World Health Organization

# Making Every Baby Count

## Audit and review of stillbirths and neonatal deaths

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# Contents

# Acronyms and abbreviations

| | |
|---|---|
| **CHW** | community health worker |
| **CRVS** | civil registration and vital statistics |
| **ENAP** | Every Newborn Action Plan |
| **HMIS** | health management information system |
| **ICD-10** | International Statistical Classification of Disease and Related Health Problems, 10th revision |
| **ICD-MM** | *The WHO application of ICD-10 to deaths during pregnancy, childbirth and puerperium* (ICD-Maternal Mortality) (WHO publication) |
| **ICD-PM** | *The WHO application of ICD-10 to deaths during the perinatal period* (ICD-Perinatal Mortality) (WHO publication) |
| **MDSR** | maternal death surveillance and response |
| **PPIP** | Perinatal Problem Identification Programme |
| **SDG** | Sustainable Development Goals |
| **SMGL** | Saving Mothers, Giving Life |
| **VA** | verbal autopsy |
| **WHA** | World Health Assembly |
| **WHO** | World Health Organization |

# Acknowledgements

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- Bhutan: National Referral Hospital, Thimphu; Phuentsholing General Hospital, Chukha; and Paro Hospital, Paro;
- Nigeria: Federal Medical Centre, Lokoja, Ebonyi State; Federal Teaching Hospital, Abakaliki, Ebonyi State; ECWA Hospital, Egbe; Maitama District Hospital, Abuja; and University of Abuja Teaching Hospital, Gwagwalada;
- Moldova: Municipality of Chisinau perinatal care centre and three regional perinatal care centres in Balti, Cahul and Orhei;
- Uganda: Fort Portal Regional Referral Hospital; Kabarole Hospital; Virika Hospital; Kyenjojo Hospital; Kakumiro Health Centre IV (Kibaale Region); Kakindo Health Centre IV (Kibaale Region); Kagadi Hospital (Kibaale Region); and Kibaale Health Centre IV (Kibaale Region).

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# Foreword

Pregnancy is a time of great anticipation for all expectant parents and their families as they envision getting to know and love a healthy baby. The presence of a long-desired baby in a woman's womb is accompanied by thoughts and dreams about what the child will look like and how his or her future will be. Experiencing a stillbirth or the death of a baby in the final stages of pregnancy, during labour or soon after delivery is a silent tragedy for mothers, fathers and families globally.

The day of birth is potentially the most dangerous day for both mothers and their babies. Significant reductions have been made in neonatal mortality during the last two decades, but there are still an estimated 2.7 million neonatal deaths and 2.6 million stillbirths every year. Most of these losses are preventable with high-quality, evidence-based interventions delivered before and during pregnancy, during labour and childbirth, and in the crucial hours and days after birth.

Countries are increasingly collecting data that will enable the burden of stillbirths and newborn deaths to be more accurately estimated. Yet in most countries, especially where the estimated burden is the highest, there is a need to strengthen the civil registration and vital statistics (CRVS) systems for counting all births and deaths and assigning cause of death. Most stillbirths and half of all neonatal deaths do not receive a birth certificate and are not registered. Improving systems for reporting births and neonatal deaths is a matter of human rights and a prerequisite for reducing stillbirths and neonatal mortality.

By counting the number of stillbirths and neonatal deaths, gathering information on where and why these deaths occurred and also by trying to understand the underlying contributing causes and avoidable factors, health-care providers, programme managers, administrators and policy-makers can help to prevent future deaths and grief for parents, and improve the quality of care provided throughout the health system.

This guide shows the way forward for health-care facilities or whole countries to introduce a system to address the burden of stillbirths and neonatal deaths. Similar to the maternal death surveillance and response (MDSR) approach to ending preventable maternal mortality, this guide and related tools provide support for identifying cases, collecting information and analysing the data collected to recommend solutions to improve the quality of care and to implement the changes within a continuous evaluation and response cycle. This guide does not suggest setting up a new system, but building on systems already in place. The approach is in line with two of the five objectives outlined in the Every Newborn Action Plan (ENAP): **Strategic Objective 2 – Improve the quality of maternal and newborn care**; and **Strategic Objective 5 – Count every newborn through measurement, programme-tracking and accountability to generate data for decision-making and action**.

It is time to make every baby count and prevent future tragedies, by learning from and effectively responding to preventable deaths.

Dr Flavia Bustreo, Assistant Director-General
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# Executive summary

Counting the numbers more accurately, and gaining a better understanding of the causes of death are key to tackling the burden of 2.7 million neonatal deaths[1] and 2.6 million stillbirths that are estimated to occur each year. Half of the world's babies do not currently receive a birth certificate; and most neonatal deaths and almost all stillbirths have no death certificate, let alone information on causes and contextual factors contributing to these deaths.[2] Many countries have limited capacity for capturing neonatal deaths beyond the level of the health-care facility, especially those countries where births are not registered, and very few countries have a system for tracking stillbirths at all, despite increasing demand for data. Consistent information about the nature and cause of death is needed for planning health systems and distributing resources, as well as for improving the quality of care at the point of service delivery.

National and regional estimates of numbers and causes of death are useful, but they do not tell the whole story.[3] Examination of individual cases identifies the underlying reasons why these deaths occurred and provides opportunities to learn what needs to be done to prevent similar deaths in the future. The majority of stillbirths, particularly those that occur in the intrapartum period, and three quarters of neonatal deaths are actually preventable.[4]

A mortality audit is the process of capturing information on the number and causes of stillbirths and neonatal deaths, and then identifying specific cases for systematic, critical analysis of the quality of care received, in a no-blame, interdisciplinary setting, with a view to improving the care provided to all mothers and babies. It is an established mechanism to examine the circumstances surrounding each death including any breakdowns in care that may have been preventable. Applying the audit cycle to the circumstances surrounding deaths is an established quality improvement strategy that can highlight breakdowns in clinical care at the local level as well as breakdowns in processes at the district or national level, and ultimately improve the civil registration and vital statistics (CRVS) system and quality of care overall.

This process is already being used in many countries in the form of maternal death surveillance and response (MDSR)[5]. This is a key strategy to collect accurate information linked to routine health systems recording how many maternal deaths occurred, where the women died, why they died, and what could be done differently to prevent similar

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1 Child mortality estimates. New York (NY): United Nations Children's Fund; 2015 (http://www.childmortality.org/index.php?r=site/index, accessed 22 February 2016).

2 Lawn JE, Blencowe H, Oza S, You D, Lee ACC, Waiswa P et al.; for The Lancet Every Newborn Study Group. Progress, priorities, and potential beyond survival. Lancet. 2014;384(9938):189–205. doi:10.1016/S0140–6736(14)60496–7.

3 Blencowe H, Cousens S, Jassir FB, Say L, Chou D, Mathers C et al. National, regional and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis. Lancet Glob Health. 2016;4(2):e98–e108. doi:10.1016/S2214–109X(15)00275–2.

4 Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? Lancet. 2014;384(9940):347–70. doi:10.1016/S0140–6736(14)60792–3.

5 Maternal death surveillance and response: technical guidance information for action to prevent maternal death. Geneva: World Health Organization; 2013 (http://apps.who.int/iris/bitstream/10665/87340/1/9789241506083_eng.pdf).

deaths in the future. The process of routine identification and timely notification of deaths is a continuous action cycle linking quality improvement from the local to the national level. Although women and their babies share the same period of highest risk, often with the same health workers present, less information has been captured for stillbirths and neonatal deaths than for maternal deaths. Even basic information about each birth and death is limited, and the practice of reviewing selected deaths is not widespread.

*The WHO application of ICD-10*[6] *to deaths during the perinatal period: ICD-PM* (ICD-perinatal mortality), published at the same time as this document, provides a new system for classifying causes of death that aims to link stillbirths and neonatal deaths to contributing maternal conditions, where applicable, in a way that is consistent across all settings and that helps to standardise and increase the amount of available information on causes of death around the critical time of childbirth.[7]

This guide, *Making every baby count: audit and review of stillbirths and neonatal deaths*, and the accompanying tools have been developed for use at multiple entry points within the health system, ranging from a few interested individuals at a single health-care facility to a nationally mandated programme covering all health-care facilities and communities. The tools (included as annexes to this document) use a simplified version of ICD-PM for the purpose of initiating audits in low-resource settings, with options to expand the classification in greater detail where feasible.

A couple of notes on terminology used in this report may be useful. Although the perinatal period as defined in ICD-10 encompasses antepartum and intrapartum stillbirths and early neonatal deaths (deaths occurring during the first seven days of life), this guide uses the term "perinatal" slightly more broadly, to refer to the perinatal period extending to four weeks after the delivery, thus also including late neonatal deaths (those occurring on days 8 to 28 days of postnatal life).

Furthermore, some users are familiar with the term "audit" when applied to deaths and mortality, while others are more familiar with the term "review", as used in the context of MDSR.[8] Experts who contributed to the development of this guide have suggested that the use of both of these terms is acceptable and thus they are used essentially interchangeably in many parts of this guide.

## Components of an audit system for stillbirths and neonatal deaths

The guide is structured around the key components required to establish an audit system for stillbirths and neonatal deaths.

- **Chapter 1** provides the overall rationale for conducting an audit and for the development of this guide in particular.

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[6] ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th revision

[7] The WHO application of ICD-10 to deaths during the perinatal period: ICD-PM. Geneva: World Health Organization; 2016.

[8] WHO, 2013, op cit.

- **Chapter 2** addresses issues around definitions and the classification of causes of death, as well as examples of various systems for classifying modifiable factors related to deaths or near misses.

- **Chapter 3** describes the six steps required to establish and complete the mortality audit cycle at the facility level:
  - setting up the system;
  - collecting information;
  - analysing information;
  - recommending solutions;
  - implementing changes; and
  - evaluating and refining the process.

- **Chapter 4** gives an overview of how to incorporate deaths that occur in the community into an existing facility-based audit system.

- **Chapter 5** highlights the importance of a supportive atmosphere for a successful audit and describes how to create an enabling environment that supports reflective practice.

- **Chapter 6** provides information on expanding a mortality audit system from individual facilities to a network of facilities at regional and national levels, including linkages to civil registration systems and community surveillance systems.

The following tools, forms and additional resources accompany this guide in the form of annexes. The tools and forms come with instructions and can be modified to fit local circumstances.

- Annex 1: Stillbirth and Neonatal Death Case Review Form
- Annex 2: Births and Deaths Summary Form
- Annex 3: Minimum set of perinatal indicators to collect for all births and perinatal deaths
- Annex 4: Approaches for classifying modifiable factors
- Annex 5: Setting up a mortality audit steering committee
- Annex 6: Sample mortality audit meeting code of practice declaration
- Annex 7: Sample calculations for reporting
- Annex 8: Stillbirth and Neonatal Mortality Audit – Meeting Minutes and Action Items Form
- Annex 9: Steps for establishing a mortality audit for stillbirths and neonatal deaths
- Annex 10: Verbal and social autopsy tool for stillbirth and neonatal deaths audits in the community.

## Key messages of this guide

- Auditing stillbirths and neonatal deaths requires capturing basic information on all births and deaths, as well as a more in-depth analysis of the critical factors involved in selected cases, with the aim of identifying and implementing ways to improve the quality of maternal and newborn care.
- The true burden of stillbirths and neonatal deaths has been unknown and thus silenced for too long. Improving measurement is the first step to understanding where action is needed.
- It is possible to establish a system to assess the burden of stillbirths and neonatal deaths, including trends in numbers and causes of death, and the data must be linked to action at the relevant level.
- These data can be used to provide accountability for results and compel decision-makers to pay due attention and respond to the problem of stillbirths and neonatal deaths. Champions and local leaders are required to lead the review and audit process and translate this information into effective action.
- In addition to leadership, appropriate protections, legal and otherwise, must be in place to create an enabling environment in which critical review of practices can take place.
- There is no long list of requirements needed to initiate a death review. Users only need to decide to learn from the experience and adapt the approach as needed.

# 1 Getting started

## 1.1 What is this guide about?

The timely dissemination of reliable data about the numbers and causes of death to those who need them for taking action is essential for planning and implementing health services *(1)*. A systematic analysis of mortality trends and events leading to deaths can help identify system breakdowns and provide information on local solutions to address deficiencies in service delivery. This process of mortality audit and feedback shows a greater impact on health-care practices and outcomes than other quality improvement strategies, particularly in settings where the audit process includes an action plan and clear targets and when there is greater opportunity for improvement in all sectors and at all levels *(2)*.

Maternal death surveillance and response (MDSR) is becoming an increasingly popular strategy for collecting data linked to routine health systems recording how many maternal deaths occurred, where the women died, why they died, and what could be done differently to prevent similar deaths in the future *(1, 3)*. The process of routine identification and timely notification of deaths is a continuous action cycle that can link quality improvement from the local to the national level. Although women and their babies share the same period of highest risk, often with the same health workers present, less information has been captured for stillbirths and neonatal deaths than for maternal deaths. Even basic information about each birth and death is limited, and the practice of reviewing deaths is not widespread.

This guide sets out key steps towards introducing a system for capturing the number and causes of all stillbirths and neonatal deaths, and reviewing selected individual cases for systematic, critical analysis of the quality of care received, in a no-blame, interdisciplinary setting. The steps of the audit cycle are described, namely: identifying cases, collecting information, analysing data, recommending solutions, implementing changes, and evaluating and refining the process. When information on deaths is aggregated to demonstrate trends, and individual deaths are systematically reviewed to identify common modifiable factors, solutions emerge to address bottlenecks that may not be otherwise apparent when individual cases are viewed in isolation.

With regard to terminology used in this guide, some readers will be more familiar with the term “audit”, which is an established term in clinical practice, while others are more familiar with the term “review” as used in the context of MDSR *(1)*. Experts who contributed to the development of this guide have suggested that the use of both of these terms is acceptable and thus they are used essentially interchangeably in many parts of this guide.

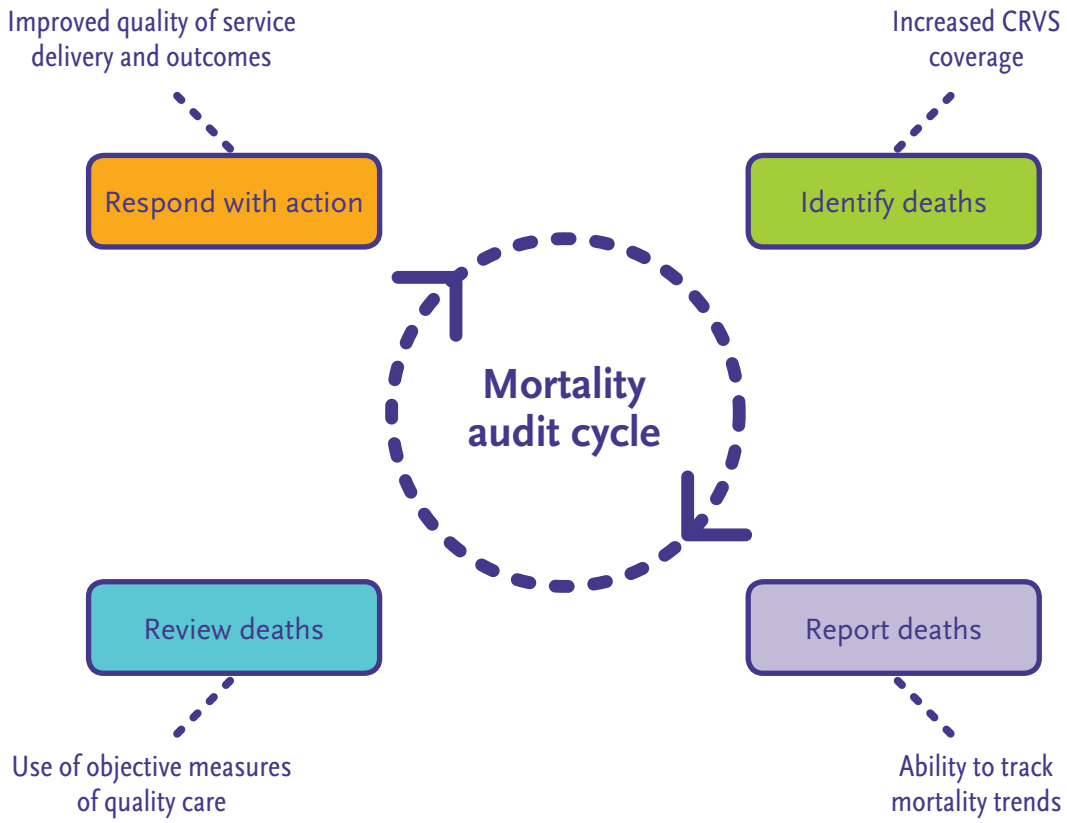
A mortality audit can have multiple entry points into the health system, ranging from a single hospital to a nationally mandated programme covering all health-care facilities and communities. This guide presumes that, at a minimum, all health-care facilities that provide care during childbirth can institute interdisciplinary review of stillbirths and neonatal deaths as part of standard practice. Around the world, more births are taking place in health-care facilities than ever before *(4)*. This guide uses the review of deaths in health-care facilities as an entry point to a broader system-wide approach. Generally, there is more information available about deaths that occur in facilities than those that happen in the community, and it is easier for health-care providers to review and learn from them. However, there is a need to ensure that all births and deaths are counted – and count – no matter where they occur.

