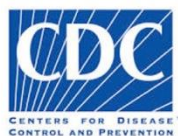


# Verbal autopsy standards:

## VA Field Interviewer Manual for the 2016 WHO VA Instrument

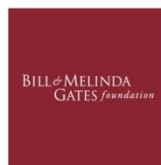
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## About this manual

This manual and its resources are the products of the effort by an expert working group led by the WHO, consisting of researchers, data users, and government agencies for the development of a standardized and simplified verbal autopsy (VA) instrument. The 2016 WHO VA instrument is intended to allow for simple and inexpensive identification of causes of death in places where no other routine system is in place, and will serve the needs of countries' civil registration and vital statistics (CRVS) systems for non-medically certified deaths. This instrument can also be used in research and disease specific programmes. The application of the 2016 VA instrument in CRVS and other routine data collection systems and research settings, will facilitate the compilation of a large database that is needed to make further improvements to the VA instruments and refine the algorithms used for assigning causes of death from VA.

This manual has been produced to assist the interviewers using the electronic version of the 2016 WHO VA instrument. The manual is part of a package of resources and tools, and should be used in conjunction with the Manual for the training of VA interviewers in the use of the 2016 WHO VA Instrument and with the Technical User Guide for Electronic Data Collection with the 2016 WHO VA Instrument.

**NOTE:** This manual has a generic section that describes principles of VA. More detail and specific training can be found in the other manuals mentioned above.

### **The question by question instructions start in the appendices.**

The manual has been produced to assist those who are responsible for training interviewers and supervisors on all aspects of VA using electronic data collection methods and automated diagnostic methods to ascertain causes of death. The manual includes detailed instructions for 18 training sessions that involve lectures, group exercises and discussions, role plays, and field practice with the supervision of VA interviews in a community.

Feedback on the manual, suggestions for amendment, and translations should be sent to [verbalautopsy@who.int](mailto:verbalautopsy@who.int). In such way, they can contribute to the continuous improvement of the material.

## Introduction

Information on deaths by age, sex, and cause are essential for understanding disease patterns in populations. These data are used to calculate several commonly used indicators that are routinely used by district and national health departments for health planning and action plans. Indicators such as infant mortality rate and maternal mortality ratio are commonly used to monitor and evaluate maternal and child health programmes. Similarly, disease specific death rates such as tuberculosis, HIV/AIDS, malaria, and dengue fever mortality rates are used to measure progress of disease control programs. There is now also the need for information on death rates from common noncommunicable diseases such as cancers, cardiovascular diseases, diabetes, and respiratory diseases; as well as from occupational hazards, for assessing disease burden, setting priorities, and monitoring progress.

The civil registration and vital statistics department of the government that has the mandate to register all births, deaths, and causes of death is the official source of such data, but such systems are not fully functional in many countries. The other source of information on deaths is routine health information systems that are also incomplete and inaccurate in many countries. To meet the need for mortality data, information on deaths is often collected through household surveys, or surveillance programs in a sample of communities in the country. However, there is a challenge in determining the cause of death, particularly for deaths that occurred at home without any medical attention, which is most often the case in developing countries.

A technique has been developed to ascertain the cause of death occurring outside health systems through interviewing caregivers of the deceased, known as verbal autopsy. Verbal autopsy (VA) is an interview with relatives of the deceased using a detailed questionnaire, to obtain information on the symptoms, signs, and other relevant events during the illness leading to death. Over the past four decades, VA has been developed and tested in many different countries, with local variations in the overall process in regard to the design of the questionnaire, specifications of the interviewer and respondent, time period between the death and the interview, and the procedure used to identify the cause of death from the completed questionnaire. More recently, the WHO has led an initiative to develop a set of common VA standards that could be applied in most settings with minor local adaptation, so that the data gathered from this process is uniform and can be used for comparative analysis within and across countries and over time.

This manual describes the essential features of VA questionnaires developed by the WHO in 2016, along with a brief explanation of various aspects that need to be taken into

consideration for implementing the interview, and question by question instructions to complete the questionnaires.<sup>1</sup>

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<sup>1</sup> *Once VA paper forms have been developed, an update to this manual will be published containing copies of the generic paper versions of the VA forms.*

## Principles of verbal autopsy

VA was principally developed to provide information on the cause of death in communities where there was very limited access to health care and medical certification of causes of death. In such situations the only viable source of information on the terminal illness is from caregivers of the deceased, most often the family members. Ascertaining causes of death from such information is based on the premise that VA respondents can accurately recall the details of the various symptoms and events that occurred during the period of illness prior to death, and that such information can be used to classify the cause(s) of death into diagnostic categories based on specific symptom complexes. Certain causes of death are easier to identify than others e.g. some pregnancy related deaths, and deaths from injuries. In addition, some common causes of adult mortality could be easy to recognize by the community, based upon their main symptoms e.g. severe chest pain from a heart attack; one-sided paralysis of the body from a brain stroke, and long-standing breathlessness and cough in chronic lung disease. However, other conditions such as tuberculosis (TB), malaria, HIV/AIDS, cancers, and diabetes have multiple and sometimes overlapping symptoms and need careful review of all information from the questionnaire to arrive at the diagnosis. Overall, the accuracy of information and subsequent diagnostic classification is based on several factors including the characteristics of the interviewers that are described in the WHO VA manual (<https://www.who.int/healthinfo/statistics/verbalautopsystandards/en/>). Below some of the most important principles which must be considered when conducting VA studies are described.

### Identifying the most appropriate respondent

The main criteria for selecting the most appropriate respondent from the family members should be the person who most closely attended to the deceased during the illness. His/her educational status and communication skills may also be considered while identifying the most appropriate respondents. This could likely be the mother in the case of an infant death, the spouse in case of an adult death, and the son/daughter in the case of deaths among the elderly. Previous experience has also suggested that for maternal deaths, the sister or other adult female relative of the deceased would be more appropriate than other relatives. In some situations, there may be a need for the primary respondent to consult other household members for specific details (e.g. someone else who accompanied the deceased on a health facility visit). In extreme situations, there may be need to take information from neighbours or other members of the same community, but as far as possible responses should be collected only from members of the household of the deceased. Where multiple respondents are consulted, this should be noted in the appropriate section of the questionnaire.

## **Optimal recall period**

The time period between the date of death and the date of the interview has important implications for the quality of information. It is generally felt that the VA interview should be conducted between six weeks and 12 months after the occurrence of death. The minimal period of six weeks allows sufficient time for the family to recover from the bereavement and be emotionally ready to share details of the event; while the maximal period of 12 months has been designed to reduce the potential for details to be forgotten or confused. While such optimal recall periods are achievable in conjunction with routine death reporting systems (death registration; mortality surveillance), this is not the case with mortality surveys, which usually compile data on events during the previous 1–3 years. In such situations, attempts should be made to keep the recall period as short as possible, particularly for infant and child deaths.

## **Community sensitization**

Community sensitization involves actions by community leaders and volunteers to inform households of the basic objectives and methods of the VA procedures, and advising them of the importance of their cooperation in the collection of accurate and relevant information. The process of community sensitisation may vary between countries. A common practice in many settings is to hold a meeting with the community leaders to explain the broad objectives of collecting data on mortality and the process of VA, who then communicate this to the community. The interviewers need to carry a letter from the community leader and/or from the health authorities to introduce themselves and the objectives of VA before getting consent to conduct VA.

## **Training of interviewers**

The quality of VA data depends on the intensity and quality of training provided to the interviewers. Training programs for interviewers should include field practice and feedback sessions. VA experience accumulated by interviewers over several months/years of implementing such interviews can also influence data quality. In case of staff turnover, appropriate arrangements should be made for orientation of new staff, as well as refresher training sessions. All these can have considerable influence on the quality of information collected at VA, and adequate attention to these details is required by the VA project management as well as the interviewers. The WHO has developed a manual to assist those who are responsible for training VA interviewers on the aspects of data collection in CRVS systems, preferably using the electronic version of the WHO 2016 VA instrument<sup>1</sup>.

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<sup>1</sup> The Manual for the Training of VA Interviewers in the Use of the 2016 WHO VA Instrument will be available on <http://www.who.int/healthinfo/statistics/verbalautopsystandards/en/>.

## **Methods for assigning causes of death**

The information collected on VA questionnaires could be analysed in two ways to determine the cause of death. One approach involves review of completed questionnaires by physicians who apply diagnostic guidelines and clinical judgement to assign causes of death. A second approach involves the application of computer algorithms to the data from questionnaires, which predict the most probable cause of death. The accuracy of both these approaches depends on the accuracy of information collected from the VA interview.

## **Variations in field implementation of verbal autopsy**

As mentioned earlier, VA interviews can be implemented alongside routine death registration or mortality surveillance systems, or as a follow up to mortality surveys. In routine implementation, the VA interviews are distributed throughout the year according to the seasonal patterns of mortality, and the interviews can be fitted into the regular work schedule. However, for surveys, the VA interviews need to be conducted in a short period after the survey data collection, and result in a heavy workload to be completed quickly. These have important implications on the data quality, and also have implications for choice of interviewer, and effect of training and community sensitization, and field supervision. The VA project team would need to take the mode of field implementation into account during planning of field operations, and make arrangements for suitable data quality assurance. VA interviewers would also need to understand these aspects and make necessary adjustments to ensure high quality data collection.

## **Ethics and data confidentiality**

Ethics and data confidentiality are key factors in the implementation of VA interviews. The main ethical principles that should be followed include

- Informed consent: VA respondents should be provided with complete information about the purpose and process of the VA interview, and asked for their consent (permission) to conduct the interview. In some settings written consent is needed but in most settings verbal consent is deemed to be sufficient.
- Autonomy in participation: VA respondents should be free to decide whether they wish to participate in the interview, and are also free to withdraw from participation at any time during the interview; and there will be no problems from any non-participation or withdrawal.
- Confidentiality of data; assurance should be given of the confidential nature of the collected information, that it would only be used for health planning and research

purposes, and that it would not be disclosed to anybody beyond the data collection agency.

- Presentation of results: Analysis of data would be presented only in total numbers of deaths by age, sex and cause for the entire community, and care would be taken not to reveal individual identity for any event.
- Feedback to community leaders on the mortality profile of the local population and its implications for health care.

In summary, it is very important for VA interviewers to be fully aware of these principles of ethics and confidentiality, and apply them diligently during field work. In particular, care should be taken not to discuss or disclose any details of completed VA interviews with any personnel other than the VA team, that too only in regard to data quality or any difficulties in interpretation of responses. Completed questionnaires in paper format must be handed over directly in person to the VA supervisory team, and should not be discussed or shown to anyone else.

## Design of questionnaires

The WHO 2016 version of VA questionnaires are organized in three separate forms as follows:

- WHO VA Questionnaire 1 — This questionnaire is for neonatal, perinatal deaths and stillbirths (deaths of children aged under four weeks).
- WHO VA Questionnaire 2 — This questionnaire is for post-neonatal and child deaths through 11 years (deaths of children aged four weeks through 11 years).
- WHO VA Questionnaire 3 — This questionnaire is for adolescent and adult deaths (death of a person aged 12 years and above).

The three forms share several common modules on identity, socioeconomic characteristics, and health services utilisation, but include specific modules on the history, symptoms and clinical events during the terminal illness preceding death. Such separation is necessary as each form targets certain common causes of death within the specific age group. For instance, the first form is designed to identify stillbirths, and deaths from prematurity (incomplete pregnancy); low birth weight; birth asphyxia; birth injuries; hypothermia, newborn bacterial sepsis, and congenital malformations, among other rarer causes. The post-neonatal and child death questionnaire addresses the above causes (except for stillbirths), as well as the common infectious diseases such as pneumonia, diarrhoea, malaria, and vaccine preventable diseases such as measles and pertussis, among others. Finally, the adolescent and adult questionnaire addresses common adult causes of death such as tuberculosis, HIV/AIDS, malaria, maternal causes, major noncommunicable diseases and injuries.

In field practice, the questionnaires will be implemented either using paper forms or in the electronic format using computer tablet devices or smartphones. The questionnaire items are

largely in the form of Yes/No response choices; with a few items that collect information either in categories (e.g. durations in days/weeks/months); or in grades of severity (e.g. fever – mild/moderate/severe). There are also some items in which an open text response is to be recorded (e.g. the cause of death mentioned by a health worker). Also, almost all items are provided with the option to record “Don’t know” or “Refused to answer”. Interviewers should take great care in ensuring that accurate responses are recorded for each item.

In the symptoms sections, there are several modules with detailed skip patterns. For instance, the module on fever starts with an initial question about fever, and if there is a positive response, goes on to elicit more details about duration, severity, pattern etc. It is important to ensure accuracy of response for the initial question, as a false negative response would result in a skip of the entire module, which could result in an overall difficulty in arriving at the correct diagnosis of the cause of death. Later in this manual (Appendices A, B and C), there are detailed descriptions and guidance provided for each item in all sections of each form, in regard to their meaning and intent, and in some instances, interpretations of potential responses. In addition, all the skip patterns are elaborated with clear instructions on the follow up questions. It is believed that such information will provide the interviewer with a better understanding of her/his task, assist them in providing some explanations (if required) to the respondents, and ensure that the responses actually relate to the exact content of the item.

In each form, in addition to the main sections that collect information on symptoms and clinical events, there are three additional sections that collect allied information. The first collects information on past history of medical conditions, as known to the family members in the form of diagnostic opinion conveyed by health professionals. This section provides important clues towards the potential causes of death, and should be enquired carefully. The information on past medical conditions may or may not directly be related to the terminal illness, but provides additional evidence to ascertain the diagnosis.

Secondly, the questionnaires include a section to note details from any available health records of the deceased, for example from hospital discharge notes, medical prescriptions, laboratory or X-ray/scan reports, among others. Often such information relates to chronic conditions such as diabetes, cardiovascular diseases, cancers, or TB. Such information could be of useful in making the diagnosis of the cause of death. Interviewers need to pay careful attention to all these sections when administering the interview.

Finally, there is an open text narrative section which requests the respondent to provide in her/his own words a brief description of the illness and terminal events. The sections explaining each questionnaire item later in this manual provides detailed instructions and guidance on how to enquire and record information from the open narrative. In some instances, respondents state some critical information in response to this item, which may not be captured in any of the other sections or items of the questionnaire.

## **Implementation of interviews**

### **Establishing contact with the household**

The conduct of VA interviews goes through several stages starting from the arrangement of the appointment for the interview. In general, the VA team will be provided with a list of deaths for which the VA would be required, with identity and contact details of the household of the deceased, including address. In most instances, it would be possible to establish contact with the household, either directly by a local VA interviewer, or through a local key informant/community representative. Such contact could be used to sensitize the household about the intention to conduct the VA interview, and schedule a convenient appointment for the same. In some instances, such prior contact and scheduling of appointment may not be possible, in which case the VA interviewer could choose an appropriate time to approach the household for the interview, potentially in the late afternoon or the end of the working day.

### **Initiating the interview**

When approaching households to initiate the interview, it would usually be necessary to first talk to the head of the household. It would be helpful to adopt an empathetic attitude and start by expressing sympathy or condolences for the death. In a few brief sentences, explain the purpose and intention of the household visit, and the need/importance of collecting information to ascertain the cause of death in the deceased. At this stage, it would also be helpful to identify the most appropriate person within the household who could be the VA respondent. The respondent is the principal person that will provide information about the deceased. He or she should be the one who was with the deceased during their illness. Usually, the household head or the spouse of the head of household is preferred respondent. For deaths of infants and children, the mother is almost always the best respondent. If these people are unavailable on the first household visit, the interviewer could schedule an appointment to return when they will be at home. If they are away from the area or otherwise will not be available for some time, then you should ask to speak to the eldest family member or relative that is at home (they should be at least 18 years of age). If this is not possible, then ask for the eldest non-relative that is a permanent member of the household (18 years of age or older).

Acceptable respondents, in order of preference, are as follows:

- head of the household or that person's spouse
- either parent (preferably the mother) in case of a child's death
- sister or adult female relative in case of potential maternal death
- eldest family member or close relative of the deceased (at least 18 years of age)

- oldest non-relative permanent resident of the deceased person's household (at least 18 years of age).

When initiating a VA interview, the introduction is very important. This is a very sensitive time for the family, so it is important that the interviewer be polite and considerate when making the first introduction. It is useful to maintain eye contact whenever feasible, to build confidence in the respondent. If culturally appropriate, some opening statements about the composition of the household and/or the respondent's occupation could help establish a rapport. It is also important to remember that in the case of a stillbirth or neonatal death, it could be emotionally challenging for the mother to respond to some of the questions. The interviewer should demonstrate good understanding and patience during the interview. Also, in the case of adult deaths resulting from violence or suicide, special precautions may need to be taken before contacting the household of the deceased, and if necessary, any permissions from local authorities for conducting the VA interview in what could be an ongoing or recently concluded medico-legal case.

## **Obtaining consent from respondents**

Before starting any interviews, the interviewer must read the consent form/VA Information Letter to the respondent, and ask if the respondent has any questions. The interviewer, if asked, should be able to explain the goals of the project and why the VA interview is being conducted, how many other sample areas are included in the survey, and how the information collected will benefit the respondents. It will also help to reassure respondents that their responses will be held in strictest confidence and that no information that would reveal anything about their specific household or the identity of the deceased will ever be released.

After addressing all questions, the respondent should be asked if (s)he wishes to participate, indicate the respondent's response, and record the respondent's signature if written consent is required. In settings where verbal consent is acceptable record that verbal consent was obtained. If the family refuses to take part, despite your efforts to persuade them, then record the information collected so far, and indicate that the family refuses to take part in the interview on the questionnaire, and close the interview.

## **Conducting the interview**

After consent is obtained from the respondent, the next step is for you to explain the format of the questionnaire and what type of questions the interview will cover. Given the length of the questionnaire it is helpful for respondents to have an idea of its structure and how long it is to prepare them before beginning the questions. This will also allow the interviewer to request patience and understanding on the part of respondents, if the interview appears repetitive or tedious, as some specific details are crucial for establishing the diagnosis.

During the interview, there are likely to be some challenging situations that may arise in the interaction. Firstly, in some instances, the respondent may become overcome with grief on recalling the terminal events or remembrance of the deceased. Under these circumstances, it is advisable that the interview should be paused, to allow the respondent to recover, and where necessary, be consoled by other members of the household present at the interview. In case it is too distracting, or the pause is prolonged, it may be necessary to postpone the interview to an alternate time point. In other instances, the responses may be indicative of a disease or condition associated with stigma e.g. suicide; or HIV/AIDS; or TB in some communities; and this may also lead to hesitation or non-committal responses and lack of engagement in the interview beyond a certain point. It would be necessary for the interviewer, on identifying this potential situation, to reassure the respondent of the strict confidentiality of the information being collected, as well as the importance of the accuracy of information. Also, there may be instances when there is more than one person present at the interview providing responses which may be different to that from the main respondent. In such cases, the interviewer should remind the main respondent the importance of confidentiality and privacy of the interview. The interviewer could ask the respondent to request the other members to cooperate and let the respondent complete the interview alone; or could if necessary, reschedule a time to come back and finish the interview. In cases where complete privacy is not possible, try to limit the number of other people present.

Finally, at the end of the interview, whether successfully completed, or terminated or postponed due to any reason, the interviewer should thank the respondent and household, and offer the potential for them to contact the interviewer or the VA team in case they need any clarification or further information regarding the process. Also, the interviewer could inform the household that after reviewing the questionnaire, there may be a small chance of the household being contacted again, for any clarification.

## **Data processing and management**

Completed VA questionnaires need to be processed and analysed in regard to the assignment of causes of death. The process for data compilation and management will depend on the mode of data collection (using paper forms or computer tablet devices) and on the mode for cause of death assignment and coding.

In the case of paper forms, all completed questionnaires are first scrutinised by VA supervisors; if errors or inconsistencies are noted by VA supervisors they can be corrected in consultation with the VA interviewers. Subsequently, the completed forms are submitted to physician reviewers who assign the cause(s) of death applying diagnostic guidelines and clinical judgement.

In case of paper based data collection for which the cause of death assignment is to be conducted using computer algorithms, after the supervisory review of completed paper questionnaires for data quality, all the paper forms are usually compiled at a central location (or a few data compilation nodes), where data from each questionnaire are entered into a database. At this stage, the database may include some standard checks for data quality and consistency. However, given the centralised data management, it reduces the opportunity for field verification and updates.

Where data are collected using computer tablet devices, the software programs have built in checks and mechanisms to restrict the potential for implausible data errors, and to ensure correct skip patterns are followed. Also, special software is used to upload the information from individual questionnaires into a central database for further data verification and processing. The VA teams should be aware of the technical challenges in maintaining functional Tablet PCs, internet connectivity, and training interviewers who can operate the tablet versions with speed and accuracy.

It is important for VA interviewers to be aware of the details of various operations and processes that will be implemented in their respective field settings, and receive appropriate training, to effectively participate in data collection and follow up mechanisms for data quality control. In some instances, paper forms may be needed as a back up to electronic data collection platforms, so knowledge and training of both processes may be required.

## **Interviewer training and field supervision**

A VA interview is a highly specialised form of health care data collection. The key differences from other common health surveys include the technical details of clinical signs and symptoms included in the questionnaire; the complicated skip patterns and importance of avoiding false negatives; the overall length of the interview, and the need to stay focussed and objective within the sensitive overall environment in addressing the facts about recent death of a household member. All these aspects need considerable and careful attention during training of interviewers, for which duration should depend on the level of experience of the interviewers. For new/inexperienced interviewers, a minimum duration of seven days is recommended – five days of classroom training and two days of field practice; whereas, training could cover a period of 3–4 days for experienced interviewers. Training should include sessions to cover interviewing skills, content of the questionnaires, mock role plays and live field practice interviews, with adequate time in feedback sessions and group discussions to familiarize field personnel with the VA procedures. Other important elements of training include the provision of rapid onsite training to replace field staff in the case of sudden staff turnover; as well as the provision of periodic refresher training programs and feedback sessions to cover key elements of the broader training programs. This manual could

serve as useful background material to support the training programs, and also be used to reinforce their learning and serve as reference material during field operations.

Another key element to support VA implementation is field supervision. In general, supervisors are field personnel with higher educational qualifications (graduate degree holders) and field experience, holding responsible technical and preferably administrative positions within the VA implementation hierarchy. Field supervisors have key roles in reviewing field performance of interviewers, providing on-site support and troubleshooting advice, ensuring adequate distribution of workload across personnel and over time, and assisting interviewers in their responsibilities towards data management and quality control. VA interviewers should be aware of the roles of supervisors and the nature of their responsibilities, so that they could approach them and use their support in a manner that would benefit the overall VA data collection system.

## Sections of the 2016 WHO verbal autopsy questionnaires

The questionnaire consists of the following sections:

1. Preset HIV-Malaria mortality and season (the project office may make this question hidden to the interviewers in the electronic format);
2. Information on the respondent and background about interview;
3. Information about the deceased and vital registration;
  - a. Information on the deceased
  - b. Civil registration numbers.
4. History of injury/accidents;
5. Health history;
  - a. Duration of illness
  - b. Medical history associated with final illness
  - c. General signs and symptoms associated with final illness
  - d. Signs and symptoms associated with pregnancy and women
  - e. Neonatal and child history, signs and symptoms
  - f. Health service utilization
  - g. Background and context
  - h. Death certificate with cause of death.
6. Open narrative (text field).
  - a. Check list of additional items to record in the narrative open space.

**Section 1** collects information about the prevalence of malaria and HIV in the area where the deceased lived and whether death occurred in rainy or dry season. This information is essential for selecting the appropriate algorithm used by some software for assigning the

cause of death. In most settings this information will be pre-completed by study staff or supervisors.

**Section 2** collects information about the respondent, consent if required in certain contexts and time the VA interview was started.

**Section 3** contains key identifying and socio-demographic information and data fields necessary for the management of completed forms.

**Section 4** provides essential information for assigning the cause of death due to accidental and intentional injuries.

**Section 5** contains several sub-sections that collect information required for assigning causes of death. Section 5a) has questions to determine the duration of the final illness; 5b) history known past or present diseases that would give clues to the causes of death; 5c) contains symptoms and signs that are relevant for all deaths; 5d) contains symptoms and signs specific to maternal deaths; 5e) contains symptoms and signs relevant for neonatal and child deaths; and 5f) contains questions about the utilisation of health services and contextual factors. Section 5g has fields for recording information from a medical certificate of cause of death if this is available.

**Section 6** is an open narrative text field that allows for comments from the interviewer and additional information from the respondent. This section is particularly useful for quality control and for providing important additional information for the cause of death assignment. To note, this section is also important in order to complete the checklist of some indicators (section 6a) that are required for assigning causes of death using Tariff 2.0. Accordingly, it is highly recommended that this section be completed and responses recorded. Considering the time taken to manually enter information from the respondent and the challenges of including all relevant information relayed, it is best if the open narrative is audio recorded. To enable audio recording, the user should simply change the type of question from text to audio in the XLS form.

In the following Appendices to this manual each question and the expected responses are explained in detail to facilitate understanding of the questions and to collect information in a standard manner





## **Appendix A: Question by question instructions for the 2016 WHO verbal autopsy questionnaire for the death of a child aged under 4 weeks**

**NOTE:** *Due to the integrated skip patterns, the identifying numbers of the questions will not always be in sequential order. Each question begins with its ID in parenthesis, e.g. “(Id10153) Did (s)he have a cough?”. Questions in [ ] are not to be read to the respondent. Throughout the document, response options are abbreviated as follows: “DK” refers to response option “Don’t know”; and “Ref” refers to response option “Refused to answer”.*

### **Preset HIV-Malaria mortality and season**

#### **(Id10002) [Is this a region of high HIV/AIDS mortality?]**

The answer to this question should be decided by the project office prior to the VA interview. The high mortality of HIV/AIDS is not based on a specified mortality of HIV in the study population, but on the regional mortality where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to >1% of deaths, LOW around 0.1% and VERY LOW <0.01%.<sup>1</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10003) [Is this a region of high malaria mortality?]**

The answer to this question should be decided by the project office prior to the VA interview. The high mortality of malaria is not based on a specified mortality of malaria in the study population, but on the regional prevalence where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to > 1% of deaths, LOW around 0.1% and VERY LOW < 0.01%.<sup>11</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10004) [During which season did (s)he die?]**

The study team should provide a list of months classified as wet or dry. Select wet or dry according to the list provided.

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<sup>1</sup> Streatfield, PK et al. HIV/AIDS-related mortality in Africa and Asia: evidence from INDEPTH health and demographic surveillance system sites. *Global Health Action*. 2014; 7: 25370.

<sup>11</sup> Streatfield PK et al. Malaria mortality in Africa and Asia: evidence from INDEPTH health and demographic surveillance system sites. *Glob Health Action*. 2014; 7: 25369.

## Information on the respondent and background about interview

### **(Id10007) [What is the name of VA respondent?]**

Record the reported name of the respondent. Report names standardly as: first name (given name), surname.

### **(Id10007a) [What is the sex of the VA respondent?]**

Record the sex of the respondent as female, male or ambiguous/intersex.

### **(Id10008) What is your/the respondent's relationship to the deceased?**

First verify if the respondent is a family member, and only if it is not a family member choose from the other response categories, like "health worker", "public official" or "another relationship". Only one response box can be selected. Select the appropriate box which represents the relationship reported by the respondent.

