times for data collection will often be early in the morning or late in the afternoon when people are less likely to be at work. As much as possible, interviews should not be conducted at mealtime. With good planning and preparation, a team of two data collectors can survey up to 8

households in one day. In remote areas, it may be advisable to have someone such as a community leader contacting households and scheduling time for the respondents to be at home on a given day and assemble their household medicines beforehand. Such planning will help data collectors and will improve data collection efficiency.

The number of data collectors depends on the sample size (see sampling) and how much time is allotted to do the actual fieldwork. In general, increasing the number of data collectors will allow the survey to be completed in less time, but will involve more complicated training and logistics.

3.2 Training data collectors

This survey will often be carried out as a component of the Level II assessment of the country pharmaceutical situation. As such, training and field-testing of the household survey will either be done at the same time using the same data collectors or at the same time using two groups of data collectors. Generally, doctors, pharmacists, nurses, or students in these disciplines are the most prepared for collecting the Level II data in health facilities and pharmacies because of their familiarity with medicines. As described above, local teachers, NGO representatives, or school leavers can be trained to collect household data. Pairing of teams should be done carefully to ensure optimal distribution of tasks.

Data collectors will be trained to ask survey questions in a standardized way, to prompt without leading respondents to an answer, and fill in answers on survey forms. During training, role-playing exercises are essential for practicing introducing the survey, gaining consent, asking questions, and filling in forms. If the questionnaire must be translated in local dialect, this translation should be done ahead of the training so that translated questions are available during the training. Training should also cover the following questions:

- *Which households should be included /excluded?*

Households should be representative of the economic status of the area. A household will be included in the survey if an eligible respondent can be identified and interviewed on the day of data collection in the local area.

- *Who should be interviewed?*

The ideal respondent is the household member who fits all of the following five criteria. However, an appropriate respondent who fills at least three of the criteria can be substituted.

- Is main health care decision maker
- Is knowledgeable about health of household members
- Is knowledgeable about health expenditures of the household
- Is knowledgeable about health utilization by household members
- Is the designed care giver for sick household members

- *How the interview should take place?*

The interviewer should be familiar with all the questions and responses choices of the questionnaire.

- Accuracy of answers will depend on the skills of data collectors. Problems may arise from rephrasing questions so it is important that the interviewer read each question as it is written, but not the responses unless specified on the questionnaire.
- The interviewer should listen carefully to the responses provided by the respondent, and record the response by ticking the most appropriate boxes or filling in the blanks as instructed.

- Responses should be marked right away on the questionnaire. Frequent responses that are not included in the options provided should be identified and mentioned to supervisors.
- Any unusual circumstances for a specific respondent should be written on the questionnaire (e.g., elderly respondent unable to hear well or multiple people in the household answering the questions).

3.3 *Field testing*

Field-testing is an essential component of training. Data collectors will need practice on selecting households, introducing the study, and interviewing household respondents to be certain that they understand all aspects of the survey and to standardize methods. Generally field-testing will be conducted in an area near the training site. During the field test, it is important to use households that will be similar to the ones encountered in all actual survey locations (urban, suburban, and rural).

All persons collecting household data should field test the survey in at least 5 households to gain practice and ensure familiarity with the questionnaire. After the field test, the data collectors should have a chance to ask questions and discuss problems in order to standardize the methods.

3.4 *Preparation prior to data collectors training and survey visits*

The national coordinator should seek appropriate assistance to create a list of country-specific household assets and obtain a worksheet of household expenditures ranges in advance of the training. Once the list of assets is consolidated, it can be inserted in the final questionnaire. The data coordinator will provide data collectors a printed copy of the table of ranges of expenditures that they will carry when visiting households.

The national coordinator should inform community and health system leaders of the survey in advance and contact them again close to the day of the intended visit. The community leader may play a role in contacting households in advance of the interviews. In some cases, it may be necessary to have local community leaders accompany data collectors as they visit households to ensure trust and cooperation.

4 Instructions for completing household survey forms

4.1 *General Instructions*

- Data collectors will bring copies of the questionnaire to the interviews. In addition, they will carry additional color-coded sheets corresponding to the acute and chronic modules as well as a reference worksheet describing the 4-week range of household expenditures according to number of household members.
- The interviewer should explain the reason for the survey in simple, clear terms. Participation in the survey is voluntary, and the respondent can refuse to be interviewed.