## 1.2 Why is this guide important?

Counting the numbers more accurately, and gaining a better understanding of the causes of death are key to tackling the burden of 2.7 million neonatal deaths *(5)* and 2.6 million stillbirths that are estimated to occur each year. Many resource-poor settings lack effective civil registration and vital statistics (CRVS) systems for counting all births and deaths and assigning cause of death. Half of the world's babies do not currently receive a birth certificate; and most neonatal deaths and almost all stillbirths receive no death certificate, let alone information on causes of death and contextual factors contributing to them *(4)*. Many countries have limited capacity for capturing data on neonatal deaths beyond the health-care facility level, especially those countries where births are not registered, and very few countries have a system for tracking stillbirths at all, despite increasing demand for data.

National estimates of numbers and causes of death are useful, but they do not tell the whole story *(6)*. Examination of individual cases provides us with underlying reasons why these deaths occurred and information about what needs to be done to prevent such deaths in the future. The majority of stillbirths, particularly those that occur in the intrapartum period, and three quarters of neonatal deaths are preventable *(7)*. Applying the audit cycle to the circumstances surrounding deaths can highlight breakdowns in clinical care at the local level as well as breakdowns in processes at the district or national level, and ultimately improve the CRVS system and quality of care overall (Figure 1.1).

FIGURE 1.1. Relationship between mortality audit and wider quality of care and CRVS systems



A mortality audit for stillbirths and neonatal deaths also contributes to global targets and achievements. This approach is in line with two of the five objectives in the Every Newborn Action Plan (ENAP): **Strategic Objective 2 – Improve the quality of maternal and newborn care**; and **Strategic Objective 5 – Count every newborn through measurement, programme-tracking and accountability to generate data for decision-making and action** *(8)*. The ENAP Measurement Improvement Roadmap and the Measurement and Accountability for Health Roadmap both aim to increase investment in and the capacity of national health management information systems (HMISs), of which mortality audit is a part *(3, 9)*. Conducting a mortality audit is also a key strategy to ensure accountability for women's and children's health, as acknowledged by the global Commission on Information and Accountability (COIA) and the new Global Strategy for Women's, Children's and Adolescents' Health 2016–2030 *(10, 11)*. In the context of the Sustainable Development Goals (SDG) framework, auditing also provides a mechanism to track progress for SDG target 3.2, which aims to reduce neonatal mortality to at least as low as 12 per 1000 live births in all countries by 2030 *(12)*.

## 1.3 Who is this guide for?

This guide will be relevant for stakeholders across the health system, including health professionals, planners and managers, epidemiologists, demographers and others who measure mortality trends, and policy-makers working in maternal and perinatal health. It may also be useful for those looking to promote linkages with CRVS systems, HMISs and community surveillance mechanisms, to ensure that every birth and death is counted. It is important that those with the power to implement the recommended changes actively participate in the process of reviewing deaths, assigning causes and identifying modifiable factors and solutions; this guide is for them.

The use of audit findings to improve health outcomes is central to the implementation of a mortality audit, both inside and outside of health-care facilities. Stakeholders at all levels who can drive change, such as community leaders, civil society and parent groups, should be involved in the processes of setting up a mortality audit system, to ensure that the recommended changes take place.

## 1.4 What does this guide aim to achieve?

Similar to the maternal death reviews conducted as part of MDSR, death reviews for stillbirths and neonatal deaths have multiple aims *(1)*. These include:

- to establish a framework to assess the burden of stillbirths and neonatal deaths, including trends in numbers and causes of death;
- to generate information about modifiable factors contributing to stillbirths and neonatal deaths and to use the information to guide action to prevent similar deaths in the future; and
- to provide accountability for results and compel decision-makers to pay due attention and respond to the problem of stillbirths and neonatal deaths.

Importantly, it is not sufficient to count deaths and calculate mortality rates, or even to identify systemic problems contributing to these deaths. A mortality audit is only useful if the reviews lead to action based on the findings *(13, 14)*. There is not a long list of requirements to begin a perinatal death review process. Instead of trying to create the perfect system on paper, start the process, learn from the experience and adapt the approach as needed.

Although the perinatal period as defined in ICD-10 encompasses antepartum and intrapartum stillbirths and early neonatal deaths (deaths occurring during the first seven days of life), this guide uses the term "perinatal" slightly more broadly, to refer to the perinatal period extending to four weeks after the delivery, thus also including late neonatal deaths (those occurring on days 8 to 28 days of postnatal life).

## 1.5 What does this guide include?

Chapter 2 addresses issues around definitions and the classification of causes of death, as well as different systems for classifying modifiable factors. Chapter 3 describes the steps required to establish and complete the mortality audit cycle for facility-based deaths, including:

- identifying cases
- collecting information
- analysing information
- recommending solutions
- implementing changes and
- evaluating and refining the process.

Chapter 4 provides an overview of how to incorporate deaths that occur at the community level into the audit system. Given the importance of a supportive environment for a successful audit, Chapter 5 describes how to create an enabling environment that supports reflective practice. Chapter 6 provides information on expanding a mortality audit system from individual health-care facilities to a network of linked facilities at the regional and national levels, including linkages to CRVS and community surveillance systems.

The following tools, forms and additional resources accompany this guide in the form of annexes. The tools and forms come with instructions and can be modified to fit local circumstances.

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# 2 Definitions and classification

This chapter provides definitions for the key terms relating to stillbirth and neonatal death outcomes. It also introduces systems for classifying causes of death and modifiable factors, with more information and tools provided in the accompanying annexes.

## 2.1 Notes on terminology

Before implementing a mortality audit system, it is helpful to understand the definitions and classification systems used for reporting deaths, as well as the contextual factors surrounding these deaths. As in other mortality surveillance systems, mortality audit for stillbirths and neonatal deaths includes basic descriptive analyses that include rates and proportions relating to pregnancy outcomes, medical causes, non-medical factors and contributing factors. This chapter provides an overview of these concepts.

In recent years, increasing attention has been paid to neonatal survival *(4, 15)* and, to a lesser but still notable extent, to stillbirths *(16, 17)*. One of the key reasons for this has been increased visibility arising from improved data and improved analysis and presentation of these data for use in policy-making and programme planning, such as the generation of annual, country-reviewed estimates of the national neonatal mortality rate. These estimates are included in global reporting and tracked in accountability frameworks, now with a long-range goal detailed in ENAP to track and drive a reduction in neonatal mortality to 12 or fewer per 1000 live births, as well as a reduction in stillbirths to 12 or fewer per 1000 total births, by 2030 *(18)*.

Determining cause of death in the absence of a post-mortem examination is challenging, particularly for stillbirths *(19)*. Yet even in better-resourced settings, the assigned cause of death may not be programmatic or linked to obvious solutions *(13, 20)*. The availability of programmatically relevant and technically credible estimates of what proportions of deaths are attributable to specific causes of death in each country has been another critical step in working to prevent millions of neonatal deaths *(21, 22)*. Disparate classification systems between CVRS systems, routine HMISs and audit forms may result in duplication and inefficient documentation *(23, 24)*. In one systematic review of 142 studies, seven different classification systems were identified for stillbirths but were applied in only 22% of studies that could have used a classification system *(24)*. Clear guidelines and a unified, relevant classification system to assign cause of death are needed.

An emerging approach that has been used in some high-income countries is to link maternal and perinatal conditions, to better address the barriers to care affecting both mother and baby. The development of *The WHO application of ICD-10 to deaths during the perinatal period: ICD-PM* aims to link stillbirths and neonatal deaths to contributing maternal conditions, where applicable, in a way that is consistent across all settings *(25)*. This will help standardize and increase information on causes of death around the critical time of childbirth. The process to assign cause of death in the context of a mortality audit should be easy to apply, comparable across settings, have a good level of agreement between observers, and result in a high percentage of classifiable cases and a low percentage of unexplained causes of death.

Please note that while ICD-PM is designated to be used for all antepartum, intrapartum and early neonatal deaths, it can also be used for late neonatal deaths, which – although falling outside the perinatal period as defined in ICD-10 – may be a consequence of events in the perinatal period.

There are also numerous ways to approach the assignment of modifiable factors relating to substandard care and contextual factors during audits of stillbirths or neonatal deaths. Modifiable factors should be assigned with the inclusion of as much detail as possible, to maximize identification of deficiencies in care and focus attention on achievable preventive strategies.

## 2.2 Mortality outcome definitions

There are a number of important considerations related to the measurement of stillbirths and neonatal deaths within mortality audit systems, including the definition and classification of stillbirths and the timing of neonatal deaths *(26)*.

### Definition and timing of stillbirths

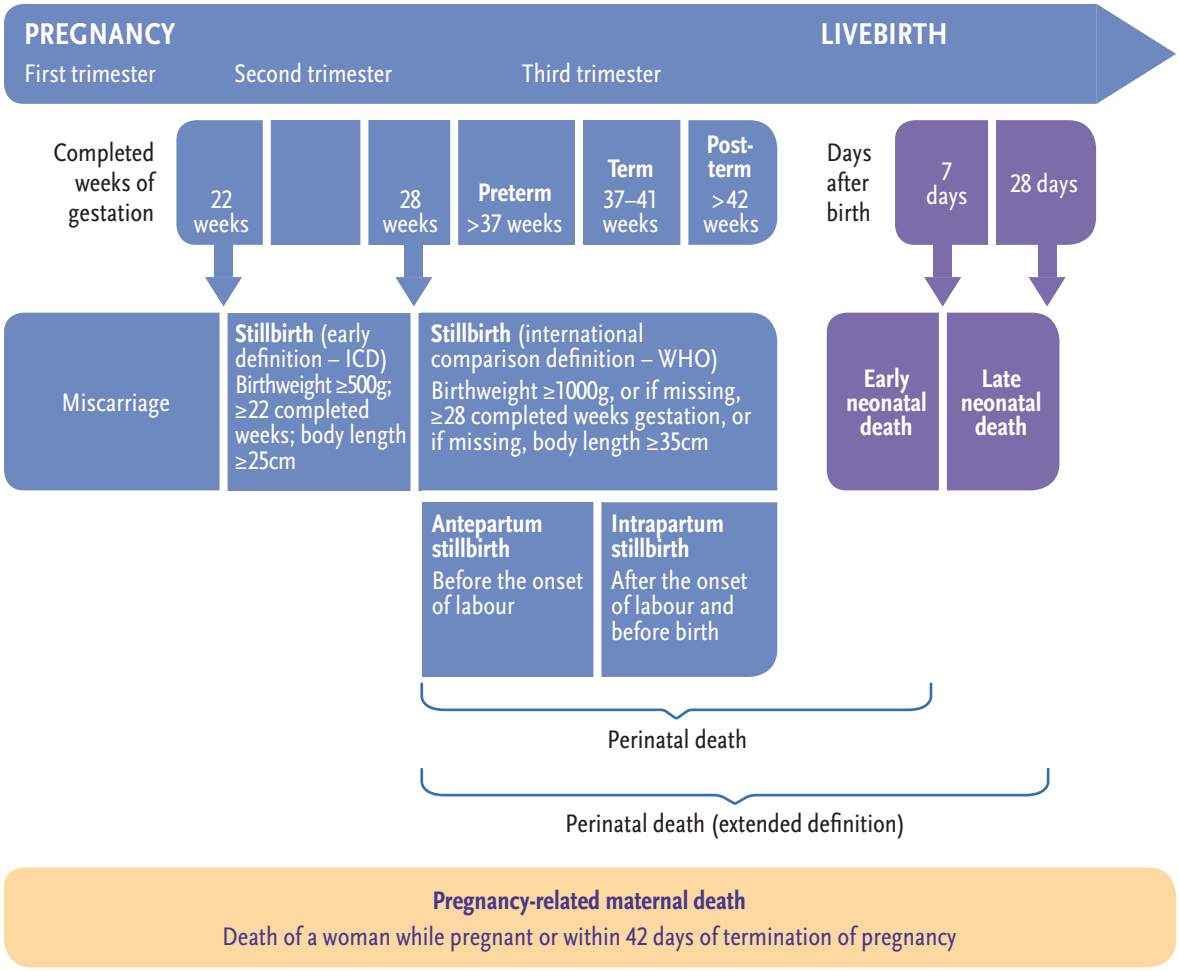
Terminology around stillbirths has changed over time, with variations across settings. For international comparability, WHO recommends reporting of late fetal deaths – for example, third-trimester stillbirths – at ≥ 1000 g birth weight, ≥ 28 completed weeks of gestation and ≥ 35 cm body length, with birth weight given priority over gestational age (Figure 2.1). While birth weight and gestational age are closely linked, they cannot be used interchangeably, since there is a range of "normal" birth weights for a given gestational age and gender, with substantial regional variations *(27)*. Therefore, a gestational age threshold has been recommended as a single parameter, because it is a better predictor of viability than birth weight, and information about gestational age is more likely to be available than birth weight for stillbirths *(28)*. In recent decades, viability has increased in settings where intensive care is available, moving the cut-off point for a death to be defined as a stillbirth (rather than a late fetal death) earlier. Most live-born babies in high-income countries survive even if they are born as early as 25 weeks of gestation, and it is recommended that outcomes are recorded for babies born before 28 weeks *(6, 23, 28)*. The probability of recording the baby as being alive at birth is associated with the perception of the baby's chances of survival *(26)*. WHO's recommended threshold of 28 completed weeks is appropriate for mortality audits in low- and middle-income settings, but it is important to note that this would miss earlier stillbirths, thus undercounting the true burden *(27)*.

A practical and programmatic grouping of stillbirths is as either antepartum (i.e. occurring before the onset of labour) or intrapartum (i.e. occurring after the onset of labour and before birth). When there is no fetal monitoring to confirm the presence of a fetal heart rate at the onset of labour, assessment of the skin appearance is frequently used to estimate the timing of the stillbirth *(27)*. Signs of skin maceration begin around 6 hours after fetal death; therefore, a "fresh" or "non-macerated" appearance of the skin is used as a surrogate measure for an intrapartum stillbirth, whereas a "macerated" appearance is judged an antepartum stillbirth. However, this assessment may underestimate the rate of intrapartum stillbirths, especially in situations where access to care is delayed *(23)*. The stillbirth rate is presented as a rate per 1000 total (live and stillborn) births (Table 2.1).

## Definition and timing of neonatal deaths

The neonatal period refers to the first 28 days of life (Figure 2.1). The early neonatal period is the first 7 days after birth, and the late neonatal period extends from 7 days to 28 completed days. The first day of life, the 24 hours following the birth, is typically called "day 1" in clinical practice, or "day 0" in surveys and vital registration. In this guide we refer to the first day of life as "day 1", and we refer to days 1–7 as the "early neonatal period", days 8–28 as the "late neonatal period", and days 1–28 as the "full neonatal period" *(26)*. Deaths on the day of birth (day 1) and in the first week of life are particularly important because they account for a large number of deaths that can be targeted by interventions around the time of birth. Around three quarters of neonatal deaths are estimated to occur during the first week of life *(26)*. Many late neonatal deaths occur at home and may not be captured in facility-level records, though they may be captured by CRVS systems with variable information on cause of death and relevant details. When deaths do occur in health-care facilities, whether in the neonatal unit, postnatal ward or paediatric ward, they should be documented and included in the audit process. Deaths that occur in the community after discharge from a health-care facility may also be considered for inclusion in the death review process if enough information is available. The neonatal mortality rate is expressed at the population level as a rate per 1000 live births (Table 2.1).

FIGURE 2.1. Pregnancy outcome definitions




*Source*: adapted from Lawn et al., 2011 *(23)*.

