**Interviewer’s Reference Manual**

**Integrated Verbal/Social Autopsy (VASA) Long-Form Questionnaire**

**For Stillbirth, Neonatal, Child and Adult Deaths**

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**About this manual**

The purpose of this manual is to provide interviewers with the information they need to conduct high quality verbal/social autopsy (VASA) or verbal autopsy (VA) interviews. The manual describes interviewers’ responsibilities and provides a question-by-question guide to the long-form VASA questionnaire. Interviewers are to use this manual as a reference guide during their training and, as needed, during their work as VA or VASA interviewers. The manual also serves as a reference for trainers and supervisors of the interviewers and for managers of a VASA project. The manual is organized according to the VASA training and questionnaire.

# About the VASA questionnaire

## **Background**

“Stillbirth” means a child that dies before being fully born. Death might occur before the birth process begins, or during birth. The definition of stillbirth also includes the duration of the pregnancy and takes into account the level of technology available in the setting that might enable a premature baby to survive. The definition recommended by the World Health Organization for most developing countries is a pregnancy loss at 28 weeks (approximately 7 months) or more. “Neonatal” is the time from birth through 27 days of age and is the period of greatest risk for death due to the often weak condition of newborns. “Child” means from 28 days (taken as 1 month) to 11 years old, and “adult” means a person 12 years or older. Most deaths of children beyond the neonatal period occur among 1–59-month-olds, and the greatest number of these deaths are of children less than two years of age. Twelve years was chosen as the dividing line between “child” and “adult” for the VASA questionnaire because the adult module includes maternal deaths. And although 15-49 years is the age group most often included in studies of maternal deaths, in some settings many marriages and pregnancies occur in girls as young as 12 years old.

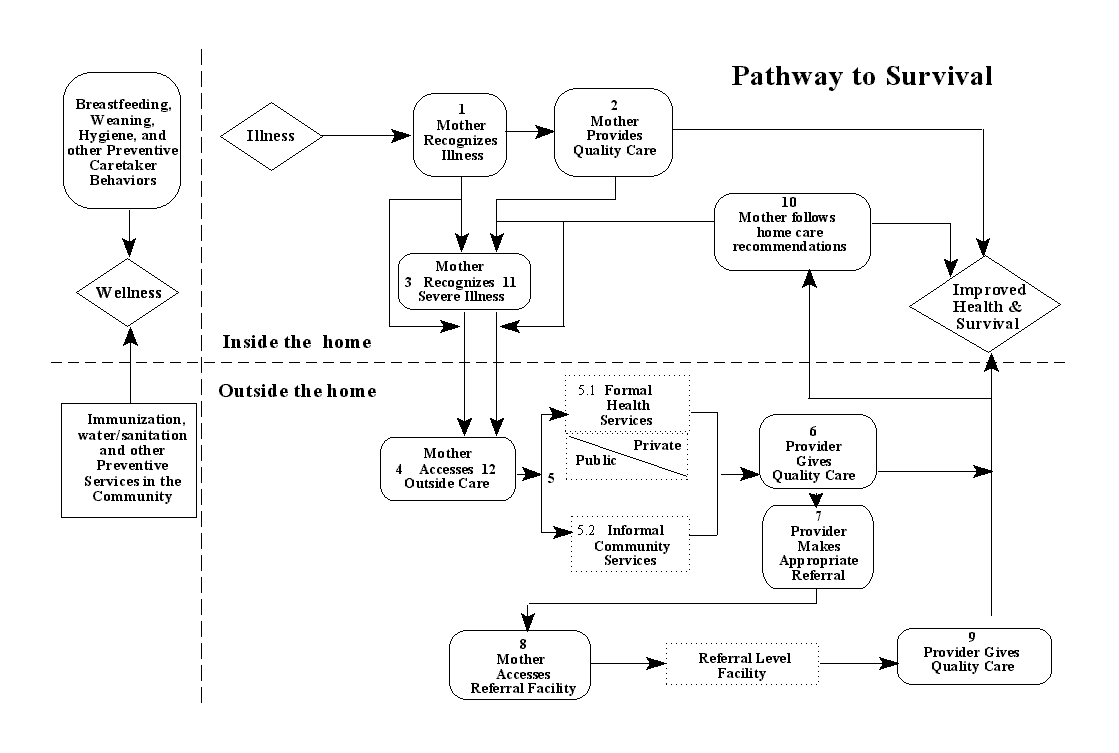
Most neonatal and child deaths in the world occur in developing countries in Africa and Asia. However, few data are available on the biological causes or behavioral and social determinants of these deaths. Such data are vital to developing effective interventions to prevent the deaths, and to contribute to accurate global estimates of the causes of death. The best way to estimate the causes and determinants of deaths in a population is on the platform of a census or a representative household survey or vital events registration system. Once the platform identifies households where there have been recent deaths, data collectors can revisit these households to conduct a verbal/social autopsy (VASA) interview. The VA part of the interview determines the biological cause of death by asking about the signs and symptoms that a person had during her illness, such as cough, difficult breathing and loose stools. A social autopsy (SA) can be conducted together with the VA to examine the behavioral and social determinants of the deaths, including actions that were taken to keep the person healthy and to care for him after he fell ill. The VASA questionnaire blends the VA and SA together to ask about all the events in the order that they occurred. For example, questions are asked about the illness signs, and then about what the deceased’s caregiver or the person herself did when she noticed the illness. The VASA questionnaire allows either a complete VASA interview to be conducted, or a VA interview alone to determine only the biological cause of death.

## **The causes and determinants of neonatal, child and adult death**

Globally, the most common causes of neonatal deaths include preterm (early) delivery, birth asphyxia (not breathing at birth or inability to cry immediately) and severe infection (septicemia, pneumonia, meningitis). Other important causes include malformations and tetanus. The most common causes of death of young children 1-59 months old are pneumonia, diarrhea and malaria. Other important causes include measles, meningitis, tuberculosis and injuries. Additional causes that are more common in older children 5-11 years old include, among others, sickle cell anemia and cancer. The relative frequency of these conditions, both for neonates and children, varies depending on the setting. In adults, non-communicable disorders such as cardiovascular (heart and blood vessels) disease and cancer are more frequent causes of death than in children. However, some infections such as tuberculosis and AIDS are still common. And in women, maternal deaths due to complications of pregnancy and delivery remain an important cause. In low-income countries, particularly in Africa, AIDS, tuberculosis and maternal conditions together account for up to half of the deaths of women of reproductive age. This is both because these conditions occur frequently and because of poor access to the quality health care needed to prevent or cure these disorders.

While a biological illness is defined as the cause of death, in fact most neonatal and child deaths result from a chain of events that includes many cultural, social and health system factors. Some neonatal and young child deaths can be prevented even before a woman becomes pregnant by ensuring that she is well nourished and that there is sufficient time between her pregnancies. Healthful practices by the family and the health system at birth and afterwards can also prevent many illnesses through actions such as providing skilled birth attendance, appropriate newborn care, proper nutrition and immunizations; and can cure most illnesses that do occur by providing quality, accessible health care that is sought on time. Social factors also play a role in adult deaths, many of which can be prevented by decreasing the use of harmful substances such as tobacco and excessive alcohol; or cured or controlled by quality health care of infectious and non-communicable conditions. The level of maternal mortality is an especially good measure of health system functioning, since almost all maternal deaths can be prevented by high quality, accessible health care.

The Pathway to Survival model describes these healthful preventive and curative care practices. While originally designed to support the Integrated Management of Childhood Illness (IMCI) approach to child health care, the model can also be used to describe an approach to overcoming much of adult mortality. The SA questions in the VASA questionnaire are based on this model.

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On the left side of the Pathway, well child and preventive care are seen to keep most children healthy. Despite this care, some children become sick. If their caregivers and health care providers follow the steps outlined on the right side of the model, most of the sick children will get better and survive. The purpose of the SA questionnaire is to learn whether the children who died received good preventive care and, when they became sick, where they fell off the Pathway; that is, which steps that might have saved them were not taken or were delayed. For this reason, the interview is done only of children and adults who died. This is why it is called a “social autopsy.”

Three types of delays can occur on the right side of the Pathway. There are delays in: 1) deciding to seek care, 2) reaching a health facility once deciding to seek care, and 3) receiving quality care once reaching the facility. Cultural and social factors that may contribute to the first delay include: 1) poverty, 2) low education, 3) women’s lack of participation in decision-making, 4) not recognizing or understanding the importance of illness signs, and 5) using traditional home care and informal providers instead of formal providers who might be able to save the sick person’s life. The second delay can be due to the time needed to organize funds to pay for transportation or health care, a lack of transport, poor roads, or long distances to a health facility where the person can receive appropriate care. The third delay may be due to a lack of needed drugs, medical supplies and equipment, or skilled health personnel at the facility. There can be some overlap in the factors contributing to the three delays; for example, concerns about the cost of transportation or health care might lead to a delay in deciding to seek care.

Important elements missing from the Pathway to Survival model for stillbirths and neonatal deaths are preventive and curative care of pregnant and laboring women. Recently, a modified Pathway to Survival was developed that addresses these missing elements.[[1]](#footnote-1) A woman’s health during pregnancy and delivery is vital to the wellbeing of her newborn child. Maternal health problems are major causes of stillbirths and neonatal deaths and might contribute to some infant deaths in the first year of life. Therefore, the sections of the VASA questionnaire devoted to stillbirths, neonatal deaths and to some extent infant deaths, also ask about antenatal care and complications of the mother’s pregnancy and delivery and careseeking for the complications. For maternal deaths, the Pathway serves to examine the woman’s and her family’s actions taken to care for her obstetric complications that caused the death.

## **The VASA project in \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (Users: complete the blanks in this section of the manual)**

The VASA project is being conducted as part of the \_\_\_\_\_\_\_\_ project’s \_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_ (e.g., sample registration system (SRS), household survey) being developed by the \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (e.g., National Statistics Institute) in partnership with the National Ministry of Health, with technical assistance provided by \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_. The purpose of the project is to increase knowledge of the biological causes and social determinants of stillbirths, neonatal, child and adult deaths in \_\_\_\_\_\_\_\_\_\_\_\_. The VASA project will return to households where a recent death was identified by the \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ to conduct a verbal/social autopsy (VASA) interview. A country working group of health program managers and policymakers will help analyze and interpret the data to better plan health services in the community and at health facilities. The findings will also be compared with other countries to assess whether the importance of particular causes and determinants differ across settings; and to help improve regional and global estimates of the causes and determinants of stillbirths and neonatal, child and adult deaths.

The VASA study manager will discuss the specifics of the project’s organization with you. In the field this will consist of teams of interviewers, each with a supervisor. Each team will cover a different part of the study area. The supervisors and data manager will compile the data collected by the individual teams. The country working group and international study partner will then work together to analyze the data.

# Interviewer roles and responsibilities

As a VASA interviewer, you will represent the project to households in your study area. You will inform bereaved families about the purpose of project and conduct the VASA interview with the appropriate family members. Your tasks include to:

* Work with your supervisor to receive your interview assignments for neonatal, child and/or adult deaths that have occurred in your area;
* Locate households where a neonatal, child and/or adult death occurred and visit the families to make appointments for conducting the interviews;
* Correctly conduct VASA interviews with family members on the appointed dates. You will collect the interview data directly on a netbook or tablet computer;
* Daily, backup the interview database on a pen drive or follow another procedure determined by the project data manager to ensure that the data are not lost;
* Provide the interview database on the pen drive to your supervisor (or use an alternate procedure to transmit the data) and discuss and solve any problems you have encountered;
* Strive for continuous self-improvement of your performance; and
* Maintain the ethical standards of the project and good relations with the community.

**Interviewer self-assessment and improvement**

One of your responsibilities as a VASA interviewer is to continually strive to improve your performance. Your supervisor is also there to assist you in overcoming any problems that occur, but to make the greatest progress you should always seek to do the best job possible. Appendix A of this manual provides an interviewer’s self-assessment checklist to help you in this task. How to use the checklist will be discussed during your training as a VASA interviewer.

**Supervisory procedures**

Your supervisor will assign deaths to you for interview and provide you with locating and background information for each death. You must return the data for the completed interviews as well as your completed self-assessment checklist to your supervisor. In some projects, you may transmit the data you collect directly to a secure server instead of to your supervisor. The supervisor’s checklist in Appendix B of this manual lists other supervisory tasks and will be discussed during the training. Some of these tasks include:

* Keep a register of the deaths for which interviews are to be conducted;
* Assign neonatal, child and/or adult deaths for interview;
* Provide needed logistical support to locate and reach the assigned households;
* Observe and critique early interviews (and later interviews as possible);
* (In some projects) Receive and compile the databases of individual interviewers. Provide the compiled database to the project field manager;
* Hold periodic meetings with the interviewers to discuss and solve problems.

Supervisors should support the interviewers in achieving their full potential as VASA interviewers. This means assisting the interviewers whenever necessary and helping them to overcome problems that they face in completing the interviews. Supervisors will have the opportunity to practice this approach during the VASA training.

# Ethical training and administering informed consent

Part of your training as a VASA interviewer or supervisor will be on ethical aspects of conducting research interviews, such as informed consent and confidentiality. This is to ensure that you are aware of the importance of these issues and will maintain the highest ethical standards in your work at all times. Some important concepts to be discussed during the ethical training are described below.

**Informed consent**

All potential respondents have the right to determine for themselves whether or not they will participate in the interview. In most countries, all respondents must be at least 15 years old to help ensure that they are capable of making this decision. Part of your job as an interviewer is to administer “informed consent” to all potential respondents. This means that you must fully inform them about the VASA project and interview before asking any questions; and that after learning all the facts the potential respondents either consent or refuse to be interviewed. Respondents must fully understand the purpose and expected duration of the interview, the risks and benefits of being interviewed, and their right to not answer any or all questions. All these and other facts are described in a “consent form,” which you must read and explain to potential respondents before conducting the interview. The respondent must either make their mark or sign the consent form, which you will then sign to testify that the person consented to be interviewed. The consent form is in Appendix C of this manual.

## **Confidentiality**

It is critical that all information obtained from the VASA interviews remains strictly confidential. You are not permitted to discuss the findings from an interview, gossip about it, or show your records to anyone other than your supervisor. Make all entries on the computerized questionnaires yourself. Do not leave your netbook, tablet or pen drive lying around where unauthorized persons may have access to it.

Maintaining confidentiality is an ethical responsibility that we all share. It is necessary to protect the respondents from any bad events that might occur as a result of the information they have provided. It is also necessary to maintain the trust of the community and assure that people will be willing to talk openly to us about the deaths.

## **Falsification of Data**

Your job as a VASA interviewer will not always be easy. There may be times when you have to visit a household more than once to meet with the best respondent. The interview may take one and a half hours or longer to complete. Many of the questions seek sensitive information that may appear to reflect badly on care provided to women and children by their families and sometimes by the health system. All these conditions can lead to temptations to falsify data in order to quickly complete the interview and not record painful facts. However, you must never falsify your work. The whole purpose of the VASA project is to collect accurate information that can be used to prevent deaths from occurring. This will be possible only if the information collected is truthful. It is your responsibility to assure that you maintain this standard. You should work as a VASA interviewer only if you are certain you can accomplish this.

# Communication and sensitivity issues

Effective communication with the respondent is of key importance in obtaining high quality information. As a VASA interviewer, you will interact with bereaved relatives of neonates, children and adults who have recently died. In addition to mastering basic communication techniques, you need to be sensitive to the emotions of these persons and know how to handle difficult situations that might arise during the interview. You will role play some of these situations during your training. Appendix D provides practice role plays together with explanations of the situations for interviewers, supervisors and VASA trainers.

## **How to approach the respondent**

Always have a positive approach. Do not use phrases such as: “Are you too busy?” or “Can you spare an hour?” Such questions invite refusal before you start. Instead, begin by restating condolences for the death and say: “I would like to ask you a few questions.” or “I would like to talk with you for a few minutes.” State the purpose of the interview and its importance for helping the community; and stress the confidential nature of the interview.

However, if a respondent insists that s/he does not wish to talk to you, do not argue. Instead, ask her/him for another day or time when s/he would be available to participate in the interview. Answer any questions the respondent asks frankly and to the best of your knowledge.

## **Selecting an environment for the interview**

It is best to conduct the interview in a private location where you and the respondent can be alone. However, it is to be expected that other family members may be present during the interview. In cases where complete privacy is not possible, try to limit the number of outsiders present.

**Basic communication techniques**

## Sit at the same level as the respondent and maintain eye contact. Always look at the respondent when administering the interview. Remember, this is a difficult time for the respondent and s/he must feel comfortable with you in order to complete the interview.

## **Build rapport with the respondent**

Try to build rapport with the respondent before discussing the case of the deceased. For example, if culturally appropriate, you may ask the respondent what work s/he does, or ask about her/his family.

**Encourage speech, listen actively, do not rush, nod your head**

These are ways of showing the respondent that you are interested in what s/he is saying and will encourage her/him to continue.

**Be non-judgmental**

Some of the respondent’s answers may lead you to feel that s/he contributed to the person’s death, for example, by not taking her for health care quickly enough. However, you must not transmit this message in any way because it will discourage the respondent from providing truthful answers. The success of the VASA project depends on all of us taking this non-blaming approach. The idea is to learn what the health system and community can do together to prevent neonatal, child and adult deaths. This can only be accomplished by working together without blaming individuals for the deaths.

## **Language problems**

If you anticipate any language difficulties, for example, that a respondent speaks a different dialect than you do, talk to your supervisor beforehand. If the respondent speaks a language that you do not speak, try to find someone else in the household to answer or interpret. If you find you are unable to conduct the interview, notify your supervisor.

**Bereaved respondents and sensitivity issues**

Persons who are mourning the death of a loved might have several emotional responses that could interfere with the interview. These might include the following, some of which are discussed below:

* Becoming sad or upset
* Getting offended or angry
* Being wary or suspicious of the entire interview or certain questions
* Not wanting to answer certain questions for unstated reasons

*Sadness, tearfulness*

First, be sure to express your sympathy and condolences for the respondent’s loss before starting the interview. It may also help respondents to know that the health program will use the VASA data to help improve care for other people in the community. If a respondent begins to cry or have great difficulty in answering questions because s/he is overcome with emotion, you should pause and offer a tissue for tears. Acknowledge how difficult it must be to answer the questions, give the respondent time to regain their composure, and ask if s/he can continue at this time. If the respondent chooses not to continue, attempt to reschedule the interview.

*Anger*

A respondent may be angry at the health program if s/he feels that an individual health worker or the health program in some way contributed to the death. The respondent might direct this anger at you if s/he sees you as a representative of the health program. Another possibility is that a respondent may blame a relative or neighbor for the death if, for example, s/he feels that this person did not provide help that was needed. This anger could also come out during the interview. If this happens, let the person express their anger. Then, again express your condolences for their loss and acknowledge that you understand that they blame the particular person or the health program. (Never state that you agree with them, just that you understand that this is their feeling.) Last, again explain that the purpose of the VASA interviews is to learn about the problems that lead to deaths in the community and to help overcome these problems.

## *Not wanting to answer certain questions*

There could be several reasons that a respondent does not want to answer certain questions. A question may rekindle painful memories; it may ask about a topic that is particularly sensitive for the respondent; the respondent may feel that they personally did not do enough to help the newborn’s mother or the child or adult and that the answer to the question would reflect badly on them, etc. Whatever the reason, you must never demand or even ask a respondent to answer a question that they have told you they do not want to answer. As stated in the informed consent, respondents’ participation is totally voluntary and they have the right to refuse to answer any or all questions. It should not be a problem for the interview if a respondent refuses to answer only a few questions. However, many refusals will compromise the quality of the interview. You should make a note about any reasons you think might be leading to the respondent’s reluctance and discuss such cases with your supervisor.

# Interview procedures and tips

**Approach the household and select the best respondent**

The VASA interview is best conducted with one or a few persons. The main caregiver of the deceased during their illness will usually be the best respondent, and the others may recall some events that the main caregiver is not aware of. However, when approaching a household in a rural village you may be met by a crowd of interested persons. Once inside the compound or the house several neighbors and family members who know little about the illness may want to participate in the interview or just observe. You must manage this situation effectively and sensitively to ensure that just the most knowledgeable person(s) remain present and that the others are not offended. These issues will be discussed during your training, and you will have the opportunity to role play some situations (in Appendix D) that you might encounter. The following offers some suggestions.

**Manage the scene and gain the trust and cooperation of households**

Consider working with a local respected person (e.g., schoolteacher, village leader) to pre-arrange the meeting and/or to accompany you to the household.

In order to have the respondent’s cooperation and obtain complete and accurate data, you must first gain the trust and confidence of the household. You can do this by making a good impression and conducting yourself in a professional, but also friendly manner.

*Understand the VASA project*

If you are knowledgeable about the project and your responsibilities respondents will be more likely to trust you and participate. You should be able to answer any questions that household members may ask about the purpose of the project and how the information they share will be used.

*Emphasize the confidentiality of the information*

You must assure participants that their responses will be held in strictest confidence. No information will ever be released to anyone outside the project in a way that reveals who provided the information.

If a household member or respondent hesitates to cooperate because of confidentiality concerns, you should fully explain how confidentiality will be maintained. Explain that no names will ever be revealed and that the information from all interviews will be combined in a report for district and national use.

## **Introducing yourself at the household**

This is a very sensitive time for the family, so it is important that you be polite and sensitive when introducing yourself. Be sure to state the purpose and confidential nature of the interview—these are key elements to gaining the family’s cooperation. An example is provided below:

*My name is* [say your name]*. I am a nurse/\_\_\_\_\_ in the \_\_\_\_\_ center, and an interviewer with the VASA Project. I have been informed that a child in your household died. I am very sorry to hear this. Please accept my sympathy. In order to improve health care, we are collecting information on recent deaths of children in this area. I would like to talk to the person in your house who took care of* [say the child’s name] *during her/his illness before death. I assure you that any information you or your family provide will be kept confidential.*

## **How to select the best respondent**

The respondent is the main person that will provide information about the deceased. S/he should be the one who was with the deceased person during the illness. For a child death, the child’s mother is usually the preferred respondent; while for an adult death, the person’s spouse may be best. In some cases, more than one person will have taken care of the deceased or been present during different stages of the illness. For example, for a neonatal death, the mother of the child may have been attended at a home birth by her mother. If the child’s mother was ill after the birth, then her sister (the child’s aunt) may have cared for the child at home and the child’s father might have taken her/him to hospital. The most knowledgeable of these persons should be selected as the respondent, recruited to be interviewed, and sign the informed consent form. The others can help recall events the respondent is not so aware of. All respondents must be at least 15 years of age. Appendix E provides model scripts for recruiting the mother or other person for interview of a stillbirth or neonatal or child death. You should practice reading these scripts during your training.

*What to do if the potential respondent(s) is away or lives elsewhere*

If the person who appears to be the best respondent is not available when you first visit the household, try to make an appointment to return when s/he will be at home. If no one is at home when you visit the house try to ask a neighbor when the family members might be at home. Then leave a message indicating that you plan to return at that time. In either case, make a note of the return date in your notebook.

Sometimes the best respondent may have moved to another village. In this case, you should discuss the situation with your supervisor. S/he will decide if you should travel to the other village or if help needs to be sought from the VASA team in another area.

## **How to handle multiple persons at the interview**

As discussed above, there may be instances when the respondent needs help from others to provide the full story of the deceased’s illness. However, it should always be clear as to who the main respondent is and, therefore, who is providing the final answers. More than one person answering the same question can lead to confusion and greatly lengthen the interview.

Some persons who were not with the mother during the pregnancy or delivery (for neonatal deaths), or with the child or adult during the illness, may insist on attending the interview or even on being the respondent. For example, the child’s father or grandmother might not let the child’s mother talk to you alone, even if she took care of the child during the illness. Or, the respondent may have other children to care for who distract her attention from the interview. Lastly, having a visitor at the household can attract many other unwanted people to observe the interview. In these cases, it is important to stress to the respondent the importance of confidentiality and privacy. You can try:

* Suggest moving to a different location
* Ask some of the bystanders to leave and come back once the interview is finished.
* Reschedule a time to come back and finish the interview

# Conducting the interview

## **Materials you will need**

Interviewers will be provided the materials listed below to help them perform their duties. Make sure that you secure them in a safe place in your home when you are not working to prevent loss, damage, or any unauthorized person seeing information that is recorded on the VASA forms.

* VASA interviewer identification card (be sure to wear it where it can be seen)
* This manual, *VASA Interviewer’s Reference Manual*
* Interviewer’s self-assessment checklist
* Blank VASA questionnaires
* Pencils or pens for writing, and erasers
* Appointments notebook
* Bag for carrying forms and other materials.

The VASA questionnaire includes a General Information module for recording background information and determining the age of the deceased person. Some of the background information will have already been collected by the platform survey and is to help you locate the household and deceased person about whom the interview is to be conducted. You will collect some other background information during the interview. This is followed by several sections about the person’s illness and social and behavioral factors. Both the VA and SA questions appear throughout the questionnaire, sometimes in separate sections and other times within the same section. Skip instructions will guide you through the questionnaire to conduct either a VA or integrated VASA interview, depending on which type is being done. The skips will also guide you through the questionnaire depending on the age of the deceased person. Appendix F of this manual provides practice interview situations for neonatal, child and adult deaths. These do not provide the details needed to answer all the questions in the format, but instead are meant to help get you started in conducting practice interviews with your fellow VASA trainees.

**General instructions for using the VASA reference manual and questionnaire**

Starting with the next section, this manual follows the order of the VASA questionnaire. It duplicates each question and its instructions, plus it provides additional information on why the question is asked and how to ask it. Use the manual together with the questionnaire.

*General instructions for conducting the interview:*

*1. Instructions:* The questionnaire includes many instructions to the interviewer, always in *italics.*

*2. How to read questions:* Read all questions exactly as they are written so all respondents are asked questions in the same way. Read slowly and clearly. Do not rush the respondent in answering. Some questions include alternate wordings depending on the situation. Follow the instructions to determine how to read the question at that time. Possibilities include:

* Words in parentheses, separated by a slash mark, for example “(you / the mother).” The correct wording depends on who the respondent is. All such questions seek to learn about the mother, so if the respondent is the mother, you would read this as “…you…”; and if the respondent is someone else, you would read this as “… the mother…”. For example, question C3064 is “Did (you / the mother) receive care from any person or health facility for (any of) the pregnancy symptom(s) that started before labor?” If the respondent is the mother, read this as “Did you receive care…?” and if the respondent is not the mother, read this as “Did the mother receive care…?”
* Similarly, some questions are asked both for child and adult deaths (and some are even for all three age groups—stillbirths/neonatal deaths, child deaths 28 days-11 years, and adult deaths 12 years and older). In this manual, for some questions like this, there are words in parentheses separated by a slash mark, such as “(you / you or <NAME>).” This is especially true in section 10 on careseeking for the illness. For these questions, read the words in front of the slash for child deaths, in which case “you” refers to the child’s main caregiver, who should be the respondent. And for adult deaths, read the words after the slash, in which case “you or <NAME>” refers to the deceased’s caregiver (the respondent) or the deceased him/herself. However, the questionnaire itself and the ODK program have been split into three modules, one for each age group, and only the relevant age-specific words have been retained in each module so you won’t need to select the correct words when conducting an interview.
* The letter “s” in parentheses is to allow a word to be in the singular or plural form, for example, “symptom(s).” Read “…symptom…” or read “…symptoms…”, depending on how many symptoms the person had.
* The words “any of” in parentheses sometimes accompany a word that can be singular or plural, for example, “(any of) the pregnancy symptom(s).” Read “…pregnancy symptom…” if there was one symptom; or read “…any of the pregnancy symptoms…” if there was more than one symptom.
* The way the words “(this / the first) symptom” should be read also depends on how many symptoms the person had. Read “…this symptom…” if there was one symptom; or read “…the first symptom…” if there was more than one symptom. (In this case, the question is asking about the first symptom that the person had.)
* The word “s/he” and “her/his” mean to read “she” or “her” if the question is about a female, and to read “he” or “his” if the question is about a male.
* “<NAME>” in capital letters between brackets means to read the deceased person’s actual name, if it is known. Children who died at a very young age might not yet have been named. In such cases, substitute the words “the baby,” “the child” or “the deceased child” for the child’s name.
* “<RELATIVES>” in capital letters between brackets means to read the type of relatives just identified by a prior question. For example, read “…the in-laws” or “…the brother…”.
* “<SYMPTOMS>” in capital letters between brackets means to insert all the previously-identified symptoms that are relevant to that question. Depending on the question, this might be the mother’s pregnancy symptoms, her labor and delivery symptoms, or the symptoms of the deceased child’s or adult’s fatal illness.
* “<HEALTH PROVIDER>” in capital letters between brackets means to read the type of health provider or health facility that the mother or child went to. The provider or facility will have been identified by the response to a prior question. For example, read “…the private doctor…” or “…the NGO hospital…”.
* Some questions include alternate forms of the entire question, according to the response to a prior question. For example, if the mother sought care for her child, the next question might be worded: “Did you have to overcome any problems to take <NAME> for health care during the illness?”; whereas if she did not seek care, the next question might be: “Did you experience any problems that kept you from taking <NAME> for health care during the illness?” Read the accompanying instructions carefully to decide which way to read the question.

*3. Question numbers:* The VASA question numbers for stillbirths and neonatal deaths all start with “N2”; those for child deaths 28 days-11 years all start with “C3”; and those for adult deaths of 12 or more years all start with “A4”. Within each age-specific module, the numbers run sequentially from the smallest to the largest number; for example, the child questions start with C3001 and advance to C3002, C3003, etc. (Due to revisions of earlier versions of the questionnaire, some question numbers may appear to be out of order.) All three age-specific modules are preceded by a General Information module, with question numbers starting with “Q1001” and advancing to Q1002, Q1003, etc. In the age-specific modules, all the N2, C3 and A4 questions are together, by themselves, without any of the other age groups’ questions. However, in this manual, some questions that are relevant to two or three of the age groups appear together. This avoids having to repeat these questions and making the manual longer than it already is. In such cases, all the relevant question numbers appear with each such question. For example, the first question in the Stillbirth/Neonatal and Child modules Section 2: Background is “Was the child part of a multiple birth?”, with question numbers N2001 and C3001. Most of the VASA’s VA questions also appear in the 2016 WHO VA questionnaire. For easy reference, this manual and the VASA questionnaire also include the WHO question numbers (in bold red font). Light blue shading of the below question boxes (and some questions within multi-question boxes) indicates VA questions that are not in the WHO VA; and light green shading indicates SA questions.

*4. Single response questions:* Most questions allow one response, either a single number or a date. Write these neatly inside the provided box or in the space above the provided lines. Most codes are 1-digit in length, but some are longer. Do not leave any box or space empty. For example, N2068 asks how many hours the labor and delivery took. Two lines are provided for the response, but if the answer is less than 10 hours, then fill the first space with a “0.” For example, the answer “2 hours” would be coded “02.” In the same way, fill the first space of any dates less than 10 with a “0”—for example, May 4, 2010 would be coded “04/05/2010.”

*5a. Duration questions with* ***different*** *time units:* Some time questions ask for a person’s age, how long something lasted, or the timing of an action, and allow responses with different time units. For example, N2005u asks how long after the delivery the mother died and allows responses in days, weeks **OR** months. Follow the instructions to enter the time unit that matches the response in the first question (N2005u, with the “u” standing for “unit”) of the series and the number for that unit in the appropriate question that follows (N2005d for days, N2005w for weeks or N2005m for months). For example, if the answer is 3 days, then mark “1” (for days) in N2005u and “03” in N2005d. You would leave N2005w and N2005m blank since they would be used only if the response was, for example, 3 weeks or 3 months.

*5b. Duration questions with* ***multiple*** *time units:* Other time questions ask how long something lasted and allow responses with multiple time units. For example, N2221 asks how long it took to reach the first health provider and allows responses in hours **AND** minutes. Follow the instructions to use both time units. For example, if the answer is 1 hour and 20 minutes, then record “01” Hours and “20” Minutes. If the answer is just 20 minutes, then record “00” Hours and “20” Minutes. And if the answer is just 1 hour, then record “01” Hours and “00” Minutes.

*6. Missing data (“Don’t know”) and Refused to answer:* The code “9,” “99,” etc. is always used to indicate the answer “Don’t know” And “8,” “88,” etc. is used to indicate that the respondent refused to answer a question. Dates can be coded as fully or partly known. For example, a birth date “99/10/2009” would mean that the respondent knew the child was born in October 2009, but did not know the day.

* For duration questions allowing **different** time units (described just above): Enter “9,” “99,” etc. in the space for the correct unit. For example, for C3019, if the respondent knows that the child was less than 1 month old when the illness started but does not know how many days old the child was, then you would enter “1” for the units question (C3019\_units) and “99” in the Days space (C3019\_a).
* For duration questions allowing **multiple** time units (described just above): Enter “9,” “99,” etc. in the space or spaces for the unknown unit or units. For example, for N2221, if the respondent knows that it took 1 hour to travel to the last health provider but does not know how many minutes more than 1 hour it took, then enter “01” Hours **AND** “99” Minutes. (However, it would not make sense to enter, for example, “99” Hours AND “20” Minutes.)

*7. Multiple response questions:* Some questions allow multiple responses. These often include an additional “probe” or “prompt” question to let the respondent know that additional responses are allowed. Continue probing or prompting until the respondent says there are no more answers. Do not read the response choices to the respondent unless there is an instruction with the question telling you to do this. A small box is provided alongside each possible response. Mark (“X”) the corresponding box for each response given. Some multiple-choice questions include the response choice “Nothing” or “Nothing else.” If none of the other possible responses apply, then mark the “Nothing” or “Nothing else” box. In that case, no other response box should be marked. All the multiple-choice questions include the response choice “Don’t know.” Mark the “Don’t know” box only if the respondent does not know any of the possible responses (including “Nothing” or “Nothing else”). In that case, no other response box should be marked, including the “Nothing” or “Nothing else” box. Mark each response given by the respondent with an “X” written neatly inside its box.

*8. Open-ended responses:* Some questions require an open-ended response, usually to *specify* additional information when the answer to the main question was “Other.” Write the specified information on the provided line(s).

*9. Correcting errors:* Avoid making stray marks. These make it difficult for the computer data entry operator to know what to digitize. Do not erase errors. Instead, strike through errors neatly with one line. Write your initials and the correct response next to the line. This keeps a record of changes made to responses and avoids later confusion.

*10. Skips:* The interview for an individual deceased person will never include every question in the questionnaire. Instructions are provided for navigating the questionnaire depending on: 1) the person’s age at death and 2) the answers to certain prior questions. Most skip instructions appear alongside the question response box and look like this: ***2 → C3019\_b***. This instruction is part of C3019\_units. It means that if the response to C3019\_units is “2” (meaning, months), then skip directly to C3019\_b, which is for the number of months. Some skip instructions appear between two questions and look like this: ***Inst\_1: If Q1601=1 (sex of deceased=male) → A4206***.This instruction is between A4156 and A4157. “Inst\_1” means “Instruction 1.” It is telling you that if the response to Q1601 (in the General Information module) = “1” (sex of the deceased = male) then skip all the following questions (because they are only for deaths of adult females) and go directly to A4206, which is for males and females. For this instruction, and some others, you must revisit a prior response to determine how to navigate to the next question.