- Before starting with the questionnaire, the interviewer should identify the household informant (or appropriate substitute), and then go through the Household Informant Consent Form with the respondent. If the respondent agrees to participate, the interviewer should complete the top part of Household Survey Form. If the household informant (or appropriate substitute) is not available or if the respondent does not want to answer questions, the interview will stop and no questions will be asked.
- Consent should be documented according to locally applicable standards for protection of human subjects. In some cases, local community leaders will provide general consent. When individual consent is required, each respondent will be asked to sign an Informed Consent Form before starting the interview. The interviewer must check that the respondent has understood the form before signing it. If the respondent is illiterate or unable to read the consent form (e.g. due to visual impairment), the form should be read by the interviewer and explained to the respondent.
- Interviews with respondents will be face-to-face, in local language(s), using paper and pencil questionnaires. Interviewers will read questions (and possible responses, if indicated) and mark the respondent's answers on the questionnaire. Responses may be verified by repeating the answers or by asking the respondent to explain. If local language is used, the questionnaire should be translated in advance of interviews.
- Every data collector should check their work at the end of each interview to capture transcription errors, omissions, and poor handwriting. In addition, the survey coordinator should check completed household questionnaires for completeness, correct and clear handwriting immediately after collection from interviewers. Systematic errors should be discussed to prevent them from re-occurring.

4.2 Guidelines for completing headers of the questionnaire

- The first line of every page is identical and must be completed as follows:
 - “Survey record number” in dark shade should never be completed during data collection. It is reserved for data entry (see instructions for data entry).
 - “Facility” is the name of the reference facility. This name should always be completed and written on each page of the questionnaire where information is collected
 - Households are numbered according to the reference facility to which they are related, usually 30 households per each reference facility. “Household number” is a unique number for each reference facility: it should always be completed and written on each page of the questionnaire where information is collected.
- ⇒ In summary, the first line of each page contains a combination: facility name + household number that is unique and identifies households. This combination, facility and household number, must be completed for every page of the questionnaire that contains household data.
- The second page of the questionnaire includes additional header fields that must be completed for each household:
 - Country
 - Region
 - Investigator

- Date of interview
 - Roster number of respondent, to find on page one
 - Distance of household from the reference facility, checking only one of the three possible fields
- Each one-page module includes two additional fields below the facility and household number fields, asking for the name (or initials) and roster number of the person with acute or chronic condition for whom information is going to be recorded. All four fields: facility, household number, sick person name (or initials), and roster number, must be completed before asking the first question of the module. Names (or initials) of sick persons will not be entered in the database.

4.3 *Instructions for completing each question of the questionnaire*

The questionnaire comprises six sections:

- Part one “*Household Roster*” collects demographic information on each household member.
- Part two “*Health Services and Illnesses*” includes 5 unique questions, plus a one-page acute illness module of 10 questions and one-page chronic disease module of 5 questions. Each acute module is to be repeated for each member with acute illness. Each chronic module is to be repeated for each member with a chronic disease.
- Part three “*Household Medicines*” collects information on medicines found in the household.
- Part four “*Opinions about Obtaining Medicines*” collects opinions of the household respondent about price and quality of medicines.
- Part five “*Experiences about Medicines*” collects opinions of the household respondent about their experience with regards to access to care and medicines, affordability of medicines, and quality of care and medicines.
- Part six “*Assets and Medicines Expenditures*” collects information on health care expenditures in relation to the socio-economic level of the household.

The interviewer will go through each part of the questionnaire with the respondent. In part two, the number of “acute” pages to complete corresponds to the number of household members who were acutely ill over the past two weeks. The number of “chronic” pages to complete corresponds to the number of household members with chronic disease.

Throughout the survey, some questions with numeric answers have spaces to record multiple digits. For these questions, if a single digit answer is to be recorded, enter a 0 in the left space so that all spaces are filled. For example, if the age of a household member is 33, enter the response as: 0|0|3|3|.

The following section provides guidelines on how to ask questions and collect answers. Each question is written in bold in a box, and followed by appropriate instructions. Questions are listed as they will be asked in a household with both acute and chronic conditions.

4.3.1 Instructions for completing the roster and access to health services questions

Question 1 – Please give the name, sex and age, relationship to head of household, education, occupation, and marital status of each of the household members who live here. Let me assure you that any information you provide will be kept confidential.