**TABLE 2.1. Mortality rate definitions and data sources**

| Indicator | Numerator | Denominator* | Data sources |
|---|---|---|---|
| **Stillbirth rate** | For international comparison: Number of babies born per year with no signs of life weighing ≥ 1000 g and after 28 completed weeks of gestation (ICD-10 also recommends including the number of deaths in fetuses born after ≥ 22 weeks of gestation or weighing ≥ 500 g) | 1000 total (live and stillborn) births | • CRVS<br>• Household surveys<br>• HMIS and audit systems (often facility-based deaths only)<br>• Estimation models |
| **Neonatal mortality rate** | Number of live born infants per year dying before 28 completed days of age | 1000 live births | |
| **Perinatal mortality rate** | Definitions vary:<br>• Number of deaths in fetuses born weighing ≥ 1000 g and after 28 completed weeks of gestation, plus neonatal deaths through the first 7 completed days after birth<br>• Number of deaths in fetuses born weighing ≥ 500 g and after 22 completed weeks of gestation, plus neonatal deaths through the first 7 completed days after birth<br>• Some definitions include all neonatal deaths up to 28 days | 1000 total (live and stillborn) births | |

ICD-10: International Classification of Diseases version 10; CRVS: civil registration and vital statistics; HMIS: health management information system.

* The time period is normally calculated per year.

*Source*: Moxon et al., 2015 *(9)*.

Definitions also vary for the perinatal mortality rate. Perinatal mortality refers to the number of stillbirths and deaths within the first week of life (early neonatal mortality), but the stillbirth definition varies to include stillbirths of either greater than 22 completed weeks or greater than 28 completed weeks of gestation. Some definitions of perinatal mortality also include the late neonatal period, or even up to 6 weeks *(29)*.

## 2.3 Medical causes of death

It is important to emphasize the difference between audit data collected for review meetings and analysis, and routinely collected data that fit standard, official definitions. The official definitions – e.g. those that are used on death certificates – should not be changed for the purposes of audit. Rather, the flexibility in definitions should only be used for the purposes of death review, to generate the most effective learning cases which link to solutions and improvement of services. Annex 1 provides a death case review form with suggested programmatically relevant categories of causes of death for stillbirths and neonatal deaths.

## Classifying causes of stillbirths and neonatal deaths

A globally unifying approach to the classification of stillbirths and neonatal deaths is important if we are to share a common language around the causes of stillbirths and neonatal deaths and make meaningful comparisons across settings. Thus perinatal deaths should be classified using *The WHO application of ICD-10 to deaths during the perinatal period: ICD-PM (25)*, which builds on the features of many other classification systems *(25, 30, 31)* and is applicable in all settings *(25, 32, 33)*.

### *Application of ICD-PM to audit*

ICD-PM is an application of ICD-10 that groups the ICD codes used to classify perinatal causes of death and those used to classify the maternal condition at the time of death, to facilitate straightforward and consistent capture that makes it easy to identify where programme intervention should be targeted to impact the health of both mother and baby *(25)*. Classifying a stillbirth or neonatal death using modified ICD-PM guidance applicable to perinatal mortality audit is a three-step process:

1. Classify the type of death based on timing as one of the following:
    - Antepartum ("macerated" stillbirth)
    - Intrapartum ("fresh" or "non-macerated" stillbirth)
    - Stillbirth, unknown timing
    - Neonatal death (hours and/or days since birth).

2. Identify the main disease or condition that caused the stillbirth or neonatal death. All of the ICD-10 codes that can be assigned to sections (a) and (b) on the death certificate (see Table 2.2) are represented in the following new broad categories, which are included on the Stillbirth and Neonatal Death Case Review Form (Annex 1) and in the Births and Deaths Summary Form (Annex 2):
    - congenital
    - antepartum complications
    - intrapartum complications
    - complications of prematurity
    - infection (select: tetanus, sepsis, pneumonia, meningitis, syphilis, diarrhoea, other)
    - other cause of stillbirth or neonatal death
    - unknown/unspecified.

3. Identify the disease or condition of the mother. The audit team should determine the maternal condition at the time of diagnosis of the perinatal death. The maternal condition at the time of perinatal death may not be the direct cause of the death but is the principal maternal condition at the time; it should be considered reasonably integrated into the pathway leading to perinatal death (e.g. hypertensive disease in a macerated stillbirth, urinary tract infection in preterm birth). If there is no maternal condition (i.e. mother is healthy), this should be documented. The definition of no contributory maternal condition identified at the time of perinatal death is "the absence of any maternal medical condition or deviation from standard intrapartum progress". Specific conditions are grouped into the following broad categories, based on guidance in *The WHO*

*application of ICD-10 to deaths during pregnancy, childbirth and puerperium: ICD-MM* (ICD-maternal mortality) *(31)*. The reference page accompanying Annex 1 provides more detail on the specific conditions in the following broad categories:

- M1: Maternal complications of pregnancy
- M2: Complications of placenta, cord and membranes
- M3: Other complications of labour and delivery
- M4: Maternal medical and surgical conditions; noxious influences
- M5: No maternal conditions identified (healthy mother).

The ICD-PM classification can be useful for a mortality audit because the focus on the mother–baby dyad highlights areas requiring programmatic intervention that will benefit both maternal and newborn outcomes. It simplifies the certification of perinatal deaths but also offers programme officers and public health workers a way to identify solutions that meet the needs of both mother and baby concurrently. The categories used in the Stillbirth and Neonatal Death Case Review Form (Annex 1) and the Births and Deaths Summary Form (Annex 2) have been collapsed to facilitate ease of data entry and analysis, but these causes of death can also be expanded to include more specific causes and categories, depending on the capacity and interest of the facility and audit team.

### *Application of ICD-PM to death certificates*

Table 2.2 shows the four sections of causes of death (a, b, c, d) on a standard perinatal death certificate, as recommended by WHO. Whenever possible, causes of death should be encoded in accordance with ICD-PM classification *(25)*. Coding rules mandate that section (a) is coded to P05–P96 (perinatal conditions) and Q00–Q99 (congenital anomalies). It should be noted that there are a number of exceptions where other codes should be used – for example, neonatal tetanus is always coded to A33 tetanus neonatorum or A50 for congenital syphilis. Assignment of the conditions in each section follows the rules for perinatal mortality coding in ICD-10 volume 2 *(34)*.

To summarize the process, one first considers coding a cause of death using a three-character code. In most cases this is a letter and two numbers (e.g. P26 Pulmonary haemorrhage originating in the perinatal period). If appropriate, this is followed by assigning a more specific cause of death using a four-character code nested under the three-character codes (e.g. P26.1 Massive pulmonary haemorrhage originating in the perinatal period).

**TABLE 2.2. Sections of causes of death on a standard perinatal death certificate**

| Causes of death |
|---|
| (a) Main disease or condition in fetus or infant |
| (b) Other diseases or conditions in fetus or infant |
| (c) Main maternal disease or condition affecting fetus or infant |
| (d) Other maternal diseases or conditions affecting fetus or infant |

The single main disease or condition in the fetus or infant is entered in section (a), whereas multiple other conditions can be entered in section (b). The single main maternal disease or condition affecting the fetus or infant, which, under current ICD-10 rules, can *only* be coded to P00–P04 (maternal conditions in perinatal death), is entered in section (c). Multiple other maternal diseases or conditions affecting the fetus or infant (P00–P04) can be entered in section (d). The assignment of three- and four-character codes for (c) and (d) is the same process as it is for the perinatal cause of death codes (a) and (b).

## 2.4 Collection of a minimum set of perinatal indicators

One of the key actions outlined in the ENAP is to develop a minimum set of perinatal indicators to collect and to ensure that all birth outcomes are recorded, with consistent definitions linked to vital registration and data derived from health-care facilities. Data currently collected and collated on births and birth outcomes vary widely across settings. While a separate form does not need to be completed for every birth and death to record this information, these key indicators should be recorded in a register or electronic HMIS and collated. At a minimum, it is essential to collect information on the following characteristics of each birth and death:

- maternal age
- place of delivery
- mode of delivery
- birth weight
- gestational age
- birth outcome.

Sample forms that capture these key pieces of information and further details are included in Annex 1 (Stillbirth and Neonatal Death Case Review Form), Annex 2 (Births and Deaths Summary Form) and Annex 3 (Minimum set of perinatal indicators to collect for all births and perinatal deaths). To further understand the context, it may be helpful to capture additional information relating to the health and sociodemographic status of the mother and the type of care she and her baby received. Box 2.1 lists additional information that may be relevant to consider when reviewing a death; it should be gathered during history taking and included in the patient file.

## Box 2.1. Background and contextual information relevant to stillbirths and neonatal deaths for review of cases

**Information on sociodemographic status:**

Parents' ages, ethnicity, occupations, education and marital status

**Information on health status and care received:**

***Pre-conception and antenatal***

- Mother's obstetric history (gravidity/parity/previous losses/caesarean deliveries)
- Was the pregnancy planned?
- Was birth control being used?
- Mother's medical history
- Antenatal care (if any): name of the institution that delivered care, gestational age at first visit, number of visits, was birth plan made, complications (including symptoms and signs), procedures and treatment
- Hospitalization (if any): complication, tests and results, procedures, diagnoses, treatments, problems encountered
- Barriers to care (if any): geographic, financial or cultural
- Exposure to environmental factors

***Intrapartum***

- Date and time of onset of labour
- Date, time and gestational age at rupture of membranes
- Place(s) where labour and delivery occurred (including the name of the institutions, if applicable)
- Management and monitoring during labour
- Date and time of onset of complications (including signs/symptoms)
- Hospitalization or consultation (record separately for each): complications, tests and results, procedures, diagnoses, treatments, problems encountered
- Date and time of birth
- Cadre who attended the birth
- Status of the baby: sex, gestational age at delivery, birth weight, Apgar score, stillborn/liveborn
- Immediate care provided to the newborn baby
- Barriers to care (if any): geographic, financial or cultural
- Timeline for the mother/family becoming aware of a problem, decision-making, transport, waiting times

***Postnatal***

- Choice of method of feeding, and date and time of first feed
- Date and time of onset of serious complications (including signs/symptoms)
- Hospitalization or consultation (record separately for each): complications, tests and results, procedures, diagnoses, treatments, problems encountered
- Barriers to care (if any): geographic, financial or cultural
- Timeline for the mother/family becoming aware of a problem, decision-making, transport, waiting times

## 2.5 Modifiable factors

A modifiable factor is something that may have prevented the death if a different course of action had been taken. Many modifiable factors involve missed opportunities within the health system. Identifying these modifiable factors, therefore, can offer potential for positive change. For example, in the case of a neonatal death it may be noted that the birth attendant did not provide bag and mask resuscitation when the baby did not respond to vigorous stimulation. In this case, there may have been a missed opportunity to avoid the situation or provide corrective action – failure to train birth attendants on resuscitation, or to provide a bag and mask in the delivery room.

Documenting the contributing and potentially modifiable factors related to each death is a priority in a mortality audit for stillbirths and neonatal deaths because it provides an opportunity to change behaviours and systems. Although at first glance a death may appear to be due to a single biological cause, further analysis usually reveals a number of contributing factors or underlying causes. Often by exploring the event and gaining a better understanding of the root causes, solutions and strategies become more apparent. Examination of these factors provides insight into whether each death may have been preventable and potential solutions that may prevent similar deaths in the future.

The terminology used to describe this concept varies, including "avoidable factors", "elements of substandard care", among others. "Modifiable factors" is the term used in this guide, to limit the opportunity for blame and point to elements of care that are potentially amenable to change.

There are also multiple systems and approaches for classifying modifiable factors *(35)*. The death case review form (Annex 1) proposes a simple approach which identifies and categorizes modifiable factors in a few ways. The first proposed method uses the well-known "three delays" model *(36)*:

- Delay 1: Were the mother, father or other family members unaware of the need for skilled care for the mother during pregnancy and birth, and for mother and baby in the neonatal period? Were they unaware of the warning signs of problems during pregnancy or in newborn infants, or were they reliant on harmful traditional medicine and practices? Were there any other sociocultural factors or barriers? (see Box 2.2)
- Delay 2: The necessary maternal and/or neonatal health services did not exist, or were inaccessible for other reasons. Was distance or cost a factor? If there was a delay in travelling to the health-care facility after a problem was identified, what were the reasons for this?
- Delay 3: The care the mother and baby received at the health-care facility was not timely or was of poor quality. Was this due to provider error, lack of supplies or equipment, or poor management?

In addition, identifying the level at which a system breakdown may have occurred provides more detail on the potential for action to prevent future deaths. The levels detailed in the death case review form in Annex 1 include:

- Family- or patient-related: e.g. late or no antenatal care; cultural inhibition to seeking care; limited or no knowledge of danger signs; financial constraints; partner restricts care-seeking; use of traditional/herbal medicine; alcohol use; attempted termination.
- Administration-related: e.g. lack of or insufficient neonatal facilities, theatre facilities resuscitation equipment, blood products or training; insufficient staff numbers; delay in anaesthesia; lack of antenatal documentation.
- Provider-related: e.g. the partograph was not used; timely action was not taken; inappropriate action was taken; iatrogenic birth; delay in referral; inadequate monitoring; delay in calling for assistance; inappropriate discharge.

### Box 2.2. Assigning modifiable factors at the patient/family/community level: a word of caution

Audit participants should be wary of placing "blame" on the patient or the family when assigning modifiable factors to a particular case. While critical delays do occur at the community level, and there can be real individual- or family-level behaviours that lead to a death, audit teams should guard against placing the burden of responsibility on the woman and/or her family. One way to guard against this is to calculate the proportion of modifiable factors that occur at the facility level and at the district/community level. If the patient-level factors are increasing or the issues remain constant over time, question whether there were any other factors at the point of care or elsewhere that could have played a role. The audit committee can also examine the recommendations that have been made and what actions have been taken. When community-related modifiable factors are identified through audit, it is important that communities are informed of the findings and that active members are involved in determining and implementing the solutions.

Identification of gaps at these three basic levels can be followed by root cause analysis to better understand underlying deficiencies in care *(37)*. A root cause analysis helps to identify all the problems that led to or contributed to an event – in this case, the stillbirth or neonatal death under review. The purpose of this analysis is to identify the factors that contributed to the death and further assess whether there are any underlying causes to the contributing factors. This analysis may help formulate integrated strategies and recommendations. The diagrams that are created during root cause analysis are known as Ishikawa diagrams or fishbone diagrams, because a completed diagram can look like the skeleton of a fish (see Annex 4 for examples).

The root cause analysis approach is adaptable, and other methodologies have been used successfully in different settings *(35)*. For example, the process of determining whether adequate care was provided can also be based on a criterion-based audit against national standards, as implemented in Uganda *(38)* and South Africa *(39)*. Assessing the care provided against a limited set of existing standards for availability of equipment, medication and staff by level of service has the potential to be less subjective than the methods described above *(38, 40)*. Additional guidance for classifying modifiable factors with varying levels of complexity and detail is provided in Annex 4.

# 3 Auditing deaths that occur at the health-care facility

This chapter provides an overview of considerations for initiating a system for reviewing stillbirths and neonatal deaths that occur at a health-care facility, and the process required to walk through each of the steps of an in-house mortality audit cycle at the health-care facility level.

## 3.1 Setting up the system

In many health-care facilities, local in-house mortality reviews are conducted as standard clinical practice and risk management. This is not always the case, however, even in facilities where there are large, multidisciplinary teams operating in well-resourced settings; but often some form of review is part of an ongoing quality improvement processes. A good principle is to review what already exists, start small and scale up gradually. A phased approach to scaling up may be applied: following introduction and institutionalization in one or a few facilities, expand the audit system to other locations, moving towards greater coverage (Figure 3.1). This chapter describes the process of introducing the mortality audit approach at an individual health-care facility, while the process of scaling up to a regional- or national-level system is described in Chapter 6.

A positive enabling environment at the national and/or regional level will make it easier to move through the various phases of the mortality audit process, but it is possible for an in-house process to start and thrive without initial external support from authorities at that level. In the pre-implementation phase, the right stakeholders need to be involved to establish the programme and raise awareness about it. In some settings, audits may be linked to existing quality improvement initiatives. If a quality improvement committee is already in place, it can be engaged to support the formation of a facility-level steering committee that will prepare cases for review and rotate facilitation of the audit meetings (Annex 5). This committee could be combined with an existing maternal death review committee, or just closely linked to it (Box 3.1), but either way, the committee should be well institutionalized within the system. The steering committee's role includes the overall responsibility for operationalizing the audit policy, providing technical assistance for the implementation of audit systems, and monitoring recommendations and follow-through.