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| **THE VASA QUESTIONNAIRE** | | | | | |
| **Study ID number:** At the top of each page is a 4+3+2 digit box that looks like this:  *Study ID #*  *Village/Cluster HH Child*  **Why we need this:** The ID number is essential to digitize and keep all of the child’s information together in one place.  **How to do it:** Before going to the field to conduct the interview, write the deceased person’s ID number in this space on each page of the questionnaire. Write the 4-digit village or cluster code, the 3-digit household code and the 2-digit child code. Your supervisor will give you the codes. If the codes require less space than provided, then fill each left hand-most box with a “0.” | | | | | |
| **SECTION 1: GENERAL INFORMATION (STILLBIRTHS, NEONATAL, CHILD AND ADULT DEATHS)**  The general information module includes six sections. It comes before the main questionnaire and is for all deaths.  **1.1: Information about the prevalence of HIV and malaria**   |  | | --- | | * *Interviewer: Before going to the field to do the interview, fill in this section according to information provided by your supervisor or that you find on the project server.* Your supervisor may have already completed this information for you. | | | | | | |
| **Q1101**  **Q1102**  ***(10002***  ***10003)*** | **Is this an area of high HIV/AIDS prevalence?**  **Is this a region of high malaria prevalence?**  **Why do this:** This information is needed for one of the verbal autopsy analysis methods called InterVA-4.  **How to do it:** The answers to these questions should be determined by the study team prior to the VASA interview. The prevalence of HIV/AIDS and malaria is not based on a specified level of HIV and malaria parasites in the study population. For HIV/AIDS, typically all countries in East and Southern Africa are classified as high prevalence and rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low prevalence. And for malaria, typically all countries in East, Central and West Africa are classified as high prevalence and rest of the regions in AFRO, SEARO, WIPRO and PAHO as low or very low prevalence. | | | | |
| **Q1103**  ***(10004)*** | **During which season did the child/she/he die?**  **Why do this:** This information is needed for one of the verbal autopsy analysis methods called InterVA-4.  **How to do it:** You will be given a list of months classified as wet or dry. Select wet or dry according to the list provided. | | | | |
| **1.2: Information about the deceased**   |  | | --- | | * *Interviewer: Before going to the field to do the interview, fill in this section from a prior record for the deceased, such as information collected by a community surveillance assistant*. Your supervisor may have already completed this information for you. |   **Why we need this:** Section 1 of the General Information module is to record essential information needed to locate the household. The VASA interview cannot be conducted without this information. | | | | | |
| **Q1201** | **Address of the household** *[Copy the household address]*  **Why we need this:** This should be the address of the household where the child death was identified. This is where you should go to conduct the VASA interview. Once arriving, you might find that the best respondent for the interview lives elsewhere. If so, you might need to go there to interview the person.  **How to do it:** The form provides space to record the state, local government authority, locality and enumeration area. There is also space to record the 3- or 4-digit code of each component. You must record the codes, since these will be digitized for data analysis. | | | | |
| **Directions to the household** *[Copy the directions to the household]*  **Why do this:** This information is to help you locate the household.  **How to do it:** This if additional information to help you locate the household where the death occurred. If available from a prior record on the project server, record clear directions to the household. Your supervisor may also be able to provide helpful locating information. | | | | |
| **Q1202** | **Name of the deceased (if known)** *[Copy the name of the deceased]*  **Why do this:** Knowing the deceased person’s name might help you locate the household where the death occurred. In households where more than one person died in recent years it can also help ensure that you conduct the interview about the correct person.  **How to do it:** Record the name of the deceased person, if known from the prior record on the project server or from your supervisor. Record “No name given” if the child died before being named. | | | | |
| **Q1203** | **Sex of deceased** *[Copy the sex of the deceased]*  **Why and how to do this:** Like the name, knowing the person’s sex might help you locate the household and conduct the interview about the correct person.  **How to do it:** Record the sex of the deceased as “1” if Male, “2” if Female or “9” if Don’t know. Get this information from the prior record on the project server or from your supervisor. | | | | |
| **Q1204** | **Date of birth of the deceased** *[Copy the day, month and year of birth of the deceased]*  **Why do this:** Knowing the person’s birth date might help conduct the interview about the correct person.  **How to do it:** Record the date of birth of the deceased person from the prior record on the project server or from information provided by your supervisor. See general instructions 4 and 6. | | | | |
| **Q1205** | **Date of death of the deceased** *[Copy the day, month and year of death of the deceased]*  **Why do this:** Knowing the deceased person’s date of death might help you conduct the interview about the correct person.  **How to do it:** Record the date of death of the person from the prior record on the project server or from information provided by your supervisor. See general instructions 4 and 6. | | | | |
| **Q1206** | **Last known age of the deceased** *[Copy the last known age of the deceased: Record days if less than 1 month —if less than 24 hours, record “00” days; Record months if 1-23 months; Record years if 2 years or older.]*  **Why we need this:** Many skips in the VASA depend on whether the death was of a neonate (less than 28 days old), a child or an adult. Some VASA modules are asked only for neonatal deaths and others only for child or adult deaths. At the household, before starting the VASA you will confirm that this was the correct age at death.  **How to do it:** Record the last known age in days, months OR years from the CSA record on the project server or from information provided by your supervisor. See general instructions 4, 5a and 6. ***Skip:***If the age at death was 1 day or more and up to 12 years, skip to Q1208 to record the mother’s name. If the age was 12 or more years, skip to Q1209. | | | | |
| **Q1207** | **Was this a stillbirth or neonatal death?** *[Copy this information from the record]*  **Why we need this:** “Stillbirth” means that the baby died late in the pregnancy or during the delivery, and so was born dead. The VASA status at birth must be known to determine the accurate cause of death.  **How to do it:** Complete this item only for deaths at less than 1 day (“00” days) of age. Get this information from the prior record on the project server or from your supervisor. Record one answer: “1” if Stillbirth or “2” if Neonatal death. | | | | |
| **Q1208**  ***(10062)*** | **Name of mother** *[Copy the name of the mother (only for stillbirths, neonatal and child deaths)]*  **Why do this:** The mother’s name can help you locate the household and the mother.  **How to do it:** Record the name of the deceased child’s mother from the CSA record on the project server or from information provided by your supervisor. | | | | |
| **Q1209**  ***(10061)*** | **Name of father or household head** *[Copy the name of the father or household head (only for stillbirths, neonatal and child deaths)]*  **Why do this:** Use the name to help locate the household and the father or household head when you go to conduct the VASA interview.  **How to do it:** For stillbirths, neonatal and child deaths, record the name of the deceased child’s father. For adult deaths, record the name of the household head. Get this information from the prior record on the project server or from your supervisor. | | | | |
| **1.3: Information about the interview**  ***Interviewer:*** *Before and after the interview, fill in this section. These questions should not be asked of the respondent.*  **Why do this:** This section is to keep a record of the interview’s administration. The instruction says to fill in the section “before and after the interview” because some items can be filled only after the interview has been completed. | | | | | |
| **Q1301** | **Language of the interview**  **Why we need this:** The VASA data will be digitized in English, so we need to have a record of the language in which the interview was conducted.  **How to do it:** Record the name of the language. If your locality has more than one language, your project might modify this item to include a checklist of the languages. If so, then record the language of the interview. | | | | |
| **Q1302**  ***(10010)*** | **Interviewer name and ID number**  **Why we need this:** The project needs to keep track of who conducted which interviews in order to help improve the interviewers’ performance.  **How to do it:** Write your name in the provided space. Record your ID number in the boxes. See general instruction 4. | | | | |
| **Q1303** | **Dates of attempted and successful interviews** | **DATE** | | **INTERIM RESULT OF THE INTERVIEW** | |
| **Q1304**  **Q1311.1** | **Date of first interview attempt and interim result code**  **Why we need this:** Many projects allow up to three attempts before abandoning the interview.  **How to do it:** Record the date of the first attempt and the interim result code. “Interim” means the temporary code used before the interview is completed. The possible codes appear after Q1310. Codes 3-12 can be used as interim results:   * Code 3 or 4: make an appointment to return when the respondent is available for the interview. * Code 5: the respondent did not give their consent and the interview must be abandoned. * Code 6: usually means the interview will not be possible. However, sometimes the child’s caregiver lives elsewhere and can be reached. For example, if the mother was away from home during the child's illness, her sister may have cared for the child. In such cases record the caregiver’s address and discuss with your supervisor whether to pursue this interview. * Code 7: try to ask a neighbor when someone might be at home and return at that time. * Code 8: a neighbor might be able to say to where the family moved. Again, discuss with your supervisor whether to pursue this interview. * Code 9: use this once you have identified the respondent and are ready to start the interview. * Code 10: Child reported dead in birth history is actually alive * Code 11: Duplicate report of death – interview already conducted * Code 12: Death not eligible – out of the study area or for another reason | | | | |
| **Q1305**  **Q1311.2** | **Date of second interview attempt and interim result code**  **Why and how to do this:** The reason and methods are the same as for the first interview attempt. | | | | |
| **Q1306**  **Q1311.3** | **Date of third interview attempt and interim result code**  **Why and how to do this:** The reason and methods are the same as for the first attempt, with the following exception. Code 3 cannot be used as the interim result—because this is the last attempt the interview can no longer be postponed. However, you can begin an interview on the third visit and then return to complete it if the respondent requests this. The interim result code in this situation would be “9. In progress.” | | | | |
| **Q1307**  ***(10012)*** | **Date interview started** *[Equals date of the last attempt]*  **Why do this:** This keeps a record of when the interview was conducted.  **How to do it:** Record the date when you began the interview. This must be the last interview attempt date. | | | | |
| **Q1308**  ***(10011)*** | **Time interview started** *[Record hour 1-24 / minutes 1-60]*  **Why do this:** This will help the project keep track of how long the interviews take.  **How to do it:** Record the time. | | | | |
| **Q1309**  **Q1311.4** | **Date interview finished** *[Equals date started or a later date]* **and final result code**  **Why do this:** This keeps a record of when the interview was conducted.  **How to do it:** Record the date when you finished the interview. This must equal or be after the start date. Codes 1-8 can be used as final results. Use code 2 if you started but did not complete the interview. If you never started the interview, then the final result code equals the last interim result code. | | | | |
| **Q1310**  *(10481)* | **Time interview finished** *[Record hour 1-24 / minutes 1-60]*  **Why do this:** This will help the project keep track of how long the interviews take.  **How to do it:** Record the time. | | | | |
| **Q1311** | **Interview result codes:**  1. Completed (Final result code)  2. Partially completed (Final result code)  3. Eligible respondent postponed interview  4. No eligible respondent at home at time of visit  5. Eligible respondent refused interview | | 6. No eligible respondent  7. No household member at home  8. Dwelling vacant / destroyed / not found  9. In progress (Interim result code)  10. Person reported dead is actually alive  11. Duplicate report of death – interview already conducted  12. Death not eligible for VASA interview | | |
| **Q1312** | **Date form checked by supervisor**  **How to do this:** Your supervisor will record this date when s/he checks the completed interview form. | | | | |
| **Q1313** | **Date entered in computer**  **How to do this:** The computer data entry clerk will record this date when s/he digitizes the interview data. | | | | |
| **IDENTIFY THE BEST RESPONDENT**  *Instructions to interviewer: Read the VASA study recruitment scripts in order to introduce yourself to the household, explain the purpose of your visit, and identify the best respondent. The recruitment scripts will guide you to ask to speak to the adult who was the deceased’s main caregiver during the illness that led to death. For stillbirths and child deaths, this will usually be the mother of the deceased. For adults, the best respondent is often the deceased’s spouse or other close relative. If the best respondent is not available, then arrange a time to revisit the household when the caregiver will be at home and free to participate in the interview* | | | | | |
| **Consent**  ***INTERVIEWER: Read the consent form to the respondent. Ask the respondent if he or she has any questions. Once any questions are answered, ask the respondent if he or she is willing to take part in the study.***  **Why do this:** The respondent must be fully informed about the study and consent to the interview before beginning.  **How to do it:** The consent process will be fully discussed during your training as a VASA interviewer. You should have read the consent form to the respondent before reaching this point. If you have not already done this, then read the consent form to the respondent. Ask the respondent if he or she has any questions. Once any questions are answered, ask the respondent if he or she is willing to take part in the study. If the answer is “No” then thank the respondent for their time and end the interview. | | | | | |
| **Q1405**  ***(10013)*** | ***INTERVIEWER:*** *Did respondent give consent?*  **How to do this:** Do not ask this question. It is addressed to you. If the respondent refuses to participate, then thank the person for their time and end the interview. Record one answer: “1” if Yes or “2” if No. | | | | |
| **1.4: Information about the respondent**  *Complete items 1401-4 from your introductory discussion with the selected respondent.* | | | | | |
| **Q1401**  ***(10007)*** | *INTERVIEWER: What is the respondent’s name.*  **Why do this:** When appropriate, you should address the respondent by her/his name during the interview.  **How to do it:** Record the respondent’s name from your introductions. | | | | |
| **Q1402** | *INTERVIEWER: Record the sex of the respondent.*  **How to do this:** Record the respondent’s sex: “1” if Male or “2” if Female, according to your observation. | | | | |
| **Q1403**  ***(10008)*** | *INTERVIEWER: Record the respondent’s relationship to the deceased.*  **Why do this:** The respondent should be the person who was the deceased’s main caregiver during the fatal illness. The computer program will use this information to determine how to word certain questions.  **How to do it:** Record one person. Use code “13” or “14” if the respondent is a male or female not included among codes 1-12 and specify the person’s relationship to the deceased. Use code 12 if the respondent is a birth attendant, and specify the type of attendant, for example “skilled” or “traditional.” See general instruction 8. | | | | |
| **Q1404**  ***(10009)*** | *INTERVIEWER: Did the respondent live with the deceased in the period leading to her/his death?*  *(If the deceased is a stillbirth, then the mother or anyone living with her would be considered to have been living with the deceased.)*  **Why we want to know this:** A person who lived with the deceased is more likely to have observed the illness and be able to correctly answer the questions asked by the interview.  **How to do it:** Record this information from your introductory discussion with the respondent. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. If the answer is No or Don’t know, then you should consider recruiting a different respondent who lived with the deceased in the period leading to his/her death. | | | | |
| **Q1406** | **How old are you?**  **Why ask this:** The respondent must be at least 15 years old, and persons under 18 years of age require their parent’s or legal guardian’s permission to be a respondent. Caring for sick persons is a responsibility that should be taken by an adult. Also, if the deceased person is a child and the respondent is the mother, then her age may be relevant to the child’s death. Childbearing at too young an age can endanger the mother and the unborn child since young mothers are at risk for certain pregnancy and delivery problems.  **How to do it:** Record the number of complete years. For example, if the age is 18 years and 5 months, record 18 years. If the respondent does not know her/his exact age, then ask her/him to estimate it. Record “99” only if the respondent cannot even estimate the age. See general instructions 4 and 6. | | | | |
| **Q1407** | **Have you ever attended school?**  **Why ask this:** Respondents with more years of schooling may be able to answer the VASA questions more accurately, so knowing if they have attended school may give us more confidence in their responses. Also, if the deceased person is a child and the respondent is the mother, then her schooling may be relevant to the child’s health. Women with no or fewer years of schooling generally have poorer health and their babies are less healthy than those of more educated women.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:***If 2 or 9, skip to Instruction 1. | | | | |
| **Q1408**  ***(10063)*** | **What is the highest level of school you attended?**  **Why ask this:** As above, respondents with more schooling may be able to provide more accurate answers to the study questions. This is also relevant if the deceased person is a child and the respondent is the mother because more educated mothers are more likely to have healthier children. This may be because they know better about how to care for themselves during pregnancy, what foods are most nutritious for themselves and their children, what illness signs indicate the need to see a health provider, and other healthful measures. They may also be more independent than less educated women, so more likely to decide on their own when to take needed actions, such as seeking health care for their children. Knowing the schooling level of the mothers in the study will allow us to determine if this may have been an important factor in their children’s deaths.  **How to do it:** Record the respondent’s highest level of schooling from the listed response choices, or record “99” for Don’t’ know or “88” for Refused to answer. | | | | |
| ***Inst\_1****: Read:* **I would now like to ask you some questions about (your / the family’s) household. Please remember that all information will be kept confidential.** *[Read ”…the family’s household.” if you are not conducting the interview at the household where the death was identified.]* | | | | | |
| **Q1414A** | **Who is the main breadwinner of the household?**  **Why ask this:** Knowing who the main breadwinner is provides a general sense of the family’s economic situation, which is an important determinant of access to health care and overall health status. Also, women who earn their own money have more control over how that money is spent, including for food and health care for themselves and their children. It would be expected that women who are their family’s main breadwinner would also have a greater say in how the family’s resources are used.  **How to do it:** Read the question and mark one response. Options 1 and 2 are only for stillbirths and neonatal and child deaths, and option 3 is only for adult deaths. Option 4 (Other: specify) can be used for deaths of any age group. | | | | |
| **Q1414** | **Does the household have:** *[Ask about each possession and mark each one “Yes”, “No” or “Don’t know.”]*  ***LOCAL ADAPTATION:*** *Modify the items listed in the questionnaire as needed to form a local wealth index. If a standard wealth index is already used in the study site, for example, based on the Demographic and Health Survey, then the same items should be used for the VASA study wealth index.*  **Why ask this:** This information is used to estimate households’ level of wealth or poverty, which may influence mortality outcomes. For example, poor households may not be able to afford medicine for sick family members without sacrificing other needs such as purchasing enough healthy food.  **How to do it:** Before asking this question, make sure you explain to the respondent the confidential nature of their answers. Some respondents may hesitate to reveal that the household owns items such as a TV or car so it is important to explain that this information will be kept confidential. Read “Does the household have \_\_\_\_\_\_\_\_\_\_\_\_\_\_?” for each item in the list. Mark (“X”) each item as: “1” if Yes, “2” if No, or “9” if Don’t know. | | | | |
| **Q141x** | **Does the family own any land?**  ***LOCAL ADAPTATION:*** *This question is optional. Include it only if needed for the local wealth index.*  **Why ask this:** This question is optional and should be included if the study setting intends to include this in forming a wealth index.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. | | | | |
| **Q1415** | **What is the main source of drinking water in the household?**  **Why ask this:** Unprotected drinking water is a major vehicle of infectious disease of the digestive tract such as diarrhea. The drinking water source is also part of the wealth index calculated to determine how well off or poor the family is.  **How to do it:** Note the respondent’s answer and discuss if necessary to record one of the twelve possible responses, or record “99” if Don’t know. See general instruction 8. | | | | |
| **Q1416** | **What type of toilet do members of the household usually use?**  **Why ask this:** Proper disposal of human waste is required to prevent contamination of drinking water and water used for other purposes such as washing. Modern and improved toilet types are generally more safe than traditional methods.  **How to do it:** Note the respondent’s answer and discuss if necessary to record one of the seven possible responses, “Other” (and specify the other toilet type) or “9” if Don’t know. See general instruction 8. | | | | |
| **Q1417** | **What is the main kind of energy the household uses for cooking?**  **Why ask this:** The type of cooking energy used is part of the wealth index that determines how well off or poor the family is. A cooking energy source that results in much smoke in the house might also influence mortality outcomes by contributing to respiratory diseases such as pneumonia.  **How to do it:** Record one of the eight possible answers, “Other” (and specify the other cooking energy type) or “9” if Don’t know. See general instruction 8. | | | | |
| **Q1418** | **What is the main source of energy the household uses for lighting?**  **Why ask this:** This is part of the information used to calculate the family’s wealth index, which indicates how well off or poor the family is. A modern energy source such as electricity may also enable schoolchildren and adults to pursue activities after dark such as reading. This, in turn, might influence mortality outcomes by providing healthful information to individuals and families.  **How to record it:** Note the respondent’s answer and record the one energy source that most closely matches their response, or record “9” Other (and specify), or “99” Don’t know. See general instruction 8. | | | | |
| **Q1419** | **What is the main material used for the floor of the house?** *[If you are able to observe the floor, then mark the correct answer and do not ask this question.]*  ***LOCAL ADAPTATION:*** *This question is optional. Include it only if needed for the local wealth index.*  **Why ask this:** This information is part of the wealth index used to estimate how well off or poor the family is.  **How to record it:** Record one answer: “1” if Earth beaten? Clay, “2” if Earth not beaten, “3” if Rudimentary wood, “4” if Adobe, “5” if Parquet or polished wood, “6” if Tiles, “7” if Cement, “8” if Other (and specify), or “9” if Don’t know. See general instruction 8. | | | | |
| **Q1420** | **What is the main material used for the roof of the house?** *[If you are able to observe the roof, then mark the correct answer and do not ask this question.]*  ***LOCAL ADAPTATION:*** *This question is optional. Include it only if needed for the local wealth index.*  **Why ask this:** This information is part of the wealth index used to estimate how well off or poor the family is.  **How to record it:** Record one answer: “1” if No roof, “2” if Grass, stem or palm, “3” if Sheets of zinc, “4” if Sheet of lusalites, “5” if Tiles, “6” if Concrete slab (cement), “7” if Other (and specify), or “9” Don’t know. See general instruction 8. | | | | |
| **Q1421** | **What is the main material used for the exterior walls of the house?** *[If you are able to observe the walls, then mark the correct answer and do not ask this question.]*  ***LOCAL ADAPTATION:*** *This question is optional. Include it only if needed for the local wealth index.*  **Why ask this:** This information is part of the wealth index used to estimate how well off or poor the family is.  **How to record it:** Record one answer: “1” if No wall, “2” if Cane, sticks, bamboo or palm, “3” if Tin, cardboard, paper or bags, “4” if Matched paws, “5” if Bark, “6” if Wood or zinc, “7” if Block of adobe, “8” if Bricks, “9” if Cement block, “10” if Other (and specify), or “99” Don’t know. See general instruction 8. | | | | |
| **1.5: Information about others at the interview** | | | | | |
| **Q1501** | ***INTERVIEWER:*** *Are there other people present during the interview?*  **Why ask this:** We need to know if other people were present who might have helped answer the questions.  **How to do it:** Do not ask this question. It is addressed to you. “Other people” means in addition to the respondent. Record “1” if Yes or “2” if No. ***Skip:*** If the answer is “No,” skip to Q1601. | | | | |
| **Q1502** | ***INTERVIEWER:*** *In addition to the respondent, how many people are present during the interview?*  **How to ask this:** Do not ask this question. It is addressed to you. Record the number of people in addition to the respondent. ***(Do not include the respondent in the count.)*** See general instructions 4 and 6. | | | | |
| **Q1503** | ***INTERVIEWER:*** *What is each other person’s relationship to the deceased person?*  **Why ask this:** This tells us who was at the interview and how familiar they may have been with the illness.  **How to do it:** Mark (“X”) each person who is at the interview. Note that the relationships here are the same as in Q1403. Specify the relationship to the person of any “Other” male or female present at the interview. If the person is a birth attendant, specify the type of attendant, such as “skilled” or “traditional.” | | | | |
| **1.6: Deceased child or adult’s sex and age at death**  *Interviewer: Now I’d like to ask you about the deceased person.* | | | | | |
| **Q1601**  *(****10019****)* | **What was the sex of the deceased?**  **Why ask this:** The sex of the deceased may influence their mortality outcome. Male children and adults generally die at younger ages than females. Also, in some settings, ill males may be taken for health care more often than ill females.  **How to do it:** Record one code: “1” if Male, “2” if Female, or “9” if Don’t know. It will be unusual, even in the case of stillbirth, that the sex is not known. | | | | |
| **Q1602**  *(****10020****)* | **Is the date of birth known?**  **Why ask this:** Ask this to determine whether you should ask when the deceased was born.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip*:** If the answer is “2” No, then skip to Q1604. | | | | |
| **Q1603**  *(****10021****)* | **When was the deceased born?** *Compare the date of birth just stated by the respondent to the birth date from the prior record (Q1204). Discuss any inconsistency with the respondent to confirm or correct the stated delivery date. You cannot change the prior record’s date.*  **Why ask this:** The birth date will help determine the person’s age at death. It is important to confirm or correct the delivery date that was identified by the prior survey or surveillance study.  **How to do it:** Record the birth date as day/month/year. For example, if the person was born on May 22, 2006, record “22/05/2006.” Also see general instructions 4 and 6. | | | | |
| **Q1604**  *(****10058****)* | **Where did the deceased die?**  **Why ask this:** The location of death helps us understand about the careseeking for the illness.  **How to do it:** This is the place where it was first noted that the person was dead. Differentiate between death at a “hospital” (i.e., health facility providing a higher level of care and where patients can be admitted to stay overnight) versus the other listed types of health providers and facilities. Also differentiate between public sector and private sector facilities. Record one code: “1” if Home, “2,” “3,” “4,” “5” or “6” if one of the public sector facilities, “7,” “8,” “9” or “10” if one of the private sector facilities, “11” if On route to a health provider or facility, “12” if Other (specify), “99” if Don’t know or “88” if Refused to answer. If the person died in a health facility, also ask for and record the name of the facility. Also, see general instruction 8. | | | | |
| **Q1605**  *(****10023****)* | **Is the date of death known?**  **Why ask this:** Ask this to determine whether you should ask when the deceased died.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip*:** If the answer is “2” No, then skip to Q1607. | | | | |
| **Q1606**  *(****10023****)* | **What was the date of death?** *Compare the date of death just stated by the respondent to the date of death from the prior record (Q1205). Discuss any inconsistency with the respondent to confirm or correct the stated date. You cannot change the prior record’s date.*  **Why ask this:** The date of death will help determine the person’s age at death. The date is also needed to calculate statistics on the deaths that occurred in a particular year. It is important to confirm or correct the date of death that was identified by the prior survey or surveillance study.  **How to do it:** Record the date of death as day/month/year. For example, if the person died on May 22, 2006, record “22/05/2006.” Also see general instructions 4 and 6. | | | | |
| ***Record only the calculated age OR the stated age. First try to calculate the age. If this is not possible, then ask the respondent for the deceased’s age at death.*** | | | | | |
| **Q1607**  ***(AAAA)*** | ***CALCULATE THE AGE AT DEATH***  *Calculate the age at death from the date of death and the birth date (Q1606 – Q1603). If only the month and year are known, calculate the approximate age in months or years. Discuss the calculated age with the respondent: I have calculated that the deceased was <CALCULATED AGE> at death. Is this correct?*  *If the respondent does not agree with the calculated age, then again discuss the birth date and date of death to make sure that these are correct. If the calculated age at death cannot be resolved, then go below to the “STATED AGE” box.*  *Record the age in days if less than 28 days—if less than 24 hours, record “00” days;*  *Record months if 28 days-23 months; Record years if 2 years or older.*  *After recording the calculated age → Q1609*  **Why do this:** The age at death establishes whether this was a neonatal, child or adult death. This will help determine the cause of death, and also to decide which of the remaining interview questions to ask. If the age at death was 0 days, then we also need to consider that the death might have actually been a stillbirth.  **How to do it:** Follow the directions to calculate the age at death. If this is not possible (because the birth or death date are not known), then ask the respondent for the person’s age at death. Also see general instructions 4, 5a and 6. ***Skip:*** If the age can be calculated, then skip to Q1609. | | | | |
| **Q1608**  ***(AAAA)*** | ***STATED AGE AT DEATH*** *[Ask only if the calculated age cannot be determined]*  **How old was the deceased at the time of death?**  *Compare the age at death just stated by the respondent to the deceased’s last known age from the prior record (Q1206). Discuss any inconsistency with the respondent to confirm or correct the stated age. You cannot change the prior record’s age. Partly known birth and death dates might help resolve the stated age. For example, if the deceased was a child that was born and died in the same month, then this is likely a neonatal death.*  *Record the age in days if less than 28 days—if less than 24 hours, record “00” days;*  *Record months if 28 days-23 months; Record years if 2 years or older.* | | | | |
| **Q1609**  ***(Age\_***  ***group)*** | *Mark the deceased’s age group at the time of death.**[Use the calculated age (Q1606 – Q1603) if known, or the stated age (Q1608). If both the calculated and stated ages are unknown, then use your best judgment to mark the person’s age at death.*  **Why do this:** The age at death establishes whether this was a neonatal, child or adult death. This will help determine the cause of death, and also to decide which of the remaining interview questions to ask. If the age at death was 0 days, then we also need to consider that the death might have actually been a stillbirth.  **How to do it:** Mark the person’s age group at the time of death. Record one code: “1” if Less than 28 days old, “2” if 1-11 months old, “3” if 12 months-4 years old, “4” if 5-11 years old, or “5” if 12 years old or more. ***Skip:*** If this was a child death 1-11 months old, then skip to the Child death form (C3001). If it was a child death 12 months-11 years old, then skip to the Child death form (C3012); and if it was an Adult death 12 years old or more, skip to the Adult form (A4001). | | | | |
| **Q1610**  ***(AAAA)*** | *If less than 28 days old at death, record the age in days, hours or minutes:*   * *If 1 day or older, record the Q1607 calculated age if available, or record the Q1608 stated age.* * *If less than 1 day, ask and record the reported age in hours.* * *If less than 1 hour, ask and record the reported age in minutes.* | | | | |
| ***Inst\_2 → SB/NN form (N2001)***  *After recording the age at death in days, hours or minutes, go to the stillbirth/neonatal death form (N2001).* | | | | |
| **SECTION 2: BACKGROUND** | | | | | |
| **2.1 GENERAL DELIVERY CONTEXT (for 0-27 days olds and 28 day-11 month olds)** | | | | | |
| **N2001**  **C3001**  ***(10354)*** | **Was the child part of a multiple birth?** *[If two or more children are born at the same time, it is counted as a multiple birth, even if one or more of the babies are born dead.]*  **Why ask this:** This is important to know because babies from multiple births carry additional risks from some causes. If two or more children are born at the same time, it is counted as multiple births even if one or more of the babies are born dead.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2”, “8” or “9,” skip to **N2003 / C3003** | | | | |
| **N2002**  **C3002**  ***(10355)*** | **Was the child the first, second or later in the birth order?**  **Why ask this:** The risks for various causes of death varies according to the order of the birth in the multiple delivery. Ask carefully the birth order of the deceased child if the child was part of a multiple pregnancy. Check the appropriate box; whether the first; or second or later in order of birth.  **How to do it:** Record one code: “1” if First, “2” if Second or later, “9” if Don’t Know or “8” Refused to answer. | | | | |
| **N2003**  **C3003**  ***(10356)*** | **Is the mother still alive?** *[If the mother is present at the interview, mark “Yes” without asking the question aloud.]*  **Why ask this:** The death of the mother may influence neonatal and child mortality outcomes.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “1,” skip to **N2006 / C3006.** | | | | |
| **N2004**  **C3004**  ***(10357)*** | **Did the mother die before, during or after the delivery?**  **Why ask this:** The timing of the death of the mother may influence neonatal and child mortality outcomes.  **How to do it:** Record one code: “1” if Before delivery, “2” if During delivery, “3” if After delivery, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “1,” “2,” “8” or “9,” skip to N2006 / C3006 *(10360)* | | | | |
| **N2005u**  **N2005d**  **N2005w**  **N2005m**  **C3005u**  **C3005d**  **C3005w**  **C3005m**  ***(10358\_units)*** | **How long after the delivery did the mother die?**  **How many days after the delivery did the mother die?**  **How many weeks after the delivery did the mother die?**  **How many months after the delivery did the mother die?**  **Why ask this:** Mothers are the most important source of care for young children, and children whose mothers die soon after delivery are at an increased risk for dying while they are young. Also, many causes of stillbirths and early neonatal deaths are due to pregnancy and delivery complications of the mother. If the mother died soon after the delivery, this would suggest that the stillbirth or neonatal death might have been due to a maternal complication, so can help determine the cause of the baby’s death.  **How to do it:** Select one unit only: Record days if less than 7 days; Record weeks if 1-27 days; Record months if 28 days or more; or record “9” if Don’t know or “8” if Refused to answer.See general instructions 4, 5a and 6. ***Skip:*** If the answer is “8” or “9,” skip to N2006 / C3006*;* if the answer is “2,” skip to N2005w / C3005w; and if the answer is “3,” skip to N2005m / C3005m. | | | | |
| **N2006**  **C3006**  ***(10360)*** | **Where was the deceased born?** *[Read the question and slowly read the choices. Respondent should hear all choices and then respond*. “Home” includes the mother’s, birth attendant’s or any other home.*] [If the child was born in a health facility, ask: What was the name of the (hospital / health facility)?]*  **Why ask this:** The place of birth of the infant may influence neonatal and child mortality outcomes. Hospitals can provide a higher level of care that might increase the chance for survival of a sick child. Differentiate between “hospital” births (i.e., health institutions with in-patient facilities) from “other health facility” (dispensaries, health centers or private clinics where patients are seen on an out-patient basis).  **How to do it:** Record one answer from the available responses. Also see general instruction 8. | | | | |
| **N2008**  **C3008**  ***(10361)*** | **Who (at the facility) assisted the delivery of the baby?** *[Read “...at the facility...” if she delivered at a health facility.] [If more than one person assisted, mark the person highest in the list.]*  **Why ask this:** Delivery (birth attendance) by a trained health provider is safer for the mother and child. Ideally, the delivery should take place at a health facility where a higher level of care is available in case the mother or baby suffers a complication.  **How to do it:** Record one code according to the response. ***Skip***: If “1,” skip to N2010 / C3010. Also see general instruction 8. | | | | |
| **N2009\_1**  **C3009\_1**  ***(10362)*** | **At birth, was the baby of usual size?** *[Show photos, explain to the respondent that even if the answer is "no" some more questions will be asked, just to make sure no important detail has been missed.*  **Why ask this:** An infant that is too small or large is at an increased risk of dying.  **How to do it:** Record one code: “1” if Yes, “2” if No, “9” if Don’t Know or “8” if Refused to answer. ***Skip***: If “1,” skip to N2010 / C3010. | | | | |
| **N2009\_2**  **C3009\_2**    ***(10363)*** | **At birth, was the baby smaller than usual, (weighing under 2.5 kg)** *[Show photos if available.]*  **Why ask this:** Low birth weight is an important factor associated with increased risk for neonatal death particularly from breathing problems, birth injury, and hypothermia. Smaller than usual size may be difficult to explain but the mothers may be able to report whether the baby was small.  **How to do it:** Record one code: “1” if Yes, “2” if No, “9” if Don’t Know or “8” if Refused to answer. ***Skip***: If “2, 8 or 9” skip to N2009\_4 / C3009\_4. | | | | |
| **N2009\_3**  **C3009\_3**  ***(10364)*** | **At birth, was the baby very much smaller than usual, (weighing under 1 kg)?** *[Show photos if available].*  **Why ask this:** This question is to identify extremely small babies, which are often stillborn. Such babies are also born premature; i.e., before the completion of at least 8 months.  **How to do it:** Record one code: “1” if Yes, “2” if No, “9” if Don’t Know or “8” if Refused to answer. ***Skip***: If “1, 2, 8 or 9” skip to N2010 / C3010. | | | | |
| **N2009\_4**  **C3009\_4**  ***(10365)*** | **At birth, was the baby larger than usual, (weighing over 4.5 kg)?** *[Show photos if available.]*  **Why ask this:** Babies born larger than usual may have problems caused by a difficult delivery. Sometimes large newborns also carry increased risks for congenital malformations.  **How to do it:** Record one code: “1” if Yes, “2” if No, “9” if Don’t Know or “8” if Refused to answer. The responses to N2009\_1, 2, 4 / C3009\_1, 2, 4 should not all be "NO". If this is the case, you should go back to one of the previous questions and correct the selection. | | | | |
| **N2010**  **C3010**  ***(10366)*** | **What was the weight of the deceased at birth?** *[Ask if the child health card is available. If the card is available and the birth weight is recorded, enter the birth weight from the card. If the card is not available, record the weight based on the respondent's report if known. Record the weight in grams in 4 digits. Respondents may give the answer in kilograms. For the data entry, convert to grams. 1 kilogram=1,000 grams. Enter "9999" for "don't know." Enter "8888" for "refuse."]*  **Why ask this:** Infants of low birth weight are at an increased risk of dying from lung problems, infections and other causes.  **How to do it:** Record the weight of the baby at birth in grams. See general instructions 4 and 6. **Skip:** If “8888” or “9999” skip to N2012/C3012. | | | | |
| **N2011**  **C3011** | *Record the source of the birth weight information.*  **Why ask this:** Information from the child’s health card is generally more reliable than from a respondent’s recall. Therefore, it is preferred to collect this information from the health card if available.  **How to do it:** Select either “1” Child’s health card or “2” Respondent’s recall. | | | | |

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| **2.2 STILLBIRTH / NEONATAL DEATH DETERMINATION (for 0-27 day olds)** | |
| **N2012**  ***(10114)*** | **Was the child born alive or dead?**  **Why ask this:** The status of the infant at birth must be known to determine the cause of death.  **How to do it:** Record one code: “1” if Alive, “2” if Dead, “9” if Don’t know or “8” Refused to answer. |
| **N2013**  ***(10105)*** | **Did the baby ever cry?**  **Why ask this:** This question helps to understand if the infant was stillborn.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2014**  ***(10109)*** | **Did the baby ever move?**  **Why ask this:** This question helps to understand if the infant was stillborn.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2015**  ***(10110)*** | **Did the baby ever breathe?**  **Why ask this:** This question helps to understand if the infant was stillborn.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2016** | *Refer to N2012-N2015. If “Dead” & no crying, movement or breathing, mark “Stillbirth.” If “Alive” & N2013-N2015= “No,” or if “Dead” and* *N2013-N2014 or N2015= “Yes,” then discuss & correct.*  **Why do this:** To determine whether this was a stillbirth or a live birth.  **How to do it:** This is for the interviewer only.   * If the answer to N2012 is “2” Dead, and the answers to ALL THREE of N2013-N2015 are “2” (“No”), then record “1” (“Stillbirth”) for N2016 and **continue to N2017**.   If the answer to N2012 is “1” Alive, and the answer to ANY ONE of N2013-N2015 is “1” (“Yes”), then record “2” (“Live birth”) for N2016 and **skip to N2023**.  If the answer to N2012 is “1” (“Alive”) and N2013-N2015 are all “2,” (“No”), then **discuss this with the respondent and correct the answer(s)**.  If the answer to N2012 is “2” (“Dead”) and ANY ONE of N2013-N2015 is “1” (“Yes”), then **discuss this with the respondent and correct the answer(s)**. |
| **2.3 GENERAL SIGNS AND SYMPTOMS FOR STILLBIRTHS** | |
| **N2017**  ***(10376)*** | **Was the baby moving in the last few days before the birth?**  **Why ask this:** This information can help to understand how healthy the baby was before the birth. Absence of movements would suggest the potential for the baby being stillborn.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2018**  ***(10377)*** | **Did the baby stop moving in the womb before labor started?**  **Why ask this:** This information can help to understand how healthy the baby was before the birth. Reduced movements leading to complete absence of movement, particularly in the days to hours before the delivery, may be a sign that death occurred prior to delivery. Mothers are usually aware of such changes and can recall and report this sign.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip***: If “2,” “8” or “9” skip to N2020. |
| **N2019u**  **N2019h**  **N2019d**  ***(10379\_unit, 10380***  ***10379)*** | **How long before labor did (you / the mother) last feel the baby move?**  **Enter how long before labor the mother last felt the baby move, in hours:** if less than 24 hours.  **Enter how long before labor the mother last felt the baby move, in days:** if 1 day or more.  **Why ask this:** The mother can often feel a healthy baby moving close to the time of the birth. If the respondent is not the mother, you need to probe whether the mother has told him/her when the baby has stopped moving.  **How to do it:** See general instructions 4, 5a and 6. Select one unit only. Be as precise as possible. If the mother last felt the baby move less than 1 day before labor began, record the number of hours (e.g. 02 would indicate 2 hours). If the mother last felt the baby move 1 day or more before labor began, record the number of days (e.g., 02 would then indicate 2 days). ***Skip***: If N2019u = “2” (days), go to N2019d to record the number of days. If N2019u= “8” or “9,” skip to N2020. After completing N2019h, skip to N2020. |
| **N2020**  ***(10115)*** | **Were there any bruises or signs of injury on the baby’s body at birth?**  **Why ask this:** The baby may be injured during a difficult birth, may present signs of injury such as a large bruise, swelling on the head, or broken bone which may lead to death of the child.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2021**  ***(10116)*** | **Was the baby’s body soft, pulpy and discolored, with the skin peeling away?**  **Why ask this:** Pulpy means that the skin was very soft and might come off when touched. Some might compare it to an overripe papaya or mango. Sometimes the term ‘macerated’ is used to describe the skin of stillborn babies. When macerated is used to describe skin, it means that the skin, sometimes discolored, has peeled or is peeling. This indicates that the baby has been dead inside the mother for at least 12 hours or longer-- days or weeks. If the term macerated is not used then listen for a similar description of skin integrity- peeling, pulpy, discolored, etc.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2022**  ***(10370)*** | **Was any part of the baby physically abnormal at the time of delivery (for example: body part too large or too small, additional growth on body or missing body part)?**  **Why ask this:** An abnormal shape of limb due to physical deformity, or any external physical abnormality can cause difficult labor, and can also be associated with other congenital malformations of internal organs which could be the cause of death. Some examples of physical abnormalities are the back or lip being open, or a limb not being shaped normally.This information can help to determine the cause of death.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2”, “8” or “9,” skip to N2051 (Maternal history). |
| **N2022\_1**  ***(10371)*** | **Did the baby/ child have a swelling or defect on the back at the time of the birth?**  **Why ask this:** To identify why the baby might have gotten sick.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. |
| **N2022\_2**  ***(10372)*** | **Did the baby/ child have a very large head at the time of the birth?**  **Why ask this:** To identify why the baby might have gotten sick.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If “1,” skip to N2051. |
| **N2022\_3**  ***(10373)*** | **Did the baby/ child have a very small head at the time of the birth?**  **Why ask this:** To identify why the baby might have gotten sick.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. |
| ***Inst\_1: STOP. After completing N2022\_3 (10373) 🡪 N2051 (10394) (Maternal History)***  ***Skip:*** Questions N2023–N2026 are asked only for neonatal deaths. Therefore, after asking N2022\_3, skip to N2051 to ask about the maternal history. | |