Write one person per row and use codes provided in each column to complete each row.

Household members share resources together. For the purposes of this survey, “a household consists of a person or group of persons, related or unrelated, who live together in the same dwelling unit, who acknowledge one adult male or female as the head of household, who share the same living arrangements, and are considered as one unit. In some cases one may find a group of people living together in the same house, but each person has separate eating arrangements; they should be counted as separate one-person households. Collective living arrangements such as hostels, army camps, boarding schools, or prisons are not considered households.” (<http://www.measuredhs.com>)

First, reassure the respondent that the information collected will remain confidential. Explain the definition of a household member: a member of the household can be someone who usually stays in the household, sleeps and shares meals there, who has that address as primary place of residence, or who spends more than 6 months a year living there. Someone currently in a hospital or other institution due to a health condition for a short-term stay would also be counted. If the respondent has adult children who do not live in the household, these should not be listed on the questionnaire. To help the respondent recall the information you need, you may want to collect data according to age or gender, starting with Column A. Then, you will record information about each member, one row at a time. Do not skip rows. Each row starts with a pre-entered unique roster number. This roster number will be used later in the questionnaire to identify members with acute or chronic conditions.

In column A, record the name (or initials) that identifies each and all household members. Each name can be a first name, a nick name, or initials. The name is asked to aid during the data collection to prevent confusion. Names will not be entered in the database for confidentiality reasons.

In column B, record the sex of the member, 1 for males and 2 for females.

In column C, record the age of the member. Use the sub-column “months” only if the member is less than one year old; if the member is over one year old, skip” months”. For example, if the member is eleven months old, write 10|10|10| 1|1|1|.

In columns D, E, F, G, and H choose appropriate codes from those provided at the top of each column. If no code corresponds to the situation of this member, write 99 and specify what the situation is in the cell.

Column D refers to the relationship of the household member to the head of the household, who may or may not be the respondent.

Column E refers to the highest level of education successfully completed

Column F refers to the occupation of the household member.

Column G refers to the marital status of the household member. Option 89 “Non Applicable” corresponds to children too young to be married.

Column H refers to the health insurance coverage of the household member.

Question 2 - How much time does it take to reach the following health care facilities or providers that are closest to your household? *Read responses and tick one box for each one of the categories.*

Question 2 refers to the time it takes with the usual means of transportation used by the household. Public facilities are hospitals, primary health care centers or dispensaries run with public funds from the government. NGO or mission facilities are run with non-government funds (faith-based or other non-governmental organizations). Private clinics, private hospitals or physicians with private practice run for-profit facilities. A traditional healer is a health care provider who uses herbs, roots, minerals or other traditional means to treat illnesses. A private pharmacy is a facility that is licensed to sell medicines; in many countries it is a facility where a pharmacist is available for advice. A drug seller is any shop that sells medicines (e.g. market, store) but is not licensed to sell medicines and has no attending pharmacist. Read one category at a time, and tick the box that corresponds best to the respondent's answer. If there is no facility of a given type located in the area, tick the > 1 hour box. If there are more than one facility of the same type, tick distance to the closest one.

It is important that data collectors be familiar with the facilities surrounding households in case the respondent does not know if the place where one buys medicines is licensed to do so, or if the local hospital is public or mission.

Question 3 - Has anyone in this household been ill in the past two weeks with an acute illness? An acute illness is a condition that appears suddenly: the person did not have it immediately before becoming ill.

1 ☐ Yes

0 ☐ No → If No, Skip to Question 5

If the respondent is not sure what an acute illness is, the interviewer may expand upon the definition: “an acute illness is an illness with a sudden onset,” “a person with an acute illness presents with complaints or signs that did not exist before,” or “an example of acute illness is sudden fever in a healthy child.” It is important to keep the 2-week time limit, so that the respondent remembers enough about the illness. If no one had an acute illness over the past two weeks, tick “No” and skip to Question 5.

Question 4 - I will now ask you a series of questions about each person who had an acute illness in the past two weeks. First, can you give the name of each person who had an acute illness over the past two weeks? *Transcribe name and roster number from the household roster.*

Complete one acute module for each person with an acute illness, one sick person per page. After collecting complete information about one person, check ‘Yes’ under “Acute illness module completed” in the corresponding row. When acute illness modules are completed and checked for all members listed above, continue on to Question 5 below. The number of completed acute illness module pages must equal the number of members with acute illness over the past two weeks.