Midwives and obstetricians are in a natural position to lead the audit process, given their knowledge of the burden of intrapartum deaths. In South Africa, midwives drive the national mortality audit process, called the Perinatal Problem Identification Programme (PPIP) *(41)*. However, recording the details of first-day and later neonatal deaths also requires crossover with other departments and specialities such as paediatrics, neonatal nursing, emergency, outpatients and pharmacy. In Brazil, for example, paediatricians hold leadership positions on perinatal review committees. In Uganda, stillbirth and neonatal death review has been successfully initiated and sustained by midwives and community representatives *(42)*. A facility-based mortality audit committee should include representatives of various departments, and stakeholders from among the facility's management team and the district medical office as well as a community liaison, if applicable. In some settings, the range of committee participants may be even further expanded *(43)*. In the United States, multi-agency child death review involves coroners, law enforcement officers, child protective services and health-care providers *(44)*, and in England, each local authority has established a multidisciplinary child death overview panel to review all child deaths (from birth to age 18) in their area *(45)*. However, such a wide stakeholder group is not essential. Involving the legal system, in particular, can undermine a collaborative environment in which shortcomings in care are openly discussed. While accountability is needed, the mortality audit process should focus on the ability of health professionals to identify opportunities to improve the health system, not assign blame.

Within each facility, at least two individuals who are willing to lead the data collection process should be identified. Larger facilities may need a bigger data collection team to share the responsibilities and achieve full coverage. If there is only one data collector who can work only part-time for the review committee, the committee may decide to select a subset of cases for review, take a thematic approach or limit the review to cases that are most likely to be preventable (see Box 3.1 and also section 3.2, Step 1).

### Box 3.1. Linking audits for stillbirths and neonatal deaths to existing facility-based maternal death reviews

It is important that the process for maternal and perinatal death review are coordinated and linked, rather that operating in parallel.

If maternal mortality and morbidity review meetings already exist at a health-care facility, with several maternal deaths or near misses to review at every meeting, teams may consider reviewing at a minimum a selection of intrapartum stillbirths and first-day neonatal deaths to avoid spending too much additional time in the meetings. If only a subset of all stillbirths and neonatal death cases is being discussed at review meetings, key details should be recorded for each patient. Given the higher numbers of stillbirths and neonatal deaths than maternal deaths, it might make sense to institutionalize separate but linked perinatal meetings once the review process has been established, especially in large facilities.

Annex 3 provides a minimum set of perinatal indicators that should be collected for each birth and death, and integrated within a broader surveillance system.

The steering committee and the district and facility management teams have a responsibility to nurture a culture that is conducive to a successful audit process in a no-blame environment. This will also contribute to accountability at the national level. Lessons learnt from maternal mortality audits indicate that successful ones were those led by committed health professionals, while less successful audits often suffered from poor leadership and a reluctance of staff to participate. Where poorly planned reviews had been running for some time with no action taken on the results, senior staff stopped attending meetings, which led to a sense of futility and demoralization among the more junior staff *(3)*. Having participants agree to a code of practice for review meetings (Annex 6) and ensuring confidentiality as much as possible can contribute to an environment where the audit is more likely to be successful *(46)*.

Once the committee is established and key actors identified, physical and financial resources may be required to adapt tools and software, and provide training to district, management and clinical staff on the new system (for more information on training, see Chapter 5). The decision of whether to adopt an electronic or paper-based system is an important one, with trade-offs on both sides. In settings with limited computer literacy and inconsistent power supplies, electronic data entry may hamper implementation *(47)*, though some success has been seen with systems that use mobile phones *(48)*. Regardless of the medium, the development of a user-friendly form that reflects local capacity for data entry is an essential component of this process.

## 3.2 The six-step mortality audit cycle

Once positive support from management is secured, the leadership of the steering committee has been appointed, and the tools are in place for data collection and for linking to regional or national systems if they exist, the process of moving through the six-step audit cycle may begin: (1) identifying cases; (2) collecting information; (3) analysing information; (4) recommending solutions; (5) implementing solutions; and (6) evaluating both the process and the outcomes, and refining the process as indicated. Each of these steps will now be described in detail.

### Step 1: Identifying cases

The aim should be to record all deliveries, births, stillbirths and neonatal deaths that occur in the delivery ward, neonatal unit and postnatal ward, ensuring that the indicators contained within the minimum set of perinatal indicators are captured in a register or a central database (Annex 3). Trends in these data can be analysed using the calculations in Annex 7.

In some settings, audit teams may be able to rely on CRVS systems to help identify events, and the process and individuals involved in death certification at the facility level should be integrated with the mortality audit process. However, as discussed in Chapter 2, even in the presence of vital registration systems with complete coverage of most events, reporting of stillbirths and neonatal deaths may not be complete. Frequently, civil registration does not require reporting of stillbirths, or they are not well reported, similar to the poor reporting of many early neonatal deaths *(4, 28)*. Cultural interpretations of when a baby becomes a "person" may also affect the willingness of health staff to audit particular deaths. Late neonatal deaths are often excluded from registers of neonatal deaths if the babies have been readmitted and then die on the paediatric ward rather than in the neonatal unit, but this is a missed opportunity to address preventable neonatal deaths and system gaps.

Advocacy may be needed around case definitions and expanding data capture to cover all stillbirths and neonatal deaths. This first step may be accompanied and supported by a national process to advocate for the introduction or improvement of perinatal death certificates to capture cause of death and maternal condition and link this information to local and national statistics.

Given the challenges of documentation and data collation in a high-volume health-care facility setting, specific strategies should be put in place to ensure that all deaths are captured in the routine health information system and filtered to the mortality audit committee so that cases can be selected for review and discussion at mortality audit meetings.

Whereas maternal deaths are rarer than stillbirths or neonatal deaths, and in many countries they are a notifiable event (i.e. an event that must be reported to the authorities), it is unlikely that policy will mandate for stillbirths and neonatal deaths to be notifiable at the national level. Even so, each stillbirth and neonatal death should be recorded. Generally speaking, the number of stillbirths and neonatal deaths will relate to the number of births that occur at any given health-care facility. Table 3.1 provides rough estimates of how many deaths can be expected at facilities of varying sizes (indicated by births per year) with a range of in-facility perinatal mortality rates (PMR), so that these estimates can be

compared to the actual numbers of registered perinatal deaths, as an indication of how well the system captures perinatal deaths, and how many cases are likely being missed. However, even in settings with fewer deaths, analysing a case with relevant learning points can still yield valuable information on modifiable factors and lead to improvements in the quality of care.

**Table 3.1. Expected number of facility-based perinatal deaths (stillbirths and deaths in the first week of life) at various levels of mortality at the facility**

| Births | Expected number* of facility-based perinatal deaths *per year* for a range of in-facility perinatal mortality rates (PMRs) | | | |
|---|---|---|---|---|
| Per year | PMR 20 | PMR 30 | PMR 40 | PMR 50 |
| 156 | 3 | 5 | 6 | 8 |
| 260 | 5 | 8 | 10 | 13 |
| 364 | 7 | 11 | 15 | 18 |
| 520 | 10 | 16 | 21 | 26 |
| 780 | 16 | 23 | 31 | 39 |
| 1040 | 21 | 31 | 42 | 52 |
| 1300 | 26 | 39 | 52 | 65 |
| 1560 | 31 | 47 | 62 | 78 |
| 2080 | 42 | 62 | 83 | 104 |
| 2600 | 52 | 78 | 104 | 130 |
| 3900 | 78 | 117 | 156 | 195 |
| 5200 | 104 | 156 | 208 | 260 |

* Calculated as: expected number = (perinatal mortality rate) × (no. of births per year) / 1000.

At any health-care facility, the number of perinatal deaths will be much higher than the number of maternal deaths. Depending on the staffing and workload at the facility, it may be prudent for the mortality audit committee to start by reviewing a selection of stillbirths and neonatal deaths, to reduce the length of review meetings. For more information, see Step 4: Recommending solutions.

If there is no pre-existing, current list of all stillbirths and neonatal deaths that occur at the health-care facility, this will need to be created by the mortality audit steering committee to improve capture of perinatal deaths for review. The list should include an identifying code or initials and the baby's date of birth, to avoid duplicate entry of the same death, as well as which unit recorded the death.

The following questions can assist in the selection of sources to investigate and use in the review process:

- Where are deaths likely to occur in the facility?

- Which deaths do I want to collect more detailed information on? (e.g. all or a subset of antepartum stillbirths, intrapartum stillbirths, early neonatal deaths, late neonatal deaths, a particular range of birth weights or gestational ages, see below and Box 3.1)
- What kinds of records exist? (e.g. labour and birth registers, postnatal registers, emergency or operating theatre records, discharge logs with status of patient, paediatric registers)
- Are the records paper-based or electronic?
- Are all the records housed in one location, or are they scattered?

Once all the places where the data might be located have been identified, a plan for systematically reviewing these sources may be created that includes a schedule for checking various registers and departments.

If the burden of stillbirths and neonatal deaths is high it may not be feasible to review all cases. Further, if human resources are limited – e.g. if there is only one data collector who can work only part-time for the review committee – the committee may decide to select a subset of cases for detailed review (e.g. only the cases that take place in the first week of each month) or to take a thematic approach (e.g. for a specified number of meetings, only deaths attributed to sepsis will be reviewed, followed by a different cause of death), or to limit review to cases that are most likely to be preventable (e.g. intrapartum stillbirths and neonatal deaths among near-term babies).

## Step 2: Collecting information

For every death, decisions must be taken as to what information is recorded, where the information is recorded, who records it, and who collates it on a periodic basis both for the death review process and for reporting to other levels within the system such as facility- and district-level administration, the national ministry of health, as well as intersectoral systems such as CRVS. It is important to limit the data collected. Having too many difficult or highly detailed questions with no apparent purpose alienates busy staff who are required to fill in the forms. If a use for the data cannot be identified, then the data should not be collected. Having a clear understanding of the data analysis plan will help with these decisions.

Ideally, deaths are reviewed within a week of the event. Depending on the interval of the mortality audit review meetings (e.g. biweekly or monthly), the total number of deliveries, stillbirths and neonatal deaths during that time period is captured on a standardized data capture form by the designated staff members. These are usually physicians or midwives, though they can be data clerks if these cadres are available. In all cases, those entering data should be trained on the system and the reasons for its use. Data abstraction/collection forms may be either paper-based or computerized/electronic, but they should include clear directions about exactly what information is to be collected. It is helpful to pilot-test and then revise these forms as needed prior to use and to allow for future review and updates. Most of the abstracted data will be quantitative, and the form should have clearly designated data entry fields. If items are pre-coded, all possible responses should be captured (including missing responses) or a space should be provided for entering other values. Because data may at times be abstracted as text, such as the description of a chain

of events that led to death, text boxes should be an option in both electronic and paper systems. They should be large enough to allow the abstractor to describe the event in full.

Key information to collect for a facility-based review is outlined in Chapter 2 (see Box 2.1). Briefly, the minimum data required cover information about the mother's condition, the baby's condition on admission and/or the at onset of labour (for antepartum and intrapartum deaths), the baby's condition at birth (stillbirth or live birth), the baby's condition on discharge from the health-care facility (alive, transferred to another facility or dead), and the date and time of birth and death (so that age at death can be calculated in hours, not just days).

A phased approach can be considered, in terms of the level of data complexity. For example, the committee at the facility can start with a form that simply captures the number of births, stillbirths and neonatal deaths, as well as details on how many were intrapartum stillbirths and intrapartum-related neonatal deaths, to assess trends over time. This is a possible first step, while gauging the willingness of the mortality audit committee to introduce a wider and more in-depth stillbirth and neonatal death review process, or to add the review of stillbirths and neonatal deaths to a more established maternal mortality or maternal near-miss audit system.

If a more comprehensive system is feasible, data captured on each death may include the programmatically relevant cause of death, linked maternal conditions, demographic data and a limited list of contributing, modifiable factors corresponding to codes for analysis and clearly linked to recommendations (see Chapter 2 and Annexes 1–4 and 7). If there is a possibility to link deaths that occur in the community to the facility's audit system, decisions can be made about how the chain of notification will operate depending on the local context. Given the challenge of locating medical records after the fact, the necessary information on each death should be extracted from the patient file and relevant medical records as soon after the birth and death as possible. Even so, delays in documentation may occur and files may be lost. In cases where lost medical records may have provided key information related to the circumstances surrounding the death (and thus possibly related to the cause of death and modifiable factors), it may still be desirable to include the case in the mortality review meeting, in order to highlight the importance of following protocol for case notes and record-keeping.

For the majority of cases, data can be abstracted from patient notes and medical records without additional research. If interviews are being conducted by the audit committee – for example, to glean more information about a specific cause of death or contributing factors – interviewers may want to collect relevant information from mothers, family members, relatives, community members and health workers. Training on interviewing techniques may be helpful, including how to probe for information in a sensitive manner without upsetting the respondent or biasing their responses, and how to help respondents recall dates and other important information. Interviewers should also be prepared to respond to questions or requests for information from the interviewee. The interviewer should always receive consent before each interview and assure respondents that the information collected will be kept confidential by the facility staff and that the privacy of the families and the health workers involved is paramount.

Sometimes information concerning the birth and death from different sources may be contradictory. Although it is not the task of any one individual to reconcile such discrepancies, it is important that they are highlighted at the stage of data collection and synthesis, with plans to rectify inconsistencies in register data and move towards better-quality inputs. Data quality should be ensured at the data entry level. South Africa's PPIP electronic database has a number of built-in validity checks *(41)*. Some are automatic on the data entry page, and other validity checks can be activated once the monthly data have been entered (e.g. critical fields must be filled in before the next field can be activated for data entry, and implausible entries – such as 60 weeks gestational age, or 20 kg birth weight – are not permitted by the software. This minimizes the potential for missing or incorrect data. Data verification should happen at the facility level before local data are relayed to any higher levels.

Variations in trend data (Annex 7) – for example, increases or decreases in deliveries or care-seeking behaviours – may need to be examined further with information from the community to understand possible explanations for these changes (see Chapter 4). Innovation and technology such as software programs can help, particularly in the rapid analysis and presentation of results, but should not be the focus of the audit process or a barrier to uptake.

## Step 3: Analysing information

It is helpful to have an analytic plan to guide the process, keeping in mind that the overall goal is to identify problems in the system that may contribute to stillbirths and neonatal deaths, especially those that could have been prevented or avoided. To accomplish this, data analysis should ideally include both qualitative and quantitative components. The quantitative analysis, based on data such as geographic location and maternal risk factors, will provide information on which groups of babies are at higher risk of death, and identify trends in mortality rates and medical causes of death. Qualitative analysis of information about contributing factors and barriers to care, among others, will provide additional insight into the problems that caused the deaths of individual babies as well as more generally providing information about groups of babies affected by similar contributing factors. For example, qualitative data can help to answer questions about individual cases such as: Did the baby die because no one realized how sick it was or because the health centre was too far away? Were the right medicines not administered or were they unavailable? Collection (by interview) and review of such qualitative data can be particularly helpful for getting more information when patient notes in a particular case are very limited, for example if cause of death is simply noted as "already dead" or "arrived too late". The use of both types of data together will provide a more rounded view of what the problems are and help the review committee identify priorities for action.

While death reviews should not primarily be a process to produce data, there are a number of informative quantitative analyses and outcomes that can be tallied by the review committee or designated staff and presented at scheduled mortality audit meetings, as well as posted publically within the ward or unit. The minimum set of perinatal indicators that could be presented in this way include *(49)*:

- the number of normal vaginal, assisted and caesarean deliveries;
- the number of maternal deaths;

- the number of antepartum (or macerated) and intrapartum (or fresh) stillbirths and early neonatal deaths; and
- in-facility stillbirth (intrapartum and antepartum) and neonatal mortality rates.

The number of major complications during labour and birth, and the reasons for caesarean section (fetal distress, obstructed labour, failed induction, placental abruptions, postpartum haemorrhage, postpartum infection, severe preeclampsia or eclampsia, etc.) may also be collated and presented. Audit committees, facility administrators or local policy-makers may want to pick one particular indicator to focus on and follow over time to see if outcomes improve after implementing audit recommendations.

Computer programs, such as the Perinatal Information System *(50)*, can be designed to run analyses and produce standardized tables, graphs and maps, which may enhance the use and reporting of data (Annex 7). Although the set-up of an automated system requires an initial investment, it will save time and money in the long run. Program maintenance and plans for updating source data and program codes should be integrated into the data management plan, as well as checks within the system to avoid erroneous data entry, where possible.