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| **2.4 BACKGROUND (FOR NEONATAL, CHILD and ADULT DEATHS)** | |
| **N2023**  **C3012**  **A4001**  ***(10017)*** | **What was the first or given name(s) of the deceased?** *[Ask this only if the name is not already known (from Q1202).*  **Why ask this:** Verify the name(s) of the deceased in the list provided by the Supervisor and reported by the respondent. Report any inconsistencies to the supervisor. If the name(s) are consistent write them legibly.  **How to do it:** Record the name of the deceased child, if known. Record “No name given” if the child died before being named. |
| ***Inst\_1: child deaths 28 days-4 years → C3019\_units***  ***Child deaths 5 – 11 years → C3013*** | |
| **A4002**  ***(10059)*** | **What was her/his marital status?**  **Why ask this:** This question is concerned with the marital status of the deceased at the time to his/her death.  **How to do it:** Record the deceased’s marital status: “1” if single, “2” if married, “3” if life-partner, “4” if divorced, “5” if widowed, “6” if too young to be married, “9” if don’t know, “8” if Refused to answer. The coding category ‘life-partner’ is similar to a common law partner. These terms indicate a partnership where people are living together continuously in a relationship equivalent to marriage. |
| **C3013**  **A4003** | **Did s/he ever attend school?**  **Why ask this:**  The questions on schooling are asked for deaths of adults and children more than four years of age. Attending school is important for a child’s development; and for an adult this provides important information about the person’s earning potential.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If answer is “8,” “2” or “9,” skip to C3017/A4006. |
| **C3015**  **A4004**  ***(10063)*** | **What is the highest level of school she/he attended?**  **Why ask this:** We want to determine the deceased’s highest level of schooling.  **How to do it:** Record the respondent’s highest level of schooling from the listed response choices, or record “99” for Don’t know or “88” for Refused to answer. |
| **C3017**  **A4006**  ***(10064)*** | **Was s/he able to read and write?** *[Record “yes” if both or either reading or writing is known to the respondent.]*  **Why do this:** Reading gives a person access to information that can increase his/her health and survival.  **How to do it:** Select appropriate response. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| ***Inst\_2: Child deaths <9 years →* C3019\_units *(10352\_units)*** | |
| **C3018**  **A4007**  ***(10065)*** | **What was her/his economic activity status in the year prior to death?** *[For example: If s/he spent most of her/his time on any economic activity such as working in the field, or selling some products, then C3018 / A4007 = 2 "mainly employed."]*  **Why do this:** This question is for the death of a child aged over 8 years and adult deaths. The deceased might have had several activities, for example, being both employed and a student. Choose the one that was probably true for most of the year preceding illness and death or that took most of the person’s time. For example: If s/he spent most of her/his time on any economic activity such as working in the field or selling some products, then C3018 / A4007= 2 "mainly employed."  **How to do it:** Select the one most appropriate response. ***Skip:*** If the response is not “2. Mainly employed (at work),” skip over C3018\_1 / A4007\_1 to C3019\_units / A4008. Otherwise, proceed to C3018\_1 / A4007\_1. |
| **A4007\_1**  **C3018\_1**  ***(10066)*** | **What was her/his occupation, that is, what kind of work did s/he mainly do?**  **Why do this:** This question will only be asked if the response to C3018 / A4007 is “2. Mainly employed (at work)”.  **How to do it:** Record the respondent’s response. Also see general instruction 8. |
| **A4008**  ***(10411)*** | **Did <NAME> drink alcohol?**  **Why do this:** Consumption of alcohol could be associated with liver disease, as well as related to mental health conditions associated with depression and suicide, and also associated with risk taking leading to road traffic accidents or inter-personal violence. While alcohol may be directly related to the specific event or circumstance leading to death, there could be an underlying risk associated with chronic or regular alcohol consumption. This question is intended to capture regular consumption at least once a week or more often. Note any specific details provided by the respondent in the free text section of the questionnaire. Because alcohol use is a sensitive issue, no further information about frequency or quantity of use is asked.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know, or “8” Refused to answer. |
| **A4009a**  ***(10412)*** | **Did s/he use tobacco?**  **Why do this:** Consumption of tobacco is related to lung cancer, oral cancer, and chronic asthma, among others. Notice that the wording of this question entails’ to ‘consume’ so as to include the capture of ‘oral chewing of tobacco; which is common in several populations.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know, or “8” Refused to answer. ***Skip:*** If “2,” “8,” or “9” skip to A4013u. |
| **A4010**  ***(10414)*** | **What kind of tobacco did s/he use?**  **Why do this:** To specify the type of tobacco used or consumed most often; if the deceased used more than one kind of tobacco, ask the respondent to specify which kind was used most of the time.  **How to do it:** Record “1” if Cigarettes, “2” if Pipe, “3” if Chewing tobacco, “4” if Other, “9” if Don’t know, “8” if Refused to answer. If the response is “1, cigarettes,” continue with A4011. ***Skip:*** If the response is another kind of tobacco (“2,” “3” or “4”), go to A4012. If response is “8” or “9” go to A4013u. |
| **A4011**  ***(10415)*** | **How many cigarettes did s/he smoke daily?**  **Why do this:** Smoking more cigarettes increases the person’s risk of tobacco-related diseases.  **How to do it:** Record the approximate number of cigarettes smoked. A valid response is between 0 and 99. If the response was more than 98 cigarettes, confirm the response and enter “98”. For don’t know, enter “99”. For refused, enter “88”. If the answer happens to be 88 cigarettes, enter instead “87” so that the response is not automatically coded as refused to answer. ***Skip:*** Once completed, go to A4013u. |
| **A4012**  ***(10416)*** | **How many times did s/he use tobacco products each day?**  **Why do this:** Greater use of tobacco products puts the person at greater risk of tobacco-related diseases.  **How to do it:** Record the approximate number of times non-cigarette tobacco products were used each day. A valid response is between 0 and 99. If the response was more than 98, confirm the response and enter “98”. For don’t know, enter “99”. For refused, enter “88”. If the answer happens to be 88 times, enter instead “87” so that the response is not automatically coded as refused to answer. |
| **N2024**  ***(10351)***  **C3019\_units**  **C3019\_a**  **C3019\_b**  ***(10352\_units***  ***10352\_a***  ***10352\_b)*** | **How many days old was the baby when the fatal illness started?**  **How old was the child when the fatal illness started?**  **Enter how old the child was when the illness started in months:** *Enter 1-11 months*  **Enter how old the child was when the illness started in years:** *Enter 1-11 years.*  **Why ask this:** The child’s age when the illness started can help determine the cause and timing of the death. In many instances of early neonatal death, this would be right from the day of birth, which would be day zero.  **How to do it:** Record the neonate’s age in days. Record the child’s age in months or years, according to the instructions. For neonates, record only days, with the maximum number of 27 days. Record “00” days if less than 24 hours. For children, record the units in C3019\_units, and then follow the skips to record 1-11 months if less than 1 year, or 1-11 years if 1 year or older. For all the questions, record “9” or “99” if the response is “Don’t know” and enter “8” or “88” if “Refused to answer.” The response should not be more than the child’s age at death.Also see general instructions 4, 5a and 6. ***Skip:*** If C3019\_units = 2 (Years), then skip to C3019\_b; or if C3019\_units = 8 or 9, skip to C3020. |
| **N2024\_1**  **C3020**  ***(10408)*** | **Before the illness that led to death, was (the baby / the child) growing normally?** *[Read “…the baby…” if less than 1 year old at death.]*  **Why ask this:** The question is to ascertain a period of normal health before the onset of the terminal illness. A positive response would clarify that the cause of neonatal death is unlikely to be related to the delivery.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2025**  ***(10120\_0)***  **C3021u**  **C3021d**  **C3021m**  **C3021y**  **A4013u**  **A4013d**  **A4013m**  **A4013y**  ***(10120\_unit 10120\_1 10121 10122)*** | **For how many days was s/he ill before death?** *(For neonates): Enter 0-27 days.*  **For how long was s/he ill before death?** *(For children and adults)*  **Enter how long the illness lasted in days:** *if the illness lasted less than 30 days, enter 0-30 days.*  **Enter how long the illness lasted in months:** *if the illness lasted less than 1 year, enter 1-11 months.*  **Enter how long the illness lasted in years:** *if the illness lasted 1 year or more, enter years. For children, enter 1-11 years.*  **Why ask this:** The length of the illness can help determine the cause and timing of the death.  **How to do it:** Record the illness duration in days, months or years. For neonates, only record days: must be less than 28 days. If less than 24 hours, enter “00” days. For children and adults, record days if less than 30 days. Record “00” days if less than 24 hours. For children and adults, If less than 1 year, record months. For children and adults, record years if 1 year or more. A valid entry for neonates is less than or equal to the age in days at death. For don't know, enter "99." For refused, enter "88." Also see general instructions 4, 5a and 6. **Skip:** For neonates, if N2025 > 00, go to N2051 (Maternal History), For child and adult deaths, if C3021u / A4013u = 2 (Months), skip to C3021m / A4013m, or if C3021u / A4013u = 3 (Years), skip to C3021y / A4013y, or if C3021u / A4013u = “8” or “9,” then go to C3022 / A4014. If C3021d / A4013d >00, skip to C3052 / A4051. After completing C3021m / A4013m or C3021y / A4013y, skip to C3052 / A4051. |
| **N2026**  **C3022**  **A4014**  ***(10123)*** | **Did s/he die suddenly?** *[Suddenly means died unexpectedly within 24 hours of being in regular health.]*  **Why ask this:** Ask whether the deceased died unexpectedly within 24 hours of being in regular health. In some cases, a person may experience acute illness and then seem to recover for some time before then experiencing sudden death. These cases can still be considered yes responses for this question. That is when it is thought a person is recuperating from an illness and then they suddenly die.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know.. |
| ***Inst\_3: Child deaths 28 days – 11 months → Section 6:* C3052 *(10367)***  ***Child deaths 1 – 11 years →* C3101** | |
| **SECTION 3: MATERNAL HISTORY (FOR STILLBIRTHS AND NEONATAL DEATHS)**  *Read:***Now, I would like to ask you some questions about (your / the mother’s) health and (your / her) pregnancy with <NAME>.** *[Here and in the following questions, read “…the mother…,” “…her…” and “…she…” if the mother is not the respondent.]*  **Why read this:** This bridge statement tells the respondent that the following questions are about the pregnancy. See general instruction 2 about how to read the questions. | |
| **N2051**  ***(10394)*** | **How many births, including stillbirths, did (you / the baby’s mother) have before this baby?**  **Why ask this:** This question attempts to record the complete childbirth history of the mother. Certain causes of neonatal death are more associated with women undergoing their first ever delivery, while others are associated with previous history of several deliveries. Hence, recording the correct total number of previous births can help with the diagnosis of the cause of neonatal death.  **How to do it:** Record the number of previous births. For don't know, enter "99." For refused, enter "88." |
| **N2052** | **During the pregnancy, did (you / the mother) see anyone for antenatal care?**  **Why ask this:** Antenatal care (ANC) is important for the health of the pregnant woman and her unborn baby. The ANC visits provide the opportunity for several health promotive and disease preventive messages to be delivered, as well as for screening tests to detect complications that require immediate treatment or vigilance for worsening of the complications requiring treatment.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If answered “2” or “9”, skip to N2058. |
| **N2054** | **How many times did (you / the mother) receive antenatal care during this pregnancy?**  **Why ask this:** Pregnant women should be seen for antenatal care at least four times during pregnancy. This enables delivery of a focused ANC interventions package, including detection and management of sexually transmitted infections and maternal complications such as preeclampsia, delivery of tetanus toxoid immunization to protect mother and baby, intermittent preventive treatment of malaria; and promotion of appropriate nutrition, skilled birth attendance, breastfeeding, and early postnatal care of mother and baby.  **How to do it:** Record the number of times the woman received ANC. See general instructions 4 and 6. |
| **N2057** | **As part of (your / the mother’s) antenatal care during this pregnancy, were any of the following done at least once?** *[Read out all options and check “Yes,” “No” or “Don’t know” for each.]*  **Why ask this:** These are some of the key interventions that quality ANC should provide to ensure a healthy pregnancy. A blood sample should be taken early in the pregnancy to check for anemia and syphilis. A urine sample is checked for excess sugar and protein and for bacteria. Blood pressure should be measured starting around the middle of the pregnancy since this is when the complication of preeclampsia starts.  **How to do it:** Ask about each intervention, and mark (“X”) the appropriate response box (“1” for Yes, “2” for No, or “9” for Don’t know) for each action as you ask about it. |
| **N2058** | **Please tell me the danger signs during pregnancy or labor and delivery that you should seek care for immediately.** *Probe:* **Tell me as many of the danger signs as you can.** *Probe:* **Can you tell me any others?** *[Check each danger sign mentioned.]*  **Why ask this:** The list includes all the danger signs of pregnancy, labor or delivery for which the World Health Organization says that women should immediately seek care. A woman is more likely to seek care for danger signs that she knows indicate the need to urgently seek care. The care that she receives could save her life and the life of her unborn baby.  **How to do it:** Read the first probe after the respondent first pauses for some time. Do not read any of the danger signs – we want to know which ones the respondent can mention spontaneously. Continue with the second probe as needed until s/he can’t name any more danger signs. Also see general instruction 7.   * After s/he is finished, write the total number of danger signs mentioned on the provided line. |
| ***Inst\_2: If Q1102 ≠“1. High” → N2065*** | |
| **N2063** | *Skip N2063-N2064 in areas without malaria.*  **During this pregnancy, did (you / the mother) sleep under an insecticide treated bed net?**  **Why ask this:** Sleeping under a bed net is to protect the mother from mosquitoes that carry malaria parasites. Malaria can be a severe disease in the mother and lead to her having a stillbirth or preterm delivery. Insecticide treated” means that the bed net has been impregnated with insecticide to discourage mosquitoes from even landing on the net. Mosquitoes that do land on the net are unable to gain entry through the tightly woven netting.  **How to do it:** If the respondent responds “Yes,” probe to determine how often she slept under an insecticide treated bed net during her pregnancy. “Always” means she slept under a bed net every night during the pregnancy; “Usually” means she missed sleeping under a bed net only a few times; and “Sometimes” means less often than “Usually” but more often than “Never.” Record one answer: “1” if Yes, usually or always, “2” if Yes, sometimes, “3” if Never, or “9” if Don’t know. |
| **N2064** | **During this pregnancy, did (you / the mother) take any drug such as <MOH-RECOMMENDED DRUGS>to prevent (you / her) from getting malaria?** *[Show the respondent pictures of MOH recommended drugs.]*  **Why ask this:** Taking an anti-malaria medicine prescribed by a government health facility also can prevent pregnant women from getting malaria. The <MOH-RECOMMENDED DRUGS> bracket should be filled by the VASA study directors before the interviews are conducted.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. |
| **N2065** | **During this pregnancy, did (you / the mother) take ARVs?**  **Why ask this:** This provides information about the HIV status of the mother and potential risk for the baby.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. |
| **SECTION 4: MATERNAL SYMPTOMS AND CARESEEKING (FOR STILLBIRTHS & NEONATAL DEATHS)** | |
| **N2080**  ***(10399 10396 10401 10397 10400 10402 10398***  ***)*** | **Now I’d like to ask you about any symptoms (you / the mother) might have had during the late part of the pregnancy. Were the last 3 months of the pregnancy complicated by any of the following symptoms that started before labor?** *[Inform the respondent that labor starts when there are painful contractions every 20 minutes or less. Then read each symptom and mark “Yes,” “No” or “Don’t know” for each.] [Read ”…the mother…” if the mother is not the respondent.]*  **Why ask this:** The listed symptoms may indicate that the woman had a complication of the pregnancy. This could have contributed to the stillbirth or neonatal death. Probe carefully for each symptom and record the response. Further explanations of some of the symptoms are provided here.  **Did (you / the mother) have:**  Convulsions (fits): are rapid twitching or jerking movements of parts of the limbs or sometimes entire limbs that usually last a few minutes and stop when the person becomes unconscious. High blood pressure during pregnancy, particularly in the last three months, may be associated with convulsions. Without proper antenatal care, such convulsions may be the only major sign of underlying high blood pressure in pregnant women. Convulsions may also occur during labor or delivery, which is very serious and readily recalled. Clarify the meaning of the term ‘convulsions’ and the period of interest (last three months).  High blood pressure: is checked during periodic ANC visits, and if high, the health worker would inform the pregnant women about high blood pressure and advise them to reduce salt in the diet, and possibly prescribe some medications. High blood pressure during pregnancy may be associated with preterm delivery and other complications. In some instances, high blood pressure may manifest only during labor or delivery.  Severe anemia or pallor and shortness of breath: In some instances, pregnancy is associated with severe ‘thinning’ of the blood, which is observed as palor of the tongue, nails, palms and eye margins. She might also have shortness of breath due to insufficient oxygen in her blood. This condition is known as anemia, and is associated with premature delivery, low birth weight, birth asphyxia and other complications.  Diabetes mellitus: can lead to birth of larger babies, with their own risks for neonatal death. Maternal diabetes is also associated with various types of congenital abnormalities including congenital heart malformations.  Severe headache: during pregnancy may be associated with high blood pressure or convulsions.  Blurred vision: means dimness of sight in normal light. This may or may not be accompanied by convulsions. Blurred vision is a subjective symptom, and may not be reported by the patient to her relatives. Explain the meaning of blurred vision, and record the response accordingly.  **(Were you / Was she):**  Too weak to get out of bed: This may also indicate that the woman had severe anemia.  **Did (you / the mother) have:**  Severe abdominal pain (before labor, not labor pain): It must be made clear for the respondent that this refers to pain that was present before any labor pain began. Such pain could be due to a problem with the placenta.  Fast or difficult breathing: could indicate a lung infection, but might also be due to severe anemia.  Puffy face: during pregnancy might be associated with high blood pressure or convulsions.  Any vaginal bleeding before the start of labor: is an important sign that is often associated with a disorder of the placenta. Vaginal bleeding should be distinguished from light spotting, which can occur before labor and is not a danger sign.  Fever: long before labor starts might indicate a serious infection of the mother’s kidneys. If the membranes rupture before labor starts, the fluid surrounding and protecting the baby can become infected and lead to infection of the baby and neonatal death.  Foul smelling vaginal discharge: indicates a serious infection, and is usually accompanied by pain in the lower abdomen and fever. Such infections can be transmitted to the neonate and lead to neonatal death.  **Did the:**  Water break 6 hours or more before labor: The water breaking before labor begins is a risk for the mother and baby developing a serious infection that could threaten the life of the baby.  Baby stopped moving before labor: Lack of fetal movement can indicate that the baby is in distress or died before the delivery.  **How to do it:** See general instruction 8. Mark (“X”) the appropriate response box (“1” for Yes, “2” for No, or “9” for Don’t know) for each complication as you ask about it. ***Skip:*** If N2080 is “17, No symptoms before labor,” skip to N2088. |
| **N2081** | **Did (you / the mother) seek care from any person or health facility for (any of) the pregnancy symptom(s) that started before labor? Care includes formal or traditional care but excludes advice.** *[Read “…for any of…” if she had more than one pregnancy symptom.]*  **Why ask this:** Several pregnancy symptoms that start before labor can contribute to a poor outcome of the pregnancy. For example, being very fatigued while doing mild work might indicate that the mother is anemic. This can contribute to asphyxia (not getting enough oxygen) of the baby during the delivery, which can cause brain damage or death of the baby. Seeking care for pregnancy symptoms should lead to treatment and improved outcomes of the pregnancy.  **How to do it:** Emphasize the word “before” so the respondent knows which symptom(s) you are asking about. Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2,” skip to N2085; if “9,” skip to N2088 for the long form (because the following questions can be asked only if we know whether the mother sought care). |
| **N2082** | **Where did (you / she) seek this care?** *Prompt:* **Was there anywhere else?** *[Probe to identify the type of provider or facility. If the woman was seen by a trained community nurse or midwife at a health facility, then mark the type of facility(ies) (1-3) where the provider was seen. Use option 4 only if the provider was seen outside of a health facility.] [Multiple answers allowed.]*  **Why ask this:** Just as with ANC and the delivery, a trained health professional is best equipped and most knowledgeable to correctly diagnose and treat pregnancy complications. However, also just as with ANC and the delivery, many women seek care from other types of providers. Therefore, we ask about all the providers where women might have sought care for their pregnancy symptoms.  **How to do it:** Keep prompting “Was there anywhere else?” until the respondent says there was nowhere else. See general instructions 7 and 8. ***Skip:*** If she did not seek care from a health provider (not response 1-4, only 5-7), then skip to N2085. If the answer is “9,” then skip to N2088 (10395-10405). This long skip is taken because all the questions up to N2088 require that the respondent knows where the mother sought health care. |
| **N2083** | *If more than one symptom started before labor and she sought care from a health provider (N2082 = 1-4), ask:* **Was there any particular symptom or symptoms that started before labor, for which (you / the mother) went to the (first) health provider?** *[Read “…the first health provider?” if she went to more than one provider.]*  **Why ask this:** This question determines whether we will ask N2084, which is to identify the pregnancy symptoms for which the mother sought care. We ask this question only if she had more than one pregnancy symptom because if she had just one, then that must be the one for which she sought care. We also ask this only if she sought care from a health provider because we want to know for which symptoms mothers sought health care.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to N2085. |
| **N2084** | **For which symptom(s) did (you / she) go?** *[Multiple answers allowed.]*  **Why ask this:** Knowing this can help us understand the mother’s perception of which symptoms require health care. If there are important symptoms that mothers are not aware of, then a Behavior Change Communication (BCC) intervention might be needed to inform women about pregnancy symptoms that require care and when and where to go for this care.  **How to do it:** Mark (“X”) the pregnancy (before labor) symptom(s) for which the mother sought health care. Symptom 16 is any “Other” symptom that was specified in N2080 (10396-10402). Also see general instruction 2. |
| **N2085** | **Some people say they have no problems accessing health care. Others say they have problems accessing care.**  *If she never went to a health provider (N2081 = 2 or N2082 = only 5-7) for any of the pregnancy symptoms, ask:* **What about (you / the mother)? Did (you / she) experience any problems that kept (you / her) from going to a health provider or facility for the problem(s) that started before labor?**  *If she went to health provider (N2082 = 1-4) for any pregnancy symptom(s), ask:* **What about (you / the mother)? Did (you / she) have to overcome any problems to go to a health provider or facility for the symptom(s) that started before labor?**  **Why ask this:** Just as with ANC and the delivery, a trained health professional is best equipped and most knowledgeable to correctly diagnose and treat pregnancy complications. Identifying constraints to seeking care from a health provider might help find ways to overcome those problems. We ask this question for all mothers because even those who sought care from a health provider might have had constraints they had to overcome.  **How to do it:** Record 1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If “2” or “9,” skip to Inst\_3. |
| **N2086** | **What were the main problems (you / she) had?** *Prompt:* **Was there anything else?** *[Multiple answers allowed.]*  **Why ask this:** We ask this question for all mothers who had a constraint to seeking care from a health provider for their pregnancy symptom(s) even if they were able to overcome the constraints. This might allow us to better understand which constraints women are able to overcome or not, and so focus on developing interventions for those that are more problematic.  **How to do it:** Mark the problems that most closely match the respondent’s answers. Continue to prompt and mark the responses until the respondent says there were no other problems. “Someone else” in response 4 means someone other than the mother. Mark ‘99’ Don’t know only if the respondent can’t name any of the problems she had. Also see general instructions 2, 7 and 8. |
| ***Inst\_3: If N2081 = 2 or N2082 = only 5-7 (Never went to a health provider for any pregnancy symptoms)***  ***→******N2088*** | |
| **N2087** | **(Were you / Was the mother) admitted to hospital for (any of) the symptom(s) that started before labor?**  **Why ask this:** Being admitted to hospital would suggest that the woman had a serious problem.  **How to do it:** Continue to emphasize the word “before.” Record “1” if Yes, “2” if No, or “9” if “Don’t know. See general instruction 2. |
| **N2088**  ***(10399 10396***  ***10401 10395 10367 10382 10403 10405 10404)*** | **Now I’d like to ask you about any symptoms (you / the mother) might have had during labor or delivery. Did (you / the mother) have any of the following symptoms during labor or delivery?** *[Read ”…the mother…” if the mother is not the respondent.] [Remind the respondent that labor starts when there are painful contractions every 20 minutes or less. Read each symptom and mark “Yes,” “No” or “Don’t know” for each.] [Do not include any symptoms here that started after the baby was delivered.]*  **Why ask this:** The listed symptoms may indicate that the woman had a complication of labor or delivery. This could have contributed to the stillbirth or neonatal death. Probe carefully for each symptom and record the response. Further explanations of some of the symptoms are provided here.  **Did (you / the mother) have:**  Convulsions (fits): see N2080 for the explanation.  High blood pressure: see N2080 for an explanation.  Severe anemia or pallor and shortness of breath: see N2080 for an explanation. This would usually be noted during the pregnancy, before labor began, but sometimes might not have been noted until the time of the labor and delivery.  Severe headache: see N2080 for an explanation.  Blurred vision: see N2080 for an explanation. Blurred vision would usually be present before labor began, but may manifest only at the time of labor or delivery.  **(Were you / Was she):**  Too weak to get out of bed: This may also indicate that the woman had severe anemia.  **Did (you / the mother) have:**  Severe abdominal pain (between contractions, not labor pain): It is important to distinguish for the respondent that this refers to pain that was not due to the labor, but was present between the labor contractions. Such pain could be due to a problem with the placenta.  Fast or difficult breathing: could indicate a lung infection, but might also be due to severe anemia.  Puffy face: might be associated with high blood pressure or convulsions. It would usually begin during the last three months of pregnancy, before the onset of labor; but in some cases it might not have been noticed until the woman was in labor.  Excessive vaginal bleeding during labor or delivery: This refers to bleeding AFTER the onset of labour pains but before the complete delivery of the baby. Excessive bleeding during labour and delivery could be due to injury to the uterus or birth canal. Confirm the timing of the bleeding as having started AFTER the onset of birth pains, and during labour before delivering the baby.  Fever: at the time of delivery is an indication of maternal infection, which could have been passed to the baby at that time. Such infections could be related to the cause of the death of the neonate, hence identifying fever in the mother is an important indicator.  Foul smelling vaginal discharge: indicates a serious infection, and is usually accompanied by pain in the lower abdomen and fever. Such infections can be transmitted to the neonate and lead to neonatal death.  Early/preterm labor (before 9 months): is a risk for the baby’s death from preterm delivery and prematurity.  Labor that lasted 12 hours or more: increases the risk for infection.  **Was the:**  Baby’s bottom, feet, arm or hand delivered before its head: The head is usually the first part of the baby to be delivered. Presentation of any other body part first e.g. bottom, feet, arm or hand, is associated with several causes of neonatal death, including birth injuries, birth asphyxia and lung infections. Mothers usually know the body part that was delivered first, and can give the true response to this question if asked carefully.  Umbilical cord delivered first: This is a relatively rare condition, but is associated with adverse neonatal outcomes. The mother may not have full knowledge of its occurrence.  Umbilical cord around the neck more than once: Mothers would know whether the cord was around the neck but may not remember how many times. It is important to verify whether the cord was wrapped more than once because the risk of death of the baby increases if it was more than once.  **How to do it:** Ask about every symptom. Mark (“X”) the appropriate response box (“1” for Yes, “2” for No, or “9” for Don’t know) for each symptom as you ask about it. ***Skip:*** If no labor/delivery symptoms, skip to N2076A. |
| **N2089A** | **When (this / the first) symptom began, (were you / was the mother) where the baby was delivered, or somewhere else?** *[Read “…the first…” if she had more than one labor or delivery symptom.] [Confirm the delivery place (N2006) and provider (N2008), and enter the response.]*  **Why ask this:** We need to know this in order to understand the process of careseeking for the symptoms. If the woman was with a health care provider when the symptom began, then we do not need to ask the following questions on careseeking.  **How to do it:** Mark one response: “1. Where the baby was delivered,” “2. Somewhere else (not where delivered)” or “9. Don’t know.” ***Skip:*** If the answer is “1,” skip to N2076A. (The questions before N2076A are about careseeking for the symptoms. If the answer is “1,” then the woman’s symptoms started where she delivered so it is assumed she did not have to seek care for them.) If the answer is “9,” then skip to N2090 to ask about the woman’s careseeking for her labor/delivery symptoms. Also see general instruction 2. |
| **N2089B** | **Where was this other place?**  **Why ask this?** If the woman’s symptoms started somewhere other than where she delivered, we want to know where this other place was. This will help us understand the process of careseeking that she followed for the symptoms.  **How to do it:** Read the possible answers to the respondent and mark one response. If necessary, discuss the possible answers with the respondent to ensure that s/he selects the correct response. Remember that ‘formal health provider’ and ‘health provider’ mean a trained health provider, such as a doctor, nurse or midwife. So, for example, if the woman was in labor at home, being attended by a traditional birth attendant, the correct response would be “1. Home, without a formal health provider.” Also see general instruction 8. |
| **N2090** | **Did (you / she) ever receive or seek any care or treatment for (any of) the labor or delivery symptom(s), including any care or treatment at home?** *[Read “…any of the symptoms” if she had more than one symptom.]*  **Why ask this:** This is where we establish whether the mother ever received or sought any care or treatment for her symptoms. “Treatment” means measures that could be taken by the woman herself or another untrained person.  **How to do it:** Emphasize the words “receive or seek” so the respondent knows that we are interested in all care that the woman sought, even if she did not succeed in reaching the provider where she was seeking care. Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” then skip to N2076A. |
| **N2091** | **Where did (you / she) receive or seek this care or treatment, including where the baby was delivered?** *Prompt:* **Was there anywhere else?** *[Probe to identify the types of providers or facilities. If the woman was seen by a trained community nurse or midwife at a health facility, then mark the type of facility(ies) (1-3) where the provider was seen. Use option 4 only if this provider was seen outside a health facility. Use options 5-7 for other persons that provided care outside a health facility.] [Multiple answers allowed.]*  **Why ask this:** This helps us understand how concerned the mother was about the symptoms and what she thought was the right thing to do. People are more likely to seek care from a health provider for symptoms that are of greater concern to them. We also need to know if the woman sought care from a health provider in order to determine which of the following questions to ask.  **How to do it:** Mark all the providers where the woman received or sought care or treatment for her labor/delivery symptoms. Continue to prompt and mark the responses until the respondent says she did not go anywhere else. Also see general instructions 2, 7 and 8. ***Skip:*** If the answer is only options 5-9 (not 1-4), then skip to N2076A. |
| **N2095** | **Was there any particular labor/delivery symptom or symptoms for which (you / the mother) first sought care from a health provider/facility?**  **Why ask this:** Knowing this can help us understand the mother’s perception of which symptoms require health care. If there are important symptoms that mothers are not aware of, then a BCC intervention might be needed.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” go to N2097. |
| **N2096** | **For which symptom(s) did (you / she) go?** [*Multiple answers allowed.*]  **Why ask this:** This is where we identify the labor or delivery symptom(s) for which the mother sought care.  **How to do it:** Mark (“X”) the labor and delivery symptom(s) for which the mother sought health care. Symptom 18 is any “Other” symptom that was specified in N2088 (10367-10405). |
| **N2097** | **How long after the labor or delivery symptom(s) began was it decided to go to a health provider/facility?** *[Mark days, hours &/or minutes as needed: e.g. 00 day, 02 hours, 10 minutes]*  **Why ask this:** Recognizing the symptoms that indicate a labor or delivery complication requiring health care and quickly deciding to do seek that care is an important step toward having a successful delivery and healthy baby. Taking too long to make this decision (the “first delay”) might contribute to the risk of the mother or baby dying. This also helps us understand which symptoms the mothers perceive to be of serious concern, and those about which they should be concerned but do not seem to recognize their severity.  **How to do it:** Record the time. Also see general instructions 4, 5b and 6. |
| **N2094** | **How many different health providers or facilities did (you / she) go to for this care, including where the baby was delivered?** *[Include providers/facilities (1-4) in N2091 where care was sought for the labor or delivery symptoms, including where the baby was delivered.]*  **Why ask this:** This provides additional context about the pathway of the deceased.  **How to do it:** Enter the number of providers in the box.Also see general instruction 4. ***Skip:*** If the answer is “1” provider/facility, skip to N2076A. |
| **N2105** | **Did any of the health providers/facilities refer (you / the mother) to where the baby was delivered?** *This question is asking about referral to another, separate facility (not a different provider in the same facility).*  **Why ask this:** This provides additional context about the pathway of the deceased.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. |
| **N2076A** | **Earlier you told me that the baby was delivered at <DELIVERY PLACE>. Please tell me who was involved in the decision about where the baby should be delivered?** *Prompt****:* Was there anyone else?**  *[Multiple answers allowed.] [Determine the delivery place from the answer to N2006.]*  **Why ask this:** Certain family members other than the mother often are the main decision makers, and this can influence where the delivery occurred. For example, in some cultures, husbands are the main decision makers, while in some others a woman’s mother-in-law might decide where she should deliver. This might have a positive or negative impact on the outcome of the delivery, depending on where the decision maker influenced the mother to deliver. Knowing where particular decision makers influenced the mother to deliver might help develop a targeted message campaign to increase health facility deliveries.  **How to do it:** Look back at the delivery place in N2006 to determine how to fill the <DELIVERY PLACE> brackets. ***Skip:*** If N2076A is “9, Don’t know,” skip to N2077. |
| **N2076B** | **Who had the strongest voice in the decision?**  **Why ask this:** Many different individuals may have influenced the decision, but information about the main decision-maker may help understand the power dynamics of the family and/or their community.  **How to do it:** Record one answer from the available responses. Also see general instruction 8. |
| **N2077** | **Some people say they have no problems accessing health care during labor/delivery. Others say they have problems accessing care during labor/delivery.**  *If she did not deliver or try to deliver with a health provider or facility (N2006=12 or N2006=1 and N2008≠1-3), ask:* **What about (you / the mother)? Did (you / she) experience any problems that kept (you / her) from delivering with a health provider or facility?**    *If she delivered with or was on route to a health provider or facility (N2006=2-11 or N2006=1 and N2008=1-3), ask:* **What about (you / the mother)? Did (you / she) have to overcome any problems to go to a health provider or facility for the delivery?**  **Why ask this:** We ask this for all mothers who had a constraint to delivering at a health facility even if they were able to overcome the constraints. This might allow us better understand which constraints women are able to overcome or not, and focus on developing interventions for those that are more problematic.  **How to do it:** Record 1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to Inst\_4. |
| **N2078** | **What were the main problems (you / she) had?** *Prompt:* **Was there anything else?** *[Multiple answers allowed.]*  **Why ask this:** We ask this question for all mothers who had a constraint to delivering with a health provider even if they were able to overcome the constraints. This might allow us better understand which constraints women are able to overcome or not, and so focus on developing interventions for those that are more problematic.  **How to do it:** Mark the problems that most closely match the respondent’s answers. Continue to prompt and mark the responses until the respondent says there were no other problems. “Someone else” in response 4 means someone other than the mother. Mark ‘99’ Don’t know only if the respondent can’t name any of the problems she had. Also see general instructions 2, 7 and 8. |
| ***Inst\_4: If N2006=1 and N2008≠1-3 OR N2006=11,12 (delivered at home without a formal provider OR delivered on route to a provider/facility) → N2067*** | |
| **N2103** | **After deciding to seek care for (the labor or delivery symptoms / the delivery), how long did it take (you / the mother) (to reach the <DELIVERY PROVIDER/FACILITY> / for the <DELIVERY PROVIDER> to reach (you / the mother))?** *[Read “…the labor or delivery symptoms…” if the woman had any symptom(s) that started before she reached the delivery provider/facility.] [Read “…for the provider to reach (you / the mother)” if the provider saw the woman at home or another location outside of a health facility.] [Mark hours &/or minutes as needed: e.g. 05 hours, 30 minutes.]*  **Why ask this:** The “second delay” in careseeking for labor or delivery symptoms, just like the first delay, can contribute to the mother or baby dying before they receive needed care. Part 1 of the second delay is the time it took to prepare to go to the provider/facility after deciding to seek care, such as arranging transportation, any money needed for the transport and care, and other necessary arrangements; and part 2 is the travel time to reach the provider. For women who sought care for their labor or delivery symptoms at home, the second delay is the time it took for the provider to reach them.  **How to do it:** Record the time. See general instructions 4, 5b & 6. Read “the labor or delivery symptoms” or “the delivery” depending on whether the mother had any symptoms for which she went to the delivery provider. Follow the above instructions to decide how to read the last part of the question. |
| **N2104** | **How long after ([you / the mother] arrived at the facility / the care provider arrived at your home) were you examined?** *Prompt:* **In other words, how long did you have to wait?**  **Why ask this:** This provides information about the third delay, which is how long it took for the patient to receive quality/appropriate care after they reached the facility.  **How to do it:** Enter the number of hours and/or minutes waited in their respective hours and minutes spaces.Enter “99” if “Don’t know.” |
| **N2067**  ***(10367)*** | **How many months long was the pregnancy before the child was born?**  **Why ask this:** The duration of the pregnancy at the time of delivery is an important factor that could help in determining the cause of death of the neonate.This question tells you the child's gestational age at the time of birth, which indicates whether the birth was early, on time or late. Early and late pregnancies can have extra problems.  **How to do it:** Ask the respondent to count the completed months from the date of the last menstrual period till the date of delivery.Record completed months. For example, if the answer is 7 and a half months or 7 months and 2 weeks, record “07.” A valid response is between 0 and 11. If the response is more than 11 months, confirm the response and enter “11”. For don't know, enter "99." For refused, enter "88."Also see general instructions 4 and 6. |
| **N2068**  ***(10382)*** | **How many hours did the labor and delivery take?** *[Record “00’ if less than 1 hour.]*  **Why ask this:** The duration of labor has important implications for the well-being of the newborn as well as the mother. Labor that lasts too long increases the mortality risk both for the mother and the baby.  **How to do it:** Enquire and record the total duration of labor from onset of pains to delivery of the baby in hours. It is expected that this response would mostly be an approximation, rather than an exact measurement. A valid response is between 0 and 99. If the response was more than 98 hours, confirm the response and enter “98”. For don’t know, enter “99”. For refused, enter "88." If the duration given happens to be 88 hours, enter "87" so that the response is not automatically coded as refused to answer. |
| **N2069\_1**  ***(10387)*** | **Was the delivery normal vaginal, without forceps or vacuum?**  **Why ask this:** Most deliveries occur with the head of the baby being delivered first, from the birth canal. Such a delivery, if it occurs without the assistance of any instruments, is termed a normal delivery. Any use of instruments, presentation other than head first, or delivery from an abdominal operation, is not normal, and is associated with different risks for the death of the neonate.  **How to do it:** Clarify the meaning of normal vaginal delivery (taking care to specify ‘head first’) to the respondent, before recording the response. Record one answer: “1” if Yes, “2” if No, “9” Don’t know or “8” if Refused to answer. ***Skip:*** If N2069\_1 is “1, yes,” go to N2070. |
| **N2069\_2**  ***(10388)*** | **Was the delivery vaginal, with forceps or vacuum?**  **Why ask this?** Delivery with the use of a forceps or vacuum extraction would suggest that the woman had a difficult delivery, with the baby’s size being large relative to the woman’s pelvic outlet.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” Don’t know or “8” if Refused to answer. ***Skip:*** If N2069\_2 is “1, yes,” go to N2070. |
| **N2069\_3** | **Was the delivery performed by C-section?**  **Why ask this:** The term ‘C-section’ refers to an abdominal operation that is used to cut open the womb and extract the child from the abdomen. Having a C-section delivery would suggest that there was a difficult pregnancy or that a problem developed during labor and delivery.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” Don’t know or “8” if Refused to answer. |
| **N2073**  ***(10383)*** | **Was the baby born 24 hours or more after the water broke?**  **Why ask this:** Usually the breaking of waters occurs a short while (up to a few hours) after the onset of labor. Leaking or breaking of water for more than 24 hours before delivery can be associated with infection and some other causes of death in newborn babies. If the water breaks before the onset of labor, this lengthens the time between the breaking of the water and delivery, and increases the risk of infection even more. Probe carefully to get the accurate response to this question.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. Also see general instructions 4 and 6. |
| **N2074**  ***(10385)*** | **What was the color of the liquor when the water broke?**  **Why ask this:** In many instances, there may not be a clear recall / response to this question. In normal circumstances, the liquor is like ‘water’; i.e no specific color.If the baby is under stress *in utero*, feces might be released into the amniotic fluid prior to birth. And such discoloration would likely be remembered.  **How to do it:** Record one code: “1” if Green or brown, “2” if Clear (normal), “3” if Other (specify), “9” if Don’t know or “8” if Refused to answer. Also see general instruction 8. |
| **N2075**  ***(10384)*** | **Was the liquor foul smelling?**  **Why ask this:** Foul smelling liquor may be due to infection of the amniotic fluid prior to birth. Mothers would be able to recall this and report. Probe carefully to get a true response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2107**  ***(10398***  ***10276)*** | **Did (you / the mother) have any of the following problems that started** **within 6 weeks after the delivery?** *[Read each symptom and mark “Yes”, “No” or “Don’t know” for each.] [Read “…the mother…” if the mother is not the respondent.]*  **Why ask this:** Maternal complications that start after the baby was delivered may influence neonatal mortality outcomes. The mother might have been too sick to care for the newborn child. If the mother herself died, this information might also help determine the cause of her death.  **How to do it:** Mark (“X”) the appropriate response box (“1” for Yes, “2” for No, or “9” for Don’t know) for each complication as you ask about it. |
| ***Inst\_5: STOP – If N2016 = 1 (Stillbirth) → N2271*** | |
| **SECTION 5: CARE OF THE NEWBORN AND SIGNS AND SYMPTOMS ASSOCIATED WITH THE FATAL ILLNESS (FOR NEONATAL DEATHS)**  *Read:***Now I would like to ask you about the newborn child’s illness and care of the child.**  **Why read this:** This bridge statement indicates that the following questions are about the care of the newborn child. | |
| ***Inst\_6: Refer to N2006 (to determine the delivery place. If N2006 = 2-10 (Facility delivery) → N2112*** | |
| **N2110** | **What tool was used for cutting the cord?**  **Why ask this:** Using an unclean instrument to cut the cord can cause a serious bacterial infection, including neonatal tetanus or neonatal sepsis leading to meningitis, pneumonia or another possibly fatal illness.  **How to do it:** Record one answer. Use code “1” if the response is any type of clean razor blade, including “new razor blade,” razor blade from a delivery kit” or “a boiled razor blade.” Also see general instruction 8. |
| **N2111** | **What material was used for tying the cord?**  **Why ask this:** Using an unclean material to tie the cord can cause the same serious infections as cutting the cord with an unclean instrument.  **How to do it:** Record one answer. Use code “1” if the response is any type of clean thread, including “clean thread,” “thread from a delivery kit” or “boiled thread.” Also see general instruction 8. |
| **N2112** | **Was anything applied to the umbilical cord stump after birth?**  **Why ask this:** Some substances commonly applied to the cord stump kill bacteria and so decrease the risk of infection. Some others, mainly some traditionally-applied substances, may be contaminated with bacteria and so increase the risk of infection. It is recommended that nothing be applied to the cord of neonates born in a health facility. If anything was applied, the next question seeks to learn what it was.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to N2114*.* |
| **N2113** | **What was it?** *[Multiple answers allowed.]*  **Why ask this:** Here we identify what substance was applied to the cord stump. It is recommended that nothing be applied to the cord stump of neonates born in a health facility. For neonates born at home in a high mortality setting (>30 neonatal deaths/1,000 live births), the World Health Organization recommends that chlorhexidine be applied to the cord stump daily during the first week of life. This corresponds most closely to response #1 (alcohol or other antiseptic). An antibiotic preparation (#2) applied to the cord stump may also protect the baby from infection but could also lead to bacterial resistance to the antibiotic. Other substances such as oils (#3), and especially animal dung, dirt, mud and ash (#4) pose great risks for infection of the cord and neonatal sepsis.  **How to do it:** Record one answer: “1” for Alcohol/other antiseptic, “2” for Antibiotic ointment/cream/powder, “3” for Castor oil, mustard oil or shea butter, “4” for Animal dung or dirt/mud/ash, “5” for Other *(specify)*, or “9” for Don’t know. Also see general instruction 8. |
| **N2114**  ***(10115)*** | **Were there any bruises or signs of injury on the baby’s body at birth?**  **Why ask this:** The baby may be injured during a difficult birth, may present signs of injury such as a large bruise, swelling on the head, or broken bone which may lead to death of the child.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2115**  ***(10370)*** | **Was any part of the baby physically abnormal at the time of delivery? (for example: body part too large or too small, additional growth on body**  **Why ask this:** An abnormal shape of limb due to physical deformity, or any external physical abnormality can cause difficult labor, and can also be associated with other congenital malformations of internal organs which could be the cause of death. Some examples of physical abnormalities are the back or lip being open, or a limb not being shaped normally.This information can help to determine the cause of death.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2117. |
| **N2116\_1**  ***(10371)*** | **Did the baby/ child have a swelling or defect on the back at the time of birth?**  **Why ask this:** This question specifically enquires about abnormalities affecting the backbone, and can appear as a swelling or defect (absence of bone or tissue) associated with the nervous system. These conditions are very rare, but would be recalled if present.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. |
| **N2116\_2**  ***(10372)*** | **Did the baby/ child have a very large head at the time of birth?**  **Why ask this:** The occurrence of a very large head is also due to conditions affecting the nervous system. This condition is very rare, but is often associated with live birth and survival for some weeks and longer, particularly with treatment. This condition would be recalled by respondents, if present.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If “1,” skip to N2117. |
| **N2116\_3**  ***(10373)*** | **Did the baby/ child have a very small head at the time of birth?**  **Why ask this:** This is usually associated with either stillbirth or survival for only a few hours. This condition is very rare, and noticed by an absence of bones of the top of the head. This is a sensitive issue, so you should be very careful not to upset the respondent while asking this question.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. |
| **N2116\_4** | **Was there any other abnormality?**  **Why ask this:** Another serious abnormality that the respondent noticed might have contributed to the baby’s death. Some examples include the intestines being outside of the body and a large split in the upper lip or the roof of the mouth.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. **Skip**: If the answer is “2,” “8” or “9,” skip to N2117. |
| **N2116\_4ot** | **What was the other abnormality?**  **Why ask this?** We need to know what the other abnormality was in order to determine if it might have contributed to the baby’s death.  **How to do it:** Record any other abnormality that the respondent mentions. |
| **N2117**  ***(10406)*** | **Was the baby blue in color at birth?**  **Why ask this:** Bluish color of the baby at birth is suggestive of some problem affecting the breathing of the baby. Mothers may be able to report that the baby was blue or became dark if carefully probed.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2118**  ***(10111)*** | **Did the baby breathe immediately after birth, even a little?**  **Why ask this:** Healthy babies begin breathing immediately after birth. Normal breathing does not include gasps or weak efforts to breathe. if there was some delay in the onset of breathing, it is an important indicator regarding the potential cause of death; if that is the case, record the answer as NO.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:***  If the answer is “2,” skip to N2120. |
| **N2119**  ***(10112)*** | **Did the baby have difficulty breathing?**  **Why ask this:** Difficulty breathing can indicate a condition such as birth asphyxia, a lung infection or other breathing problem.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2120**  ***(10113)*** | **Was anything done to try to help the baby breathe at birth?**  **Why ask this:** Efforts to help the baby breathe may indicate that the baby was not breathing normally at birth. Efforts to help could be in the form of stimulation/ rubbing of the back/ buttocks, chest compression, or oral resuscitation. This would be readily recalled by the respondent and should be confirmed if there is a positive response. Assistance to breathe could have been provided for both stillbirths as well as live births with delayed/difficult breathing.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2121**  ***(10105)*** | **Did the baby cry immediately after birth, even if only a little bit?**    **Why ask this:** Healthy babies cry immediately or soon after birth, so we want to know how soon the baby cried. The timing of the first cry is indicative of whether the baby’s health was effected by events during the pregnancy, labor or delivery.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. Probe carefully whether the baby cried immediately after birth, and if so, record the response as YES. In some instances, there may have been some delay between birth, and the first cry. In such a case, record the response as NO, and proceed with the next question. ***Skip:*** If the answer is “1,” skip to N2123 |
| **N2122**  ***(10106)*** | **How many minutes after birth did the baby first cry?**  **Why ask this:** If the baby cried immediately, record as “00” minutes. However, if the cry was delayed, then the time it took between birth and the first cry is a helpful indicator to assess whether the baby died from events that occurred during labour or delivery.  **How to do it:** Probe carefully to find out the time and record in minutes. A valid response is between 0-60 minutes. If the baby never cried, use code “98” and cross-check with N2013 (Did the baby ever cry?) in the stillbirth determination section. If N2013 = Yes, then discuss this with the respondent to reconcile. If N2013 should be “No,” then this may have been a stillbirth and you must redo the stillbirth determination section. Record “99” if Don’t know or “88” if Refused to answer. ***Skip:*** If the answer is “98, Never cried,” go to N2126. |
| **N2123**  ***(10107)*** | **Did the baby stop being able to cry?**  **Why ask this:** A baby that that cried at birth may become weak and stop crying later on. This might indicate a severe illness.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9”, skip to N2126. |
| **N2124**  ***(10108)*** | **How many hours before death did the baby stop crying?**  **Why ask this:** The time from when the baby stopped crying to when s/he died provides useful information on the progress of the illness and for diagnosing the cause of death.  **How to do it:** Probe carefully to get the accurate number. If less than 1 hour, mark “00” hours. If the response was more than 98 hours, confirm the response and enter “98”. If the answer is 88, enter "87" so the response won't be automatically coded as refused to answer. Enter "99" for "don't know." Enter "88" for "Refused to answer. |
| **N2126** | **After the birth, was the baby put directly on the bare skin of (your / the mother’s) chest?** *[Show the woman a picture of skin-to-skin position.]*  **Why ask this:** All newborn babies should be placed directly on the bare skin of their mother’s chest as soon after birth as possible unless they have a problem requiring immediate medical care. This promotes bonding between the mother and baby, encourages immediate breastfeeding, and helps keeps the baby warm.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. ***Skip:*** If “2” or “9,” go to N2132. |
| **N2128** | **Before being placed on the bare skin of (your / the mother’s) chest, was the baby wrapped up?**  **Why ask this:** Wrapping a newborn baby in a blanket after birth is a common practice. However, this keeps the baby and mother from being in direct skin-to-skin contact, and so prevents many of the benefits of this practice.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. |
| **Inst\_7: If the delivery was not preterm (N2066 ≠ 1 and N2067 = 9,10) or**  **not in a health facility (N2006 = 1, 11, 12, 99, 88) *→* N2132** | |
| **N2130** | *For babies delivered preterm (N2067<9 months) in a health facility (N2006=2-10), ask:***For how many days was the baby put directly on the bare skin of (your / the mother’s) chest?** *[If less than 1 day, record “00.”]*  **Why ask this:** Mothers that begin KMC with their preterm baby in a health facility should continue this practice after they return home with the baby. It is recommended that KMC continue until the baby reaches 40 weeks of age, including the weeks of gestation plus the weeks after birth.  **How to do it:** Record the number of complete days. Record “00” if less than 1 day. |
| **N2132** | **Did (you / the mother) or a wet nurse ever breastfeed the baby?**  **Why ask this:** Breastfeeding provides the best nutrition and protects newborns against infectious diseases.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” go to N2135. |
| **N2133** | **How long after birth was the baby first put to the breast?** *[If immediately or less than 1 hour, record ’00’ hours.] [If less than 24 hours, record hours; otherwise record days.]*  **Why ask this:** The earliest milk produced by the mother, called colostrum, has a high concentration of antibodies that protect the newborn and infant from infectious diseases. To be most effective in preventing disease, breastfeeding should start within 1 hour after birth unless the baby has a problem that prevents this.  **How to do it:** Record “Immediately” if breastfeeding began within minutes after the birth. Record “Less than 1 hour if breastfeeding began more than a few minutes after the birth, but within 1 hour. Record the number of hours if breastfeeding began 1-23 hours after birth; or the number of days if 1 day or more. Record “9” if Don’t know. Also see general instructions 4, 5a and 6. |
| **N2134** | **On the day before the fatal illness began, was the baby being breastfed?**  **Why ask this:** It is recommended that children be breastfed until they are 2 years old. The answer to this question allows us to know whether the baby was breastfed at least up until the time of the illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know. |
| **N2135** | **On the day before the fatal illness began, was the baby being given any…?** *[Read all options and record “Yes,” “No” or “Don’t know” for each.]*  **Why ask this:** Infants should be exclusively breastfed for the first 6 months of life, meaning they should be given no other liquids or solid foods, including even water. This provides the best nutrition for the baby, while also decreasing the risk of contracting diarrhea from contaminated food or water. If any other liquids or semisolid or solid foods were given, we know that the baby was not being exclusively breastfed.  **How to do it:** Read all the options, one at a time, and mark (“X”) 1 if Yes, 2 if No, or 9 if Don’t know for each. If the answer is “Yes” for option 11 (any other liquid, semisolid or solid food), then specify the other liquid or food. |
| **N2136**  ***(10271)*** | **Was the baby able to suckle or bottle-feed in a normal way during the first day of life?**  **Why ask this:** A healthy baby is able to suckle immediately or soon after birth.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1,” skip to N2138. |
| **N2137**  ***(10272)*** | **Did the baby ever suckle in a normal way?**  **Why ask this:** We want to know if the baby ever suckled in a normal way even if it was not in the first day of life. This question is asked to enquire if there was a normal healthy effort at suckling, or if there was any weakness of lethargy in the suckling effort. Clarify the distinction between ‘normal/healthy’ and weak/lethargic’ effort. Also, suckling could be affected by certain congenital defects of the lips, mouth or throat. Where necessary, explain these aspects of normal and problems with suckling, and record the response accordingly.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2141 |
| **N2138**  ***(10273)*** | **Did the baby stop being able to suckle in a normal way?**  **Why ask this:** Stopping normal suckling might be a sign of a serious illness. In certain infections, such as tetanus, the baby loses the ability to suckle. The mother can recognise this and is able to report such a stoppage if asked carefully.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2141. |
| **N2139**  ***(10274\_a)*** | **How many days after birth did the baby stop suckling?** *[Less than 24 hours = “00” days]*  **Why ask this:** Knowing this might help determine the cause of the baby’s death. The number of days after birth the baby stopped sucking is an important indicator to diagnose neonatal tetanus.  **How to do it:** Enter "99" for "don't know." Enter "88" for "refuse."See general instructions 4 and 6. |
| **N2141**  ***(10219)*** | **During the illness that led to death, did the baby have spasms or convulsions?**  **Why ask this:** Spasms or convulsions might indicate a serious infection of the brain or spinal cord. Convulsions are rapid twitching or jerking movements of the jaw, eyeballs, or parts of the limbs, or sometimes the entire limbs, which frequently subside with the loss of consciousness. The common term for convulsions is fits, and there is often a local term for such movements. If necessary, demonstrate the convulsive movements of limbs (and eyeballs), and record the response accordingly. In neonates, the fits usually involve an isolated body part or the eyes, or twitching of the jaw. Jerking of limbs is very rare.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “9” or “8,” skip to N2144. |
| **N2142**  ***(10275)*** | **Did the baby have convulsions starting in the first 24 hours of life?**  **Why ask this:** This question is to identify the onset of convulsions immediately after birth, within the first day of life, which are likely to be associated with some congenital disorders of the brain or other abnormalities of chemicals in the blood.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1,” skip to N2144. |
| **N2143**  ***(10276)*** | **Did the baby have convulsions starting more than 24 hours after birth?** *[If both N2142 and N2143 = “No,” discuss and reconcile this with the respondent.]*  **Why ask this:** Convulsions occurring after the first day of life could be associated with birth asphyxia, neonatal tetanus or other serious infections of the brain and spinal cord.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2144**  ***(10277)*** | **Did the baby’s body become stiff, with the head arched backwards?**  **Why ask this:** The neonate’s body can become stiff and arched backwards in neonatal tetanus. Mothers can recognise this and report when asked. If the respondent has difficulty in understanding this question, demonstrate a stiff body arching backwards.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2145**  ***(10281)*** | **During the illness that led to death, did the baby become unresponsive or unconscious?**  **Why ask this:** “Unresponsive or unconscious" means the infant was unable to respond to any stimuli such as light, sounds or touch. This can indicate a serious infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “9” or “8,” skip to N2149. |
| **N2146**  ***(10282)*** | **Did the baby become unresponsive or unconscious soon after birth, within less than 24 hours?**  **Why ask this:** This question is to ascertain the timing of unconsciousness, which can help determine whether the cause of the illness is related to events during the pregnancy and birth or after the birth.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1,” skip to N2148. |
| **N2147**  ***(10283)*** | **Did the baby become unresponsive or unconscious more than 24 hours after birth?** *[If both N2146 and N2147 = “No,” discuss and reconcile this with the respondent.]*  **Why ask this:** This question is also to ascertain the timing of unconsciousness, which can help determine whether the cause of the illness is related to events during the pregnancy and birth or after the birth.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2148** | **Was s/he unconscious for more than 24 hours before death?**  **Why ask this:** “Unconscious" means the infant was unable to respond to any stimuli such as light, sounds or touch. This can indicate a serious infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2149**  ***(10286)*** | **During the illness that led to death, did the baby become lethargic, after a period of normal activity?**  **Why ask this:** Lethargy means lack of strength or activity, with dullness in eyes. This sign may not be easily recalled by the respondent. Need to explain carefully what is meant lethargy or to demonstrate how a lethargic baby will look like. Lethargy can indicate a serious infection. If the baby never had a period of normal activity, the answer should be "NO".  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2150**  ***(10287)*** | **During the illness that led to death, did the baby have pus drainage from the umbilical cord stump?**  **Why ask this:** “Pus" is thick, creamy or yellowish liquid. It indicates a serious infection. This is an important source for infection in the neonate, and this sign can be readily recognized and recalled by respondents  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2151**  ***(10287)*** | **During the illness that led to death, did the baby have redness of the umbilical cord stump?**  **Why ask this:** This can indicate the presence of an infection of the cord stump. This is an important source for infection in the neonate, and this sign can be readily recognized and recalled by respondents  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the response is “2,” “8” or “9,” skip to N2153. |
| **N2152** | **Did the redness of the umbilical cord stump extend onto the abdominal skin?**  **Why ask this:** The redness extending to the skin can indicate a more serious infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2153** | **During the illness that led to death, did the baby have skin bumps containing pus or a single large area with pus?**  **Why ask this:** “Pus" is thick, creamy or yellowish liquid. Pus in the skin can indicate a serious skin infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2154**  ***(10288)*** | **During the illness that led to death, did the baby have skin ulcer(s) or pit(s)?**  **Why ask this:** An ulcer is a raw-looking area of the skin that looks scooped out, like a pit. This is a serious infection of the skin.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2155**  ***(10147)*** | **During the illness that led to death, did the baby have fever?**  **Why ask this:** "Fever" means the infant felt hot to the touch, or the temperature measured with a thermometer was abnormally high. Fever usually indicates that an infection is present. Most communities / languages have a local term for fever. Mention the local term for fever in the translated version of the questionnaire, which should be used to probe. Ask this question carefully, and double-check a negative response, which will lead to a skip pattern that misses out several detailed questions about the fever.  **How to do it:** Record: “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2159. |
| **N2157**  ***(10148\_a)*** | **How many days did the fever last?** *[Less than 24 hours = “00” days]*  **Why ask this:** The duration of the fever can help to know how serious it was. In most acute infections, fever is present for at least 1-2 days during the period leading to death. In some chronic infections, fever can be present for a longer duration. Obtaining the approximate duration is helpful in making the diagnosis of the specific infection.  **How to do it:** If less than one day or 24 hours, enter “00”. Use one week = 7 days to determine the number of days. For don’t know, enter “99”. For refused, enter “88.” See general instructions 4 and 6. |
| **N2158**  ***(10149)*** | **Did the fever continue until death?**  **Why ask this:** In the case of fevers of longer duration, it is important to know whether the fever was also a part of the terminal illness period prior to death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. See general instructions 4 and 6. |
| **N2159**  ***(10284)*** | **During the illness that led to death, did the baby become cold to touch?**  **Why ask this:** Coldness of the body indicates body temperature is below normal, and this is associated with serious illness. However, this is a subjective sign, and may not be easily recalled by the respondent.  **How to do it:** Explain carefully what is meant by cold to touch. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2162 (10153). |
| **N2160**  ***(10285)*** | **How many days old was the baby when s/he started feeling cold to touch?** *[Less than 24 hours = “00” days].*  **Why ask this:** Knowing this helps determine whether being cold to touch was part of the baby’s fatal illness.  **How to do it:** Use 1 week = 7 days to determine the number of days. For don't know, enter "99." For refused, enter "88." See general instructions 4 and 6. |
| **N2162**  ***(10153)*** | **Did the baby have a cough?**  **Why ask this:** Cough can be a sign of a lung infection or other health problem related to the throat or chest. Although cough may not be a prominent sign of disease in newborn infants, it can be recalled by the mother, and is a useful diagnostic sign.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2165. |
| **N2163**  ***(10158)*** | **Did s/he make a whooping sound when coughing?**  **Why ask this:** In some instances, the child may make a loud whooping sound while breathing in before a bout of coughing. This is a characteristic sound which may be recalled by the respondent, particularly when the cough was termed to be severe.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2165**  ***(10159)*** | **During the illness that led to death, did the baby have difficulty breathing?**  **Why ask this:** “Difficult breathing" means that the baby was working harder than normal to breathe. This might be accompanied by abnormally noisy breathing, several types of which will be addressed by other questions later in this section of the interview. This could indicate a serious infection or other lung problem.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2167. |
| **N2166** | **At what age did the difficult breathing start?** *[Less than 24 hours = “00” days]*  **Why ask this:** Knowing this might help determine the cause of the baby’s death since different illness conditions with difficult breathing characteristically occur at different ages during the neonatal period.  **How to do it:** See general instructions 4 and 6. |
| **N2166\_1**  ***(10161\_0)*** | **For how many days did the difficult breathing last?** *[Less than 24 hours =”00” days]*  **Why ask this:** The duration of the difficult breathing can help understand the severity of the illness and its relationship to the cause of death.  **How to do it:** Use 1 week = 7 days to determine the number of days. For don't know, enter "99." For refused, enter "88." See general instructions 4 and 6. |
| **N2167**  ***(10166)*** | **During the illness that led to death, did the baby have fast breathing?**  **Why ask this:** “Fast breathing” means the baby was breathing faster than normal. Fast breathing usually accompanies fever, and is one of the signs of pneumonia in neonates. It can also occur soon after birth in preterm babies without an infection. It is a subtle sign, and may not be noticed to be independent of breathlessness or noisy breathing. This is usually a subjective observation of the respondent, so record the response as told, without further probing.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2170*.* |
| **N2168** | **At what age did the fast breathing start?** *[Less than 24 hours = “00” days]*  **Why ask this:** Knowing this might help determine the cause of the baby’s death since different illness conditions with fast breathing characteristically occur at different ages during the neonatal period.  **How to do it:** See general instructions 4 and 6. |
| **N2169**  ***(10167\_a)*** | **For how many days did the fast breathing last?** *[Less than 24 hours = “00” days]*  **Why ask this:** Usually the duration of fast breathing will be similar to the duration of the final illness. If the respondent reports a longer duration of fast breathing than the final illness clarify that you are asking about the fast breathing during the final illness.  **How to do it:** Use 1 week = 7 days to determine the number of days. For don’t know, enter “99”. For refused, enter “88”. See general instructions 4 and 6. |
| **N2170**  ***(10168)*** | **During the illness that led to death, did the baby have breathlessness?**  **Why ask this:** Breathlessness is defined as taking deep breaths, or a having a feeling of or observed to be making an excessive or extra effort to breathe. A short period of breathlessness can occur in association with pneumonia as part of the terminal illness in neonates.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2172. |
| **N2171**  ***(10169\_a)*** | **For how many days did the breathlessness last?** *[Less than 24 hours = “00” days]*  **Why ask this:** Record the number of days for which the child was breathless. A valid duration cannot be longer than the age in days of the deceased.  **How to do it:** Use 1 week = 7 days to determine the number of days.For don't know, enter "99." For refused, enter "88."See general instructions 4 and 6. |
| **N2172**  ***(10172)*** | **During the illness that led to death, did you see the lower chest wall/ribs being pulled in as the baby breathed?** *[Show photo]*  **Why ask this:** Usually the chest wall rises and expands during inspiration. In case of airway obstruction or severe lung disease, there is a reversal, with the lower chest wall (particularly the spaces between ribs) being pulled inwards while breathing in. This can be noticed by a person who is closely caring for the sick neonate.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2173**  ***(10173\_nc)*** | **During the illness that led to death, did her/his breathing sound like any of the following?** *[Demonstrate each sound]*  **Why ask this:** The most common abnormal breath sound is a whistling sound produced in the chest, during the ‘breathing out’ phase of respiration, which is referred to as wheezing. Other abnormal sounds produced during difficult breathing are stridor (while breathing in) and grunting (while breathing out), observed in infants with respiratory illness. VA interviewers should be aware of and be able to describe and/or demonstrate these examples of difficult breathing that produce abnormal sounds, and record the response accordingly.  **How to do it:** Ask about each of the following three symptoms. |
| **N2174**  ***(10173\_nc)*** | **Stridor?** *[Demonstrate stridor]*  **Why ask this:** Stridor occurs when the baby has difficulty breathing in, and indicates a problem/blockage in the upper airway found in the throat.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2175**  ***(10173\_nc)*** | **Grunting?** *[Demonstrate grunting]*  **Why ask this:** Grunting occurs when the baby has difficulty breathing out, and indicates a serious lung infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2176**  ***(10173\_nc)*** | **Wheezing?** *[Demonstrate wheezing]*  **Why ask this:** Wheezing occurs mainly when the baby is breathing out, but might also be heard during inspiration. Wheezing in neonates usually indicates a serious lung infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2177a**  ***(10278)*** | **During the illness that led to death, did the baby have a bulging or raised fontanelle?** *[Show photo]*  **Why ask this:** The fontanelle is a soft spot on the top and toward the front of the baby’s head. 'Bulging' means that it was pushed out and tense when the infant was in a sitting position; when accompanied by fever, this usually indicates there is a severe infection of the brain. Mothers can recognise and report this correctly if it was present. Probe carefully in order to get an accurate response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2177**  ***(10279)*** | **Did s/he have a sunken fontanelle during the illness that led to death?** *[Show photo]*  **Why ask this:** When the body gets dehydrated as in the case of diarrhea, or severe fever, the fontanelle can become depressed or sunken. This may be a difficult sign for the mother or caregiver to notice or recall. However, if probed carefully they can respond correctly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2178**  ***(10289)*** | **During the illness that led to death, did s/he have yellow skin, palms (hand) or soles (foot)?**  **Why ask this:** This asks about generalised yellow discoloration of skin and palms, feet. Sometimes, the yellow discoloration of the eyes may not be easily observed, but that of the whole body may be observed and recalled. The urine is also dark yellow; and there is often a local term for jaundice**,** which is a serious condition that can lead to death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2179**  ***(10265)*** | **During the illness that led to death, did the baby have yellow discoloration of the eyes?**  **Why ask this:** Yellow discoloration of the eyes, known as jaundice is often present in neonates, and is usually mild. However, in the new born, it can occur in relation to problems with the blood group of the mother and baby, particularly observed within 1-2 days after birth. It can also be seen with severe infections. Sometimes in advanced stages there is also yellow discoloration of palms or skin, and if observed, the urine is also of an intense yellow color.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2180**  ***(10233)*** | **During the illness that led to death, did the baby have any skin rash?**  **Why ask this:** "Rash" is a skin abnormality that is not a cut or bruise. It usually appears as a collection of red spots on the skin, or sometimes as a red blotch or a patch on the skin. Sometimes these can get infected, and develop bubbles of pus, or become crusts, which can be associated with the cause of death. Rashes are sometimes associated with irritation, itching or pain.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2181**  ***(10240)*** | **During the illness that led to death, did the baby have an area(s) of skin with redness and swelling?**  **Why ask this:** “Swelling” means the area was raised more than normal. Redness and swelling can indicate a serious infection of the area. Such infections can be associated with fever and can lead to death.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2182**  ***(10239)*** | **During the illness that led to death, did s/he have areas of the skin that turned black?**  **Why ask this:** The skin turning black may mean that there was bleeding inside the skin, which could be due to an infection that caused the death.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. |
| **N2183**  ***(10241)*** | **During the illness that led to death, did the baby bleed from anywhere?**  **Why ask this:** This refers to epsodes of spontaneous abnormal bleeding resulting from a disorder of the blood clotting system, which could be caused by blood cancers, severe infections, liver disease etc. The bleeding could be external, or under the skin, or into internal joints and organs.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2185. |
| **N2184** | *Record from where the baby bled:*  **Why record this:** Knowing this helps determine whether the bleeding was part of the baby’s fatal illness.  **How to do it:** Record the area described by the respondent in the provided space. |
| **N2185**  ***(10181)*** | **During the illness that led to death, did s/he have more frequent loose or liquid stools than usual?**  **Why ask this:** The frequent passage of loose or watery stools, with or without blood, is commonly known as diarrhea. There may be local terms to describe it. Ensure that the local term is included in the translated version of the questionnaire and use the local term to probe.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to N2188. |
| **N2186**  ***(10183)*** | **How many stools did the baby have on the day that loose liquid stools were most frequent?**  **Why ask this:** The frequency of the diarrhea can help to know how serious it was. Ask the respondent the maximum number of times the deceased had diarrhea on any day in the period immediately preceding death.  **How to do it:** Record the number of stools. For don't know, enter "99." For refused, enter "88." See general instructions 4 and 6. |
| **N2187**  ***(10184\_a)*** | **How many days before death did the frequent loose or liquid stools start?**  **Why ask this:** This question is asked to specifically relate the episode of diarrhea to the death. If acute diarrhea, record the number of days from onset to death. If chronic diarrhea, record the duration of the final episode.  **How to do it:** For don't know, enter "99." For refused, enter "88." See general instructions 4 and 6. |
| **N2188**  ***(10186)*** | **At any time during the fatal illness was there blood in the stools?**  **Why ask this:** In some infections, there may be blood in the stools, mostly in children and adults, but rarely in neonates. It is common for this to be observed by carers of sick neonates, if present.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2189**  ***(10188)*** | **During the illness that led to death, did the baby vomit everything?**  **Why ask this:** This means the baby vomited after every feed. We ask this to distinguish single or infrequent episodes of vomiting, which may not be significant, from relentless vomiting, which indicates the presence of a serious illness.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2189a**  ***(10189)*** | **Did s/he vomit in the week preceding death?**  **Why ask this:** This question is asked to confirm whether the patient had an episode of vomiting specifically during the week preceding death. Although this question might seem to be a repetition of the previous question, it provides confirmation about this symptom.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2189b**  ***(10290)*** | **Did the baby appear to be healthy and then just die suddenly?** *[Suddenly means died unexpectedly within 24 hours of being in regular health.]*  **Why ask this:** Newborn infants can appear to be healthy and then die suddenly. This might happen because newborns can have very mild or unrecognized signs of an illness yet be much sicker than they appear to be. Young infants might also sometimes die in their sleep, even if they appeared healthy when they were put to bed in the evening.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |

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| **SECTION 6: SIGNS AND SYMPTOMS ASSOCIATED WITH THE FATAL ILLNESS (FOR INFANT DEATHS 28 DAYS–11 MONTHS OLD)**  ***Read:* Now I’d like to ask you about the pregnancy and <NAME>’s condition in the first month of life.** | | | | | | |
| **C3052**  ***(10367)*** | | | | **How many months long was the pregnancy before birth?**  **Why ask this:** The duration of the pregnancy at the time of delivery is an important factor that could help determine the cause of death of the child. Delivery at less than 8 months of pregnancy is associated with smaller size babies, which carry the risks from breathing problems, birth injuries, and hypothermia (cold to touch). This question tells you the child's gestational age at the time of birth, which indicates whether the birth was early, on time or late. Early and late pregnancies can have extra problems.  **How to do it:** Count completed months from date of last menstrual period until date of delivery. Record completed months. For example, if the answer is 7 and a half months, record “07.” Also see general instructions 4 and 6. A valid response is between 0 and 11. If the response is more than 11 months, confirm the response and enter “11”. For don’t know, enter “99”. For refused, enter “88”. | | |
| **C3053**  ***(10368)*** | | | | **Were there any complications in the late part of the pregnancy (defined as the last 3 months, before labor)?**  **Why ask this:** Complications refer to specific medical conditions that have been sufficient to require medical attention. These could include episodes of high fever, high blood pressure, convulsions, bleeding, leakage of fluid from the birth canal, or slowing or stoppage of the movements of the child, among others.  **How to do it:** Ask carefully giving the above examples, as may be required. Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **C3053a**  ***(10369)*** | | | | **Were there any complications during labor or delivery?**  **Why ask this:** Complications during labor or delivery refer to a fever or infection, leakage of fluid from the birth canal before onset of pain, very slow progression or obstruction of labor, birth canal injuries to the mother, or heavy bleeding, among others.  **How to do it:** Ask carefully, giving the above examples, as may be required. Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **Inst\_4: If no pregnancy complications: (C3053≠1) → Inst\_5** | | | | | | |
| **C3064** | | | | **Did (you / the mother) receive care from any person or health facility for (any of) the pregnancy symptom(s) that started before labor?** *[Read “…for any of…” if she had more than one pregnancy symptom.]*  **Why ask this:** Several pre-labor symptoms can contribute to a poor pregnancy outcome. For example, blurred vision might indicate that the mother has preeclampsia, which can contribute to a preterm delivery. Seeking care for pregnancy symptoms could lead to improved outcomes of the pregnancy.  **How to do it:** Emphasize the word “before” so the respondent knows which symptom(s) you are asking about. Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to Inst\_5. | | |
| **C3065** | | | | **Where did (you / she) receive this care?** *Prompt:* **Was there anywhere else?** *[Probe to identify the type of provider or facility. If the woman was seen by a trained community nurse or midwife at a health facility, then mark the type of facility(ies) (1-3) where the provider was seen. Use option 4 only if the provider was seen outside of a health facility.] [Multiple answers allowed.]*  **Why ask this:** Just as with ANC and the delivery, a trained health professional is best equipped and most knowledgeable to correctly diagnose and treat pregnancy complications. However, also just as with ANC and the delivery, many women seek care from other types of providers. Therefore, we ask about all the providers where women might have sought care for their pregnancy symptoms.  **How to do it:** Keep prompting “Was there anywhere else?” until the respondent says there was nowhere else. See general instructions 7 and 8. | | |
| **Inst\_5: If no labor/delivery complications: (C3053a≠1) → C3071.**  **How to do it:** The next set of questions is about careseeking during labor or delivery, so they will be skipped if there were no labor/delivery complications. | | | | | | |
| **C3066** | | | | **Did (you / she) ever receive or seek any care or treatment for (any of) the labor or delivery symptom(s), including any care or treatment at home?** *[Read “…any of the symptoms” if she had more than one symptom.] [Care includes formal or traditional care but excludes advice.]*  **Why ask this:** This is where we establish whether the mother ever received any care or treatment for her symptoms. “Treatment” means measures taken by the woman herself or another untrained person.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” go to C3071. | | |
| **C3067** | | | | **Where did (you / she) receive or seek this care or treatment, including where the baby was delivered?** *Prompt:* **Was there anywhere else?** *[Probe to identify the types of providers or facilities. If the woman was seen by a trained community nurse or midwife at a health facility, then mark the type of facility(ies) (1-3) where the provider was seen. Use option 4 only if this provider was seen outside a health facility. Use options 5-7 for other persons that provided care outside a health facility.] [Multiple answers allowed.]*  **Why ask this:** This helps us understand how concerned the mother was about the symptoms and what she thought was the right thing to do. People are more likely to seek care from a health provider for symptoms that are of greater concern to them. We also need to know if the woman sought care from a health provider in order to determine which of the following questions to ask.  **How to do it:** Mark all the providers where the woman received or sought care or treatment for her labor/delivery symptoms. Continue to prompt and mark the responses until the respondent says she did not go anywhere else. Also see general instructions 2, 7 and 8. ***Skip:*** If the answer is only options 5-9 (not 1-4), skip to C3071. | | |
| **C3069** | | | | **Did any of the health providers/facilities refer (you / the mother) to where the baby was delivered?** *[This question is asking about referral to another, separate facility (not a different provider in the same facility).]*  **Why ask this:** The fact that the woman had a stillbirth or neonatal death suggests that she had a severe labor or delivery complication. If a health provider cannot properly care for a seriously ill person, they should refer them to a higher level of care that has better equipment and more highly trained providers. Finding that a high percentage of mothers with labor/delivery complications were not referred, especially by lower level facilities such as health posts or community health workers, would suggest that there is a problem with the quality of care. Ideally, a survey of health facilities and providers should be conducted together with the VASA study to obtain more direct information on the quality of care provided in the area.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if “Don’t know. | | |
| **C3071** | | | | **Were there any bruises or signs of injury on the baby’s body at birth?**  **Why ask this:** The baby may be injured during a difficult birth, may present signs of injury such as a large bruise, swelling on the head, or broken bone which may lead to death of the child.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3072**  ***(10370)*** | | | | **Was any part of the baby physically abnormal at the time of delivery (for example: body part too large or too small, additional growth on body)?**  **Why ask this:** An abnormal shape of limb due to physical deformity, or any external physical abnormality can cause difficult labor, and can also be associated with other congenital malformations of internal organs which could be the cause of death. Some examples of physical abnormalities are the back or lip being open, a limb not being shaped normally, the head being too large or small, and the tissues of the back being open with the spine exposed.This information can help to determine the cause of death.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3074. | | |
| **C3073\_1**  ***(10371)*** | | | | **Did the baby/ child have a swelling or defect on the back at the time of birth?**  **Why ask this:** This question specifically enquires about abnormalities affecting the backbone, and can appear as a swelling or defect (absence of parts i.e., bone or tissue) associated with the nervous system. These conditions are very rare, but would be recalled if present.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. | | |
| **C3073\_2**  ***(10372)*** | | | | **Did the baby/ child have a very large head at the time of birth?**  **Why ask this:** The occurrence of a very large head is also due to conditions affecting the nervous system. Again, this condition is very rare, but is often associated with live birth and survival for some weeks and longer, particularly with treatment. This condition is also noticeable and would be recalled by respondents, if present.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If “1” skip to C3074. | | |
| **C3073\_3**  ***(10373)*** | | | | **Did the baby/ child have a very small head at the time of birth?**  **Why ask this:** This is usually associated with either stillbirth or survival for only a few hours. This condition is very rare, and noticed by an absence of bones of the top of the head. This is a sensitive issue, so need to be very careful not to upset the respondent while asking this question.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. | | |
| **C3073\_4** | | | **Was there any other abnormality?**  **Why ask this:** Another serious abnormality that the respondent noticed might have contributed to the baby’s death. Some examples include the intestines being outside of the body and a large split in the upper lip or the roof of the mouth.  **How to do it:** Record “1” if the answer is “Yes,” “2” if “No,” “9” if Don’t know or “8” if Refused to answer. **Skip**: If the answer is “2,” “8” or “9,” skip to C3074. | | |
| **C3073\_4ot** | | | **What was the other abnormality?**  **Why ask this?** We need to know what was the other abnormality in order to determine if it might have contributed to the baby’s death.  **How to do it:** Record any other abnormality that the respondent mentions. | | |
| **C3074** | | | | **Did the baby breathe immediately after birth, even a little?**  **Why ask this:** Healthy babies begin breathing immediately after birth. Normal breathing does not include gasps or weak efforts to breathe. If there was some delay in the onset of breathing, it is an important indicator regarding the potential cause of death, Most babies with such a condition would die in the first month of life, but some might survive the neonatal period and die in the following months.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3075** | | | | **Did the baby cry immediately after birth, even if only a little bit?**    **Why ask this:** Healthy babies cry immediately or soon after birth, so we want to know how soon the baby cried. The timing of the first cry is indicative of whether the baby’s health was affected by events during the pregnancy, labor or delivery.  **How to do it:** In some instances, there may have been some delay (from one to several minutes) between birth, and the first cry. In such a case, record the response as NO, and proceed with the next question. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1,” skip to C3078. | | |
| **C3076** | | | | **How long after birth did the baby first cry?** *[Mark ONE response]*  **Why ask this:** Healthy babies cry immediately or soon after birth, so we want to know how soon the baby cried. If the cry was delayed, then the time it took between birth and the first cry is a helpful indicator to assess whether the baby died from events that occurred during labor or delivery.  **How to do it:** Discuss with the respondent and enter one response. For don’t know, enter “9”. For refused, enter “8”. | | |
| **C3078** | | | | **After the birth, was the baby put directly on the bare skin of (your / the mother’s) chest?** *[Show the woman a picture of skin-to-skin position.]*  **Why ask this:** All newborn babies should be placed directly on the bare skin of their mother’s chest as soon after birth as possible unless they have a problem requiring immediate medical care. This promotes bonding between the mother and baby, encourages immediate breastfeeding, and helps keeps the baby warm.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know. ***Skip:*** If “2” or “9,” go to C3084 | | |
| **C3080** | | | | **Before being placed on the bare skin of (your / the mother’s) chest, was the baby wrapped up?**  **Why ask this:** Wrapping a newborn baby in a blanket after birth is a common practice. However, this keeps the baby and mother from being in direct skin-to-skin contact, and so prevents many of the benefits of this practice.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if Don’t know. | | |
| **Inst\_6: If the delivery was not preterm (C3052=9,10) or**  **not in a health facility (C3006=1, 11, 12, 99, 88) *→* C3084** | | | | | | |
| **C3082** | | | | *For babies delivered preterm (C3052<9 months) in a health facility (C3006=3-10), ask:***For how many days was the baby put directly on the bare skin of (your / the mother’s) chest?** *[If less than 1 day, record “00.”]*  **Why ask this:** Mothers that begin KMC with their preterm baby in a health facility should continue this practice after they return home with the baby. It is recommended that KMC continue until the baby reaches 40 weeks of age, including the weeks of gestation plus the weeks after birth.  **How to do it:** Record the number of complete days. Record “00” if less than 1 day. Record “99” if don’t know. | | |
| **C3084**  ***(10271)*** | | | | **Was the baby able to suckle or bottle-feed within the first 24 hours after birth?**  **Why ask this:** A healthy baby is able to suckle immediately or soon after birth. Normal suckling or feeding is a sign of good health in the newborn. Absence of suckling at birth is indicative of certain conditions.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1,” skip to C3086. | | |
| **C3085**  ***(10272)*** | | | | **Did the baby ever suckle in a normal way?**  **Why ask this:** We want to know if the baby ever suckled in a normal way even if it was not in the first day of life. This question is asked to enquire if there was a normal healthy effort at suckling, or if there was any weakness of lethargy in the suckling effort. Clarify the distinction between ‘normal/healthy’ and weak/lethargic’ effort. Also, suckling could be affected by certain congenital defects of the lips, mouth or throat. Where necessary, explain these aspects of normal and problems with suckling, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3089 | | |
| **C3086**  ***(10273)*** | | | | **Did the baby stop being able to suckle in a normal way?**  **Why ask this:** Stopping normal suckling might be a sign of a serious illness. In certain infections, such as tetanus, the baby loses the ability to suckle. The mother can recognise this and is able to report such a stoppage if asked care.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3089. | | |
| **C3087\_units**  **C3087\_b**  **C3087\_c**  ***(10274\_units 10274\_b 10274\_c)*** | | | | **How long after birth did the baby stop suckling?**  **Enter how long after birth the baby stopped suckling in days:**  **Enter how long after birth the baby stopped suckling in months:**  **Why ask this:** Knowing this might help determine the cause of the baby’s death. The number of days after birth the baby stopped sucking is an important indicator to diagnose neonatal tetanus and other causes of neonatal sepsis (severe infection).  **How to do it**: Select the best unit according to the response – days or months. A valid response is between 0-30 days or 1-11 months. For less than 1 day or 24 hours, enter “00” days. Use 1 week = 7 days. A likely response is less than 12 months. If the response given was greater than 11 months, confirm the response, and enter “11”. See general instructions 4 and 6. ***Skip:*** If C3087\_units = “2,” skip to C2087c. If C3087\_units = “8” or “9,” skip to C3088. If the response is in days, after completing C3087\_b skip to C3088. For C3087\_b and C3087\_c, record “99” if the answer is Don’t know. | | |
| **C3089** | | | | **During the illness that led to death, did the baby become cold to touch?**  **Why ask this:** Coldness of the body indicates that body temperature is below normal, and this is associated with serious illness. However, this is a subjective sign, and may not be easily recalled by the respondent.  **How to do it:** Explain carefully what is meant by cold to touch. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip*:** If the answer is “2,” “8” or “9,” skip to C3091. | | |
| **C3090** | | | | **At what age did the baby start feeling cold to touch?**  **Why ask this:** Coldness of the body indicates body temperature is below normal, and this is associated with serious illness. However, this is a subjective sign, and may not be easily recalled by the respondent.  **How to do it:** Record in days if less than 1 month, or in months if 1 month or more. Less than 24 hours = “00” days.See general instructions 4 and 6. For don't know, enter "99". For refused, enter "88". | | |
| **C3091**  ***(10275)*** | | | | **Did the baby have convulsions starting in the first 24 hours of life?**  **Why ask this:** Convulsions in newborns are observed as jerking movements of limbs or eyeballs. This question is to identify the onset of convulsions immediately after birth, within the first day of life, which are likely to be associated with some congenital disorders of the brain or other abnormalities of chemicals in the blood.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “1. Yes,” then skip to C3093. | | |
| **C3092**  ***(10276)*** | | | | **Did the baby have convulsions starting more than 24 hours after birth?**  **Why ask this:** Convulsions occurring after the first day of life could be associated with birth asphyxia, neonatal tetanus, and other causes of neonatal sepsis (severe infection).  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3093**  ***(10277)*** | | | | **Did the baby’s body become stiff, with the head arched backwards?**  **Why ask this:** The neonate’s body can become stiff and arched backwards in neonatal tetanus. Mothers can recognise this and report when asked. A baby with neonatal tetanus would die in the first month of life without good medical care. If a baby survives the first month, it might suffer complications leading to death in the following months.  **How to do it:** If the respondent has difficulty in understanding this question, demonstrate a stiff body arching backwards. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3094**  ***(10278)*** | | | | **During the illness that led to death, did the baby have a bulging or raised fontanelle?** *[Show photo]*  **Why ask this:** The fontanelle is a soft spot on the top of the baby’s head, which can get swollen and raised when there is an infection of the brain. 'Bulging' means that it was swollen and pushed out and tense when the infant was in a sitting position. Mothers can recognise and report this correctly if it was present.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3095**  ***(10279)*** | | | | **Did s/he have a sunken fontanelle during the illness that led to death?** *[Show photo]*  **Why ask this:** When the body gets dehydrated as in the case of diarrhea, or severe fever, the fontanelle can become depressed or sunken, and can be clearly recognized by the caregiver.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3096** | | | | **During the illness that led to death, did the baby become lethargic, after a period of normal activity?**  **Why ask this:** Lethargy means lack of strength or activity, with dullness in eyes. This sign may not be easily recalled by the respondent.  **How to do it:** Explain carefully what is meant by lethargy or to demonstrate how a lethargic baby will look like. If the baby never had a period of normal activity –the answer should be "NO". Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **C3097**  ***(10281)*** | | | | **During the baby’s first month of life, did s/he become unresponsive or unconscious?**  **Why ask this:** “Unresponsive or unconscious" means the infant was unable to respond to any stimuli such as light, sounds or touch. This can indicate a serious infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “No,” Don’t know” or “Refused to answer,” then skip to C3101. | | |
| **C3098**  ***(10282)*** | | | | **Did the baby become unresponsive or unconscious soon after birth, within less than 24 hours?** *[See 10271 on p. xx]*  **Why ask this:** “Unresponsive or unconscious" means the infant was unable to respond to any stimuli such as light, sounds or touch. This can indicate a serious infection.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “Yes,” skip to C3101. | | |
| **C3099**  ***(10283)*** | | | | **Did the baby become unresponsive or unconscious more than 24 hours after birth?** *[If both C3098 and C3099 = “No,” discuss and reconcile this with the respondent.]*  **Why ask this:** “Unresponsive or unconscious" means the infant was unable to respond to any stimuli such as light, sounds or touch. This can indicate a serious infection. A sick infant could be sleeping for long periods, so identifying unconsciousness might require checking whether they could not be aroused even for feeding. Prolonged unconsciousness suggests that there is a disease or disorder of the brain or central nervous system. A short period of unconsciousness usually precedes death, even without a brain disorder or disease.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **SECTION 7: PREVENTIVE CARE OF POST-NEONATES (FOR CHILD DEATHS 28 DAYS—11 YEARS OLD)**  *Read:***Now I would like to ask you (some more questions) about the care of the child before the fatal illness began.** *[For children 1-11 months old, include the words “some more questions.”]*  **Why read this:** This bridge statement indicates that the following questions are about the care of the child. We ask these questions for all children 1 month to 11 years old, but include the words “some more questions” for children 1-11 months of age because above we already asked some questions about the care of these younger children.  **How to do it:** Always see general instruction 2 to help decide how to read the questions. | | | | | | |
| **Inst\_7a: If Q1102 ≠ “1.High” *→*  Inst\_7b** | | | | | | |
| **C3101** | | | | *Skip C3101 in areas without malaria.*  **Before (her / his) fatal illness began, did <NAME> sleep under an insecticide treated bed net?**  **Why ask this:** Regularly sleeping under a bed net can protect the child from mosquitoes that carry malaria parasites. Malaria can be a severe disease leading to death. Insecticide treated” means that the bed net has been impregnated with insecticide to discourage mosquitoes from even landing on the net. Mosquitoes that do land on the net are unable to gain entry through the tightly woven netting.  **How to do it:** Record one answer: “1” if Usually or always, “2” if Sometimes, “3” if Never or “9” if Don’t know. | | |
| **Inst\_7b: If age >1 year (>23 months) *→* C3111**  ***Skip:*** Questions C3104–C3107 ask about preventive measures that are most important for children 1-23 months old, so they are not asked for older children. | | | | | | |
| **C3104** | | | | **Was <NAME> ever breastfed?**  **Why ask this:** Breastfeeding provides the best nutrition for infants and protects them against infectious diseases.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to C3107. | | |
| **C3106** | | | | **Was <NAME> being breastfed on the day before the fatal illness began?**  **Why ask this:** It is recommended that children be breastfed until they are 2 years old. The answer to this question allows us to know whether the child was breastfed at least up until the time of the illness.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “1,” skip to C3107. | | |
| **C3106A** | | | | **How old was the child when s/he stopped breastfeeding?** *[Enter 1-23 months.]*  **Why ask this:** Infants should be exclusively breastfed for the first 6 months of life. This will give information about breastfeeding of the child and also enable calculation of whether breastfeeding was stopped when the child became ill.  **How to do it:** Enter the number of months in the space provided. Enter “99” if “Don’t know.” | | |
| **C3107** | | | | **On the day before the illness began, was <NAME> being given any…?** *[Read all options and record “Yes,” “No” or “Don’t know” for each.]*  **Why ask this:** Infants should be exclusively breastfed for the first 6 months of life. At that time, complementary feeding should begin with other liquids and solid, semi-solid and soft foods. When we analyze the VASA data, we will examine whether a nutritious diet was being received according to the child’s age.  **How to do it:** Read all the options, one at a time, and mark (“X”) “1” if Yes, “2” if No, or “9” if Don’t know for each. If the answer is “Yes” for option 6 (any other liquids), then specify the other liquid. | | |
| **Inst\_7c: If age<1 year *→* C3112**  ***Skip*:** Questions C3111 are about vaccinations. We only ask these for children 1 year or older because they are the ones who might have completed all childhood vaccinations. | | | | | | |
| **C3111** | | | | **Did <NAME> ever receive any vaccinations to prevent her/him from getting diseases, including vaccinations received in a national immunization day campaign?**  **Why ask this:** We want to do our best to identify the vaccinations that the child received. At the end of the vaccination questions, you will record the source of the information.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” go to C3112. | | |
| *Ask the respondent to see the child’s vaccination or health card, and record the below vaccinations from the card. If there is no card or if the card is incomplete, then read as necessary:* **Please tell me if <NAME> received any of the following vaccinations:** |  | |
|  | | **.1** | | **Did <NAME> ever receive a BCG vaccination against tuberculosis, that is, an injection in the arm or shoulder that usually causes a scar?**  **Why ask this:** BCG vaccination prevents children from getting sick with meningitis from the tuberculosis bacteria. This is a serious illness that can cause death.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. | | |
| **.2** | | **Did s/he ever receive oral polio vaccine, that is, about two drops in the mouth to prevent polio?**  **Why ask this:** Polio vaccination prevents children from getting sick with polio. This is a serious illness that can cause death or paralysis.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If “2” or “9,” skip to C3111.5 | | |
| **.3** | | **Did <NAME> receive the first oral polio vaccine in the first two weeks after birth or later?**  **Why ask this:** Children should receive four doses of the oral polio vaccine. It is best for the first dose to be given just after birth.  **How to do it:** Record “1” if First two weeks after birth, “2” if Later, or “9” if Don’t know. | | |
| **.4** | | How many times did <NAME> receive the oral polio vaccine?  **Why ask this:** Children should receive four doses of the oral polio vaccine.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **.5** | | **Did <NAME> ever receive a DPT vaccination, that is, an injection in the thighs or buttocks, sometimes given at the same time as polio drops or a Hep B vaccination?**  **Why ask this:** DPT vaccination prevents children from getting sick with diphtheria, pertussis and tetanus. These are all serious illnesses that can cause death.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If answered “2” or “9,” skip to C3111.7. | | |
| **.6** | | **How many times did s/he receive a DPT vaccination?**  **Why ask this:** In many countries, DPT vaccination is given three or more times by the age of 18 months, with an extra dose given around the age of 5 years. However, this varies by country. When we analyze the VASA data, we will examine whether the required number of DPT vaccinations was received according to the child’s age.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **.7** | | **Did <NAME> ever receive a PENTA (DPT+HepB+Hib) vaccination, that is, an injection in the thighs or buttocks instead of a Hep B or DPT vaccination, sometimes given at the same time as polio drops?**  **Why ask this:** PENTA includes the DPT, Hep B and Hemophilus influenza vaccines. In many countries, PENTA is now given instead of these separate vaccinations. Some children may have received one of the older vaccines when they were younger, and then PENTA after it was introduced to the country.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If answered “2” or “9” skip to C3111.9. | | |
| **.8** | | **How many times did s/he receive a PENTA (DPT+HepB+Hib) vaccination?**  **Why ask this:** Some children may have received all PENTA doses, instead of DPT or Hep B. But children who already received one or more DPT or Hep B doses may receive fewer PENTA doses. When we analyze the VASA data, we will examine whether the required number of PENTA and/or DPT vaccinations was received according to the child’s age.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **.9** | | **Did <NAME> ever receive a pneumococcal (PCV) vaccination, that is, an injection in the shoulder or thigh at the age of 6 weeks or older?**  **Why ask this:** Pneumococcal vaccination prevents serious illnesses and death causes by the pneumococcus bacteria, including pneumonia and meningitis.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If answered “2” or “9,” go to C3111.11. | | |
| **.10** | | **How many times did s/he receive a PCV vaccination?**  **Why ask this:** In many countries, PCV vaccination is given three or more times by the age of 18 months, with an extra dose given around the age of 5 years. However, this varies by country. When we analyze the VASA data, we will examine whether the required number of PCV vaccinations was received according to the child’s age.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **.11** | | **Did <NAME> ever receive a rotavirus (RV) vaccination, that is, a liquid medication given by putting drops in the baby’s mouth, sometimes given around the same time as polio drops or a Hep B vaccination?**  **Why ask this:** Rotavirus is the most common cause of serious viral diarrhea in young children in developing countries. Vaccination against this virus can prevent many cases of serious diarrhea and death.  **How to do it:** Record “Yes,” “No” or “Don’t know.” ***Skip:*** If answered “No” or “Don’t know,” go to C3111.13. | | |
| **.12** | | **How many times did s/he receive a rotavirus vaccination?**  **Why ask this:** There are two different versions of the rotavirus vaccine. One version requires that two doses be given, while the other requires three doses. In order to determine whether the child received the full vaccination series, it will be necessary to check which version of the vaccine is used in your country.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **.13** | | **Did <NAME> ever receive an Inactivated polio vaccine (IPV), that is, an injection in the shoulder or thigh at the age of 6 weeks or older to prevent polio?**  **Why ask this:** All countries give children at least one dose of IPV, either instead of, or in addition to OPV.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if Don’t know. | | |
| **.14** | | **Did <NAME> ever receive a measles or MMR vaccination, that is, a shot in the arm at the age of 9 months or older, to prevent measles?**  **Why ask this:** Measles vaccination is usually given at age 9 to 12 months. When we analyze the VASA data, we will examine whether the measles vaccination was received according to the child’s age.  **How to do it:** Record “Yes,” “No” or “Don’t know.” ***Skip:*** If answered “No” or “Don’t know,” skip to C3111A. | | |
|  | | **.15** | | **How many times did s/he receive the measles or MMR vaccination?**  **Why ask this:** Measles vaccination is usually given at age 9 to 12 months. When we analyze the VASA data, we will examine whether the measles vaccination was received according to the child’s age. MMR should be administered several times so it is important to know how many times it was administered.  **How to do it:** Record the number of times. Record “99” if don’t know. See general instructions 4 and 6. | | |
| **C3111A** | | | | *Record the source of the vaccination information.*  **Why do this:** Information from the child’s health card is generally more reliable than from a respondent’s recall. Therefore, it is preferred to collect this information from the health card if available.  **How to do it:** Record the source of the information: 1. Child’s health card, 2. Respondent’s recall (no card was available or seen) or 3. Health card AND respondent’s recall. See general instructions 4 and 6. | | |
| **C3112** | | | | **(Before / In the six months before) the fatal illness, did <NAME> receive at least one dose of Vitamin A?** *[Read “Before…” if the child lived less than 6 months.] [Show ampoule/capsule/syrup]*  **Why ask this:** Vitamin A deficiency of pregnant women and children is a common problem in many developing countries that leads to childhood blindness and increased mortality. Receiving supplementary Vitamin A has been shown to decrease mortality in children over 6 months of age, and possibly also in younger children whose mothers were vitamin A deficient during their pregnancy.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if Don’t know. | | |
| **SECTION 8: SIGNS AND SYMPTOMS ASSOCIATED WITH THE FATAL ILLNESS (FOR CHILD DEATHS 28 DAYS – 11 YEARS OLD)**  *Read:* **Now I’d like to ask you (some more questions) about <NAME>’s illness.** *[For children 28 days-11 months old, include the words “some more questions.”]*  **Why read this:** This bridge statement indicates that the following questions are about the child’s illness.  **How to do it:** See general instruction 2 to decide how to read the questions. | | | | | | |
| **C3121**  ***(10147)*** | | | **During the illness that led to death, did <NAME> have a fever?**  **Why ask this:** "Fever" means the child felt abnomally warm or hot to the touch, or the temperature measured with a thermometer was abnormally high. Fever usually indicates that an infection is present and is associated with other symptoms.  **How to do it:** Record: “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to C3127. | | | |
| **C3122** | | | **At what age did the fever start?**  **Why ask this:** The age at which the fever began can help relate the symptom to the actual cause of death since different illnesses are more or less common at particular ages. In case the illness began in a neonate who survived beyond the first month of life, this can also help us identify neonatal causes of death in infants up to 1 year old.  **How to do it:** Record in days if less than 1 month, or in months if 1 to 11 months, or in years if 1 year or more. Less than 24 hours = “00” days. Record “99” days, months and years if don’t know. | | | |
| **C3123\_units**  **C3123\_b**  **C3123\_c**  ***(10148\_units)***  ***(10148\_b)***  ***(10148\_c)*** | | | **How long did the fever last?**  **Enter how long the fever lasted in days:** if the fever lasted 0-30 days.  **Enter how long the fever lasted in months:** if the fever lasted 1-60 months.  **Why ask this:** In most infections, fever is present for several days during the period leading to death. Obtaining the approximate duration of the fever can help to know how serious it was and to make the diagnosis of a specific infection.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter "60". ***Skips:*** If the fever lasted months (C3123\_units=2) skip to C3123\_c; if ”8. Refused” or “9. Don’t’ know,” skip to C3124. After entering the number of days the fever lasted in C3123\_b skip to C3124. | | | |
| **C3124**  ***(10149)*** | | | **Did the fever continue until death?**  **Why ask this:** This is important to relate the fever to the actual cause of death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3125**  ***(10150)*** | | | **How severe was the fever?**  **Why ask this:** Knowing this helps determine whether the fever was part of the illness that led to death.  Severity refers to the degree of fever, which may be rather high in some conditions, when the body feels very hot. In many instances, it may be difficult for the respondent to define the severity of fever, hence record the degree of severity perceived and reported by the respondent.  **How to do it:** Record: “1” if Mild, “2” if Moderate, “3” if Severe, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3126**  ***(10151)*** | | | **What was the pattern of the fever?**  **Why ask this:** Some infections produce characteristics patterns of fever – continuous, or on and off, or fever only at night.  **How to do it:** In case the question is not directly understood, mention these different patterns and enquire if the fever followed any of these patterns, and record the response accordingly. Record one code: “1” if Continuous, “2” if On and off, “3” if Only at night, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3127**  ***(10152)*** | | | **Did the child have night sweats?**  **Why ask this:** In some illness like Tuberculosis or some cancers, the person can have excessive sweating at night, which is often noticed by wetness of the bedsheet.  **How to do it:** In case necessary, mention this characteristic i.e. wetness of the bedsheet, to denote whether there was unusual excessive sweating at nights. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3128**  ***(10269)*** | | | **During the illness, did the child have sunken eyes?**  **Why ask this:** Deep sunken eyes may be observed in sick infants and very young children, and is a sign of markedly decreased water in the body. This is an important sign that helps diagnose the cause of death, but is subtle, and may not be easily observed or recalled by the respondent.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3129**  ***(10270)*** | | | **Did s/he drink a lot more water than usual?**  **Why ask this:** The occurrence of increased thirst is also a sign of dehydration, but this usually appears when the dehydration is in an advanced stage, particularly in children. This is a subtle sign, and may not be easily recalled or reported in the presence of more prominent signs of illness.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3130**  ***(10181)*** | | | **During the illness that led to death, did s/he have more frequent loose or liquid stools than usual?**  **Why ask this:** The frequent passage of loose or watery stools, with or without blood, is commonly known as diarrhea. There may be local terms to describe it.  **How to do it:** Ask the respondent about his/her understanding of diarrhea (having more frequent loose or liquid stools than usual); if unclear or wrong, explain to the respondent what is diarrhea.Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3137. | | | |
| **C3130\_units**  **C3130\_a**  **C3130\_b**  ***(10182\_units)***  ***(10182\_a)***  ***(10182\_b)*** | | | **How long did s/he have frequent loose or liquid stools?**  **Enter how long s/he had frequent loose of liquid stools in days:** if the stools lasted 0-30 days.  **Enter how long s/he had frequent loose or liquid stools in months:** if the stools lasted 1-60 months.  **Why ask this:** The longer that the diarrhea lasted, the more likely it is that the child became dehydrated.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter "60". ***Skips:*** If the diarrhea lasted months (C3130\_units=2) skip to C3130\_b; if ”8. Refused” or “9. Don’t’ know,” skip to C3131. After entering the number of days the diarrhea lasted in C3130\_a skip to C3131. | | | |
| **C3131**  ***(10183)*** | | | **How many stools did <NAME> have on the day that loose liquid stools were most frequent?**  **Why ask this:** The frequency of diarrhea can help to know how serious it was. Ask the respondent the most number of times the deceased had diarrhea on any day in the period immediately preceding death.  **How to do it:** Record the number of stools. See general instructions 4 and 6. A valid response is between 0 and 20. If the response was more than 20 stools, confirm the response and enter “20”. For don’t know, enter “99”. For refused, enter “88”. | | | |
| **C3132\_units**  **C3132\_b**  **C3132\_c**  ***(10184\_units)***  ***(10184\_b)***  ***(10184\_c)*** | | | **How long before death did the frequent loose or liquid stools start?**  **Enter how long before death the frequent loose or liquid stools started in days:** if the stools started 0-30 days before death.  **Enter how long before death the frequent loose or liquid stools started in months:** if the stools started 1-60 months before death.  **Why ask this:** This question is asked to specifically relate the episode of diarrhoea to the death. If acute diarrhea (only a few days), record the number of days from onset to death. If chronic diarrhoea (recurrent episodes over several weeks), record the duration of the final episode.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter "60". ***Skips:*** If the diarrhea lasted months (C3132\_units=2) skip to C3132\_c; if ”8. Refused” or “9. Don’t’ know,” skip to C3133. After entering the number of days the diarrhea lasted in C3132\_b skip to C3133. | | | |
| **C3133**  **(10185)** | | | **Did the frequent loose or liquid stools continue until death?**  **Why ask this:** Knowing this helps determine whether the diarrhea was part of the illness that led to death. However, in some instances, the deceased may have slipped into unconsciousness and not consumed food for some time before death, therefore the diarrhea may have stopped before death. Then, the response to this question would need to be taken into consideration along with the responses to other questions in regard to formulating a diagnosis of diarrhea as the cause of death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3135**  ***(10186)*** | | | **At any time during the fatal illness was there visible blood in the loose or liquid stools?**  **Why ask this:** It is common for blood in loose stools to be recognised and recalled by family members of infants or young children with diarrhea.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3137. | | | |
| **C3136**  ***(10187)*** | | | **Was there blood in the stool up until death?**  **Why ask this:** Blood in the stools might indicate that the child had a serious bacterial infection. This is also a confirmatory question for this specific symptom, and contributes to the diagnosis of diarrhea as the cause of death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3137**  ***(10188)*** | | | **During the illness that led to death, did the child vomit?**  **Why ask this:** Vomiting is a well-recognized symptom common to abdominal disease, but can occur in other conditions such as meningitis and other systemic infectious diseases.    **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If “No,” “Don’t know” or “Refused to answer,” skip to C3141. | | | |
| **C3138**  ***(10189)*** | | | **Did s/he vomit in the week preceding death?**  **Why ask this:** Although vomiting may not have been a prominent symptom of the illness that caused death, presence of an episode of vomiting in the preceding week could complicate or exacerbate the illness.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3139**  ***(10191)*** | | | **Did s/he vomit blood?**  **Why ask this:** Vomiting of blood is an important sign of stomach or liver disease, and if of considerable volume, could have precipitated death. Fresh blood in the vomit is easily recognized and creates immediate awareness and concern about the illness. It is important to carefully distinguish between vomiting of blood (contents from the stomach) and coughing of blood (from the chest); as this is sometimes confused among respondents. Clarify with the respondent and note the response accordingly.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3140**  ***(10192)*** | | | **Was the vomit black?**  **Why ask this:** In some instances, there could be minor bleeding into the stomach over a period of hours, before accumulating into sufficient volume to trigger vomiting. In such cases, the contents of the vomitus do not appear as bright red, as the blood gets mixed with other stomach contents and changes color to a blackish, semisolid substance.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3141**  ***(10193)*** | | | **Did s/he have any belly (abdominal) problem?**  **How to do it:** Explain to the respondent that belly problems could be pain, protruding abdomen or a mass.  Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3142**  ***(10194)*** | | | **Did s/he have any belly (abdominal) pain?**  **Why ask this:** The presence of abdominal pain can give an indication as to the nature of the abdominal condition, and could also have led to an attempt to seek medical care or relief for the pain. The pain could be only a discomfort, or could be dull, continuous or cramping in nature. If there is a positive response, try and clarify the nature of the abdominal pain, if possible, to ascertain the accuracy of the response. The respondent may not be able to provide details, in which case record the response as stated.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip***: If “No,” “Don’t know” or “Refused to answer, skip to C3146. | | | |
| **C3143**  ***(10195)*** | | | **Was the belly (abdominal) pain severe?**  **Why ask this:** The severity of the pain can help formulating the diagnosis. Severe pain that resulted in collapse or fainting, and required medical assistance would be recorded as a positive response. Clarify this aspect of severity, and enquire of any associated events with the pain e.g vomiting, restlessness etc.    **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3144\_units**  **C3144**  **C3144\_a**  **C3144\_b**  ***(10196\_units)***  ***10196***  ***10197\_a***  ***10198)*** | | | **For how long did s/he have belly (abdominal) pain?**  **Enter how long she had belly (abdominal) pain in hours:** if the pain lasted less than 1 day (24 hours)  **Enter how long she had belly (abdominal) pain in days:** if the pain lasted 1-30 days  **Enter how long she had belly (abdominal) pain in months:** if the pain lasted 1-60 months  **Why ask this:** The time relationship between the symptom and the event of death is important to determine the cause of death.  **How to do it:** Enter one unit only: hours, days or months. Enter 0-23 hours, 1-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skips:*** For **C3144\_units**, if “2. Days,” skip to C3144\_a; and if “3. Months,” skip to C3144b. If "Don't know" or "Refused to answer" and if the response to C3143 was "Yes", go to C3145. If the response to C3143 was "No", "Don't know" or "Refused to answer", skip to C3146. **For C3144**, if C3143=Yes, go to C3145. If the response to C3143 was "No", "Don't know" or "Refused to answer", skip to C3146. **For C3144\_a**, If C3143 =Yes, go to C3145. If the response to C3143 was "No", "Don't know" or "Refused to answer", go to C3146. **For C3144\_b**, if C3143=Yes, go to C3145. If the response to C3143 was "No", "Don't know" or "Refused to answer", skip to C3146. | | | |
| **C3145**  ***(10199)*** | | | **Was the pain in the upper or lower abdomen?**  **Why ask this:** The site of acute abdominal pain is also an important clue, but this is more of a subjective perception by the deceased, and may not be clearly communicated to the respondent. Hence, it could be difficult for the respondent to provide an accurate recall and response to this question. Show the upper quadrant of the abdomen and ask whether the deceased pointed that area when s/he had the p’lain.  **How to do it:** Record: “1” if Upper, “2” if Lower, “3” if Upper and lower, “9” if Don’t know or “8” Refused. | | | |
| **C3146**  ***(10200)*** | | | **Did s/he have a more than usually protruding abdomen?**  **Why ask this:** An unusually protruding abdomen could be due to distension from obstruction, malnutrition or liver disease. Distension due to obstruction of the intestines starts rapidly and lasts for only a few days because the person would need to seek urgent treatment to survive the condition. With malnutrition, the large size of the belly is in contrast with the thin limbs. More rarely, liver disease in children can cause an accumulation of fluid in the abdomen, and this results in an increase in the size of the belly making it unusually prominent and protruding. There could also be an accumulation of gas and other intestinal contents with obstruction, but this is very rare, as compared to the accumulation of fluid. This increase in size of the belly is often observed and recalled by relatives of the deceased.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3149. | | | |
| **C3147\_unit**  **C3147\_a**  **C3147\_b**  ***(10201\_unit***  ***10201\_a***  ***10202)*** | | | **For how long before death did s/he have a more than usually protruding belly (abdomen)?**  **Enter how long before death s/he had a more than usually protruding belly (abdomen) in days:** if the protruding belly lasted 0-30 days  **Enter how long before death (s)he had a more than usually protruding belly (abdomen) in months:** if the protruding belly lasted 1-60 months  **Why ask this:** The duration of the protruding belly in children that is associated with malnutrition is of relevance.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If C3147\_unit=”2. Months,” skip to C3147\_b; if “9. Don’t know” or “8. Refused to answer,” skip to C3148. | | | |
| **C3148**  ***(10203)*** | | | **How rapidly did s/he develop the protruding abdomen?**  **Why ask this:** The onset and progression of this sign follows different patterns in different conditions; in intestinal obstruction it would be relatively short (a matter of hours – 2 or 3 days); but is more gradual in the other more common conditions such as malnutrition or liver failure.  **How to do it:** Record “1” if Rapidly, “2” if Slowly, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3149**  ***(10204)*** | | | **Did s/he have a mass in the abdomen?**  **Why ask this:** Abdominal mass is a localized swelling or enlargement in one area of the abdomen. This may not be seen visibly by respondents, in which case it could only be reported by the deceased to his relatives, as a sense of heaviness or discomfort.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skipto C3151 *(10153).* | | | |
| **C3150\_unit**  **C3150\_a**  **C3150\_b**  ***(10205\_unit***  ***10205\_a***  ***10206)*** | | | **For how long did s/he have a mass in the belly (abdomen)?**  **Enter how long (s)he had a mass in the belly (abdomen) in days:** if the mass lasted 0-30 days  **Enter how long (s)he had a mass in the belly (abdomen) in months:** if the mass lasted 1-60 months  **Why ask this:** The duration for which the mass was present could help guide the diagnosis. Record the duration in the appropriate response box.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If C3150\_unit = “2”, skip to C3150\_b; if Don’t know or Refused, go to C3151. For days, after completing C3150\_a, go to C3151. | | | |
| **C3151**  ***(10153)*** | | | **During the illness that led to death, did the child have a cough?**  **Why ask this:** Cough is a common symptom and very important sign of infections and other conditions of the respiratory system. Respiratory conditions such as pneumonia are sometimes present during terminal stages of other illnesses, hence a positive response to this question can be found.  **How to do it:** Record: “1” if Yes, “2” if No, or “9” if Don’t know. **Skip**: If answered “2” or “9,” skip to C3158. | | | |
| **C3152\_units**  **C3152\_a**  **C3152\_b**  ***(10154\_units***  ***10154\_b***  ***10154\_c)*** | | | **For how long did s/he have a cough?**  **Enter how long she had a cough in days:** if the cough lasted 0-30 days  **Enter how long she had a cough in months:** if the cough lasted 1-60 months  **Why ask this:** The duration of cough helps determine whether the respiratory condition was the principal illness leading to death, when cough is present along with symptoms pertaining to other body systems. In some cases, there may be frequent, recurrent episodes of cough over several years, so if required, the interviewer should clarify this point with the respondent.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If C3152\_units = “2” go to C3152\_b; if “8” or “9,” go to C3153. For days, after completing C3152\_a, go to C3153. | | | |
| **C3153**  ***(10155)*** | | | **Was the cough productive, with sputum?**  **Why ask this:** Often a person may have just dry cough. When someone is suffering from diseases like pneumonia or TB, a bout of cough could end with the spitting of some secretions produced from the breathing tubes in the chest, which is termed as phlegm (sputum). The secretions could be clear or whitish fluid, or colored (pus), or even blood.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3154**  ***(10156)*** | | | **Was the cough very severe?**  **Why ask this:** Knowing this might help to understand what type of illness the child had. The severity of the cough refers to its prominence among the symptoms present in the deceased.  **How to do it:** “Severe” means that the cough was harsh. It is often difficult define severity. However, one could assess the severity of cough by asking if there were prolonged bouts of cough, or whether the cough was aggravated by a lying down position or physical exertion, and/or it affected sleep. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3155**  ***(10158)*** | | | **Did the child make a whooping sound when coughing?**  **Why ask this:** In some instances, the child may make a loud whooping sound while breathing in before a bout of coughing. This is a characteristic sound which may be recalled by the respondent, particularly when the cough was termed to be severe.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3156** | | | **Did the child vomit after s/he coughed?**  **Why ask this:** Vomiting after coughing would suggest that the cough was very severe.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3157**  ***(10157)*** | | | **Did s/he cough up blood?**  **Why ask this:** A child with pneumonia may produce streaks of blood in the sputum. This may also occur in tuberculosis and lung cancer, but these conditions are relatively rare in children. Presence of blood in the sputum is a readily recognized sign, and something that respondents are likely to remember, as told to them by the deceased or witnessed by them. This sign often also triggers an attempt to seek health care, hence is usually remembered by relatives.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3158**  ***(10159)*** | | | **During the illness that led to death, did <NAME> have difficulty breathing?**  **Why ask this:** Difficult breathing" means that the child was working harder than normal to breathe. This could indicate a serious infection or other lung problem. Breathing difficulties are an important feature that aid in identification of the cause of death, and can be observed by abnormally noisy breathing. Patients with difficulty in breathing usually complain of some obstruction in the airway inside the chest or the airway. The obstruction could produce abnormal sounds.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3161. | | | |
| **C3159\_units**  **C3159\_a**  **C3159\_b**  **C3159\_c**  ***(10161\_unit***  ***10161\_1 10162***  ***10163)*** | | | **For how long did the difficult breathing last?**  **Enter how long the difficult breathing lasted in days:** if the difficult breathing lasted 0-30 days  **Enter how long the difficult breathing lasted in months:** if the difficult breathing lasted 1-60 months  **Enter how long the difficult breathing lasted in years:** if the difficult breathing lasted 1-60 months  **Why ask this:** Duration of the difficult breathing can help understand the severity of the illness and its relationship to the cause of death. In young children with asthma, difficult breathing may be present for months or years. In the case of breathing difficulty with pneumonia, it may be present for a few days up to 1-2 weeks, during the illness. In very young children (neonates and infants), the difficulty may be present only for several hours or up to 2-3 days. Hence, depending on the age and the likely condition, the response on duration of difficulty in breathing could vary.  **How to do it:** Enter one unit only: days, months or years. Enter 0-30 days, 1-11 months or 1 or more years. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If C3159\_units = 2, go to C3159\_b; if “3” go to C3159\_c; if “8. Refused to answer” or “9. Don’t know,” go to C3160. For days or months, after completing C3159\_a or C3159\_b, go to C3160. | | | |
| **C3160**  ***(10165)*** | | | **Was the difficult breathing continuous or on and off?**  **Why ask this:** Knowing this might help determine the cause of the child’s death. The breathing difficulty causing wheezing in asthma is on and off, over months and years, and is an important feature. Noisy difficult breathing associated with childhood pneumonia can be continuous during the illness. In infant pneumonia, noisy breathing occurs only continuously with each breath, during the terminal illness, for only several hours up to 2-3 days prior to death.  **How to do it:** Record: “1” if Continuous, “2” if On and off, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3161**  ***(10166)*** | | | **During the illness that led to death, did <NAME> have fast breathing?**  **Why ask this:** “Fast breathing” means the child was breathing faster than normal. This could indicate a serious infection or other lung problem. Fast breathing usually accompanies fever, and is one of the signs of pneumonia in infants and children. The breathing rate is rapid, but is a subtle sign, and may not be noticed to be independent of breathlessness or noisy breathing. This is usually a subjective observation of the respondent, so record the response as told, without further probing.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to 3164. | | | |
| **C3162** | | | **At what age did the fast breathing start?**  **Why ask this:** Fast breathing may be part of different illnesses that start at different ages. Knowing the age at which the fast breathing started might help determine which of these illnesses caused the child’s death.  **How to do it:** Record the age in days if less than 1 month, in months if 1-11 months, or in years if 12 months or more. Less than 24 hours = “00” days. If Don’t know, enter “99” days, months and years. | | | |
| **C3163\_units**  **C3163\_a**  **C3163\_b**  ***(10167\_units***  ***10167\_b***  ***10167\_c)*** | | | **How long did the fast breathing last?** *[Less than 24 hours = “00” days]*  **Enter how long the fast breathing lasted in days:** if the fast breathing lasted 0-30 days  **Enter how long the fast breathing lasted in months:** if the fast breathing lasted 1-60 months  **Why ask this:** Usually the duration of fast breathing will be similar to the duration of the final illness. If the respondent reports a longer duration of fast breathing than the final illness, then clarify that you are asking about the fast breathing during the final illness.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instruction 4 and 6. ***Skip:*** If C3163\_units = “2,” go to C3163\_b; if “8” or “9,” go to C3164. For days, after completing C3163\_a, go to C3164. | | | |
| **C3164**  ***(10168)*** | | | **During the illness that led to death, did the child have breathlessness?**  **Why ask this:** Breathlessness can be described as a feeling of ‘air hunger’, and is usually observed either as episodic breathlessness as in asthma, or as progressive continuous breathlessness as in heart failure, which may occur in congenital heart disease in children. It usually manifests as having to make an extra effort to breath, including a heaving chest, and prominent use of neck muscles. It may or may not be associated with noisy breathing. A short period of breathlessness can occur in association with pneumonia as part of the terminal illness, commonly observed as fast breathing at rest, particularly in children. Take care to clarify these aspects to the respondent as may be required, and record the response carefully.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3166. | | | |
| **C3165\_unts**  **C3165\_a**  **C3165\_b**  ***(10169\_units***  ***10169\_b***  ***10169\_c)*** | | | **How long did s/he have breathlessness?**  **Enter how long s/he had breathlessness in days:** if the breathlessness lasted 0-30 days  **Enter how long s/he had fast breathlessness in months:** if the breathlessness lasted 1-60 months  **Why ask this:** Usually breathlessness associated with congenital heart disease will last several weeks or months, while breathlessness in the final episode of asthma usually lasts only for a few days. In children with pneumonia, it may also be for a few days only.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instruction 4 and 6. ***Skip:*** If C3165\_units = “2,” go to C3165\_b; if “8” or “9,” go to C3166. For days, after completing C3165\_a, go to C3166. | | | |
| **C3166**  ***(10172)*** | | | *[Ask this question only for children <5 years old.]*  **During the illness that led to death, did you see the lower chest wall/ribs being pulled in as the child breathed?** *[Show photo]*  **Why ask this:** The chest wall usually rises and expands during inspiration. This reverses with airway obstruction or severe lung disease, with the lower chest wall (particularly the spaces between ribs) being pulled inwards while breathing in. This can be noticed by a person who is closely caring for the sick child.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3167**  ***(10173\_nc0)*** | | | **During the illness that led to death, did her/his breathing sound like any of the following?** *[Demonstrate each sound]*  **Why ask this:** These sounds might indicate the presence of a severe breathing problem. The most common abnormal breath sound is a whistling sound produced in the chest, during the ‘breathing out’ phase of respiration, which is referred to as wheezing. | | | |
| **C3168**  ***(10173\_nc1)*** | | | **Stridor?** *[Demonstrate stridor]*  **Why ask this:** “Stridor” sounds like a whistling noise coming from the neck and indicates that the child is having difficulty breathing IN.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3169**  ***(10173\_nc2)*** | | | **Grunting?** *[Demonstrate grunting]*  **Why ask this:** “Grunting” indicates that the child is having difficulty when breathing OUT.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3170**  ***(10173\_nc3)*** | | | **Wheezing?** *[Demonstrate wheezing]*  **Why ask this:** “Wheezing” sounds like a whistling coming from the chest and usually indicates that the child is having difficulty breathing OUT.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3171**  ***(10174)*** | | | **Did s/he have chest pain?**  **Why ask this:** Chest pain has many possible causes that fall into two major categories: cardiac and non-cardiac causes. In children, chest pain largely arises from non-cardiac conditions affecting the respiratory system, mainly pneumonia; non-cardiac chest pain is less severe, usually aggravated by breathing or coughing and lasts several days. This question aims to identify whether chest pain occurred during the illness preceding death, in relation to pneumonia. In cardiac conditions such as heart attack, cardiac chest pain starts suddenly, is often very severe, lasts for about 30 minutes to an hour, and usually subsides only with medical attention.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3173*.* | | | |
| **C3172**  ***(10176)*** | | | **How many days before death did s/he have chest pain?**  **Why ask this:** Pain associated with chest disease such as pneumonia could have been present for several days. It is associated with breathing and is not very severe.  **How to do it:** Record the response in number of days; if less than 1 day or 24 hours, enter “0”. Use 1 week = 7 days. For don’t know, enter “99”. For refused, enter “88”. A valid response is between 0 and 99. If the duration response happens to be 88 days, enter instead “87” so that the response won’t be automatically coded as refused to answer. | | | |
| **C3173**  ***(10207)*** | | | **Did <NAME> have a severe headache?**  **Why ask this:** Headache is a common and usually fairly minor symptom. It is important for the interviewer to stress the word ‘severe’ in order to relate the headache to the potential cause of death. Severe headache can be reported in many conditions including meningitis, malaria and dengue fever; and when reported by a child would generally be considered an important clinical feature.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | | |
| **C3174**  ***(10208)*** | | | **Did <NAME> have a stiff neck during the illness that led to death?**  **Why ask this:** “Stiff neck” means the child was unable to move his/her neck in a normal way, such as the inability to bend the neck forward to touch the chin to the chest, or in difficulty in raising head from the pillow. This can indicate a serious infection of the brain and spine (such as meningitis in children).  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3176. | | | |
| **C3175\_units**  **C3175\_a**  **C3175\_b**  ***(10209\_units***  ***10209\_a***  ***10209\_b)*** | | | **How long before death did s/he have a stiff neck?**  **Enter how long before death did (s)he have stiff neck in days:** if the stiff neck lasted 0-30 days  **Enter how long before death did (s)he have stiff neck in months:** if the stiff neck lasted 1-60 months  **Why ask this:** The duration for which stiff neck was observed is important for determining the diagnosis. It usually lasts for only a few days during the terminal illness prior to death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. *Less than 1 day = “00” days.* See general instruction 4 and 6. **Skip:** If C3175\_units = “2,” go to C3175\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3176. For days, after completing C3175\_a, go to C3176. | | | |
| **C3176**  ***(10210)*** | | | **Did <NAME> have a painful neck during the illness that led to death?**  **Why ask this:** “Painful neck” means the child experienced pain while trying to bend his/her neck forward in a normal way. It is usually associated with stiff neck. The pain is severe enough to cause the child to oppose movement of the neck when someone else tries to bend it forward. This pain can indicate a serious infection of the tissues surrounding the brain.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skip to C3178. | | | |
| **C3177\_units**  **C3177\_a**  **C3177\_b**  ***(10211\_units***  ***10211\_a***  ***10211\_b)*** | | | **How long before death did (s)he have a painful neck?**  **Enter how long before death (s)he had a painful neck in days:** if the painful neck lasted 0-30 days  **Enter how long before death (s)he had a painful neck in months:** if the painful neck lasted 1-60 months  **Why ask this:** Because painful neck is usually associated with stiff neck, they should last about the same amount of time. If the child is reported to have had both a stiff and painful neck that lasted different amounts of time during the illness, then discuss this with the respondent to clarify that s/he understands the meaning of these questions.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. *Less than 1 day = “00” days.* See general instruction 4 and 6. ***Skip:*** If C3177\_units = “2” go to C3177\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3178. For days, after completing C3177\_a, go to C3178. | | | |
| **C3178**  ***(10214)*** | | | **Was <NAME> unconscious during the illness that led to death?**  **Why ask this:** Unconsciousness means the complete inability to arouse the individual with no movement except for breathing. The individual does not respond even to physical stimuli including pain. Death due to any illness is usually preceded by a period of loss of consciousness. This series of questions is oriented toward identifying loss of consciousness as an important specific factor associated with the illness leading to death, usually indicating involvement of the brain. Sometimes there is some hesitation or uncertainty about this question. Even if the response is NO, clarify what is meant by unconsciousness as described above, and proceed to ask the next question.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3182. | | | |
| **C3179\_units**  **C3179\_a**  **C3179\_b**  ***(10216\_units***  ***10216\_a***  ***10216\_b)*** | | | **How long before death did unconsciousness start?**  **Enter how long before death unconsciousness started in hours:** if unconsciousness lasted 0-23 hours  **Enter how long before death unconsciousness started in days:** if unconsciousness lasted 1-99 days  **Why ask this:** Unconsciousness of a longer period is more likely to indicate that the cause of death was specifically related to a problem with the brain.  **How to do it:** Enter one unit only: hours or days. Enter 0-23 hours or 1-98 days. Less than 1 hour = 0 hours; 1 week = 7 days. A likely response is less than 99 days. If the response given was 99 days or greater than 99 days, confirm the response, and enter “98”. ***Skip:*** If C3179\_units = “2,” go to C3179\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3180. For hours, after completing C3179\_a, go to C3180. | | | |
| **C3180**  ***(10217)*** | | | **Did the unconsciousness start suddenly, quickly (at most within a single day)?**  **Why ask this:** Loss of consciousness could occur gradually, occurring off and on over a period of hours/days before the terminal loss of consciousness prior to death. This is usually the case for infectious diseases. This question is aimed at ascertaining sudden loss of consciousness within at most a day, which occurs in cerebrovascular disease, which is rare in children. Clarify this aspect with the respondent as required, and record the response.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3181**  ***(10218)*** | | | **Did the unconsciousness continue until death?**  **Why ask this:** This question confirms the relationship between loss of consciousness for over a day and continuing till death (i.e., a condition known as coma), as a feature of the terminal illness that caused death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3182**  ***(10219)*** | | | **During the illness that led to death, did <NAME> have convulsions?**  **Why ask this:** Spasms or convulsions might indicate a serious infection of the brain or spinal cord. Convulsions are rapid twitching or jerking movements of parts of the limbs or sometimes entire limbs, which frequently subside with the loss of consciousness. The common term for convulsions is fits, and there is often a local term for such movements. Fits are indicative of certain illnesses, including epilepsy, and other diseases which cause abnormal levels of chemicals in the blood that cause fits.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3186\_1*.* | | | |
| **C3183**  ***(10220)*** | | | **Did s/he experience any generalized convulsions or fits during the illness that led to death?**  **Why ask this:** This question refers to convulsions that affect the whole body i.e both arms and both legs, with considerable jerking, and usually subsiding in unconsciousness. In other forms, convulsions affect only one or two limbs, or sometimes only affect the eyeballs/face/clenching or chattering of teeth etc.  **How to do it:** This question refers only to convulsions affecting the whole body, so clarify this aspect, and record the response accordingly. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3186\_1*.* | | | |
| **C3184**  ***(10221)*** | | | **For how many minutes did the convulsions last?**  **Why ask this:** Record the number of minutes the respondent reports for the duration of the convulsion.  **How to do it:** Record the duration in minutes. *Less than 1 minute = “00” minutes*. Use 1 hour=60 minutes to determine the number of minutes. For don’t know, enter “99”. For refused, enter “88”. A valid response is between 0 and 99. If the response was more than 98 minutes, confirm the response and enter “98”. If the answer to duration happens to be 88 minutes, enter instead “87“ so that the response is not automatically coded as refused to answer. | | | |
| **C3185**  ***(10222)*** | | | **Did s/he become unconscious immediately after the convulsion?**  **Why ask this:** Loss of consciousness usually occurs after a generalised convulsion, so a positive response will confirm the occurrence, and thus help aid the diagnosis.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3186\_1**  ***(10223)*** | | | **Did the child have any urine problem?**  **Why ask this:** This is a general question to identify if the deceased had any problems with urination. The key problems with urination that are related to specific causes of death are difficulty in passing urine, passing less or no urine for some period, increased frequency of urination, and passage of blood in the urine.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3189*.* | | | |
| **C3186**  ***(10226)*** | | | **During the fatal illness, did s/he ever pass blood in the urine?**  **Why ask this:** Passage of blood in the urine is a major feature of urinary stones, or bladder or kidney cancer. This can also happen in some parasite infections. There is passage of fresh blood and would be readily observed by the child or his/her carers, which possibly led to seeking of health care. Hence, if this symptom was present, there is a good likelihood of a positive response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3187**  ***(10224)*** | | | **Did s/he stop urinating?**  **Why ask this:** We ask this question because stoppage of urination can be a symptom of obstruction to the canal that carries urine from the bladder out of the body. In other instances, terminal stages of disorders of the kidney can result in the stoppage of urine. Stoppage of urination is also a feature of dehydration associated with diarrheal disease in children. In all these instances, a positive response aids the diagnosis along with other symptoms and signs of the main condition. Clarify with the respondent about the period of relative stoppage of urination, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3188**  ***(10225)*** | | | **During s/he go to urinate more often than usual?**  **Why ask this:** Frequent passage of urine is observed in persons with either severe urinary tract infection or uncontrolled diabetes. The person could have been observed to make frequent visits to the toilet / frequent wetting of bedclothes; during the terminal illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3189**  ***(10227)*** | | | **Did s/he have sores or ulcers anywhere on the body?**  **Why ask this:** Sores are chronic skin ulcers that do not heal, and persist over a long time. They are usually caused by constant pressure, such as those produced on the back as a result of a long-standing bedridden state. Sometimes, they can appear as non-healing conditions as a result of poor health, with a weak immune system, as may occur in childhood malnutrition, or diabetes.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3191. | | | |
| **C3190**  ***(10229)*** | | | **Did the sores or ulcers have pus?**  **Why ask this:** Sores sometimes appear initially as tiny bubbles on the skin, called blisters. “Blisters” are raised skin that contains fluid. Such blisters may be observed in infants or young children, along with fever. Often, the clear fluid changes into pus.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3191**  ***(10230)*** | | | **Did s/he have an ulcer (pit) on the foot?**  **Why ask this:** This item specifically identifies whether the ulcer was located on the foot. In certain conditions, chronic, non-healing ulcers appear on the foot. These ulcers are prone to becoming septic (see next question), and often keep enlarging in size. Presence of such ulcers is a vital clue in the diagnosis of these conditions. This has considerable significance in the case of individuals with diabetes.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3194. | | | |
| **C3192**  ***(10231)*** | | | **Did the ulcer on the foot ooze pus?**  **Why ask this:** The presence of pus in the ulcer is an important diagnostic sign. Pus is a thick fluid which could be green or yellow in color, which continually accumulates on the floor of the ulcer.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3194. | | | |
| **C3193\_units**  **C3193\_a**  **C3193\_b**  ***(10232\_units***  ***10232\_a***  ***10232\_b)*** | | | **How long did the ulcer on the foot ooze pus?**  **Enter how long the ulcer oozed pus in days:** if the ulcer oozed pus 0-30 days  **Enter how long the ulcer oozed pus in months:** if the ulcer oozed pus 1-60 months  **Why ask this:** The duration for which the infected ulcer was present on the foot indicates the severity of the condition, and its potential contribution among the factors causing death. Longer duration also indicates the difficulty in treating or controlling the underlying factors such as diabetes, hence also guiding the diagnosis of the underlying cause of death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If C3193\_units = “2,” go to C3193\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3194. For days, after completing C3193\_a, go to C3194. | | | |
| **C3194**  ***(10233)*** | | | **During the illness that led to death, did <NAME> have a skin rash?**  **Why ask this:** "Rash" is a skin abnormality that is not a cut or bruise. It usually appears as a collection of red spots on the skin, or sometimes as a red blotch or a patch on the skin. It is sometimes associated with irritation, itching or pain.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3198. | | | |
| **C3195\_a**  ***(10235)*** | | | **Where was the rash?**  **Why ask this:** It is important to know where exactly the rash may be located on the body. This is because, the location of the rash is characteristic for certain conditions, and could assist in diagnosing them. Also, this will help us know whether this problem was part of the illness that led to death.  **How to do it:** Record one answer: “1” if Face, “2” if Trunk/Abdomen, “3” if Extremities, “4” if Everywhere, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3195** | | | **Where did the rash start?**  **Why ask this:** The onset of a rash differs for different types of infections, so knowing this can help determine the cause of death.  **How to do it:** Record one answer: “1” if Face, “2” if Trunk/Abdomen, “3” if Extremities, “4” if Everywhere, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3196**  ***(10234)*** | | | **How many days did the rash last?**  **Why ask this:** The duration of the rash will help us understand the severity. Also, because the particular duration of the rash is characteristic for different illnesses, knowing the duration can help determine the cause of death.  **How to do it:** Record the duration in days. Less than 1 day or 24 hours = “00” days. 1 week = 7 days. 1 month = 30 days. For don’t know, enter “99”. For refused, enter “88”. A valid response is between 0 and 98. If the response was more than 98 days, confirm the response and enter “98”. If the answer happens to be 88 days, enter instead “87” so that the response is not automatically coded as refused to answer. | | | |
| **C3197**  ***(10236)*** | | | **Did s/he have a measles rash (use local term)?**  **Why ask this:** Measles is a condition associated with skin rashes, that occurs mostly in early childhood. Occasionally such infections may also occur in older children or adults, but the presentation may not be accompanied by rash, and is usually in the form of fever and respiratory illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3198**  ***(10240)*** | | | **During the illness that led to death, did the child have an area(s) of skin with redness and swelling?**  **Why ask this:** “Swelling” means the area was raised more than normal. Areas of redness and swelling of the skin are indicative of bacterial infections, which in very young children could lead to bacterial sepsis. On occasions, such areas of redness and swelling also occur along with pus filled sores or ulcers, when there is severe generalised skin infection, which is sometimes observed in infants.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3199**  ***(10243)*** | | | **Did <NAME> have noticeable weight loss?** *[hint: limbs (legs, arms) become very thin: Show photo]*  **Why ask this:** This question is about a previously healthy child rapidly losing weight during the illness/ period preceding death. Certain diseases are associated with rapid weight loss, which could be described as ‘becoming very thin and weak’, ‘developing sunken cheeks’, ‘clothes/belt becoming loose’ etc. This is different from the chronically thin child, which is the subject of the next question.  **How to do it:** Clarify these aspects with the respondent to confirm or exclude weight loss, and record the response accordingly. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3199\_1**  ***(10244)*** | | | **Was s/he severely thin or wasted?** *[show photo]*  **Why ask this:** This question aims at identifying malnutrition in the deceased. The individual may have been consistently underweight for a prolonged period, and not have experienced rapid weight loss in the terminal stage. A chronically thin or wasted individual would have had malnutrition which predisposes to several infections leading to death. This is also observed in terminal stages of cancer, and some other chronic diseases which could affect nutritional intake over time.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3200**  ***(10249)*** | | | **During the illness that led to death, did <NAME> have swollen legs or feet?**  **Why ask this:** Swollen feet, ankles and even legs may occur due to the accumulation of fluid in congenital heart disease, or kidney disease, or the presence of malnutrition, among other conditions. Several diseases produce an imbalance in water regulation, resulting in its accumulation in the dependent parts of the body. Such accumulation most often appears as a collection of fluid around the ankles, the presence of which could be recalled by respondents.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3203. | | | |
| **C3201\_units**  **C3201\_a**  **C3201\_b**  ***(10250\_units***  ***10250\_a***  ***10250\_b)*** | | | **How long did the swelling last?**  **Enter how long the swelling lasted in days:** if the swelling lasted 0-30 days  **Enter how long the swelling lasted in months:** if the swelling lasted 1-60 months  **Why ask this:** The duration for which fluid collection was present is important to understand the progression over time of the condition and its severity. It could occur off and on, particularly if the patient was receiving treatment for the condition. Probe carefully and record the number of days for which swollen ankles or legs were present during the terminal illness.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If C3201\_units = “2,” go to C3201\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3202. For days, after completing C3201\_a, go to C3202. | | | |
| **C3202**  ***(10251)*** | | | **Did s/he have both feet swollen?**  **Why ask this:** In some instances, there may be swelling of only one foot, in which case the underlying condition would be different, more likely to be a local condition in the affected leg, rather than heart or kidney disease or malnutrition. Hence, it is important to confirm that the swelling was on both feet.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3203**  ***10247*** | | | **Did s/he have puffiness of the face?**  **Why ask this:** Puffiness or swelling in the face is observed when there is accumulation of fluid (or water) particularly in the spaces/bags around the eyes, and other parts. This accumulation of fluid is in important diagnostic sign, particularly of kidney disease, but also in some hormonal disorders. It can be observed and recalled by respondents, if prominent.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to*C3205.* | | | |
| **C3204\_units**  **C3204\_a**  **C3204\_b**  ***(10248\_units***  ***10248\_a***  ***10248\_b)*** | | | **How long did s/he have puffiness of the face?**  **Enter how long (s)he had puffiness of the face in days:** if the puffiness lasted 0-30 days  **Enter how long (s)he had puffiness of the face in months:** if the puffiness lasted 1-60 months  **Why ask this:** The duration of puffiness of face before death is important to understand the presence of chronic kidney disease. In children with kidney disease resulting from infections, the puffiness would be present only for a few weeks prior to the death. The patient may have been under treatment, in which case the puffiness could have been off and on over several months.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60*”.* ***Skip:*** If C3204\_units = “2,” go to C3204\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3205. For days, after completing C3204\_a, go to C3205. | | | |
| **C3205**  ***(10252)*** | | | **Did s/he have general puffiness all over her/his body?**  **Why ask this:** Long standing disorders lead to fluid accumulation in the soft tissues in different parts of the body including legs, abdomen, arms and hands, face, as well as in the lung. Such generalised fluid accumulation could occur in kidney disease, heart failure and liver failure, and some other rarer causes. Also, the generalised fluid accumulation develops gradually over a period of days to weeks. Clarify these aspects with the respondent, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3206**  ***(10238)*** | | | **During the illness that led to death, did <NAME>’s skin flake off in patches?**  **Why ask this:** In children with long standing malnutrition, the skin becomes extremely dry and tends to break away or peel off in patches. This is a readily recognised and useful diagnostic sign.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3207**  ***(10265)*** | | | **Did s/he have yellow discoloration of the eyes?**  **Why ask this:** Yellow discoloration of the eyes is indicative of diseases of the liver, and is commonly known as jaundice. It is an important sign and readily recognised and recalled if present. Sometimes in advanced stages there is also yellow discoloration of palms or skin, and if observed, the urine is also of an intense yellow color.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3209. | | | |
| **C3208\_units**  **C3208\_a**  **C3208\_b**  ***(10266\_units***  ***10266\_a***  ***10266\_b)*** | | | **For how long did s/he have the yellow discoloration?**  **Enter how long the yellow eyes lasted in days:** if the yellow eyes lasted 0-30 days  **Enter how long the yellow eyes lasted in months:** if the yellow eyes lasted 1-60 months  **Why ask this:** The duration for which yellowish discoloration was present helps indicate the severity of the illness. Ascertain if jaundice was present throughout the terminal illness leading to death, and record the duration of the color change.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If C3208\_units = “2,” go to C3208\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3209. For days, after completing C3208\_a, go to C3209. | | | |
| **C3209**  ***(10267)*** | | | **Did <NAME>’s hair change in color to a reddish or yellowish color?**  **Why ask this:** In children with black colored hair, a change in the hair color to red, dull brown or yellow is indicative of moderate to advanced malnutrition. This may occur in conjunction with other symptoms such as thinness, wasting, and infections.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3210**  ***(10268)*** | | | **Did s/he look pale (thinning/lack of blood) or have pale palms, eyes or nail bed?**  **Why ask this:** Long term deficiency of the blood results in a pale, whitish appearance of the lips, tongue, and eye sac. Sometime it is referred to as thinning of blood. This can be due to chronic blood loss, destruction or decreased production of blood due to infection of cancer. Pale appearance could be recognized and recalled by respondents.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3212**  ***(10255)*** | | | **Did s/he have any lumps on the neck?**  **Why ask this:** This question is to confirm the presence of lumps on the side of the neck. In some instances, the lump may break through the skin and some whitish material or pus may ooze from the lump. In such situations, there is a likelihood of an attempt to seek medical care, and if so, there may be an opinion as to the medical cause for the lump, and the treatment received. Clarify these aspects, and if there is a positive response, note the additional details in the section on access to health care, or in the open narrative section.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3213**  ***(10256)*** | | | **Did s/he have any lumps on the armpit?**  **Why ask this:** This question is to confirm the presence of lumps in the armpit. They could be associated with immune deficiency, infections, or certain forms of childhood cancer. These may have been difficult for the respondent to observe, unless pointed out by the deceased, or notified by a health professional.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3214**  ***(10257)*** | | | **Did s/he have any lumps on the groin?**  **Why ask this:** This question is to confirm the presence of lumps in the groin, which is the junction between the body and the lower limb. Presence of lumps in two or more different locations is also indicative of a condition affecting the body more widely, rather than a local disorder.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3215**  ***(10246)*** | | | **Did s/he have stiffness of the whole body or was unable to open the mouth?**  **Why ask this:** Certain nervous system infections particularly in very young children result in complete stiffness and rigidity (tightness) of the back and all limbs, along with a tight jaw with inability to open the mouth. This is usually a dramatic sign and can be recalled by respondents who have cared for the deceased child during the terminal illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3216**  ***(10258)*** | | | **Was s/he in any way paralyzed?**  **Why ask this:** Paralysis implies the weakness or loss of strength or power in certain parts of the body. The weakness may be partial or sometimes total, with complete loss of power. Paralysis is an important feature of diseases or injuries to the nervous system.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3219*.* | | | |
| **C3217**  ***(10259)*** | | | **Did s/he have paralysis of only one side of the body?**  **Why ask this:** Paralysis of one side of the body (right arm and leg; or left arm and leg) is a classical feature of disease of the blood supply to the brain, which is one of the common causes of death among adults and the elderly in most populations. It is relatively rare in children. Paralysis of one side of the body is a very clearly recognizable sign and is readily recalled by relatives of the deceased.  **How to do it:** Clarify the presence of this sign, and record the response accordingly. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3218**  ***(10260)*** | | | **Which were the limbs or body parts paralyzed?**  **Why ask this:** It is important to confirm whether the paralysis was affecting only a particular limb, or parts of the body or the whole body.  **How to do it:** Select one answer to mark the specific body parts that were observed to have been paralysed; or mark “9” for Don’t know or “8” for Refused to answer. | | | |
| **C3219**  ***(10261)*** | | | **Did s/he have difficulty swallowing?**  **Why ask this:** Difficulty when swallowing in children could be due to a range of conditions including congenital anomaly of the digestive system, or developmental brain disorders which impair motor functions, , i.e., the function of muscles of the body, including the muscles of the throat, which could affect swallowing. Difficulty in swallowing could also be a feature of infections such as meningitis or cerebral malaria. In such cases, feeding may be associated with cough or vomiting.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3222. | | | |
| **C3220\_unts**  **C3220\_a**  **C3220\_b**  ***(10262\_units***  ***10262\_a***  ***10262\_b)*** | | | **For how long before death did s/he have difficulty swallowing?**  **Enter for how long before death s/he had difficulty swallowing in days:** if the difficult swallowing lasted 0-30 days  **Enter for how long before death s/he had difficulty swallowing in months:** if the difficult swallowing lasted 1-60 months  **Why ask this:** The duration indicates the severity and potential progression of this symptom, and aids with the diagnosis. Presence of the symptom from early ages would suggest a developmental disorder or digestive system anomaly.  **How to do it:** Carefully elicit the duration of the symptom with probing about the onset and progression, and confirm the duration of this symptom till death, and record the response accordingly. Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If C3220\_units = “2,” go to C3220\_b; if “8. Refused to answer” or “9. Don’t know,” go to C3221. For days, after completing C3220\_a, go to C3221. | | | |
| **C3221**  ***(10263)*** | | | **Was the difficulty with swallowing with solids, liquids or both?**  **Why ask this:** In certain conditions, there may be difficulty in swallowing both solids and liquids. Often however, initially, there may be difficulty only in swallowing solids, and later on, difficulty in swallowing of all types of food and drink. In rare instances of a problem with the food pipe the child may have more difficulty with swallowing liquids – with cough, vomiting, etc, but less difficulty with solids. Hence, clarify these aspects to the respondent.  **How to do it:** Record one answer: “1” if Solids, “2” if Liquids or “3” if Both. | | | |
| **C3222**  ***(10264)*** | | | **Did s/he have pain upon swallowing?**  **Why ask this:** In some instances, there could be pain associated with the difficulty in swallowing, as a burning or squeezing pain in the center of the chest, behind the breastbone, or in the upper stomach. Painful swallowing of this nature is specific to certain conditions. When present, it is usually reported by the ill person to her/his attendants. Sometimes respondents cannot distinguish whether there was difficulty or pain on swallowing, hence the question is asked in both ways.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3223**  ***(10245)*** | | | **During the illness that led to death, did <NAME> have a whitish rash inside the mouth or on the tongue?**  **Why ask this:** Whitish patches inside the mouth or on the tongue are indicative of infections in those with very weak immune systems. Immune systems provide a defence for the body to fight against infections. This sign may be difficult for the respondent, unless they are told of this by the patient or by a health care provider. Record the response as reported.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3224**  ***(10241)*** | | | **During the illness that led to death, did <NAME> bleed from anywhere?**  **Why ask this:** This question refers to episodes of spontaneous abnormal bleeding (not associated with injury or at the most only a minor injury) resulting from a disorder of the blood clotting system. Clotting system disorders are caused by blood cancers, severe infections, liver disease etc. .The bleeding could be external, or under the skin, or into internal joints and organs.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to C3226. | | | |
| **C3225**  ***(10242)*** | | | **Did s/he bleed from the nose, mouth or anus?**  **Why ask this:** This question is a follow up question to confirm the abnormal bleeding reported in the previous question. Bleeding from the nose, gums, oral mucosa, and anus is commonly observed in case of bleeding due to blood clotting disorders and infections like dengue and Ebola.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **C3226**  ***(10239)*** | | | **During the illness that led to death, did s/he have areas of the skin that turned black?**  **Why ask this:** We ask this because it might indicate the child had bleeding into the skin, which could be due to an infection that caused the death. Black colored patches of skin are a sign of bleeding under the skin, and is observed in certain disorders of the blood e.g., leukaemia. Black patches are also noticed when there is severe infection with septicaemia, particularly in infants.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | |
| **SECTION 9: SIGNS AND SYMPTOMS ASSOCIATED WITH THE FATAL ILLNESS (FOR ADULT DEATHS 12 YEARS AND ABOVE)**  **Read: Now I’d like to ask you about <NAME>’s illness.** | | | | | | |
| **A4051**  ***(10147)*** | | | | **During the illness that led to death, did <NAME> have a fever?**  **Why ask this:** "Fever" means the deceased felt abnormally warm or hot to the touch, or the temperature measured with a thermometer was abnormally high. Fever usually indicates that an infection is present and is associated with other symptoms.  **How to do it:** Ask this question carefully, and double-check a negative response, which will lead to a skip pattern that misses out several detailed questions about the fever. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4057. | | |
| **A4052\_units**  **A4052\_b**  **A4052\_c**  ***(10148\_units***  ***10148\_b***  ***10148\_c)*** | | | | **How long did the fever last?** *[Less than 24 hours = “00” days]*  **Enter how long the fever lasted in days:** if the fever lasted 0-30 days.  **Enter how long the fever lasted in months:** if the fever lasted 1-60 months.  **Why ask this:** In most infections, fever is present for several days during the period leading to death. Obtaining the approximate duration is helpful in making the diagnosis of the specific infection. The duration of the fever can help to know how serious it was.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. See general instructions 4 and 6. ***Skip:*** If A4052\_units = “2,” go to A4052\_c; if “8. Refused to answer” or “9. Don’t know,” go to A4053. For days, after completing A4052\_b, go to A4053. | | |
| **A4053**  ***(10149)*** | | | | **Did the fever continue until death?**  **Why ask this:** This is important to relate the fever to the actual cause of death.  **How to do it:** Record: “1” if Yes, “2” if No, , “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4054**  ***(10150)*** | | | | **How severe was the fever?**  **Why ask this:** Knowing this helps determine whether the fever was part of the illness that led to death.  Severity refers to the degree of fever, which may be rather high in some conditions, when the body feels very hot. In many instances, it may be difficult for the respondent to define the severity of fever, hence record the degree of severity perceived and reported by the respondent.  **How to do it:** Record one code: “1” if Mild, “2” if Moderate, “3” if Severe, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4055**  ***(10151)*** | | | | **What was the pattern of the fever?**  **Why ask this:** Some infections produce characteristics patterns of fever – continuous, or on and off, or fever only in the evenings. Knowing the pattern might help determine what caused the fever. In case the question is not directly understood, mention these different patterns and enquire if the fever followed any of these patterns, and record the response accordingly.  **How to do it:** Record one code: “1” if Continuous, “2” if On and off, “3” if Only at night, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4056**  ***(10152)*** | | | | **Did the deceased have night sweats?**  **Why ask this:** In some illness like Tuberculosis or some cancers, the person can have excessive sweating at night, which is often noticed by wetness of the bedsheet. In case necessary, mention this characteristic i.e wetness of the bedsheet, to denote whether there was unusual excessive sweating at nights.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4057**  ***(10270)*** | | | | **Did s/he drink a lot more water than usual?**  **Why ask this:** The occurrence of increased thirst is a sign of dehydration, and usually appears when the dehydration is in an advanced stage. This is a subtle sign and may not be easily recalled or reported in the presence of more prominent signs of illness. In adults, increased thirst and drinking of water may be observed in individuals with severe uncontrolled diabetes.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4058**  ***(10181)*** | | | | **During the illness that led to death, did s/he have more frequent loose or liquid stools than usual?**  **Why ask this:** The frequent passage of loose or watery stools, with or without blood, is commonly known as diarrhea.  **How to do it:** Ask the respondent about his/her understanding of what is diarrhea (having more frequent loose or liquid stools than usual); if unclear or wrong, explain to the respondent what is diarrhea.Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4060. | | |
| **A4059\_units**  **A4059\_a**  **A4059\_b**  ***(10182\_units***  ***10182\_a***  ***10182\_b)*** | | | | **How long did s/he have frequent loose or liquid stools?**  **Enter how long (s)he had frequent loose or liquid stools in days:** if the stools lasted 0-30 days.  **Enter how long (s)he had frequent loose or liquid stools in months:** if the stools lasted 1-60 months.  **Why ask this:** This question is asked if the deceased reported having more frequent loose or liquid stools than usual. This could occur over varying periods of time; e.g in conditions such as HIV/AIDS, chronic malnutrition; or celiac disease, the affected individual could have diarrhea over prolonged periods extending over weeks or months. On the other hand, it may be an episode of diarrhea immediately preceding death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4059\_units is “2,” go to A4059\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4060. For days, after completing A4059\_a, go to A4060. | | |
| **A4060**  ***(10186)*** | | | | **At any time during the fatal illness was there blood in the stools?**  **Why ask this:** Blood in stools may be related to the diarrhea, if present; but for adults, it may be independent of diarrhea, and related to colorectal disease. It is common for affected individuals to report this symptom, if present, to family members. Hence, ask this question carefully even if there was no history of diarrhea.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip***: If the answer is “No,” “Don’t know” or “Refused to answer,” skip to A4062. | | |
| **A4061**  ***(10187)*** | | | | **Was there blood in the stools up until death?**  **Why ask this:** diarrhea This is a confirmatory question for this specific symptom of passing blood in the stool. Persistence of bloody stools till death is suggestive of colorectal cancer.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4062**  ***(10188)*** | | | | **During the illness that led to death, did the deceased vomit?**  **Why ask this:** Vomiting is a well-recognised symptom common to abdominal disease, but can occur in other conditions such as meningitis and other systemic infectious disease.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4063**  ***(10189)*** | | | | **Did s/he vomit in the week preceding death?**  **Why ask this:** Although vomiting may not have been a prominent symptom of the illness that caused death, presence of an episode of vomiting in the preceding week could complicate or exacerbate the illness.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “No,” “Don’t know” or “Refused to answer” AND A4062 = “Yes” (s/he vomited), then skip to A4064\_1. If “No,” “Don’t know” or “Refused to answer” AND A4062 ≠ “Yes” (s/he did not vomit, or Don’t know or Refused to answer if she vomited), then skip to A4066. | | |
| **A4064\_units**  **A4064\_a**  **A4064\_b**  ***(10190\_units***  ***10190\_a***  ***10190\_b)*** | | | | **How long before death did s/he vomit?**  **Enter how long before death s/he vomited in days:** if the stools lasted 0-30 days.  **Enter how long before death s/he vomited in months:** if the stools lasted 1-60 months.  **Why ask this:** It is helpful to know the period of time over which the episodes of vomiting were present before death, in order to understand the relationship of this symptom to a potential cause.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4064\_units = “2,” go to A4064\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4064\_1. For days, after completing A4064\_a, go to A4064\_1. | | |
| **A4064\_1**  ***(10191)*** | | | | **Was there blood in the vomit?**  **Why ask this:** Vomiting of blood is an important sign of stomach or liver disease, and if of considerable volume, could have precipitated death. Fresh blood in the vomit is easily r ecognized and creates immediate awareness and concern about the illness. It is important to carefully distinguish between vomiting of blood (contents from the stomach) and coughing of blood (from the chest); as this is sometimes confused among respondents.  **How to do it:** If the response is “Yes,” clarify with the respondent whether the blood is coming from the stomach or the chest. If from the chest, then record “No” for the response. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4065**  ***(10192)*** | | | | **Was the vomit black?**  **Why ask this:** In some instances, there could be minor bleeding into the stomach over a period of hours, before accumulating into sufficient volume to trigger vomiting. In such cases, the contents of the vomitus do not appear as bright red, as the blood gets mixed with other stomach contents and changes color to a blackish, semisolid substance.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4066**  ***(10193)*** | | | | **Did s/he have any belly (abdominal) problems?**  **How to do it:** Explain to the respondent that problems could be pain, protruding abdomen or a mass. Record “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4067**  ***(10194)*** | | | | **Did s/he have belly (abdominal) pain?**  **Why ask this:** The presence of abdominal pain can give an indication as to the nature of the abdominal condition and could also have led to an attempt to seek medical care or relief for the pain. The pain could be only a discomfort, or could be dull, continuous or cramping in nature. In some instances, the pain of a heart attack may be felt or described as an acute pain in the upper abdomen. In general, this question focuses on the presence of a sudden onset of abdominal pain.  **How to do it:** If there is a positive response, try and clarify the nature of the abdominal pain, if possible, to ascertain the accuracy of the response. The respondent may not be able to provide details, in which case record the response as stated. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip***: If the answer is “No,” “Don’t know” or “Refused to answer,” skip to A4071. | | |
| **A4068**  ***(10195)*** | | | | **Was the belly (abdominal) pain severe?**  **Why ask this:** The severity of the pain can help formulating the diagnosis. Severe pain that resulted in collapse and required medical assistance would be recorded as a positive response.  **How to do it:** Probe carefully and ensure that a negative response is recorded only if there was some non-specific, transient pain. Any direct response from the respondent as a "YES" even without qualification should be recorded as such and proceed with the following questions.Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4069\_units**  **A4069\_a**  **A4069\_b**  **A4069\_c**  ***(10196\_units***  ***10196***  ***10197\_a***  ***10198)*** | | | | **For how long did s/he have belly (abdominal) pain?**  **Enter how long s/he had belly (abdominal) pain in hours:** if the pain lasted 0-23 hours.  **Enter how long s/he had belly (abdominal) pain in days:** if the pain lasted 1-30 days.  **Enter how long s/he had belly (abdominal) pain in months:** if the pain lasted 1-60 months.  **Why ask this:** The time relationship between the symptom and the event of death is important to determine the cause of death.  **How to do it:** Enter one unit only: hours, days or months. Enter 0-23 hours, 1-30 days or 1-60 months. Less than 1 hour = 0 hours; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60” months. ***Skip***: If A4069\_units = “2” go to A4069\_b; if “3” go to A4069\_c; if “8. Refused to answer” or “9. Don’t know,” go to A4070. After completing A4069\_a (hours) or A4069\_b (days), go to A4070. | | |
| **A4070**  ***(10199)*** | | | | **Was the pain in the upper or lower belly (abdomen)?**  **Why ask this:** The site of acute abdominal pain is also an important clue, but this is more of a subjective perception by the deceased and may not be clearly communicated to the respondent. Hence, it could be difficult for the respondent to provide an accurate recall and response to this question. Show the upper quadrant of the abdomen and ask whether the deceased pointed that area when S/he had the pain.  **How to do it:** Record: “1” if Upper abdomen, “2” if Lower abdomen, “3” if Upper and lower abdomen, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4071**  ***(10200)*** | | | | **Did s/he have a more than usually protruding belly (abdomen)?**  **Why ask this**: Certain diseases (most commonly liver failure) cause an accumulation of fluid in the abdomen, and this results in an increase in the size of the belly making it unusually prominent and protruding. Also, in case of intestinal obstruction, there could be an accumulation of gas and other intestinal contents, but this is very rare, as compared to the accumulation of fluid. This increase in size of the belly is often observed and recalled by relatives of deceased.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skipto A4074*.* | | |
| **A4072\_unit**  **A4072\_a**  **A4072\_b**  ***(10201\_unit***  ***10201\_a***  ***10202)*** | | | | **For how long before death did s/he have a more than usually protruding belly (abdomen)?**  **Enter how long before death s/he had a more than usually protruding belly (abdomen) in days:** if the pain lasted 0-30 days.  **Enter how long before death s/he had a more than usually protruding belly (abdomen) in months:** if the pain lasted 1-60 months.  **Why ask this:** Distension of abdomen due to obstruction of intestine starts rapidly and last for few days during which time the person would need to seek urgent treatment to survive the condition. It is possible that the deceased would have sought some medical attention for relief, as this condition could be associated with significant discomfort, breathlessness, and reduction in mobility.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4072\_units = “2,” go to A4072\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4073. For days, after completing A4072\_a, go to A4073. | | |
| **A4073**  ***(10203)*** | | | | **How rapidly did s/he develop the protruding abdomen?**  **Why ask this:** The onset and progression of this sign follows different patterns in different conditions; in intestinal obstruction, it would be relatively short (a matter of hours – 2/3 days); but is more gradual in the other more common conditions such as malnutrition or liver failure.  **How to do it:** Record “1” if Rapidly, “2” if Slowly, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4074**  ***(10204)*** | | | | **Did s/he have a mass in the abdomen?**  **Why ask this:** Abdominal mass is a localized swelling or enlargement in one area of the abdomen. This may not be seen visibly by respondents, and could only be reported by the deceased to his relatives, as a sense of heaviness or discomfort.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skipto A4076. | | |
| **A4075\_unit**  **A4075\_a**  **A4075\_b**  ***(10205\_unit***  ***10205\_a***  ***10206)*** | | | | **For how long before death did s/he have a mass in the belly (abdomen)?**  **Enter how long (s)he had a mass in the belly (abdomen) in days:** if the mass lasted 0-30 days.  **Enter how long (s)he had a mass in the belly (abdomen) in months:** if the mass lasted 1-60 months.  **Why ask this:** The duration for which the mass was present could help guide the diagnosis.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4075\_unit = “2” go to A4075\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4076. For days, after completing A4075\_a, go to A4076. | | |
| **A4076**  ***(10153)*** | | | | **During the illness that led to death, did the deceased have a cough?**  **Why ask this:** Cough is a common symptom and very important sign of infections and other conditions of the respiratory system. Respiratory conditions such as pneumonia are sometimes present during terminal stages of other illnesses especially in the elderly, hence a positive response to this question can be found.  **How to do it:** Ask this question with care and double check a negative response, as this will lead to a skip of all other questions on cough. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. **Skip**: If “2,” “8” or “9,” skip to A4081. | | |
| **A4077\_units**  **A4077\_a**  **A4077\_b**  ***(10154\_units***  ***10154\_a***  ***10154\_b)*** | | | | **For how long did s/he have a cough?** *[Less than 24 hours = “00” days]*  **Enter how long s/he had a cough in days:** if the cough lasted 0-30 days.  **Enter how long s/he had a cough in months:** if the cough lasted 1-60 months.  **Why ask this:** Knowing this helps determine whether the cough was part of the illness that led to death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. **Skip:** if A4077\_units = “2,” go to A4077\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4078. For days, after completing A4077\_a, go to A4078. | | |
| **A4078**  ***(10155)*** | | | | **Was the cough productive, with sputum?**  **Why ask this:** Often a person may have just dry cough. When someone is suffering from diseases like pneumonia or TB, a coughing bout could end with spitting of some secretions produced by the breathing tubes in the chest, which is termed as phlegm (sputum). The secretions could be clear or whitish fluid, or colored (pus), or even blood. There is often a local term for phlegm, which should be used to probe.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4079**  ***(10156)*** | | | | **Was the cough very severe?**  **Why ask this:** The severity of the cough refers to its prominence among the symptoms present in the deceased. One could assess the severity of cough by asking whether there were prolonged coughing spells, or the cough was aggravated by lying down position or physical exertion, and/or it affected sleep.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused. | | |
| **A4080**  ***(10157)*** | | | | **Did s/he cough up blood?**  **Why ask this:** A person suffering from diseases such as TB or lung cancer can cough blood or have streaks of blood in the sputum.. Presence of blood in the sputum is a readily recognized sign, and something that respondents are likely to remember, as told to them by the deceased or witnessed by them. This sign often also triggers an attempt to seek health care, hence is usually remembered by relatives.  **How to do it**: In some instances (particularly TB), there may be a considerable amount of frank blood that is coughed up. It is important to distinguish between coughing and vomiting of a large amount of blood; which could occur in liver disease. You need to probe whether the person coughed blood or vomited blood, in order to distinguish between different causes. You may have to demonstrate the difference between coughing and vomiting. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4081**  ***(10159)*** | | | | **During the illness that led to death, did <NAME> have difficulty breathing?**  **Why ask this:** Difficult breathing" means that the person was working harder than normal to breathe. This could indicate a serious infection or other lung problem. Breathing difficulties are an important feature that aid identification of the cause of death, and can be observed by abnormally noisy breathing. Patients with difficulty in breathing usually complain of some obstruction in the airway inside the chest or the airway. The obstruction could produce abnormal sounds, the most common of which is a whistling sound produced in the chest, during the ‘breathing out’ phase of respiration, which is referred to as wheezing.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skip to A4084. | |
| **A4082\_units**  **A4082\_a**  **A4082\_b**  **A4082\_c**  ***(10161\_unit***  ***10161\_\_1***  ***10162***  ***10163)*** | | | | **For how long did the difficulty breathing last?**  **Enter how long the difficult breathing lasted in days:** if the difficult breathing lasted 0-30 days.  **Enter how long the difficult breathing lasted in months:** if the difficult breathing lasted 1-11 months.  **Enter how long the difficult breathing lasted in years:** if the difficult breathing lasted 1-11 years.  **Why ask this:**  Duration of the difficult breathing can help understand the severity of the illness and its relationship to the cause of death. In adults with chronic obstructive lung disease this difficulty is usually present over a prolonged period of many years, and gradually increasing in severity. On the other hand, in heart failure in the elderly, the difficulty may be only in the terminal 1-2 years. In children or young adults with asthma, it is usually for a few years, and may be difficult to recall because of its relationship with different seasons. Hence, depending on the age and the likely condition, the response on duration of difficulty in breathing could vary.  **How to do it:** Enter one unit only: days, months or years. Enter 0-30 days, 1-11 months or 1-11 years. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If A4082\_unit = “2,” go to A4082\_b; if “3” go to A4082\_c; if “8. Refused to answer” or “9. Don’t know,” go to A4083. For days or months, after completing A4082\_a (days) or A4082\_b (months), go to A4083. | | |
| **A4083**  ***(10165)*** | | | | **Was the difficulty breathing continuous or on and off?**  **Why ask this:** As described above, the breathing difficulty causing wheezing in adults is on and off, over months and years, and is an important feature. Clarify whether the difficulty in breathing during the final illness was continuous or on and off.  **How to do it:** Record “1” Continuous, “2” On and off, “9” Don’t know or “8” Refused to answer. | | |
| **A4084**  ***(10166)*** | | | | **During the illness that led to death, did <NAME> have fast breathing?**  **Why ask this:** Fast breathing usually accompanies fever, and is often observed in pneumonia. This is a subtle sign, and may not be noticed to be independent of breathlessness or noisy breathing. This could indicate a serious infection or other lung problem.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skip to A4086. | | |
| **A4085\_units**  **A4085\_a**  **A4085\_b**  ***(10167\_units***  ***10167\_b***  ***10167\_c)*** | | | | **How long did the fast breathing last?**  **Enter how long the fast breathing lasted in days:** if the fast breathing lasted 0-30 days.  **Enter how long the fast breathing lasted in months:** if the fast breathing lasted 1-60 months.  **Why ask this:**  Usually the duration of fast breathing in the case of pneumonia will be similar to the duration of the final illness.  **How to do it:** If the respondent reports a longer duration of fast breathing than the final illness, clarify that you are asking about the fast breathing during the final illness. Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If A4085\_units = “2,” go to A4085\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4086. For days, after completing A4085**\_a,** go to A4086. | | |
| **A4086**  ***(10168)*** | | | | **During the illness that led to death, did the s/he have breathlessness?**  **Why ask this:** Breathlessness can be described as a feeling of ‘air hunger’. It usually manifests as having to make an extra effort for breathing, including a heaving chest, and prominent use of neck muscles. It is commonly observed as episodic breathlessness as in chronic obstructive lung disease or asthma, or as progressive continuous breathlessness as in heart failure. Episodic breathlessness associated with airway obstruction is usually accompanied by cough with sputum, with recurrences increasing in frequency over a period of years. Breathlessness associated with heart disease is usually aggravated by walking and gradually gets worse and a person can become breathless even at rest. However typically it takes weeks or months for someone to progress to the state of breathlessness at rest.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. Skip: If the answer is “2,” “8” or “9,” skip to A4090. | | |
| **A4087\_units**  **A4087\_a**  **A4087\_b**  ***(10169\_units***  ***10169\_b***  ***10169\_c)*** | | | | **How long did s/he have breathlessness?**  **Enter how long s/he had breathlessness in days:** if the breathlessness lasted 0-30 days.  **Enter how long s/he had breathlessness in months:** if the breathlessness lasted 1-60 months.  **Why ask this:**  Usually history of breathlessness associated with heart diseases will be several weeks. However, episodes of breathlessness in chronic obstructive lung disease usually last only for a few days, in the final episode before death; but overall breathlessness may have been present for several years.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4087\_units = “2,” go to A4087\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4088. For days, after completing A4087\_a, go to A4088. | | |
| **A4088**  ***(10170)*** | | | | **Was s/he unable to carry out daily routines due to breathlessness?**  **Why ask this:** Ask whether the deceased was not able to do things like taking bath, dressing up, walking short distance, because of the breathlessness. A person with severe breathlessness will struggle to do these daily routines and will need assistance from someone.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer.  NOTE: This question is asked with a negative intent. A POSITIVE RESPONSE INDICATES THAT THE PERSON WAS ILL. A NEGATIVE RESPONSE INDICATES THAT THE PERSON HAD NO PROBLEM OF THIS NATURE. TAKE CARE IN RECORDING THE RESPONSE ACCURATELY | | |
| **A4089**  ***(10171)*** | | | | **Was s/he breathless while lying flat?**  **Why ask this:** In advanced stages of heart failure or COPD, breathlessness even occurs when lying flat, and often interferes with sleep. In many instances, the person sleeps in a propped-up position with several pillows to support the back and neck. Ask whether the deceased was breathless while lying flat during the final illness and record the response.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4090**  ***(10173\_a)*** | | | | **During the illness that led to death, did s/he have wheezing?** *[Demonstrate the sound.]*  **Why ask this:** “Wheezing” is a whistling sound that comes from the chest and indicates that the person is having difficulty breathing OUT.  **How to How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4091**  ***(10174)*** | | | | **Did s/he have chest pain?**  **Why ask this:** Chest pain has many possible causes that fall into two major categories: cardiac and non-cardiac causes. This question aims to identify whether chest pain occurred during the illness preceding death, and to identify cardiac chest pain related to heart attack. Cardiac chest pain starts suddenly, is often very severe, lasts for about 30 minutes to an hour, and usually subsides only with medical attention. On the other hand, non-cardiac chest pain is less severe, is usually aggravated by breathing or coughing; and lasts several days.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4095*.* | | |
| **A4092**  ***(10175)*** | | | | **Was the chest pain severe?**  **Why ask this:** Severity of chest pain can be judged from descriptions of extreme heaviness or tightness in central chest completely overwhelming all the individual’s functions and activities, with sweating and possibly collapse. Less severe chest pain is associated with breath movements or local tenderness on chest wall and is often non-cardiac chest pain. This is usually tolerated, and brought to the attention of caregivers over time; in contrast to cardiac chest pain which is severe and dramatic in its effects.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4093**  ***(10176)*** | | | | **How many days before death did s/he have chest pain?**  **Why ask this:** Chest pain associated with cardiac disease is usually of acute onset and short duration. It often occurs within 24 hours before death. However, there may have been previous episodes of acute sudden chest pain, or chronic chest pain under medication, which may appear on exercise. If there were multiple episodes, record the duration since the last severe chest pain episode before death.  On the other hand, however pain associated with chest disease such as pneumonia could have been present for several days, and is associated with breathing, and is not very severe.  **How to do it:** Record the number of days. Less than 1 day or 24 hours = “00” days. 1 week = 7 days.See general instruction 4 and 6. For don't know, enter "99." For refused, enter "88." | | |
| **A4094\_units**  **A4094\_a**  **A4094\_b**  **A4094\_c**  ***(10178\_unit***  ***10178***  ***10179***  ***10179\_1)*** | | | | **How long did the chest pain last?**  **Enter how long the chest pain lasted, in minutes:** if the chest pain lasted 0-59 minutes.  **Enter how long the chest pain lasted in hours:** if the chest pain lasted 1-23 hours.  **Enter how long the chest pain lasted in days:** if the chest pain lasted 1 or more days (or if the respondent can answer only “less than 1 day” (This = 0 days).  **Why ask this:** Sometimes, the bout of chest pain leads to unconsciousness and death, within a short period (30 minutes or so) after the onset of chest pain. Acute chest pain of cardiac origin could last for 2-3 hours or so. Hence, the duration of chest pain is important for establishing the diagnosis.  **How to do it:** Enter one unit only: days, months or years. Enter 0-59 minutes, 1-23 hours or 1-30 days. 1 week = 7 days. If days are entered, the number should be equal to or less than the number of days before death s/he had chest pain (the response to A4093). See general instructions 4 and 6. ***Skip:*** If A4094\_unit = “2,” go to A4094\_b; if “3” go to A4094\_c; if “8. Refused to answer” or “9. Don’t know,” go to A4095. For minutes or hours, after completing A4094\_a (minutes) or A4094\_b (hours), go to A4095. | | |
| **A4095**  ***(10207)*** | | | | **Did <NAME> have a severe headache?**  **Why ask this:** Headache is a common and relatively minor symptom. It is important for the interviewer to stress on the word ‘severe’, in order to relate the headache to the potential cause of death. Clarify the importance of severity to the respondent, and record the response accordingly. Severe headache can be reported in many conditions including meningitis and malaria. Sudden, severe headache followed by unconsciousness is sometimes observed in cerebrovascular disease / stroke.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4096**  ***(10208)*** | | | | **Did <NAME> have a stiff neck during the illness that led to death?**  **Why ask this:** A stiff neck is generally identified by the inability to bend the neck forward to touch the chin to the chest, or in difficulty in raising head from the pillow. This can indicate a serious infection of the brain (such as meningitis) or spine.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skip to A4098. | | |
| **A4097\_units**  **A4097\_a**  **A4097\_b**  ***(10209\_units***  ***10209\_a***  ***10209\_b)*** | | | | **How long before death did s/he have a stiff neck?**  **Enter how long before death did (s)he have stiff neck in days:** if the stiff neck lasted 0-30 days.  **Enter how long before death did (s)he have stiff neck in months:** if the stiff neck lasted 1-60 months.  **Why ask this:** The duration for which stiff neck was observed is important for determining the diagnosis. It is usually for only a few days during the terminal illness prior to death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip***: If A4097\_units = “2,” go to A4097\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4098. For days, after completing A4097\_a, go to A4098. | | |
| **A4098**  ***(10210)*** | | | | **Did <NAME> have a painful neck during the illness that led to death?**  **Why ask this:** “Painful neck” means the deceased was in pain while trying to move his/her neck in a normal way. This can indicate a serious infection of the brain or spine. In some communities, there could be a chance of confusion between a stiff neck and a painful neck. Hence, this question has been included in case there is a possibility that there may be a positive response here instead of the previous question.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If “2,” “8” or “9,” skip to A4100. | | |
| **A4099\_units**  **A4099\_a**  **A4099\_b**  ***(10211\_units***  ***10211\_a***  ***10211\_b)*** | | | | **How long before death did s/he have painful neck?**  **Enter how long before death s/he had a painful neck, in days:** if the painful neck lasted 0-30 days.  **Enter how long before death s/he had a painful neck, in months:** if the painful neck lasted 1-60 months.  **Why ask this:** Knowing this can help determine the cause of death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4099\_units = “2,” go to A4099\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4100. For days, after completing A4099\_a, go to A4100. | | |
| **A4100**  ***(10212)*** | | | | **Did s/he have mental confusion?**  **Why ask this:** Confusion is an important sign of chronic conditions causing dementia (e.g Alzheimer’s disease; long term effect following paralysis; etc). Confusion implies disorientation in person, time and space. During the terminal illness, the person may have episodes when they do not recognise people, or are unaware of their location (in hospital or at home); or may not be aware of the time, part of day, month etc. Confusion is sometimes associated with periodic agitated or restless behaviour, with no obvious reason. It is not the same as unconsciousness. In fact, there is no associated impairment of consciousness.  **How to do it:** This question only pertains to long standing confusion lasting several months or years. Clarify this with the respondent, and record the response accordingly. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4102*.* | | |
| **A4101\_units**  **A4101\_a**  **A4101\_b**  ***(10213\_units***  ***10213\_a***  ***10213\_b)*** | | | | **How long did s/he have mental confusion?**  **Enter how long s/he had mental confusion, in days:** if the mental confusion lasted 0-30 days.  **Enter how long s/he had mental confusion, in months:** if the mental confusion lasted 1-60 months.  **Why ask this:** The duration for which confusion was present is important for the diagnosis. The response to this question confirms the presence of long-term confusion, as sought from this question.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. For long term unconsciousness (coma) of 3 years = 36 months. See general instructions 4 and 6. ***Skip:*** If A4101\_units = “2,” go to A4101\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4102. For days, after completing A4101\_a, go to A4102. | | |
| **A4102**  ***(10214)*** | | | | **Was <NAME> unconscious during the illness that led to death?**  **Why ask this:** Unconsciousness means the complete inability to arouse the individual with no movement except for breathing. The individual does not respond even to physical stimuli including pain. Death due to any illness is usually preceded by a period of loss of consciousness. This series of questions is oriented toward identifying loss of consciousness as an important specific factor associated with the illness leading to death, usually indicating involvement of the brain.  **How to do it:** Sometimes there is some hesitation or uncertainty about this question. Even if the response is NO, clarify what is meant by unconsciousness as described above, and proceed to ask the next question. Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4106*.* | | |
| **A4103**  ***(10215)*** | | | | **Was s/he unconsciousness for more than 24 hours before death?**  **Why ask this:** This question clarifies whether duration of unconsciousness was more than one day, which is important to establish the diagnosis.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4104**  ***(10217)*** | | | | **Did the unconsciousness start suddenly, quickly (at most within a single day)?**  **Why ask this:** Loss of consciousness could occur suddenly in the case of stroke (cerebrovascular disease), or more gradually occurring off and on over a period of hours/days in loss of consciousness associated with brain infections or other conditions. This question is aimed at ascertaining sudden loss of consciousness within at most a day, which occurs in cerebrovascular disease.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4105**  ***(10218)*** | | | | **Did the unconsciousness continue until death?**  **Why ask this:** This question confirms the relationship between loss of consciousness lasting more than 24 hours continuing till death (i.e., a condition known as coma), as a feature of the terminal illness that caused death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4106**  ***(10219)*** | | | | **During the illness that led to death, did <NAME> have convulsions?**  **Why ask this:** Spasms or convulsions might indicate a serious infection of the brain or spinal cord. Convulsions are rapid twitching or jerking movements of parts of the limbs or sometimes entire limbs, which frequently subsides with the loss of consciousness. Appearance of such fits is indicative of certain illnesses, including epilepsy, and other diseases which cause abnormal levels of chemicals in the blood which causes fits.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4109*.* | | |
| **A4107**  ***(10221)*** | | | | **For how many minutes did the convulsions last?**  **Why ask this:** Record the number of minutes the respondent reports for the duration of the convulsion.  **How to do it:** Record the duration in minutes. Record Don’t know as “99” and Refused to answer as “88.” Less than 1 minute = “00” minutes. 1 hour = 60 minutes. | | |
| **A4108**  ***(10222)*** | | | | **Did s/he become unconscious immediately after the convulsion?**  **Why ask this:** Loss of consciousness usually occurs after a generalised convulsion, so a positive response will confirm the occurrence, and thus help aid the diagnosis.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4109**  ***(10223)*** | | | | **Did the deceased have any urine problems?**  **Why ask this:** This is a general question to identify if the deceased had any problems with urination. The key problems with urination that are related to specific causes of death are difficulty in passing urine, passing less or no urine for some period, increased frequency of urination, and passage of blood in the urine. Ask whether S/he had any of these problems.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4113*.* | | |
| **A4110**  ***(10226)*** | | | | **During the fatal illness, did s/he ever pass blood in the urine?**  **Why ask this:** Passage of blood in the urine is a major feature of urinary stones, or bladder or kidney cancer. This can also happen in some parasite infection. There is passage of fresh blood and would be readily observed by the deceased and reported to the relatives, possibly led to seeking of health care. Hence, if this symptom was present, there is a good likelihood of a positive response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4111**  ***(10224)*** | | | | **Did s/he stop urinating?**  **Why ask this:** We ask this question because stoppage of urination for over a day or two prior to death can be due to disorder or failure of the kidney. Less commonly, it may be a symptom of obstruction to the canal that carries urine from the bladder out of the body, but this is accompanied by severe abdominal pain. In kidney disease, usually there is a considerable period of illness prior to the development of stoppage of urination.  **How to do it:** Clarify with the respondent about the period of relative stoppage of urination, and record the response accordingly. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4112**  ***(10225)*** | | | | **During s/he go to urinate more often than usual?**  **Why ask this:** Frequent passage of urine is observed in patients with either severe urinary tract infection or uncontrolled diabetes. The patient could have been observed to make frequent visits to the toilet / frequent wetting of bedclothes; during the terminal illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4113**  ***(10227)*** | | | | **Did she have sores or ulcers anywhere on the body?**  **Why ask this:** Disorders of the skin are sometimes observed during the illness preceding death. These could have been in the form of sores or ulcers, or blisters, or infected or ‘septic’ wounds, and could be associated with chronic ill health. In adults/elderly, there may be deep infected ulcers on the foot or pressure sores on the back or buttocks as a result of a long-standing bedridden state.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4115. | | |
| **A4114**  ***(10229)*** | | | | **Did the sores or ulcers have pus?**  **Why ask this:** Sores sometimes appear initially as tiny bubbles on the skin, called blisters. “Blisters” are raised skin that contains fluid. Such blisters may be observed in infants or young children, along with fever. Often, the clear fluid changes into pus. In other instances, chronic pressure sores may get infected and be filled with pus.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4115**  ***(10230)*** | | | | **Did s/he have an ulcer (pit) on the foot?**  **Why ask this:** This item specifically identifies whether the ulcer was located on the foot. In certain conditions, particularly among the elderly and in diabetics, chronic, non-healing ulcers appear on the foot. These ulcers are prone to becoming septic (see next question), and often keep enlarging in size with poor chances of healing. Presence of such ulcers is a vital clue in the diagnosis of these conditions. This has considerable significance in the case of individuals with diabetes.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4118. | | |
| **A4116**  ***(10231)*** | | | | **Did the ulcer on the foot ooze pus?**  **Why ask this:** The presence of pus in the non-healing ulcer is an important diagnostic sign. Pus is a thick fluid that could be green or yellow in color, which continually accumulates on the floor of the ulcer.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4118. | | |
| **A4117\_units**  **A4117\_a**  **A4117\_b**  ***(10232\_units***  ***10232\_a***  ***10232\_b)*** | | | | **How long did the ulcer on the foot ooze pus?**  **Enter how long the ulcer on the foot oozed pus in days:** if the ulcer on the foot oozed pus 0-30 days.  **Enter how long the ulcer on the foot oozed pus in months:** if the foot ulcer oozed pus 1-60 months.  **Why ask this:** The duration for which the infected ulcer was present on the foot indicates the severity of the condition, and its potential contribution among the factors causing death. Longer duration also indicates the difficulty in treating or controlling the underlying factors such as diabetes, hence also guiding the diagnosis of the underlying cause of death.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4117\_units = “2,” go to A4117\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4118. For days, after completing A4117\_a, go to A4118. | | |
| **A4118**  ***(10233)*** | | | | **During the illness that led to death, did <NAME> have any skin rash?**  **Why ask this:** "Rash" is a skin abnormality that is not a cut or bruise. It usually appears as a collection of red spots on the skin, or sometimes as a red blotch or a patch on the skin. It is sometimes associated with irritation, itching or pain.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4123. | | |
| **A4119**  ***(10235)*** | | | | **Where was the rash?**  **Why ask this:** It is important to know where exactly the rash may be located on the body. This is because, the location of the rash is characteristic for certain conditions, and could assist in diagnosing them. Also, this will help us know whether this problem was part of the illness that led to death.  **How to do it:** Record one response: “1” if Face, “2” if Trunk/Abdomen, “3” if Extremities, “4” if Everywhere, “9” if Don’t know or “8” if Refused to answer. ‘Trunk’ refers to the chest/back/abdominal area. ‘Extremities’ refers to the arms and legs. | | |
| **A4120** | | | | **Where did the rash start?**  **Why ask this:** In some diseases, such as measles, the rash starts very characteristically in one particular part of the body and then advances from there. Therefore, knowing where the rash started might help determine the cause of death.  **How to do it:** Record one answer: “1” if Face, “2” if Trunk/Abdomen, “3” if Extremities, “4” if Everywhere, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4121**  ***(10234)*** | | | | **How many days did the rash last?**  **Why ask this:** The duration of the rash will help us understand the severity and also whether this problem was part of the illness that led to death.  **How to do it:** Record the duration in days. If less than 1 day or 24 hours, enter “0” days. Use 1 week = 7 days or 1 month = 30 days to determine the number of days. | | |
| **A4122**  ***(10236)*** | | | | **Did s/he have a measles rash (use local term)?**  **Why ask this:** Measles is a condition associated with skin rashes, that occurs mostly in early childhood. Occasionally such infections may also occur in older children or adults, but the presentation may not be accompanied by rash, and is usually in the form of fever and respiratory illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4123**  ***(10237)*** | | | | **Did s/he ever have shingles or herpes zoster?**  **Why ask this:** This is a specific form of skin condition which is associated with problems with the immune system. In some instances, a localised patch of rash with small blisters containing clear fluid occurs in a line along the ribs, or on the face, which is accompanied by an electric current like burning pain. The occurrence of such infectious rash can be associated with other serious symptoms involving the lungs or brain.  **How to do it:** This is quite rare. Ask the respondent whether the deceased complained of a localised patch of rash with burning pain. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4124**  ***(10243)*** | | | | **Did s/he have noticeable weight loss?** *[hint: limbs (legs, arms) become very thin]*  **Why ask this:** Certain diseases are characteristically associated with rapid weight loss preceding death, which could be described as ‘becoming very thin and weak’, ‘developing sunken cheeks’, ‘clothes/ belt becoming loose’ etc. Weight loss of over 10% within three months or so is an important sign.  **How to do it:** Clarify these aspects with the respondent to confirm or exclude weight loss, and record the response accordingly. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer.Irrespective of whether the response is YES or NO, the next question should be asked. | | |
| **A4125**  ***(10244)*** | | | | **Was s/he severely thin or wasted?** *[Show photo]*  **Why ask this:** This question aims at identifying malnutrition in the deceased. The individual may have been consistently underweight for a prolonged period, and not have experienced a rapid weight loss in the terminal stage. A chronically thin or wasted individual would have had malnutrition which predisposes to several infections leading to death. This is also observed in terminal stages of cancer, and some other chronic diseases which could affect nutritional intake over time.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4126**  ***(10249)*** | | | | **During the illness that led to death, did <NAME> have swollen legs or feet?**  **Why ask this:** Swollen feet, ankles and even legs may occur due to the accumulation of fluid in diseases of the heart and circulation, or kidney disease. Several diseases produce an imbalance in water regulation, resulting in its accumulation in the dependent parts of the body. Such accumulation most often appears as collection of fluid around the ankles, the presence of which could be recalled by respondents.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4129*.* | | |
| **A4127\_units**  **A4127\_a**  **A4127\_b**  ***(10250\_units***  ***10250\_a***  ***10250\_b)*** | | | | **How long did the swelling last?**  **Enter how long the swelling lasted, in days:** if the swelling lasted 0-30 days.  **Enter how long the swelling last, in months:** if the swelling lasted 1-60 months.  **Why ask this:** The duration for which fluid collection was present is important to understand the chronicity and severity of the condition. It could occur off and on, particularly if the patient was receiving treatment for the condition. Probe carefully and record the number of days for which swollen ankles were present during the terminal illness.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4127\_units = “2,” go to A4127\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4128. For days, after completing A4127\_a, go to A4128. | | |
| **A4128**  ***(10251)*** | | | | **Did s/he have both feet swollen?**  **Why ask this:** In some instances, there may be swelling of only one foot, in which case the underlying condition would be different, more likely to be a local condition in the affected leg, rather than heart or kidney disease. Hence, it is important to confirm that the swelling was on both feet.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4129**  ***(10247)*** | | | | **Did s/he have puffiness of the face?**  **Why ask this:** Puffiness or swelling in the face is observed when there is accumulation of fluid (or water) particularly in the spaces/bags around the eyes, and other parts. This accumulation of fluid is in important diagnostic sign, particularly of kidney disease, but also in some hormonal disorders. It can be observed and recalled by respondents, if prominent. Such facial puffiness may be present with or without any fluid accumulation on other parts of the body such as the ankles or feet, as asked in a later question.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4131*.* | | |
| **A4130\_units**  **A4130\_a**  **A4130\_b**  ***(10248\_units***  ***10248\_a***  ***10248\_b)*** | | | | **How long did s/he have puffiness of the face?**  **Enter how long s/he had puffiness of the face, in days:** if the puffiness lasted 0-30 days.  **Enter how long s/he had puffiness of the face, in months:** if the puffiness lasted 1-60 months.  **Why ask this:** The duration of face puffiness before death is important, to understand the presence of chronic kidney disease. The patient may have been under treatment, in which case the puffiness could have been off and on over several months.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. ***Skip:*** If A4130\_units = “2,” go to A4130\_b; if “8” or “9,” go to A4131. For days, after completing A4130\_a, go to A4131. | | |
| **A4131**  ***(10252)*** | | | | **Did s/he have general puffiness all over her/his body?**  **Why ask this:** Long standing disorders lead to fluid accumulation in the soft tissues in different parts of the body including legs, abdomen, arms and hands, face, as well as in the lung. Such generalised fluid accumulation could occur in kidney disease, heart failure and liver failure, and some other rarer causes. Also, the generalised fluid accumulation develops gradually over a period of days to weeks. Clarify these aspects with the respondent, and record the response accordingly  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4132**  ***(10238)*** | | | | **During the illness that led to death, did <NAME>’s skin flake off in patches?**  **Why ask this:** In persons with long standing malnutrition, the skin becomes extremely dry and tends to break away or peel off in patches. This is a readily recognised and useful diagnostic sign.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4133**  ***(10265)*** | | | | **Did s/he have yellow discoloration of the eyes?**  **Why ask this:** Yellow discoloration of the eyes is indicative of liver diseases, and is commonly known as jaundice. It is an important and readily recognised and recalled sign. Sometimes in advanced stages there is also yellow discoloration of palms or skin, and if observed, the urine is also of an intense yellow color.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4135*.* | | |
| **A4134\_units**  **A4134\_a**  **A4134\_b**  ***(10266\_units***  ***10266\_a***  ***10266\_b)*** | | | | **For how long did s/he have the yellow discoloration?**  **Enter how long s/he had yellow discoloration, in days:** if the discoloration lasted 0-30 days.  **Enter how long s/he had yellow discoloration, in months:** if the discoloration lasted 1-60 months.  **Why ask this:** The duration of the yellowish discoloration helps indicate the severity of the illness.  **How to do it:** Enter one unit only: days or months. Enter 0-30 days or 1-60 months. Less than 1 day or 24 hours = 0 days; 1 week = 7 days. See general instructions 4 and 6. A likely response is less than 60 months. If the response given was greater than 60 months, confirm the response, and enter “60”. ***Skip:*** If A4134\_units = “2,” go to A4134\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4135. For days, after completing A4134\_a, go to A4135. | | |
| **A4135**  ***(10267)*** | | | | **Did <NAME>’s hair change in color to a reddish or yellowish color?**  **Why ask this:** In persons with black colored hair, a change in the hair color to red, dull brown or yellow is indicative of moderate to advanced malnutrition. This may occur in conjunction with other symptoms such as thinness, wasting, and infections.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4136**  ***(10268)*** | | | | **Did s/he look pale (thinning/lack of blood) or have pale palms, eyes or nail bed?**  **Why ask this:** Long term deficiency of the blood results in a pale, whitish appearance of the lips, tongue, and eye sac. Sometime it is referred to as thinning of blood. This can be due to chronic blood loss, destruction or decreased production of blood due to infection of cancer. Pale appearance could be recognized and recalled by respondents.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4138**  ***(10254)*** | | | | **Did s/he have any lumps or lesions in the mouth?**  **Why ask this:** Small, purple or brown lumps may be observed in the mouth in some patients with weak immune systems. These lumps may bleed or get infected during chewing etc. The presence of these lumps or patches may be suggestive of more severe systemic disease. In other rarer situations, there may be a chronic swelling or growth situated on the tongue or gums, which would be some form of cancer of the mouth. There may be a likelihood of an attempt to seek medical care for its diagnosis and treatment.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4139**  ***(10255)*** | | | | **Did s/he have any lumps on the neck?**  **Why ask this:** This question is to confirm the presence of lumps on the side of the neck. In some instances, the lump may break through the skin and some whitish material or pus may ooze from the lump. In such situations, there is a likelihood of an attempt to seek medical care, and if so, there may be an opinion as to the medical cause for the lump, and the treatment received.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4140**  ***(10256)*** | | | | **Did s/he have any lumps on the armpit?**  **Why ask this:** This question is to confirm the presence of lumps in the armpit. These may have been difficult to have been observed by the respondent, unless pointed out by the deceased, or notified by a health professional.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4144**  ***(10257)*** | | | | **Did s/he have any lumps on the groin?**  **Why ask this:** This question is to confirm the presence of lumps in the groin, which is the junction between the body and the lower limb.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4145**  ***(10246)*** | | | | **Did s/he have stiffness of the whole body or was unable to open the mouth?**  **Why ask this:** Certain nervous system infections result in complete stiffness and rigidity (tightness) of the back and all limbs, along with a tight jaw with inability to open the mouth. This is usually a dramatic sign, and can be recalled by respondents who have cared for the deceased during the terminal illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4146**  ***(10258)*** | | | | **Was s/he in any way paralyzed?**  **Why ask this:** Paralysis implies the weakness or loss of strength or power in certain parts of the body. The weakness may be partial or sometimes total, with complete loss of power. Paralysis is usually an easily recognized and recalled sign, and is an important feature of diseases or injuries to the nervous system.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4149*.* | | |
| **A4147**  ***(10259)*** | | | | **Did s/he have paralysis of only one side of the body?**  **Why ask this:** Paralysis of one side of the body (right arm and leg; or left arm and leg) is a classical feature of disease of the blood supply to the brain, which is one of the common causes of death among adults and the elderly in most populations. It is relatively rare in children. Paralysis of one side of the body is a very clearly recognizable sign, and is readily recalled by relatives of the deceased.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4148**  ***(10260)*** | | | | **Which were the limbs or body parts paralyzed?**  **Why ask this:** It is important to confirm whether the paralysis was affecting only a particular limb, or parts of the body or the whole body  **How to do it:** Discuss the listed body parts with the respondent and record one answer: “1” if Right side (arm and leg), “2” if Left side (arm and leg), “3” if Lower part of the body (both legs), “4” if Upper part of the body (both arms), “5” if One leg only, “6” if One arm only, “7” if the whole body, or “10” if an “Other” body part. Record “9” if Don’t know or “8” if Refused to answer. | | |
| **A4149**  ***(10261)*** | | | | **Did s/he have difficulty swallowing?**  **Why ask this:**  Difficulty when swallowing is the sensation that food is stuck in the throat or upper abdomen. This may be felt high in the neck or lower down, behind the breastbone (sternum), or near the entry into the belly. This is a subjective sensation and is usually reported by patients (and recalled by relatives) especially when interfering with daily food intake, which is when it is readily recognized and recalled by relatives.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4152. | | |
| **A4150\_units**  **A4150\_a**  **A4150\_b**  ***(10262\_units***  ***10262\_a***  ***10262\_b)*** | | | | **For how long before death did s/he have difficulty swallowing?**  **Enter how long before death s/he had difficulty swallowing in days:** if the difficulty lasted 0-30 days.  **Enter how long before death s/he had difficulty swallowing in months:** if the difficulty lasted 1-60 months.  **Why ask this:** The duration indicates the severity and potential progression of this symptom, and aids with the diagnosis. Difficulty in swallowing progressing over a period of several weeks is usually observed with major conditions such as cancers of the throat, food pipe and/or stomach.  **How to do it:** Record days or months. If less than 1 day, record ‘00’ days; 1 week = 7 days. ***Skip:*** If A4150\_units = “2,” go to A4150\_b; if “8. Refused to answer” or “9. Don’t know,” go to A4151. For days, after completing A4150\_a, go to A4151. | | |
| **A4151**  ***(10263)*** | | | | **Was the difficulty with swallowing with solids, liquids or both?**  **Why ask this:** In certain conditions, there may be difficulty in swallowing both solids and liquids. Often however, initially, there may be difficulty only in swallowing solids, and later on, difficulty in swallowing of all types of food and drink.  **How to do it:** Record one answer: “1” if Solids, “2” if Liquids, “3” if Both, “9” if Don’t know, or “8” if Refused. | | |
| **A4152**  ***(10264)*** | | | | **Did s/he have pain upon swallowing?**  **Why ask this:** In some instances, there could be pain associated with the difficulty in swallowing, as a burning or squeezing pain in the centre of the chest, behind the breastbone, or in the upper stomach. Painful swallowing of this nature is specific to certain conditions.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4153**  ***(10245)*** | | | | **During the illness that led to death, did <NAME> have a whitish rash inside the mouth or on the tongue?**  **Why ask this:** Whitish patches inside the mouth or on the tongue are indicative of infections in those with very weak immune systems. Immune systems provide a defence for the body to fight against infections. This sign may be difficult for the respondent, unless they are told of this by the patient or by a health care provider.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4154**  ***(10241)*** | | | | **During the illness that led to death, did <NAME> bleed from anywhere?**  **Why ask this:** This question refers to episodes of spontaneous abnormal bleeding resulting from a disorder of the blood clotting system, which could be caused by blood cancers, severe infections, liver disease etc. The bleeding could be external, or under the skin, or into internal joints and organs. This question refers to bleeding that is not associated with any specific injury. This question also does not refer to abnormal bleeding from any of the organ systems (stomach, lungs, rectum, urinary and genital tracts), which could be associated with cancer.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toA4156. | | |
| **A4155**  ***(10242)*** | | | | **Did s/he bleed from the nose, mouth or anus?**  **Why ask this:** This question is a follow up question to confirm the abnormal bleeding reported in the previous question. Bleeding from the nose, gums, oral mucosa, and anus is commonly observed in case of bleeding due to blood clotting disorders and infections like dengue and Ebola.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4156** | | | | **During the illness that led to death, did s/he have areas of the skin that turned black?**  **Why ask this:** Black colored patches of skin are a sign of bleeding under the skin, and is observed in certain disorders of the blood e.g., leukaemia. Bleeding into the skin can also be seen in infections like dengue and Ebola.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| ***Inst\_1: If Q1601=1 (sex of deceased = male) → A4206*** | | | | | | |
| **A4157**  ***(10294)*** | | | | **Did she have any swelling or lump in the breast?**  **Why ask this:** A swelling or lump in the breast that remains unresolved over a period of weeks during the period leading to death is a significant sign of potential cancer of the breast. This usually occurs in middle aged or elderly women. Although this is an internal sign, and hence may not be directly observed by respondents, this condition may have been brought to the notice of female caregivers in the family, and may trigger an attempt to seek health care.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4158**  ***(10295)*** | | | | **Did she have any ulcers (pits) in the breast?**  **Why ask this:** In some instances, the growth in the breast may break through the skin and cause a non-healing ulcer. This is an openly observable sign, and is usually brought to the attention of caregivers, to clean and dress the wound. Hence, there is a high likelihood of recall when present. Also, there may have been an attempt to seek health care, with the potential for a medical opinion as to diagnosis.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4159**  ***(10296)*** | | | | **Did she ever have a period or menstruate?**  **Why ask this:** This question is to confirm whether the deceased had attained puberty / menarche, with monthly cycles of bleeding from the womb. If yes, the cause of her death could potentially be linked to pregnancy-related conditions. Some probing or clarification may be necessary if the deceased was very young e.g. 12-15 years; otherwise in most instances, this question would be straightforward with a straightforward response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip***: If the answer is “2,” “8” or “9,” skip to A4166*.* | | |
| **A4160**  ***(10297)*** | | | | **When she had her period, did she have vaginal bleeding in between menstrual periods?**  **Why ask this:** This question is about bleeding between two regular monthly cycles of bleeding. Irregular vaginal bleeding in between menstrual periods is associated with several conditions arising in the female reproductive organs. This could sometimes be associated with pain and passage of clots.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4161\_1*.* | | |
| **A4161**  ***(10298)*** | | | | **Was the bleeding excessive?**  **Why ask this:** Sometimes there may be a few drops of blood or scant bleeding around the time of mid cycle, which could be considered normal. Excessive refers to bleeding that requires specific and continuous attention to menstrual hygiene over a period of several hours or days, which occurs in between regular menstrual periods.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4161\_1**  ***(10301)*** | | | | **Was there excessive vaginal bleeding in the week prior to death?**  **Why ask this:** Excessive vaginal bleeding in the week before death could be related to the terminal illness. This excessive bleeding could be related to pregnancy, labor, delivery or not related to any of these. Whatever the case, record the response to vaginal bleeding in the week preceding death here. Some degree of bleeding occurs naturally during and immediately after delivery, which is usually controlled by standard procedures by birth attendants. Bleeding which does not get easily controlled and is continuous and prolonged over several hours could be considered excessive, and referred as such by the birth attendant team to household members, and this could potentially be recalled, with particular reference to its occurrence in the immediate week after delivery. On the other hand, there could be excessive bleeding not associated with pregnancy or delivery, at any age. In relation to menstrual bleeding, it may be considered excessive when a woman bleeds more than seven days (one week), or uses more than six well-soaked sanitary pads per day.  **How to do it:** Clarify the term ‘excessive’ as well as the occurrence in the few days immediately preceding death, and record the response accordingly. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4162**  ***(10299)*** | | | | **Did her menstrual period stop naturally because of menopause or removal of the uterus?** *(If woman was <40, do not ask and just click ‘No’.)*  **Why ask this:** This question is relevant for women who may have experienced the natural menopause, or stoppage of regular monthly cycles of bleeding that happens during late adulthood. If the deceased has attained menopause one could exclude the possibility of pregnancy related deaths.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” then skip to A4163. | | |
| **A4163\_1**  ***(10300)*** | | | | **Did she have vaginal bleeding after cessation of menstruation?**  **Why ask this:** This question is relevant for women who have experienced menopause or removal of uterus. An interval of several months to years after attainment of menopause following which there is occurrence of vaginal bleeding is highly suggestive of genital tract cancers. Ensure that there is a clear interval between menopause and reoccurrence of vaginal bleeding. If possible, record details provided by the respondent in the free text section of the questionnaire.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip***: After marking A4163\_1, skip to A4206*.* | | |
| **A4163**  ***(10302)*** | | | | **At the time of death was her period overdue?**  **Why ask this:** This question is to identify if the deceased was known to be pregnant or could have potentially been pregnant at the time of death. In some instances of early pregnancy, the overdue period may not be known even to close female relatives. However, in more advanced pregnancies beyond 2-3 months, this is generally known by members of the household.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to A4166*.* | | |
| **A4164**  ***(10303)*** | | | | **For how many weeks had her period been overdue?**  **Why ask this:** This question clarifies the likely duration of pregnancy, if known. In early stages, the overdue period may not confirm pregnancy, unless the household is aware of the result of any specific pregnancy test, if done. Nevertheless, any information of this nature could help diagnose the likelihood of the death being related to early pregnancy.  **How to do it:** Record the answer in weeks. | | |
| **A4166**  ***(10304)*** | | | | **Did she have a sharp pain in her belly (abdomen) shortly before death?**  **Why ask this**: The abdomen is part of the body below the rib cage and above the pelvic bones. It is important to know whether the deceased complained of abdominal pain during her illness, and the severity of pain.Certain maternal causes are associated with acute, intense pain in the abdomen in the period leading to death, and if really intense, the incidence of such pain is usually brought to the notice of near relatives. Such acute pain could be experienced very early in the pregnancy, when the deceased or relatives may not even be aware of the pregnancy. In other instances, acute pain may be felt later when the pregnancy is in an advanced stage.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4167**  ***(10305)*** | | | | **Was she pregnant (and not yet in labor) at the time of death?**  **Why ask this:** This question particularly refers to the deceased having been confirmed to be pregnant at the time of death, and still carrying the pregnancy. That is, the death happened while pregnant, and before the development of any labor pains or onset or completion of delivery. Knowledge of pregnancy may be obvious after about 3 months. However, earlier than this, when the pregnancy is overdue only by a few weeks, it may be known to only immediate relatives such as the husband or sister. Confirmation of pregnancy is an important diagnostic contribution to the cause of death.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the response to this question is YES, then confirm that the death had occurred before onset of labor. If confirmed, then record the response as YES, and then skip to *A4178\_1*. If the respondent states that the death had occurred during or after delivery, record the answer to this question as "NO"; and proceed to the next question. Also, if the response is "DK/RA", continue with the next question. | | |
| **A4168\_1**  ***(10312)*** | | | | **Did she die during labor or delivery, abortion or miscarriage?**  **Why ask this:** This question is to confirm whether the death occurred during the process of delivering the baby i.e the death occurred after the labor pains had started and some signs of progression of labor had been observed. However, the death occurred before the delivery was completed. Complete delivery is defined as delivery of the baby and the placenta. This fact may be sometimes difficult for respondents who are not familiar with the process of labor – hence the choice of respondent is important – where available, a female relative with close proximity should be chosen as the respondent, even if not a member of the household.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “Yes,” skip to A4173\_1*.* | | |
| **A4168\_3**  ***(10314)*** | | | | **Did she die within 24 hours after delivery, abortion or miscarriage?**  **Why ask this:** This question is used to ascertain the time period between delivery and death. Several maternal causes are known to cause death within the first day after delivery, most importantly bleeding that occurs after delivery of the child.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “Yes,” skip to A4173\_1to determine whether she gave birth to a live baby. | | |
| **A4168**  ***(10306)*** | | | | **Did she die within 6 weeks of delivery, abortion or miscarriage?**  **Why ask this:** In many instances, the death may have occurred during or soon after delivery, or abortion or miscarriage; that is, after the end of the pregnancy. Pregnancy related deaths are considered to be due to maternal causes even after the termination of the pregnancy up to a period of 6 weeks, whether the termination was due to occurrence of a term or near term live or stillbirth, or an abortion or miscarriage. ‘Miscarriage’ is the natural, spontaneous failure of pregnancy during the first or second trimester. It is also known as ‘spontaneous abortion.’ Most resource-limited countries use a 28-week cut-off for determination of stillbirth, meaning that those that died before 28 weeks in utero are intrauterine fetal deaths and when expelled are miscarriages or spontaneous abortions. The term ‘induced abortion’ refers to an intervention used to terminate the pregnancy. Where necessary, clarify the terms miscarriage and abortion. Also, clarify the time relationship between the end of pregnancy and death, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused. ***Skip:*** If the response is "2", “8” or “9,” skip to A4173 to ask about a possible maternal death within 1 year of delivery. | | |
| **A4173\_1**  ***(10316)*** | | | | **Did she give birth to a live baby (within 6 weeks of her death)?**  **Why ask this:** This question confirms that the woman delivered a live baby in the 6 weeks before her death**.**  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** After marking the response to A4173\_1, proceed to A4178\_1. | | |
| **A4173**  ***(10308)*** | | | | **Did she die less than 1 year after being pregnant, having an abortion or delivering a baby?**  **Why ask this:** This question relates to the previous question, and attempts to confirm whether the death occurred within 1 year of the delivery or termination of the pregnancy. The cut-off of one year is considered to be the outer bound for the definition of late maternal deaths. The inclusion of “after being pregnant” in this question is intended to encompass the possibility of early pregnancy losses of various kinds before death, which may not be understood to be “deliveries”.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused. ***Skip:*** If the response is "No,” “Don’t know” or “Refused,” skip to A4178\_2 to confirm that this was not a maternal death. | | |
| **A4173\_2** | | | | **Did she give birth to a live baby (within 1 year of her death)?**  **Why ask this:** This question confirms that the woman delivered a live baby in the 1 year before her death**.**  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** After marking the response to A4173\_2, proceed to A4178\_1. | | |
| **A4178\_2**  ***(10310)*** | | | | **Please confirm, when she died, she was NEITHER pregnant NOR had delivered, had an abortion or miscarried within 12 months of when she died--Is that right?**  *[This question serves to confirm that no maternal death is missed.]*  **Why ask this:** Negative responses to all five of these questions is suggestive of the situation that the deceased was not pregnant at the time of death, and also, that the death had not occurred any time within I year of any delivery or termination of pregnancy. In which case, there is absolutely no potential for the deceased to have a cause of death which is related to pregnancy. Hence, a "YES" response to this question (A4178\_2) confirms that the death was not associated in any manner with pregnancy, and hence rules out any maternal causes. Therefore, there is no need for further questions related to maternal causes; and the interview could skip to the section on injury-related deaths, i.e., A4206.  **How to do it:** If the response to A4178\_2 is “Yes” (this was not a maternal death) or “Refused to answer,” then skip to A4206 to ask about injuries and accidents. If the response to A417\_2 is "NO/DK" (the deceased woman was pregnant or she recently delivered, had an abortion or miscarried), it indicates some uncertainty as to whether the cause of death could have been a maternal or pregnancy-related cause. Hence, if "NO/DK", go back to A4163; and repeat the questions, to ascertain whether the women could have been pregnant or recently delivered before death. | | |
| **A4178\_1**  ***(10309)*** | | | | **For how many months was she pregnant?**  **Why ask this:** This question is to be asked only if the respondent had said YES to A4167 (*10305)*, that the deceased was pregnant at the time of death. It is directed to record the actual duration of the pregnancy in completed months, at the time of death.  **How to do it:** Record the answer in completed months of pregnancy, e.g. 7.5 months is written as 7 months. A valid response is between 0 and 11. If the response is more than 11 months, confirm the response and enter “11”. | | |
| **A4178A** | | | | **During the pregnancy, did she see anyone for antenatal care?**  **Why ask this:** Antenatal care (ANC) is important for the health of the pregnant woman and her unborn baby. The ANC visits provide the opportunity for several health promotive and disease preventive messages to be delivered, as well as for screening tests to detect complications that require immediate treatment or vigilance for worsening of the complications requiring treatment.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9”, skip to A4178. | | |
| **A4178B** | | | | **How many times did she receive antenatal care during the pregnancy?**  **Why ask this:** Pregnant women should be seen for antenatal care at least four times during pregnancy. This enables delivery of a focused ANC interventions package, including detection and management of sexually transmitted infections and maternal complications such as preeclampsia, delivery of tetanus toxoid immunization to protect mother and baby, intermittent preventive treatment of malaria; and promotion of appropriate nutrition, skilled birth attendance, breastfeeding, and early postnatal care of mother and baby.  **How to do it:** Record the number of times the woman received ANC. Use “99” for Don’t know responses. See general instructions 4 and 6. | | |
| **A4178**  ***(10317)*** | | | | **Did she die during or after a multiple pregnancy?**  **Why ask this:** Certain maternal causes are more likely to occur in association with twin pregnancy. Clarify if there was a twin or multiple pregnancy, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. ***Skip:*** if A4167=1 or A4168\_1=1 or A4168\_3=1 or A4173\_1≠1 or A4173\_2≠1 then skip to A4180. Otherwise, continue to A4179 to ask about breastfeeding of the baby. | | |
| **A4179**  ***(10318)*** | | | | **Was she breastfeeding the child in the days before death?**  **Why ask this:** This question is to be asked only if the maternal death occurred more than 24 hours after the delivery. This can be confirmed if the responses to A4173 and A4175 are NO, and the answer to A4179 is YES.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know, or “8” if Refused to answer. | | |
| **A4180**  ***(10319)*** | | | | **How many births, including stillbirths, did she/the mother have before this pregnancy?**  **Why ask this:** Ask and record the obstetric history prior to this birth. Exclude abortions (spontaneous or induced) and miscarriages that occurred in the first six months of pregnancy. Multiple births should be counted as separate events. For example, delivering twins is equal to two births.  **How to do it:** Record one answer. A valid response is between 0 and 20. If the response is more than 20 births, confirm the response and enter “20”. For Don’t know, enter “99”. For Refused, enter “88.” ***Skip:*** If the answer to this question is ZERO; i.e., this is the first delivery (including stillbirth), then proceed to A4182. If the answer is ONE or any number greater than ONE, then proceed to the next question. | | |
| **A4181**  ***(10320)*** | | | | **Had she had any Caesarean section before this pregnancy?**  **Why ask this:** Ask and record whether any of her prior deliveries had taken place through operations. The history of previous Caesarean section increases the risk of certain maternal causes of death.  **How to do it:** Some respondents may not be aware of the term Caesarean section so you can also ask about a surgical or operative abdominal delivery. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4182**  ***(10321)*** | | | | **During this pregnancy, did she suffer from high blood pressure?**  **Why ask this:** Nowadays many pregnant women will have their blood pressure checked as part of antenatal care, and presence of high blood pressure if detected is notified to the patients. Ask if the deceased had been diagnosed with high blood pressure during an antenatal care consultation, and record the response. It’s important to determine if the woman had high blood pressure as if the pressure is high it may be related to heart disease or stroke. High blood pressure starting during the third trimester is due to a condition specific to pregnancy that is accompanied by other symptoms such as blurred vision, severe headache and sometimes convulsions.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4183**  ***(10322)*** | | | | **Did she have foul smelling vaginal discharge during the pregnancy or after delivery?**  **Why ask this:** Foul smelling vaginal discharge is indicative of infection of the birth canal, and is sometimes noticed after delivery, but occasionally during pregnancy. There may be accompanying signs of pain in the lower abdomen and fever. Probe carefully and record the responses.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4184**  ***(10323)*** | | | | **During the last 3 months of the pregnancy, did she suffer from convulsions?**  **Why ask this:** Convulsions are rapid twitching or jerking movements of parts of the limbs or sometimes the entire limbs which frequently subside with the loss of consciousness. The common term for convulsions is fits, and there is often a local term for such movements. Convulsions are a serious sign, and are usually remembered by observers, and hence reported by respondents. Confirm the definition of convulsions carefully, if necessary with a demonstration, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4185**  ***(10324)*** | | | | **During the last 3 months of the pregnancy, did she suffer from blurred vision?**  **Why ask this:** Blurred vision means dimness of sight in normal light. This may or may not be accompanied by convulsions. Blurred vision is a subjective symptom, and may not be reported by the patient to her relatives. Explain the meaning of blurred vision, and record the response accordingly  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4186**  ***(10325)*** | | | | **Did bleeding occur while she was pregnant?**  **Why ask this:** This question enquires about bleeding from the birth canal during the duration of pregnancy BEFORE the onset of birth pains or delivery. During pregnancy, the presence and timing of the bleeding is indicative of specific conditions. Note that the bleeding occurs while the deceased was still carrying the pregnancy. If bleeding was present, the following questions attempt to clarify more specific details of the timing of the bleeding during pregnancy  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip to Inst\_1a. | | |
| **A4186\_1**  ***(10326)*** | | | | **Was there vaginal bleeding during the first 6 months of the pregnancy?**  **Why ask this:** This is to differentiate bleeding during the first 6 months of pregnancy with that occurring closer to full term. Bleeding in first six months leading to death is commonly associated with abortion or miscarriage, or some more rare conditions. Confirm the duration of pregnancy at which bleeding occurred, and record the response.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4187**  ***(10327)*** | | | | **Was there vaginal bleeding during the last 3 months of the pregnancy but before labor started?**  **Why ask this:** Excessive bleeding closer to full term is commonly associated with disorders of the placenta. Confirm that this bleeding had occurred BEFORE the onset of ANY birth pains; and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| ***Inst\_1a: If A4167 = 1 → A4193*** | | | | | | |
| **A4188**  ***(10328)*** | | | | **Did she have excessive bleeding during labor or delivery?**  **Why ask this:** This question refers to bleeding during the birth process AFTER the onset of labor pains but before the complete delivery of the birth. Complete delivery is considered when the baby and the placenta have been delivered. Excessive bleeding during labor and delivery could be due to injury to the uterus (use local term) or birth canal. Confirm the timing of the bleeding as having started AFTER the onset of birth pains, and during labor before delivering the baby, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4189**  ***(10329\_1)*** | | | | **Did she have excessive bleeding after delivery?**  **Why ask this:** Here the excessive quantity of blood AFTER birth is what we ask for.Some bleeding is normal immediately (up to 1-2 hours) after the delivery or spontaneous abortion (miscarriage). However, excessive bleeding (more than the normal expectation of up to 500 ml in addition to the placenta (afterbirth) leading to death within 1-2 days of delivery is usually distinctly remembered and reported as such by family respondents. In such cases, even if the delivery were at home, the excessive bleeding would be reported by the attending midwife, and would have led to an attempt to seek health care, which would also be recalled. Use these probes to confirm excessive bleeding.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4190**  ***(10330)*** | | | | **Was the placenta completely delivered?**  **Why ask this:** The term placenta refers to the material that is delivered attached to the internal end of the umbilical cord. It is commonly referred to as afterbirth, and there is usually a local term for it. The afterbirth is mostly delivered intact i.e in one piece, with no breaks, tears or lacerations. Midwives are known to examine the placenta before it is discarded, particularly in the event of bleeding. However, this knowledge may or may not have been communicated to the relatives, so clarify these details with the respondent.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4191**  ***(10331)*** | | | | **Did she deliver or try to deliver an abnormally positioned baby?**  **Why ask this:** Again, the position of the baby would be known to the attending midwife, but is usually communicated to family members. Enquire the respondent about his/hers understanding of what is an abnormally positioned baby; if unclear or wrong, explain that it refers to babies whose first body part exiting the vagina is not the head.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4192**  ***(10332)*** | | | | **For how many hours was she in labor?**  **Why ask this:** The length of time from the start of birth pains till the delivery of the baby is an important indicator of the likely cause of death. In first pregnancies, this is likely to be within 6-12 hours (average 8 hours); and in subsequent pregnancies is shorter. A prolonged labor more than 12 hours is likely to be remembered by relatives.  **How to do it:** Record the answer in Hours. Less than 60 minutes = 0 hours. 1 day=24 hours. Enter "99" for "Don't know". Enter "88" for Refused to answer. A valid response is between 0 and 99. If the response was more than 98 hours, confirm the response and enter “98”. If the answer to duration happens to be 88 hours, enter instead “87” so that the response is not automatically coded as refused to answer. | | |
| **A4193**  ***(10333)*** | | | | **Did she attempt to terminate the pregnancy?**  **Why ask this:** This question is to identify if the deceased had attempted to end the pregnancy due to any reason, and whether through medical attention or using other means. In some instances, such non-professional attempts can have adverse consequences including excessive bleeding or infection. Close family relatives may be aware of such intentions or attempts, but may not be forthcoming in the response, owing to social circumstances and stigma. Hence, ask the question carefully, and explain the meaning of ‘attempt to terminate’; as required.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If A4193 = ”2. No,” “9” or “8,” then skip to Inst\_1b. Otherwise, continue to A4193\_1. | | |
| **A4193\_1** | | | | **How did she do this?**  **Why ask this:** Different means of terminating a pregnancy can potentially cause more or less harm through bleeding or infection.  **How to do it:** Record the one method that most closely matches the response. ***Skip:*** After recording the response to A4193\_1, follow inst\_1b to determine whether to ask the next questions or skip to A4198. | | |
| ***Inst\_1b: if A4173\_1 (10316) = 1 or A4173\_2 (10316\_2) = 1 🡪 A4198 (10337)*** | | | | | | |
| **A4194**  ***(10334)*** | | | | **Did she recently have a pregnancy that ended in an abortion (spontaneous or induced)?**  **Why ask this:** This question is specifically targeted to identify if the death was associated with an abortion. The word ‘spontaneous’ implies that the abortion occurred naturally (by itself); and the word ‘induced’ means that the abortion was specifically caused by some medical action.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” and A4167≠1, skip to A4198*.* If the answer is “2,” “8” or “9,” and A4167=1, skip to A4205\_1. | | |
| **A4195**  ***(10335)*** | | | | **Did she die during an abortion (spontaneous or induced)?**  **Why ask this:** This question enquires whether the death occurred while the abortion was in process, i.e before the completion of the expulsion; or within a few hours after the start of the abortion. Excessive bleeding is a common cause of death occurring during or immediately after the abortion. Confirm the time period of death with the abortion and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “1”, skip to A4198\_1*.* | | |
| **A4196**  ***(10336)*** | | | | **Did she die within 6 weeks of having an abortion (spontaneous or induced)?**  **Why ask this:** In some instances, the individual may survive the immediate period after the abortion, but death may occur after a few days or weeks, as a result of the longer-term effects of blood loss or infections. This question attempts is to confirm whether the death occurred within a period of 6 weeks, when the cause of death could be due to a complication of the abortion. Family members are likely to know the approximate time period between abortion and death, particularly if it was a medical abortion.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** *If the answer is “1,” skip to A4198\_1.* | | |
| **A4197**  ***(10336\_1)*** | | | | **Did she die more than 6 weeks but less than 1 year after having an abortion (spontaneous or induced)?**  **Why ask this:** Knowing this helps in the cause of death determination.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4198\_1**  ***(10329\_2)*** | | | | **Did she have excessive bleeding (during / after) abortion?**  **Why ask this:** Some bleeding is normal immediately (up to 1-2 hours) after the delivery or spontaneous abortion (miscarriage). However, excessive bleeding (more than the normal expectation of up to 500 ml in addition to the placenta (afterbirth) leading to death within 1-2 days of delivery is usually distinctly remembered and reported as such by family respondents. In such cases, even if the delivery were at home, the excessive bleeding would be reported by the attending midwife, and would have led to an attempt to seek health care, which would also be recalled. Use these probes to confirm excessive bleeding.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4198**  ***(10337)*** | | | | **Where did she (give birth / complete the miscarriage / have the abortion)?**  **Why ask this:** Ask the respondent about the location where the delivery occurred, and record the response accordingly.  **How to do it:** Record one answer: “1” if Hospital, “2” if Other health facility, “3” if Home, “4” if on route to hospital or facility, “5” if Other, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4200**  ***(10339)*** | | | | **Who (delivered the baby / completed the miscarriage / performed the abortion)?**  **Why ask this:** Knowing who delivered the baby is important and would be known to relatives of the deceased.  **How to do it:** Record one answer: “1” if Doctor, “2” if Midwife, “3” if Nurse, “4” if Relative, “5” if Self (the mother), “6” if Traditional birth attendant, “7” if Other, “9” if Don’t know or “8” if Refused to answer. If multiple providers assisted, circle the person highest in the list. ***Skip:*** The next questions are about delivery and so are not asked for women who died during or after an abortion or miscarriage. Therefore, if A4194, A4195, A4196 or A4197 = “1. Yes,” skip to A4205\_1*.* | | |
| **A4202**  ***(10342)*** | | | | **Was the delivery normal vaginal, without forceps or vacuum?**  **Why ask this:** A normal vaginal delivery is one in which the head of the baby is delivery first; and there is no support or assistance to the process through use of instruments. Instrumental deliveries, using forceps or a vacuum, are only conducted in health facilities, and the family members are usually informed if this was conducted. Confirm the mode of delivery, and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “Yes,” skip to A4205\_1*.* | | |
| **A4203**  ***(10343)*** | | | | **Was the delivery vaginal, with forceps or vacuum?**  **Why ask this:** This question is asking whether instrumentation was used to assist the delivery.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the answer is “Yes,” skip to A4205\_1 *.* | | |
| **A4204**  ***(10344)*** | | | | **Was the delivery a Caesarean section?**  **Why ask this:** Difficult deliveries and pregnancy in women with other medical problems is often managed by conducting an operative delivery known as Caesarean section. Again, family members would be well aware if such an operation had been conducted to deliver the baby, and will be reported by the respondent.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4205\_1**  ***(10340)*** | | | | **Did she have an operation to remove her uterus shortly before death?**  **Why ask this:** In some instances, there could be a prolonged labor, and this might be due to some obstruction of delivery, leading to a tear of the uterus. This is dealt with by an emergency operation in which the torn uterus is removed. The uterus may also be removed if the woman is bleeding heavily and the bleeding cannot be stabilized any other way. However, despite this action, the mother is sometimes already in a critical condition, and death can occur even after the operation. Though rare, relatives are known to recall such events, so clarify if required and record the response accordingly.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **INJURIES AND ACCIDENTS (FOR NEONATAL, CHILD AND ADULT DEATHS)**  *Read:***Now, I’d like to ask you about any injuries or accidents that <NAME> may have suffered.** | | | | | | |
| **N2190**  **C3227**  **A4206**  ***(10077)*** | | | | **Did <NAME> suffer from any injury or accident that led to her/his death?**  **Why ask this:** This is an opening question to check whether the death was associated with any injury or accident. In general, the questions are straightforward and readily understood, with little potential for error in the response, except in the case of stigma or apprehension of involvement with police or other administration.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If the answer is “Yes,” then ask the following questions to determine the type of injury or accident. ***Skip*:** If the answer is "NO", then skip to (N2192 / C3250 / A4250). However, if the answer is "Don’t know” or “Refused to answer,” then probe further and continue with the subsequent questions. | | |
| **N2190\_1**  **C3227\_1**  **A4206\_1**  ***(10079)*** | | | | **Was it a road traffic accident?**  **Why ask this:** Road traffic accidents are the most common cause of deaths from injuries in developing countries.  **How to do it:** Clarify with respondents that you do not need to have been in a vehicle to have suffered a road traffic injury, for example for deaths of pedestrians. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip***: If the response is "Yes," ask (N2190\_2 and N2190\_3 / C3227\_2 and C3227\_3 / A4206\_2 and A4206\_3), and then skip (N2190\_4-19 / C3227\_4-19 / A4206\_4-19). If the answer is “No,” “Don’t know” or “Refused to answer, then skip directly to (N2190\_4 / C3227\_4 / A4206\_4). | | |
| **N2190\_2**  **C3227\_2**  **A4206\_2**  ***(10080)*** | | | | **What was her/his role in the road traffic accident?**  **Why ask this:** Details of this nature are essential for accurate coding of the cause of death.  **How to do it:** Check whether the deceased was a pedestrian, driver or any other role. Select the appropriate box based on the response. Record one answer from the list of possible responses in the questionnaire. Mark “9” if the response is “Don’t know” or “8” if “Refused to answer.” | | |
| **N2190\_3**  **C3227\_3**  **A4206\_3**  ***(10081)*** | | | | **What was the counterpart that was hit during the road traffic accident?**  **Why ask this:** The counterpart is the other object with which the injured person or vehicle carrying the injured person came into contact with. Details of this nature are essential for accurate coding of the cause of death.  **How to do it:** Record one answer from the list of possible responses in the questionnaire. Mark “9” if the response is “Don’t know” or “8” if “Refused to answer.” ***Skip:*** After marking the response, skip to (N2190\_20 / C3227\_20 / A4206\_20). | | |
| **N2190\_4**  **C3227\_4**  **A4206\_4**  ***(10082)*** | | | | **Was (s)he injured in a non-road transport accident?**  **Why ask this:** Enquire and record if the death was due to an accident in transport other than on the road. Examples include fatal injury from a train, boat or aircraft accident.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If "Yes,” record the nature of the accident and the injuries sustained in the free text section of the questionnaire. | | |
| **N2190\_5**  **C3227\_5**  **A4206\_5**  ***(10083)*** | | | | **Was (s)he injured in a fall?**  *This includes accidental falls and cases unknown to be accidental or due to intentional violence.*  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If "Yes," then record the body parts that were injured in the narrative section of the questionnaire. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. | | |
| **N2190\_6**  **C3227\_6**  **A4206\_6**  ***(10084)*** | | | | **Was there any poisoning?**  *This includes accidental poisonings and cases unknown to be accidental or due to intentional violence.*  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If the death was due to poisoning from pesticides, kerosene, or any other chemicals, record “Yes,” and note the nature of the poison in the narrative section. Ask if the poisoning was suicidal, and ensure the correct response to question N2190\_21. | | |
| **N2190\_7**  **C3227\_7**  **A4206\_7**  ***(10085)*** | | | | **Did (s)he die of drowning?**  *This includes accidental drowning and cases unknown to be accidental or due to intentional violence.*  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If the response is "Yes," record the location where the drowning occurred – river / lake / sea / swimming pool - in the narrative section of the questionnaire. | | |
| **N2190\_8**  **C3227\_8**  **A4206\_8**  ***(10086)*** | | | | **Was (s)he injured by a bite or sting by venomous animal?**  *This includes accidental injuries and cases unknown to be accidental or due to intentional violence.*    **How to do it:** Record "YES", if the injury was due to snake bite or poisonous insect. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip*:** If the answer is “Yes,” then skip to N2190\_10 / C3227\_10 / A4206\_10. | | |
| **N2190\_9**  **C3227\_9**  **A4206\_9**  ***(10087)*** | | | | **Was (s)he injured by an animal or insect (non-venomous)?**  **How to do it:** Record "YES" in the case of dog bite, or injuries from an attack by another animal, and record the detail in the response to the next question. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip*:** If the answer is “No,” “Don’t know” or “Refused to answer,” then skip to N2190\_11 / C3227\_11 / A4206\_11. | | |
| **N2190\_10**  **C3227\_10**  **A4206\_10**  ***(10088)*** | | | | **What was the animal/insect?**  **How to do it:** Record one response: “1” if Dog, “2” if Snake, “3” if Insect or scorpion, “4” if Other, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_11**  **C3227\_11**  **A4206\_11**  ***(10089)*** | | | | **Was (s)he injured by burns/fire?**  **Why ask this:** Burn injuries resulting in death usually cover extensive parts of the body. If the response is "Yes," then record the parts of the body affected by burns in the narrative section of the questionnaire.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_12**  **C3227\_12**  **A4206\_12**  ***(10090)*** | | | | **Was (s)he subject to violence (suicide, homicide, abuse)?** *Don't say suicide for under-12-year olds.*  **Why ask this:** This is a sensitive question, given the traumatic personal event or involvement of others in the event of death. Ensure that this question is put across in an empathetic manner, and allow sufficient time for the respondent to answer.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_13**  **C3227\_13**  **A4206\_13**  ***(10091)*** | | | | **Was (s)he injured by a firearm?**  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_14**  **C3227\_14**  **A4206\_14**  ***(10092)*** | | | | **Was (s)he stabbed, cut or pierced?**  **Why ask this:** The use of sharp instruments such as knife or sword should be recorded here.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_15**  **C3227\_15**  **A4206\_15**  ***(10093)*** | | | | **Was (s)he strangled?**  **How to do it:** Use the local term for choking of the neck by force, whether by hand, rope or other object. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_16**  **C3227\_16**  **A4206\_16**  ***(10094)*** | | | | **Was (s)he injured by a blunt force?**  **Why ask this:** Injury caused by blunt force such as a stick or a heavy object, which does not cause direct external injury, can be sufficiently serious to cause fractures, internal bleeding and death.  **How to do it:** Explain the meaning of blunt force, and record the response accordingly. Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_17**  **C3227\_17**  **A4206\_17**  ***(10095)*** | | | | **Was (s)he injured by a force of nature?**  **Why ask this:** Forces of nature include lightning, flood, earthquake, etc.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If the response is "Yes, then record the force of nature in the narrative section of the questionnaire. | | |
| **N2190\_18**  **C3227\_18**  **A4206\_18**  ***(10096)*** | | | | **Was it electrocution?**  *This includes accidental electrocution and cases unknown to be accidental or due to intentional violence.*  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_19**  **C3227\_19**  **A4206\_19**  ***(10097)*** | | | | **Did (s)he encounter any other injury?**  **Why ask this:** In case the injury occurred under circumstances that do not fit into the above categories (e.g., hanging, landmine blast, etc.) record the response accordingly.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2190\_20**  **C3227\_20**  **A4206\_20**  ***(10098)*** | | | | **Was the injury accidental?**  **Why ask this:**This question identifies whether the injury was unintentional.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip*:** If the answer is “Yes,” then skip to (N2191 / C3228 / A4207). | | |
| **N2190\_21**  **C3227\_21**  **A4206\_21**  ***(10099)*** | | | | **Was the injury self-inflicted?**  Why ask this: This is a subjective opinion of the respondent. If possible, try to corroborate the evidence with other local information, and record notes in the narrative portion of the questionnaire.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip*:** If the answer is “Yes,” then skip to (N2191 / C3228 / A4207). | | |
| **N2190\_22**  **C3227\_22**  **A4206\_22**  ***(10100)*** | | | | **Was the injury intentionally inflicted by someone else?**  **Why ask this:** Enquire if the injury was caused by an act of violence either directly by another person or by a circumstance intentionally created by another person. This information can help to determine the cause of death.  **How to do it:** Record: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **N2191**  **C3228**  **A4207** | | | | **How long did <NAME> survive after the injury?** *[Record hours if less than 24 hours—Less than 1 hour = “00” hours; Record days if 1 day or more.]*  **Why ask this:** Knowing this can help determine if the injury or accident was the cause of death.  **How to do it:** Record the number of hours or days. See general instructions 4, 5a and 6. The number of hours or days cannot be more than the person’s age at death. Record “99” if don’t know. | | |