There may have been several persons with an acute illness over the past two weeks (e.g., flu, contagious disease). Enter the name (or initials) of all persons with an acute illness over the past two weeks in the first column of the table. Use the roster that you completed on the first page to

match each sick person with his/her own roster number, and write the roster number in the corresponding field. Once all names (or initials) and roster numbers have been recorded, start collecting information on the acute illness pages starting with Question 7. After one “acute” page has been completed for one acutely sick member, tick “yes” in the last column of his/her row.

4.3.2 *Instructions for completing the acute illness module*

Once all members with an acute illness over the past two weeks have been listed in the first and second columns of the Question 4 table, go to the first “acute” page and enter data for each recently sick member, one member at a time. The acute illness module is a one-page module used to collect information on each person in the household who had an acute illness over the past two weeks.

Acute page header

ACUTE

| | |
|--------------------------------|---|
| Sick Person Name: _____ | Roster Number <input type="text"/> <input type="text"/> <input type="text"/> |
|--------------------------------|---|

Each “acute” page must identify not only the facility and household number but also the member for whom information is collected. That is why the “acute” page has its own header below the facility and household number fields, asking the name and roster number of the person with acute illness for whom information is going to be collected. All four fields: facility, household number, sick person name, and roster number, must be completed before asking Question 7. The sick person name will not be entered in the database.

Question 7 - What type of health problems/symptoms did (*first name*) have during this illness? *Do not read. Tick one box for **each** group of symptoms mentioned:*

This question allows the respondent to describe the symptoms of the sickness episode. Symptoms are loosely grouped by category or organ system. Do not read the responses. Let the respondent describe the symptoms, and tick the category/organ system group (or groups) that is closest to the respondent’s description. If the respondent cannot specify or recall the symptoms, mark *Do not know*. If a respondent describes symptoms that you cannot classify, tick “Yes” for *Other* and write the symptom next to *Other*.

Question 8 - How serious do you think this illness was? *Read the choices. Tick one box.*
 1 ☐ Very Serious 2 ☐ Somewhat Serious 3 ☐ Not Serious

The household respondent is asked to assess the gravity/ severity of the acute illness. The opinion of respondent is recorded, not that of interviewer or sick person.

Question 9 - At any point, did (*first name*) (or anybody else on his/her behalf) seek care for this illness outside the home?
 1 ☐ Yes 0 ☐ No → if No, Skip to Question 11

This question determines whether anyone in the household tried to access health care services outside of those available at home for this illness. If the answer is “No,” skip to Question 11.

Question 10 - From which of the following sources of care did (*first name*) receive care at any time during the illness? *Read responses and tick one box for each of the categories:*

See the description of the different facility types above in Question 2. Several facilities may have been visited over the past two weeks because of this acute illness. Read one facility at a time and tick the respondent's answer for each facility.

Question 11 - Did he/she take any medicine during the acute illness, including medicines taken during hospitalisation?

1 ☐ Yes

0 ☐ No → if No, Skip to Question 16

Count medicines from any source, including those taken at home or those received during hospitalization. If the answer is "No", skip to Question 16 on why no medicine was taken.

Question 12 - Which medicines were taken during this illness? *Write one medicine per row, and use codes provided in each column to collect information about each medicine.*

This question may take time to answer if several medicines were taken during the illness. The interviewer should emphasize that the purpose of this question is to collect detailed information about all medicines taken for the acute illness only. The list of medicines should include those recommended or prescribed by any source of care, including those taken at home without advice.

Record all medicines taken for the acute illness in Column A of the table, one on each row. Include medicines used by self-medication and those advised by family members or neighbors. For each medicine mentioned by the respondent, there are seven questions to answer in that medicine's row. Avoid "cannot recall" responses; jog the respondent's memory by asking additional questions (e.g., tablet or syrup? what color? how many times taken?). Remember that these questions are intended to aid memory and not bias responses.

Once the respondent names each medicine, ask the details about that medicine. Finish each row from column A to D before going to the next row. Use codes provided in columns B to D to document answers to questions. If several codes apply, write them in the corresponding cell. If the code is 99, write 99 followed by the actual answer.