Indicator tallies over time are simple and quick to prepare, but more detail could be gained from geographically mapping key details related to specific indicators – for example, if a number of women presenting with obstructed labour come from a specific area, there may be a transport or other issue affecting access to the health-care facility. Mapping cases may be time-consuming but can provide more information about the population's care-seeking behaviour, existing social and health services and the natural environment.

For each individual case, a death case review form with key details should be completed ahead of the meeting (see Annex 1: Stillbirth and Neonatal Death Case Review Form), by compiling data from multiple sources. While the form is concise, it should include all relevant information, both medical and non-medical, as well as some standard demographic data. Although it is more efficient for a designated individual or small group to complete the whole form – including the direct causes of death, related maternal conditions and modifiable factors – before the mortality audit meeting, these sections may also be discussed and completed during the meeting itself until the designated individuals are comfortable with completing the process independently.

The review team should remain open to considering all possible problems and factors revealed by the data. Different methods of classifying modifiable factors are detailed in Chapter 2 and Annex 4. The combined quantitative and qualitative analysis will allow identification of patterns and trends of problems, both non-medical and medical, that lead to deaths. The interpretation of and action in response to the results of the quantitative analysis – i.e. information about the most common problems contributing to stillbirths and neonatal deaths – will be the job of the health-care facility staff, management and local leaders who are members of the mortality audit committee.

Additional analyses that could be helpful include the approximate number of deliveries and deaths and their distribution by place of occurrence (home, health centre, public hospital, private hospital or other level/type of hospital). Where more detailed demographic

information exists, mapping the geographic location of towns and health-care facilities, as well as roads and rivers, may also provide valuable information on access and sociodemographic factors that may be related to the deaths.

## Step 4: Recommending solutions

One of the most challenging parts of the review process is the formulation of appropriate recommendations, but this step is critical to the process. As data and trends are examined, patterns of problems will become evident. Moving from problems to solutions requires more effort and creativity but is an integral part of the process to prevent similar deaths in the future.

The type of solutions identified will depend on the individuals responsible for the investigation, the breadth of stakeholder involvement and the level of development and local resources. The recommendations may relate to a one-off action or an ongoing activity, and they may need to balance priorities based on the burden of various causes of mortality and the feasibility of implementing the various solutions. Review committees will be able to determine from the results of their own analyses which mixture of strategies will be best suited to their circumstances, including their access to resources. However, solutions should always be SMART: specific, measurable, appropriate, relevant and time-bound. The responsibility for tracking the progress of each solution should also be assigned to specific individuals. Even if the designated person is not solely responsible for making the change, assigning implementation and monitoring tasks to individuals reduces the likelihood of failure to follow through with action.

Mortality audit meetings where the basic overview of number of deaths is presented can take place as regularly as every morning. However, a larger periodic review meeting is necessary for detailed review of select cases. To institutionalize the system, a formal platform should be created to present the findings of the audit process. In larger facilities, this meeting may already be a mandatory event across departments. In other settings, attendance may vary by shift, department and discipline, but attendance should be encouraged.

At the mortality audit meeting, a skilled, independent and accepted chairperson is needed to guide the discussion. While the tendency is to designate a senior clinician as the chairperson, such as a doctor, it is important to consider nurses and midwives for the role, and to involve them in the process. Aggregated statistics and trends should be presented, with selected individual cases also presented anonymously and without bias. The presentation of cases may include as much information as available, from antenatal care through to the point of death. The facilitator may refer participants back to best practice guidelines, where available. A discussion should follow the presentation, reflecting on the modifiable factors of specific cases, and any changes in trends from meeting to meeting. The group should attempt to reach consensus on appropriate, evidence-based strategies required to address the main gaps in care that have come to light. At this stage, a framework to define what went well and what could have been done differently to provide better care in a no-blame environment can be helpful, along with minuted notes of recommendations, suggested actions and the person responsible for implementing and/or tracking each (see Annex 8 for guidance on taking minutes at mortality audit meetings and following up on action items).

Possible actions include interventions in the health-care facility, in peripheral or linked local health services and in the wider public sector, as well as in the community. Information from facility-based quality improvement approaches may point to the need for changes in clinical practice (direct patient care) or modification of service provision at the system level, such as how to provide the necessary drugs and trained personnel at a health-care facility or perhaps the need to establish clinical guidelines for care. Community-based approaches may point to the need for the development of health promotion and education programmes as well as possible changes in community service provision, changing home practices or improved infrastructure, such as roads, bridges and communication technology. These solutions are beyond the scope of the review committee to address, and necessitate links to a regional or national audit committee or higher-level authority, and community leaders. It is important for all of these elements to be included, especially in audit systems that extend beyond a single or regional grouping of health-care facilities. Nevertheless, audit findings and actions should also always include recommendations that are achievable at the point of care.

Dissemination of audit findings is important at multiple levels. The general principle around dissemination is to get the key messages to those who can implement the findings and make a real difference towards saving babies' lives. Some examples include: ministries of health; local and regional planners and politicians; professional organizations; leaders in peripheral sectors such as education and social security; private sector health professionals and institutions; health promotion experts; academic institutions; and local health-care managers or supervisors not involved in the mortality audit committee. If a community liaison role exists, relevant findings for the community, particularly around the first delay in seeking care, should be shared in appropriate forums (see also Chapter 4). Health-care institutions may use radio stations, local newspapers and civil society organizations to share information with community members and elicit feedback *(47)*.

A periodic report is one way to disseminate the findings and recommendations. The report should be written in clear, easy-to-follow language, and should include some standard sections such as data trends covering numbers of births and deaths, causes and modifiable factors, as well as recommendations and the solutions enacted. The report may be kept as an internal document, copied and distributed to all staff, or it could also be shared with all relevant stakeholders and concerned community members. While the report should be clear and straightforward about the potential for improving care, it should do so without placing blame. Positive vignettes – for example, the case of a near miss that was prevented because of a gap identified and addressed by the audit committee – can be presented alongside recommendations and progress towards solutions. These case studies are helpful narratives that communicate the findings of an audit in a very practical way. Another option is a short, less formal newsletter that could be drafted by delegated members of the audit committee following each meeting, to share in a non-threatening way the recommendations arising out of the meetings and the actions taken.

## Step 5: Implementing changes

Taking action to prevent stillbirths and neonatal deaths is the reason for the entire audit cycle. A number of problems and potential actions are likely to be identified in almost any review. These can be separated into short-, medium- and long-term actions, with specific

time frames for each. It is also important that the responsibility for implementing and/or monitoring each recommendation arising from the mortality audit meeting is assigned to one or more team members. While recommendations based on modifiable factors that fall under the purview of administration may be acted on quickly within a responsive management structure (e.g. ambulance availability or lack of resuscitation equipment), it may be more effective to first focus on the modifiable causes that are within the control of health workers (e.g. detailed history taking and correct partograph use) and then use successes emerging from subsequent mortality audit meetings as an advocacy tool to prompt management to further action. In addition to following up on items that have not been completed, it is important to celebrate progress and identify successful changes when they occur.

Lessons learnt through experience with maternal mortality audits point to three interdependent factors contributing to recommendations resulting in successful solutions. These factors were (i) *individual* responsibility and sense of ownership; (ii) a proactive *institutional* ethos that promotes learning as a crucial part of improving services and quality of care; and (iii) a supportive political and policy environment at the *national* and/or *local* level *(46, 51)*. In programmes where staff members were disinterested, uncooperative or even obstructive, failure and disenchantment followed. Disenfranchisement and thus failure to fully participate and engage with the recommended changes has been shown to arise from an environment lacking in professionalism and self-reflective learning, where there is a fear of blame and punishment, and disillusionment with a persistent lack of action on the recommendations made in earlier meetings or reports *(3)*. If, on the other hand, the audit takes place in a forward-looking and safety conscious culture, long-lasting improvements can be made. Healthy hospitals that support their staff understand that errors are unintentional, and in these settings learning from adverse events is encouraged, and the leadership open and fair. The importance of leadership within the enabling environment is discussed in more detail in Chapter 5. Overarching conditions that lead to implementation of recommendations from audits include good leadership, task-oriented minutes (Annex 8), staff stability, good communication with academic departments and clinics, and the existence of guidelines and protocols *(52)*. Similarly, conditions hindering implementation included poor communication between health workers and the community, frequent staff rotation, staff shortages, unresponsive management, inadequate financial resources, poor attendance at review meetings and an absence of skilled supervisors.

Experience from maternal death reviews indicates that a multifaceted approach is needed to translate recommendations into action. In the QUARITE trial *(53, 54)*, which showed a substantial reduction in maternal mortality in low-resource facilities in Senegal and Mali, a bundle of three interventions was implemented:

- involving opinion leaders to champion the process, the findings and the actions for change in the local health-care facility;
- engaging a quality improvement committee that would conduct case reviews and determine whether recommendations are being acted on; and
- strengthening the capacity of health-care professionals, using drills and simulations.

## Step 6: Evaluating and refining

The final step in the audit cycle involves looking back to evaluate what worked and what did not, and then refining and adapting the approach in order to move forward with an improved process. Evaluation goes back into the action cycle to examine how successful it was in identifying deaths, collecting, reviewing and analysing the information, and identifying the problems that contribute to stillbirths and neonatal deaths. In general, the purpose of evaluation is to ensure that the approach used is both efficient in the way it works and effective in instituting beneficial practices.

Documenting changes over time, through an annual review meeting or report as described above, helps to identify successful components and those still needing work. Once the process has begun, maintenance and supervision is critical. Systems that can provide real-time feedback linked to data showing long-term trends (e.g. reduction in the rate of intrapartum stillbirths over a five-year period, after introduction of better quality intrapartum care) can be motivating for users. A list of questions has been developed to help users assess and reflect on progress at each stage of implementation, from creating awareness of the need for a mortality auditing process to integrating it into routine practice; this is provided in Box 3.2 *(47)*.

In addition to the ongoing evaluation of the process of acting on the recommended solutions, as well as monitoring indicators that provide a quick snapshot of whether the system and outcomes are improving, a more detailed periodic evaluation is useful, particularly if: (i) the indicators demonstrate that outcomes are not improving despite actions being taken; or (ii) mortality rates are not decreasing. While it is important to look at reductions in mortality rates, trends in these rates are not always the best illustration of improvements in care, because there are many factors that influence the in-facility mortality rate. Improvements in the community, in the health system or in society in general, and changes in the types of delays or modifiable factors that are being identified will prove insightful. A more detailed evaluation can also be used to assess whether the system can function more efficiently. Ideally, there should also be a periodic evaluation of the quality of the information captured, particularly if the system is not linked to an HMIS and CRVS.

A summary of these six steps is provided in Annex 9 as a quick reference.

### Box 3.2. Questions for reflection on the implementation and maintenance of the audit system

- How can review meetings be improved and used more effectively?
- How often and to whom is feedback given?
- What are the gaps in our feedback procedures?
- How can the feedback to service providers and senior management in the facility be improved?
- How can engagement in the audit process, the use of the findings and the application of recommendations be improved?
- How can feedback outside the facility be improved, e.g.at district or provincial levels and in the community?
- How can involvement from each of these levels be improved?
- Who is responsible for keeping the audit system together, e.g. one person, a team, formally or informally designated?
- Who is leading the audit? Who takes responsibility when the leader is not there? What kind of succession plan do we have?
- How do staffing issues such as rotations and turnover influence the audit activities?
- If lacking, how can staff stability be improved?
- What is our facility's responsibility in reaching out to another facility or facilities to introduce and establish an audit programme?

*Source*: Belizan et al., 2011 *(47)*.

# 4 Auditing deaths that occur in the community

This chapter provides an overview of considerations for initiating a system for auditing stillbirths and neonatal deaths that occur in the community. Family and caregiver narratives within a traditional verbal and social autopsy interview can help identify social, behavioural and health system contributors, in addition to the biological causes of death, as a means of generating information about key delays and modifiable factors.

## 4.1 The importance of review and response to deaths in the community

In many countries, despite high average rates of antenatal care and increasing rates of facility-based delivery, even in resource-limited settings, many births still occur at home, without any contact with health-care facilities or providers. Therefore, many stillbirths and neonatal deaths also still occur at home. Many of these families will have had contact with a health-care facility or community health worker (CHW) during pregnancy and/or delivery. Identification and review of these stillbirths and neonatal deaths occurring in the community is needed to help complete the picture of why these deaths are occurring and how they can be prevented. Identification and analysis of these deaths requires the facility-based and district-level mortality audit committee and the community to be accountable to each other for sharing information and enacting changes.

Factors contributing to stillbirths and neonatal deaths in the community may be different from those contributing to facility-based deaths and may not be identified by the facility-based mortality audit process. For example, reviews of deaths occurring in the community may identify barriers to care that may not have been faced by individuals who were able to reach and receive care at health-care facilities.

Many stillbirths and neonatal deaths can be attributed, at least in part, to factors that occur in the community, such as poverty and poor access to services, poor social and nutritional status of girls and women, harmful practices around pregnancy and childbirth, and perceptions about and use of health services. Yet everyone in the community wants healthy children. Thus, whatever approach is used, it is important that the people whose lives will be affected by the findings of the review process feel that their voices will be heard when solutions are being developed.

The process of setting up a system for identifying, reviewing and responding to stillbirths and neonatal deaths at the community level is also intrinsically valuable for the connections it fosters among stakeholders in the community, at health-care facilities and within the public health infrastructure.

## 4.2 Setting up the system

There are two primary additional roles that must be competently filled when setting up a process for community mortality audits, including designated community-based "identifier-reporters" and reviewers. In addition, a mechanism for transmission of information must be in place. These three key components of the system for auditing deaths that occur in the community are discussed below.

### Identifier-reporters

Identifier-reporters are those who will be informed of or able to identify stillbirths and neonatal deaths in the community as soon as they occur and then promptly relay information about them to the health system. These could include CHWs (who may be volunteers or salaried workers), community or village leaders, community representatives appointed or elected specifically for this purpose, or individuals employed by another existing initiative

(e.g. individuals who conduct routine home visits during pregnancy and the postnatal period). To facilitate their role as reporters, in order to effectively relay the information, they should be formally connected to the health system through a primary health centre, hospital or district office.

Where a public health system already has a network of CHWs in place, it may be effective to train them to take on the identifier-reporter role. Many countries, however, do not have unified networks of CHWs with sufficient coverage. Alternatively, identification/notification programmes could be run through district or sub-district networks of identifier-reporters to capture stillbirths and neonatal deaths in smaller areas. For example, in Cameroon, several programmes have worked with village mothers' associations or women's associations to assist community-level identification of programme-related outcomes.

It may be possible in some settings to integrate the reporting of stillbirths and neonatal deaths within other existing public health surveillance efforts. Community-based maternal death surveillance and response (MDSR) and integrated disease surveillance and response systems may provide platforms for expansion to include perinatal deaths. In Indonesia, for example, a training programme for professional midwives to be deployed in villages facilitated the initiation of community-based perinatal death review *(55)*.

Other public health programmes, including those outside maternal, newborn and child health, may also provide these opportunities. For example, if a region has an ongoing polio vaccination campaign to target remote communities, it may be possible to train the community-based volunteers or campaign staff to identify stillbirths and neonatal deaths in these communities and notify the health system of their occurrence. For example, the "Reaching Every District" (RED) strategy was undertaken by a group of immunization-targeting partners of WHO in 2002 to improve surveillance by re-establishing outreach services to communities in both urban and rural areas *(56)*.

A variety of reporting mechanisms can be designed to successfully relay information from community-based identifier-reporters to the public health system, as discussed in the section on transmission of information, below.

## Reviewers

Reviewers are community representatives who participate in perinatal mortality audits. The composition and roles of the membership of facility-based or national-level steering committees for these audits are described in Annex 5. There are a few additional considerations that are particularly important to the community, including representation, communication and advocacy.

The first consideration in the selection of reviewers of stillbirths and neonatal deaths in the community is that of *representation* of the community perspective on these deaths. Including a member of the community in the facility-based review committee may help gather more complete information from the community's perspective on what led to each stillbirth or neonatal death. For example, a CHW participating in a review may be able to contribute information on why a family did not seek care earlier or why transportation may have been delayed.

The second consideration is that of *communication* with the community. Including someone with the capacity to provide feedback on the findings of the perinatal death review to the community has the potential to build trust between the public health system and the community, and increase the likelihood of successful completion of community-based interventions designed in response to review findings. Care must be taken to select an appropriate person for this critical role, as the relationship between the community and the public health system may be jeopardized if communication is not done well. For example, an unskilled communicator may assign blame to particular individuals who provided care for a terminal illness or health problem during pregnancy or childbirth; this could have serious consequences for both the individual's safety in the short term and trust between the community and the health system in the long term.