### **(Id10009) Did you/the respondent live with the deceased in the period leading to her/his death?**

Select the appropriate response. In the case of stillbirths or neonatal deaths, additional clarification may be needed from the respondent before directly selecting a response.

- If the respondent is the mother and it was a stillbirth, record "YES".
- If the respondent is the mother and it was a neonatal death, the response is likely "YES", BUT may be "NO" if the respondent indicates a circumstance where they were not with their neonate.
- If the respondent is not the mother and it was a stillbirth, record "YES" if the respondent indicates that (s)he lived with the mother of the deceased.
- If the respondent is not the mother and it was a neonate, if the respondent lived with the mother, the response is likely "YES". However, this depends on the circumstances (e.g. the respondent and mother were not with the neonate). So further explanation from the respondent may be needed.

**NOTE:** Unless a specific timescale is specified, the questions refer generally to the time period "during the illness leading to death". Some conditions (e.g. breathing difficulties in COPD) may be experienced consistently for a long time, eventually leading to death. Other conditions or illnesses may have shown symptoms in the past, but if the person recovered from these symptoms prior to the death, they are not likely related to the death.

### **(Id10010) [Name of VA interviewer]**

Record the name of the main VA interviewer here. The project office may add a list of interviewer names or recommend a standard format for reporting names (e.g. first name, surname).

**(Id10010a) [Age of VA interviewer]**

Record the age in years of the main VA interviewer here.

**(Id10010b) [Sex of VA interviewer]**

Record the sex of the main VA interviewer as female, male or ambiguous/intersex.

**(Id10010c) [ID of VA interviewer]**

Record a unique identifier code for the main VA interviewer. The interviewer ID can have numbers and letters. The project office should maintain a listing of the interviewer names and unique identifier codes.

**(Id10011) [Time of the start of the interview]**

Record the time the interview started. Remember to select am or pm to ensure that you have the correct time. In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

**(Id10012) [Date of interview]**

Record the date of interview. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK. In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

**(Id10013) [Did the respondent give consent]**

Select the appropriate response. If the respondent did not give consent, close the interview here, and record the time the interview was completed.

## **Information about the deceased and vital registration**

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### **Information on the deceased**

**(Id10017) What was the first or given name(s) of the deceased?**

**(Id10018) What was the surname (or family name) of the deceased?**

Verify the name(s) of the deceased in the paperwork on the assigned verbal autopsy case with what is reported by the respondent. If it is inconsistent, report this to the supervisor. If the name is consistent, record the name (if using paper form ensure it is legible). In Id10017 you are asked for the first or given name(s) of the deceased. In Id10018 you are asked for the surname (or family name) of the deceased.

**(Id10019) What was the sex of the deceased?**

Verify the biological sex of the deceased in the paperwork on the assigned verbal autopsy case with what is reported by the respondent. If it is inconsistent, report this to the supervisor.

Make sure you select the correct response box. If you select the wrong box, the cause of death could be incorrect.

If the biological sex is not typically male or female, select “ambiguous genitalia/intersex”. This selection may be the appropriate choice if the baby had a rare condition in which an infant's external genitals do not appear to be clearly either male or female. In such cases, the genitals may not be well-formed or the baby may have characteristics of both sexes.

**(Id10020) Is the date of birth known?**

If you do not know the full date of birth, select the option “NO”; you will then skip the next question on date of birth (Id10021) to specify the date – and jump to the question on knowing the date of death (Id10022). This happens automatically in ODK. In some cases, particularly for elderly adults, the use of community calendars of significant historical events may facilitate the approximation of a year of birth.

If the response is “YES”, complete the date of birth.

**(Id10021) When was the deceased born?**

Record the date of birth. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK.

**(Id10022) Is the date of death known?**

The list of deaths in the paperwork on the assigned verbal autopsy case should have this information, but the question should also be asked of respondents.

**NOTE:** For ODK you will need to have the full date of death to enter it. If you do not have the full date of death you should select “NO”. Then in ODK, you will be asked an additional question about the year of death. Fill in the year of death in four digits. For the paper version of the questionnaire, if they are unsure of the date enter the year of death if known.

**(Id10023\_a) When did (s)he die?**

The death information from the paperwork on the assigned verbal autopsy should have this information. You should still ask the respondent and then record their response for the date of death using the day/month/year (dd/mm/yyyy) format. This will be a calendar format for ODK, so you will need to put in the full date. For the paper questionnaire, you will fill in the boxes provided. If they are unsure of the exact date, record the year of death. If the deceased was a stillborn baby, enter the date of delivery as the date of death.

If you have recorded the full date of birth and the full date of death, the electronic device will automatically select the questionnaire corresponding to one of the three age groups: neonate, child or adult. Therefore, be very careful in completing the date of birth and date of death. If you make a mistake in the date of birth or death you will fill in a wrong questionnaire.

**(age\_group): [What age group corresponds to the deceased?]**

This item applies for the electronic data collection format only. If you were unable to complete the full date of birth or date death you will be forced to select a questionnaire corresponding to the three age groups: neonate, child or adult. Select the age group of the deceased, based on your assessment of the age of the deceased. Select this option very carefully. If you make a mistake in the age group, important questions will be skipped because some sections of questionnaire depend on the age group to determine the questions asked. Note that this question is used to determine which sequence of questions to use. This is a required question. If the respondent does not know the exact age, enter the best estimate.

**(age\_neonate\_days): How many days old was the baby? [Enter neonate's age in days:]**

If you have selected the neonatal questionnaire, you have to enter the age in days. Neonatal age is under 28 days, or 0 to 27 completed days; a valid entry is between 0 and 27. If the neonate is less than 1 day or 24 hours, enter "0" days.

**(Id10058) Where did the deceased die?**

Record the site of death by selecting the appropriate box.

**NOTE:** The questions from Id10051 to Id10073 are related to citizenship, socio-economics are not required for assessing causes of death.

**(Id10051) [Is there a need to collect additional demographic data on the deceased?]**

The project site will determine if this information should be collected. If you choose "NO", you will skip details about the place of residence, education, and family. If you select "YES", proceed with the next question. Site programmers may make this question hidden to the interviewers.

**(Id10052) What was her/his citizenship/nationality?**

Select the appropriate response according to the local definitions for citizenship. A naturalized citizen is an individual that was born elsewhere but now has become a citizen of the country. A foreign national is an individual who is not a citizen of the host country in which (s)he is residing or temporarily staying.

**(Id10053) What was her/his ethnicity?**

Record the reported ethnicity. Do not probe too much if the respondent is uncomfortable. Enter "--", if this information is not available or if the respondent is not happy to report the ethnicity.

**(Id10054) What was her/his place of birth?**

Record the reported place of birth. Specify here village and district. A question on the facility and circumstances will be asked later. Enter a "--" if this information is not available or unknown.

**(Id10055) What was her/his place of usual residence? (the place where the person lived most of the year).**

For perinatal cases, just ask for the address of the health facility or if released and at home, the home address. For neonatal deaths, the place of residence will usually be the same location as where the death occurred.

**(Id10057) Where did the death occur (specify country, province, district, village)**

You can fill in the city/town instead of village if more applicable.

**(Id10061) What was the name of the father?**

Record the father's name. Report names standardly as first name (given name), surname. This information may be used for civil registration purposes and/or to assist in matching or location purposes.

**(Id10062) What was the name of the mother?**

Record the mother's name. Report names standardly as first name (given name), surname. This information may be used for civil registration purposes and/or to assist in matching or location purposes.

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## **Civil registration numbers**

**(Id10069) [Is there a need to collect civil registration numbers on the deceased?]**

This question should be determined by the coordinator of the data collection activity and determined by the context in which VA is being conducted. If "YES", ask to see the certificate or death registration paperwork. You will use this paperwork to complete the next questions and fill in any information that is available. Enter "-", for unknown data. If "NO", skip to Id10104. Site programmers could make this question hidden to the interviewers if desired.

**(Id10069\_a) Do you have a Death Certificate from the Civil Registry?**

Ask to see the certificate or death registration paperwork. Interviewers should be familiarized with the local civil registry authority and the appropriate death registration form(s) that contain the relevant death registration information as requested in this section.

If "YES" and the paperwork is available, continue with Id10070–Id10073. If the paperwork is not available, skip to Id10104.

**(Id10070) [Death registration number/certificate]**

Record the registration or certificate number. Note that respondents may have a "death notification" 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.

**(Id10071) [Is the date of registration available? / Date of registration in day/month/year (dd/mm/yyyy)]**

Record the date of registration if known.

**(Id10072) [Place of registration]**

Record the full details of place of registration. This may include the name of the village/town/municipality where the death was registered. Enter “-”, if this information is not available. The project site may add a drop down list of location options.

**(Id10073) [National identification number of deceased]**

Record the National Identification Number. For newborns that have no ID number, use the mother’s ID. If the mother’s ID is not available, use the father’s ID. If this information is unknown or not available, enter “-”. Note whose ID was entered in the blank after the ID has been recorded.

## **Verification of possible stillbirth**

**(Id10104) Did the baby ever cry?**

Crying is a sign of breathing. If a baby cried at birth, it indicates that the baby was alive at birth. In some instances, the baby may not cry but still there may be a visible breathing effort, but this may be difficult to observe. Hence the reliance on the cry at birth, to signify breathing, and therefore life. There is a separate question on breathing later on in this section. This question only pertains to crying.

This is an important filter question, as a negative response will point towards a stillbirth. Stillbirth refers to babies born with no signs of life at or after 28 weeks of gestation. Fetal death before 28 weeks is regarded as abortion or miscarriage.

If "NO/DK/Ref", skip to Id10109. If "YES", proceed with the next question.

**(Id10105) Did the baby cry immediately after birth, even if only a little bit?**

The timing of the first cry is indicative of whether the baby’s health was affected by events during the pregnancy, labour or delivery. 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 (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.

**(Id10106) How many minutes after birth did the baby first cry?**

This question is relevant for both potential responses to the previous question. If the answer to Id10105 was "YES", then this question aims to confirm the timing. If the baby cried immediately, record as “0” (zero) 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. Probe carefully to find out the time and

record in minutes. A valid response is between 0–60 minutes. For don't know, enter "99". For refused to answer, enter "88". If the respondent states that the baby never cried, revert back to Id10104 and enter the correct response.

**(Id10107) Did the baby stop being able to cry?**

A baby that cried at birth may become weak and stop crying later on. This is an indicator for some causes of neonatal deaths. Probe carefully to get the true response. If "NO/DK/Ref", skip to Id10109.

**(Id10108) How many hours before death did the baby stop crying?**

The duration between the cessation of the baby's having the ability to cry and death is a useful indicator for diagnosing the specific cause of death in the neonate, giving some information on the progression of the illness that led to the baby's death. Probe carefully to get the accurate number of hours before death that the baby stopped crying. If less than an hour mark 0 in hours. 60 minutes = 1 hour. A valid response is between 0 and 99. For don't know, enter "99". For refused to answer, enter "88". If the response was more than 98 hours, confirm the response and enter "98". If the respondent's answer is 88, enter instead "87" so that the response will not be automatically coded as refused to answer.

**(Id10109) Did the baby ever move?**

Similar to the question about the first cry after birth, this question too is very important to understand if the infant was stillborn or alive at birth. Probe carefully to find out whether the mother noticed any movement of the baby after birth, in terms of movement of limbs, or the head. Movement in regard to breathing is covered in the next question.

**(Id10110) Did the baby ever breathe?**

If the response to this question is "YES", it confirms that this was a live birth. As mentioned earlier, although the baby may not have cried at birth, the birth attendant or mother may have noticed a breathing effort. This question helps to understand if the infant was stillborn or alive at the time of birth.

In some instances, there may be some hesitation or confusion on the part of the respondent, in the response to the previous question. This question helps also to confirm the presence of an effort at breathing, which may have been observed in the form of movement of the chest wall, or neck muscles or nostrils. These are subtle signs. A slight effort at breathing is a sign of life, and it distinguishes between live and stillbirth.

If the answer is "NO", it is an important negative response, which could lead to the diagnosis of stillbirth. Hence, any negative, "DK/Ref" response should be clarified and confirmed. If "NO/DK/Ref" skip to Id10114.

**(Id10111) Did the baby breathe immediately after birth, even a little?**

This question helps to confirm a positive response to the previous question. Probe carefully to get the true response in order to make this important distinction, and record "YES" if the

baby breathed immediately after birth. On the other hand, if there was some delay in the onset of breathing, it is an important indicator regarding the potential cause of death. In which case, record the answer as "NO", and proceed with the next question.

**(Id10112) Did the baby have a breathing problem?**

This question clarifies whether there was a noticeable issue in regard to the breathing of the baby. The acknowledgement of a breathing problem at birth is an important indicator of conditions such as birth asphyxia.

**(Id10113) Was the baby given assistance to breathe at birth?**

The provision of special attention to assist with breathing at birth is indicative of there being a serious problem with the health of the newborn. Assistance 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 in there is a positive response. Assistance to breathe could have been provided for both stillbirths as well as live births with delayed/difficult breathing, so the response needs to be taken in conjunction with the responses to previous questions.

**(Id10114) If the baby didn't show any sign of life, was it born dead?**

This question serves to finally determine if the baby was born alive or dead. This question is to be asked only if the responses to Id10104; Id10109; and Id10110 are any combination of "NO/DK/Ref".

A "YES" response to this question would indicate that the baby was born dead. In which case, the "YES" response would need to be followed up with questions Id10115 and Id10116; and subsequent instructions after Id10116.

On the other hand, there may be a possibility that despite the nature of answers to previous questions, the respondent may say "NO", (i.e. the baby was not born dead), in this case, proceed to the next question i.e. Id10115.

**(Id10115) Were there any bruises or signs of injury on baby's body after the birth?**

Birth injury means an injury that occurred during birth, such as a large bruise, swelling on the head, or broken bone which may lead to death of the child.

After asking and recording the response to Id10115, apply the following instructions, which are based on the response to Id10114.

If the response to Id10114 was "YES" (i.e. stillborn child); then proceed to Id10116.

If the response to Id10114 was "NO/DK/Ref" (i.e. live born); then proceed to Id10077.

**(Id10116) Was the baby's body soft, pulpy and discoloured and the skin peeling away?**

Ask this question only if the response to Id10114 was "YES", i.e. it was a stillbirth.

In this question we are looking to assess the integrity of the skin of a stillborn baby. 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 discoloured, has peeled or is peeling. Macerated means the body was pulpy. This indicates that the baby has been dead inside the mother for some time. If the term macerated is not used then listen for a similar description of skin integrity – peeling, pulpy, discoloured, etc.

After Id10116, if this was a stillbirth, skip to Id10354.

## **History of injuries/accidents**

This section is specifically designed to enquire and record information and details for deaths caused by an injury. In general, deaths from injuries, whether accidental or intentional, are reported to the police, and subsequently follow a forensic/coronial process for determining the cause of death. The VA process using household enquiry may or may not be considered necessary or appropriate for ascertaining the cause, depending on the government directives on this subject. Nevertheless, a set of questions have been included in the questionnaire, and should be enquired from respondents (following the sequence and skip patterns as below), as permitted by the government authorities. Whenever possible, the official police or medico-legal opinion as to the cause of death should be sought from local authorities after the completion of VA interview, and added to this VA questionnaire, to enable the accurate ascertainment of cause of death.

### **(Id10077) Did (s)he suffer from any injury or accident that led to her/his death?**

This is an opening question to check whether the death was associated with any injury or accident. If the response is “YES”, proceed with the following questions. These questions are generally 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.

If the answer is "NO", then skip to Id10351. However, if the answer is "DK/Ref", the interviewer should probe further and continue with the subsequent questions.

### **(Id10079) Was it a road traffic accident?**

Road traffic accidents are the most common causes of deaths from injuries in developing countries. You do not need to have been in a vehicle to have suffered a road traffic injury, for example for deaths of pedestrians. If the response to Id10079 is "YES", questions Id10080 and Id10081 should be asked, then questions Id10082–Id10097 should be skipped. If the answer is "NO/DK/Ref", then skip to Id10082.

**(Id10080) What was her/his role in the road traffic accident?**

Check whether the deceased was a pedestrian, driver or any other role. Details of this nature are essential for accurate coding of the cause of death. Select the appropriate box based on the response.

A deceased neonate could have been a passenger in one of the affected vehicles, or may have been carried by a pedestrian. Record the details as such.

**(Id10081) What was the counterpart that was hit in the road traffic accident?**

The counterpart is the other object with which the injured person or vehicle carrying the injured person came into contact. These details are essential for accurate coding of the cause of death. Select the appropriate box based on the response, then questions Id10082–Id10097 should be skipped. Go to Id10098.

**(Id10082) Was (s)he injured in a non-road transport accident?**

Enquire and record if the death was due to an accident in transport other than on the road, e.g. fatal injury from train / boat / aircraft accident. If "YES", record the nature of the accident and the injuries sustained in the free text section of the questionnaire.

**(Id10083) Was (s)he injured in a fall?**

If the response is "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.

**(Id10084) Was there any poisoning?**

If the death was due to poisoning from pesticides, kerosene, or any other chemicals, record "YES" here, and note the nature of the poison in the narrative section. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. Poisoning from snakebite or animal sting etc. is not to be included here.

**(Id10085) Did (s)he die of drowning?**

If the response is "YES", record the location where the drowning occurred – river/lake/sea/swimming pool – 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.

**(Id10086) Was (s)he injured by a bite or sting by a venomous animal?**

Record "YES", if the injury was due to snake bite or any other poisonous insect. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. If "YES", skip to Id10088.

**(Id10087) Was (s)he injured by an animal or insect (non-venomous)?**

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. If "NO/DK/Ref", skip to Id10089.

**(Id10088) What was the animal / insect?**

Select dog, snake, insect, scorpion, or other. If not known, select "DK".

**(Id10089) Was (s)he injured by burns/fire?**

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.

**(Id10090) Was (s)he subject to violence (suicide, homicide, abuse)?**

This is a sensitive question, given the traumatic personal event or involvement of others in the event of death. Don't read out the word "suicide" and ensure that this question is put across in an empathetic manner, and allow sufficient time for the respondent to answer.

**(Id10091) Was (s)he injured by a firearm?**

Use the local term for firearms, and record the response.

**(Id10092) Was (s)he stabbed, cut or pierced?**

The use of sharp instruments such as knife or sword should be recorded here.

**(Id10093) Was (s)he strangled?**

Use the local term for choking of the neck by force, whether by hand, rope or other object.

**(Id10094) Was (s)he injured by a blunt force?**

Injury caused by blunt force such as a stick or a heavy object, which may not cause direct external injury but can be sufficiently serious to cause fractures, internal bleeding and death. Explain the meaning of blunt force, and record the response accordingly.

**(Id10095) Was (s)he injured by a force of nature?**

Forces of nature include lightning, flood, earthquake etc. If the response is "YES", then record the force of nature in the narrative section of the questionnaire.

**(Id10096) Was it electrocution?**

If the death was due to electric shock, record "YES" here. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence.

**(Id10097) Did (s)he encounter any other injury?**

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 in the narrative section.

**(Id10098) Was the injury accidental?**

This question identifies whether the injury was unintentional. If "YES", go to Id10351.

**(Id10100) Was the injury intentionally inflicted by someone else?**

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 (e.g. act of terrorism).

## Health history

### **(Id10351) How many days old was the baby when the fatal illness started?**

This question is asked to determine the age in days at the start of the illness. In most instances of early neonatal death, this would be right from the day of birth, day zero. You should only answer in days. The maximum number of days for neonates is 27 days. Less than 24 hours = 0 days. Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88". Response should not be more than the age of the neonate at death.

### **(Id10408) Before the illness that led to death, was the baby/the child growing normally?**

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.

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## Duration of illness

### **(Id10120\_0) For how many days was (s)he ill before death?**

Ask the number of days (s)he was ill during the illness that lead to death. If less than 24 hours, enter "0". For don't know, enter "99". For refused, enter "88". A valid entry is less than the neonate's age at death.

### **(Id10123) Did (s)he die suddenly?**

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.

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## General signs and symptoms associated with final illness

### **(Id10147) Did (s)he have a fever?**

Fever is a term used when the body feels abnormally warm or hot to touch, and/or when a thermometer records an abnormally high temperature. Fever is a common symptom of infections, and is often present in combination with other symptoms. Fever is a subtle sign in newborn infants, and may not be noticed by the mother or relatives. Most communities / languages have a local term for fever, which should be included in the local language translated version of the questionnaire.

If the response is "NO/DK/Ref", skip to Id10153.

**(Id10148\_a) How many days did the fever last?**

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. If less than 1 day or 24 hours, enter “0”. Use 1 week = 7 days to determine the number of days. For don’t know, enter “99”. For refused, enter “88”.

**(Id10149) Did the fever continue until death?**

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.

**(Id10153) Did (s)he have a cough?**

We ask this because 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.

If "NO/DK/Ref", skip to Id10159.

**(Id10158) Did (s)he make a whooping sound when coughing?**

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.

**(Id10159) Did (s)he have any difficulty breathing?**

Breathing difficulties are an important feature that aid identification of the cause of death, and can be observed in the form of abnormally noisy breathing, as if created by some sort of obstruction in the airways (windpipe).

If the response is "NO/DK/Ref", skip to Id10166.

**(Id10161\_0) For how many days did the difficulty breathing last?**

Duration of the difficult breathing can help understand the severity of the illness and its relationship to the cause of death. Record the number of days for which the child was observed to be having difficulty breathing. If it was observed only less than 1 day = 0 days. A response to the duration of difficulty breathing can go from 0–30 days. Use 1 week = 7 days to determine the number of days. For don’t know, enter “99”. For refused, enter “88”.

**(Id10166) During the illness that led to death, did (s)he have fast breathing?**

Fast breathing usually accompanies fever, and is one of the signs of pneumonia in neonates. This 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.

If the response is "NO/DK/Ref", skip to Id10168.

**(Id10167\_a) For how many days did the fast breathing last?**

The duration of fast breathing indicates severity of illness but is a difficult sign for recognition and recall. If less than 1 day or 24 hours, enter "0". A valid duration cannot be longer than the age in days of the deceased. Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88".

**(Id10168) Did (s)he have breathlessness?**

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.

If the response is "NO/DK/Ref", skip to Id10172.

**(Id10169\_a) For how many days did s(he) have breathlessness?**

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. If less than 1 day or 24 hours, enter "0". Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88".

**(Id10172) Did you see the lower chest wall/ribs being pulled in as the child breathed in?**

Usually the chest walls rise and expand 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. Some communities have a local term for this sign. If so, include this term in the local translated version of the questionnaire.

**(Id10173) During the illness that led to death did her/his breathing sound like any of the following: stridor, grunting or wheezing**

VA interviewers should be aware of and be able to describe and/or demonstrate these examples of difficulty in breathing which produce abnormal sounds, and record the response accordingly.

These include a whistling sound (commonly called wheezing). Other abnormal sounds produced during difficult breathing in neonates with respiratory illness are stridor (noisy while breathing in) and grunting (noisy while breathing out). Use audio files if available.

Demonstrate the three different types of breathing and ask whether (s)he had any of them. Select the relevant box.

**(Id10181) Did (s)he have more frequent loose or liquid stools than usual?**

Ask the respondent about her/his understanding of what is diarrhoea (having more frequent loose or liquid stools than usual); if unclear or wrong, explain to the respondent that diarrhoea is the frequent passage of loose or watery stools, with or without blood. There

may be local terms to describe it, if so include them in the local translated version of the questionnaire.

If "NO/DK/Ref", skip to Id10186.

**(Id10183) How many stools did the baby or child have on the day that loose liquid stools were most frequent?**

This question records the frequency of diarrhoea. Ask the respondent the maximum number of times the deceased had diarrhoea on any day in the period immediately preceding death, and record this number in the space provided.

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".

**(Id10184\_a) How many days before death did the frequent loose or liquid stools start?**

This question is asked to specifically relate the episode of diarrhoea to the death. If acute diarrhoea, record the number of days from onset to death. If chronic diarrhoea, record the duration of the final episode. If less than 1 day or 24 hours, enter "0" days. A valid duration cannot be longer than the age in days of the deceased. Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88".

**(Id10186) At any time during the final illness was there blood in the stools?**

It may be related to the diarrhoea, if present. In some infections, there may be blood in the stools, but mostly in children and adults, but rare in neonates. It is common for this to be observed by carers of sick neonates, if present.

**(Id10188) Did (s)he vomit?**

Vomiting is a well-recognised symptom common to abdominal disease, but can occur in other conditions such as meningitis, urinary tract infection or other systemic infections. Its association with other symptoms can assist with identification of the cause of death.

**(Id10189) To clarify: Did (s)he vomit in the week preceding the death?**

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.

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.

**(Id10214) Was (s)he unconscious during the illness that led to death?**

Unconsciousness means the complete inability to arouse the neonate with no movement except for breathing. The child does not respond even to physical stimuli, including pain. Sick neonates could be sleeping for long periods, but one needs to check if they could not be aroused even for feeding. The identification of unconsciousness is largely in regard to its

suggestion of brain or central nervous system disease or disorder. A short period of unconsciousness usually precedes death. In the case of neonates, delineating unconsciousness as a specific symptom of brain or nervous system involvement is difficult.

If the response to this question is "NO/DK/Ref", skip to Id10219.

**(Id10215) Was (s)he unconscious for more than 24 hours before death?**

This question aims to identify periods of unconsciousness lasting for periods longer than a day, which might be indicative of specific conditions/infections involving the central nervous system.

**(Id10219) Did (s)he have convulsions?**

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.

**(Id10233) During the illness that led to death, did (s)he have any skin rash?**

"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. These can be associated with the cause of death. There may be local terms to describe it, if so include them in the local translated version of the questionnaire.

**(Id10239) During the illness that led to death, did he/she have areas of the skin that turned black?**

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.

**(Id10240) During the illness that led to death, did he/she have areas of the skin with redness and swelling?**

Skin infections can sometimes be observed as patches of redness and swelling, without the presence of any pus, or any liquid. Such infections can be associated with fever and can lead to death.

**(Id10241) During the illness that led to death, did (s)he bleed from anywhere?**

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.

**(Id10265) Did (s)he have yellow discolouration of the eyes?**

Yellow discolouration 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 discolouration of palms or skin, and if observed, the urine is also of an intense yellow colour.

**(Id10271) Was the baby able to suckle or bottle-feed within the first 24 hours 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.

**(Id10272) Did the baby ever suckle in a normal way?**

This question is asked to enquire if there was a normal healthy effort at suckling, or if there was any weakness or 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.

**(Id10273) Did the baby stop suckling?**

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.

If "NO/DK/Ref", skip to Id10275.

**(Id10274\_a) How many days after birth did the baby stop suckling?**

The number of days after birth the baby stopped sucking is an important indicator to diagnose neonatal tetanus. Probe carefully to get an accurate response. Less than 1 day = “0”. For don’t know, enter “99”. For refuse, enter “88”. Response should be no more than the neonatal age in days at death.

**(Id10275) Did the baby have convulsions starting within the first 24 hours of life?**

An earlier question enquired about convulsions, 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.

If "YES", skip to Id10277.