In column A, record the name of the medicine. If the respondent cannot recall the name, ask to see any of the medicine that remains. If the name is still unknown, ask the respondent to describe the medicines by category (e.g., antibiotic, antimalarial, etc.) or by symptoms treated (e.g., for fever, cough, etc).

In column B, record how the medicine was administered: oral (code 1: pills, tablets...), injection (code 2), or other route of administration (code 99, and specify).

In column C, record who prescribed or recommended the medicine using the codes provided.

In column D, record where the medicine was obtained, using codes provided.

Question 13 - How much did your household pay for medicines used to treat this illness?

|_|_|_|_|_|_|_| local currency

Record how much was spent out-of-pocket (in local currency) for all medicines used to treat this illness, subtracting any amount reimbursed/paid by insurance. Do not count the cost of medicines already owned or not purchased for this illness. Write "0" if nothing was paid out-of-pocket.

Question 14 - Was this cost covered by health insurance?1 ☐ Yes, entirely2 ☐ Part of it was covered0 ☐ No

'Coverage' includes planned reimbursements by the health insurance. Tick one of the three options.

Question 15 - Did (first name) take all medicines that were recommended or prescribed?1 ☐ Yes → *if Yes, this one-page acute module is now complete, go back to Question 4* 0 ☐ No

Record whether all of the medicines recommended or prescribed were actually taken by the patient. If the answer is "No", go to Question 16. If the answer is "Yes", the "acute" page is complete, and you can go back to Question 4 and tick "yes" for "acute illness module completed" before starting a new "acute" page for the next member with an acute illness over the past two weeks. When data for all members with acute illness have been collected, and "yes" ticked for all "acute illness module completed", continue on to Question 5.

Question 16 - If answer to Questions 11 or 15 is No, ask the following question: I am going to give you some possible reasons why (first name) did not take medicines. Can you tell me whether these were reasons why?

This question investigates why the sick person did not take the medicines as prescribed or recommended during the acute illness. Read one statement at a time, and tick whether the respondent agrees or disagrees with statement. The respondent may agree with several statements. After you complete Question 16.k, the "acute" page is complete, and you can go back to Question 4 and tick "yes" for "acute illness module completed" before starting a new "acute" page for the next member with an acute illness over the past two weeks. When data for all members with acute illness have been collected, and "yes" ticked for all "acute illness module completed", continue on to Question 5.

Question 5 - Has anyone in this household ever been told by a doctor or other health care provider that they have a chronic disease? A chronic disease is an illness that will not go away or takes a long time to go away, even when treated.1 ☐ Yes0 ☐ No → **If No, Skip to Question 22**

This question starts a new series focusing on chronic diseases. If the respondent has given information on members with acute illness, you should explain the shift in focus to the respondent by saying, "We are done with discussing acute illnesses. We are now going to talk about a different type of illness..." If the respondent is not sure what a chronic disease is, you may expand upon the definition: "a chronic disease is an illness that lasts a long time or is permanent," "it is an illness that may get slowly worse over time," or "examples of chronic diseases are high blood pressure, diabetes or asthma." Tick "No" if nobody in this household has ever been told by a doctor or other health care provider that they have a chronic disease, and skip to Question 22.

Question 6 - For each person with a chronic disease, I will now ask you a series of questions about this disease. First, can you give the name of each person with a chronic disease? Transcribe name and roster number from the household roster.

Complete one chronic module for each person with a chronic disease, one sick person per page. After collecting complete information about one person, check 'Yes' under "Chronic disease module completed" in the corresponding row above. When chronic disease modules are completed and checked for all members listed above, continue on to Question 22. The number of completed 'Chronic disease module' pages must equal the number of members with chronic diseases.

There may be several persons with a chronic disease in this household (e.g., one person with diabetes, another with epilepsy, etc.). Enter the name (or initials) of all persons with a chronic disease in the first column of the table. Use the roster you have completed on the first page to match each person with a chronic disease with his/her own roster number, and write the roster number in the corresponding field. Once all names (or initials) and roster numbers have been recorded, start collecting information on the chronic disease pages, starting with Question 17. Once one "chronic" page has been completed for one member with chronic disease, tick "yes" in the last column of his/her row.