The third consideration is that of ensuring *advocacy* on behalf of the community. The inclusion of community representatives with decision-making power in the reviews could increase the likelihood of appropriate community-based interventions being implemented to prevent future perinatal deaths, and of community members supporting any proposed community-based interventions.

## Transmission of information

The last consideration in getting started with a community-based perinatal death review process is to set up a mechanism for the transmission of information.

A very important consideration is how community-based identifier-reporters will notify the health system of a stillbirth or neonatal death that has occurred. There are two major ways to structure this transmission of information from the community: (i) report directly to a specific health-care facility (also known as reporting "in series") or (ii) report to the lowest level of the public health administration, such as the county, district, sub-district or parish health office (also known as reporting "in parallel").

Community reporting through local health-care facilities, or reporting in series, has multiple potential advantages:

- Setting up infrastructure for community-based reporting through health-care facilities has clear potential to improve the frequency and quality of communication between health-care facilities and the communities they serve.
- Reporting "in series" has the potential to decrease the chance of duplicate reporting of a particular perinatal death.
- Centralizing the review of stillbirths and neonatal deaths to include both facility- and community-based deaths allows the formulation of recommendations and interventions that address modifiable factors in both facilities and communities.

Community reporting through local health-care facilities may not be feasible if the local health-care facility does not have a functional mortality audit committee in place. Similarly, it may not be advisable if the community of interest does not have realistic access to quality facility-based care, if the relationship between a community and its health-care facility is so poor as to disincentivize reporting, or if the public health leadership prefers communities to report directly to district health offices or other local public health infrastructure.

The most effective mechanism for information flow may partially depend on the way in which death reporting from the community is envisioned to take place by the ministry of health, and the availability of any existing systems for reporting from the community. For example, death identification and notification via mobile technology has the potential to improve rates of timely reporting from the community, and may be better suited to reporting "in parallel" to district health offices if no specific individual(s) can be identified at the health-care facility level to receive these reports or if a data capture system already exists at the district health office.

## 4.3 The six-step mortality audit cycle from the community perspective

Once identifier-reporters, reviewers and the mechanism for information transmission have been selected and established, the process of a mortality audit that includes deaths that occur in the community can begin. The remainder of this chapter will consider the same six steps of the perinatal death audit cycle, as described in Chapter 3, but from the perspective of the community.

### Step 1: Identifying cases for review

There are three sub-steps within the process of identifying cases for review: (1) ensuring a strong mechanism for identification of all deaths; (2) ensuring a strong mechanism for notification and reporting of all deaths; and (3) selecting cases to review from among all occurring cases.

#### *Step 1.1: Identification of all deaths*

Cases may be identified by community-based identifier-reporters through varied means of active surveillance. They should aim to capture all stillbirths and neonatal deaths in their communities, regardless of where the deaths and care prior to death occurred. Box 4.1 describes the "Saving Mothers, Giving Life" project to reduce maternal and newborn mortality through community involvement in mortality surveillance and response, as implemented in Uganda.

Community-based identifier-reporters can make use of several sources of information about the occurrence of stillbirths and neonatal deaths. In small communities, rumours and word-of-mouth communication at small community social gatherings may be a good source of information. Household visits, whether done through perinatal death review or another programme (such as routine home visits for pregnancy and newborn care), may be a much more complete source of information about pregnancies and their outcomes, including stillbirths and neonatal deaths. Questions about recent stillbirths and neonatal deaths can be added to any existing standard sets of questions for volunteers or CHWs employed by partner programmes, with appropriate training. Lastly, demographic surveillance sites are likely to be a more complete source of information about stillbirths and neonatal deaths, although such surveillance systems are not common worldwide.

Once a stillbirth or neonatal death has been identified, the community-based identifier-reporter should transmit the information they have about this death to a pre-designated

focal point either at the local health-care facility, the district health office or other local public health body, in accordance with the agreed mechanism for information transmission (see "Transmission of information" in section 4.2 above, and Step 1.2 below).

Only after all deaths are captured will the committee be able to make a representative selection of deaths to be reviewed (see Step 1.3).

### Box 4.1. Case study in identification: Saving Mothers, Giving Life in Uganda

Uganda was one of two countries selected for a pilot project – Saving Mothers, Giving Life (SMGL) – to rapidly reduce maternal and neonatal deaths through community- and facility-based interventions. The SMGL model employs a comprehensive approach that builds on existing district health systems and implements evidence-based practices to improve maternal and perinatal survival.

Through the SMGL initiative, over 4000 village health teams (government cadres of mostly volunteer CHWs) were trained, one team for each 100–300 households, to identify any deaths of women of reproductive age and neonatal deaths through routine monthly monitoring visits. Currently, about 3800 village health teams continue to report monthly the number of deaths among women of reproductive age and newborns identified in the previous 30 days. Their reports are compiled and submitted to sub-district health coordinators. Approximately six to eight weeks after a death report, the household is visited by a team trained in verbal autopsy (VA) procedures. Complete VAs are used to identify causes of neonatal death and contributing factors, thus obtaining information critical to designing interventions to prevent future deaths.

**Improving the system: lessons learnt**

In establishing a district-level maternal and neonatal death surveillance system in Uganda, partners learnt that:

- **Identification of maternal and neonatal deaths is enhanced through continuous cross-checking of deaths between facilities and communities**.
- **Continuous supervision and quality assurance of the SMGL maternal and neonatal mortality surveillance system needs to be carefully planned, implemented and maintained**. This includes clear case definitions, periodic reminders on both the importance of and the process for reporting, accountability, monitoring results, information sharing and linkages with action.
- **Real-time data on maternal and neonatal deaths in communities were used at village health team meetings to advocate for increasing prevention and community mobilization activities**. The leadership of Kibaale district allocated resources for building a bridge that helped connect several communities with high mortality rates to the main road and thus improved access to emergency obstetric care.

The Ministry of Health is planning to scale up the MDSR and neonatal death surveillance and response from the four districts where SMGL was implemented to other, non-SMGL districts. The Uganda adaptation of the WHO maternal death surveillance and response (MDSR) guidance *(1)* was launched in September 2015. It is based on the experience in the SMGL-supported districts and includes the tools, standard operation procedures and monitoring processes developed and refined by the project. The verbal and social autopsy tool used for gathering information about perinatal deaths is included in Annex 10.

*Source*: MDSR Action Network, 2016 *(57)*.

### *Step 1.2: Notification and reporting of deaths*

Deaths may be reported through mobile networks, paper forms or oral reports. The choice of method depends on what will best facilitate the reliable transmission of information from identifier-reporters to the public health system in the local context.

The information initially captured about a death in the community may be different from the information initially captured about a death in a health-care facility. For deaths in health-care facilities, the aim is to capture all information contained within the minimum set of perinatal indicators (Annex 3). For deaths in communities, in contrast, the main goal is just to *notify* the health system of the death itself by reporting it through appropriate channels (as selected when designing the mechanism for transmission of information: see section 4.2: Setting up the system). The specific information to be initially collected in the case of deaths in the community must be tailored to the level of education of the identifier-reporters, and will likely need to be minimized in order to encourage expedient transmission of information about the death.

Box 4.2 presents a case study from South Kalimantan, Indonesia.

#### Box 4.2. Case study in notification and reporting: Safe motherhood in South Kalimantan

In 1995, the Indonesian Ministry of Health introduced additional safe motherhood services in three rural districts of South Kalimantan, which included initiation and support of maternal and perinatal death review processes. Village midwives were deployed to live in communities and were responsible for identifying and reporting all maternal and perinatal deaths in each community to the health centre. Midwives learned about these deaths either through their role in caring for the women before the deaths occurred, or because they had received reports from village leaders or traditional birth attendants.

Following a post-mortem interview, and follow-up investigation to document any health services the woman or baby received before their death, the village midwife assigns a cause of death and reports it directly to a health centre, where a senior midwife or doctor checks that the information collected is complete and consistent, and verifies the accuracy of the cause of death. All interview forms and data collected are sent to the district health office.

*Source*: Supratikto et al., 2002 *(55)*.

### *Step 1.3: Selecting cases for review*

Once all identified cases have been reported, the information about those cases can be compiled at the facility level for analysis and review, then either *all* cases or a *selection* of cases can be prepared for presentation and discussion at a multidisciplinary review meeting.

To ensure time for adequate review, and given the unfortunately high numbers of perinatal deaths in many environments, it is often necessary to select a small number of cases

for review. In the Indonesian safe motherhood project, for example, to facilitate full participatory discussion, the number of cases considered is limited to two or three per review meeting *(55)*.

There are several strategies available for case selection. One strategy is to select those deaths with the most *information* available for discussion since, by extension, these cases are most likely to yield fruitful discussions. A study of community neonatal death audits in Uttar Pradesh, India, for example, defined selection criteria for deaths to include, among others, the occurrence of the death within the past year and the willingness of the family of the deceased newborn to discuss the circumstances leading up to death *(58)*. Another strategy is to select a representative "case mix" of perinatal deaths *(13)*. In the safe motherhood project in Indonesia, for example, cases are selected on the basis of the nature of the problems identified and the frequency with which the medical causes of death occur *(55)*.

## Step 2: Collecting information

It is particularly important in communities to ensure that sufficient data are collected to contribute to a meaningful understanding of deaths. This may be challenging because, in the context of the community, programmes must often rely exclusively on lay people as both the sources and the collectors of information. Successful collection of information will pave the way for effective perinatal death review and formulation of solutions. Four key considerations are discussed here.

### *(i) From whom should the information be collected?*

If the death occurred in the community without any contact with a health-care facility, then the family and any non-facility-based care providers will be the only sources of information. If the death occurred in a facility or after contact with a facility, these facility-based data should also be collected, as described in Chapter 3.

It is also important to bear in mind who will be willing and able to provide the best information. If the mother of the deceased is still living, she is likely to be the source of the most comprehensive information. If the mother is also deceased, consider those who lived with the mother (e.g. her spouse, her mother, her sisters, other wives if applicable) at the time surrounding the perinatal death. If possible and applicable, information should also be obtained from those who provided care to the mother and baby during pregnancy, labour and/or delivery.

Non-facility-based care providers may include trained midwives, lay midwives, doulas, traditional healers and relatives. They can also provide extremely important information and should be included in the data collection process whenever possible.

### *(ii) Who should collect the information?*

It may be that the initial identifier-reporter of the death will be the same person assigned to collect further information about the death when the family and/or care providers are available for interview. In some cases, however, there may be reasons to assign different people to collect this information.

It may be easier for an information collector/interviewer from outside the community than for community-based reporters to obtain sensitive information. Although CHWs living in the community may be the most reliable source of information on the *occurrence* of any death in their community, they may not be able to obtain the most reliable information about factors that may have contributed to that death if family members are hesitant to share information about stigmatized topics with members of their own community. Additionally, if the identifier-reporter was involved in the woman's care, their presence during more detailed data collection could bias the responses from the woman or her family. Non-medical interviewers may be preferred.

It may also be more practical to designate separate information collectors/interviewers. The most frequent method of information collection about community-based deaths is through verbal autopsy (VA), discussed below. VA requires training, and the quality of information gained may improve with practice. Therefore, it may be ideal to have a large cadre of community-based death identifier-reporters and a smaller, more intensively trained and practised cadre of VA interviewers.

### *(iii) What information should be collected?*

VA provides a thorough, structured way to collect valuable information about stillbirths and neonatal deaths that can be used in the context of a review of a specific perinatal death to identify causes of death and contributing factors, and to provide data that will help to develop strategies to prevent future deaths.

VA is a structured interview using a questionnaire administered to caregivers or family members of the deceased (often the mother, in the case of stillbirths and neonatal deaths) at or near the time of death to elicit information about signs and symptoms and their durations, as well as other pertinent information about the period before the death (Annex 10). The VA also usually includes a social autopsy which explores the social, cultural, behavioural and health systems issues that may have contributed to the death.

Annex 10 of this guide includes a verbal and social autopsy questionnaire from a community-based surveillance project that can be used to conduct interviews specifically related to stillbirths and neonatal deaths. When more contextual factors are needed to examine circumstances surrounding the time of death, social autopsy is a useful tool. The verbal and social autopsy tool included in this guidance contains elements of both verbal and social autopsy, including questions about the health status of the mother, details about her labour and delivery, a structured symptom and duration checklist, an open narrative section and detailed information about the three delays, which are described in section 2.5.

The purpose of VA is to identify the causes and contributing factors for the stillbirth or neonatal death in the community where no higher-quality data sources or more definitive diagnostics exist. VA can provide information to help perinatal mortality audit committees identify factors contributing to stillbirths and neonatal deaths in the community. VA may also be used for deaths that occurred in facilities, when additional information from caregivers needs to be included in the review.

### *(iv) When should information be collected via verbal and/or social autopsy?*

The period of time passing between the death and the verbal and social autopsy is known as the "recall period". The goal is to select a recall period that will be long enough to allow adequate mourning, but not so long that a respondent's ability to recollect and report relevant information will be impaired. A systematic review by WHO of VA practices internationally found a wide range of recall periods, with some programmes performing interviews "as soon as possible" and others waiting for a "minimum of four weeks" to allow an adequate mourning period, while the maximum recall period ranged from "six months to an indefinite amount of time" *(59)*. A recall period of 1 to 12 months is generally considered acceptable, and a validation study of adult deaths demonstrated no significant effect on sensitivity or specificity using differences in length of recall period of 1 to 21 months *(60)*, though accurate recall periods for adult and perinatal deaths may differ. Generally, shorter recall periods are preferable, and recall after periods of more than 1 year should be interpreted with caution *(61)*. The goal is to achieve timely reviews in order to inform recommendations and interventions to prevent future perinatal deaths; therefore, we recommend performing verbal and social autopsy as soon after the death as is culturally acceptable.

## Step 3: Analysing information

Community stillbirths and neonatal deaths can be included in perinatal death reviews at the facility level, at dedicated community-level review meetings, at district level meetings or through a combination of all three. Community representation at perinatal mortality audit meetings is discussed under "Reviewers" in section 4.2: Setting up the system. During review of cases of perinatal deaths that occurred in the community, the audit team can use verbal and social autopsy results to assign a probable cause of death using standardized international certification and coding methods, and to identify any delays in receiving care that contributed to the death. This information can then be added to the compiled list of all deaths, as discussed in Chapter 3.

At the facility level, district level and higher, numbers of stillbirths and neonatal deaths in the community can be added to those identified in facilities. These summary statistics can be compared with expected numbers of stillbirths and neonatal deaths to evaluate the completeness of data and provide the basis for recommendations even if each death is not individually reviewed. The suggested minimum list of data elements that should be compiled to form these summary statistics is included in Annex 3.

In addition to the standard analyses applied to all deaths, there are several analyses that may be particularly helpful or revealing when applied to deaths that occurred in the community. Trends over time can help identify where seasonality is occurring within deaths at the community level, and whether or not such seasonal trends are observed at the facility level. This may help characterize the impact of malaria, for example, in an area undergoing changes in mosquito control. Time-related trends may also be extremely valuable at the single-day level; a preponderance of deaths at night, for example, may provoke a discussion of whether barriers to seeking or receiving care are greater at night, and how those barriers might be mitigated.

Geospatial analyses may be very beneficial at the community level. Geolocalization of deaths in the community may visually highlight areas without adequate access to care, or may help characterize particular transportation barriers.

## Step 4: Recommending solutions

Recommending realistic solutions to reduce deaths in the community is challenging. The characteristics of high-quality recommendations are covered in Chapter 3, but there are at least two aspects of recommending solutions that are worth addressing with particular ramifications for the community: capacity and communication.

### *(i) Capacity to implement a recommendation*

This is an extremely important consideration when formulating a recommendation that impacts the community. If a recommendation is formulated in collaboration with community leaders and in partnership with community members empowered to make the recommended change, it can be powerful and effective. In contrast, however, if recommendations that the community has no ability to enact are "handed down" to the community from a perinatal mortality audit committee, they can cause distrust between the community members and the health system.

### *(ii) Communication with the community*

This is also of highest priority. Results and recommendations of perinatal mortality audits must be disseminated in a way that communicates information effectively, sensitively and via a medium that is accessible to all community members. Perhaps most important is the principle of community-based dissemination: when communities of lay people are left out of the plans for information dissemination, this represents a lost opportunity for enhancing relationships and building capacity for positive change within the community.

Effective communication with the community can be enhanced early on in the process through the selection of appropriate community representatives to participate in the perinatal mortality audit committees. Communication and capacity can both be enhanced by early involvement of community leaders, especially in formulating recommendations. Lastly, communication is enhanced by using forms of media favoured by the community, which may include radio, television, theatre and murals, in addition to written materials.