**(Id10276) Did the baby have convulsions starting more than 24 hours after birth?**

Convulsions occurring after the first day of life could be associated with neonatal tetanus.

**(Id10277) Did the baby's body become stiff, with the back arched backwards?**

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.

**(Id10278) During the illness that led to death, did the baby have a bulging or raised fontanelle?**

"Fontanelle" is the soft spot toward the front of an infant's head. "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. Probe carefully in order to get an accurate response.

If "YES", skip to Id10281.

**(Id10279) During the illness that led to death, did the baby have a sunken fontanelle?**

A sunken fontanelle, or the soft spot in the front of the head, is a sign of serious dehydration. This may be a difficult sign for the mother or caregiver to notice or recall. However, if probed carefully they can respond correctly.

**(Id10281) During the illness that led to death, did the baby become unresponsive or unconscious?**

**(Id10282) Did the baby become unresponsive or unconscious soon after birth, within less than 24 hours?**

**(Id10283) Did the baby become unresponsive or unconscious more than 24 hours after birth?**

Unconsciousness means the complete inability to arouse the neonate with no movement except for breathing. The child does not respond even to physical stimuli including pain. Sick neonates could be sleeping for long periods, but need to check if they could not be aroused even for feeding. The identification of unconsciousness is largely in regard to its suggestion of brain or central nervous system disease or disorder. A short period of unconsciousness usually precedes death. In the case of neonates, delineating unconsciousness as a specific symptom of brain or nervous system involvement is difficult. If "NO/DK/Ref" to Id10281, skip to Id10284.

**(Id10284) During the illness that led to death, did the baby become cold to touch?**

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. Need to explain carefully what is meant by cold to touch.

If "NO/DK/Ref", skip to Id10286. If "YES", proceed to the next question.

**(Id10285) How many days old was the baby when it started feeling cold to touch?**

Ask the respondent for the age in days when the baby first felt cold to touch. If less than 1 day or 24 hours, enter "0" days. Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88". Response should be no more than the neonatal age in days at death.

**(Id10286) During the illness that led to death, did the baby become lethargic, after a period of normal activity?**

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 by lethargy or to demonstrate how a lethargic baby will look like. If the baby never had a period of normal activity –this should be "NO".

**(Id10287) Did the baby have redness or pus drainage from the umbilical cord stump?**

Redness of umbilical cord stump might indicate a serious infection of the stump. This is an important source for infection in the neonate, and this sign can be readily recognized and recalled by respondents.

**(Id10288) During the illness that led to death, did the baby have skin ulcer(s) or pits?**

Presence of skin ulcer or pits, particularly if they are filled with a yellowish fluid (pus), indicates the sign of serious skin infection, which could be related to the cause of death.

**(Id10289) During the illness that led to death, did the baby have yellow skin, palms (hand) or soles (foot)?**

A previous question asked about yellow discolouration of the eyes. This question is to crosscheck the response to that question, and asks about generalised yellow discolouration of skin and palms, feet. Sometimes, the yellow discolouration 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.

**(Id10290) Did the baby or infant appear to be healthy and then just die suddenly?**

It is rare but sometimes an infant will seem to be healthy and then die suddenly. The death could happen during the sleep. In some instances, this may be the main information provided by the respondent. Record the response as mentioned, and if there are any other details, record them in the narrative section of the questionnaire.

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**Neonatal and child history, signs and symptoms**

**(Id10354) Was the child part of a multiple birth?**

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.

If "NO/DK/Ref", skip to Id10356.

**(Id10355) Was the child the first, second, or later in the birth order?**

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.

**(Id10356) Is the mother still alive?**

If the mother is present at the interview, select "YES" without asking the question aloud. If the mother is not present at the interview, ask if the mother of the deceased child is still alive.

If the mother is alive, i.e. the response is "YES", skip to Id10360. If the response is "NO", proceed with the next question.

**(Id10357) Did the mother die before, during or after the delivery?**

Select the appropriate option. If the mother died before or during delivery, skip to Id10360.

If the mother died after the delivery, proceed with Id10358.

**(Id10358\_units) How long after the delivery did the mother die?**

Select the best unit according to the response – days, weeks, or months. A valid response is between 0–6 days, 1–7 weeks, or 2–12 months. If the mother died less than 24 hours after delivery, record "0" days. If the response was greater than 6 days, ask the respondent to report time in weeks. If the response was greater than 7 weeks, ask the respondent to report time in months. A likely response is less than 12 months. If the response given was greater than 12 months, confirm the response, and enter "12".

**(Id10360) Where was the deceased born?**

Read the question and slowly read the first five choices. Respondent should hear all five choices first and then respond. Mark the appropriate box that corresponds with the place where the delivery occurred. Differentiate between "hospital" births (i.e. health institutions with in-patient facilities) from "other health facility" (dispensaries, health centres or private clinics where patients are seen on out-patient basis). *SELECT ONLY ONE BOX.*

**(Id10361) Did you/the mother receive professional assistance during the delivery?**

Explain to the respondent what is meant by professional assistance: delivery attended by a medical professional (doctor, nurse, or midwife). The nature of assistance received at delivery is helpful in understanding the factors that could have led to the death of the neonate. Professional assistance refers to either a medically qualified doctor, qualified nurse, or certified trained midwife only. This variable is very important for monitoring and evaluation of health services.

**(Id10362) At birth, was the baby of usual size?**

Babies who are not of usual size (i.e. either too small or too large) carry increased risks for specific causes of death. If available, show a photo of baby's various sizes.

If the response to Id10362 is "YES", then skip to Id10366.

If the response is "NO"; i.e. the baby was not of usual size, or "DK/Ref" then proceed with the next question.

**(Id10363) At birth, was the baby smaller than usual, (weighing under 2.5 kg)?**

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.

If "NO/DK/Ref", skip to Id10365. If "YES", proceed with the next question.

**(Id10364) At birth, was the baby very much smaller than usual, (weighing under 1 kg)?**

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.

Record the response to this question – either "YES/NO/DK/Ref" and skip to Id10366.

**(Id10365) At birth, was the baby larger than usual, (weighing over 4.5 kg)?**

This question is to be asked only if the response to Id10363 was "NO/DK/Ref".

Babies born larger than usual are associated with problems caused to the mother during delivery, but sometimes the new born also carries increased risks from birth injuries, and from congenital malformations, and diabetes.

**NOTE:** The responses to Id10362, Id10363, and Id10365 should not all be "NO". If this is the case, you should go back to one of the previous questions and correct the selection.

**(Id10366) What was the weight (in grams) 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 four digits. Respondents may give the response in kilograms. For data entry, convert to grams. 1 kilogram = 1,000 grams. Enter "9999" for don't know. Enter "8888" for refused to answer. A valid response is between 0 and 9999.

**(Id10367) How many months long was the pregnancy before the child was born?**

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. Delivery at less than 8 months pregnancy is associated with smaller size babies, which carry the risks from breathing problems, birth injuries, and hypothermia (cold to touch). Record the duration carefully, asking the respondent to count the completed months from the date of last menstrual period till the date of delivery. If the respondent gives an answer in half-months (e.g. 6.5 months) or months and weeks (e.g. 6 months and 2 weeks), round down (e.g. enter "6") to enter the completed months. A valid response is between 0–11. If the response is more than 11 months, confirm the response and enter "11". For don't know, enter "99". For refused, enter "88".

**(Id10368) Were there any complications in the late part of the pregnancy (defined as the last 3 months, before labour)?**

Complications refer to specific medical conditions that have been sufficient to require medical attention. These could include episodes of high fever, or high blood pressure, or convulsions, or bleeding, or leakage of fluid from the birth canal, or slowing or stoppage of the movements of the child, among others. Ask carefully giving the above examples, as may be required.

**(Id10369) Were there any complications during labour or delivery?**

Complications during labour or delivery refer to a fever or infection, the occurrence of leakage of fluid from the birth canal before onset of pains, or very slow progression or obstruction of labour, or occurrence of birth canal injuries to the mother, or heavy bleeding, among others. Ask carefully, giving these examples if required.

**(Id10370) Was any part of the baby physically abnormal at time of delivery? (for example: body part too large or too small, additional growth on body)?**

An abnormal shape of limb due to physical deformity, or any external physical abnormality can cause difficult labour, and can also be associated with other congenital malformations of internal organs which could be the cause of death.

If the answer is "NO", skip to Id10376. If "YES/DK/Ref" proceed with the next questions.

**(Id10371) Did the baby/ child have a swelling or defect on the back at time of birth?**

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.

**(Id10372) Did the baby/ child have a very large head at time of birth?**

Similarly, 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.

If "YES", skip to Id10394.

**(Id10373) Did the baby/ child have a very small head at time of birth?**

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.

**(Id10394) How many births, including stillbirths, did the baby's mother have before this baby?**

This question attempts to record the complete childbirth history of the mother. Certain causes of neonatal deaths 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.

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".

**(Id10376) Was the baby moving in the last few days before birth?**

This question is to confirm the well-being of the foetus during the period leading up to the delivery. Absence of movements would suggest the potential for the baby being stillborn. Note that this question is not required for the automated analysis software, but it serves as an internal consistency check.

**(Id10377) Did the baby stop moving in the womb before labour started?**

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. At a minimum, it is a warning sign that there may be a problem with the health of the foetus. Mothers are usually aware of such changes, and can recall and report this sign.

If the response is "NO" skip to Id10382.

**NOTE:** Id10379 should be asked even if Id10377 is "DK/Ref" because this information may be known.

**(Id10379\_unit) How long before labour did you/the mother last feel the baby move?**

In case there was a stoppage of movement, mothers will be able to recall the number of hours or days before delivery the baby stopped moving. It might also be the case that the respondent or health worker had examined the mother.

If the respondent is not the mother, you need to probe whether the mother has told her/him when the baby had stopped moving.

Select the appropriate unit according to the response and enter the duration: 0–23 hours or 1–60 days. Use 1 week = 7 days. A likely response is less than 60 days. If the response given was greater than 60 days, confirm the response, and enter "60". Note that this question is not used by the automated analysis software, but it is important for physician review.

**(Id10382) How many hours did labour and delivery take?**

The duration of labour has important implications for the well-being of the newborn as well as the mother. Enquire and record the total duration of labour from onset of pains to delivery of placenta in hours. It is expected that this response would mostly be an approximation, rather than an exact measurement. If less than 1 hour enter "0" hours. 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.

**(Id10383) Was the baby born 24 hours or more after the water broke?**

Usually the breaking of waters occurs a short while (up to a few hours) before onset of delivery. 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. Probe carefully to get the accurate response to this question.

**(Id10384) Was the liquor foul smelling?**

Liquor (water in the womb) may have a bad smell if there is an infection. Mothers would be able to recall this and report. Probe carefully to get a true response.

**(Id10385) What was the colour of the liquor when the water broke?**

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 colour). In some instances, it may be stained with greenish black or brown substances. Such discolouration would likely be remembered, so an unclear or uncertain response would usually suggest that the waters were clear. Select the appropriate response. For any abnormal description record the response as stated, in the narrative section.

**(Id10387) Was the delivery normal vaginal, without forceps or vacuum?**

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 a normal delivery, and is associated with a different pattern of risks for the death of the neonate. Clarify the meaning of normal vaginal delivery (taking care to specify “head first”) to the respondent, before recording the response.

**If the response is "YES", skip to Id10391. If the response is "NO/DK/Ref", proceed with the next question.**

**(Id10388) Was the delivery vaginal, with forceps or vacuum?**

Often, a local term is applied for the use of instruments to assist the delivery. Enquire using this term, and mark the response accordingly.

Mark the response as accordingly, and if "YES", then skip to Id10391. If "NO/DK/Ref", proceed with the next question.

**(Id10389) Was the delivery a Caesarean section?**

The term “Caesarean” refers to an abdominal operation that is used to cut open the womb and extract the child from the abdomen. This term “Caesarean” is commonly known to members of the community, but where necessary, the local words or terms for delivery of child through abdominal operation could be used.

**(Id10391) Did you/the mother receive any vaccinations since reaching adulthood including during this pregnancy?**

Pregnant women are given vaccine injections to prevent the occurrence of a serious infection to newborn infants. Vaccination during previous pregnancies can also provide some degree of protection, hence this question asks for any such vaccinations after reaching adulthood.

If the response is "NO/DK/Ref", then skip to Id10395.

**(Id10392) How many doses?**

If the mother received any vaccinations, record the number of such injections received during the current pregnancy, or previous pregnancies. A valid response is between 0–9. If the response is more than 9 doses, confirm the response and enter "9". For don't know, enter "99". For refused, enter "88".

**(Id10393) Did you/the mother receive tetanus toxoid (TT) vaccine?**

This question is asked to identify whether there is specific knowledge as to the nature of the vaccine received, i.e. against tetanus. A positive response to this question would help to rule out tetanus as a cause of death of neonates. Try carefully to get a correct response to this question.

**(Id10395) During labour, did the baby's mother suffer from fever?**

Fever at the time of delivery is an indication of maternal infections, 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.

**(Id10396) During the last 3 months of pregnancy, labour or delivery, did you/the baby's mother suffer from high blood pressure?**

Blood pressure is checked during periodic antenatal care 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 low birth weight and premature delivery and other complications. In some instances, high blood pressure may manifest only during labour or delivery. Mothers and/or their relative would be able to recall and report about high blood pressure and so probe carefully.

**(Id10397) Did you/the baby's mother have diabetes mellitus?**

Maternal diabetes is associated with birth of larger sized babies, which have their own risks for neonatal death. Maternal diabetes is also associated with various types of congenital abnormalities including congenital heart malformations.

The next series of questions relate to the health of the mother during pregnancy and delivery. These symptoms and signs are helpful in identifying the cause of death in the neonate. Mention the nature of the following questions, and the reason for asking them, and then proceed.

**(Id10398) Did you/the baby's mother have foul smelling vaginal discharge during pregnancy or after delivery?**

Foul smelling secretions from the child birth canal indicate a serious infection, and are usually accompanied by pain in the lower abdomen, and fever. Such infections can be transmitted to the neonate, and cause serious illness leading to neonatal death. It is likely for the mother to remember and recall this sign if probed carefully.

**(Id10399) During the last 3 months of pregnancy, labour or delivery, did you/the baby's mother suffer from convulsions?**

Convulsions are rapid twitching or jerking movements of parts of the limbs or sometimes entire limbs, that usually lasts for few minutes and stops when the person becomes unconscious. The common term for convulsions is fits, and there is often a local term for such movements. In some instances, high blood pressure during pregnancy can lead to such fits, particularly in the last 3 months. In the absence of proper antenatal care, such convulsions may be the only major sign of underlying high blood pressure in pregnant women, with its known risks to the neonate as described above. Convulsions may also only occur during labour or delivery, which is a serious and dramatic event, and would be readily recalled. Clarify the meaning of the term convulsions, the period of interest (last 3 months) and record the response.

**(Id10400) During the last 3 months of pregnancy did you/the baby's mother suffer from blurred vision?**

Blurred vision is defined as seeing objects without clear shape or margins, or seeing double objects. This is also a sign of high blood pressure in pregnancy, but may be difficult to remember and recall by the mother but careful probing may obtain an accurate response.

**(Id10401) Did you/the baby's mother have severe anaemia?**

In some instances, pregnancy is associated with severe "thinning" of the blood, which is observed as white or light colour of the tongue, nails, palms and eye margins. This condition is known as anaemia, and is associated with premature delivery, low birth weight, birth asphyxia and other complications. Hence, identification of maternal anaemia helps with the diagnosis of the cause of neonatal death.

**(Id10402) Did you/the baby's mother have vaginal bleeding during the last 3 months of pregnancy but before labour started?**

Bleeding from the birth canal before the start of labour is an important sign, and is often associated with a disorder of the placenta (use local term). Excessive bleeding endangers the life of both the mother and the neonate. This is usually readily recalled and reported by the mother.

**(Id10403) Did the baby's bottom, feet, arm or hand come out of the vagina before its head?**

The first part of the baby to be delivered is usually the head. 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, severe problems with breathing 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.

**(Id10404) Was the umbilical cord wrapped more than once around the neck of the child at birth?**

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 baby increase if it was more than once.

**(Id10405) Was the 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.

**(Id10406) Was the baby blue in colour at birth?**

Bluish colour 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.

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**Health service utilisation**

In many instances of deaths that occur at home, there is a potential for the deceased to have received some form of medical attention during the illness that led to death. The treatment could have been in the form of a duration of hospitalisation which later resulted in the person being discharged prior to death, which sometimes occurs in instances where there is no potential cure, or the treatment is too expensive, or a cultural preference for terminal care at home. In such instances, there is a likelihood of household members to be aware of the nature of medical treatment provided, as well as some information on the likely disease or condition that the patient was suffering. In the following questions, record specific responses about health services as asked, and record any other or allied information on health services or medical opinion as to the cause in the narrative section of the questionnaire. This section should always be completed at the end of the interview.

**(Id10418) Did (s)he receive any treatment for the illness that lead to death?**

This question refers to formal health treatment, and not traditional medicines, home remedies or non-professional treatment. If the response to this question is "NO", then you will skip to Id10428.

**NOTE:** These questions should be answered according to whether the patient received the treatment OR needed the treatment, as recommended by a health professional.

**(Id10419) Did (s)he receive 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 diarrhoea, 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.

**(Id10420) Did (s)he receive (or need) 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.

**(Id10421) Did (s)he receive (or need) a 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.**

**(Id10422) Did (s)he receive (or need) treatment/food through a tube passed through the 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.

**(Id10423) Did (s)he receive (or need) 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.

**(Id10424) Did (s)he receive (or need) 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. This question may or may not be relevant, given the epidemiological profile of the country or region of the country where this questionnaire is being administered. Also, the patient's relatives may not know these details. Explain the question carefully, and record the response accordingly.

**(Id10425) Did (s)he have (or need) an operation for the 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. If the response is "YES", enquire from the

relatives if they know the medical condition (e.g. cancer, stomach ulcer, heart disease etc.) that was the reason for the operation; and note the details in the narrative section of the questionnaire.

**(Id10428) Had (s)he receive any immunizations?**

This question is to confirm whether the neonate received immunizations at the time of birth. If the response is "YES", proceed to the next question. If the response is "NO/DK/Ref", then skip to Id10432.

**(Id10429) Do you have the child's vaccination card?**

Note that countries may have a local term for this card, e.g. "Road to Health" card or "Mother Child Booklet". Use the local term.

If "YES", proceed to the next question. If "NO/DK/Ref", skip to Id10432.

**(Id10430) Can I see the vaccination card (note the vaccines the child received)?**

Ask the respondent to give you the vaccination card.

**(Id10431) Select EPI vaccines done**

Check all vaccines that are indicated on the card. For vaccines that require multiple doses, only check the box if all doses have been received. This includes for children who died before the final doses were received, even if they had received all vaccines appropriate for their age.

It is recommended that local guidance is compiled into a tool for interviewers to know which vaccines and what doses should be received for a given age. During training, interviewers should be trained on the use of the respective "vaccination schedule tool".

**(Id10432) Was care sought outside the home while (s)he had this illness?**

This series of questions is to confirm that health care was sought anywhere outside the home. This refers to both locations (hospitals, health centres, and pharmacies) and individuals (physicians, community-based practitioners, trained birth attendants, traditional healers, homeopaths, religious healers, relatives/friends). If the response to this question is "NO/DK/Ref", then skip to Id10435.

**(Id10433) Where or from whom did you seek care?**

Read out the list of options from the list, and select all that are applicable, since there may have been attempts to seek several different health care options.

**(Id10434) What was the name and address of any hospital, health centre or clinic where care was sought.**

In the space provided, record the main institution where health care was provided, including investigations, diagnosis, treatment and other facilities. Enter "-", if this information is not available.

**(Id10435) Did a health care worker tell you the cause of death?**

If the response is "NO/DK/Ref", then skip to Id10437.

**(Id10436) What did the health care worker say?**

Record details of any verbally communicated information on the likely cause of death here.

**(Id10437) Do you have any health records that belonged to the deceased?**

This could include 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. If "YES", proceed to the next question. If "NO/DK/Ref", skip to Id10445.

**(Id10438) Can I see the health records?**

Seek consent from relatives to see the health records, and note the details as per the following question. In case there is refusal to show the health records; then skip to Id10445.

**(Id10439) [Is the date of the most recent (last) visit available? / Record the date of the most recent (last) visit]**

If the date is available, record the visit date for the final consultation. Note any details of the diagnosis, laboratory tests, and treatment etc. in the narrative section of the questionnaire.

**(Id10445) Has the deceased's (biological) mother ever been tested for HIV?**

If respondents are unsure, it may be useful to ask to see the mother's antenatal clinic card where this information is often recorded.

**(Id10446) Has the deceased's (biological) mother ever been told that she had HIV/AIDS by a health worker?**

This may a sensitive issue, but is very important information that may help determine the cause of death.

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**Background and context**

**(Id10450) In the final days before death, did s/he travel to a hospital or health facility?**

Enter "YES" if the deceased was a stillbirth delivered in a health facility or a live birth delivered in a health facility that died before leaving the facility. If the answer is "NO/DK/Ref", then skip to Id10455.

**(Id10451) Did (s)he use motorised transport to get to the hospital or health facility?**

If the respondents did travel to a health facility, ask what mode of transport they used to get there. Record "YES" here if some motorized form (car, truck, tractor, motorcycle, scooter or ambulance) was used.

**(Id10452) Were there any problems during admission to the hospital or health facility?**

Ask the respondent whether there were any problems such as delays, paperwork, queues or no staff encountered at the health facility.

**(Id10453) Were there any problems with the way (s)he was treated (medical treatment, procedures, interpersonal attitudes, respect, dignity) in the hospital or health facility?**

Enquire whether there were any problems with how the deceased or family were treated at the health facility.

**(Id10454) Were there any problems getting medications or diagnostic tests in the hospital or health facility?**

Enquire whether there were any problems with receipt of medications or diagnostic tests at the health facility.

**(Id10455) Does it take more than 2 hours to get to the nearest hospital or health facility from the deceased's household?**

Enquire whether the person who died lived in a household from where it would reasonably take more than 2 hours to reach the nearest 24-hour health facility by the means of transport available to the household members.

**(Id10456) In the final days before death, were there any doubts about whether medical care was needed?**

Ask if there were any doubts among those assisting in the final illness (family members, etc.) about whether the final illness was sufficiently serious to need treatment at a health facility.

**(Id10457) In the final days before death, was traditional medicine used?**

If a major part of treatment for the final illness was provided by any kind of traditional or alternative practitioner (herbal remedies, massages, drinks, foods, amulets, spells or blessings provided by traditional healers, witch doctors or shaman) select "YES" here.

**(Id10458) In the final days before death, did anyone use a telephone or cell phone to call for help?**

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. This may have been used to call for help or arrange transportation.

**(Id10459) Over the course of illness, did the total costs of care and treatment prohibit other household payments?**

Select "YES", if the total costs incurred in the final illness were sufficiently great to mean that other kinds of household expenses (food, fuel, travel, education etc.) could not be met, or caused debt or sale of household assets.

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**Death certificate with cause of death**

The following information serves only to complete cause of death information in some environments. In routine Civil Registration Vital Statistics (CRVS) they could be skipped from the interview and information be collected from other sources if available.

**(Id10462) Was a medical certificate of cause of death issued?**

Ask the respondent if there is a medical certificate of the cause of death for the person that died. The medical certificate of cause of death is commonly obtained from a physician at a hospital and should be distinguished from the Death Certificate which is issued by the civil registration organisation. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other “certificates” such as the burial permit that this question may be confused with.

If the answer is "NO/DK/Ref", skip to Id10476 – “Open narrative” section.

**(Id10463) Can I see the medical death certificate of cause of death?**

Ask if you can see the medical certificate of cause of death in order to record information about the cause of death. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other “certificates” such as the burial permit that this question may be confused with.

Fill in the following questions only if you are shown the copy of the certificate. Do not fill in just based on oral statements. Record “NO” if medical information about the cause of death is not available. If the answer is "NO/DK/Ref" skip to Id10476 – “Open narrative” section.

**(Id10464) and (Id10465) [Record the immediate cause of death from the certificate (line 1a) and the duration of that cause.]**

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 Id10464–Id10473.

Copy the cause of death from the first line of the death certificate. There should always be a cause recorded here. If a duration for which that cause was experienced is also recorded in the column beside the cause, enter that in Id10465.

**(Id10466) and (Id10467) [Record the first antecedent cause of death from the certificate (line 1b) and the duration of that cause (1b).]**

Copy the cause from the second line of the death certificate if there is one listed as well as its duration.

**(Id10468) and (Id10469) [Record the second antecedent cause of death from the death certificate (line 1c) and the duration of that cause (1c).]**

Copy the cause from the third line of the death certificate if there is one listed as well as its duration.

**(Id10470) and (Id10471) [Record the third antecedent cause of death from the certificate (line 1d) and the duration of that cause (Id).]**

Copy the cause from the fourth line of the death certificate if there is one listed as well as its duration.

**(Id10472) and (Id10473) [Record the contributing cause(s) of death from the certificate (part 2) and the duration of that cause.]**

List any contributing causes recorded in Part II of the death certificate.

## **Open narrative**

### **(Id10476) Narrative description**

Ask respondents to describe in their own words whether they have anything to add to the information they have provided so far. You will read “Thank you for your information. Now can you please tell me in your own words about the events that led to the death?”

Allow the respondent to tell you about the illness in his or her own words. Once the respondent has completed the initial response, prompt for additional information as relevant:

- Symptom recognition (when were first symptoms recognised, what other symptoms did s(he) have, when did the respondent/family realise it was severe, who recognized the first and severe symptoms);
- Timing (how long it took from first symptoms to realising it was severe);
- Actions taken in home and outside the home (how long after first symptom(s) and severe symptom(s) was any action taken, what actions, was there any treatment given, what treatment, who made the decision to seek or not to seek care, reason for this action, if care outside the home was not sought – why?);
- Transport (time spent from making the decision for seeking care outside the home to getting transport, type of transportation used to reach the first level of care and any potential referrals, time spent during transport, any delays that may have occurred before reaching care).
- Provider behaviour (advice given, treatment given, how long did it take to receive the care after reaching health care services, complete referral history, timing of referral, time spent on travel to and between facilities, reasons for not going or delaying referral, referral experience).

During the response, record detailed *written* notes of what is mentioned. Make sure to capture key items such as signs and symptoms, timing of care seeking, and any points that need to be clarified. If using an electronic data capture system (e.g. ODK), enter the notes into the electronic system *after* concluding the interview.

The checklist below provides a list of additional items that may be included in the open narrative if identified in the interview. You should feel free to denote additional items even if they are not included on the checklist.

#### **CHECKLIST OF ADDITIONAL ITEMS TO RECORD IN THE NARRATIVE OPEN SPACE**

If there is an official police or medico-legal opinion as to the cause of death – provided by local authorities (usually for accidents or injuries).

#### **Additional information about injuries**

If the family reported an injury, record the specifics of the injury (type, mode, location of event, and affected body parts that were injured);

If it was self-inflicted even when you did not ask;

If it was an accident in transport other than on the road, e.g. fatal injury from train / boat / aircraft;

If a fall, record the body parts injured;

If a poisoning from pesticides, kerosene, or any other chemicals, record the type of poison;

If a drowning, record location where the drowning occurred – river / lake / sea / swimming pool, etc.;

If injured by burns / fire, record the all of the body parts affected by burns and how the burn occurred;

If injured by a force of nature, record the type of force of nature (lightning, flood, earthquake, etc.).