4.3.3 Instructions for completing the chronic disease module

Once all members with a chronic disease have been listed in the first and second columns of the Question 6 table, go to the "chronic" pages and enter data, one member at a time. The chronic disease module is a one-page module used to collect information on each person with chronic disease in the household.

Chronic Page Header

CHRONIC

| | |
|--------------------------------|----------------------|
| Sick Person Name: _____ | Roster Number |
|--------------------------------|----------------------|

Each "chronic" page must identify not only the facility and household number but also the member for whom information is collected. That is why the "chronic" page has its own header below the facility and household number fields, asking the name and roster number of the person with chronic illness for whom information is going to be recorded. All four fields: facility, household number, sick person name, and roster number, must be completed before asking Question 17. The sick person name will not be entered in the database.

Question 17 - Which chronic diseases does (first name) have? Read responses. Tick one box for each disease mentioned.

This question allows the respondent to describe the chronic disease. Read one chronic disease at a time and tick "Yes," "No," or "Doesn't know" for each of them. If the respondent mentions a disease that is not on the list, tick "Yes" for *Other* and briefly describe the disease.

Question 18 - Has (*first name*) been told by a doctor or other health care provider that he/she should be taking medicines to treat this disease?

1 ☐ Yes 0 ☐ No → if No, this one-page chronic module is now complete, go back to Question 6.

Some people with chronic disease might never have been told to take medicines. If the answer is “No,” the “chronic” page is complete, and you can go back to Question 6 and tick “yes” for “chronic disease module completed” before starting a new “chronic” page for the next member with a chronic disease. When data for all members with chronic disease have been collected, continue to Question 22.

Question 19 - Which medicines has (*first name*) been told to take for this chronic disease and for any other condition? Write one medicine per row, and use codes provided in each column to collect information about each medicine.

This question may take time to answer if the person takes several medications. The interviewer should emphasize that the purpose of this question is to collect detailed information about medicines taken a chronic disease. The list of medicines should include those recommended or prescribed by any source of care, including those taken at home without advice.

Record all medicines taken for the chronic disease in Column A of the table, one medicine per row. For each medicine mentioned by the respondent, there are five questions to answer in that medicine’s row. Avoid “cannot recall” responses; jog the respondent’s memory by asking additional questions (e.g., tablet or capsule? what color? how many times taken? etc). Remember that these questions are intended to aid memory and not bias responses.

Once the respondent names each medicine, ask the details about the medicine. Finish each row from column A to E before going to the next row. Use codes provided in columns B to E to document answers to questions. If several codes apply, write them in the corresponding cell. If the code is 99, write 99 followed by the actual answer.

In column A, record the name of the medicine. If the respondent cannot recall the name, ask to see any of the medicine that remains. If the name is still unknown, ask the respondent to describe the medicines by category (e.g., diuretic, corticoid, etc.) or by illness treated (e.g., for diabetes, blood pressure, etc.).

In column B, record if the prescription is filled regularly

In column C, record the number of days of supply usually purchased/obtained at a time.

In column D, record how much was spent out-of-pocket for the last month, in local currency, subtracting any amount reimbursed/paid by insurance. Write “0” if nothing was paid out-of-pocket for the medicines.

In column E, tick “Yes” if the cost of the medicine for the past month was covered or was/will be reimbursed by health insurance in total or in part, otherwise tick “No”.

In column F, record actions taken if medicine is not available at insured site

The last row of Q19 is to be completed only if the cost of each medicine is not known. If that is the case, write down the total usual cost for a month of medicines.

Question 20 - Sometimes people cannot take all medicines as directed. Does (*first name*) usually take all medicines as recommended?

1 ☐ Yes → if Yes, this one-page chronic module is now complete, go back to Question 6 0 ☐ No

A critical component of treatment of chronic diseases is the ability to take medicines for prolonged periods of time without significant interruption. The question aims at usual

practice, not unusual, brief interruptions. Record whether the medicines recommended or prescribed are taken by the patient. If the answer is “No”, go to Question 21. If the answer is “Yes”, the “chronic” page is complete, and you can go back to Question 6 and tick “yes” for “chronic disease module completed” before starting a new “chronic” page for the next member with a chronic disease. When data for all members with chronic disease have been collected, continue to Question 22.