## Steps 5 and 6: Implementing changes, evaluating and refining

Intentional, consistent involvement of the community in perinatal death audit can help reduce perinatal deaths at both facility and community levels. Recommended solutions are most likely to be implemented successfully when a community participates in perinatal death review and in formulating the solutions, when the solutions are within the community's capacity to enact, and when the process is undertaken in an environment of consistent, strong communication between the community and the local health-care facility.

Creating a mechanism of public accountability for implementing recommendations can be a trust-building, empowering aspect of communication and can contribute to participatory evaluation of changes, involving the community. For example, a perinatal death

review committee might present a recommended solution for community uptake, along with time-bound benchmarks to show that progress is being made. This local plan would then hold the community accountable to achieving what it set out in the benchmarks. An example of this may be institutionalizing a community support mechanism for funding emergency transportation to health-care facilities, or having local leaders promote healthy pregnancy and postnatal care practices.

Ensuring the presence of community members at regular perinatal death review meetings or on a specific evaluation committee can help ensure that the chosen interventions maintain and strengthen the community voice. Box 4.3 provides examples of community participation in implementing changes. Community-led refinements can be made to ongoing interventions to ensure that interventions are reaching their intended target and that projects are being completed on time. The presence of community leaders can positively impact ongoing interventions both in the community and at health-care facilities through creative solutions to unexpected challenges and through advocacy to resolve any existing barriers to change.

### Box 4.3. Involving the community in implementing changes

A community-level "Social Audit for Community Action" was conducted in rural Uttar Pradesh, India *(13)*. Community members from 152 villages were asked to recall the causes of deaths among children under 5 years of age in the prior year and identify preventive measures that could have been taken by the family or community. Intrapartum-related events accounted for 13.5% of neonatal deaths. Delay in recognizing the seriousness of the problem and arranging for transport and funds were identified as major contributors to neonatal deaths and were targeted for behaviour change by the community mobilizers. Another study to examine the feasibility of community audit was undertaken in Shivgarh, Uttar Pradesh, and involved in-depth interviews with family members of deceased neonates, and focus group discussions with family and community members. Both approaches involved the community in identifying modifiable factors in each death and discussing solutions, and the presence of an educated/experienced community member or health worker served as a catalyst *(13)*. Community neonatal death audit was found to be acceptable and feasible.

In South Africa, a dynamic "Partnership Defined Quality" process was applied to address surging neonatal and infant mortality rates in a peri-urban township in Durban. Unique to quality improvement efforts, the process fostered active partnerships between health-care providers and community members through dialogue, planning and collective action by learning from what went wrong and lessons emerging from the facility-based mortality review at the local hospital and health centres. Documented improvements in the quality of care resulted in increased trust from the community and demand for maternal and newborn services *(62)*.

# 5 Creating an enabling environment for change

Simply holding meetings and discussing deaths does not necessarily enable change or improve quality of care. Leadership and supervision within a supportive environment are essential to ensure the completion of the audit cycle. This chapter describes legal and supervisory considerations and educational models that help provide opportunities for positive change.

## 5.1 Creating an enabling environment to effect change

Evidence from countries that have functional mortality audit systems for maternal deaths, stillbirths and neonatal deaths shows the importance of an enabling environment for implementation of change at all levels. Change is undertaken by individuals doing the right thing at the right time. How does this change occur?

Interventions are not implemented in a vacuum; individuals must be held accountable with appropriate follow-up, and change agents are needed to lead the way. At the national level, support from senior managers in the ministry of health is essential. As individuals within facilities or through a formal stewardship body at national level, leaders have the ability to create a culture of accountability at all levels. This should involve correction but also celebration, affirmation, encouragement and reward *(47)*. Supportive administrators and health professionals can make all the difference between success and failure *(3)*.

In practical terms, one way of creating this environment at the national level is by linking mortality audit for stillbirths and neonatal deaths to maternal audit where MDSR is being implemented, in concert with national health goals and mortality reduction targets. A national implementation plan may be guided by a working group at the ministry of health, with involvement of other key experts. Understanding the linkages and interactions between ministries and their partners is critical to the development of multisectoral programme coordination and implementation. Under the guidance of the ministry of health, the roles and responsibilities of various departments, ministries, professional associations, the private sector and other relevant partners should be identified. The active involvement of professional associations (e.g. neonatologists, obstetricians, paediatricians, midwives and nurses) is critical, as is the participation of other stakeholders (e.g. hospital administrators, social scientists, epidemiologists, information system specialists, health planners, monitoring and evaluation personnel, civil society representatives).

## 5.2 Legal and ethical issues

### Legal protection

To ensure that a mortality audit is initiated in a safe environment for open discussion among staff, it is important to consider the legal and ethical issues that come into play when investigating stillbirths and neonatal deaths. The laws and customs of a particular country or culture can have a significant impact in terms of facilitating or hindering access to information, the involvement of families and health professionals, the conduct of the review, and the ways the findings are used. In some countries with a high level of malpractice litigation, fear of lawsuits has limited data collection and the use of mortality audit processes.

While the principles of mortality auditing may be standard across settings, legal aspects can vary from one country to another. In addition to having participants agree to and sign a code of practice before each review meeting (Annex 6), it may be beneficial to have administrators seek local legal counsel early in the process of establishing a mortality audit committee and process, to ensure the protection of staff and patients throughout the process. If a supportive health policy framework already exists for maternal death review, this

will help facilitate the process for stillbirth and neonatal mortality auditing also. It is essential that there are separate processes for handling legal misconduct and professional discipline that are independent of the mortality audit process.

## Access to information

Local mortality audit committee members will usually be the only people in the review process who know the names of the mother and baby and the health workers involved in the case. Names may be on the initial report forms to help identify and locate cases and to avoid duplication; however, they should be replaced by case numbers as soon as possible, to protect confidentiality of the patient and staff involved. The minutes of the meetings should be kept in such a way that there can be no linkage to actions taken related to specific individuals or cases. This is the responsibility of the local data collectors or review coordinator. In addition, any possibly identifying information should be removed from all records, notes and reports before they are sent to any other individuals or groups for further review or completion. Staff must maintain confidentiality and ensure that all materials are kept in a secure locked space when not in use.

## Use of the results

The goal of both the approaches presented in this guide is to identify why stillbirths and neonatal deaths occur, so that changes can be made to prevent similar events in the future and reduce mortality rates. The purpose is not to cast blame. In fact, once the data are collected, it is not even necessary to know the identities of the patients or practitioners. Mortality audits for stillbirths and neonatal deaths should not be used to blame or punish individuals, groups or institutions. They are not designed to discipline providers or review their qualifications. Reviews that are carried out in a manner seeking to attribute blame for an adverse event are unlikely to get the willing cooperation of health-care providers. Health workers do need to be accountable for their actions. However, accountability can be encouraged by carrying out any of the approaches in a way that seeks to improve care by educating both the health-care providers and the community. Occasionally it will be necessary for appropriate persons (e.g. supervisors, licensing boards, general medical councils) to take action against health-care providers who are persistently negligent, despite efforts to encourage and train them. However, a process that reviews the factors leading to stillbirths and neonatal deaths necessitates legal protection and should be separate from any disciplinary processes.

## Ethical considerations

Privacy is an ethical consideration that is important for both families and health workers. The baby's family has the right to privacy, although it may frequently be impossible to investigate a stillbirth or neonatal death and maintain complete privacy. Families and health workers need to be assured that, as much as possible, their privacy will be maintained. The identities of the babies whose deaths are being investigated, their families and the health-care providers involved in their care should be kept confidential, known only to those doing the actual investigation. Data collection forms, case summaries, review meeting minutes and any reports or other dissemination of results should contain no personal identifiers.

In addition, review committee members should be instructed not to disclose any confidential information about cases (including names of family or medical or other staff involved, or any details of the discussions or findings of the review process) outside the review group. Ideally, anyone with access to any information that contains personal identifiers should sign a confidentiality agreement, stating that they will not disclose this information. All records of the cases reviewed and any discussion should be kept secure; hard copies of information should be kept in locked cabinets/offices, and electronic data kept in password-protected files. In some types of review, such as confidential enquiries, complete anonymity is the rule. However, in others, such as facility- and community-based case reviews, the identity of both the deceased and the health workers involved in the care are typically known, though care is taken to remove identifying markers in the notes as soon as possible.

## 5.3 Developing and disseminating policy and guidelines

A clear, supportive policy has been one of the prerequisites for success in maternal mortality audit *(46, 51)*. In some cases this has also involved an enabling legal framework, which may need to be in place before the process begins. Any fear of participation in such audits can be removed by affording legal protection for assisting in such enquiries while ensuring cases of gross malpractice will continue to be dealt with by the existing legal procedures. National guidelines for how to set up an audit committee and conduct meetings, clear guidance on information transmission, and standardized tools are also helpful. Clear norms and practice standards for each level of the health system may facilitate a more objective assessment of modifiable factors associated with each death *(38, 63)*. These will require periodic review and updating as new evidence emerges, as with the national clinical guidelines. This process can be led by the national steering committee with ministry of health guidance.

National guidelines for stillbirth and neonatal death mortality audit may mandate that particular staff members are designated at various levels to oversee the system and that the associated tasks and responsibilities are included in their job descriptions. In settings where midwives provide the majority of care at birth and during the postnatal period, the system should be developed in such a way that midwives can complete the process from start to finish and provide leadership at all levels. If resources permit, an outreach person or regional coordinator who is familiar with the tools and meeting structure can serve as a liaison between clinical staff, senior management and district decision-makers. This person can be a valuable resource, especially in ensuring that recommendations result in actions that are followed up. This system has been one of the key drivers of institutionalization and successful outcomes in South Africa *(41, 47)*.

## 5.4 Staff training, ongoing supervision and leadership

District health staff, administrative staff, health workers and other relevant stakeholders require training specific to their role in the audit process and the level of implementation of the audit system. This training may be conducted by the ministry of health or through professional associations. In Uganda, both the Association of Gynaecologists and Obstetricians and the Uganda Paediatric Association have been involved in training on the national

Maternal and Perinatal Death Review Guidelines *(48)*. In South Africa, a PPIP coordinator appointed by the national Medical Research Council oversees all provincial training with a colleague and provides ongoing follow-up such as ensuring that the facilities send their data to the central database *(41)*. Yearly provincial workshops are held to show the staff at health-care facilities how to install the audit software program, enter data and fill in the data collection tools, perform data validity checks and do basic analyses of common indicators.

Experience has shown that it is important to explain at the outset to those involved at each level of the review process why specific pieces of information need to be collected and for what purposes, so that data are collected for a reason and not for their own sake. Training should also include an overview of a death review meeting, and guidance on appropriate conduct, including confidentiality. If time allows, the training may also include continuing medical education on management of common maternal and perinatal conditions.

Frequent staff rotation of nurse-midwives in maternity and newborn units can have an impact on service delivery, and can be detrimental to the success of the mortality audit process. A key enabling factor is to create, recognize and reward core leadership skills among experienced midwives, nurses, clinical officers, anaesthetists and medical staff who represent the institutional memory and continuity as well as relevant clinical knowledge and skills. These individuals would be the key leaders on the mortality audit steering committee, responsible for orienting new staff, providing guidance in clinical areas for less experienced staff and able to feed in most effectively to audit discussions because of their experience and credibility within the institution. It is important to remember that leaders may or may not be managers, and they are most likely to be role models for effective teamwork for the rest of the staff. The success of an audit process depends on these individuals to build teams and implement solutions rather than assign blame.

# 6 Scaling up audit for quality and health care improvement

To facilitate wide-reaching change and promote accountability at all levels of the system, it is important for policy-makers to seize opportunities to create a standardized national mortality audit system. This chapter describes the creation of a mortality audit infrastructure and systems that link to existing data architecture and policy response beyond individual health-care facilities.

## 6.1 Moving from single facilities to regional and national levels

Once local systems for comprehensive and systematic review of stillbirths and neonatal deaths have been institutionalized as routine practice with documented changes in practice and quality of care, other facilities, districts or health regions within a country may take note and explore the feasibility of adopting a similar approach. With some additional resources to coordinate this standardized system, data can be centrally collated, tracked and disseminated.

A larger number of deaths enables a more detailed analysis to be undertaken with a broader population base, potentially enabling triangulation with other data sources such as CRVS and the HMIS. In some cases, a central (national-level) committee may just gather data from facility-based reviews and report broad trends, but in other cases a separate review process might also be put in place at a district or regional (subnational) level. One benefit of a regional-level review is that the forms can be made anonymous, and assessors from other facilities can review cases, providing an independent opinion and recommendations. At this level, general lessons may also be derived which reveal systemic bottlenecks and thus highlight a path towards broader changes. For example, the results may point to the need for regional review of pre-service training procedures or transport systems.

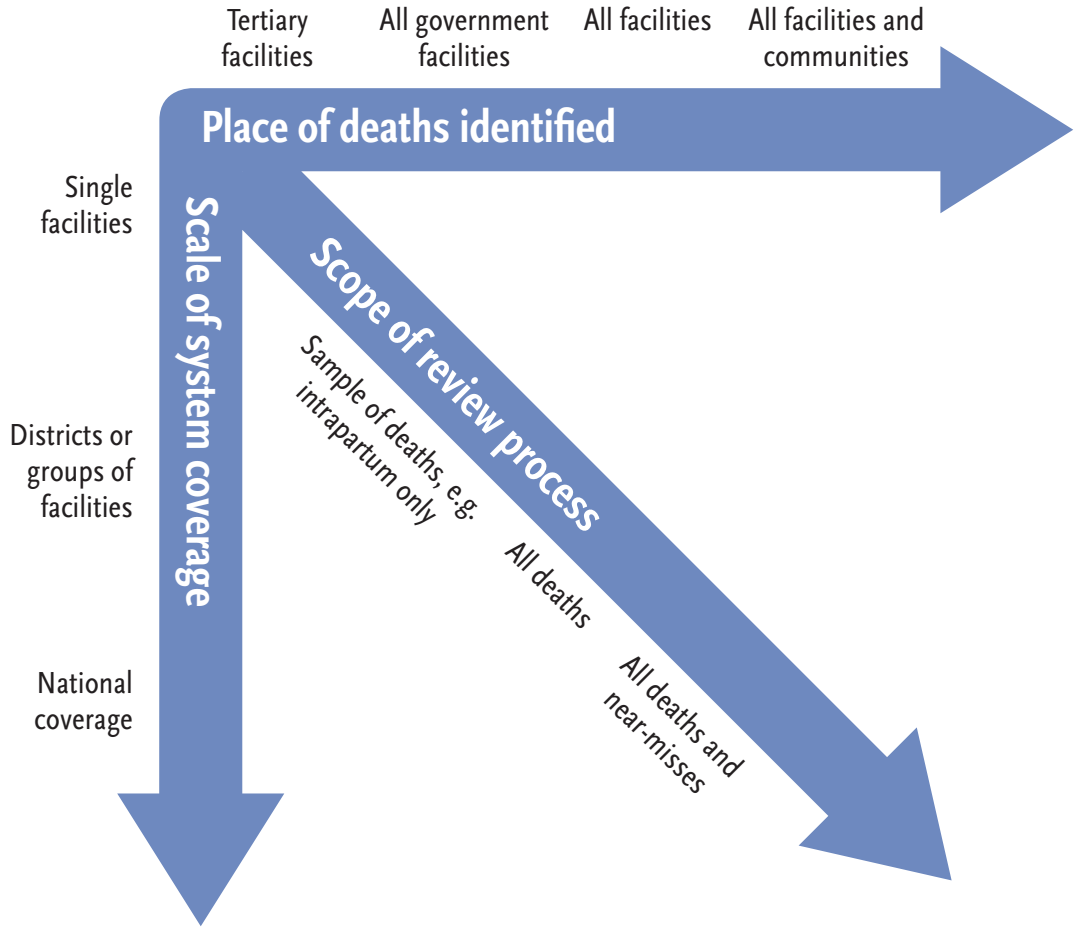
If a decision is made to undertake a national audit programme with leadership from the central level, there are a number of factors to be considered in a phased approach *(5)*, including:

- *Who leads?* Will coordination take place at the national level or through regional committees, or both? Will it be governed by the ministry of health exclusively, associations of health professionals or a multistakeholder group that includes partners, civil society, community representatives, etc.?
- *Where are deaths identified?* Does the system cover just public-sector health-care facilities or all facilities? Are deaths that occur in the community included? If so, how is information gathered about those deaths? How does the mortality audit system feed into or get information from the HMIS and/or CRVS?
- *What is the scope of implementation?* Do single facilities conduct reviews on their own, or are they done within practice groupings or districts, or both? Is implementation mandated or voluntary?
- *What is the depth and breadth of the review process?* Does the committee review a selected sample of cases, all deaths or all deaths and near misses? How does the committee decide which cases to review and how often?