#### **Additional findings in the deceased**

If the deceased had any birth defects, describe body part(s) and what it looked like, and/or if the deceased had ambiguous genitalia/intersex.

If you recorded the birth weight given to you and it was self-reported (not verified on the records), then record that the birth weight was reported by the respondent here.

If the deceased appeared healthy and died suddenly (unexpectedly within 24 hours of being in regular health) and there are any other details about the death, record them (e.g. happened during the sleep). In some instances, this may be the main information provided by the respondent.

If the deceased had a recent health visit, note any details of the diagnosis, laboratory tests, and treatment etc. in the open narrative section of the questionnaire.

If there is any additional information on health services or medical opinions provided on the cause of death for the deceased who may have attended medical care prior to his/her death, record that here.

If the deceased received or needed treatment or food passed through the nose, enquire how long feedings were provided through the tube and whether the tube was in place prior to death, and record relevant information here.

If the deceased had any presence of lumps on the neck, if there was an opinion as to the medical cause for the lump and (s)he received treatment, record relevant information here.

If the deceased had an operation, enquire from the respondent if (s)he knows the medical condition (e.g. cancer, stomach ulcer, heart disease, etc.) that was the reason for the operation; note relevant details here.

### **Maternal and delivery information**

For stillbirths and neonatal deaths, record any details of the pregnancy, labour and delivery.

If the water broke for delivery, and the water was abnormal, record any description here.

If the mother died and you obtained any additional information, record what you learned about the mother's death (e.g. timing of death in relation to delivery, symptoms, etc.).

**[Id10479: Select any of the following words that were mentioned as present in the narrative.]**

This question lists some of the key risks associated with mortality in the age group of the deceased. After the respondent has provided their description of the circumstances surrounding the death read back through and record all of the key words which they may have mentioned that were present in the deceased.

**[Comment: Comment]**

Record any additional details about the interviewer here.

**(d10481) [Record the time at the end of the interview.]**

In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

## **Appendix B: Question by question instructions for the 2016 WHO verbal autopsy questionnaire for the death of a child aged 4 weeks through 11 years**

**NOTE:** *Due to the integrated skip patterns, the identifying numbers of the questions will not always be in sequential order. Each question begins with its ID in parenthesis, e.g. “(Id10153) Did (s)he have a cough?”. Questions in [ ] are not to be read to the respondent. Throughout the document, response options are abbreviated as follows: “DK” refers to response option “Don’t know”; and “Ref” refers to response option “Refused to answer”.*

### **Preset HIV-Malaria mortality and season**

#### **(Id10002) [Is this a region of high HIV/AIDS mortality?]**

The answer to this question should be decided by the project office prior to the VA interview. The high mortality of HIV/AIDS is not based on a specified mortality level of HIV in the study population, but on the regional mortality where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to > 1% of deaths due to HIV/AIDS (malaria), LOW around 0.1%, VERY LOW < 0.01%.<sup>1</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10003) [Is this a region of high malaria mortality?]**

The answer to this question should be decided by the project office prior to the VA interview. The high mortality of malaria is not based on a specified mortality of malaria in the study population, but on the regional prevalence where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to > 1% of deaths, LOW around 0.1% and VERY LOW < 0.01%.<sup>1</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10004) [During which season did (s)he die?]**

The program office will specify which months are considered “wet” and which months are considered “dry”. You should record the response according to the month in which the deceased died.

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<sup>1</sup> Streatfield PK et al. Malaria mortality in Africa and Asia: evidence from INDEPTH health and demographic surveillance system sites. *Glob Health Action*. 2014; 7: 25369.

## **Information on the respondent and background about interview**

### **(Id10007) [What is the name of VA respondent?]**

Record the reported name of the respondent. Report names standardly as first name (given name), surname.

### **(Id10007a) [What is the sex of the VA respondent?]**

Record the sex of the respondent as female, male or ambiguous/intersex.

### **(Id10008) What is your/the respondent's relationship to the deceased?**

First verify if the respondent is a family member, and only if it is not a family member choose from the other response categories, like "health worker", "public official" or "another relationship". Only one response box can be selected. Select the appropriate box which represents the relationship reported by the respondent.

### **(Id10009) Did you/the respondent live with the deceased in the period leading to her/his death?**

Select the appropriate response.

**NOTE:** Unless a specific timescale is specified, the questions refer generally to the time period "during the illness leading to death". Some conditions (e.g. breathing difficulties in COPD) may be experienced consistently for a long time, eventually leading to death. Other conditions or illnesses may have shown symptoms in the past, but if the person recovered from these symptoms prior to the death, they are not likely related to the death.

### **(Id10010) [Name of the VA interviewer]**

Record the name of the main VA interviewer here. The project office may add a list of interviewer names or recommend a standard format for reporting names (e.g. first name)

### **(Id10010a) [Age of VA interviewer]**

Record the age of the main VA interviewer here.

### **(Id10010b) [Sex of VA interviewer]**

Record the sex of the main VA interviewer as female, male or ambiguous/intersex.

### **(Id10010c) [ID of VA interviewer]**

Record a unique identifier code for the main VA interviewer. The interviewer ID can have numbers and letters. The project office should maintain a listing of the interviewer names and unique identifier codes.

### **(Id10011) [Time of the start of the interview]**

Record the time the interview started. Remember to select "am" or "pm" to ensure that you have the correct time.

**(Id10012) [Date of interview]**

Record the date of interview. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK.

**(Id10013) [Did the respondent give consent]**

Select the appropriate response. If the respondent did not give consent, close the interview here, and record the time the interview was completed.

## Information about the deceased and vital registration

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### Information on the deceased

**(Id10017) What was the first or given name(s) of the deceased?****(Id10018) What was the surname (or family name) of the deceased?**

Verify the name(s) of the deceased in the paperwork on the assigned verbal autopsy case with what is reported by the respondent. If it is inconsistent, report this to the supervisor. If the name is consistent, record the name (if using paper form ensure it is legible). In Id10017 you are asked for the first or given name(s) of the deceased. In Id10018 you are asked for the surname (or family name) of the deceased.

**(Id10019) What was the sex of the deceased?**

Verify the biological sex of the deceased in the paperwork on the assigned verbal autopsy case with what is reported by the respondent. If it is inconsistent, report this to your supervisor. Make sure you select the correct response box. If you select the wrong box, the cause of death could be incorrect. If the sex is not typically male or female, select “ambiguous genitalia/intersex”. This selection may be the appropriate choice if the child's external genitals do not appear to be typically either male or female. In such cases, the genitals may not be well-formed or the child may have characteristics of both sexes. Add a note in the open ended narrative section with any details the respondent provides.

**(Id10020) Is the date of birth known?**

If you do not know the full date of birth, select the option “NO”; you will then skip the next question on date of birth (Id10021) to specify the date – and jump to the question on knowing the date of death (Id10022). This happens automatically in ODK. In some cases, particularly for elderly adults, the use of community calendars of significant historical events may facilitate the approximation of a year of birth.

If the response is “YES”, complete the date of birth.

**(Id10021) When was the deceased born?**

Record the date of birth. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK.

**(Id10022) Is the date of death known?**

The list of deaths obtained in the paperwork on the assigned verbal autopsy case should have this information but the question should also be asked of respondents.

**NOTE:** For ODK you will need to have the full date of death to enter it. If you do not have the full date of death you should select "NO". Then in ODK you will be asked an additional question about the year of death. Fill in the year of death in four digits. For the paper version of the questionnaire, if they are unsure of the date enter the year of death if known.

**(Id10023) When did (s)he die?**

The death information from the paperwork on the assigned verbal autopsy should have this information. You should still ask the respondent and then record their response for the date of death using the day/month/year (dd/mm/yyyy) format. This will be a calendar format for ODK so you will need to put in the full date. For the paper questionnaire, you will fill in the boxes provided. If they are unsure of the exact date record the year of death.

If you have recorded the full date of birth and the full date of death, the electronic device will automatically select the questionnaire corresponding to one of the three age groups: neonate, child or adult. **Therefore, be very careful in completing the full date of birth and date of death. If you make a mistake in the date of birth or death, you will fill in the wrong questionnaire.**

**(age\_group): [What age group corresponds to the deceased?]**

**This item applies for the electronic data collection format only.** If you were unable to complete the full date of birth or date death, you will be forced to select a questionnaire corresponding to the three age groups: neonate, child or adult. Select the age group of the deceased, based on your assessment of the age of the deceased. Select this option very carefully. If you make a mistake in the age group, important questions will be skipped because some sections of questionnaire depend on the age group to determine the questions asked. Note that this question is used to determine which sequence of questions to use. This is a required question. If the respondent does not know the exact age, enter the best estimate.

**(age\_child\_unit): How old was the child? [Enter child's age in:]**

If you have selected the child questionnaire you have to enter at least the age in days, months, or years. A valid response is between 28–60 days, 1–59 months, or 1–11 years.

**(Id10058) Where did the deceased die?**

**Record the site of death by selecting the appropriate box.**

**NOTE:** The questions from Id10051 to Id10073 are related to citizenship, socio-economics are not required for assessing causes of death.

**(Id10051) [Is there a need to collect additional demographic data on the deceased?]**

The project site will determine if this information should be collected. If you choose "NO", you will skip details about the place of residence, education, and family. If you select "YES", proceed with the next question. Site programmers may make this question hidden to the interviewers.

**(Id10052) What was her/his citizenship/nationality?**

Select the appropriate response according to the local definitions for citizenship. A naturalized citizen is an individual that was born elsewhere but now has become a citizen of the country. A foreign national is an individual who is not a citizen of the host country in which s(he) is residing or temporarily staying.

**(Id10053) What was her/his ethnicity?**

Record the reported ethnicity. Do not probe too much if the respondent is uncomfortable. Enter "-" if this information is not available or if the respondent is not happy to report the ethnicity.

**NOTE:** For Id10054–Id10057, in the electronic questionnaire, location items may be separated and customized with drop-down lists.

**(Id10054) What was her/his place of birth?**

Record the reported place of birth. Record the reported place of birth. Specify here village and district. A question on the facility and circumstances will be asked later. Enter a "-" if this information is not available or unknown.

**(Id10055) What was her/his place of usual residence? (the place where the person lived most of the year).**

For perinatal cases, just ask for the address of the health facility or if released and at home, the home address.

**(Id10057) Where did the death occur (specify country, province, district, village)**

You can fill in the city/town instead of village if more applicable.

**(Id10061) What was the name of the father?**

Record the father's name. Report names standardly as first name (given name), surname. This information may be used for civil registration purposes and/or to assist in matching or location purposes.

**(Id10062) What was the name of the mother?**

Record the mother's name. Report names standardly as first name (given name), surname. This information may be used for civil registration purposes and/or to assist in matching or location purposes.

**(Id10063) What was her/his highest level of schooling?**

*This should be asked for any deceased individual 4 years or older.* If this a child less than 4 years of age, select "no formal education". Note that this action will only be needed if completing paper questionnaire. ODK version will skip over this question if deceased is aged less than 4 years old.

**(Id10064) Was (s)he able to read and/or write?**

*This should be asked for a deceased individual 6 years or older.* If this is a child less than 6 years of age, select "NO". Note that this action will only be needed if completing paper questionnaire. ODK version will skip over this question if deceased is aged less than 6 years old. Answer "YES" also if only one of either reading or writing was known to the deceased.

**(Id10065) What was her/his economic activity status in year prior to death?**

*This should be asked for a deceased individual 8 years or older.* If this a child less than 8 years of age, select "other". If the response is "Mainly employed", proceed with the next question. Otherwise, skip to Id10069. Note that this action will only be needed if completing paper questionnaire. ODK version will skip over this question if deceased is aged less than 8 years old.

**(Id10066) What was her/his occupation, that is, what kind of work did (s)he mainly do?**

This question will only be asked if the response to Id10065 is "Mainly employed". Record the appropriate response. This question will be skipped for a child less than 8 years old. Note that this action will only be needed if completing paper questionnaire. ODK version will skip over this question if deceased is aged less than 8 years old.

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**Civil registration numbers**

**(Id10069) [Is there a need to collect civil registration numbers on the deceased?]**

This question should be determined by the coordinator of the data collection activity and determined by the context in which VA is being conducted. If "YES", ask to see the certificate or death registration paperwork. You will use this paperwork to complete the next questions and fill in any information that is available. If "NO", skip to Id10077. Site programmers could make this question hidden to the interviewers if desired.

**(Id10069\_a) Do you have a Death Certificate from the Civil Registry?**

Ask to see the certificate or death registration paperwork. Ask to see the certificate or death registration paperwork. Interviewers should be familiarized with the local civil registry authority and the appropriate death registration form(s) that contain the relevant death registration information as requested in this section.

If "YES" and the paperwork is available, continue with Id10070–Id10073. If the paperwork is not available, skip to Id10077.

**(Id10070) [Death registration number/certificate]**

Record the registration or certificate number. Note that respondents may have a “death notification” skip 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.

**(Id10071) [Is the date of registration available? / Date of registration in day/month/year (dd/mm/yyyy)]**

Record the date of registration if known.

**(Id10072) [Place of registration:]**

Record the full details of place of registration. This may include the name of the village / town / municipality where the death was registered. Enter “-”, if this information is not available. The project site may add a drop down list of location options. For the electronic questionnaire, location items may be separated and customized with drop-down lists.

**(Id10073) [National identification number of deceased]**

Record the National Identification Number. Enter “-”, if this information is not available. For children that have no ID number, use the mother’s ID. If the mother’s ID is not available, use the father’s ID. If this information is unknown or not available, enter “-”. Note whose ID was entered in the blank after the ID has been recorded.

## **History of injuries/accidents**

This section is specifically designed to enquire and record information and details for deaths caused by an injury. In general, deaths from injuries, whether accidental or intentional, are reported to the police, and subsequently follow a forensic/coronial process for determining the cause of death. The VA process using household enquiry may or may not be considered necessary or appropriate for ascertaining the cause, depending on the government directives on this subject. Whenever possible, the official police or medico-legal opinion as to the cause of death should be sought from local authorities after the completion of VA interview, and added to the VA information (if no more appropriate location is identified), to enable the accurate ascertainment of cause of death.

**(Id10077) Did (s)he suffer from any injury or accident that led to her/his death?**

This is an opening question to check whether the death was associated with any injury or accident. If the response is “YES”, proceed with the following questions. These questions are generally 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.

If the answer is "NO", then skip to Id10408. However, if the answer is "DK/Ref", the interviewer should probe further and continue with the subsequent questions.

**(Id10079) Was it a road traffic accident?**

Road traffic accidents are the most common causes of deaths from injuries in developing countries. You do not need to have been in a vehicle to have suffered a road traffic injury, for example for deaths of pedestrians. If the response to Id10079 is "YES", questions Id10080 and Id10081 should be asked, then questions Id10082–Id10097 should be skipped. If the answer is "NO", then skip to Id10082.

**(Id10080) What was her/his role in the road traffic accident?**

Check whether the deceased was a pedestrian, driver or any other role. Details of this nature are essential for accurate coding of the cause of death. Select the appropriate box based on the response.

A deceased child could have been a passenger in one of the affected vehicles, or may have been carried by a pedestrian. Record the details as such.

**(Id10081) What was the counterpart that was hit in the road traffic accident?**

The counterpart is the other object with which the injured person or vehicle carrying the injured person came into contact. These details are essential for accurate coding of the cause of death. Select the appropriate box based on the response. Go to Id10098.

**(Id10082) Was (s)he injured in a non-road transport accident?**

Enquire and record if the death was due to an accident in transport other than on the road e.g. fatal injury from train / boat / aircraft accident. If "YES", record the nature of the accident and the injuries sustained in the free text section of the questionnaire.

**(Id10083) Was (s)he injured in a fall?**

If the response is "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.

**(Id10084) Was there any poisoning?**

If the death was due to poisoning from pesticides, kerosene, or any other chemicals, record "YES" here, and note the nature of the poison in the narrative section. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. Poisoning from snakebite or animal sting, etc. is not to be included here.

**(Id10085) Did (s)he die of drowning?**

If the response is "YES", record the location where the drowning occurred – river/lake/sea/swimming pool – 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.

**(Id10086) Was (s)he injured by a bite or sting by a venomous animal?**

Record "YES" if the injury was due to snake bite or any other poisonous insect. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. If "YES", skip to Id10088.

**(Id10087) Was (s)he injured by an animal or insect (non-venomous)?**

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. If "NO/DK/Ref", skip to Id10089.

**(Id10088) What was the animal / insect?**

Select dog, snake, insect, scorpion, or other. If not known, select "DK".

**(Id10089) Was (s)he injured by burns / fire?**

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.

**(Id10090) Was (s)he subject to violence (suicide, homicide, abuse)?**

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.

**NOTE:** The term suicide should not be used for children. It is included in the standard ODK question that applies to all ages, but it should NOT be said in the case of children.

**(Id10091) Was (s)he injured by a fire arm?**

Use the local term for firearms, and record the response.

**(Id10092) Was (s)he stabbed, cut or pierced?**

The use of sharp instruments such as knife or sword should be recorded here.

**(Id10093) Was (s)he strangled?**

Use the local term for choking of the neck by force, whether by hand, rope or other object.

**(Id10094) Was (s)he injured by a blunt force?**

Injury caused by blunt force such as a stick or a heavy object, which may not cause direct external injury but can be sufficiently serious to cause fractures, internal bleeding and death. Explain the meaning of blunt force, and record the response accordingly.

**(Id10095) Was (s)he injured by a force of nature?**

Forces of nature include lightning, flood, earthquake etc. If the response is "YES", then record the force of nature in the narrative section of the questionnaire.

**(Id10096) Was it electrocution?**

If the death was due to electric shock, record "YES" here. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence.

**(Id10097) Did (s)he encounter any other injury?**

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.

**(Id10098) Was the injury accidental?**

This question identifies whether the injury was unintentional. If "YES", go to Id10408.

**(Id10100) Was the injury intentionally inflicted by someone else?**

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 (e.g. act of terrorism).

## **Health history**

**(Id10408) Before the illness that led to death, was the baby / the child growing normally?**

This is to ascertain a period of normal health before the onset of the terminal illness. A positive response would clarify that the cause of death is unlikely to be related to the delivery. Ask for all children.

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## **Duration of illness**

**(Id10120\_unit) For how long was (s)he ill before death?**

Select the best unit according to the response – days, months, or years. If less than 24 hours, select days and enter "0". If the response was greater than 30 days, ask the respondent to report in either months or years. If the response was greater than 11 months, ask the respondent to report in years. A valid response is less than the child's age at death.

**(Id10123) Did (s)he die suddenly?**

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.

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## **Medical history associated with final illness**

**(Id10125) Was there any diagnosis by a health professional of tuberculosis?**

Ask whether the deceased was diagnosed to have tuberculosis during the final illness that led to death. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10126) Was an HIV test ever positive?**

Ask if the deceased child had ever been tested for HIV, and if so, whether found positive.

**(Id10127) Was there any diagnosis by a health professional of AIDS?**

Ask whether the deceased was ever diagnosed to have AIDS, the final illness in HIV that leads to death. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10128) Did (s)he have a recent positive test by a health professional for malaria?**

Ask whether a malaria test (dipstick or blood slide) was done during the illness that led 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. If the response to this question is "YES", skip to Id10130.

**(Id10129) Did (s)he have a recent negative test by a health professional for malaria?**

Ask whether a malaria test (dipstick or blood slide) was done during the illness that led 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.

**(Id10130) Was there any diagnosis by a health professional of dengue fever?**

Ask whether a diagnosis of dengue was done during the illness that led to death. There may be a local term for dengue fever. If there is one, ensure that it is mentioned in the translated questionnaire, and use that term to ask about dengue fever. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10131) Was there any diagnosis by a health professional of measles?**

Ask whether a diagnosis of measles was done during the illness that led to death. There may be a local term for measles. If there is one, ensure that it is mentioned in the translated questionnaire, and use that term to ask about measles. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10133) Was there any diagnosis by a health professional of heart disease?**

Ask whether the deceased was ever diagnosed to have heart disease by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10134) Was there any diagnosis by a health professional of diabetes?**

Ask whether the deceased was diagnosed to have diabetes by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for diabetes. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10135) Was there any diagnosis by a health professional of asthma?**

Ask whether the deceased was diagnosed to have asthma by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for asthma. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe. You may have to demonstrate how a patient with asthma will struggle to breath.

**(Id10136) Was there any diagnosis by a health professional of epilepsy?**

Ask whether the deceased was diagnosed to have epilepsy by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for epilepsy. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe. You may have to demonstrate an episode of epilepsy.

**(Id10137) Was there any diagnosis by a health professional of cancer?**

Ask whether the deceased was ever diagnosed to have cancer by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for cancer. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10142) Was there any diagnosis by a health professional of sickle cell disease?**

Ask whether the deceased was ever diagnosed to have sickle cell disease on by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for sickle disease. This is a condition where the person has thinning of blood and becomes ill repeatedly and diagnosed by examining the blood. If there is a local term, ensure that it is mentioned in the translated questionnaire and use the local term to probe.

**(Id10143) Was there any diagnosis by a health professional of kidney disease?**

Ask whether the deceased was diagnosed to have kidney disease by a physician or any other health worker recently or during the final illness. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for kidney disease. If there is one, ensure that it is mentioned in the translated questionnaire and use the local term to probe.

**(Id10144) Was there any diagnosis by a health professional of liver disease?**

Ask whether the deceased was diagnosed to have liver disease by a physician or any other health worker recently or during the final illness. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for liver disease. If there is one, ensure that it is mentioned in the translated questionnaire and use the local term to probe.

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**General signs and symptoms associated with final illness**

**(Id10147) Did (s)he have a fever?**

Fever is a term used when the body feels abnormally warm or hot to touch, and/or when a thermometer records an abnormally high temperature. Fever most always results from infections, and is associated with other symptoms. 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.

If "NO/DK/Ref", skip to Id10152.

**(Id10148\_units) How long did the fever last?**

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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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".

**(Id10149) Did the fever continue until death?**

This is important to relate the fever to the actual cause of death.

**(Id10150) How severe was the fever?**

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. Select the appropriate response.

**(Id10151) What was the pattern of the fever?**

Some infections produce characteristic patterns of fever – continuous, or on and off, or fever only at night. 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.

**(Id10152) Did (s)he have night sweats?**

In some illness like tuberculosis or some cancers, the person can have excessive sweating at night, which is often noticed by wetness of the bed sheet. In case necessary, mention this characteristic i.e. wetness of the bed sheet, to denote whether there was unusual excessive sweating at nights.

**(Id101539) Did (s)he have a cough?**

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. Ask this question with care and double check a negative response, as this will lead to a skip of all other questions on cough. If there is a positive response for cough, care should be taken in following up closely with the subsequent questions characterising the cough.

If "NO/DK/Ref", skip to Id10159.

**(Id10154\_units) For how long did (s)he have a cough?**

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. Probe carefully and if necessary double check to ensure an accurate response to the duration of cough during the period leading to death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter "0" days. Use 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".

**(Id10155) Was the cough productive, with sputum?**

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 coloured (pus), or even blood (see Id10157). There is often a local term for phlegm, which should be used to probe.

**(Id10156) Was the cough very severe?**

The severity of the cough refers to its prominence among the symptoms present in the deceased. It is often difficult to 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 lying down position or physical exertion, and/or it affected sleep.

**(Id10157) Did (s)he cough up blood?**

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.

**(Id10158) Did (s)he make a whooping sound when coughing?**

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.

**(Id10159) Did (s)he have any difficulty breathing?**

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.

This is a filter question, hence the interviewer should clarify to the respondent the above descriptions/demonstrations of difficulty, and take care to ensure that there is no false negative response.

If "NO/DK/Ref", skip to Id10166.

**(Id10161\_unit) For how long did the difficult breathing last?**

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, the difficulty with breathing occurs as specific episodes lasting for a few days, at the most.

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. Select the best

unit according to the response – days, months, or years. If less than 24 hours, select days and enter “0”. If the response was greater than 30 days, ask the respondent to report in either months or years. If the response was greater than 11 months, ask the respondent to report in years. A valid response is less than the age at death.

**(Id10165) Was the difficulty continuous or on and off?**

As described above, 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 neonatal and 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. Clarify whether the difficulty in breathing during the final illness was continuous or on and off.

**(Id10166) During the final illness that led to death, did (s)he have fast breathing?**

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.

If "NO/DK/Ref", skip to Id10168.

**(Id10167\_units) How long did the fast breathing last?**

Usually the duration of fast breathing in the case of pneumonia will be similar to the duration of the final illness. If the respondent reports a longer duration of fast breathing than final illness clarify that you are asking about the fast breathing during the final illness.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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".

**(Id10168) Did (s)he have breathlessness?**

Breathlessness can be described as a feeling of “air hunger”, and is usually observed in 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 for breathing, 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. If "NO/DK/Ref", skip to Id10172.

**(Id10169\_units) How long did (s)he have breathlessness?**

Usually history of breathlessness associated with congenital heart diseases will be several weeks. However, episodes of breathlessness in asthma usually last only for a few days, in the final episode before death. In the case of breathlessness in children with pneumonia, it may also be for a few days only.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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".

**(Id10172) Did you see the lower chest wall / ribs being pulled in as the child breathed in?**

Usually the chest walls rise and expand 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 child. Some communities have a local term for this sign. If so, include this term in the local translated version of the questionnaire.

**(Id10173) During the illness that led to death did her/his breathing sound like any of the following: stridor, grunting or wheezing.**

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 (inspiratory) and grunting (expiratory), observed in infants with respiratory illness. VA interviewers should be aware of and be able to describe and/or demonstrate these examples of difficulty in breathing which produce abnormal sounds, and record the response accordingly.

Demonstrate the three different types of breathing and ask whether (s)he had any of them, and select the appropriate box. Play audio files if available.

**(Id10174) Did (s)he have chest pain?**

Chest pain has many possible causes that fall into two major categories: cardiac and non-cardiac causes. In children, chest pain largely arises from conditions affecting the respiratory system, mainly pneumonia. This question aims to identify whether chest pain occurred during the illness preceding death, in relation to pneumonia.

If "NO/DK/Ref", skip to Id10181.

**(Id10176) How many days before death did (s)he have chest pain?**

Pain associated with chest disease such as pneumonia could have been present for several days. Record the response in number of days; if less than 1 day or 24 hours, enter “0” days. 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.

**(Id10181) Did (s)he have more frequent loose or liquid stools than usual?**

Ask the respondent about her/his understanding of what is diarrhoea (having more frequent loose or liquid stools than usual); if unclear or wrong, explain to the respondent what is diarrhoea. The frequent passage of loose or watery stools, with or without blood, is commonly known as diarrhoea. 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.

If "NO/DK/Ref", skip to Id10186.

**(Id10182\_units) How long did (s)he have frequent loose or liquid stools?**

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 coeliac disease, the affected individual could have diarrhoea over prolonged periods extending over weeks or months. On the other hand, it may be an episode of diarrhoea immediately preceding death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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".

**(Id10183) How many stools did the baby or child have on the day that loose liquid stools were most frequent?**

This question records the frequency of diarrhoea. Ask the respondent the maximum number of times the deceased had diarrhoea on any day in the period immediately preceding death, and record this number in the space provided.