Question 21 - *If answer to Question 20 is No, ask the following question: I am going to give you some possible reasons why (first name) may not always take medicines as recommended. Can you tell me whether these are the reasons why he/she does not take medicines?*

This question investigates why the sick person did not usually take medicines for the chronic disease as recommended. Read one statement at a time, and tick whether the respondent agrees or disagrees with this statement. The respondent may agree with more than one statement. After you complete Question 21.k, the “chronic” page is complete, and you can go back to Question 6 and tick “yes” for “chronic disease module completed” before starting a new “chronic” page for the next member with a chronic disease. When data for all members with chronic disease have been collected, continue to Question 22.

4.3.4 Instructions for completing questions 22 to 37

Question 22 Do you have any medicines available at home today?
 1 ☐ Yes 0 ☐ No → if No, Skip to Question 25

Prompt the respondent to remember all medicines that might be present in the house, including those purchased without a prescription. If the answer is no, tick “No” and skip to the next section at Question 24.

Question 23 - Can I please see all of them? *Write one medicine per row, and use codes provided in each column to collect information about each medicine.*

This question may take time to answer if many medicines are present in the house. All the medicines shown by the respondent should be recorded, one medicine on each row of the table. If more than 12 medicines are present, ask the respondent to identify the twelve most frequently used and record information about them.

For each medicine recorded in column A, there are six questions to answer in that medicine’s row. Go through medicines one at a time and complete columns A to E before going to the next medicine. Use codes provided in columns B to E to document answers. If several codes apply, write them in the corresponding cell. If the code is 99, write 99 followed by the actual answer. In column A, record the name of one medicine. Often, the name of medicine is written on the label. If not, ask the respondent for the name. If the respondent cannot recall the name, ask the respondent to describe the medicines by category (e.g., antibiotic, antimalarial, etc.) or by symptoms treated (e.g., for fever, cough, etc).

In column B, record where the medicine was obtained, using codes provided.

In column C, record why the respondent keeps this medicine at home.

In column D, record information about the appropriateness of the medicine's label. Record "Yes" only if the medicine was correctly labeled with the name, the dose and the expiry date. Otherwise tick "No".

In column E, record information about the acceptability of the medicine's primary package. Record that the primary package is acceptable "Yes" only if it is an envelope or a closable container having only one type of medicine. Otherwise tick "No".

Question 24 - I am going to read you a series of opinions about price and quality of medicines. For each opinion, please tell me whether you agree or disagree. Do not read the option "Do not know". Tick it if the respondent does not want to answer or is unable to choose between "agree" and "disagree". Read statements & tick one box for each statement.

Read the first statement and then ask the respondent, "Would you say that you agree or disagree with this statement?" Do not read the option "do not know". Tick it only if the respondent does not want to answer, or is unable to choose between "agree" and "disagree". Read each succeeding statement at a time and allow the respondent to say what he/she thinks about the statement.

Questions 25, 26 and 27 - I am going to read you a series of opinions about three topics related to care and medicines: access, affordability, and quality. There are no correct answers. For each opinion, please tell me whether you agree or disagree. Do not read the option "Do not know". Tick it if the respondent does not want to answer or is unable to choose between "agree" and "disagree". Read statements, and tick one box for each statement.

25 - The first set of opinions is about access to care and medicines.

26 - The second set of opinions is about affordability of medicines.

27 - The first set of opinions is about quality of care and medicines.

Each of the three questions has an identical format, recording the respondent's opinion on different aspects of access to medicines. Read the first statement and then ask the respondent, "Would you say that you agree or disagree with this statement?" Do not read the option "do not know". Tick it only if the respondent does not want to answer, or is unable to choose between "agree" and "disagree". Read each succeeding statement at a time and allow the respondent to say what he/she thinks about the statement.

Finally I would like to ask a few questions about the possessions that are in your home and how much your household spends. Remember that any information you provide will be kept confidential.

Question 28 - Can you please tell me how many rooms (bedrooms, dining room, kitchen ...) are in your home?

|_|_|_| Rooms

Record all rooms in the house, including all bathrooms, garage, anything that is a separate room.