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| **POSTNATAL CARE OF THE NEWBORN (FOR NEONATAL DEATHS)**  *Read:*Now, I’d like to ask you about care the baby received soon after birth. | |
| **N2192** | *Check N2006 to determine if the baby was born in a health facility (codes 2-10):*  **Why do this:** The next questions are only for children who were born in a health facility.  **How to do it:** Record: “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to N2199. |
| **N2193** | **After the birth, did the baby leave the delivery facility alive or did s/he die in the facility?**  **Why ask this:** The next questions are only for children who were born in a health facility and left the facility alive. Discuss with the respondent to be certain s/he understands that the response “Died in the facility” does NOT include babies who left the facility after being born and then returned later to the same facility and died.  **How to do it:** Record one answer: “1” if Yes, left alive, “2” if Died in the facility, or “9” if Don’t know. ***Skip:*** If the answer is “No” or “Don’t know,” then skip to N2203. |
| **N2194** | **How long after birth did the baby leave the facility?** *[Record hours if less than 24 hours—if less than 1 hour, record ‘00’ hours; Record days if 1 day or more.]*  **Why ask this:** Standards differ by country, but in general mother and baby should remain in the delivery facility for at least 24 hours after the birth. This allows for an adequate period of observation to ensure that neither the mother nor baby are developing any problems requiring further medical care. If the baby was in the facility for several days after birth, this would suggest that the baby was very sick soon after birth.  **How to do it:** Record days or hours, according to the instructions. Also see general instructions 4, 5a & 6. |
| **N2195** | **Before leaving the facility, did anyone physically examine the baby, for example, check the temperature or check the cord?**  **Why ask this:** A nurse or doctor should examine all newborn babies to ensure they are healthy before they leave the delivery facility. Abnormal body temperature (fever or cold to touch) and cord problems such as redness or pus discharge may indicate a serious infection, so should be checked before the baby is discharged.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. |
| **N2197** | **Prior to being discharged (were you / was the mother) told about signs and symptoms for which the baby needs immediate care?**  **Why ask this:** Mothers should know the signs and symptoms of a possible serious illness of their baby so they can quickly seek health care for a sick child. This might prevent the child from getting sicker and dying.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. |
| **N2198** | **After discharge, before the fatal illness began, was the baby ever seen by a trained health worker or nurse at home or in the community, or by a doctor or nurse at a health facility?** *[Multiple answers (responses 1 and 2) allowed.] Then ask:* **How old was the baby when first seen by (this / any of these) provider(s)?**  **Why ask this:** Well-baby checks provide an opportunity to deliver and reinforce preventive health messages, such as instruction in proper cord care and nutrition. Also, a health provider might detect early signs of an illness and begin treatment. This could keep a mild illness from becoming serious.  **How to do it:** Mark whether the baby was seen by a provider in the community (“1”) and/or at a health facility (“2”). Mark (“3”) and no other option if the baby was never seen, or “9” if the answer is Don’t know. Last, if the baby was seen by a community and/or health facility provider, record the baby’s age when first seen by any of these providers. (Therefore, only one age should be recorded.) Also see general instruction 4, 7 and 9. |
| ***Inst\_8 →******N2203***  ***Skip:*** All neonates born in a health facility go to N2203. N2199-N2202 are for children born outside of a facility. | |
| **N2199** | **After the birth, did the delivery attendant examine the baby, for example, check the temperature or check the cord?**  **Why ask this:** The delivery attendant should examine the newborn baby to ensure s/he is healthy. Abnormal body temperature (fever or cold to touch) and cord problems such as redness or pus discharge may indicate a serious infection, so these should be checked.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. |
| **N2201** | **After the birth of the baby, did the delivery attendant tell (you / the mother) about signs and symptoms for which the baby needs immediate care?**  **Why ask this:** Mothers should know the signs of a possible serious illness of their baby so they can quickly seek health care for a sick child. This might prevent the child from getting sicker and dying.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. |
| **N2202** | **In the days after delivery, before the fatal illness began, was the baby ever seen by a trained health worker or nurse at home or in the community, or by a doctor or nurse at a health facility?** *[Multiple answers (responses 1 and 2) allowed.] Then ask:* **How old was the baby when first seen by (this / any of these) provider(s)?**  **Why ask this:** Well-baby checks provide an opportunity to deliver and reinforce preventive health messages, such as instruction in proper cord care and nutrition. Also, a health provider might detect early signs of an illness and begin treatment. This could keep a mild illness from becoming serious.  **How to do it:** Mark whether the baby was seen by a provider in the community (“1”) and/or at a health facility (“2”). Both “1” and “2” are allowed if the baby was seen by a provider in the community and another provider in a health facility. Mark (“3”) and no other option if the baby was never seen, or “9” if the answer is Don’t know. Last, if the baby was seen by a community and/or health facility provider, record the baby’s age in days when first seen by any of these providers. (Therefore, only one age should be recorded.) Less than 1 day (24 hours) = 00 days. Also see general instructions 4, 7 and 9. |
| **N2203** | **Did the baby receive ARVs after delivery?**  **Why ask this:** Knowing whether a baby of an HIV positive mother received ARVs may provide information about the quality of care he/she received.  **How to do it:** Record one response: “1” if Yes, “2” if No, or “9” if Don’t know. |