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”.

**(Id10184\_units) How long before death did the frequent loose or liquid stools start?**

This question is asked to specifically relate the episode of diarrhoea to the death. If acute diarrhoea (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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10185) Did the frequent loose or liquid stools continue until death?**

A positive response to this question gives substantial basis for considering diarrhoea among the potential causes of death. However, in some instances, the deceased may have slipped

into unconsciousness and not consumed food for some time before death, therefore the diarrhoea 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 diarrhoea as the cause of death.

**(Id10186) At any time during the final illness was there blood in the stools?**

It is common for blood in loose stools to be recognised and recalled by family members of infants or young children with diarrhoea.

**If the answer is "NO/DK/Ref", skip to Id10188.(Id10187) Was there blood in the stool up until death?**

This is a confirmatory question for this specific symptom, and contributes to the diagnosis of diarrhoea as the cause of death.

**(Id10188) Did (s)he vomit?**

Vomiting is a well-recognised symptom common to abdominal disease, but can occur in other conditions such as meningitis and other systemic infectious disease.

**(Id10189) To clarify: Did (s)he vomit in the week preceding the death?**

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.

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.

If "NO/DK/Ref", skip to Id10193.

**(Id10191) Was there blood in the vomit?**

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.

**NOTE:** This question is asked when there is a positive response to either Id10188 or Id10189.

**(Id10192) Was the vomit black?**

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 vomit do not appear as bright red, as the blood gets mixed with other stomach contents and changes colour to a blackish, semisolid substance.

**NOTE:** This question is asked when there is a positive response to either Id10188 or Id10189.

**(Id10193) Did (s)he have any belly (abdominal) problem?**

Explain to the respondent that problems could be pain, protruding abdomen or a mass. Note that Id10194, Id10200, and Id10204 will be asked regardless of the answer to this question for clarity. (Id10194) Did (s)he have belly (abdominal) pain?

Both Id10193 and Id10194 are required for the automated analysis software. Thus, this question will be asked regardless of the response to the previous question. 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.

There may be a local term to describe it. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10200.

**(Id10195) Was the belly (abdominal) pain severe?**

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.) and record these in the "Open Narrative" section.

**(Id10196\_unit) For how long did (s)he have belly (abdominal) pain?**

The time relationship between the symptom and the event of death is important to determine the cause of death. Record the reported number of hours the pain lasted. Select the best unit according to the response – hours, days, or months. A valid response is between 0–23 hours, 1–30 days, or 1–60 months. Use 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".

**(Id10199) Was the pain in the upper or lower belly (abdomen)?**

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. For children, this question is only asked if the response to Id10195 was "YES", indicating severe abdominal pain.

**(Id10200) Did (s)he have a more than usually protruding belly (abdomen)?**

A more than usually protruding abdomen is sometimes observed in children with malnutrition. The 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. 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.

If "NO/DK/Ref", skip to Id10204.

**(Id10201\_unit) For how long before death did (s)he have a more than usually protruding belly (abdomen)?**

Distension of abdomen due to obstruction of intestine starts rapidly and last for few days because the person needs to seek urgent treatment to survive the condition. The duration of months has relevance for the protruding belly in children that is associated with malnutrition. 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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10203) How rapidly did (s)he develop the protruding belly (abdomen)?**

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.

**(Id10204) Did (s)he have any mass in the belly (abdomen)?**

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. Often, there could have been an attempt to seek medical care, which could be recalled by relatives. In which case, there is likelihood as to a medical opinion as to the confirmation of the mass, as well as potential for availability of a diagnosis which may be recalled by the respondent. If there is a positive response, probe carefully, and remember to come back to this issue during enquiry about health records (paper questionnaire in Section 9), and record all relevant details on health care access and diagnostic information in that section.

If "NO/DK/Ref", skip to Id10207.

**(Id10205\_unit) For how long did (s)he have a mass in the belly (abdomen)?**

The duration for which the mass was present could help guide the diagnosis. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10207) Did (s)he have a severe headache?**

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. Headache can be reported in many conditions including meningitis, malaria and dengue fever. However, a child reporting headache would generally be considered as an important clinical feature, and could be considered as severe.

There may be a local term to describe it. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

**(Id10208) Did (s)he have a stiff neck during illness that led to death?**

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. It is an important feature of meningitis (a brain infection), particularly in children. This sign may not be easily observed or recalled by the respondent. If required, clarify to the respondent the description as provided above, and record the response.

If "NO/DK/Ref", skip to Id10210.

**(Id10209\_units) How long before death did (s)he have stiff neck?**

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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter "0" days. Use 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".

**(Id10210) Did (s)he have a painful neck during the illness that led to death?**

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.

If "NO/DK/Ref", skip to Id10214.

**(Id10211\_units) How long before death did (s)he have a painful neck?**

Ask and record the duration of painful neck during the illness preceding death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter "0" days. Use 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".

**(Id10214) Was (s)he unconscious during the illness that led to death?**

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 towards identifying loss of consciousness as an important specific factor associated with the illness leading to death, usually indicating involvement of the brain.

There may be a local term to describe unconsciousness. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10219.

**(Id10215) Was (s)he unconscious for more than 24 hours before death?**

This question is asked to identify whether the loss of consciousness was associated with a condition involving the brain such as an infection, and not just a feature of the terminal stages of illness. Such conditions of the brain usually result in unconsciousness longer than 1 day.

If "YES", skip to Id10217. If "NO/DK/Ref", proceed to the next question.

**(Id10216\_units) How long before death did unconsciousness start?**

Select the best unit according to the response – hours or days. A valid response is between 0–23 hours or 1–99 days. Use 1 week = 7 days. A likely response is less than 99 days. If the response given was greater than 99 days, confirm the response, and enter “99”.

**(Id10217) Did the unconsciousness start suddenly, quickly (at least within a single day)?**

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.

**(Id10218) Did the unconsciousness continue until death?**

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.

**(Id10219) Did (s)he have convulsions?**

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. 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.

If necessary, demonstrate the convulsive movements of limbs (and eyeballs), and record the response accordingly.

If "NO/DK/Ref", skip to Id10223.

**(Id10220) Did (s)he experience any generalized convulsions or fits during the illness that led to death?**

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. This question refers only to convulsions affecting the whole body, so clarify this aspect, and record the response accordingly.

**(Id10221) For how many minutes did the convulsions last?**

Record the number of minutes the respondent reports for the duration of the convulsion. The answer could be given in another unit, but for data entry use minutes. Less than 1 minute = "0". 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.

**(Id10222) Did (s)he become unconscious immediately after the convulsions?**

Loss of consciousness usually occurs after a generalised convulsion, so a positive response will confirm the occurrence, and thus help aid the diagnosis.

**(Id10223) Did (s)he have any urine problems?**

Explain to the respondent that urine problems refer to urinating a lot or not at all, and blood in the urine. 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.

If "NO/DK/Ref", skip to Id10227.

**(Id10225) Did (s)he go to urinate more often than usual?**

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.

**(Id10226) During the final illness did (s)he ever pass blood in the urine?**

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 blood and would be

readily observed by the child or hi(s)her carers, possibly leading to seeking of health care. Hence, if this symptom was present, there is a good likelihood of a positive response.

**(Id10224) Did (s)he stop urinating?**

This means the deceased stopped urinating. 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 diarrhoeal 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 / duration of relative stoppage of urination, and record the response accordingly.

**NOTE:** It is possible that an individual both urinated more often than usual (Id10225) AND stopped urinating; both conditions could exist at different times.

**(Id10227) Did (s)he have sores or ulcers anywhere on the body?**

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 bed ridden 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.

There may be local terms to describe it. Ensure that the local terms are included in the translated version of the questionnaire, and use the local terms to probe.

If "NO/DK/Ref", skip to Id10230.

**(Id10229) Did the sores have clear fluid or pus?**

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.

**(Id10230) Did (s)he have an ulcer (pit) on the foot?**

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.

If "NO/DK/Ref", skip to Id10233.

**(Id10231) Did the ulcer on the foot ooze pus?**

The presence of pus in the ulcer is an important diagnostic sign. Pus is a thick fluid which could be green or yellow in colour, which continually accumulates on the floor of the ulcer.

If "NO/DK/Ref", skip to Id10233.

**(Id10232\_units) How long did the ulcer on the foot ooze pus?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10233) During the illness that led to death, did (s)he have any skin rash?**

"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.

There may be a local term to describe skin rash. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10238.

**(Id10234) For how many days did (s)he have the skin rash?**

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. 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. 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 days, confirm the response and enter “98”. If the answer to duration happens to be 88 days, enter instead “87” so that the response is not automatically coded as refused to answer. (Id10235) Where was the rash?

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. Multiple responses are allowed for this item, so check all the locations that apply.

**(Id10236) Did (s)he have measles rash (use local term)?**

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.

**(Id10238) During the illness that led to death, did her/his skin flake off in patches?**

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 sign when present, and is a useful diagnostic sign.

**(Id10239) During the illness that led to death, did she/he have areas of the skin that turned black?**

Black coloured 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.

**(Id10240) During the illness that led to death, did she/he have areas of the skin with redness and swelling?**

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.

**(Id10241) During the illness that led to death, did (s)he bleed from anywhere?**

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 (through the skin, gum, mouth, nose, anus), or under the skin, or into internal joints and organs.

If "NO/DK/Ref", skip to Id10243.

**(Id10242) Did (s)he bleed from the nose, mouth or anus?**

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.

**(Id10243) Did (s)he have noticeable weight loss?**

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. This weight loss is different from the chronically thin child, which is the subject of the next question. This one gathers information of a previously healthy child rapidly losing weight during the illness/period preceding death. Clarify these aspects with the respondent to confirm or exclude weight loss, and record the response accordingly.

**(Id10244) Was (s)he severely thin or wasted?**

This question aims at identifying malnutrition in the deceased. The individual may have been consistently underweight for a prolonged period, and not having 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.

**(Id10245) During the illness that led to death, did (s)he have a whitish rash inside the mouth or on the tongue?**

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 observed by the carer.

There may be a local term to describe rash. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

**(Id10246) Did (s)he have stiffness of the whole body or was unable to open the mouth?**

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.

**(Id10247) Did (s)he have puffiness of the face?**

Puffiness or swelling in the face is observed when there is accumulation of fluid particularly in the spaces/bags around the eyes, and other parts. This accumulation of fluid is an important diagnostic sign, particularly of kidney disease in children. It can be observed and recalled by respondents, if prominent.

If "NO/DK/Ref", skip to Id10249.

**(Id10248\_units) How long did (s)he have puffiness of the face?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10249) During the illness that led to death, did (s)he have swollen legs or feet?**

Swollen feet, ankles and even legs may occur due to the accumulation of fluid in congenital heart disease, kidney disease, or in 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 collection of fluid around the ankles, the presence of which could be recalled by respondents.

If "NO/DK/Ref", skip to Id10252.

**(Id10250\_units) How long did the swelling last?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10251) Did (s)he have both feet swollen?**

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.

**(Id10252) Did (s)he have general puffiness all over his/her body?**

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, among 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.

**(Id10253) Did (s)he have any lumps?**

Lumps are small, solid and painless swellings that are sometimes observed near the armpit, neck or groin. They are seen in association with certain types of infections or rarely, in certain cancers. In some instances, the lumps may be present in multiple locations and on both sides, indicative of a more generalised form of disease. Unless the lumps are rather large, or the patient is in a bed ridden state, they may not be observed by the respondent.

There may be a local term to describe lumps. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10258.

**(Id10255) Did (s)he have any lumps on the neck?**

This question is to confirm the presence of lumps on 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.

**(Id10256) Did (s)he have any lumps on the armpit?**

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.

**(Id10257) Did (s)he have any lumps on the groin?**

This question is to confirm the presence of lumps in the groin, at the junction between the lower limb and the body trunk. 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.

**(Id10258) Was (s)he in any way paralysed?**

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.

If "NO/DK/Ref", skip to Id10261.

**(Id10259) Did (s)he have paralysis of only one side of the body?**

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. Several communities even have a local term to describe this condition. Clarify the presence of this sign, and record the response accordingly.

**(Id10260) Which were the limbs or body parts paralysed?**

It is important to confirm whether the paralysis was affecting only a particular limb, or parts of the body or the whole body. Mark the specific body parts that were observed to have been paralysed. This question allows for multiple responses; select the box(es) that apply.

**(Id10261) Did (s)he have difficulty swallowing?**

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.

If "NO/DK/Ref", skip to Id10264.

**(Id10262\_units) For how long before death did (s)he have difficulty swallowing?**

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. 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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10263) Was the difficulty with swallowing with solids, liquids or both?**

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.

**(Id10264) Did (s)he have pain upon swallowing?**

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. 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.

**(Id10265) Did (s)he have yellow discoloration of the eyes?**

Yellow discolouration 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. There is often a local term used for this sign. Sometimes in advanced stages there is also yellow discolouration of palms or skin, and if observed, the urine is also of an intense yellow colour.

If "NO/DK/Ref", skip to Id10267.

**(Id10266\_units) For how long did (s)he have the yellow discoloration?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10267) Did her/his hair change in colour to a reddish or yellowish colour?**

In children with black coloured hair, a change in the hair colour 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.

**(Id10268) Did (s)he look pale (thinning/lack of blood) or have pale palms, eyes or nail beds?**

Long term deficiency of the blood results in a pale, whitish appearance of the lips, tongue, and eye sac. Sometimes 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.

**(Id10269) Did (s)he have sunken eyes?**

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.

**(Id20270) Did (s)he drink a lot more water than usual?**

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.

**(Id10271) Was the baby able to suckle or bottle-feed within the first 24 hours 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. Ask only for deceased who were < 1 year old.

**(Id10272) Did the baby ever suckle in a normal way?**

This question is asked to enquire if there was a normal healthy effort at suckling, or if there was any weakness or 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. Ask only for deceased who were < 1 year old.

**(Id10273) Did the baby stop suckling?**

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. Ask only for deceased who were <1 year.

If "NO/DK/Ref", skip to Id10275.

**(Id10274\_units) How long after birth did the baby stop suckling?**

Ask only for deceased who were < 1 year old. The number of days after birth the baby stopped sucking is an important indicator to diagnose neonatal tetanus. Probe carefully to get an accurate response. 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 "0" 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".

**(Id10275) Did the baby have convulsions starting within the first 24 hours of life?**

An earlier question enquired about convulsions, observed as jerking movements of limbs or eyeballs. Id10275 and Id10276 are to confirm the timing and 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. Ask only for deceased who were < 1 year old.

If "YES", skip to Id10277.

**(Id10276) Did the baby have convulsions starting more than 24 hours after birth?**

Convulsions occurring after the first day of life could be associated with neonatal tetanus. Ask only for deceased who were <1 year.

**(Id10277) Did the baby's body become stiff, with the back arched backwards?**

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. Ask only for deceased who were < 1 year old.

**(Id1027) During the illness that led to death, did the baby have a bulging or raised fontanelle?**

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. Ask only for deceased who were < 18 months of age.

If "YES", skip to Id10281.

**(Id10279) During the illness that led to death, did the baby have a sunken fontanelle?**

When the body gets dehydrated as in the case of diarrhoea, or severe fever, the fontanelle can become depressed or sunken, and can be clearly recognised by the carer. Ask only for deceased who were <18 months of age.

**(Id10281) During the illness that led to death, did the baby become unresponsive or unconscious?**

**(Id10282) Did the baby become unresponsive or unconscious soon after birth, within less than 24 hours?**

**(Id10283) Did the baby become unresponsive or unconscious more than 24 hours after birth?**

Unconsciousness means the complete inability to arouse the neonate with no movement except for breathing. The child does not respond even to physical stimuli including pain. Sick neonates could be sleeping for long periods, but need to check if they could not be aroused even for feeding. The identification of unconsciousness is largely in regard to its suggestion of brain or central nervous system disease or disorder. A short period of unconsciousness usually precedes death. In the case of neonates, delineating unconsciousness as a specific symptom of brain or nervous system involvement is difficult. Ask only for deceased who were < 1 year old.

If "NO/DK/Ref" to Id10281, skip to Id10284.

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## Neonatal and child history, signs and symptoms

### **(Id10352\_units) How old was the child when the fatal illness started?**

Ask for all children. Select the best unit according to the response – months or years. A valid response is between 1–11 months or 1–11 years. The age entered should not exceed the age at death.

### **(Id10354) Was the child part of a multiple birth?**

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. Ask only for deceased who were < 1 year old.

If "NO/DK/Ref", skip to Id10356.

### **(Id10355) Was the child the first, second, or later in the birth order?**

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. Ask only for deceased who were < 1 year old.

### **(Id10356) Is the mother still alive?**

If the mother is present at the interview, select "YES" without asking the question aloud. If the mother is not present at the interview, ask if the mother of the deceased child is still alive. Ask only for deceased who were < 1 year old.

If the mother is alive, i.e. the response is "YES", skip to Id10360. If the response is "NO", proceed with the next question.

### **(Id10357) Did the mother die before, during or after the delivery?**

Select the appropriate option. Ask only for deceased who were < 1 year old.

If the mother died before or during delivery, skip to Id10360. If the mother died after the delivery, proceed with Id10358\_units.

### **(Id10358\_units) How long after the delivery did the mother die?**

Ask only for deceased who were less than 1 year old. Select the best unit according to the response – days, weeks, or months. A valid response is between 0–6 days, 1–7 weeks, or 2–12 months. If the mother died less than 24 hours after delivery, record "0" days. If the response was greater than 6 days, ask the respondent to report time in weeks. If the response was greater than 7 weeks, ask the respondent to report time in months. A likely response is less than 12 months. If the response given was greater than 12 months, confirm the response, and enter "12".

**(Id10360) Where was the deceased born?**

Read the question and slowly read the first 5 choices. Respondent should hear all 5 choices first and then respond. Mark the appropriate box that corresponds with the place where the delivery occurred. Differentiate between “hospital” births (i.e. health institutions with in-patient facilities) from “other health facility” (dispensaries, health centres or private clinics where patients are seen on out-patient basis). *CHECK ONLY ONE BOX*. Ask only for deceased who were < 1 year old.

**(Id10361) Did you/the mother receive professional assistance during the delivery?**

Explain to the respondent what is meant by professional assistance: delivery attended by a medical professional (doctor, nurse, or midwife). The nature of assistance received at delivery is helpful in understanding the factors that could have led to the death of the neonate. Professional assistance refers to either a medically qualified doctor, qualified nurse, or certified trained midwife only. This variable is very important for monitoring and evaluation of health services. Ensure the correct professional type of assistance, and then record the response. Ask only for deceased who were < 1 year old.

**(Id10362) At birth, was the baby of usual size?**

Babies who are not of usual size (i.e. either too small or too large) carry increased risks for specific causes of death. If available, show a photo of baby’s various sizes.

If the response to Id10362 is "YES", then skip to Id10366.

If the response is "NO"; i.e. the baby was not of usual size, or "DK/Ref" then proceed with the next question.

**(Id10363) At birth, was the baby smaller than usual, (weighing under 2.5 kg)?**

Low birth weight is an important factor associated with increased risk for neonatal death particularly from breathing problems, birth injury, and hypothermia. Small than usual size may be difficult to explain but the mothers may be able to report whether the baby was small. Ask only for deceased who were < 1 year.

If "NO/DK/Ref", skip to Id10365. If "YES", proceed with the next question.

**(Id10364) At birth, was the baby very much smaller than usual, (weighing under 1 kg)?**

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. Record the response to this question –either "YES, NO, or DK/Ref" and skip to Id10366.

Ask only for deceased who were < 1 year old.

**(Id10365) At birth, was the baby larger than usual, (weighing over 4.5 kg)?**

This question is to be asked only if the response to Id10363 was "NO/DK/Ref".

Babies born larger than usual are associated with problems caused to the mother during delivery, but sometimes the new born also carries increased risks from birth injuries, and from congenital malformations, and diabetes. Ask only for deceased who were <1 year.

**NOTE:** The responses to Id10362, Id10363, and Id10365 should not all be "NO". If this is the case, you should go back to one of the previous questions and correct the selection.

**(Id10366) What was the weight (in grams) of the deceased at birth?**

Ask for all children. 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 response in kilograms. For data entry, convert to grams. 1 kilogram = 1,000 grams. Enter "9999" for don't know. Enter "8888" for refused to answer. A valid response is between 0 and 9999.

**(Id10367) How many months long was the pregnancy before the child was born?**

Ask for all children.

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. Delivery at less than 8 months pregnancy is associated with smaller size babies, which carry the risks from breathing problems, birth injuries, and hypothermia (cold to touch). Record the duration carefully, asking the respondent to count the completed months from the date of last menstrual period till the date of delivery. If the respondent gives an answer in half-months (e.g. 6.5 months) or months and weeks (e.g. 6 months and 2 weeks), round down (e.g. enter "6") to enter the completed months. 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".

**(Id10368) Were there any complications in the late part of the pregnancy (defined as the last 3 months, before labour)?**

Complications refer to specific medical conditions that have been sufficient to require medical attention. These could include episodes of high fever, or high blood pressure, or convulsions, or bleeding, or leakage of fluid from the birth canal, or slowing or stoppage of the movements of the child, among others. Ask carefully giving the above examples, as may be required. Ask for all children.

**(Id10369) Were there any complications during labour or delivery?**

Complications during labour or delivery refer to a fever or infection, the occurrence of leakage of fluid from the birth canal before onset of pain; or very slow progression or obstruction of labour: or occurrence of birth canal injuries to the mother; or heavy bleeding, among others. Ask carefully, giving these examples if required. Ask for all children.

If the child is under 1 year, proceed with the next questions. If the child is 1 year or older, skip to Id10418.

**(Id10370) Was any part of the baby physically abnormal at time of delivery? (for example: body part too large or too small, additional growth on body)?**

An abnormal shape of limb due to physical deformity, or any external physical abnormality can cause difficult labour, and can also be associated with other congenital malformations of internal organs which could be the cause of death. Ask only for deceased who were < 1 year old.

If the answer is "NO" skip to Id10394. If the answer is "YES", "DK/Ref", proceed with the next questions.

**(Id10371) Did the baby/ child have a swelling or defect on the back at time of birth?**

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. Ask only for deceased who were < 1 year old.

**(Id10372) Did the baby / child have a very large head at time of birth?**

Similarly, 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. Ask only for deceased who were < 1 year old.

If "YES", skip to Id10394.

**(Id10373) Did the baby / child have a very small head at time of birth?**

This is usually associated with either stillbirth or survival for only 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. Ask only for deceased who were < 1 year old.

**(Id10394) How many births, including stillbirths, did the baby's mother have before this baby?**

This question attempts to record the complete childbirth history of the mother. Certain causes of neonatal deaths 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. Ask only for deceased who were < 1 year old. 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".

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**Health service utilisation**

Although a death may have occurred at home, it's possible that the deceased received some form of medical attention during the illness that led to death. The individual may have been treated in the hospital and then discharged prior to death, which may occur where there is no potential cure, the treatment is too expensive, or if there is a cultural preference for terminal care at home. In such instances, it's likely that household members may be aware of the likely disease or condition that the patient was suffering and the nature of medical treatment provided. In the following questions, you will record specific responses about health services. This section should always be completed at the end of the interview. You should also record any additional information on health services or medical opinions provided on the cause of death in the narrative section of the questionnaire.

**(Id10418) Did (s)he receive any treatment for the illness that lead to death?**

This question refers to formal health treatment, and not home remedies or non-professional treatment. If the response to this question is "NO", then you will skip to Id10428.

**(Id10419) Did (s)he receive 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 diarrhoea, particularly children. This is an effective remedy which is known to prevent death.

**NOTE:** The automated analysis software requires questions Id10420–Id10425. These questions should be answered according to whether the patient **received** the treatment OR **needed** the treatment.

**(Id10420) Did (s)he receive (or need) 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.

**(Id10421) Did (s)he receive (or need) a 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.

**(Id10422) Did (s)he receive (or need) treatment/food through a tube passed through the nose?**

Feeding through the nasal tube indicates potential damage to the nervous system. Problems with nasal tube feeding can result in partial vomiting (aspiration) and infection of the lungs, leading to death. Enquire how long feedings were provided through the tube, and whether the tube was in place right prior to death. Record all these details in the narrative section of the questionnaire.

**(Id10423) Did (s)he receive (or need) injectable antibiotics?**

Injectable antibiotics are medications administered by needle to treat bacterial infections. They may indicate a serious infection and are almost always only administered in health facilities. However, details of such treatment may or may not be shared with family members.

**(Id10424) Did (s)he receive (or need) 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 usually taken on a daily and a long-term basis. The patient's relatives may not know these details. Explain the question carefully, and record the response accordingly.

**(Id10425) Did (s)he have (or need) an operation for the 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. If the response is "YES", enquire from the relatives if they know the medical condition (e.g. cancer, stomach ulcer; heart disease etc.) that was the reason for the operation; and note the details in the narrative section of the questionnaire. If the answer is "NO/DK/Ref", skip to Id10427.

**(Id10426) Did (s)he have the operation within 1 month before death?**

The timing of the operation will help ascertain any links between the treatment and the cause of death.

**(Id10427) Was (s)he discharged from hospital very ill?**

Discharge refers to a patient leaving a hospital after receiving approval from a medical provider. This question is only asked if the response to Id10418 was "YES", indicating that there was some level of hospitalization.

**(Id10428) Did (s)he receive any immunizations?**

**This question is to confirm whether the neonate received immunizations at the time of birth. If the response is "YES", proceed to the next question. If the response is "NO/DK/Ref", then skip to Id10432.****(Id10429) Do you have the child's vaccination card?**

Note that countries may have a local term for this card, e.g. "Road to Health" card or "Mother Child Booklet". Use the local term.

If "YES", proceed to the next question. If "NO/DK/Ref", skip to Id10432.

**(Id10430) Can I see the vaccination card (note the vaccines the child received)?**

Ask the respondent to give you the vaccination card.

**(Id10431) Select EPI vaccines done**

Check all vaccines that are indicated on the card. For vaccines that require multiple doses, only check the box if **all doses** have been received. This includes for children who died before the final doses were received, even if they had received all vaccines appropriate for their age.

It is recommended that local guidance is compiled into a tool for interviewers to know which vaccines and what doses should be received for a given age. During training, interviewers should be trained on the use of the respective "vaccination schedule tool".

**(Id10432) Was care sought outside the home while (s)he had this illness?**

This series of questions is to determine if any health care was sought *anywhere outside the home*. This question includes both locations (hospitals, health centres, and pharmacies) and individuals (physicians, community-based practitioners, trained birth attendants, traditional healers, homeopaths, religious healers, relatives/friends). If the response to this question is "NO/DK/Ref", then skip to Id10435.

**(Id10433) Where or from whom did you seek care?**

Read out the list of options from the list, and select all that are applicable, since there may have been attempts to seek several different health care options.

**(Id10434) What was the name and address of any hospital, health centre or clinic where care was sought**

In the space provided, record the main institution where health care was provided, including investigations, diagnosis, treatment and other facilities. Enter "-", if this information is not available.

**(Id10435) Did a health care worker tell you the cause of death?**

If the response is "NO/DK/Ref", then skip to Id10437.