Question 29 - Does anyone in your household have: *(Items are country-specific. These items should be identified and listed before the survey by referring to Section 3.3. of the manual)*

Question 30 - Does your household have:

Question 31 - Does anyone in your household have: *(Electricity-dependent items are country-specific. These items should be identified and listed before the survey by referring to Section 3.3 of the manual)*

In Questions 29 & 31, permanent asset items have been left blank. These will be country specific, and will be agreed upon before you start administering the survey in your country. These items will be chosen to discriminate people of different social status: low, medium and high income groups. Signs of wealth vary from country to country. Depending on the country, examples of items may be a house, a piece of land, farm animals such as cows or poultry, air conditioners, motor vehicles, “more than one bicycle”, refrigerator, television, computer. The goal is to find out whether or not the household (or a member of the household) possesses assets that reflect social status. In questions requiring a yes/no answer, such as whether or not the household possesses an item, it does not matter how many of that item the household may have. Likewise, the condition of the item (for example if the item is a television, whether it is working or not, no differentiation between color and black/white, record any TV) or its value is not of interest. Difficulties may arise if a household possesses a certain item that they say is borrowed, does not belong to them, or is shared with other people outside the household. In such cases, explain to the respondent that the key is whether or not the household has access to the asset in question on a regular basis. For example, one member of a household may drive a taxi for work, which he or she does not own. Since the household can use this taxi for transportation and other personal needs, the correct response as to whether or not the household possesses a car would be “Yes”. You should provide such explanation to the respondent only if asked. Otherwise, simply mark the response and move on to the next question. It is not necessary for the respondent to show you a particular object in order to confirm that they possess it.

Question 32 - In the last week, how much did your household spend on food? Include the value of any food produced and consumed by the household; exclude alcohol, tobacco, and restaurant meals:

|_|_|_|_|_|_|_| in local currency

The interviewer should not force consistency between the totals reported in one question and the sum of answers in the others. All amounts are to be recorded in local currency. If the value was paid in-kind, then the local currency value of the in-kind payment should be included.

Note the recall period of one week for food expenditures. Food expenditures include all food prepared and consumed by the household, along with food purchased and consumed outside the household (e.g. snacks, bag lunches). However, they should exclude meals at sit-down restaurants, and expenditures on alcohol or tobacco.

Question 33 -I now will give you five different levels of spending. Please choose the level that is closest to what your household spent in total over the past 4 weeks. *(Ranges of expenditures corresponding to A, B, C, D, and E are computed for each county. They are proportional to household size and are expressed in local currency)*

1 ☐ A

2 ☐ B

3 ☐ C

4 ☐ D

5 ☐ E

Question 33 asks the respondent to choose among different ranges of money: A, B, C, D, or E to tell how much his/her household spends in total over 4 weeks. Before asking Question 33,

the data collector will look at the table of ranges of expenditures and choose the row corresponding to the number of household members to identify the amounts that correspond to A, B, C, D, and E.

Note the recall period of four weeks. Explain to the respondent that total spending should include the value of all goods and services consumed or used by the household, including food. Enumerate the components to respondent: food, housing, health expenses, education bills, electricity, water, telephone, heating, gas, gifts.... This would include things produced by the household for its own consumption (e.g. eggs from backyard chickens). It would exclude things purchased for use in a home business.

Question 34 - Can you provide the actual total amount?

1 ☐ Yes, in local currency 0 ☐ No

This is a yes/no question. A calculation worksheet may be useful as an aide memoir in estimating total household expenditures. However, the respondent may not want or cannot answer this question. If that is the case, tick “No”.

Question 35 - In the last 4 weeks, how much did your household spend on:

Note the recall period of four weeks. For expenditures that may have been incurred on an annual, bi-annual, or periodic basis, etc., such health insurance premiums, but have not actually occurred in the past month, average monthly costs should be apportioned to the appropriate category, if possible.

Ask how much is spent on medicines for the entire household during an average month. Alternatively, the amount spent during any week of the current month may be used, as long as it is multiplied by four to obtain the amount spent in four weeks. Include all medicines discussed earlier or bought for acute or chronic treatment. This question should cover the cost of all medicines taken by any member of the household for prevention, such as vitamins, or treatment of acute or chronic disease.

Question 36 - If yes, who is the main earner in the household?

Write his/her roster number here:

Go to the first page of the questionnaire, i.e. the household roster, find out the roster number of the main earner in the household, go back to Question 37, and write down his/her roster number.

Question 37 – Is there another major source of income?

Thank the interviewed person and reassure about the confidentiality of his/her answers.

Before ending the interview, repeat to the respondent that all his/her answers will remain confidential and will be used only for the purpose of understanding better how people use medicines.