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| **SECTION 10: CARESEEKING FOR THE FATAL ILLNESS (FOR NEONATAL, CHILD AND ADULT DEATHS)**  *Read:***Now, I’d like to ask you about <NAME>’s fatal illness and the care and treatments that s/he received.**  **Why read this:** This bridge statement indicates that the following questions are about the person’s illness.  **How to do it:** See general instruction 2 (about how to read questions) for this question and all others in section 10. | | | | | | | | | | | |
| **N2210**  **C3250**  **A4250** | | **Where was <NAME> when her/his illness began?**  **Why ask this:** This provides important information about the deceased’s careseeking pathway and how to navigate several of the following questions.  **How to do it:** Record one answer from the available responses. Note the important differences between responses 1, 2 and 3. Response 1 is for neonates, children and adults whose fatal illness began at home or elsewhere in the community (but not for neonates and children who were with a birth attendant). Response 2 is for neonates, infants 2-11 months old and pregnancy-related adult deaths whose illness began while they were with a traditional or skilled birth attendant, at their own or someone else’s home. Response 3 is for neonates, infants 2-11 months old and pregnancy-related adult deaths whose illness began while they were at the health facility where they were born or delivered. Response 4 is for any other place or situation. Discuss with the respondent to make sure you enter the correct response. Also see general instruction 8. | | | | | | | | | |
| **N2211**  **C3251** | | *For neonatal/child deaths only:* **When it was first noticed that <NAME> was ill, was s/he… 1) Feeding normally, feeding poorly, or not feeding at all? 2) Normally active, less active than normal, or not moving?** *[Read the choices and mark “Normal,” “Moderate,” “Severe” or “Don’t know” for each condition.]*  **Why ask this:** Mothers can often tell that their child is ill by their not feeding normally or being less active than usual. Health professionals also recognize these as signs of a serious illness. Therefore, a mother’s report of these problems both suggests that she recognized her child had a serious illness and allows us to estimate how severe the illness was. In this question, we want to determine how severe the illness was when it was first noticed that the child was sick.  **How to do it:** Ask about each condition one at a time, starting with the introductory phrase. For example, for the second condition ask: “When it was first noticed that <NAME> was ill, was s/he normally active, less active than normal, or not moving?” For each condition: Mark “1” if the child was Normal (feeding normally, normally active), “2” if Medium ill (feeding poorly, less active than normal), “3” if Abnormal (not feeding at all, not moving), or “9” if Don’t know. | | | | | | | | | |
| **N2212**  **C3252**  **A4251** | | **Did <NAME> receive, or did you or s/he give or seek any care or treatment for the fatal illness?**  **Why ask this:** This is where we start examining the care that was provided for the person’s illness and where s/he fell off the Pathway to Survival.  **How to do it:** Here we are asking about care or treatment given at home and by all kinds of providers. This includes traditional healers, pharmacists and drug sellers; and all health providers and facilities such as trained community health workers, nurses, midwives, private doctors, clinics and hospitals. Emphasize the word “seek” because we also want to know about careseeking that was unsuccessful because the person died on route to the provider. In such cases, we want to learn what problems constrained successful careseeking. Record one answer: “1” if Yes, “2” if No (because care was not thought to be needed, or was otherwise not given or sought), or “9” if Don’t know.  ***Skips:***  For neonates: if the answer is “2” and N2210=2, skip to N2213A. If the answer is “2” and N2210=1 or 4, skip to N2214A. If the answer is 2 and N2210=3 and N2006=2, 3, 7 or 8, go to N2222A. If the answer is “2” and N2210=3 and N2006≠2, 3, 7 or 8, go to N2223. The reason for the different skips is that if the neonate’s illness began at home with a birth attendant (N2210=2), then we want to know if the attendant referred the baby to a health facility for further care. Even an SBA outside of a facility is not considered the first provider because they would be able to provide only limited life-saving care for the child. Therefore, we ask N2213A-D to learn if the SBA/TBA referred the child to a facility for further care. And if the neonate’s illness began at the delivery facility (N2210=3) and the facility was a hospital, health center or clinic (N2006=2,3,7 or 8) that can admit patients to the facility, then we want to ask how many days the baby stayed at the facility after the birth.  For infants 28 days-11 months old: The skips are the same as for neonates for the same reasons: If the answer is “2” and C3250=2, skip to C3253A. If the answer is “2” and C3250=1 or 4, skip to C3254A. If the answer is “2” and C3250=3 and C3006=2, 3, 7 or 8, go to C3262A. If the answer is 2 and C3250=3 & C3006≠2, 3, 7 or 8, go to C3263.  For children 1-11 years old: If the answer is “2,” then, just as for 28 day-11-month-olds, skip to C3254A (*2 & C3250=1, 4 →* C3254A) to ask about the decision maker(s).  For adults: If the answer is “2,” then skip to A4253A. There is no question about referral by a home birth attendant for maternal deaths because if the birth attendant was a formal provider such as a midwife, she is considered the woman’s first provider and A4261 will ask whether she referred the woman.  For all age groups: If the answer is “1,” there is no skip—enter the careseeking matrix to ask about care that was received/sought; if the answer is “9,” go to the death certificate (N2271 / C3351 / A4351). | | | | | | | | | |
| **This manual continues here with the adult format question A4252. The same question for neonates (N2213) and children (C3253) plus some additional questions for those ages that are not in the adult format will be presented afterward. The adult questions will come back in where they are again the same as for neonates and children.** | | | | | | | | | | | |
| **A4252** | | **Please tell me everything was done for <NAME>’s fatal illness inside the home and all the places outside the home (he / she) went or was taken for health care. Start with the first care or treatment <NAME> received and then, in order, tell me all the other care and treatments s/he received. Also tell me what symptoms were present when each action was taken.** *[Include any health care provider <NAME> was on route to but did not reach before dying.]*  *For all adults:*   1. *If the illness lasted 3 months or more, ask about the first three actions taken at the start of the illness and the middle of the illness, and about the last three actions at the end of the illness. Circle ‘S’ (Start), ‘M’ (Middle) or ‘E’ (End) for each action.* 2. *Check one other care or health care provider box for each action row. Check ‘Trained CHW, nurse or midwife’ only if the provider was seen outside a facility.* 3. *For pregnancy-related deaths only: Mark any provider or facility where the woman aborted or delivered.* 4. *Record the day of the illness (01, 02, 03, etc.) on which the first action was taken.* 5. *Record the symptom(s) that were present when each action was taken.*   **Why ask this:** This is where we identify all the steps taken for the person on the Pathway to Survival. We also determine the symptoms for which each action was taken. This helps us understand the sick adult’s perception of the symptoms and what should be done about them.  **How to do it**: Emphasize that we also want to know about careseeking that was not successful because the person died after leaving home but before reaching the provider/facility. Ask about one action at a time, in order, from first to last. Fill one row per action. Mark (“X”) the response boxes and fill in the symptoms in each action row according to steps 1-5 described above. Step 1: is to gain a fuller picture of the careseeking that was taken during longer illnesses. Step 2 is where you mark one column-2 box for each action row. If an action was to seek care from a CHW, nurse or midwife, probe to ascertain that the provider was a trained health professional. If not, then mark the correct “Other care” box. Step 3 in the adult format is only for pregnancy-related deaths: Mark any health care provider or facility chosen in step 2 to indicate that the woman had an abortion or gave birth at that provider/facility. Action box 4 is to record the illness day on which the first action was taken. For example, if the sick adult took action 1 on the second day of the illness, then you would record “02” in the provided space. In step 5, record the symptoms that were present when each action was taken. This helps us learn which symptoms concerned sick adults and so may have motivated them to take particular actions. | | | | | | | | | |
| **(1)**  **Action** | **(2)**  **Other care** | | | | **(2)**  **Health care providers** | | | | **(3)** | **(4)** | **(5)** |
| **# and Illness phase – (S)tart, (M)id, (E)nd** | **Home care (own, relative, neighbor, friend)** | | **Tra-ditional or non-formal provider** | **Phar-macist or drug seller** | **Trained community health**  **worker (CHW), nurse, or midwife** | **Private doctor**  **or clinic**  **(formal/**  **unsure)** | **NGO or govern-ment clinic** | **Hospital** | **Woman aborted or delivered at this provider** | **Illness day first action was taken** | **What symptoms were present when the action was taken?** |
| 1.  S M E | 🞎 | | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | \_\_ \_\_ |  |
| 2.  S M E | 🞎 | | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 |  |  |