**(Id10436) What did the health care worker say?**

Record details of any verbally communicated information on the likely cause of death here.

**(Id10437) Do you have any health care records that belonged to the deceased?**

This could include 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. If "YES", proceed to the next question. If "NO/DK/Ref", skip to Id10445.

**(Id10438) Can I see the health records?**

Seek consent from relatives to see the health records, and note the details as per the following question. In case there is refusal to show the health records; then skip to Id10445.

**(Id10439) [Is the date of the most recent (last) visit available? / Record the date of the most recent (last) visit]**

If the date is available, record the visit date for the final consultation. Note any details of the diagnosis, laboratory tests, and treatment etc. in the narrative section of the questionnaire.

**(Id10445) Has the deceased's (biological) mother ever been tested for HIV?**

If respondents are unsure, it may be useful to ask to see the mother's antenatal clinic card where this information is often recorded.

**(Id10446) Has the deceased's (biological) mother ever been told she had HIV/AIDS by a health worker?**

This may a sensitive issue, but is very important information that may help determine the cause of death.

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## **Background and context**

**(Id10450) In the final days before death, did (s)he travel to a hospital or health facility?**

Enter "YES" if the deceased was a stillbirth delivered in a health facility or a live birth delivered in a health facility that died before leaving the facility. If the answer is "NO/DK/Ref", then skip to Id10455.

**(Id10451) Did (s)he use motorised transport to get to the hospital or health facility?**

If the respondents did travel to a health facility, ask what mode of transport they used to get there. Record "YES" here if some motorized form (car, truck, tractor, motorcycle, scooter or ambulance) was used.

**(Id10452) Were there any problems during admission to the hospital or health facility?**

Ask the respondent whether there were any problems such as delays, paperwork, queues or no staff encountered at the health facility.

**(Id 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?**

Enquire whether there were any problems with how the deceased or family were treated at the health facility.

**(Id10454) Were there any problems getting medications or diagnostic tests in the hospital or health facility?**

Enquire whether there were any problems with receipt of medications or diagnostic tests at the health facility.

**(Id10455) Does it take more than 2 hours to get to the nearest hospital or health facility from the deceased's household?**

Enquire whether the person who died lived in a household from where it would reasonably take more than 2 hours to reach the nearest 24-hour health facility by the means of transport available to the household members.

**(Id10456) In the final days before death, were there any doubts about whether medical care was needed?**

Ask if there were any doubts among those assisting in the final illness (family members, etc.) about whether the final illness was sufficiently serious to need treatment at a health facility.

**(Id10457) In the final days before death, was traditional medicine used?**

If a major part of treatment for the final illness was provided by any kind of traditional or alternative practitioner (herbal remedies, massages, drinks, foods, amulets, spells or blessings provided by traditional healers, witch doctors or shaman) select "YES" here.

**(Id10458) In the final days before death, did anyone use a telephone or cell phone to call for help?**

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. This may have been used to call for help or arrange transportation.

**(Id10459) Over the course of illness, did the total costs of care and treatment prohibit other household payments?**

Select "YES", if the total costs incurred in the final illness were sufficiently great to mean that other kinds of household expenses (food, fuel, travel, education etc.) could not be met, or caused debt or sale of household assets.

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**Death certificate with cause of death**

The following information serves only to complete cause of death information in some environments. In routine Civil Registration Vital Statistics (CRVS) they could be skipped from the interview and information be collected from other sources if available.

**(Id10462) Was a medical certificate of cause of death issued?**

Ask the respondent if there is a medical certificate of the cause of death for the person that died. The medical certificate of cause of death is commonly obtained from a physician at a hospital and should be distinguished from the Death Certificate which is issued by the civil registration organisation. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other "certificates" such as the burial permit that this question may be confused with.

If the answer is "NO/DK/Ref", skip to Id10476 – "Open narrative" section.

**(Id10463) Can I see the medical certificate of cause of death?**

Ask if you can see the medical certificate of cause of death in order to record information about the cause of death. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other "certificates" such as the burial permit that this question may be confused with.

Fill in the following questions only if you are shown the copy of the certificate. Do not fill in just based on oral statements. Record “NO” if medical information about the cause of death is not available. If the answer is "NO" skip to Id10476 – “Open narrative” section.

**(Id10464) and (Id10465) [Record the immediate cause of death from the certificate (line 1a) and the duration of that cause.]**

**NOTE:** This section aims to collect information from the international standard medical certificate of cause of death. This level of detail may or may not present in the death certificate issued to the family. If this detail is not present, fill in “-” for Id10464–Id10473.

Copy the cause of death from the first line of the death certificate. There should always be a cause recorded here. If a duration for which that cause was experienced is also recorded in the column beside the cause, enter that in Id10465.

**(Id10466) and (Id10467) [Record the first antecedent cause of death from the certificate (line 1b) and the duration of that cause (1b).]**

Copy the cause from the second line of the death certificate if there is one listed as well as its duration.

**(Id10468) and (Id10469) [Record the second antecedent cause of death from the death certificate (line 1c) and the duration of that cause (1c).]**

Copy the cause from the third line of the death certificate if there is one listed as well as its duration.

**(Id10470) and (Id10471) [Record the third antecedent cause of death from the certificate (line 1d) and the duration of that cause (1d).]**

Copy the cause from the fourth line of the death certificate if there is one listed as well as its duration.

**(Id10472) and (Id10473) [Record the contributing cause(s) of death from the certificate (part 2) and the duration of that cause (part 2).]**

List any contributing causes recorded in Part II of the death certificate.

## **Open narrative**

### **(Id10476) Narrative description**

Ask respondents to describe in their own words whether they have anything to add to the information they have provided so far. You will read “Thank you for your information. Now can you please tell me in your own words about the events that led to the death?”

Allow the respondent to tell you about the illness in his or her own words. Once the respondent has completed the initial response, prompt for additional information as relevant:

- Symptom recognition (when were first symptoms recognised, what other symptoms

did (s)he have, when did the respondent/family realise it was severe, who recognized the first and severe symptoms);

- Timing (how long it took from first symptoms to realising it was severe);
- Actions taken in home and outside the home (how long after first symptom(s) and severe symptom(s) was any action taken, what actions, was there any treatment given, what treatment, who made the decision to seek or not to seek care, reason for this action, if care outside the home was not sought – why?)
- Transport (time spent from making the decision for seeking care outside the home to getting transport, type of transportation used to reach the first level of care and any potential referrals, time spent during transport, any delays that may have occurred before reaching care).
- Provider behaviour (advice given, treatment given, how long did it take to receive the care after reaching health care services, complete referral history, timing of referral, time spent on travel to and between facilities, reasons for not going or delaying referral, referral experience).

During the response, record detailed *written* notes of what is mentioned. Make sure to capture key items such as signs and symptoms, timing of care seeking, and any points that need to be clarified. If using an electronic data capture system (e.g. ODK), enter the notes into the electronic system *after* concluding the interview.

The checklist below provides a list of additional items that may be included in the open narrative if identified in the interview. You should feel free to denote additional items even if they are not included on the checklist.

#### **CHECKLIST OF ADDITIONAL ITEMS TO RECORD IN THE NARRATIVE OPEN SPACE**

**If there is an official police or medico legal opinion as to the cause of death – provided by local authorities (usually for accidents or injuries). Additional information about injuries**

- If the family reported an injury, record the specifics of the injury (type, mode, location of event, and affected body parts that were injured);
- If it was self-inflicted even when you did not ask;
- if it was an accident in transport other than on the road E.g. fatal injury from train / boat / aircraft;
- If a fall, record the body parts injured;
- If a poisoning from pesticides, kerosene, or any other chemicals, record the type of poison;
- If a drowning, record location where the drowning occurred – river / lake / sea / swimming pool, etc.;
- If injured by burns/fire, record the all of the body parts affected by burns and how the burn occurred;

- If injured by a force of nature, record the type of force of nature (lightning, flood, earthquake, etc.).

#### **Additional findings in the deceased**

- If the deceased had any birth defects, describe body part(s) and what it looked like, and/or if the deceased had ambiguous genitalia/intersex.
- If you recorded the birth weight given to you and it was self-reported (not verified on the records), then record that the birth weight was reported by the respondent here.
- If the deceased appeared healthy and died suddenly (unexpectedly within 24 hours of being in regular health) and there are any other details about the death, record them (e.g. happened during the sleep). In some instances, this may be the main information provided by the respondent.
- If the deceased had a recent health visit, note any details of the diagnosis, laboratory tests, and treatment etc. in the open narrative section of the questionnaire.
- If there is any additional information on health services or medical opinions provided on the cause of death for the deceased who may have attended medical care prior to his/her death, record that here.
- If the deceased received or needed treatment or food passed through the nose, enquire how long feedings were provided through the tube and whether the tube was in place prior to death, and record relevant information here.
- If the deceased had any presence of lumps on the neck, if there was an opinion as to the medical cause for the lump and (s)he received treatment, record relevant information here.
- If the deceased had an operation, enquire from the respondent if s(he) knows the medical condition (e.g. cancer, stomach ulcer, heart disease, etc.) that was the reason for the operation; note relevant details here.

#### **(Id10478) [Select any of the following words that were mentioned as present in the narrative?]**

This question lists some of the key risks associated with mortality in the age group of the deceased. After the respondent has provided their description of the circumstances surrounding the death read back through and record all of the key words which they may have mentioned that the deceased had.

#### **[Comment: Comment]**

Record any additional details about the interviewer here.

**(Id10481) [Record the time at the end of the interview.]**

In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

## Appendix C: Question by question instructions for the 2016 WHO verbal autopsy questionnaire for the death of a person aged 12 years and above

**NOTE:** *Due to the integrated skip patterns, the identifying numbers of the questions will not always be in sequential order. Each question begins with its ID in parenthesis, e.g. “(Id10153) Did (s)he have a cough?”. Questions in [ ] are not to be read to the respondent. Throughout the document, response options are abbreviated as follows: “DK” refers to response option “Don’t know”; and “Ref” refers to response option “Refused to answer”.*

### Preset HIV-Malaria mortality and season

#### **(Id10002) [Is this a region of high HIV/AIDS mortality?]**

The answer this question should be decided by the project office prior to the VA interview. The high mortality of HIV/AIDS is not based on a specified mortality level of HIV in the study population, but on the regional mortality where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to > 1% of deaths due to HIV/AIDS (malaria), LOW around 0.1%, VERY LOW < 0.01%.<sup>1</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10003) [Is this a region of high malaria mortality?]**

The answer to this question should be decided by the project office prior to the VA interview. The high mortality of malaria is not based on a specified mortality of malaria in the study population, but on the regional prevalence where the population is located. Typically, all countries in East and Southern Africa are classified as high mortality and the rest of the regions in AFRO, SEARO, WPRO and PAHO as low or very low mortality. HIGH corresponds to > 1% of deaths, LOW around 0.1% and VERY LOW < 0.01%.<sup>1</sup> Filling in during the interview is not mandatory; the project office may make this question hidden to the interviewers.

#### **(Id10004) [During which season did (s)he die?]**

You will be given list of months classified as wet or dry. Select wet or dry according to the list provided.

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<sup>1</sup> Streatfield PK et al. Malaria mortality in Africa and Asia: evidence from INDEPTH health and demographic surveillance system sites. *Glob Health Action*. 2014; 7: 25369.

## **Information on the respondent and background about interview**

### **(Id10007) [What is the name of VA respondent?]**

Record the reported name of the respondent. You may adopt a standard format for reporting names (e.g. first name, surname).

### **(Id10007a) [What is the sex of the VA respondent?]**

Record the sex of the respondent as female, male or ambiguous/intersex.

### **(Id10008) What is your/the respondent's relationship to the deceased?**

First verify if the respondent is a family member, and only if it is not a family member choose from the other response categories, like "health worker", "public official" or "another relationship". Only one response box can be selected. Select the appropriate box which represents the relationship reported by the respondent.

### **(Id10009) Did you/the respondent live with the deceased in the period leading to her/his death?**

Select the appropriate response.

**NOTE:** Unless a specific timescale is specified, the questions refer generally to the time period "during the illness leading to death". Some conditions (e.g. breathing difficulties in chronic obstructive pulmonary disease) may be experienced consistently for a long time, eventually leading to death. Other conditions or illnesses may have shown symptoms in the past, but if the person recovered from these symptoms prior to the death, they are not likely related to the death.

### **(Id10010) [Name of the VA interviewer]**

Record the name of the main VA interviewer here. You may adopt a standard format for reporting names (e.g. first name, surname).

### **(Id10010a) [Age of VA interviewer]**

Record the age of the main VA interviewer here.

### **(Id10010b) [Sex of VA interviewer]**

Record the sex of the main VA interviewer as female, male or ambiguous/intersex.

### **(Id10010c) [ID of VA interviewer]**

Record a unique identifier code for the main VA interviewer. The interviewer ID can have numbers and letters. The project office should maintain a listing of the interviewer names and unique identifier codes.

### **(Id10011) [Time of the start of the interview]**

Record the time the interview started. Remember to select "am" or "pm" to ensure that you have the correct time. In the standard ODK programming, this item is hidden from

interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

**(Id10012) [Date of interview]**

Record the date of interview. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK. In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.

**(Id10013) [Did the respondent give consent]**

Select the appropriate response. If the respondent did not give consent, close the interview here, and record the time the interview was completed.

## Information about the deceased and vital registration

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### Information on the Deceased

**(Id10017) What was the first or given name(s) of the deceased?**

**(Id10018) What was the surname (or family name) of the deceased? What was the surname or family name(s) of the deceased?**

Verify the name(s) of the deceased in the paperwork on the assigned verbal autopsy case with what is reported by the respondent. If it is inconsistent, report this to the supervisor. If the name is consistent, record the name (if using paper form ensure it is legible). In Id10017 you are asked for the first or given name(s) of the deceased. In Id10018 you are asked for the surname (or family name) of the deceased.

**(Id10019) What was the sex of the deceased?**

Verify the biological sex of the deceased in list provided by the Supervisor and that reported by the respondent. If it is inconsistent, report to the supervisor. Make sure you select the correct box. If you select the wrong box, the cause of death could be incorrect. For example, if the deceased is a female but you select the male box, all questions specific to female deaths, including pregnancy, would be skipped and this could lead to an incorrect cause of death. If the sex is not typically male or female, select “ambiguous genitalia/intersex”. This selection may be the appropriate choice if the deceased had rare condition in which a person's external genitals do not appear to be typically either male or female. In such cases, the genitals may not be well-formed or the person may have characteristics of both sexes. Add a note in the open ended narrative section with any details the respondent provides.

**(Id10020) Is the date of birth known?**

If you do not know the full date of birth, select the option “No”; you will then skip the next question on date of birth (Id10021) to specify the date – and jump to the question on knowing

the date of death (Id10022). This happens automatically in ODK. In some cases, particularly for elderly adults, the use of community calendars of significant historical events may facilitate the approximation of a year of birth.

If the response is "YES", complete the date of birth.

**(Id10021) When was the deceased born?**

Record the date of birth. The format for date is in day, month, year (dd/mm/yyyy). This will be a calendar format for ODK.

**(Id10022) Is the date of death known?**

The list of deaths obtained in the paperwork on the assigned verbal autopsy case should have this information but the question should also be asked of respondents.

**NOTE:** For ODK you will need to have the full date of death to enter it. If you do not have the full date of death or the interviewee refuses, you should select "NO". Then in ODK you will be asked an additional question about the year of death. Fill in the year of death in four digits. For the paper version of the questionnaire, if they are unsure of the date enter the year of death if known.

**(Id10023) When did (s)he die?**

The death information from the paperwork on the assigned verbal autopsy should have this information. You should still ask the respondent and then record their response for the date of death using the day/month/year (dd/mm/yyyy) format. This will be a calendar format for ODK so you will need to put in the full date. For the paper questionnaire, you will fill in the boxes provided. If they are unsure of the exact date, record the year of death.

If you have recorded the full date of birth and date of death, the electronic device will automatically select the questionnaire corresponding to one of the three age groups: neonate, child or adult. **Therefore, be very careful in completing the full date of birth and date of death. If you make a mistake in the full date of birth or death, you will fill in the wrong questionnaire.**

**(age\_group): [What age group corresponds to the deceased?]**

This item applies for the electronic data collection format only. If you were unable to complete the full date of birth or the full date death, you will be forced to select a questionnaire corresponding to the three age groups: neonate, child or adult. Select the age group of the deceased, based on your assessment of the age of the deceased. **Select this option very carefully.** If you make a mistake in the age group, important questions will be skipped because some sections of questionnaire depend on the age group to determine the questions asked. Note that this question is used to determine which sequence of questions to use. This is a required question. If the respondent does not know the exact age, enter the best estimate.

**(age\_adult): [Enter adult's age in years:]**

If you have selected the adult questionnaire you have to enter the age in years. A valid response is between 12–120 years. If the response was more than 120 years, confirm the response and enter “120”.

**(Id10058) Where did the deceased die?**

Record the site of death by selecting the appropriate box.

**(Id10051) [Is there a need to collect additional demographic data on the deceased?]**

The questions from Id10051 to Id10073 are related to citizenship and socio-economic status and are not required for assessing causes of death. These are optional questions and depend on the context. Id10051 should be determined by the coordinator of the data collection activity and determined by the context in which VA is being conducted. Select "YES/NO". If you choose "NO", this question allows to skip asking details about the place of residence, education, and family. If "YES", proceed with the next question. If "NO", skip to Id10069. Note that irrespective of the answer to Id10051, the question on marital status (Id10059) will always be asked for adults.

**(Id10052) What was her/his citizenship/nationality?**

Select the appropriate response according to the local definitions for citizenship. A naturalized citizen is an individual that was born elsewhere but now has become a citizen of the country. A foreign national is an individual who is not a citizen of the host country in which s/he is residing or temporarily staying.

**(Id10053) What was her/his ethnicity?**

Record the reported ethnicity. Do not probe too much if the respondent is uncomfortable. Enter “-”, if this information is not available or if the respondent is not happy to report the ethnicity leave this blank.

**(Id10054) What was her/his place of birth?**

Record the reported place of birth. Record the reported place of birth. Specify here village and district. A question on the facility and circumstances will be asked later. Enter a “-” if this information is not available or unknown.

**(Id10055) What was her/his place of usual residence? (the place where the person lived most of the year).**

Specify country, province, district, and city, town, or village.

**(Id10057) Where did the death occur? (specify country, province, district, village)**

You can fill in the city/town instead of village if more applicable.

**(Id10059) What was her/his marital status?**

Select the appropriate response. A 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. Note that setting specific terms may be relevant and where possible use local terminology to ascertain marital status. **(Id10060\_check) [Is the date of marriage available?]**

**(Id10060) What was the date of marriage?**

If the date of marriage is available, record the date of the marriage.

**(Id10063) What was her/his highest level of schooling?**

Select the appropriate response.

**(Id10064) Was (s)he able to read and/or write?**

Select appropriate response. Answer "YES" also if only one of either reading or writing was known to the deceased.

**(Id10065) What was her/his economic activity status in year prior to death?**

The deceased might have had several activities. Choose the one that was probably true for most of the year preceding illness and death. Select appropriate response. If the response is "Mainly employed", proceed with the next question. Otherwise, skip to Id10069.

**(Id10066) What was her/his occupation, that is, what kind of work did (s)he mainly do?**

This question will only be asked if the response to Id10065 is "Mainly employed". Record the appropriate response.

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**Civil registration numbers**

**(Id10069) [Is there a need to collect civil registration numbers on the deceased?]**

This question should be determined by the coordinator of the data collection activity and determined by the context in which VA is being conducted. If "YES", ask to see the certificate or death registration paperwork. You will use this paperwork to complete the next questions and fill in any information that is available. If "NO", skip to Id10077. Site programmers could make this question hidden to the interviewers if desired.

**(Id10069\_a) Do you have a Death Certificate from the Civil Registry?**

Ask to see the certificate or death registration paperwork. Ask to see the certificate or death registration paperwork. Interviewers should be familiarized with the local civil registry authority and the appropriate death registration form(s) that contain the relevant death registration information as requested in this section.

If "YES" and the paperwork is available, continue with Id10070–Id10073. If the paperwork is not available, skip to Id10077.

**(Id10070) [Death registration number/certificate]**

Record the registration or certificate number. Note that respondents may have a “death notification” skip 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.

**(Id10071) [Is the date of registration available? / Date of registration in day/month/year (dd/mm/yyyy)]**

If the date of registration is available, enter day, month, and year.

**(Id10072) [Place of registration:]**

Record the full details of the place in regard to the name of the village / town / municipality where the death was registered. Enter “-”, if this information is not available. The project site may add a drop-down list of location options if using electronic data collection.

**(Id10073) [National identification number of deceased]**

Enter “-”, if this information is not available.

## **History of injuries/accidents**

This section is specifically designed to enquire and record information and details in regard to the death being caused by an injury. In general, deaths from injuries, whether accidental or intentional, are reported to the police, and subsequently follow a forensic/coronial process for determining the cause of death. The VA process using household enquiry may or may not be considered necessary or appropriate for ascertaining the cause, depending on the government directives on this subject. Nevertheless, a set of questions have been included in the questionnaire, and should be enquired from respondents (following the sequence and skip patterns as below), as permitted by the government authorities. Finally, wherever possible, the official police or medico-legal opinion as to the cause of death should be sought from local authorities after the completion of VA interview, and added to this VA questionnaire, to enable the accurate ascertainment of cause of death.

**(Id10077) Did (s)he suffer from any injury or accident that led to her/his death?**

This is an opening question to check whether the death was associated with any injury or accident. If the response is "YES", proceed with the following questions. 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.

If the answer is "NO", then skip to Id10120\_unit. However, if the answer is "DK/Ref", the interviewer should probe further and continue with the subsequent questions.

**(Id10079) Was it a road traffic accident?**

Road traffic accidents are the most common causes of deaths from injuries in developing countries. It may be useful to clarify with respondents when asking this question that you do not need to have been in a vehicle to have suffered a road traffic injury, for example for deaths of pedestrians. If the response to Id10079 is "YES", questions Id10080 and Id10081 should be asked, then questions Id10082–Id10097 should be skipped. If the answer is "NO/DK/Ref", then skip to Id10082.

**(Id10080) What was his/(s)her role in the road traffic accident?**

Check whether the deceased was a pedestrian, driver or any other role. Details of this nature are essential for accurate coding of the cause of death. Select the appropriate box based on the response.

**(Id10081) What was the counterpart that was hit in the road traffic accident?**

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. Select the appropriate box based on the response. Go to Id10098.

**(Id10082) Was (s)he injured in a non-road transport accident?**

Enquire and record if the death was due to an accident in transport other than on the road, e.g. fatal injury from train / boat / aircraft accident. If "YES", record the nature of the accident and the injuries sustained in the free text section of the questionnaire.

**(Id10083) Was (s)he injured in a fall?**

If the response is "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.

**(Id10084) Was there any poisoning?**

If the death was due to poisoning from pesticides, kerosene, or any other chemicals, record "YES" here, and note the nature of the poison in the narrative section. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. Poisoning from snakebite or animal sting, etc. is not to be included here. Enquire if the poisoning was suicidal, and ensure the correct response to question Id10099.

**(Id10085) Did (s)he die of drowning?**

If the response is "YES", record the location where the drowning occurred – river/lake/sea/swimming pool – 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.

**(Id10086) Was (s)he injured by a bite or sting by a venomous animal?**

Record "YES" if the injury was due to snake bite or any other poisonous insect. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence. If "YES", skip to Id10088.

**(Id10087) Was (s)he injured by an animal or insect (non-venomous)?**

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

If "NO/DK/Ref" skip to Id10089.

**(Id10088) What was the animal / insect?**

Select dog, snake, insect, scorpion, or other. If not known, select "DK".

**(Id10089) Was (s)he injured by burns/fire?**

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.

**(Id10090) Was (s)he subject to violence (suicide, homicide, abuse)?**

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.

**NOTE:** For adult questionnaires this question includes suicide as a form of violence.

**(Id10091) Was (s)he injured by a fire arm?**

Use the local term for firearms, and record the response.

**(Id10092) Was (s)he stabbed, cut or pierced?**

The use of sharp instruments such as knife or sword should be recorded here.

**(Id10093) Was (s)he strangled?**

Use the local term for choking of the neck by force, whether by hand, rope or other object.

**(Id10094): Was (s)he injured by a blunt force?**

Injury caused by blunt force such as a stick or a heavy object, which does not cause direct external injury but can be sufficiently serious to cause fractures, internal bleeding and death. Explain the meaning of blunt force, and record the response accordingly.

**(Id10095) Was (s)he injured by a force of nature?**

Forces of nature include lightning, flood, earthquake etc. If the response is "YES", then record the force of nature in the narrative section of the questionnaire.

**(Id10096) Was it electrocution?**

If the death was due to electric shock, record "YES" here. This includes accidents and cases where it is unknown if it was an accident or whether there was intentional violence.

**(Id10097) Did (s)he suffer from any other injury?**

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.

**(Id10098) Was the injury accidental?**

This question identifies whether the injury was unintentional. If "YES", go to Id10120.

**(Id10099) Was the injury self-inflicted?**

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. If "YES", go to Id10120.

**(Id10100) Was the injury intentionally inflicted by someone else?**

Enquire if the injury or accident was caused by an act of violence either directly by another person or by a circumstance intentionally created by another person (e.g. act of terrorism).

## **Health history**

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### **Duration of illness**

**(Id10120\_unit) For how long was (s)he ill before death?**

Select the best unit according to the response – days, months, or years. If less than 24 hours, select days and enter "0". If the response was greater than 30 days, ask the respondent to report in either months or years. If the response was greater than 11 months, ask the respondent to report in years. A valid response is less than the age at death.

**(Id10123) Did (s)he die suddenly?**

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.

### **Medical history associated with final illness**

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Questions in this section are asking about the diseases that were known to be present at the time of death. These questions are not about the previous histories of illness unrelated to the illness that lead to the death. For example, someone might have had malaria, dengue, or

measles in the past but they may not be the cause of death. However, chronic conditions such as diabetes, hypertension, tuberculosis, cancer, chronic obstructive lung disease, etc. could have a bearing on the final diagnosis of the cause of death. Hence, proceed carefully through the entire list, and in the event of a positive response to any of the questions below, ask for any documentary evidence of the diagnosis in the form of a clinical note, laboratory or imaging report, prescription, hospital discharge card, etc. Also attempt to ascertain the identity and address of the physician/ health facility where the diagnosis was established, and note the details in Section 9.

**(Id10125) Was there any diagnosis by a physician or health worker of tuberculosis?**

Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10126) Was an HIV test ever positive?**

Ask if the deceased had ever been tested for HIV, and if so, whether the test was ever positive.

**(Id10127) Was there any diagnosis by a health professional of AIDS?**

Ask whether the deceased was ever diagnosed to have AIDS, the final illness in HIV that leads to death. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10128) Did (s)he have a recent positive test by a health professional for malaria?**

Ask whether a malaria test (dipstick or blood slide) was done during the illness that lead to death and if “yes”, was it 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. If the response to this question is "YES", skip to Id10130.

**(Id10129) Did (s)he have a recent negative test by a health professional for malaria?**

Ask whether a malaria test (dipstick or blood slide) was done during the illness that lead to death and if “yes” was it 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.