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| **Now we go to the same question for neonates (N2213) and children (C3253) plus the additional questions for those ages that are not in the adult format.** | | | | | | | | | | | | |
| **N2213**  **C3253** | | | **Please tell me everything was done for <NAME>’s fatal illness inside the home and all the places outside the home (he / she) went or was taken for health care. Start with the first care or treatment <NAME> received and then, in order, tell me all the other care and treatments s/he received. Also tell me what symptoms were present when each action was taken.** *[Include any health care provider <NAME> was on route to but did not reach before dying.]*  *For Neonates:*   1. *Check one other care or health care provider box for each action row. Check ‘Trained CHW, nurse or midwife’ only if the provider was seen outside a facility. For action row 1 for neonates whose illness started at birth, this can include a nurse or midwife who attended the birth outside a facility if s/he also treated the newborn child.* 2. *If Action 1 was the health facility (private doctor, clinic or hospital) where the child was delivered, then check the ”This is the delivery facility” box. This box should be checked if N2210=3 AND the facility provided any treatment for the child’s illness before leaving the facility after the birth.* 3. *Record the day of the illness (01, 02, 03, etc.) on which the first action was taken.*   *(5) Record the symptom(s) that were present when each action was taken.*  *For Children 28 days–11 years old:*   1. *If the illness lasted 3 months or more, ask about the first three actions taken at the start of the illness and the middle of the illness, and about the last three actions at the end of the illness. Circle ‘S’ (Start), ‘M’ (Middle) or ‘E’ (End) for each action.* 2. *Check one other care or health care provider box for each action row. Check ‘Trained CHW, nurse or midwife’ only if the provider was seen outside a facility. For 28 day-11 month olds only: If the illness started at birth, Action row 1 can include a nurse or midwife who attended the birth outside a facility if s/he also treated the newborn child.*   *(3) For 28 day-11 month old deaths only: If the illness began at the health facility (private doctor, clinic or hospital) where the child was delivered and Action 1 was the facility, then check the ‘This is the delivery facility’ box. This box should be checked only if C3250=3 AND the facility provided any treatment for the child’s illness before leaving the facility after the birth.*  *(4) Record the day of the illness (01, 02, 03, etc.) on which the first action was taken.*  *(5) Record the symptom(s) that were present when each action was taken.*  **Why ask this:** This is where we identify all the steps taken for the person on the Pathway to Survival. We also determine the symptoms for which each action was taken. This helps us understand the child caregiver’s perception of the symptoms and what should be done about them.  **How to do it**: Emphasize that we also want to know about careseeking that was not successful because the person died after leaving home but before reaching the provider/facility. Ask about one action at a time, in order, from first to last. Fill one row per action. Mark (“X”) the response boxes and fill in the symptoms in each action row according to steps 1-5 described above. Step 1: is to gain a fuller picture of the careseeking that was taken during longer illnesses. Step 2 is where you mark one column-2 box for each action row. If an action was to seek care from a CHW, nurse or midwife, probe to ascertain that the provider was a trained health professional. If not, then mark the correct “Other care” box. Action box 3 (“This is the delivery facility”) is only for neonates and 28 day-11 month olds whose illness began at the health facility where they were delivered. This box should not be checked if the child was delivered by a traditional or formal provider outside of a health facility. Step 4 is to record the illness day on which the first action was taken. For example, if the child’s caregiver took action 1 on the second day of the illness, then you would record “02” in the provided space. In step 5, record the symptoms that were present when each action was taken. This helps us learn which symptoms concerned child caregivers and so may have motivated them to take particular actions. | | | | | | | | | |
| **(1)**  **Action** | **(2)**  **Other care** | | | | **(2)**  **Health care providers** | | | | **(3)** | **(4)** | **(5)** |
| **# and Illness phase – (S)tart, (M)id, (E)nd** | **Home care (own, relative, neighbor, friend)** | | **Tra-ditional or non-formal provider** | **Phar-macist or drug seller** | **Trained community health**  **worker (CHW), nurse, or midwife** | **Private doctor**  **or clinic**  **(formal/**  **unsure)** | **NGO or govern-ment clinic** | **Hospital** | **This is the delivery facility** | **Illness day first action was taken** | **What symptoms were present when the action was taken?** |
| 1.  S M E | 🞎 | | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | \_\_ \_\_ |  |
| 2.  S M E | 🞎 | | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 | 🞎 |  |  |  |
| ***Inst\_9a / 8a: If N2210 = 3 / If 28 days-11 months old and C3250 = 3***  ***(illness began at the health facility where the child was delivered)***  ***BUT***  ***N2213\_Action\_1\_(3) ≠ ‘X’ / C3253\_Action\_1\_(3) ≠ ‘X’***  ***(The delivery facility was not reported as the first action, i.e., the respondent’s perception was that the facility did not provide any treatment for the child’s illness before leaving the facility after the birth)***  ***AND***  ***N2006 ≠ 2, 3, 7 or 8 / C3006 ≠ 2, 3, 7 or 8***  ***(The baby was not delivered at a hospital, health center or clinic) →* N2223 / C3263**  ***Skip*:** This instruction is for neonates and infants whose illness began at a lower-level delivery facility where patients do not stay overnight, such as a health post (not a hospital, health center or clinic) that provided no treatment for the neonate / infant before leaving the facility after birth. The skip goes to N2223 / C3263 to ask if the facility referred the baby / infant. | | | | | | | | | | | | |
| ***Inst\_9b / 8b: If N2210 = 3 / If 28 days-11 months old and C3250 = 3***  ***(illness began at the health facility where the child was delivered)***  ***BUT***  ***N2213\_Action\_1\_(3) ≠ ‘X’ / C3253\_Action\_1\_(3) ≠ ‘X’***  ***(The delivery facility was not reported as the first action, i.e., the respondent’s perception was that the facility did not provide any treatment for the child’s illness before leaving the facility after the birth)***  ***AND***  ***N2006 2, 3, 7 or 8 / C3006 = 2, 3, 7 or 8***  ***(The baby was delivered at a hospital, health center or clinic) →* N2222A / C3262A**  ***Skip*:** This instruction is for neonates / infantswhose illness began at an upper-level delivery facility where patients stay overnight (such as a hospital, health facility or clinic) that provided no treatment for the neonate / infant before leaving the facility after birth. The skip goes to N222A / C3262A to ask how long the baby / infant stayed at the delivery facility. | | | | | | | | | | | | |
| ***Inst\_9c / 8c: If N2210 = 3 / If 28 days-11 months old and C3250 = 3***  ***(Illness began at the health facility where the child was delivered)***  ***AND***  ***N2213\_Action\_1\_(3) = ‘X’ / C3253\_Action\_1\_(3) = ‘X’***  ***(The delivery facility was reported as the first action, i.e., the respondent’s perception was that the delivery facility provided treatment for the child’s illness before leaving the facility after the birth)***  ***→ N2221A/ C3261A***  ***Skip*:** This instruction is for neonates / infants whose illness began at the delivery facility of any level (hospital, health center, clinic, health post) that provided treatment for the neonate / infant before leaving the facility after birth. The skip goes to N2221A / C3261A to ask how long after the illness began did the baby / infant first receive care. | | | | | | | | | | | | |
| ***Inst\_10 / Inst\_9: If N2210 = 1, 4, 9 / C3250 = 1, 4, 9***  ***(Illness did not begin at home with an SBA/TBA or at the delivery facility) OR if >11 months old***  ***→ N2214A / C3254A***  ***Skip:*** This instruction is for all other neonates / infants whose illness did not begin at home with an SBA/TBA or at the delivery facility AND it’s also for all children who are more than 11 months old (1 year old or older). The skip goes to N2214A / C3254A to ask who decided about the child’s health care.  The only groups not covered by one of the above skip instructions are neonates and infants whose illness began at home with an SBA or TBA who the respondent says provided some care for the child. These groups do not skip, so they go directly to the next question (N2213A / C3253A) to ask whether the birth attendant referred the child. | | | | | | | | | | | | |
| **N2213A**  **C3253A** | | | *Ask N2213A / C3253A only if (newborn’s / 28 day-11 month old’s) illness began at home with an SBA or TBA (N2210=2).*  **Did the SBA/TBA refer <NAME> to a health facility?**  **Why ask this:** If the neonate’s or infant’s illness started soon after birth, while they were still at (their mother’s or another) home with their (skilled or traditional) birth attendant, then we want to know if the birth attendant referred the child to a health facility. Even a midwife or other skilled birth attendant who delivers a baby outside of a facility can provide only very limited care for a very sick newborn. Therefore, it is best if they refer the child to a health facility where they can receive more advanced care.  **How to do it:** Record one answer: “1” if Yes,” “2” if No or “9” if “Don’t know.” ***Skip:*** If the answer is “2,” skip to N2213D / C3253D. | | | | | | | | | |
| **N2213B**  **C3253B** | | | **To where was <NAME> referred?** *Probe to identify the name and type of provider or facility. Knowing the name of the facility might help determine its type. If the child was referred to a trained CHW, nurse or midwife at a health facility, then mark the type of facility. Use option 5 or 10 only if the provider was to be seen outside of a health facility.*  **Why ask this:** Identifying the type of referral facility may provide some information about the level of need the SBA/TBA assessed for the baby/child. Knowing the name of the facility might help determine its type.  **How to do it:** Select the type of facility and then write the name of the provider/facility in the open text field. | | | | | | | | | |
| **N2213C**  **C3253C** | | | **Did the SBA/TBA arrange transportation for <NAME> to reach the referral facility?**  **Why ask this:** Arranging for transportation is a component of quality of care for referral services.  **How to do it:** Record one answer: “Yes,” “No” or “Don’t know.” Then continue with the next question. | | | | | | | | | |
| **N2213D**  **C3253D** | | | Was <NAME> alive when s/he left the SBA/TBA?  **Why ask this:** This is a screening question for the next set of questions.  **How to do it:** Record one answer: “1. Yes, left alive” or “2. No, died at this provider.” ***Skip:*** If “No, died at this provider.” Then skip to N2271/C3351. | | | | | | | | | |
| **The next question is where the adult format comes back into the picture.** | | | | | | | | | | | | |
| **N2214A**  **C3254A**  **A4253A** | | | **Please tell me, who was involved in the decision about whether, when and where to take the baby / child / <NAME> for health care?** *Prompt:* **Was there anyone else?** *[Multiple answers allowed.]*  **Why ask this:** The child’s caregiver is usually her/his mother. However, certain family members other than the mother often are the main decision makers about what do for the child’s illness. For an adult, the person him or herself or another family member might have decided where to seek care.  **How to do it:** Record all answers that apply. If more than one person decided, probe to identify all individuals involved in the decision-making. Note that the possible response choices for adult deaths are somewhat different than for neonatal and child deaths. Also see general instruction 7. ***Skip:*** If the answer is “9” Don’t know, skip to N2215 / C3255 / A4254. | | | | | | | | | |
| **N2214B**  **C3254B**  **A4253B** | | | **Who had the strongest voice in the decision?**  **Why ask this:** Although several people may have been involved in the decision, it is helpful to know who the main decision-maker was.  **How to do it:** Select the person with the strongest voice in the decision. Also refer to general instruction 8. | | | | | | | | | |
| **N2215**  **C3255**  **A4254** | | | **Some people say they have no problems accessing health care. Others say they have problems accessing care.**  *If the deceased (child / adult) was never taken or went to a health provider, ask:* **What about (you / <NAME>)? Did (you / (s/he) experience any problems that (kept you from taking <NAME> for health care / that kept her/him from seeking care) during the illness?**    *If the deceased (child / adult) was taken or sought health care, ask:* **What about (you / <NAME>)? Did (you / s/he) have to overcome any problems to (take <NAME> / go) for health care during the illness?**  **Why ask this:** We ask this for all child caregivers and deceased adults, including those who sought health care, to determine if they had any constraints that kept them for seeking care or that they had to overcome in order to seek care, during the fatal illness.  **How to do it:** Record 1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer is “2” or “9,” skip to Inst\_11a (neonates) / Inst\_10a (children) / Inst\_2a (adults). | | | | | | | | | |
| **N2216**  **C3256**  **A4255** | | | **What were the main problems (you / s/he) had?** *Prompt:* **Was there anything else?** *[Multiple answers allowed.]*  **Why ask this:** We ask this question for all child caregivers and deceased adults who had a constraint for seeking health care during the fatal illness even if they were able to overcome the constraints. This might allow us better understand which constraints people are able to overcome or not, and so focus on developing interventions for those that are more problematic.  **How to do it:** Mark the problems that most closely match the respondent’s answers. Continue to prompt and mark the responses until the respondent says there were no other problems. “Someone else” in response 4 means someone other than the child’s caregiver or the deceased adult. Mark ‘99’ Don’t know only if the respondent can’t name any of the problems s/he had. Also see general instructions 2, 7 and 8. | | | | | | | | | |
| ***(Neonates)***  ***Inst\_11a: If N2212 = 2 (No care given or sought) → N2271***  ***Inst\_11b: If N2213 ≠ “Health provider” (Never took to a health provider) → N2247***  ***(If N2210=2 (neonate delivered at home with an SBA/TBA),***  ***then “Health provider” does not include “CHW, nurse or midwife” in N2213 action row 1)***  ***(Children)***  ***Inst\_10a: If* C3252 =2 *(No care given or sought) → C3351***  ***Inst\_10b: If* C3253 *≠ “Health provider” (Never took to a health provider) →* C3287**  ***(If C3250=2 (28 day-11 month old delivered at home with an SBA/TBA),***  ***then “Health provider” does not include “CHW, nurse or midwife” in C3253 action row 1)***  ***(Adults)***  ***Inst\_2a: If A4251 = 2 (No care given or sought) → A4351***  ***Inst\_2b: If A4252 ≠ “Health provider” (Never took to a health provider) → A4283***  If no care of any type was given or sought, then the interview proceeds to ask about the death certificate.  N2217-N2246 / C3257-C3286 / A4256-A4282 are about care the deceased person received from one or more health care providers. Therefore, these questions are not asked if the person was not taken to a provider. | | | | | | | | | | | | |
| **N2217**  **C3257**  **A4256** | | | *Refer to N2213/C3253/A4252 for the first health provider and related symptoms:* **You mentioned that (you took <NAME> / <NAME> went) to the (first) health provider, I mean the <FIRST HEALTH PROVIDER> with <SYMPTOM(S)>. How long had <NAME> had (this / these) symptom(s) when it was decided to go to the <FIRST HEALTH PROVIDER>?** *[Read “…to the first…” if took or tried to take to more than one health provider.] [Mark days, hours &/or minutes as needed: e.g. 00 day, 02 hours, 10 minutes]*  **Why ask this:** Recognizing the symptoms that indicate a serious illness requiring health care and quickly deciding to do seek that care is an important step toward recovering from the illness. Taking too long to make this decision (the “first delay”) might contribute to the risk of dying from a serious illness. This also helps us understand which symptoms people perceive to be of serious concern, and those about which they should be concerned but do not seem to recognize their severity.  **How to do it:** Record the days, hours and/or minutes, as required. Also see general instructions 2, 4, 5b and 6. Follow the instructions to determine which health provider and symptoms to insert in the question where it says “<FIRST HEALTH PROVIDER>” and “<SYMPTOMS>.” | | | | | | | | | |

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| ***Formal health careseeking matrix:*** *Ask the following questions for the first and last health providers where care was sought for the fatal illness. Ask all the questions for the First Health Provider before going on to the Last Health Provider.*  *Before asking about the first health provider, read:* **Now I would like to ask you about <NAME>’s visit to the (first) health provider, I mean the <FIRST HEALTH PROVIDER>.** *[Read “first” if went to or received care from more than one provider.]*  *Before asking about the last health provider, read:* **Now I would like to ask you about <NAME>’s visit to the last health provider, I mean the <LAST HEALTH PROVIDER>.** | | | | | |
| **– ILLNESS MATRIX QUESTIONS –** | | | **FIRST HEALTH PROVIDER** | **LAST HEALTH PROVIDER** | |
|  | | | **N2218 / C3258** | **N2228 / C3268** | |
| *For neonatal and child deaths only:* **At the time when it was decided to take <NAME> to the <FIRST/LAST HEALTH PROVIDER>, was s/he…1) Feeding normally, feeding poorly, or not feeding at all? 2) Normally active, less active than normal, or not moving?** *[Read the choices & mark “Normal,” “Moderate,” “Severe” or “Don’t know” for each condition.]*  **Why ask this:** See the explanation for N2211 / C3251. By that question, we wanted to determine how severe the illness was when it was first noticed that the child was sick. Here, we are estimating the illness severity at the time the decision was made to seek health care. By comparing illness severity at earlier and later points in the illness, we can track how this changed over time. *For neonatal/child deaths only:*  **How to do it:** See “How to do it” for N2211 / C3251. Also look back at N2213 / C3253 to determine how many health providers/facilities the child was taken to, and the type (e.g., NGO clinic, hospital) of the first and last health providers. Read the introductory statement in the gray box above the matrix before asking about the first or last provider. Then, here (and in all following questions) where it says “<FIRST/LAST HEALTH PROVIDER>,” insert the first type (e.g., hospital) of provider/facility when asking about the first provider/facility and insert the last type when asking about the last provider/facility. | | | | | |
|  | | | **N2219 / C3259 / A4257** | **N2229 / C3269 / A4266** | |
| **What was the name of the <FIRST/LAST HEALTH PROVIDER> where you took <NAME> / where <NAME> went?** *Probe to identify the name and type of provider or facility. Knowing the name of the facility might help determine its type. If the deceased was seen by a trained CHW, nurse or midwife at a health facility, then mark the type of facility where the provider was seen. Use option 5 or 10 only if the provider was seen outside of a health facility.*  **Why ask this:** We want to identify the specific types of health providers where care was sought for the person. It is best that a very sick person seeks care at a hospital, which should be better equipped and with more highly trained personnel who can provide the needed care. However, people often seek care for a severe illness from providers who are closer to their home or less expensive, such as community health workers or local clinics.  **How to do it:** Ask for the name of the provider or facility and use this information to probe and identify the type of provider. If the response is a CHW, nurse or midwife, probe carefully to ascertain where s/he was seen. If seen at a health facility, do not use response options 5 or 10. See general instruction 4 to record one response. Then write the name of the provider/facility in the provided space. | | | | | |
|  | | | **N2220 / C3260 / A4258** | **N2230 / C3270 / A4267** | |
| *For health care at a facility (N2219/N2229 / C3259/C3269 / A4257/A4266 = 1-4, 6-9, 11), ask:* **Did <NAME> reach the <FIRST/LAST HEALTH PROVIDER> before s/he died?**  *For health care outside a facility, ask:* **Did the <FIRST/LAST HEALTH PROVIDER> reach <NAME> before s/he died?**  *[If “No,” discuss with respondent to determine correct response: 2 or 3.]*  **Why ask this:** This helps us understand how severely ill the child or adult was at the time of the careseeking. It also helps us navigate the following questions in the matrix.  **How to do it:** Record one answer. ***Skip:*** If the answer to N2220 / C3260 / A4258 is “2,” go to N2247 / C3287 / A4283.This is because there are no more questions about health providers/facilities to ask in this section if the person died before reaching the first provider. If the answer is “3” or “9,” go to Inst\_12 (neonates) / Inst\_11 (children) / Inst\_3 (adults), to check whether they saw another provider. If the answer to N2230 / C3270 / A4267= 2, 3 or 9, go to Instr\_13 (neonates) / Inst\_12 (children) / Inst\_4 (adults). | | | | | |
|  | | | **A4258A** |  | |
| *Ask only for pregnancy-related deaths:*  **What was her condition when she arrived at the <FIRST HEALTH PROVIDER>? Was she…** [*Respondent should hear all the choices and then give one response.]*  **Why ask this:** It can be useful to know how severe a woman’s illness was upon her arrival at the first health provider. This can provide information about the need for referral and also about the facility’s ability to treat the woman in her condition.Delay in arrival at a health facility until it is too late to save the woman is a problem in many settings.  **How to do it:** Select the appropriate choice. Choose “9” if “Don’t know.” Also refer to general instruction 8. | | | | | |
|  | | | **N2221 / C3261 / A4259** |  | |
| **How long did it take, from the time it was decided to seek care to the time when (<NAME> reached the <FIRST HEALTH PROVIDER> / the <FIRST HEALTH PROVIDER> reached <NAME>?** *[Read “…for the provider to reach <NAME>” if the provider saw the deceased at home or another location outside of a health facility. (N2219 / C3259 / A4257 or N2229 / C3269 / A4266 = 5, 10) [Mark days, hours &/or minutes as needed: e.g. 01 day, 05 hours, 30 minutes]*  **Why ask this:** The “second delay” in health careseeking, just like the first delay, can contribute to a very sick person dying before they receive needed care. Part 1 of the second delay is the time it took to prepare to go to the provider/facility after deciding to seek care, such as arranging transportation, any money needed for the transport and care, and other needed arrangements; and part 2 is the travel time to get to the provider. For people who sought care for their illness at home, the second delay is the time it took for the provider to reach them.  **How to do it:** Discuss what you mean by “how long did it take” with the respondent to ensure that s/he understands to include the time to make the arrangements to travel and the travel time itself. Record the time. Also see general instructions 4, 5b and 6. | | | | | |
|  | | | **N2221A / C3261A / A4259A** | **N2231A / C3271A / A4268A** | |
| **How long after (the illness began / arriving at the <FIRST/LAST HEALTH PROVIDER>) did <NAME> first receive care?** [*Mark hours &/or minutes as needed: e.g. 02 hours, 10 minutes.] [For N2221A / C3261A, read “…after the illness began…” if the child’s illness began at the delivery facility.]*  N2221A / C3261A is the first question asked after listing all actions taken for neonates and 28 day-11 month old infants whose illness began at their delivery facility that provided treatment for the illness. For these neonates and infants, the question is “How long after the illness began…?” while for neonates and children who arrived at the provider (at a facility or in the community) from outside, the question is “How long after arriving at the provider…?” For adults, the question is always “How long after arriving…?.  **Why to ask this:** This is a part of the third delay and also a component of the quality of care provided.  **How to do it:** Fill in the hours and minutes as appropriate and use “99” for “Don’t know.” ***Skip*** ***for N2221A/C3261A:*** *If illness began at the delivery facility and N2006/C3006 ≠ 2,3,7,8 (Hospital, Health center, Clinic) go to* N2223/C3263. *If illness did not begin at delivery facility and N2219/C3259 ≠ 1,2,7,8 (Hospital, Health center, Clinic) go to* N2223/C3263.***Skip for N2231A/C3271A:*** *If N2229/C3269 ≠ 1,2,7,8 (Hospital, Health center, Clinic) go to N2233/C3273.* ***Skip for A4259A/A4268A:*** If A4257/A4266 ≠ 1,2,7,8 (Hospital, Health center, Clinic), go to A4261/A4270.  *[N2219/C3259 was skipped for neonates and infants whose illness began at the delivery facility, so the name of the facility for these children must come from N2006/C3006 (the delivery place).] For adults, it’s only necessary to check the provider in A4257/A4266 and skip to A4261/A4270 if the provider was not a hospital. For all age groups, N2231A / C3271A / A4268A also just check the provider type in N2229 / C3269 / A4266.* | | | | | |
|  | | | **N2222A / C3262A / A4260A** | **N2232A / C3272A / A4269A** | |
| **How many days did <NAME> stay at the (delivery facility / health facility)?** *[Mark ‘00’ if less than 1 day.] [Read “…delivery facility?” if <NAME>’s illness began in the delivery facility before leaving after the birth.]*  **Why to ask this:** The length of stay at the facility helps to track the person’s illness episode through the Pathway to Survival. It might also help understand how severe the illness was at that time, since a longer facility stay might indicate that the person was more severely ill. The “facility” in this case can be any hospital or facility with inpatient services.  **How to do it:**Fill in the number of days. Use ‘00’ if less than 1 day and ‘99’ if “Don’t know.” | | | | | |
|  | | | **N2223 / C3263 / A4261** | **N2233 / C3273 / A4270** | |
| **Did the <FIRST/LAST HEALTH PROVIDER> refer <NAME> to another health provider or facility?**  **Why ask this:** Because the person’s illness resulted in their death, we can assume that they were very sick when seen by the health provider; and for the neonates and children we have additional information on their illness severity from N2218/N2227 and C3258/C3267. If a health provider cannot properly care for a seriously ill person, they should refer them to a higher level of care that has better equipment and more highly trained providers. Finding that a high percentage of the deceased were not referred, especially by lower level facilities such as health posts or community health workers, would suggest that there is a problem with the quality of care. Ideally, a survey of health facilities and providers should be conducted together with the VASA study to obtain more direct information on the quality of care provided in the area.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if “Don’t know.” ***Skip:*** If the answer is “No” or “Don’t know,” skip to N2226 / C3266 / A4264 (if answering N2223 / C3263 / A4261) or skip to N2236 / C3276 / A4273 (if answering N2233 / C3273 / A4270). | | | | | |
|  | | | **N2224 / C3264 / A4262** | **N2234 / C3274 / A4271** | |
| **To where was <NAME> referred?** *Probe to identify the name and type of provider or facility. Knowing the name of the facility might help determine its type. If the child/deceased was seen by a trained CHW, nurse or midwife at a health facility, then mark the type of facility where the provider was seen. Use option 5 or 11 only if the provider was seen outside of a health facility.*  **Why ask this:** If the provider could not properly care for the sick person, then they should have referred them to a higher level of care. We can determine if this was done by comparing the level of care of the initial provider/facility (N2219 / C3259 / A4257 or N2229 / C3269 / A4266) to that of the referral provider/facility in the next question.  **How to do it:** Ask for the name of the provider or facility and use this information to probe and identify the type of provider. If the response is a CHW, nurse or midwife, probe carefully to ascertain where s/he was seen. If seen at a health facility, do not use response options 5 or 10. See general instruction 4 to record one response. Then write the name of the provider/facility in the provided space. | | | | | |
|  | | | **N2225 / C3265 / A4263** | **N2235 / C3275 / A4272** | |
| **Did the health provider/facility arrange transportation for <NAME> to reach the referral facility?**  **Why to ask this:** This is an indicator of quality of care provided by the health facility and improves the likelihood that the referral will be completed.  **How to do it:** Record one answer: “1” if “Yes,” “2” if “No,” or “9” if “Don’t know.” | | | | | |
|  | | | **N2226 / C3266 / A4264** | **N2236 / C3276 / A4273** | |
| **Did <NAME> leave the <FIRST/LAST HEALTH PROVIDER> alive?**  **Why ask this:** This clarifies whether the person had died by this time, which helps us understand how severe the illness was when the person went to the provider. This information is also needed to properly navigate the following questions.  **How to do it:** Record “1” if Yes or “2” if No. ***Skip:*** For an adult death, if the answer to A4264 is “1” then go to Inst\_3, and for A4273 all answers skip to Inst\_4. (For both neonatal and child deaths, there is no skip for either of these questions if the answer is “1.”) For all ages, if the answer to N2226 / C3266 / A4264 is 2, go to Inst\_14 (neonates) / Instr\_13 (children) / Inst\_5 (adults). For N2236 / C3276, if the answer is “2,” then go to Inst\_13 (neonates) / Inst\_12 (children). As stated above, all answers to A4273 skip to Inst\_4. | | | | | |
|  | | | **N2227 / C3267** | **N2237 / C3277** | |
| *For neonatal and child deaths only:* **At the time of leaving the <FIRST/LAST HEALTH PROVIDER>, was <NAME>…** **1) Feeding normally, feeding poorly, or not feeding at all? 2) Normally active, less active than normal, or not moving?** *[Read the choices and mark “Normal,” “Moderate,” “Severe” or “Don’t know” for each condition.]*  **Why ask this:** See the explanation for N2211 / C3251. By that question, we wanted to determine how severe the illness was when it was first noticed that the child was sick. In N2218/N2228 and C3258/C3268, we examined the illness severity when the decision was made to seek care at the first or last provider. And here we are estimating the illness severity at the time of leaving those same providers. By comparing illness severity at earlier and later points in the illness, we can track how this changed over time.  **How to do it:** See “How to do it” for N2211 / C3251. ***Skip:*** After completing N2227/C3267, go to Inst 12 (neonates) / Inst\_11 (children); and after completing N2237 / C3277, go to Inst\_13 (neonates) / Inst\_12 (children). | | | | | |
| ***Inst\_12 / Inst\_11 / Inst\_3: Check N2213 / C3253 / A4252 → If taken to another health provider…*** | | | ***Neonate → N2228***  ***Child → C3268***  ***Adult → A4266***  ***(LAST PROVIDER)*** |  | |
| ***Inst\_13 / Inst\_12 / Inst\_4: If N2223 / C3263 / A4261 = 1 (referred) or N2233 / C3273 / A4270 = 1 (referred) → continue with N2238 / C3278 / A4274. Otherwise → Inst\_14 (neonates) / Inst\_13 (children) / Inst\_5 (adults)*** | | | | | |
| **N2238**  **C3278 A4274** | **Did (you take the child / <NAME> go) to (all) the health provider(s) where s/he was referred?** *[Read “all the health providers…” if the deceased was referred by both the first and last providers.]*  **Why ask this:** Referring a very sick person to a higher level of care is a key element of quality health care. However, it is just as important that the child caregiver or sick adult complies with the referral. If they don’t, there might be several reasons for this, which are examined by the following questions.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. If both the first and last providers referred the person, then record “1” only if the child’s caregiver or sick adult complied with both referrals. | | | | |
| **N2239**  **C3279 A4275** | **Some people say they have no problems accessing health care. Others say they have problems accessing care.**  *If not taken/did not go to (all) the referral provider(s), ask: For neonatal/child deaths:* **What about you? Did you experience any problems that kept you from taking <NAME> to a health provider where s/he was referred?** *For adult deaths:* **What about <NAME>? Did s/he experience any problems that kept (her / him) from going to a health provider where s/he was referred?**  *If taken to (all) the referral provider(s), ask: For neonatal/child deaths:* **What about you? Did you have to overcome any problems to take <NAME> to a health provider where s/he was referred?** *For adult deaths****:* What about <NAME>? Did s/he have to overcome any problems to go a health provider where s/he was referred?**  **Why ask this:** Appropriate referral of very sick persons to a higher level of care is a key element of quality health care that can help return a person with a serious illness to health. Constraints to complying with a referral might prevent persons from receiving this needed higher level care. Some persons might have a constraint that they are able to overcome, so we ask this question both for those who complied and did not comply with a referral.  **How to do it:** Record one answer: “1” if Yes, “2” if No, or “9” if Don’t know. Ask the question the first way (“…that kept you/her/him…”) if the sick person did not go to even one of the providers where s/he was referred. Read the question the second way (“…have to overcome…”) only if the person went to all the providers to which s/he was referred. ***Skip:*** If the answer is “2” or “9,” skip to Inst\_14 (neonates) / Inst\_13 (children) / Inst\_5 (adults). | | | | |
| **N2240 C3280 A4276** | **What were the main problems (you / s/he) had?** *Prompt:* **Was there anything else?** *[Multiple answers allowed.]*  **Why ask this:** We ask this question for all persons who had a constraint to seeking referral care even if they were able to overcome the constraint and reach the provider. This might allow us to gain a better understanding of which constraints people are able to overcome or not, and what other factors (such as the sick person’s or caregivers’ age) allow some people to overcome these constraints while others are not able to do so.  **How to do it:** Mark the concerns/problems that most closely match the respondent’s answers. Continue to prompt and mark the responses until the respondent says there were no other problems. “Someone else” in response 4 means someone other than the caregiver respondent. This might occur for deaths in which the caregiver is someone other than the household’s main decision maker for health careseeking. ”Provider didn’t say referral so important” in reponse 16 could mean that the health provider did not give a referral slip, which might lead the caergiver or sick person to think the referral was not important. Or the respondent just might not have felt that the provider strongly expressed the importance of the referral. Also see general instructions 2, 7 and 8. | | | | |
| ***Inst\_14: If N2006 = 2-10 (born at a health facility) OR***  ***N2219, N2229, N2224 or N2234 = 1-4, 6-9 or 11 (seen at any health facility) → continue with N2244;***  ***Otherwise → N2247***  ***Inst\_13: If C3006 = 2-10 (born at a health facility) OR***  ***C3259, C3269, C3264 or C3274 = 1-4, 6-9 or 11 (seen at any health facility) → continue with C3284;***  ***Otherwise →C3287)***  ***Inst\_5: If A4257, A4266, A4262 or A4271 = 1-4, 6-9 or 11 (seen at any health facility) → continue with A4280;***  ***Otherwise → A4283)***  **How to do it:** The next three questions are about problems in health facilities, so if the child/deceased was not born/seen in a health facility, they are skipped. | | | | | |
| **N2244 C3284 A4280**  ***(10452)*** | **Were there any problems during admission to the hospital or health facility?**  **Why ask this:** Ask the respondent whether there were any problems such as delays, paperwork, queues or no staff encountered at the health facility.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | | |
| **N2245 C3285 A4281**  ***(10453)*** | **Were there any problems with the way (s)he was treated (medical treatment, procedures, interpersonal attitudes, respect, dignity) in the hospital or health facility?**  **Why ask this:** Enquire whether there were any problems with how the deceased or family were treated at the health facility.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | | |
| **N2246 C3286 A4282**  ***(10454)*** | **Were there any problems getting medications, or diagnostic tests in the hospital or health facility?**  **Why ask this:** Enquire whether there were any problems with receipt of medications or diagnostic tests at the health facility.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | | |
| **N2247 C3287 A4283**  ***(10458)*** | **In the final days before death, did anyone use a telephone or cell phone to call for help?**  **How to do it:** Select YES if a telephone of any kind (working landline, or cell phone charged and with credit) was used by those assisting in the final 24 hours of the illness for example to call for help or arrange transportation. Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | | | |
| **N2248 C3288 A4284** | **How many days after (<LAST ACTION N2213 / C3253 / A4252> / leaving the first/last health provider) did <NAME> die?**  **Why ask this:** This helps us understand how serious the person’s illness was at the time of the referenced action. The sooner they died after the action, the sicker they were likely to be at the time.  **How to do it:** Carefully follow the instruction to decide which way to word the question. If some care was given, but the ill person never went to a health provider, then insert the last action taken where it says “<LAST ACTION N2213 / C3253 / A4252>.” If the person went to only one health provider/facility, then read “…after leaving the first health provider…”. If s/he went to more than one health provider/facility, then read “…after leaving the last health provider.” Record the number of days. See general instruction 4. | | | | |
| ***Inst\_15: If N2213 ≠ “Health Provider” (Never took to a health provider) → N2271***  ***(If N2210=2 (neonate delivered at home with an SBA),***  ***then “Health provider” does not include “CHW, nurse or midwife” in N2213 action row 1)***  ***Inst\_14: If C3253 ≠ “Health Provider” (Never took to a health provider) → C3351***  ***(If C3250=2 (28 day-11 month old delivered at home with a birth attendant),***  ***then “Health provider” does not include “CHW, nurse or midwife” in C3253 action row 1)***  ***Inst\_6: If A4252 ≠ “Health Provider” (Never took to a health provider) → A4351*** | | | | | |
| **SECTION 11 : TREATMENTS RECEIVED DURING THE FATAL ILLNESS (FOR NEONATAL, CHILD AND ADULT DEATHS)** | | | | |
| **N2251**  **C3301**  **A4301**  ***(10418)*** | | **Did <NAME> receive any treatment for the illness that led to death?**  **Why ask this:** This question refers to formal health treatment, and not traditional medicines, home remedies or non-professional treatment.Oral rehydration is the only treatment that could be provided at home by an informal provider or caregiver such as a parent or other relative. Asking about treatments received for the illness serves two purposes: 1) Knowing the treatments received might provide an idea as to what was the cause of the person’s illness; and 2) this also might help examine the quality of care that the person received for their illness.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. ***Skip:*** If the answer is “2,” “8” or “9,” skip toN2253 / C3304 / A4304 to ask to see any health records the respondent might have for the illness. | | |
| **N2252\_1-7**  **C3302\_1-7**  **A4302\_1-7**  ***(10419-***  ***10425)*** | | **Did s/he receive…**  **Why ask this:**  Oral rehydration salts: Oral rehydration salts are supplied as a packet of powder which is to be dissolved in water and given to individuals suffering from diarrhea, particularly children. This is an effective remedy which is known to prevent death. This question only refers to packets supplied by health professionals, and not home made solutions. This question is directed to assess the availability and access to health services.  Intravenous fluids (drip) treatment: A drip is usually administered in a health centre by a trained health care worker. Administration of a drip is suggestive of serious conditions such as dehydration.  Blood transfusion: A blood transfusion is also an indication of the severity of the illness, and can be suggestive of causes of death associated with acute blood loss.  Treatment/food through tube passed through nose: Feeding through the nasal tube indicates potential damage to the nervous system, and problems in such manner of feeding can result in partial vomiting and infection of the lungs, leading to death. Enquire about the duration for which feeding was provided through the tube, and whether the tube was in place right up to death, and record all these details in the narrative section of the questionnaire.  Injectable antibiotics: Injectable antibiotics are medications against bacterial infections administered by needle. They are indicative of serious infection of any part or parts of the body, and are administered almost always only in health facilities. However, details of such treatment may or may not be shared with family members.  Antiretroviral therapy (ART): ART drug therapy is given to patients with HIV. This therapy consists of pills for adults and often liquid suspensions (syrups) for children that are taken usually on a daily and a long term basis. The deceased’s relatives may not know these details. Explain the question carefully, and record the response accordingly.  Operation for illness: An operation may also be an indication of illness severity. The medical reason for the operation is likely to be known to the relatives.  **How to do it:** Ask about each treatment, and for each record “1” if Yes, it was received, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** After marking the response for an operation (C3302\_7 for children / A4302\_7 for adults), skip to the first health care records question (C3304 / A4304) if the person did not have an operation (or Don’t know or Refused to answer) for the illness. | | |
| **C3303**  **A4303**  **(*10426)*** | | **Did s/he have the operation within 1 month before death?**  **Why ask this:** The timing of the operation will help ascertain any link between the treatment and the cause of death.  **How to do it:** Record one answer: “1” if Yes, “2” if No, “9” if Don’t know or “8” Refused to answer. | | |
| **N2253 C3304 A4304**  ***(10437)*** | | **Do you have any health records that belonged to the deceased?**  **Why ask this:** It is important to know whether the child had health records as more information concerning her/his illness can be extracted from the documents. This could include a health facility discharge card; outpatient service card; drug treatment prescription; laboratory reports; X-ray or scan reports; inter-facility referral letters; health insurance claim documents etc.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the answer “2,” “8” or “9,” skip to N2259 / C3310\_1 / A4310\_1. | | |
| **N2254 C3305 A4305**  ***(10438)*** | | **Can I see the health records?**  **Why ask this:** It is important to receive consent from the respondent to see the health records.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. If any health records are available and the respondent consents for you to see them, complete the following questionnaire items from the records. The questions for these items are directed to you – you do not need to read these questions to the respondent. ***Skip:*** If the answer is “2,” skip to N2259 / C3310\_1 / A4310\_1. | | |
| **N2255\_1-2 check C3306\_1-2 check A4306\_1-2 check**  ***(10439\_check***  ***10440\_check)*** | | ***Is the date of the most recent (last) visit available?***  ***Is the date of the second most recent visit available?***  **How to do this:** Check to see if the dates are available and proceed accordingly. ***Skip:*** If N2255\_1check / C3306\_1check / A4306\_1check is “2, No”, go to N2255\_2check /C3306\_2check / A4306\_2check. If N2255\_2check / C3306\_2check / A4306\_2check is “2, No,” go to N2256 / C3307 / A4307. | | |
| **N2255\_1-2 C3306\_1-2**  **A4306\_1-2**  ***(10439***  ***10440)*** | | ***Record the dates of the two most recent visits***  **How to do this:** If the dates are available, record the date for the most recent (final) visit and the last visit before the final visit. Note any details of the diagnosis, laboratory tests, and treatment in the questionnaire section for the health records note (N2258 / C3309 / A4309). See general instructions 4 and 6. | | |
| **N2256 C3307 A4307**  ***(10441)*** | | ***Record the date of the last note on the health records***  **Why do this:** The date would reveal when the child was treated in the health facility.  **How to do it:** Record the date. See general instructions 4 and 6. | | |
| **N2257 C3308 A4308**  ***(10442***  ***10443)*** | | ***Record the weight (in kilograms) written at the most recent (last)/second most recent visit.***  **Why do this:**  A child’s weight, combined with information on their age and sex, is a good indicator of nutritional status. Malnutrition is an important contributor to child deaths caused by infectious diseases, and sometimes is the sole cause of death. Malnutrition can also contribute to deaths of older individuals, but this is less common. In adults, weight loss between two visits may be due to a chronic disease such as cancer.  **How to do it:** Record the deceased’s weight (in kilograms) found in the record of the last visit to the health provider. For adults, also record the weight at the second most recent (next-to-last) visit. See general instructions 4 and 6. | | |
| **N2258 C3309 A4309**  ***(10444)*** | | *Transcribe the last note on the health records*  **Why do this:** This information can help to determine the accurate cause of death. This is a very important element of the whole VASA interview. Carefully record the information in detail. Where the information may not be clear, ask if a photocopy of the note could be provided, to enable the confirmation of the cause of death. If provided, attach the copy to the completed questionnaire. If a smartphone or tablet is available, you may ask if a digital photo could be taken of the health records.  **How to do it:** Copy (write down) the exact note as it appears on the medical record in the provided space. | | |
| **C3310\_**  **1-11**  **A4310\_**  **1-11**  ***(10125***  ***10130-31***  ***10133-37***  ***10142-44)*** | | **During the final illness, did a health professional diagnose…?** *[Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.]*  **Why ask this:** These eleven questions are not asked for neonates since these are illnesses of children and adults. Diagnoses made by doctors are generally more accurate than verbal autopsy diagnoses, especially if they are supported by laboratory tests and other studies. This may also be true for other well-trained health professionals. Knowing the diagnoses that were made by health professionals can be used to help strengthen verbal autopsy diagnoses. These eleven questions are asked for child and adult diagnoses that might have caused the death.  **How to do it:** For each possible diagnosis, remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Ask the question for each possible diagnosis and record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **A4311\_1-5**  ***(10132***  ***10138-41)*** | | **During the final illness, did a health professional diagnose…?**  **Why ask this:** These five questions are asked only for adults since the diagnoses are rare in children.  **How to do it:** For each possible diagnosis, remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Ask the question for each possible diagnosis and record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. | | |
| **C3311**  **A4312**  ***(10128)*** | | **Did the deceased have a recent positive test by a health professional for malaria?**  **Why do this:** This information can help to determine the accurate cause of death.  **How to do i**t: Ask whether a malaria test (dipstick or blood slide) was done during the illness that lead to death and if yes whether the test was positive. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip***: If the response is “1,” skip to C3313 / A4314. (10435). | | |
| **C3312**  **A4313**  ***(10129)*** | | **Did the deceased have a recent negative test by a health professional for malaria?**  **Why do this:** This information can help to determine the accurate cause of death.  **How to do i**t: Ask whether a malaria test (dipstick or blood slide) was done during the illness that lead to death and if yes whether the test was negative. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Record “1” if Yes, “2” if No, or “9” if Don’t know. | | |
| **N2259**  **C3313**  **A4314**  ***(10435)*** | | **Did a health care worker tell you the cause of death?**  **Why do this:** This information might help determine the accurate cause of death.  **How to do i**t: Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. ***Skip:*** If the response is “2,” “8” or “9,” skip to the death certificate (N2271 / C3351 / A4351). | | |
| **N2260**  **C3314**  **A4315**  ***(10436)*** | | **What did the health worker say?**  **How to do i**t: Record details of any verbally communicated information on the likely cause of death. | | |
| **SECTION 12: DEATH CERTIFICATE AND CIVIL REGISTRATION (FOR STILLBIRTHS, NEONATAL, CHILD AND ADULT DEATHS)** | | | | |
| **N2271**  **C3351**  **A4351**  ***(10462)*** | | **Was a death certificate issued?**  **Why ask this:** If a death certificate is available it can help to determine the accurate cause of death.  **How to do it:** Record “1” if Yes, “2” if No, or “9” if Don’t know. ***Skip:*** If the response is “2,” “8” or “9,” skip to N2283 / C3363 / A4363. | | |
| **N2272**  **C3352**  **A4352**  ***(10463)*** | | **Can I see the death certificate?**  **Why ask this:** Ask if you can see the death certificate in order to record information about the cause of death. Fill in the following questions only if you are shown the copy of the certificate. Do not fill in just based on oral statements.  **How to do it:** Record “1” if Yes or “2” if No. ***Skip:*** If the response is “2,” skip to N2283 / C3363 / A4363. | | |
| **N2273**  **C3353**  **A4353**  ***(10464)*** | | ***Record the immediate cause of death from the death certificate:***  **Why do this:** This section aims to collect information from the international standard medical certificate of cause of death. This level of detail may or may not be present in the death certificate issued to the family. If this detail is not present, fill in “-“ for the VASA’s death certificate questions. Copy the cause of death from the first line of the death certificate. There should always be a cause recorded here.  **How to do it:** This is the first in the list of causes of death on the certificate. Copy (write) the immediate cause of death in the provided space. | | |
| **N2274**  **C3354**  **A4354**  ***(10465)*** | | ***Duration (1a)***  **Why do this:** Duration is how long the cause was present before the person died. Causes of death on the certificate are recorded in the order in which they occurred, with the cause that started first being placed on the lowest line. This means that causes lower down on the certificate must have started before higher up causes. A longer duration for each lower cause confirms that it started before the higher up ones and that the certificate was completed correctly.  **How to do it:** If a duration for which the immediate cause (N2273 / C3353 / A4353) was experienced is also recorded in the column beside the cause, enter that in N2274 / C3354 / A4354. Depending on the information available in the certificate, record years, months, days, hours and/or minutes. | | |
| **N2275**  **C3355**  **A4355**  ***(10466)*** | | ***Record the first underlying cause of death from the death certificate:***  **Why do this:** This information can help determine the accurate cause of death. The first underlying cause had to start before the immediate cause, and it led to the immediate cause’s occurrence. For example, the first underlying cause may have been a severe bone infection that led a generalized severe infection (sepsis) as the immediate cause of death.  **How to do it:** This is the second in the list of causes of death on the certificate. Copy (write) the first underlying cause of death in the provided space. | | |
| **N2276**  **C3356**  **A4356**  ***(10467)*** | | ***Duration (1b)***  **How to do it:** Record the duration for the first underlying cause of death. Depending on the information available in the certificate, record years, months, days, hours and/or minutes. | | |
| **N2277**  **C3357**  **A4357**  ***(10468)*** | | ***Record the second underlying cause of death from the death certificate:***  **Why do this:** This information can help to determine the accurate cause of death. The second underlying cause had to start before the first underlying cause, and it led to the first underlying cause’s occurrence. Continuing with the above example, the second underlying cause may have been a severe leg injury, which led to the first underlying cause of a severe bone infection, which led to a generalized severe infection (sepsis) as the immediate cause of death  **How to do it:** This is the third in the list of causes of death on the certificate. Copy (write) the second underlying cause of death in the provided space. | | |
| **N2278**  **C3358**  **A4358**  ***(10469)*** | | ***Duration (1c)***  **How to do it:** If available on the certificate, record the duration for the second underlying cause of death. Depending on the available information, record years, months, days, hours and/or minutes. | | |
| **N2283**  **C3363**  **A4363**  ***(10069\_a)*** | | **Do you have a death registration certificate?**  **How to do it:** Ask to see the certificate or death registration paperwork. If "YES" and the paperwork is available, complete the death registration number in the next item of the VASA questionnaire. ***Skip:*** If the paperwork is not available (response “2 Yes, card not seen,” “3 No registration,” “8 Refused to answer” or “9 Don’t know”), skip to Inst\_16 (neonatal deaths) / Inst\_15 (child deaths) / A4402 (adult deaths). | | |
| **N2284**  **C3364**  **A4364**  ***(10070)*** | | ***Record the death registration number***  **Why do this:** Death registration is an important government function that is the first step toward cause of death certification.  **How to do it:** Record the registration or certificate number. Note that respondents may have a “death notification” slip with a “notification” number or a “death certificate” with a “certificate”, “registration”, “serial”, or other number type. The project office should ensure all interviewers are clear on what number is to be recorded. The project office may adapt this item to the local numbering customs. Enter “-“, if this information is not available. | | |
| **SECTION 13A: THE HOUSEHOLD (FOR STILLBIRTHS, NEONATAL and CHILD DEATHS)**  *N2291-N2298 and C3401-C3408 are just for stillbirths, neonatal and child deaths. Adult deaths: go to Section 13B.*  *Read:***Now I would like to ask you some other questions about (yourself / the child’s mother).** *[f the respondent is the mother, read “about yourself.” If the respondent is not the mother, read “…about the child’s mother.”]*  **Why read this:** This bridge statement indicates that the following questions are about the mother. | | | | |
| ***Inst\_16 / Inst\_15: If Q1403 = 2 (Respondent is the child’s mother) → N2294 / C3404***  ***Skip:***Check Q1403 to determine if the respondent is the mother. If yes, then skip to N2294 / C3404. (N2291-N2293 / C3401-C3403 are about the mother’s age and years of schooling. However, if the mother is the respondent, then we already asked these questions about her in the General Information module.) | | | | |
| **N2291**  **C3401** | | **How old (is the child’s mother / was the child’s mother when she died)?** *[Check N2003 / C3003: If the mother died, read “How old was the child’s mother when she died?]*  **Why ask this:** Mother’s age is an important determinant of child health. Having a baby too young or too old increases the risk of maternal complications during the pregnancy and delivery, which increases the risk of stillbirth and neonatal death. Young mothers are also less experienced in caring for children and may also be less educated, both of which may increase their child’s risk of getting sick and dying.  **How to do it:** Record the number of years. If the respondent doesn’t know the mother’s exact age, then ask her/him to estimate it. Record “99” (Don’t know) only if the respondent cannot even estimate the age. | | |
| **N2292**  **C3402** | | **Did the child’s mother ever attend school?**  **Why ask this:** Mothers’ schooling is relevant to their children’s health. Women with no or fewer years of schooling generally have poorer health and their babies are less healthy than those of more educated women.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. ***Skip:***If 2 or 9, skip to N2294 / C3404. | | |
| **N2293**  **C3403** | | **What is the highest level of school she attended?**  **Why ask this:** More educated mothers are more likely to have healthier children. This may be because they know better about how to care for themselves during pregnancy, what foods are most nutritious for themselves and their children, what illness signs indicate the need to see a health provider, and other healthful measures. They may also be more independent than less educated women, so more likely to decide on their own when to take needed actions, such as seeking health care for their children. Knowing the schooling level of the mothers in the VASA study will allow us to determine if this may have been an important factor in their children’s deaths.  **How to do it:** Record the respondent’s highest level of schooling from the listed response choices, or record “99” for Don’t’ know or “88” for Refused to answer. | | |
| **N2294**  **C3404** | | **What (is your / was the mother’s) main economic activity in the year prior to the child’s death?** *For example: If she had any economic activity such as worked in the field, or sold some products, then N2294 / C3404 = 2 "mainly employed."*  **Why ask this:** Knowing the mother’s economic activity may provide some information about the socioeconomic status of the household and also her position in the household.  **How to do it:** Select one response. Use “9” if Don’t know or “8” if Refused to answer. Refer also to general instruction 8. | | |
| **N2295**  **C3405** | | **At the time of the child’s death, (were you / was the child’s mother) married or living together with a man as if married?** *[Read “…was the child’s mother…” if the respondent is not the mother.]*  **Why ask this:** Women who are married or in a stable relationship as if married have greater access to social and economic support. This may increase the health and survival of their children.  **How to do it:** Record one answer: “1” if Yes, Married, “2” if Yes, living with a man (other than her husband), “3” if No, not in union, “4” if No, mother was deceased then (at the time of the child’s death), or “9” if Don’t know. ***Skip:*** If the answer is “3,” “4” or “9” go to Section 13B. | | |
| **N2297**  **C3407** | | **Did (your / the mother’s) (husband / partner) ever attend school?** *[Read “…partner…” if she was living with a man.]*  **Why ask this:** If the woman’s husband or partner attended school, he is more likely to have a higher paying job or occupation. This could contribute to the economic support of the woman’s children, which might lead to their increased health and survival.  **How to do it:** Record one answer: “1” if Yes, “2” if No or “9” if Don’t know. ***Skip:***If “2” or “9,” go to Section 13B. | | |
| **N2298**  **C3408** | | **What was the highest level of school he attended?**  **Why ask this:** The higher the level of school that the woman’s husband or partner attended, the more likely he would be to have a higher paying job or occupation. This could contribute to the economic security of the family and improved health of the children.  **How to do it:** Record the respondent’s highest level of schooling from the listed response choices, or record “99” for Don’t’ know or “88” for Refused to answer. | | |
| **SECTION 13B: THE HOUSEHOLD (continued) (FOR STILLBIRTHS, NEONATAL, CHILD AND ADULT DEATHS)**  *Read:***Now I would like to ask you some questions about (your / the mother’s / the deceased’s) household.**    *[Stillbirths and neonatal deaths: If the respondent is not the mother, read “…the mother’s…;” and ask N2301-N2304 about the mother’s household.]*  *[Child deaths: Always read “…your…” and ask C3411-C3414 about the respondent’s household.]*  *[Adult deaths: Ask A4402-A4405 about the deceased’s household.]*   * **Why read this:** This bridge statement indicates that the following questions are about the mother’s or other child caregiver’s household (in the case of stillbirths, neonatal and child deaths) or the deceased person’s household (in the case of adult deaths). | | | | |
| **N2301**  **C3411**  **A4402** | | **Where did (you / the mother / <NAME>) stay during the (last days of the pregnancy / fatal illness)?** *[For neonates, read “…the mother…” if the respondent is not the child’s mother.]*  **Why ask this:** Where a person or their caregiver stayed during the person’s illness could affect their access to health care. This will also help determine how to word some of the following questions in this and the next section of the questionnaire. For stillbirths and neonatal deaths, we ask where the mother stayed during the last days of the pregnancy because she might have had to seek care for a complication that occurred late in the pregnancy or during labor/delivery. For children and adults, we ask where the child’s caregiver or the adult stayed during their illness.  **How to do it:** For stillbirths and neonatal deaths, read “you” or “the mother” depending on who the respondent is. For child deaths, the respondent should be the child’s caregiver, so you should always be able to read “you.” For adult deaths, you can say the deceased person’s name. Record one answer, depending on where the person stayed. ***Skip:*** If the answer to N2301 / C3411 / A4402 is “9,” skip to Inst\_17 (stillbirths and neonates) / C3454 / A4454. | | |
| **N2304**  **C3414**  **A4405** | | **In an emergency, how long would it take to reach the nearest health facility from (this / that) location?** *[Mark hours &/or minutes as needed: e.g. 01 hour, 30 minutes]*  **Why ask this:** The time it takes to reach a health facility is a measure of health care access. We ask about the time to reach the nearest health facility in an emergency because this is a situation that might occur during a serious illness.    **How to do it:** Read “…that location…” if the interview is being conducted somewhere other than where the mother stayed during her pregnancy (for stillbirths and neonatal deaths) / the child’s caregiver stayed during the child fatal illness / the deceased adult stayed during her/his fatal illness.. See general instructions 4, 5b and 6. | | |

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| **SECTION 14: SOCIAL CAPITAL and HIV/AIDS QUESTIONS (FOR STILLBIRTHS, NEONATAL, CHILD AND ADULT DEATHS)**  *Read:***Now, I have some questions about (your / the mother’s / your <RELATIVES’> / the mother’s <RELATIVES’> / <NAME>’s / <NAME>’s <RELATIVE>s’) community.**  *The following questions are about the community where the (mother for stillbirths and neonatal deaths / respondent for child deaths / deceased for adult deaths) stayed during the (last days of her pregnancy (N2301) / child’s illness (C3411 / fatal illness (A4402)).*  *.*  *[SBs and NN deaths: If the respondent is not the mother, read “…the mother’s…” or “…the mothers’ <RELATIVES’>...;” and ask N2311-2313 about the mother and her community or her relatives’ community.*  *Child deaths: Read either “…your…” or “…your <RELATIVES’>…;” and ask C3451–* *C3453 about the respondent and her/his community or her/his relatives’ community.*  *Adult deaths*: *Read either “…<NAME>’s…” or “<NAME>’s <RELATIVES’>…” and ask A4451-4453 about the deceased and her/his community or her/his relatives’ community.*  **Why read this:** This bridge statement indicates that the following questions are about the community where the stillbirth’s or neonate’s mother stayed during the last days of the pregnancy, or where the child’s caregiver or deceased adult stayed during the fatal illness.  **How to do it:** Here and below, carefully follow these instructions to decide how to read the question. This depends on: 1) whether the death was of a neonate, child or adult; 2) the child’s birth status (alive/dead) and age at death, 3) whether the respondent for stillbirths and neonatal deaths is the mother or someone else; and 4) where the mother or other child caregiver or deceased adult stayed during the last days of the pregnancy or the fatal illness. This last information was determined from the responses to N2301 / C3411 / A4402. See general instruction 2. | |
| **N2311**  **C3451**  **A4451** | **In the 12 months before <NAME>’s death, did the people in the (village / neighborhood) work together on any of the following issues that affect the entire community or part of the community?** *[Read all the issues and mark “Yes,” “No” or “Don’t know” for each one.]*  **Why ask this:** Social capital questions ask about indicators of the level of trust and support for others in a community. Just like individual and household factors, these community factors can affect the ability of individuals to manage a stressful event like a difficult pregnancy or severe illness. This first question examines how well community members work together to solve problems that affect many people in the community. This is thought to demonstrate community cohesion, meaning that people in the community work together to help each other.  **How to do it:** Read “…neighborhood…” if the community is part of a town or city. See general instruction 8. For each issue, record “1” if Yes, “2” if No, or “9” if Don’t know. |
| **N2313A**  **C3453A**  **A4453A** | **(Were you / Was the mother / Was <NAME>) able to turn to any person or group in the community for help during (the pregnancy / (or) the child’s fatal illness / her/his fatal illness)?** *[For stillbirths, read “…the pregnancy?”] [For neonatal deaths, read “…the pregnancy or the child’s fatal illness?”] [For child deaths, read “…the child’s fatal illness?”] [For adult deaths, read “…her/his fatal illness?”]*  **Why ask this:** This second social capital question focuses on the ability of the sick child’s mother or other caregiver and the sick adult to reach out to family members, friends and others in the community for help during the illness. Caring for a sick child or for oneself when sick can be extremely stressful, especially if one has to manage other responsibilities such as taking care of other children or helping to support a family. Being able to turn to others for help can alleviate some of the stress and enable a person to better manage the stressful situation.  **How to do it:** Mark one response: “1 Yes,” “2 No” or “9 Don’t know.” ***Skip:*** If the answer is “2” or “9,” skip to Inst 17 (stillbirth/neonatal), C3454 (children) or A4454 (adult). |
| **N2313**  **C3453**  **A4453** | **What persons or groups (were you / was she / was <NAME>) able to turn to for help?** *[Prompt:* **Was there anyone else?** *Multiple answers allowed. Continue prompting until the respondent says there was no one else.]*    **Why ask this:** This expands on the response given to N2313A / C3453A / A4453A by determining who the (caregiver / mother / deceased adult) sought help from. This information might prove helpful in developing an intervention that aims to strengthen a community’s social capital.  **How to do it:** See general instruction 8. Mark (“X”) for each applicable type of group or person. |
| ***Inst\_17: If N2016 = 1 (Stillbirth) → N2316*** | |
| **C3454**  **A4454**  ***(10126)*** | ***Read:*****Now I have four last questions about the (child and the child’s mother / deceased and the spouse/partner of the deceased). Did the (child / deceased) ever have a positive HIV test?**  **Why ask this:** We want to know if the deceased child or adult ever had a positive test for HIV, which is the virus that causes AIDS. It is understandable that this question is very sensitive so be extra sensitive when asking this and the following questions.  **How to do it**: Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **C3455**  **A4455**  ***(10127)*** | **Was there any diagnosis by a health professional that the (child / deceased) had AIDS?**  **Why ask this:** We want to know if the deceased child or adult was ever diagnosed to have AIDS, which is the final illness caused by the HIV virus. It is understandable that this question is very sensitive so be extra sensitive when asking these questions.  **How to do it**: Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2316**  **C3456**  **A4456**  ***(10445)*** | **For neonates: *Read*: Now I have two last questions about the child’s mother. (Have you / Has the child’s biological mother) ever been tested for HIV?**  **For children and adults: Did (you / the child’s biological mother / the deceased’s spouse/partner) ever have a positive HIV test?**  **Why ask this:** If a neonate’s mother was tested for HIV, it might mean that she or a health worker thought she might have the virus that causes AiDS. And if a person who was physically close to the deceased child or adult had a positive HIV test, the virus might have been passed on to the deceased. It is understandable that this question is very sensitive so be extra sensitive when asking these questions.  **How to do it:** Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |
| **N2317**  **C3457**  **A4457**  ***(10446)*** | **Was there any diagnosis by a health professional that (you / the child’s biological mother / the deceased’s spouse/partner) had AIDS?**  **Why ask this:** Being diagnosed with AIDS is different than testing positive for HIV, the virus that causes AIDS. If a person who was physically close to the deceased child or adult was diagnosed with AIDS, then the HIV virus that causes AIDS might have been passed on to the deceased. It is understandable that this question is very sensitive so be extra sensitive when asking these questions.  **How to do it:** Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.Record “1” if Yes, “2” if No, “9” if Don’t know or “8” if Refused to answer. |

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| **SECTION 15: OPEN ENDED RESPONSE AND INTERVIEWER COMMENTS/OBSERVATIONS (FOR STILLBIRTHS, NEONATAL, CHILD AND ADULTDEATHS)**  **N2321**  **C3471**  **A4471**  ***(10476)***  *Read:* **Thank you for answering the many questions that I’ve asked. Would you like to tell me about <NAME>’s illness in your own words? Also, is there anything else about her/his illness that I did not ask and you would like to tell me about?** *After the respondent(s) finishes, ask*: **Is there anything else?** *Write the respondent’s exact words. After s/he has finished, read this back and ask her/him to correct any errors in what you wrote.*  **Why ask this:** This information will be helpful for the final assessment of the cause of death and can provide information that was not provided by the interview questions.  **How to do it:** Write down what the respondent tells you in her/his own words. Do not prompt except for asking whether there was anything else after the respondent finishes. While recording, underline any unfamiliar terms. | |
| ***Inst\_18: If stillbirth → End interview*** | |
| **N2322**  **C3472**  **A4472**  ***(10479***  ***10478***  ***10477)*** | ***Interviewer:*** *Mark any of the following words that were mentioned as present in the narrative.*  **Why do this:** This is a list of some of the key risks associated with mortality in the age group of the deceased.  **How to do it**: After the respondent has provided their description of the circumstances surrounding the death read back through and record all the key words that they mentioned. |
| **END OF INTERVIEW.**  **THANK RESPONDENT FOR HER/HIS PARTICIPATION.**  *Interviewer: Use this space to write down your comments and observations about the interview.*  **Why do this:** This information will be helpful for the final assessment of the cause of death.  **How to do it:** Write down any additional comments or observations in the provided space. | |

APPENDIX A: INTERVIEWER’S SELF-ASSESSMENT CHECKLIST

Interview and informed consent forms (before the interview)

A. \_\_\_ Have blank consent forms

B. \_\_\_ Have a blank VASA format for reference

C. \_\_\_ Have the VASA format given by the supervisor for the respective death, with Section 1 filled by the supervisor

Locating information and transportation

A. \_\_\_ Understand address and locating information for assigned interview

B. \_\_\_ Understand transportation method to interview location

C. \_\_\_ Meeting(s) arranged with village leader/other community member(s), if needed to help locate or be introduced to a household with a death

At the household, before the interview

A. \_\_\_ Inform household member of the reason for the interview

B. \_\_\_ Show household member my personal identification

C. \_\_\_ Ask to speak with the person(s) who know the most about the circumstances of the deceased’s death

D. \_\_\_ Arrange another visit if the best respondent(s) were not home or preferred another interview time

E. \_\_\_ Read and explained (if necessary) the informed consent form to the respondent(s)

F. \_\_\_ Obtain each respondent’s mark on a separate consent form

Completed interview

A. \_\_\_ Interviewer ID information (section 2 of VASA format) is complete

B. \_\_\_ Deceased’s ID information is complete on each page of the VASA format

C. \_\_\_ All sections of the format are complete, with all pages present

D. \_\_\_ Read all questions exactly as written on the VASA format

E. \_\_\_ No or only a few questions answered, “Don’t know”

or

\_\_\_ If several “DK,” list problem questions by section and number:

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

F. \_\_\_ Respondents answered all questions

or

\_\_\_ If a respondent refused to answer a question, record the number and reason: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

G. \_\_\_ Responses within the interview were consistent with each other

or

\_\_\_ Any inconsistent responses were resolved during the interview

H. \_\_\_ Answered any questions the respondents asked

Interaction with supervisor and interviewer team

A. \_\_\_ Submit completed VASA format and marked consent form(s) to the supervisor

B. \_\_\_ Discuss checklist and any problems with supervisor

C. \_\_\_ Resolved problems:

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

D. \_\_\_ Unresolved problems that may require a change in procedures:

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

E. \_\_\_ Give any death reports received in the community to supervisor

F. \_\_\_ Participate in team meeting (date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_)

APPENDIX B: SUPERVISOR’S CHECKLIST

Death notification and registration

A. \_\_\_ Meet with death notifier to receive completed notification formats

B. \_\_\_ Classify notified deaths and appropriately fill the register

C. \_\_\_ Classify interviewed deaths and appropriately fill the register

Before an interview

A. Fill Section 1 of the VASA format for all deaths

B. Develop work plan with the interviewer team

\_\_\_ Assign interviews (give “Section 1-filled” VASA format to the assigned team)

\_\_\_ Set a time and place for regular team meeting

C. Provide logistical support (if needed)

\_\_\_ Assist with transportation to the field

\_\_\_ Help locate households for interview

During an interview

A. \_\_\_ Observe interview (early in project) by interviewer number: \_\_\_

\_\_\_ Observe interview (later, if problems) by interviewer number: \_\_\_

After an interview

A. Collect and review completed VASA interview forms and marked consent forms

\_\_\_ Check for frequent “Don’t know” responses

\_\_\_ Check for missing data

\_\_\_ Check for internal inconsistencies

B. \_\_\_ Discuss any problems found on the forms with the appropriate interviewers

C. \_\_\_ Review interviewer checklists and discuss any problems

D. \_\_\_ Repeat problem interview by interviewer number: \_\_\_

E. \_\_\_ Certify corrected and complete VASA formats

Other times

A. \_\_\_ Meet with community member/leader: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

B. Team problem solving meeting:

\_\_\_ Discuss left-over problem: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Discuss left-over problem: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Modify work procedure: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ Modify work plan: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

APPENDIX C: MODEL CONSENT FORM

**ORAL CONSENT SCRIPT**

**Oral consent for participants in the verbal/social autopsy interview**

**Study Title: A Verbal/Social Autopsy Study to Improve Estimates of the Causes and Determinants of Stillbirths, Neonatal and Child Mortality in <Country name>**

**Principal Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**IRB No.: xxxx**

**PI Version Date: Version 1 – MM/DD/YYYY**

**PURPOSE**

We invite you to take part in a research study. The purpose is to increase our knowledge of the causes of stillbirths and of deaths of newborns and children. The study also examines how people know when woman and their children need health care and any problems they have getting this care. You are being invited to participate because you had a (pregnancy that did not result in a live birth / newborn that died / young child that died) (recently / some time ago).

**PROCEDURES**

*For pregnancy terminations, read:*

If you agree to participate, I will ask you some questions about (your / your relative’s) pregnancy and delivery and the care sought for these. You may refuse to answer any questions that you do not wish to answer.

*For neonatal deaths, read:*

If you agree to participate, I will ask you some questions about (your / your relative’s) pregnancy and delivery and the care sought for these. I will also ask about the illness of (your / your relative’s) child and any care sought for the illness. You may refuse to answer any questions that you do not wish to answer

*For child deaths, read:*

If you agree to participate, I will ask you some questions about the illness of (your / your relative’s) child and any care sought for the illness. You may refuse to answer any questions that you do not wish to answer.

**RISKS/DISCOMFORTS**

There are some risks to your participating in the study. Some questions could make you feel uncomfortable by reminding you of the (pregnancy loss / child’s illness and death). If you feel too upset at any time, I will stop the interview until you feel alright to continue. If the interview is too stressful, you are free to quit the study. The interview will take about one and a half hours to complete.

**CONFIDENTIALITY**

All research carries some risk that information about you may become known to people outside of the study. However, we will do all we can to protect the information you provide. Your responses to the interview will be entered in a computer, but your name will be hidden. The information will be used only for the research. Your responses will never be reported alone and your name will not be used in any way.

**BENEFITS**

There is no direct benefit to you from being in this study. Health care provided to women and children in your community may improve as a result of the information gathered in the study.

**VOLUNTARY PARTICIPATION**

You do not have to agree to be in this study, and you may change your mind at any time. There will be no penalty if you decide to quit the study.

* If you have questions or complaints about this study, you may contact the local investigator: Ms. <Principal Investigator’s name>, <Implementing agency>, <Address>, <Phone #>.
* If you have any questions about your rights as a research participant, or if you think you have not been treated fairly, you may contact the <Country> IRB at: <Ethics committee name>, <Address>, <Phone #>, <E-mail>, <website>.

**PERMISSION TO PROCEED**

Is it okay to proceed with the interview? Yes  No

**Participant’s Agreement**

I have (read / understand) the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

*Cluster HH Child*

Study ID # of Research Participant

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

Signature of Research Team Member Obtaining Consent Date

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

Printed Name of Research Team Member Obtaining Consent

APPENDIX D: ROLE PLAY GUIDE

**Interviewers**: This guide presents some situations that you might encounter and so should practice handling during your training. This will help prepare you in case one of the situations occurs during a real interview.

You will play the roles both of the interviewer and the respondent during the training exercise. This will help you better understand respondents’ concerns and actions and will help you learn to handle these situations. Work closely with your fellow trainees now and later. They can help you conduct successful interviews.

**Supervisors**: This guide provides information about how to handle the situations that VASA interviewers might encounter. You may find this information helpful when assisting the interviewers under your supervision.

**Trainers**: This guide provides information about how to handle the situations that VASA interviewers might encounter. You may find this information helpful in training the interviewers and their supervisors.

You should first discuss a problem situation with the interviewers and supervisors. Discuss why and when the situation might arise, and possible ways to deal with the problem. Let the interviewers ask questions and discuss the situation among themselves and the supervisors. Then conduct the role play for that situation.

Assign different interviewers and supervisors to act out each situation. You can do this by writing each role, such as "interviewer,” “the deceased’s mother," "the deceased’s sister" or “supervisor” on a separate card and handing one to each person who will act a part in that role play. The entire group should observe each role play. As much as possible, interviewers should decide how to handle the situations by themselves. This will give them confidence in similar situations in the field. After acting out a situation unassisted, the group should comment on what they observed. Use your own experience and this guide to provide help when needed. Try not to tell the interviewers the right thing to do. Rather, give hints or ask questions that will help them get back on the right path. Then let them find their way.

Also assign the supervisors to critique and provide feedback to the interviewers. This will provide the practice they need for their supervisory role. Your job at this point is to observe the role plays and the interaction of the interviewers and supervisors. Provide feedback to both, including how they might improve the supervisory experience. Useful supervision does not focus on criticism. It provides constructive feedback. You can demonstrate this through your own supervisory methods.

Situation 1—a crowd of interested observers gathers about

You go to a household where you were told that a young man died. Several people are standing about in front of the house. You introduce yourself and your reason for being there, and ask to speak with the person or persons who know the most about the circumstances of the young man’s death. The man’s sister says she knows about the illness and invites you into the house. Several people follow. The sister answers some questions, but others in the room also answer some questions. Some of their responses contradict each other, and they have difficulty deciding who is correct.

Guide to situation 1

Crowd control at the interview location can be difficult for the interviewer to manage. The project may decide to send an additional person with the interviewer team to assist with this sort of situation. The interviewer’s task is to identify the main respondent (or respondents, if different persons know about different phases of the woman’s illness) and to get the answers to the VASA questions from these persons. This is easiest if the main respondents are the only persons present at the interview. Accomplishing this must be done sensitively and cannot be forced if the respondent(s) want other persons there. Questions should be directed to the appropriate respondent (the one who knows the most about the illness phase being discussed), and answers sought from her or him. If other persons in the room give contradictory responses, the main respondent’s answer should be sought and recorded. If the main respondent clearly does not know the answer to a question, then the response “don’t know” should be recorded in the VASA format.

Situation 2—the best respondent is not available at the time of the initial visit

You go to a household where a woman died. You ask to speak to the person or persons who know the most about the circumstances of the death. Depending on the situation, this may be the woman’s mother, her sister, her husband or someone else who was with her during her illness or when she died. You are told that the best respondent is the woman’s mother but that she is not home.

Guide to situation 2

Interviewers may encounter this situation frequently. When the best respondent is not at home, the interviewer should attempt to make an appointment to return when this person will be available. If the family member who greeted the interviewer at the door cannot make the appointment, the interviewer should ask when to return to see the respondent. Acting out this situation in a role play will reinforce these lessons.

Situation 3—the family denies a death occurred

You go to a household where you were informed there was a neonatal death. You knock on the door--a man opens it. You explain why you have come to the house. The man responds that you must have the wrong house. He says that no baby from this household has ever died. He seems tense, and politely asks you to leave.

Guide to situation 3

1) The interviewer may indeed have the wrong address, 2) the family with the death may have moved, or 3) the family may have decided they don’t want to be interviewed. Addresses in some areas are inaccurate, so the interviewer should try to confirm whether s/he is in the right place. If it appears s/he is at the right address, it is best to not confront the person. The interviewer should thank them and leave. A block leader or other community organization may be able to help the project understand the problem and obtain the interview.

Situation 4—a second respondent is needed to obtain complete information

You are interviewing the sister-in-law of a woman who died in hospital. The woman’s husband was sick during her illness so the sister-in-law cared for her. She answers questions about the woman’s symptoms without difficulty, but has trouble with questions on the timing of some events. She explains that she did not go to the hospital with her sister-in-law. She is not sure if she went to other health facilities before going to the hospital, nor how long she was in the hospital before she died.

Guide to situation 4

Respondents should be asked only about events that they may know about. The interviewer should ask if another person accompanied the woman on her way to the hospital or during the time she was in the hospital. If so, this person should be interviewed about this time. If not, then it is better to not ask about this time.

Situation 5—a second respondent who lives far away is needed

You introduce yourself at a household where a child died, and ask to speak with the person or persons who know the most about the circumstances of the child’s death. The child’s father tells you that he took the child to the hospital when he/she became very ill and you begin the interview. He easily answers several questions, but has difficulty describing the early part of his child’s illness and tells you that he/she was at her grandparents’ house when the illness started. The grandparents live in a different village about one hour’s travel away.

Guide to situation 5

This is a variant of situation 3. There definitely are two main respondents (each was present for a different part of the child’s illness), but one lives some distance away. The interviewer should attempt to question each respondent about the phase of the child’s illness that s/he witnessed. In the situation described, it would probably be best for the interviewer to first visit the child’s grandparents to learn about the early part of his/her illness, and to next interview the father about the latter part of the illness. If possible to arrange to bring them together, it would likely be more efficient to interview the grandparents and father together.

Situation 6—the respondent is actively mourning the death

You are interviewing a man about the death of his wife. The woman died three months before the interview. The interview has been going well, with the husband remembering symptoms and events with little trouble. As you ask questions about the time closer to death, the husband slows in his responses and begins to cry. He tries to control himself but starts to cry harder.

Guide to situation 6

Many respondents still may be in mourning at the time of the interview. Interviewers need to be sensitive to respondent’s feelings and concerns. They should acknowledge the painful situation before the interview begins. This can be done by expressing empathy about the woman’s death. It may also help respondents to know that the health program and community plan to use the VASA information to improve care for other women. Interviewers should pause during an interview if a respondent cries or has great difficulty answering questions. S/he can be offered a tissue for tears, and the interviewer should acknowledge how difficult it is to answer the questions. She should give the respondent time to regain his or her composure, and ask if she can continue the interview at this time. If the respondent chooses not to continue, the interviewer should attempt to reschedule the interview.

Situation 7—the respondent is uncertain of many answers

You are interviewing a woman about her son-in-law’s death. She answers several questions with little hesitation, but then has trouble with a question. She answers “Yes,” then changes her answer to “No,” then pauses and says “I think so.”

Guide to situation 7

Many questions in the VASA format allow a “don’t know” response. If the respondent is not sure of her answer, it is best to record the response as “don’t know.” The respondent may not understand a question, so the interviewer should repeat it more slowly. S/he may also re-phrase the question if alternate terms are provided with the question. If a respondent answers “don’t know” to more than a few questions, this should raise the possibility that s/he is not the best respondent for this death (or a particular phase of the illness, if there are different respondents for other phases of the illness.) The interviewer should discuss such cases with her or his supervisor and decide whether to seek out a different respondent.

Situation 8—the respondent does not seem to be answering the questions openly

You go to a household where you were told that a woman died. You identify the woman’s mother-in-law as the best respondent about the labor and her father-in-law as the best respondent about the journey to the hospital and you begin the interview. The respondents seem to have trouble answering some of the questions and often glance at each other as if they are waiting for the other to answer. Also, some of their responses contradict each other. For example, when asked about careseeking, the mother-in-law says that the first thing the family did when they noticed the woman was ill was to call a midwife to the house. But the father-in-law disagreed and said that the first thing they did was to seek a taxi to take the woman to the hospital.

Guide to situation 8

Respondents may have hidden motives for their replies to the VASA questions, and this may compromise the accuracy of the information they provide. They may feel guilty that they did not provide proper care for a woman and so contributed to her death. They may also fear loss of compensation for the death if it is determined that they did not do their part to seek needed care for the woman. Family issues may also be involved. For example, the woman’s family (her parents, brothers and sisters) may blame the in-laws for not providing proper care for her, and this may cause the in-laws to be wary about the answers they give. Whatever the reason, if the interviewer suspects that the respondent(s) are not being fully open in their replies, s/he should discuss this with her supervisor. It may be possible to address the respondents’ concerns and hence their reluctance to answer openly. If not, then it may be necessary to seek other respondents to complete the interview. Such situations may require the supervisor to visit the family to make this determination.

APPENDIX E: MODEL RECRUITMENT SCRIPTS (for a stillbirth, neonatal or child death)

**Address to Household head or other first adult contact at the household**

My name is <YOUR NAME>. I am coming from the <AGENCY NAME>. For the purpose of improving health care, we are collecting information on maternal and child health in this area. I would like to talk to <MOTHER’S NAME>. Is she around?

*INTERVIEWER: If the possible respondent is available, continue:*

**Address to Mother (Note: this example is for the mother of a deceased child)**

My name is <YOUR NAME>. I am coming from the <AGENCY NAME>. You informed us during our last visit that you had suffered a (child death / pregnancy termination). I am very sorry to hear this. Please accept my sympathies. Before asking you any further questions, I would like to confirm your age. Are you at least 15 years old?

*INTERVIEWER: If the mother is at least 15 years old, then continue:*

For the purpose of improving health care, we are collecting information on the reported child deaths and stillbirths in this area.

*For pregnancy terminations, read:*

I want to ask you some questions about the events and any symptoms that you had during your pregnancy that did not result in a live birth. Can I tell you more now about the questions?

*For neonatal deaths, read*:

I want to ask you some questions about the events and any symptoms that you had during your pregnancy with <CHILD’s NAME>. I also want to ask about the events and any symptoms that <CHILD’s NAME> had during her/his illness before death. Can I tell you more now about the questions?

*For child deaths, read:*

I want to ask you some questions about the events and any symptoms that <CHILD’s NAME> had during her/his illness before death. Can I tell you more now about the questions?

*INTERVIEWER: If the mother is not available try to make an appointment to return when she will be there. If the mother will not be available, then continue:*

**Address to Household head or other first adult contact at the household**

Your household was selected because <MOTHER’s NAME> reported during our last visit that she had suffered a (child death / pregnancy termination). I am very sorry to hear this. Please accept my sympathies. Because <MOTHER’s NAME> will not be available, is there someone else at least 15 years old I can talk to who helped care for (<CHILD’s NAME> during her/his illness before death? / <MOTHER’s NAME> during her pregnancy)?

*INTERVIEWER: If another caregiver is available, continue:*

**Address to Other Caregiver**

My name is <YOUR NAME>. I am coming from the <AGENCY NAME>. <MOTHER’s NAME> informed us during our last visit that she had suffered a (child death / pregnancy termination). I am very sorry to hear this. Please accept my sympathies. For the purpose of improving health care, we are collecting information on the reported child deaths and stillbirths in this area.

*For pregnancy terminations, read:*

I want to ask you some questions about the events and any symptoms that <MOTHER’s NAME> had during her pregnancy that did not result in a live birth. Can I tell you more now about the questions?

*For neonatal deaths, read*:

I want to ask you some questions about the events and any symptoms that <MOTHER’s NAME> had during her pregnancy with <CHILD’s NAME>. I also want to ask about the events and any symptoms that <CHILD’s NAME> had during her/his illness before death. Can I tell you more now about the questions?

*For child deaths, read:*

I want to ask you some questions about the events and any symptoms that <CHILD’s NAME> had during her/his illness before death. Can I tell you more now about the questions?

*INTERVIEWER: If another caregiver is not available, try to make an appointment to return when the person who cared most closely for (<CHILD’s NAME> during the illness / <MOTHER’s NAME> during the pregnancy) will be there. The person must be at least 15 years old.*

APPENDIX F: PRACTICE INTERVIEW SITUATIONS

**Neonatal deaths**

Scenario 1 – Early neonatal death on the day of birth

A 20-year-old woman delivered her third child after a 38-week pregnancy. During the last part of her pregnancy, the woman suffered from swelling of her hands and face, blurred vision and a severe headache. She saw a village doctor for these problems, who gave her medicine for high blood pressure and told her to rest more. However, the problems did not improve. When her contractions started, she went to the local health center for the delivery since she could not afford a taxi, and in any case the nearest hospital was more than two hours away. During her labor, there were signs that the baby was not getting enough oxygen; and at birth the baby did not breathe immediately, had to be resuscitated, and did not cry for the first five minutes. The baby was put in an incubator that the health office had recently supplied the health center with, and once every hour was brought to the mother to breastfeed. However, the baby was too weak and could not suck well. Late in the evening of the first day of life, the baby’s breathing became weaker and then stopped.

Scenario 2 – Late neonatal death of a 3-week old child

A 23-year-old mother gave birth to her third child after an uneventful pregnancy. The woman’s mother helped care for her daughter’s other two children, a 1-year-old and a 2.5-year-old, during the pregnancy. However, after the pregnancy, the woman’s mother had to return to her own village. Her husband was also away, working in a different district, and there was no one else to help care for the other children. The woman breastfed her new baby, but she thought the baby was not getting enough milk, so also gave the baby formula from a bottle. All was well for the first two weeks, but then the baby started to have more loose stools than usual and the eyes began to look sunken. The mother took the baby to the local health center, where a health worker showed her how to mix and give the baby ORS and gave her ORS powder to make more at home. The mother followed the health worker’s instructions, using water from the home well to prepare ORS and give this to the baby after each feeding. She also continued giving the baby formula to make sure the baby got enough nourishment. However, the diarrhea continued and the baby seemed weaker, having difficulty latching onto the breast and taking formula from a bottle. After two days, the mother thought to return to the health center, but was delayed by needing to also care for her other two children. The next day, the baby was even weaker and later in the day passed away.

**Child deaths**

Scenario 1 – Possible neonatal cause of death in a 3-month-old

An 18-year-old woman gave birth to her first child at a government hospital, attended by a midwife. She had some light spotting during the seventh month of her pregnancy, for which she sought care at an NGO health clinic. The clinic sent her home with instructions to rest and go to the hospital if the bleeding continued. Three days later, the bleeding became heavier and she began having contractions. She went to the government hospital, where her labor and the baby’s condition were monitored. The baby was found to be distressed and after seven hours of labor a Caesarean section was performed. A 1.8-kilogram baby of estimated gestational age 32 weeks was delivered. The baby was not breathing at birth and had to be resuscitated by a pediatrician who assisted the midwife. The baby had a weak suck from the time of birth so could not feed well. She also had trouble maintaining her body temperature and was cold to touch. She started having convulsions on the second day of life. The convulsions gradually lessened and the baby began to breastfeed and to be kept close by the mother until they both left the hospital after one week. The baby continued having difficulty feeding at home and was not gaining weight. The mother’s mother tried to assist, but she did not have any experience with preterm babies so was not of much help. When the baby was 1 month old, the mother tried a home treatment leaf rub suggested by her mother. This did not help so she took the child to the town health center. A doctor there recommended a soft, nutritious diet that the baby was able to take and she improved somewhat on this diet but continued to gain weight only at a very slow pace. One and one-half months later the baby got sicker, first with diarrhea and then fast breathing, difficult breathing and fever. The mother took the child back to the hospital where she was born. The hospital gave her antibiotics but was not able to increase her food intake. The baby’s condition worsened over the next days and she passed away.

Scenario 2 – Neonatal cause of death in a 4-month-old

A 21-year-old woman gave birth to her second child at a private hospital. The pregnancy was unremarkable, without any complications either before or during labor, but the baby was born with a large defect in the roof of the mouth and upper lip (cleft palate and lip). This caused problems with the baby’s feeding so a tube had to be inserted through the baby’s nose down into the stomach through which the baby was fed a liquid formula. However, this sometimes led to a problem— if too much liquid was given at one time some would come back up into the baby’s throat and be aspirated into the lungs. Over the first 3 months of life, this twice led to the baby having pneumonia with fast and difficult breathing, chest indrawing and fever. For both of these episodes the mother took the child to her local health center, where the baby was successfully treated with antibiotics. The mother was also advised at these times on the amount of formula to give at one time to prevent aspiration. At the age of 4 months, an operation was done to repair the defect. Unfortunately, the operation was only partially successful and two weeks later the baby again aspirated and developed pneumonia, this time more severe. The mother took the child to hospital, where she stayed for three days with worsening symptoms of grunting and lethargy before passing away.

Scenario 3 – 15-month-old child with a fatal illness

A healthy 15-month-old child developed a fever, cough and difficult breathing. The mother treated the child at home with antibiotics left over from a past illness. On the second day of the illness the child began holding his neck stiffly as if it was painful and then started to have seizures. The parents became alarmed and decided to take the child to the government hospital where he could receive free care. However, they had trouble arranging transportation since they lived in a rural area with infrequent bus service. They had to wait one full day for the next bus, by which time the child’s condition had worsened. He was now barely conscious and with high fever, and continued to have convulsions. Almost as soon as they reached the hospital, the doctor there referred the child to the district hospital where he said the child could receive better care. However, there was no ambulance to take the child, and there was another delay of two hours waiting for the next bus to take the child. On reaching the hospital, the child was unconscious. He was immediately started on an IV, and antibiotics were started through the IV drip, but he died after being in the hospital emergency ward for only one hour.

Scenario 4 – 20-month-old child with a fatal illness

A healthy 20-month-old child developed an illness with fever, chills, headache, nausea and vomiting. The child lived in an area where malaria used to be common, but had decreased in recent years so the child was not sleeping under a bed net. His parents treated the illness at home with a medicine given to them by their neighbor who said it helped their own child when she had a fever. However, in less than two days the illness had become much worse. The headache was now severe, the child became very drowsy, had pales palms and nails, and he developed seizures. The parents became alarmed and took the child to a spiritual healer who lived nearby for treatment of the seizures. The healer blessed the child and assured the parents that the child would get better soon. However, by the next day the child was unconscious and still having seizures. The parents took the child to the nearest health center where they gave the child an intravenous medicine and arranged for an ambulance to take him to the district hospital. The ambulance was on the way to the hospital with the parents and the child, but he died before arriving at the hospital.

**Maternal deaths**

Scenario 1 – Postpartum hemorrhage

A 28-year-old woman, gravida 6, para 5, delivered at home with the help of an untrained dai. Her labor lasted 14 hours with difficult pushing for more than 2 hours. The baby was large and had difficulty breathing at birth. The woman had some bleeding during the birth, which continued after delivery of the placenta. The dai was concerned about the bleeding because she had seen this before in other women. After 1 hour the husband became concerned and decided to seek help. Many difficulties were experienced in finding a vehicle and the woman died on the way to the hospital.

Scenario 2 – Post-abortion sepsis

A 21-year-old woman, gravida 4, para 3, had an abortion performed by a quack who inserted a traditional root in her vagina to end the pregnancy. One day after the abortion the woman had fever and chills. The next day she noticed a foul-smelling vaginal discharge and had pain in her abdomen. She became more ill over the next days, with increased fever and sweats. She sought care from a neighbor who was knowledgeable about traditional medicines. He treated her with an application of leaves to her abdomen and hot tea. She became sicker over the next day and went to see the ANM at her local health subcenter. The ANM referred her to hospital but the woman did not go because of a lack of money for transportation and treatment. She saw her neighbor again and received another traditional medicine. However, her illness worsened, with increased fever and pain. She became incoherent and then unconscious for 1 day, after which she died at home.

Scenario 3 – Antepartum hemorrhage

A 25-year-old woman, gravida 3, para 2, had light vaginal bleeding early in her pregnancy that stopped by the third month. The bleeding recurred in the sixth month, occurring periodically and becoming heavier with each episode. She sought care from her ANM for several of these episodes. During the last episode, in the eighth month of pregnancy, the woman had heavy bleeding and felt faint and cold. She sought care from the ANM, who referred her to the hospital. Her husband was away so she had trouble getting money to go to the hospital. Once she got the money, she went to the nearest CHC, which took more than 1 hour to reach. The doctor at the CHC said she needed a transfusion and referred her to the district hospital. It took her another hour to reach the district hospital. When she arrived she was already unconscious and she died soon after.

**Adult deaths (non-maternal)**

Scenario 1 – 15-year-old injured in a motorbike accident who developed fever

A 15-year-old boy learned how to drive a motorbike when school was off for a summer vacation. His father, though he didn’t like the idea, had to help him as he was the only son, and desired to drive the new motorbike that his father had recently purchased. He promised his father that he would drive only on local streets. One day when his father had to go to district headquarters for work, the boy was tempted to take the motorbike to the main road, and was driving without a helmet. The road wasn’t busy, and he started to speed up and passed a few high speeding cars to get behind a pick-up truck. The truck was also speeding but suddenly stopped to avoid running a red light. The boy couldn’t manage to stop in time and collided heavily with the pick-up truck. He was found unconscious as he was thrown from his motorbike and smacked down to the road hard. He had a significant bump on his head along with bruises and lacerations throughout his upper and lower limbs. He had a few seizures when people got him in a car to take him to the district hospital, which was 60 kilometers away. When the boy arrived at the emergency room, the duty doctor examined and found him with a severe traumatic brain injury, and he was already in a coma. He remained in the comatose state for next six days before he succumbed to his injuries and died.

Scenario 2 – 35-year-old who died from HIV/AIDS

A 35-year old woman had been sick for the last 10 years with occasional fever, oral yeast infection, diarrhea, and swelling of the neck. Recently she felt very tired, lost a lot of weight, and suffered from a chest infection. Other recent symptoms included recurring fever, intermittent stomach pain and a lump she could feel in her stomach, chronic diarrhea, swollen glands, persistent white lesions on her tongue, and skin rashes. Due to increased stomach pain she was admitted to the district hospital and underwent surgery. She learned from the hospital nurse that a blood test showed she had been suffering from an infection, and that her stomach lump developed following that infection. Her husband had passed away about five years ago from a similar illness that lasted eight years, but without stomach complications. Her situation didn’t improve much after the surgery and she was advised to have another operation. However, by then she was extremely weak and also didn’t have enough money for a second surgery. Her stomach pain was severe and her chest had become re-infected, causing her difficulty in breathing. After fighting this disease for 10 years, she passed away at her village home.

Scenario 3 – 58-year-old who suffered a heart attack

A 58-year-old obese man was the manager of a non-government organization (NGO) and was recently under great stress at work. The employees were demanding a higher salary scale despite the NGO having difficulty raising funds compared to the previous year. He was a chain smoker, and recently on a medical examination was found to have very high blood pressure. Laboratory tests showed that he had diabetes and high cholesterol for which he was prescribed medication. He was advised to quit smoking as well. He started the medication but was not very regular in taking them. Moreover, he couldn’t give up smoking, and thought he would attempt this once the stressful work situation would subside. One day at work, he felt tightness, squeezing and pain in his chest. The office staff drove him to the nearby health facility. On the way he felt increased chest pain, which was spreading to his neck, jaw and back, and he started to have shortness of breath and a cold sweat. After examining him, the facility in-charge immediately referred him to the nearest specialty hospital, about a two-hour drive away by ambulance. Upon arrival at the hospital, the emergency doctor found him dead.

Scenario 4 – 65-year-old who died from cancer

A 65-year old man had been feeling sick with a sensation of being very full during meals and having difficulty swallowing. He felt bloated after eating and had frequent burping and heartburn. He took over-the-counter medication for this problem; however, his indigestion did not resolve. After several months he developed stomach ache and pain in the breastbone. He was vomiting after meals, and recently noticed blood in his vomit. Gradually, he became more sick and was losing weight. He developed fluid in the stomach that caused it to feel lumpy to the touch. He lost his appetite and started to have black stools that contained blood. He felt a lump above his left neck bone and some swelling in his belly. He didn’t have money to go to a hospital so his family discussed his illness with a local NGO that managed to transfer him to the district hospital. He was examined there and diagnosed with a chronic disease at the terminal stage. His condition was so poor that available further treatment couldn’t be administered. His family decided to bring him back to his village home the next day, but he died in the hospital early in the morning.

1. Kalter HD, Setel PW, Deviany PE, Nugraheni SA, Sumarmi S, Weaver EH, Latief K, Rianty T, Nandiaty F, Anggondowati T, Achadi EL. Modified Pathway to Survival highlights importance of rapid access to quality institutional delivery care to decrease neonatal mortality in Serang and Jember districts, Java, Indonesia. *J Glob Health*, 2023; doi: 10.7189/jogh.13.04020. [↑](#footnote-ref-1)