**(Id10130) Was there any diagnosis by a health professional of dengue fever?**

Ask whether a diagnosis of dengue was done during the illness that lead to death. There may be a local term for dengue fever. If there is one, ensure that it is mentioned in the translated questionnaire, and use that term to ask about dengue fever. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10131) Was there any diagnosis by a health professional of measles?**

Ask whether a diagnosis of measles was done during the illness that led to death. There may be a local term for measles. If there is one, ensure that it is mentioned in the translated questionnaire, and use that term to ask about measles. Remind the respondent that we are

asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10132) Was there any diagnosis by a health professional of high blood pressure?**

Ask whether the deceased was ever diagnosed to have high blood pressure by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for hypertension. If there is one, ensure that it is mentioned in the translated questionnaire, and use that term to probe.

**(Id10133) Was there any diagnosis by a health professional of heart disease?**

Ask whether the deceased was ever diagnosed to have heart disease by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

**(Id10134) Was there any diagnosis by a health professional of diabetes?**

Ask whether the deceased was diagnosed to have diabetes by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for diabetes. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10135) Was there any diagnosis by a physician or health worker of asthma?**

Ask whether the deceased was diagnosed to have asthma by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for asthma. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe. You may have to demonstrate how a patient with asthma will struggle to breath.

**(Id10136) Was there any diagnosis by a health professional of epilepsy?**

Ask whether the deceased was diagnosed to have epilepsy by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for epilepsy. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe. You may have to demonstrate an episode of epilepsy

**(Id10137) Was there any diagnosis by a health professional of cancer?**

Ask whether the deceased was ever diagnosed to have cancer by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for cancer. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10138) Was there any diagnosis by a health professional of Chronic Obstructive Pulmonary Disease (COPD)?**

Ask whether the deceased was diagnosed to have COPD by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness. Persons with COPD have frequent spells of breathlessness along with bouts of cough and sputum, often requiring medical attention for relief and treatment.

**(Id10139) Was there any diagnosis by a health professional of dementia?**

Ask whether the deceased was ever diagnosed to have dementia by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

You may need to find out the local term for dementia. This is a condition where the person becomes more forgetful usually this happens for old people. If there is a local term, ensure that it is mentioned in the translated questionnaire, and use the local term to probe

**(Id10140) Was there any diagnosis by a physician or health worker of depression?**

Ask whether the deceased was ever diagnosed to have depression by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

You may need to find out the local term for depression. This is a condition where the person becomes more withdrawn from the family and community, isolated, less communicative and unhappy. If there is a local term for depression, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10141) Was there any diagnosis by a health professional of stroke?**

Ask whether the deceased was diagnosed to have stroke by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for stroke. This is a condition where the person suddenly becomes unconscious and/or have paralysis of one side of the body. If there is a local term for stroke, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

**(Id10142) Was there any diagnosis by a health professional of sickle cell disease?**

Ask whether the deceased was ever diagnosed to have sickle cell disease on by a physician or any other health worker. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for sickle disease. This is a condition where the person has thinning of blood and becomes ill repeatedly and diagnosed by examining the blood. If there is a local term, ensure that it is mentioned in the translated questionnaire and use the local term to probe.

**(Id10143) Was there any diagnosis by a health professional of kidney disease?**

Ask whether the deceased was diagnosed to have kidney disease on by a physician or any other health worker recently or during the final illness. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for kidney disease. If there is one, ensure that it is mentioned in the translated questionnaire and use the local term to probe.

**(Id10144) Was there any diagnosis by a health professional of liver disease?**

Ask whether the deceased was diagnosed to have liver disease on by a physician or any other health worker recently or during the final illness. Remind the respondent that we are asking for the diagnosis assessed by a doctor, health worker, or other health professional during the final illness.

There may be a local term for liver disease. If there is one, ensure that it is mentioned in the translated questionnaire, and use the local term to probe.

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**General signs and symptoms associated with final illness**

**(Id10147) Did (s)he have a fever?**

Fever is a term used when the body feels abnormally warm or hot to touch, and/or when a thermometer records an abnormally high temperature. Fever almost always results from infections, and is associated with other symptoms. 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.

If "NO/DK/Ref", skip to Id10152.

**(Id10148\_units) How long did the fever last?**

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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10149) Did the fever continue until death?**

This is important to relate the fever to the actual cause of death.

**(Id10150) How severe was the fever?**

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. Select the appropriate response.

**(Id10151) What was the pattern of the fever?**

Some infections produce characteristics patterns of fever – continuous, or on and off; or fever only at night. 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.

**(Id10152) Did (s)he have night sweats?**

In some illness like Tuberculosis or some cancers, the person can have excessive sweating at night, which is often noticed by wetness of the bed sheet. In case necessary, mention this characteristic i.e. wetness of the bed sheet, to denote whether there was unusual excessive sweating at nights.

**(Id10153) Did (s)he have a cough?**

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. Ask this question with care and double check a negative response, as this will lead to a skip of all other questions on cough. If there is a positive response for cough, care should be taken in following up closely with the subsequent questions characterising the cough.

If "NO/DK/Ref", skip to Id10159.

**(Id10154\_units) For how long did (s)he have a cough?**

The duration of cough helps determine whether the respiratory condition was the principal illness leading to death, when coughing 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. Probe carefully and if necessary double check to ensure an accurate response to the duration of cough during the period leading to death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10155) Was the cough productive, with sputum?**

A person may have just dry cough. When someone is suffering from diseases like pneumonia or TB, or chronic obstructive lung disease, 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 coloured (pus), or even blood that may be dark brown in colour. There is often a local term for phlegm, which should be used to probe, and record the response.

**(Id10156) Was the cough very severe?**

The severity of the cough refers to its prominence among the symptoms present in the deceased. It is often difficult to define severity. However, 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.

**(Id10157) Did (s)he cough up blood?**

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.

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. Once this is clarified, record the response accordingly.

**(Id10159) Did (s)he have any difficulty breathing?**

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.

This is a filter question, hence the interviewer should clarify to the respondent the above descriptions/demonstrations of difficulty, and take care to ensure that there is no false negative response.

If "NO/DK/Ref", skip to Id10166.

**(Id10161\_unit) For how long did the difficult breathing last?**

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.

Select the best unit according to the response – days, months, or years. If less than 24 hours, select days and enter “0”. If the response was greater than 30 days, ask the respondent to report in either months or years. If the response was greater than 11 months, ask the respondent to report in years. A valid response is less than the age at death.

**(Id10165) Was the difficulty continuous or on and off?**

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.

**(Id10166) During the illness that led to death, did (s)he have fast breathing?**

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 is usually a subjective observation of the respondent, so record the response as told, without further probing.

IF "NO/DK/Ref", skip to Id10168.

**(Id10167\_units) How long did the fast breathing last?**

Usually the duration of fast breathing in the case of pneumonia will be similar to the duration of the final illness. If the respondent reports a longer duration of fast breathing than final illness clarify that you are asking about the fast breathing during the final illness.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10168) Did (s)he have breathlessness?**

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.

Take care to clarify these aspects to the respondent as may be required, and record the response carefully.

If "NO/DK/Ref", skip to Id10173\_a.

**(Id10169\_units) How long did s(he) have breathlessness?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10170) Was (s)he unable to carry out daily routines due to breathlessness?**

Ask whether the deceased was not able to do things like taking a bath, dressing up, or walking a short distance, because of the breathlessness. A person with severe breathlessness will struggle to do these daily routines and will need assistance from someone.

**NOTE:** This question is asked with a negative intent. Take care in recording the response accurately.

A POSITIVE RESPONSE INDICATES THAT THE PERSON WAS ILL.

A NEGATIVE RESPONSE INDICATES THAT THE PERSON HAD NO PROBLEM OF THIS NATURE.

**(Id10171) Was (s)he breathless while lying flat?**

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.

**(Id10173\_a) During the illness that led to death did (s)he have wheezing?**

Wheezing is a whistling sound that comes from the chest while breathing out. The VA interviewer should be trained to demonstrate wheezing to the respondent. Play audio file if available.

**(Id10174) Did (s)he have chest pain?**

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.

If necessary, clarify what is meant by chest pain according to the types above, and record the response accordingly.

If "NO/DK/Ref", skip to Id10181.

**(Id10175) Was the chest pain severe?**

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.

**(Id10176) How many days before death did (s)he have chest pain?**

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. Record the response in number of days; if less than 1 day or 24 hours, enter 0 days. Use 1 week = 7 days to determine the number of days. For don't know, enter "99". For refused, enter "88". A valid response is between 0 and 99. If the answer happens to be 88 days, enter instead "87" so that the response is not automatically coded as refused to answer.

**(Id10178\_unit) How long did the chest pain last?**

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. Select the best unit according to the response – minutes, hours, or days. A valid

response is between 0–59 minutes, 1–23 hours, or days less than response for Id10176: How many days before death did (s)he have chest pain. Use 1 week = 7 days. Note that this question is not used by the automated analysis software, but it is important for physician review.

**(Id10181) Did (s)he have more frequent loose or liquid stools than usual?**

Ask the respondent about her/his understanding of what is diarrhoea (having more frequent loose or liquid stools than usual); if unclear or wrong, explain to the respondent what is diarrhoea. The frequent passage of loose or watery stools, with or without blood, is commonly known as diarrhoea. 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.

If "NO/DK/Ref", skip to Id10186.

**(Id10182\_units) How long did (s)he have frequent loose or liquid stools?**

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 coeliac disease, the affected individual could have diarrhoea over prolonged periods extending over weeks or months. On the other hand, it may be an episode of diarrhoea immediately preceding death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10186) At any time during the final illness was there blood in the stools?**

This question is to be asked of every respondent. It may be related to the diarrhoea, if present; but for adults, it may be independent of diarrhoea, 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 diarrhoea.

If "NO/DK/Ref", skip to Id10188.

**(Id10187) Was there blood in the stool up until death?**

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.

**(Id10188) Did (s)he vomit?**

Vomiting is a well-recognised symptom common to abdominal disease, but can occur in other conditions such as meningitis and other systemic infectious disease.

**(Id10189) To clarify: Did (s)he vomit in the week preceding the death?**

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.

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.

If "NO/DK/Ref", skip to Id10193. However, if the response to Id10188 was "YES" proceed to Id10190\_units.

**(Id10190\_units) How long before death did (s)he vomit?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter "0" days. Use 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".

Note that this question should be asked in case of a "YES" response to either Id10188 or Id10189.

**(Id10191) Was there blood in the vomit?**

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.

**NOTE:** This question is asked when there is a positive response to either Id10188 or Id10189.

**(Id10192) Was the vomit black?**

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 colour to a blackish, semisolid substance. There may be more than one episode of such vomiting of blackish substance.

**NOTE:** This question is asked when there is a positive response to either Id10188 or Id10189.

**(Id10193) Did (s)he have any belly (abdominal) problem?**

Explain to the respondent that problems could include pain, protruding abdomen or a mass. Note that Id10194, Id10200, and Id10204 will be asked regardless of the answer to this question for clarity.

**(Id10194) Did (s)he have belly (abdominal) pain?**

Both Id10193 and Id10194 are required for the automated analysis software. Thus, this question will be asked regardless of the response to the previous question. 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. 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.

There may be a local term to describe it. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If the response is "NO/DK/Ref", skip to Id10200.

**(Id10195) Was the belly (abdominal) pain severe?**

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. 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.

**(Id10196\_unit) For how long did (s)he have belly (abdominal) pain?**

The time relationship between the symptom and the event of death is important to determine the cause of death. Select the best unit according to the response – hours, days, or months. A valid response is between 0–23 hours, 1–30 days, or 1–60 months. Use 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".

**(Id10199) Was the pain in the upper or lower belly (abdomen)?**

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 /lower half of the abdomen and ask whether the deceased pointed to that area when (s)he had the pain.

**(Id10200) Did (s)he have a more than usually protruding belly (abdomen)?**

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.

If "NO/DK/Ref", skip to Id10204.

**(Id10201\_unit) For how long before death did (s)he have a more than usually protruding belly (abdomen)?**

Distension of abdomen due to obstruction of intestine starts rapidly and last for few days because the person 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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10203) How rapidly did (s)he develop the protruding belly (abdomen)?**

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 liver failure, cancers and heart failure. Clarify and record the response.

**(Id10204) Did (s)he have any mass in the belly (abdomen)?**

Abdominal mass is a localized swelling or enlargement in one area of the abdomen. This may not be seen visibly by respondents, and may only be reported by the deceased to his relatives, as a sense of heaviness or discomfort. Often, there could have been an attempt to seek medical care, which could be recalled by relatives. In which case, there is potential for availability of a diagnosis which may be recalled by the respondent. If there is a positive response, probe carefully, and remember to come back to this issue during enquiry about health records in Section 9, and record all relevant details on health care access and diagnostic information in that section.

If the answer is "NO/DK/Ref", skip to Id10207.

**(Id10205\_unit) For how long did (s)he have a mass in the belly (abdomen)?**

The duration for which the mass was present could help guide the diagnosis. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10207) Did (s)he have a severe headache?**

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.

There may be a local term to describe it. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

**(Id10208) Did (s)he have a stiff neck during illness that led to death?**

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. It is an important feature of meningitis (a brain infection), particularly in children. This sign may not be easily observed or recalled by the respondent. If required, clarify to the respondent the description as provided above, and record the response.

If "NO/DK/Ref", skip to Id10210.

**(Id10209\_units) How long before death did (s)he have stiff neck?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10210) Did (s)he have a painful neck during the illness that led to death?**

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.

If "NO/DK/Ref", skip to Id10212.

**(Id10211\_units) How long before death did (s)he have a painful neck?**

Ask and record the duration of painful neck during the illness preceding death.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10212) Did (s)he have mental confusion?**

“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 losing consciousness. In fact, there is no associated impairment of consciousness.

“Confusion” is an important sign of chronic conditions causing dementia (e.g. Alzheimer’s disease; long term effect following paralysis; etc.). This question only pertains to long standing mental confusion lasting several months or years. Clarify these points with the respondent, and record the response accordingly.

If "NO/DK/Ref", skip to Id10214.

**(Id10213\_units) How long did (s)he have mental confusion?**

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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10214) Was (s)he unconscious during the illness that led to death?**

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.

There may be a local term to describe unconsciousness. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10219.

**(Id10215) Was (s)he unconscious for more than 24 hours before death?**

This question is like a repetition of the previous question, but is asked to clarify the response; and more importantly to clarify whether the duration of unconsciousness was more than 1 day, which is important to establish the diagnosis.

If "NO/DK/Ref", skip to Id10219.

**(Id10217) Did the unconsciousness start suddenly, quickly (at least within a single day)?**

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. Clarify this aspect with the respondent as required, and record the response.

**(Id10218) Did the unconsciousness continue until death?**

This question confirms the direct relationship between loss of consciousness lasting more than 24 hours and continuing till death, as a feature of the terminal illness that caused death.

**(Id10219) Did (s)he have convulsions?**

Convulsions are rapid twitching or jerking movements of parts of the limbs or sometimes entire limbs, which frequently subsides with the loss of consciousness. The common term for convulsions is fits, and there is often a local term for such movements. 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.

If necessary, demonstrate the convulsive movements of limbs (and eyeballs), and record the response accordingly.

If "NO/DK/Ref", skip to Id10223.

**(Id10221) For how many minutes did the convulsions last?**

Record the number of minutes the respondent reports for the duration of the convulsion. The answer could be given in another unit, but for data entry use minutes. Less than 1 minute = "0". 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.

**(Id10222) Did (s)he become unconscious immediately after the convulsions?**

Loss of consciousness usually occurs after a generalised convulsion, so a positive response will confirm the occurrence, and thus help aid the diagnosis.

**(Id10223) Did (s)he have any urine problems?**

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.

If "NO/DK/Ref", skip to Id10227.

**(Id10225) Did (s)he go to urinate more often than usual?**

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.

**(Id10226) During the final illness did (s)he ever pass blood in the urine?**

Passage of blood in the urine is a major feature of urinary bladder or kidney cancer. This can also happen in some parasitic infections. There is passage of frank (red) blood and would be readily recognised by the patient, and reported to the relatives, and possibly leading to seeking of health care. Hence, if this symptom was present, there is a good likelihood of a positive response.

**(Id10224) Did (s)he stop urinating?**

This means the deceased stopped urinating. 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. Clarify what is meant by stoppage of urine, and record the response as told.

**NOTE:** It is possible that an individual both urinated more often than usual (Id10225) AND stopped urinating; both conditions could exist at different times.

**(Id10227) Did (s)he have any sores or ulcers anywhere on the body?**

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. Clarify these points with the respondent, and record the response accordingly.

There may be local terms to describe it. Ensure that the local terms are included in the translated version of the questionnaire, and use the local terms to probe.

**(Id10228) Did (s)he have sores?**

Sores are chronic skin infections 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 bed ridden state. Sometimes, they can appear as non-healing conditions as a result of poor health, with a weak immune system, as may occur in diabetes, or in bed-ridden patients. In adolescents and adults, they may initially appear as blisters or raised patches of skin with fluid in them.

If "NO/DK/Ref", skip to Id10230.

**(Id10229) Did the sores have clear fluid or pus?**

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, the chronic pressure sore may get infected and be filled with pus.

**(Id10230) Did (s)he have an ulcer (pit) on the foot?**

This item specifically identifies whether the ulcer was located on the foot, and is asked even if there were negative responses to previous questions on sores or ulcers.

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.

If "NO/DK/Ref", skip to Id10233.

**(Id10231) Did the ulcer on the foot ooze pus?**

The presence of pus in the non-healing ulcer on the foot is an important diagnostic sign. Pus is a thick fluid which could be green or yellow in colour, which continually accumulates on the floor of the ulcer.

If "NO/DK/Ref", skip to Id10233.

**(Id10232\_units) How long did the ulcer on the foot ooze pus?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter "0" days. Use 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".

**(Id10233) During the illness that led to death, did (s)he have any skin rash?**

"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.

There may be a local term to describe skin rash. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10237.

**(Id10234) For how many days did (s)he have the skin rash?**

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. 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. 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 days, confirm the response and enter "98". If the answer to duration happens to be 88 days, enter instead "87" so that the response is not automatically coded as refused to answer.

**(Id10235) Where was the rash?**

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. Check the appropriate boxes, multiple responses are allowed.

- "Trunk" refers to the chest/back/abdominal area
- "Extremities" refers to the arms and legs.

**(Id10236) Did (s)he have measles rash (use local term)?**

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.

**(Id10237) Did (s)he ever have shingles or herpes zoster?**

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. This is quite rare. Ask the respondent whether the deceased complained of a localised patch of rash with burning pain.

**(Id10238) During the illness that led to death, did her/his skin flake off in patches?**

In a person with long standing malnutrition, the skin becomes extremely dry and tends to break away or peel off in patches. This is a readily recognised sign when present, and is a useful diagnostic sign.

**(Id10241) During the illness that led to death, did (s)he bleed from anywhere?**

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.

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 (through the skin, gum, mouth, nose, anus), or under the skin, or into internal joints and organs.

If "NO/DK/Ref", skip to Id10243.

**(Id10242) Did (s)he bleed from the nose, mouth or anus?**

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.

**(Id10243) Did (s)he have noticeable weight loss?**

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 3 months or so is an important sign. Clarify these aspects with the respondent to confirm or exclude weight loss, and record the response accordingly.

Irrespective of whether the response is "YES/NO/DK/Ref", the next question should be asked.

**(Id10244) Was (s)he severely thin or wasted?**

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.

**(Id10245) During the illness that led to death, did (s)he have a whitish rash inside the mouth or on the tongue?**

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.

There may be a local term to describe rash. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

**(Id10246) Did (s)he have stiffness of the whole body or was unable to open the mouth?**

Certain nervous system infections result in complete stiffness and rigidity 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.

**(Id10247) Did (s)he have puffiness of the face?**

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 an 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.

If "NO/DK/Ref", skip to Id10249.

**(Id10248\_units) How long did (s)he have puffiness of the face?**

The duration of puffiness of face 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. Ask and record the duration of puffiness of face during the terminal illness.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10249) During the illness that led to death, did (s)he have swollen legs or feet?**

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.

If "NO/DK/Ref", skip to Id10252.

**(Id10250\_units) How long did the swelling last?**

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.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10251) Did (s)he have both feet swollen?**

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.

**(Id10252) Did (s)he have general puffiness all over her/his body?**

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.

**(Id10253) Did (s)he have any lumps?**

Lumps are small, solid and painless swellings that are sometimes observed near the armpit, neck or groin. They are seen in association with certain types of infections or rarely, in certain cancers. In some instances, the lumps may be present in multiple locations and on both sides, indicative of a more generalised form of disease. Unless the lumps are rather large, or the patient is in a bed ridden state, they may not be observed by the respondent.

There may be a local term to describe lumps. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If "NO/DK/Ref", skip to Id10258.

**(Id10254) Did (s)he have any lumps or lesions in the mouth?**

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. Probe carefully if there is a positive response and record the response accordingly.

**(Id10255) Did (s)he have any lumps on the neck?**

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.

**(Id10256) Did (s)he have any lumps on the armpit?**

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.

**(Id10257) Did (s)he have any lumps on the groin?**

This question is to confirm the presence of lumps in the groin, which is the junction between the body and the lower limb.

**(Id10258) Was (s)he in any way paralysed?**

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.

If "NO/DK/Ref", skip to Id10261.

**(Id10259) Did (s)he have paralysis of only one side of the body?**

Paralysis of one side of the body (right arm and leg; or left arm and leg) is a classical feature of obstruction of the blood supply to the brain, which is one of the common causes of death among adults and the elderly in most populations. Paralysis of one side of the body is a very clearly recognizable sign, and is readily recalled by relatives of the deceased. Several communities even have a local term to describe this condition. Clarify the presence of this sign, and record the response accordingly.

**(Id10260) Which were the limbs or body parts that were paralysed?**

It is important to confirm whether the paralysis was affecting only a particular limb, or parts of the body or the whole body. Mark the specific body parts that were observed to have been paralysed. Select all that apply.

**(Id10261) Did (s)he have difficulty swallowing?**

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. This is an important symptom, so probe carefully and try to ensure there is no false negative response.

If "NO/DK/Ref", skip to Id10264.

**(Id10262\_units) For how long before death did (s)he have difficulty swallowing?**

The duration indicates the severity and progression of this symptom. 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. Carefully elicit the duration of the symptom with probing about the onset and progression, and confirm the presence of this symptom till death, and record the response accordingly.

Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10263) Was the difficulty with swallowing with solids, liquids or both?**

In certain conditions there may be difficulty in swallowing solid or liquid only. Often however, initially, there may be difficulty only in swallowing solids, and later on, difficulty in swallowing of all types of food and drink.

**(Id10264) Did (s)he have pain upon swallowing?**

Occasionally, there may be some confusion between difficulty in swallowing and pain in swallowing, hence this question is asked in this manner. Also, 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. If necessary, clarify that this question specifically refers to pain that occurs while swallowing.

**(Id10265) Did (s)he have yellow discoloration of the eyes?**

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. There is often a local term used for this 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 colour.

If "NO/DK/Ref", skip to Id10267.

**(Id10266\_units) For how long did (s)he have the yellow discoloration?**

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. Select the best unit according to the response – days or months. A valid response is between 0–30 days or 1–60 months. For less than 1 day or 24 hours, enter “0” days. Use 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”.

**(Id10267) Did her/his hair change colour to a reddish or yellowish colour?**

In older children with black coloured hair, a change in the hair colour 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.

**(Id10268) Did (s)he look pale (thinning/lack of blood) or have pale palms, eyes or nail beds?**

Long term deficiency of the blood results in a pale, whitish appearance of the lips, tongue, and eye sac. Sometimes 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 or cancer. Pale appearance could be recognized and recalled by respondents.

**(Id10270) Did (s)he drink a lot more water than usual?**

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. In adults, increased thirst and drinking of water may be observed in individuals with severe uncontrolled diabetes.

**Check sex of the deceased (Question Id10019)**

IF FEMALE or AMBIGUOUS/INTERSEX, continue with the following section. IF MALE skip to Id10411 – “Risk factors” sub-section.

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**Signs and symptoms associated with pregnancy and women**

This section consists of questions to be asked only to women, and are targeted to identify a range of causes specific to pregnancy-related causes of death as well as cancers of reproductive tract. In many instances, the accurate answers to these questions may only be known to adult female relatives of the deceased e.g. sister, mother, mother-in-law or other relatives who lived in the same household around the time of death. When choosing the respondent for an adult female death, try to ascertain the individual who had the greatest proximity to the deceased in terms of her health condition, rather than presence within the household around the time of death. Take care to ask each question carefully, and to follow the skip patterns.

**(Id10294) Did she have any swelling or lump in the breast?**

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. Probe carefully and record the response accordingly.

**(Id10295) Did she have any ulcers (pits) in the breast?**

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. Clarify these aspects, and record all details in relevant sections of the questionnaire.

**(Id10296) Did she ever have a period or menstruate?**

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.

If "NO/DK/Ref", then skip to Id10304.

**(Id10297) When she had her period, did she have vaginal bleeding in between menstrual periods?**

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.

If "NO/DK/Ref", then skip to Id10301.

**(Id10298) Was the bleeding excessive?**

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.

**NOTE:** Questions Id10299–Id10303 have been reordered for more logical sequencing. They are listed below in the order in which they appear in the electronic questionnaire.

**(Id10301) Was there excessive vaginal bleeding in the week prior to death?**

Excessive vaginal bleeding in the week before death could be related to the terminal illness. This excessive bleeding could be related to pregnancy, labour, 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 7 days (1 week), or uses more than six well-soaked sanitary pads per day.

Clarify the term “excessive” as well as the occurrence in the few days immediately preceding death, and record the response accordingly.

**NOTE:** Questions Id10299 and Id10300 are intended for women of menopausal age – generally for women above the age of 40 years. However, it is possible that some women will

have had menopause earlier or the age of the woman is unknown. Therefore, these questions should be asked for all women.

**(Id10299) Did her menstrual period stop naturally because of menopause or removal of uterus?**

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 or due to surgical removal of the uterus. There may be a local language term or phrase for menopause, which should be used in the translated version of the questionnaire.

If the deceased has attained menopause or if the deceased's uterus was removed, one could exclude the possibility of pregnancy related deaths.

There may be a local term to describe menopause. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

If the response is "YES", go to Id10300. If "NO/DK/Ref", go to Id10302.

**(Id10302) At the time of death was her period overdue?**

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. Probe carefully and record the response.

If the response is "YES", go to Id10303. If "NO/DK/Ref", skip to Id10304.

**(Id10303) For how many weeks had her period been overdue?**

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.

Less than 1 week = 0 weeks. Use 7 days = 1 week to determine the number of weeks. 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 weeks, confirm the response and enter "98".

After this question, go to Id10304.

**(Id10300) Did she have vaginal bleeding after cessation of menstruation?**

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 recurrence of vaginal bleeding. If possible, record details provided by the respondent in the narrative section of the questionnaire. This question does not need to be asked of non-menopausal women.

After this question, go to Id10310.

**(Id10304) Did she have a sharp pain in her belly (abdomen) shortly before death?**

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, including ectopic pregnancy, are associated with acute, intense pain in the abdomen in the period leading to death, and if really intense, 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. This question does not apply to women whose menstrual period stopped naturally because of menopause or removal of uterus.

**(Id10305) Was she pregnant or in labour at the time of death?**

This question aims to determine if the deceased was pregnant at the time of death. That is, a "YES" response to this question means a foetus or baby remained in the mother's body after she died, even if she was already in labour.

Knowledge of pregnancy may be obvious after about 3 months. However, earlier than this, when the period 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.

Note that the question will be asked even following a "NO" response to Id10296 (Did she ever have a period or menstruate). This is to ensure that all pregnant women are captured, such as the case of a young woman getting pregnant before observing her first period, or in the case of a false negative response to Id10296.

If the response to Id10305 is "YES", then skip to question Id10309.

If the respondent states that she was not pregnant or that the death occurred during or after delivery when she was already not carrying the foetus/baby, record the answer to this question as "NO"; and proceed to the next question.

If the response to Id10305 is "DK/Ref", continue to the next question.

**(Id10306) Did she die within 6 weeks of delivery, abortion or miscarriage?**

In many instances, the death may have occurred during or soon after delivery, 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. A "YES" response to this question means that a foetus or baby was lost or removed or delivered (vaginally or by C-section) within 6 weeks before she died, whether the baby survived or not.

Miscarriage is broadly defined for the purpose of this interview as a natural, spontaneous failure of pregnancy, usually in the first or second trimester. Spontaneous abortion may overlap somewhat with miscarriage but usually captures later second trimester abortions. Most resource-limited countries use a 28 week cut-off for determination of stillbirth. This means that those that died before 28 weeks in utero are intrauterine fetal deaths, and when expelled are abortions. An induced abortion refers to an intervention used to terminate the pregnancy. Where necessary, clarify the terms miscarriage and abortion. Clarify the time relationship between the end of pregnancy and death, and record the response accordingly.

If the response is "YES", skip to Id10309. If "NO/DK/Ref", proceed to the next question.

**(Id10307) Did this woman die more than 6 weeks after being pregnant or delivering a baby?**

In some instances, the death may have occurred after 6 weeks of the end of the pregnancy, but up to 1 year since the end of the pregnancy. This question is asked to identify deaths which occur beyond the standard definition of 6 weeks for pregnancy-related deaths but which may still be linked to pregnancy, delivery, or the postpartum period. Deaths occurring more than 6 weeks but less than 1 year after the end of pregnancy are referred to as 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".

If "NO/DK/Ref", skip to question Id10310.

**(Id10308) Was this a woman who died less than 1 year after being pregnant or delivering a baby?**

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 1 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".

If the response is "YES", skip to Id10309. If "NO/DK/Ref", skip to question Id10310.

**(Id10309) For how many months was she pregnant?**

This question is to be asked if the respondent had said YES to Id10305, Id10306 or Id10308. It is directed to record the actual duration of the pregnancy in months, at the time of death.

Write the number of 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". For don't know, enter "99". For refused, enter "88".

From a "YES" response to Id10105, after this question, skip to Id10312.

From a "YES" response to Id10106, after this question, skip to Id10313.

From a "YES" response to Id10108, after this question, skip to Id10317.

**(Id10310) 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 is to be asked if the responses to Id10305/Id10306/Id10308 are all NO/DK/Ref.

Negative responses to all 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 1 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 (Id10310) 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 sub-section on "Risk factors" (i.e. Id10411).

If the response to Id10310 is "NO/DK/Ref", it indicates some uncertainty as to whether the cause of death could have been a maternal or pregnancy-related cause. Hence, IF "NO", go back to Id10305; and repeat the questions, to ascertain whether the women could have been pregnant or recently delivered before death, and follow the process again to Id10310.

If the death was related to pregnancy, proceed with Id10312.

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**Questions about possible maternal deaths**

**(Id10312) Did she die during labour or delivery?**

This question is to confirm whether the death occurred during the process of delivering the baby, i.e. the death occurred after the labour pains had started and some signs of progression of labour had been observed. However, the death occurred before the delivery was completed. Complete delivery is defined as delivery of the baby. Cases in which death occurs from incomplete placental delivery should be considered post-partum.

This determination may be sometimes difficult for respondents who are not familiar with the process of labour – 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.

If the answer is "YES", and the answer to Id10305=YES then skip to Id10316. If the answer is "NO", and the answer to Id10305=YES then skip to Id10317.

**(Id10313) Did she die after delivering a baby?**

Most maternal deaths occur just after the delivery. This question is to confirm that the death occurred after the baby was delivered, and not during pregnancy or labour (period of delivery); and is only asked if Id10305=NO and Id10306=YES.

If "YES", proceed with the next question. If "NO/DK/Ref", skip to Id10315.

**(Id10314) Did she die within 24 hours after delivery?**

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 baby.

If "YES", go to ID10316. If "NO/DK/Ref", continue to the next question.

**(Id10315) Did she die within 6 weeks of childbirth?**

This question ascertains whether the death had occurred beyond the immediate period after delivery or termination of pregnancy, but within a period of 6 weeks. Certain maternal causes such as infection of the birth canal or delayed effects of the injuries to the birth canal can cause death a few days or weeks after the delivery.

If the response to Id10306 was "NO" then the response to this question should also be "NO". In ODK this is auto-calculated and this question is skipped (if Id10306=NO).

**(Id10316) Did she give birth to a live baby (within 6 weeks of her death)?**

This question confirms the woman having delivered a live baby in the period of 6 weeks before her death.

**NOTE:** Add detail on live baby – a live baby shows signs of life such as breathing, crying, screaming, or movement.

**(Id10317) Did she die during or after a multiple pregnancy?**

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.

**(Id10318) Was she breastfeeding the child in the days before death?**

This question is to be asked only if the maternal death had occurred after 24 hours since the delivery. This can be confirmed if the responses to Id10312 and Id10314 are "NO", and the answer to Id10316 is "YES".

**(Id10319) How many births, including stillbirths, did she/the mother have before this baby?**

Ask and record the obstetric history prior to this birth. Exclude abortions (spontaneous or induced) and miscarriages that occurred in the first 6 months of pregnancy. Multiple births should be counted as separate events. For example, delivering twins is equal to 2 births.

If the answer to this question is "ZERO (0)"; i.e. this is the first delivery (including stillbirth), then proceed to Id10321. If the answer is "ONE or any number greater than ONE", then proceed to the next question. 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".

If the interview has reached this stage; it is confirmed that the death is from a maternal cause. The next set of questions attempt to gather information that will guide the diagnosis of the specific maternal cause of death. The main causes relate to birth canal injuries and bleeding,

maternal high blood pressure, difficult labour, or birth canal infections. The following questions may seem a bit detailed, but request the patience and cooperation of the respondent before continuing with the interview.

**(Id10320) Had she had any previous Caesarean section?**

Ask and record whether any of the child birth had taken place through operations. The history of previous Caesarean section increases the risk of certain maternal causes of death. Some respondents may not be aware of the term Caesarean section so you can also ask about a surgical or operative abdominal delivery.

**(Id10321) During pregnancy, did she suffer from high blood pressure?**

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 is 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.

**(Id10322) Did she have foul smelling vaginal discharge during pregnancy or after delivery?**

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.

**NOTE:** Questions Id10323 and Id10324 are only relevant in the third trimester of pregnancy. For analysis, it is important to cross check responses to these questions against the length of the pregnancy (Id10309).

**(Id10323) During the last 3 months of pregnancy, did she suffer from convulsions?**

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.

Convulsions can indicate eclampsia (toxaemia of pregnancy), epilepsy, or several other serious medical conditions. The timing of the onset of these convulsions is important to distinguish the condition.

**(Id10324) During the last 3 months of pregnancy did she suffer from blurred vision?**

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.

**(Id10325) Did bleeding occur while she was pregnant?**

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

If "NO/DK/Ref", then skip to Id10328.

**(Id10326) Was there vaginal bleeding during the first 6 months of pregnancy?**

This is to differentiate bleeding during the first 6 months of pregnancy with that occurring closer to full term. Bleeding in first 6 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.

**(Id10327) Was there vaginal bleeding during the last 3 months of pregnancy but before labour started?**

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.

**NOTE:** Questions Id10328-Id10332 should NOT be asked for women that died during pregnancy before the onset of labour (i.e. Id10305=YES and 10312=NO).

**(Id10328) Did she have excessive bleeding during labour or delivery?**

This question refers to bleeding during the birth process AFTER the onset of labour pains but before the complete delivery of the birth. Excessive bleeding during labour 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 labour before delivering the baby, and record the response accordingly.

**(Id10329) Did she have excessive bleeding after delivery or abortion?**

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.

**NOTE:** Questions Id10330-Id10333 are relevant in cases on abortion, as “abortion” in this context means abortion or miscarriage (with incomplete miscarriage being possible).

**(Id10330) Was the placenta completely delivered?**

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.

There may be a local term to describe placenta. Ensure that the local term is included in the translated version of the questionnaire, and use the local term to probe.

**(Id10331) Did she deliver or try to deliver an abnormally positioned baby?**

Again, the position of the baby would be known to the attending midwife, but is usually communicated to family members. Enquire carefully, ask for the abnormal position if known, and record the details in the narrative section of the questionnaire, along with the positive response to this question. Sometimes the family may not know that there was an arm or hand that came through the birth canal first, this would indicate an abnormally positioned baby.

**(Id10332) For how many hours was she in labour?**

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 labour of more than 12 hours is likely to be remembered by relatives. The answer could be given in another unit, but for data entry use 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.

**(Id10333) Did she attempt to terminate the pregnancy?**

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. If there are culturally acceptable terms that could be used to probe for this answer, they should be used.

**NOTE:** Id10334, Id10335 and Id10336 should NOT be asked if there was a live birth (i.e. Id10316 = "YES").

**(Id10334) Did she recently have a pregnancy that ended in an abortion (spontaneous or induced)?**

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 external action.

If "NO/DK/Ref", then skip to question Id10337.

**(Id10335) Did she die during an abortion?**

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.

If “YES”, then skip to question Id10337.

**(Id10336) Did she die within 6 weeks of having an abortion?**

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 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. Note that this question is NOT asked if the woman died during labour (Id10312=YES).

**NOTE:** Questions Id10337-Id10339 and Id10342-Id10347 should NOT be asked for women that died during pregnancy before the onset of labour (i.e. Id10305=YES and 10312=NO).

**(Id10337) Where did she give birth/complete the miscarriage/ have the abortion?**

Ask the respondent about the location where the delivery, miscarriage or abortion occurred, and record the response accordingly.

**(Id10338) Did she receive professional assistance during the delivery?**

Explain to the respondent what is meant by professional assistance: delivery attended by a medical professional (doctor, nurse or midwife). The nature of assistance received at delivery is helpful in understanding the factors that could have led to maternal or neonatal deaths. Professional assistance refers to either a medically qualified doctor, qualified nurse, or certified trained midwife only. Professional includes skilled birth attendants.

**(Id10339) Who delivered the baby/ completed the miscarriage/ performed the abortion?**

Select the appropriate response. If multiple providers assisted, circle the person with the highest skill level. Note that there may be some inconsistencies in the responses to Id10338

and Id10339, depending on differing definitions across cultures. Try to get non-contradictory responses and record any details for clarification in the “Open narrative” section.

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### **How did the mother deliver her baby?**

These questions provide circumstantial evidence as to the potential cause of death.

**NOTE:** Questions Id10342-Id10347 should NOT be asked in case of an abortion (i.e. Id10334/Id10335/Id10336=YES) – the interview should continue to Id10340.

#### **(Id10342) Was the delivery normal vaginal, without forceps or vacuum?**

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.

If the response is "YES", skip to Id10347. If the response is "NO/DK/Ref", proceed to the next question.

#### **(Id10343) Was the delivery vaginal, with forceps or vacuum?**

If instrumentation was used to assist the delivery, record “YES” here, and skip to Id10347. These instruments (forceps or vacuum) may be placed on the baby’s head or in some cases used to assist with a breech delivery (forceps).

If the response is "NO/DK/Ref", proceed with the next question.

#### **(Id10344) Was the delivery a Caesarean section?**

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.

#### **(Id10347) Was the baby born more than one month early?**

Delivery before the completion of the full duration of pregnancy — less than 8 completed months — may be associated with specific maternal risks. Enquire whether the duration was only 8 months or less at the time of delivery.

#### **(Id10340) Did she have an operation to remove her uterus shortly before death?**

In some instances, there could be a prolonged labour, 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 either repaired or 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.

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## **Risk factors**

Consumption of alcohol and tobacco are linked to several diseases or circumstances which could be related to the cause of death. In some instances, there could be a social stigma associated with such risk factors (e.g. alcohol consumption in certain communities or age-sex groups etc.). Hence before asking these questions, it would be useful for the interviewer to first judge whether there is likelihood of any potential sensitivity to these questions, and if so, to make some statements acknowledging the sensitivity, but the need to make certain whether these risks were present or not, in order to obtain the best possible information to determine the cause of death.

### **(Id10411) Did (s)he drink alcohol?**

Consumption of alcohol could be associated with liver disease, as well as in relation to mental health conditions associated with depression and suicide, and also associated with risk taking leading to road traffic accidents or interpersonal 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 narrative section of the questionnaire. This question is used by the automated analysis software. Because alcohol use is a sensitive issue, no further information about frequency or quantity of use is asked.

### **(Id10412) Did (s)he use tobacco?**

Select the appropriate response.

### **(Id10413) Did (s)he smoke tobacco (cigarette, cigar, pipe, etc.)?**

The term “smoke” is used in this question to specifically capture kinds of tobacco that are smoked. This question does not aim to capture use or consumption of chewing tobacco.

Smoking tobacco is related to lung cancer, oral cancer, and chronic asthma, among others.

### **(Id10414) What kind of tobacco did (s)he use?**

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. If the response is “cigarettes”, go to Id10415. If the response is “another kind of tobacco”, go to Id10416.

### **(Id10415) How many cigarettes did (s)he smoke daily?**

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. For any response, skip to Id10418.

**(Id10416) How many times did (s)he use tobacco products each day?**

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.

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**Health service utilisation**

In many instances of deaths that occur at home, there is a potential for the deceased to have received some form of medical attention during the illness that led to death. The treatment could have been in the form of a duration of hospitalisation which later resulted in the person being discharged prior to death, which sometimes occurs in instances where there is no potential cure, or the treatment is too expensive, or a cultural preference for terminal care at home. In such instances, there is a likelihood of household members to be aware of the nature of medical treatment provided, as well as some information on the likely disease or condition that the patient was suffering. In the following questions, record specific responses about health services as asked, and record any other or allied information on health services or medical opinion as to the cause in the narrative section of the questionnaire. This section should always be completed at the end of the interview – following the normal order as presented by ODK or in the paper form.

**(Id10418) Did (s)he receive any treatment for the illness that lead to death?**

This question refers to formal health treatment, and not home remedies or non-professional treatment. If the response to this question is "NO/DK/Ref", then skip to Id10432.

**(Id10419) Did (s)he receive 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 diarrhoea, particularly children. This is an effective remedy which is known to prevent death.

**NOTE:** The automated analysis software requires questions Id10420–Id10425. These questions should be answered according to whether the patient received the treatment OR needed the treatment.

**(Id10420) Did (s)he receive (or need) 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.

**(Id10421) Did (s)he receive (or need) a 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.

**(Id10422) Did (s)he receive (or need) treatment/food through a tube passed through the 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.

**(Id10423) Did (s)he receive (or need) 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.

**(Id10424) Did (s)he receive (or need) 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. This question may or may not be relevant, given the epidemiological profile of the country or region of the country where this questionnaire is being administered. Also, the patient's relatives may not know these details. Explain the question carefully, and record the response accordingly

**(Id10425) Did (s)he have (or need) an operation for the illness?**

An operation is also an indication of the severity of the illness, and moreover, the medical reason for the operation is likely to be known to the relatives. If the response is "YES", enquire from the relatives if they know the medical condition (e.g. cancer, stomach ulcer; heart disease etc.) that was the reason for the operation; and note the details in the narrative section of the questionnaire.

If the answer is "NO/DK/Ref", skip to Id10427.

**(Id10426) Did (s)he have the operation within 1 month before death?**

The timing of the operation will help ascertain any links between the treatment and the cause of death

**(Id10427) Was (s)he discharged from hospital very ill?**

Discharge refers to a patient leaving a hospital after receiving approval from a medical provider. This question is only asked if the response to Id10418 was "YES", indicating that there was some level of hospitalization.

**(Id10432) Was care sought outside the home while (s)he had this illness?**

This series of questions is to confirm that health care was anywhere outside the home. This refers to both locations (hospitals, health centres, and pharmacies) and individuals (physicians, community-based practitioners, trained birth attendants, traditional healers, homeopaths, religious healers, relatives/friends). If the response to this question is "NO/DK/Ref", then skip to Id10435.

**(Id10433) Where or from whom did you seek care?**

Read out the list of options from the list, and select all that are applicable, since there may have been attempts to seek several different health care options.

**(Id10434) What was the name and address of any hospital, health centre or clinic where care was sought**

Over here, record the main institution where health care was provided, including investigations, diagnosis, treatment and other facilities. Enter "-", if this information is not applicable.

**(Id10435) Did a health care worker tell you the cause of death?**

If the response is "NO/DK/Ref", then skip to Id10437.

**(Id10436) What did the health care worker say?**

Record details of any verbally communicated information on the likely cause of death here.

**(Id10437) Do you have any health care records that belonged to the deceased?**

This could include 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.

If "YES", proceed to the next question. If "NO/DK/Ref", skip to Id10450.

**(Id10438) Can I see the health records?**

Seek consent from relatives to see the health records, and note the details as per the following question. In case there is refusal to show the health records; then skip to Id10450.

**(Id10439) [Is the date of the most recent (last) visit available? / Record the date of the most recent (last) visit.]**

If the date is available, record the visit date for the final consultation. Note any details of the diagnosis, laboratory tests, and treatment etc. in the narrative section of the questionnaire.

**(Id10440) [Is the date of the second most recent visit available? / Record the date of the second most recent visit.]**

Record the visit date for the second last consultation. These dates will help link the health care utilisation information and diagnoses with the actual event of the death, and therefore

the likelihood of there being a relationship between the diagnosis of the illness and the cause of death.

**(Id10441) [Is the date of the last note on the health records available? / Record the date of the last note on the health records.]**

Record the date of the last note on the health record.

**(Id10442) [Record the weight (in kilograms) written at the most recent (last) visit]**

**(Id10443) [Record the weight (in kilograms) written at the second most recent visit]**

**(Id10444) [Transcribe the last note on the health records (including any/all diagnoses mentioned on the health record).]**

This is a very important element of the whole verbal autopsy 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. For Id10442 and Id10443, if the information is not available, record "9999" for don't know, and enter "8888" for refused to answer.

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## **Background and context**

**(Id10450) In the final days before death, did s/he travel to a hospital or health facility?**

If "NO/DK/Ref", skip to Id10455.

**(Id10451) Did (s)he use motorised transport to get to the hospital or health facility?**

If the respondents did travel to a health facility ask what mode of transport they used to get there and record "YES" here if some motorized form (car, truck, tractor, motorcycle, scooter or ambulance) was used.

**(Id10452) Were there any problems during admission to the hospital or health facility?**

Ask the respondent whether there were any problems such as delays, paperwork, queues or no staff encountered at the health facility.

**(Id10453) Were there any problems with the way (s)he was treated (medical treatment, procedures, interpersonal attitudes, respect, dignity) in the hospital or health facility?**

Enquire whether there were any problems with how the deceased or family were treated at the health facility.

**(Id10454) Were there any problems getting medications, or diagnostic tests in the hospital or health facility?**

Enquire whether there were any problems with receipt of medications or diagnostic tests at the health facility.

**(Id10455) Does it take more than 2 hours to get to the nearest hospital or health facility from the deceased's household?**

Enquire whether the person who died lived in a household from where it would reasonably take more than 2 hours to reach the nearest 24-hour health facility by the means of transport available to the household members.

**(Id10456) In the final days before death, were there any doubts about whether medical care was needed?**

Ask if there were doubts among those assisting in the final illness (family members, etc.) about whether the final illness was sufficiently serious to need treatment at a health facility.

**(Id10457) In the final days before death, was traditional medicine used?**

If a major part of treatment for the final illness was provided by any kind of traditional or alternative practitioner (herbal remedies, massages, drinks, foods, amulets, spells or blessings provided by traditional healers, witch doctors or shaman) select "YES" here.

**(Id10458) In the final days before death, did anyone use a telephone or cell phone to call for help?**

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.

**(Id10459) Over the course of illness, did the total costs of care and treatment prohibit other household payments?**

Select "YES", if the total costs incurred in the final illness were sufficiently great to mean that other kinds of household expenses (food, fuel, travel, education etc.) could not be met, or caused debt or sale of household assets.

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**Death certificate with cause of death**

The following information serves only to complete cause of death information in some environments. In routine Civil Registration Vital Statistics (CRVS) they could be skipped from the interview and information be collected from other sources if available.

**(Id10462) Was a medical certificate of cause of death issued?**

Ask the respondent if there is a medical certificate of the cause of death for the person that died. The medical certificate of cause of death is commonly obtained from a physician at a hospital and should be distinguished from the Death Certificate which is issued by the civil registration organisation. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other "certificates" such as the burial permit that this question may be confused with.

If the answer is "NO/DK/Ref", skip to Id10476 – “Open narrative” section.

**(Id10463) Can I see the medical certificate of cause of death?**

Ask if you can see the medical certificate of cause of death in order to record information about the cause of death. During country adaptation, countries should specify the specific name of the local civil registration authority that issues the Death Certificates; country adaptation should also indicate if there are other “certificates” such as the burial permit that this question may be confused with.

Fill in the following questions only if you are shown the copy of the certificate. Do not fill in just based on oral statements. Record “NO” if medical information about the cause of death is not available. If the answer is "NO/DK/Ref", skip to Id10476 – “Open narrative” section.

**(Id10464) and (Id10465) [Record the immediate cause of death from the certificate (line 1a) and the duration of that cause.]**

**NOTE:** 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 Id10464–Id10473.

Copy the cause of death from the first line of the death certificate. There should always be a cause recorded here. If a duration for which that cause was experienced is also recorded in the column beside the cause, enter that in Id10465

**(Id10466) and (Id10467) Record the first antecedent cause of death from the certificate (line 1b) and the duration of that cause (1b).]**

Copy the cause from the second line of the death certificate if there is one listed as well as its duration.

**(Id10468) and (Id10469) [Record the second antecedent cause of death from the death certificate (line 1c) and the duration of that cause (1c).]**

Copy the cause from the third line of the death certificate if there is one listed as well as its duration.

**(Id10470) and (Id10471) [Record the third antecedent cause of death from the certificate (line 1d) and the duration of that cause (1d).]**

Copy the cause from the fourth line of the death certificate if there is one listed as well as its duration.

**(Id10472) and (Id10473) [Record the contributing cause(s) of death from the certificate (part 2) and the duration of that cause (part 2).]**

List any contributing causes recorded in Part II of the death certificate.

## Open narrative

### (Id10476) Narrative description

Ask respondents to describe in their own words whether they have anything to add to the information they have provided so far. You will read “Thank you for your information. Now can you please tell me in your own words about the events that led to the death?”

Allow the respondent to tell you about the illness in his or her own words. Once the respondent has completed the initial response, prompt for additional information as relevant:

- Symptom recognition (when were first symptoms recognised, what other symptoms did (s)he have, when did the respondent/family realise it was severe, who recognized the first and severe symptoms);
- Timing (how long it took from first symptoms to realising it was severe);
- Actions taken in home and outside the home (how long after first symptom(s) and severe symptom(s) was any action taken, what actions, was there any treatment given, what treatment, who made the decision to seek or not to seek care, reason for this action, if care outside the home was not sought – why?)
- Transport (time spent from making the decision for seeking care outside the home to getting transport, type of transportation used to reach the first level of care and any potential referrals, time spent during transport, any delays that may have occurred before reaching care).
- Provider behaviour (advice given, treatment given, how long did it take to receive the care after reaching health care services, complete referral history, timing of referral, time spent on travel to and between facilities, reasons for not going or delaying referral, referral experience).

During the response, record detailed *written* notes of what is mentioned. Make sure to capture key items such as signs and symptoms, timing of care seeking, and any points that need to be clarified. If using an electronic data capture system (e.g. ODK), enter the notes into the electronic system *after* concluding the interview.

The checklist below provides a list of additional items that may be included in the open narrative if identified in the interview. You should feel free to denote additional items even if they are not included on the checklist.

### CHECKLIST OF ADDITIONAL ITEMS TO RECORD IN THE NARRATIVE OPEN SPACE

If there is an official police or medico legal opinion as to the cause of death – provided by local authorities (usually for accidents or injuries).

#### Additional information about injuries

- If the family reported an injury, record the specifics of the injury (type, mode, location of event, and affected body parts that were injured);
- If it was self-inflicted even when you did not ask;

- if it was an accident in transport other than on the road E.g. fatal injury from train / boat / aircraft;
- If a fall, record the body parts injured;
- If a poisoning from pesticides, kerosene, or any other chemicals, record the type of poison;
- If a drowning, record location where the drowning occurred – river/lake/sea/swimming pool, etc.;
- If injured by burns/fire, record the all of the body parts affected by burns and how the burn occurred;
- If injured by a force of nature, record the type of force of nature (lightning, flood, earthquake, etc.).

#### **Additional findings in the deceased**

- If the deceased had any birth defects, describe body part(s) and what it looked like, and/or if the deceased had ambiguous genitalia/intersex.
- If you recorded the birth weight given to you and it was self-reported (not verified on the records), then record that the birth weight was reported by the respondent here.
- If the deceased appeared healthy and died suddenly (unexpectedly within 24 hours of being in regular health) and there are any other details about the death, record them (e.g. happened during the sleep). In some instances, this may be the main information provided by the respondent.
- If the deceased had a recent health visit, note any details of the diagnosis, laboratory tests, and treatment etc. in the open narrative section of the questionnaire.
- If there is any additional information on health services or medical opinions provided on the cause of death for the deceased who may have attended medical care prior to his/her death, record that here.
- If the deceased received or needed treatment or food passed through the nose, enquire how long feedings were provided through the tube and whether the tube was in place prior to death, and record relevant information here.
- If the deceased had any presence of lumps on the neck, if there was an opinion as to the medical cause for the lump and (s)he received treatment, record relevant information here.
- If the deceased had an operation, enquire from the respondent if (s)he knows the medical condition (e.g. cancer, stomach ulcer, heart disease, etc.) that was the reason for the operation; note relevant details here.

#### **Maternal and delivery information**

- If the water broke for delivery, and the water was abnormal, record any description here.

If the mother died and you obtained any additional information, record what you learned about the mother's death (e.g. timing of death in relation to delivery, symptoms, etc.).

**(Id10477) Select any of the following words that were mentioned as present in the narrative.]**

This question lists some of the key risks associated with mortality in the age group of the deceased. After the respondent has provided their description of the circumstances surrounding the death read back through and record all of the key words which they may have mentioned that the deceased had.

**[Comment: Comment]**

Record any additional details about the interviewer here.

**(Id10481) [Record the time at the end of the interview.]**

In the standard ODK programming, this item is hidden from interviewers and will be completed automatically. However, the project office may choose to make this question visible if preferred.