Figure 6.1 illustrates the dimensions of this phased introduction of mortality audits from single facilities to the national level.

Experiences from high-income countries such as Australia *(64, 65)*, New Zealand *(66)*, the Netherlands *(67–69)* and the United Kingdom have shown the potential for sustained, widespread implementation when there is high-level national leadership. Where local drivers exist without an overarching national or regional coordinating body, national systems can still arise from the ground up, as seen in South Africa *(13, 41)*.

FIGURE 6.1. Dimensions of a phased introduction of mortality audits for stillbirths and neonatal deaths




*Source*: adapted from WHO, 2013 *(1)*.

Even if the ministry of health leads the national review process, a multistakeholder committee should be established, including representatives of health professional associations, communities, various departments and facility management, as well as the district medical office and community liaison, if applicable (see Annex 5 for a more detailed list of potential participants). This structure can be similar to the local level, with broad representation across disciplines but with more capacity for programme management and system-wide change *(43)*.

While a standardized national mortality audit system for stillbirths and neonatal deaths may be a goal, the final structure and scope of any mortality audit system will differ in facilities and regions according to the local context and challenges. Implementation strategies should, therefore, be adaptable and easily customized even within countries. This chapter addresses some of the key ingredients of a national perinatal mortality audit system.

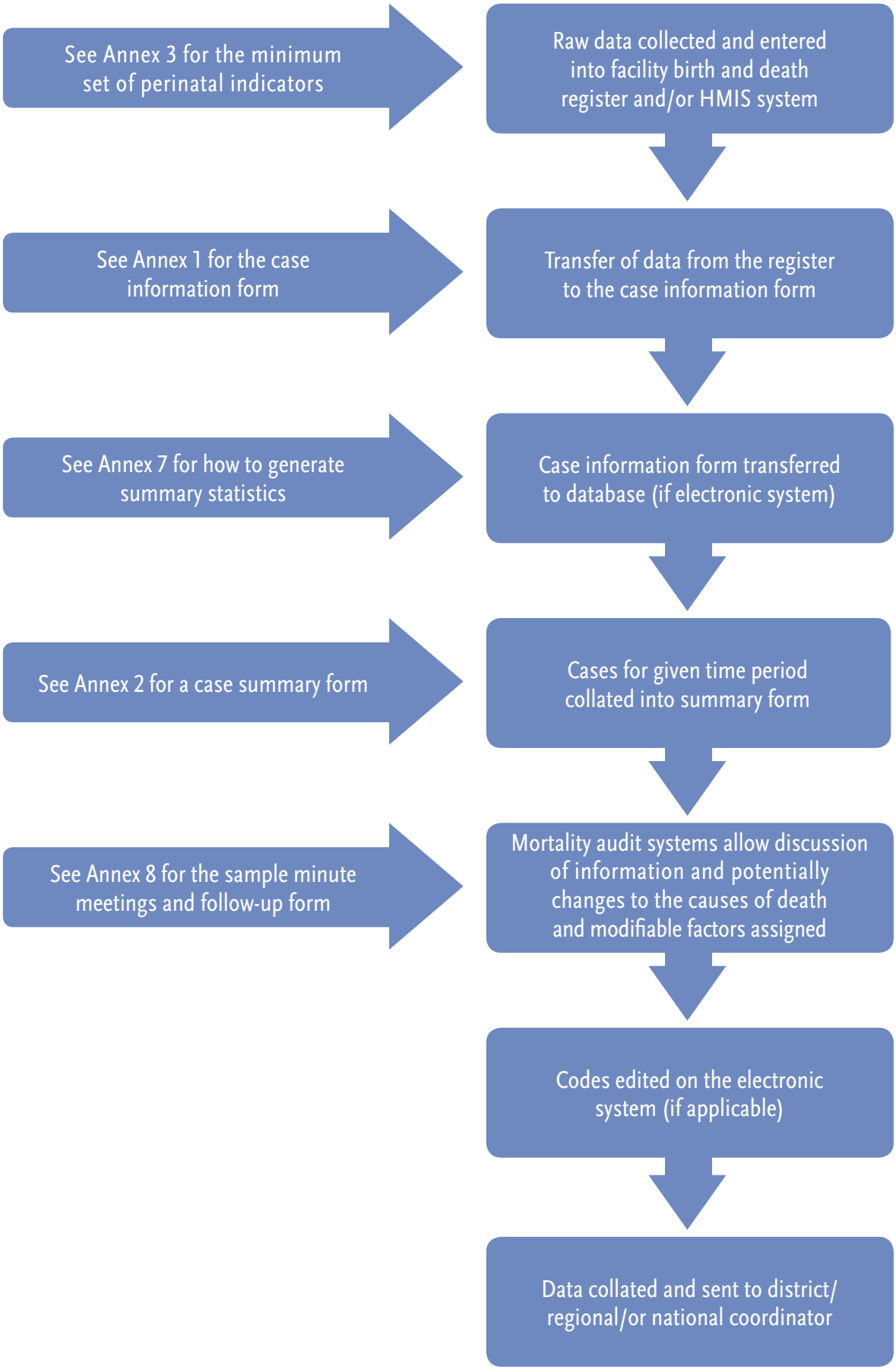
## 6.2 Collating data and linking to existing information infrastructure

A data flow algorithm may be useful for assigning responsibility to named people along the path of data collection (see Figure 6.2). This brings the vital step of accountability into the process. Different individuals may be involved depending on the size of the facility, the capacity for electronic data collection and the level of integration with existing information systems. The staff responsible for each stage could be physicians, midwives or data clerks, but there should be clearly designated individuals trained on the system, with the mortality audit coordinator or steering committee overseeing the process, including integration with CRVS and the HMIS.

Reports emerging from single-facility mortality audit committees can be collated and linked to other outputs. A multi-facility review report may have broader audiences: all the facilities involved in the review, other facilities in the area (public and private), various decision-makers, insurance companies and teaching institutions, as well as national authorities and the public. A national confidential enquiry will produce a comprehensive report that is widely distributed to all its stakeholders, including being available to the public. The frequency of publication of these reports will depend on the number of cases reviewed and the willingness of stakeholders to write, edit and publish findings. However, remedial action does not need to wait for the report to be published. Sometimes the findings of a single case review can reveal a significant problem that needs to be addressed immediately. The frequency and importance of other problems may only become apparent after the information from the qualitative review is quantitatively analysed.

The ENAP Measurement Improvement Roadmap (2015–2020) has outlined tools to be developed and has created an opportunity to embed improved newborn data and tools into national health systems through World Health Assembly (WHA) commitments to improve the use of key newborn data in countries *(18)*. Progress in meeting milestones is reviewed annually at the WHA – the establishment of this annual reporting obligation has supported a transparent accountability mechanism with a specific focus on the use of newborn data. Mortality audit, in addition to improved birth and death registration, promoting a minimum set of perinatal indicators to be collected, and actions to test, validate and institutionalize proposed coverage indicators, is a key component of this improvement agenda. The roadmap presents a unique opportunity to strengthen routine HMISs, linking these data with CRVS and population-based surveys *(9)*.

FIGURE 6.2. Example of data flow in a mortality audit system for stillbirths and neonatal deaths




*Source*: adapted from Rhoda et al., 2015 *(41)*

## 6.3 Ensuring appropriate resources and logistical support

The scope of a national mortality audit process for stillbirths and neonatal deaths will depend on the number of deaths, the resources required and the capacity of the system to deliver it. Having a sense of the ideal number and frequency of training programmes, steering committee meetings and consolidated reports will help establish a budget for setting up and running the system. While deciding on such issues, the steering committee may find it helpful to draw on the experience of other groups or countries that have instituted a similar review approach. A national annual report is extremely helpful to track progress in outcomes and actions on recommendations, but this does require dedicated staff time. Sustained funding is required for a national steering committee to meet and follow up on the progress of recommendations. Resources are also required to address gaps in the system, including targeting districts that are not yet using the system – usually weaker or poorer-performing facilities or districts. While there is an extra cost of central data collation, it is less than the returns on efficiency and impact in the health system overall.

# Conclusion

There is growing demand for information about how to implement and scale up mortality auditing for stillbirths and neonatal deaths as a central element of a quality improvement strategy; audit emerged as the third priority in the development domain for the post-2015 research agenda *(70)*. These remaining research questions go beyond overarching quality improvement jargon and seek answers to specific, practical implementation questions. Many of the questions about impact, best practices for managing review meetings and how to follow up on action items in busy maternity units are also similar to questions raised in the context of maternal death reviews, and the two should be linked, especially where there are fewer maternal deaths. In many low-income settings, the lack of community participation is also a critical gap and a challenge for an equitable process with a positive impact on the families most at risk. There are a number of community participation mechanisms that could be adapted and tested with the aim of building a more comprehensive, effective audit practice.

Each death that is reviewed has the potential to tell a story about what could have been done differently to identify the solutions that should have been available for each woman and baby. Though inputs are needed at every level of the health system and beyond, health workers have the power to change what is in front of them. The system requires leaders to champion the process, especially to ensure a no-blame environment, and to access change agents at other levels to address larger, systemic concerns. It has been suggested that we are entering the third revolution in global public health: from metrics and evaluation to accountability, and now to improved quality of care *(71)*. The mortality audit approach has grown out of the knowledge of the importance of the first two themes to address the third. The benefits of audits and feedback have been acknowledged by development partners and governments for their success in preventing further unnecessary deaths of mothers; these tools should also now be used to prevent the deaths of their babies.

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# Annexes



# Annex 1: Stillbirth and Neonatal Death Case Review Form (and guidance for completion)

## Annex 1a: Stillbirth and Neonatal Death Case Review Form

**Section 1: Identification**

| | | |
|---|---|---|
| 1.1 | ID # mother | |
| 1.2 | ID # baby | |
| 1.3 | Facility name: | |
| 1.4 | Type of care available: | comprehensive EmOC / basic EmOC / first aid / home delivery |
| 1.5 | District name: | |
| 1.6 | Referred | not referred / referred in from: / referred out to: |

**Section 2: Pregnancy progress and care**

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 2.1 | Obstetric history | all pregnancies | all births | total live births | dead | stillbirths | neonatal deaths | abortions |
| 2.2 | Mother's age | y | | | | | | |
| 2.3 | Type of pregnancy | singleton | | twin | | higher multiple = | | unknown |
| 2.4 | Antenatal care number of visits | 4 or more | | 3 | 2 | 1 | no visits | unknown |

*adjust as per local context*

| | | | | | | |
|---|---|---|---|---|---|---|
| 2.5 | Malaria prophylaxis | not needed | IPT3+ | IPT2 | IPT1 | not received / unknown |
| 2.6 | Tetanus toxoid vaccination | | TT2+ | | TT1 | not received / unknown |
| 2.7 | HIV status | | HIV-negative | HIV-positive | | not done / unknown |
| 2.7.1 | HIV-positive action | | | NVP | HAART | other, specify |
| 2.8 | Syphilis test | | negative | syphilis-positive | | not done / unknown |

**Section 3: Labour and birth**

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 3.1 | Mother's LMP | DD | MM | YYYY | unknown | | | |
| 3.2 | Date of birth | DD | MM | YYYY | | | | |
| 3.2.1 | Time of birth | : | h | | | | | |
| 3.3 | Gestational age | | | weeks | unknown | | | |
| 3.3.1 | Method of determination | sure LMP dates | | | unsure LMP dates | | other, specify | |
| | | early ultrasound | | | late ultrasound | | | |
| 3.4 | Place of delivery | | | facility | home | road | other, specify | unknown |
| 3.4.1 | Attendant at delivery | midwife | nurse | doctor | other, specify | | no one | unknown |
| 3.5 | Onset of labour | | | spontaneous | induced | c/s before onset | | unknown |
| 3.6 | Fetal heart sounds on admission | | | no | yes | | | unknown |
| 3.7 | Partograph used | | | no | yes | | | unknown |
| 3.8 | Mode of delivery | | | CVD | assisted vaginal | caesarean | other, specify | unknown |
| 3.9 | Time between decision for action and birth | n/a | | < 30 mins | 30–60 min | > 60 mins | | unknown |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 3.10 | Apgar score | 1 min = | 4 or more | 3 or less | | | unknown |
| | | 5 min = | 4 or more | 3 or less | | | unknown |
| 3.11 | Resuscitation | not needed | bag + mask | not done | other, specify | | unknown |
| 3.12 | Sex of baby | male | female | | | | unknown |
| 3.13 | Birth weight | g | ≥ 2500 g | 1500–2499 g | 1000–1499 g | < 1000 g | unknown |
| | | | | LBW | VLBW | ELBW | |

## Section 4: Details of the death

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 4.1 | Date of death | DD | MM | YYYY | | | | | | |
| | 4.1.1 Time of death | : | h | | | | | | | |
| 4.2 | Type of death (circle one) | neonatal death | intrapartum stillbirth | antepartum stillbirth | stillbirth, unknown timing | | | | | |
| 4.3 | Main maternal condition | none identified | Main maternal condition followed by the corresponding number. Use the reference page below to write in corresponding number. Include more than one if applicable | | | | | | | unknown |
| 4.4 | Cause of death (circle one) | | | | | | M1 | M2 | M3 | M4 | M5 | other | unknown |
| | a. congenital | | | | | | | | | | | | |
| | b. antepartum complications | | | | | | | | | | | | |
| | c. intrapartum complications | | | | | | | | | | | | |
| | d. complications of prematurity | | | | | | | | | | | | |
| | e. infection | Tetanus | Sepsis | Pneumonia | Meningitis | | | | | | | | |
| | | Syphilis | Diarrhoea | Other, specify if known: | | | | | | | | | |
| | f. other, specify | | | | | | | | | | | | |
| | g. unknown/unspecified | | | | | | | | | | | | |

## Section 5: Critical delays and modifiable factors

| | | | |
|---|---|---|---|
| 5.1 | Critical delays | delay 1. not identified | 1. delay recognizing need for care: |
| | | delay 2. not identified | 2. delay seeking care: |
| | | delay 3. not identified | 3. delay receiving care: |
| 5.2 | Modifiable factors | | |
| | Family-related | none identified | specify: |
| | e.g. late/no antenatal care; cultural inhibition to seeking care; no knowledge of danger signs; financial constraints; partner restricts care-seeking; use of traditional/ herbal medicine; smoking / drug / alcohol abuse; attempted termination; etc. | | |
| | Administration-related | none identified | specify: |
| | e.g. neonatal facilities; theatre facilities; resuscitation equipment; blood products; lack of training; insufficient staff numbers; anaesthetic delay; no antenatal documentation; etc. | | |
| | Provider-related | none identified | specify: |
| | e.g. partogram not used; action not taken; inappropriate action taken; iatrogenic delivery; delay in referral; inadequate monitoring; delay in calling for assistance; inappropriate discharge; etc | | |
| | other | none identified | specify: |

Actions to address the critical delays and modifiable factors

Form completed by: _____

Date: _____

c/s: caesarean section; CVD: cephalic vaginal delivery; ELBW: extremely low birth weight; EmOC: emergency obstetric care; HAART: highly active antiretroviral therapy; HIV: human immunodeficiency virus; IPT: intermittent preventive treatment; LBW: low birth weight; LMP: last menstrual period; NVP: nevirapine prophylaxis; TT: tetanus toxoid; VLBW: very low birth weight

# Reference page: Maternal conditions

| ICD-PM maternal condition group | Main maternal conditions included in group |
|---|---|
| M1: Maternal complications of pregnancy | 1. incompetent cervix<br>2. preterm rupture of membranes<br>3. oligohydramnios / polyhydramnios<br>4. multiple pregnancy<br>5. maternal death<br>6. malpresentation before labour<br>7. other complications of pregnancy |
| M2: Complications of placenta, cord and membranes | 1. placenta praevia<br>2. other forms of placental separation and haemorrhage<br>3. placental dysfunction, infarction, insufficiency<br>4. fetal–placental transfusion syndromes<br>5. prolapsed cord / other compression of umbilical cord<br>6. chorioamnionitis<br>7. other complications of membranes |
| M3: Other complications of labour and delivery | 1. breech delivery and extraction<br>2. other malpresentation, malposition, and disproportion during labour and delivery<br>3. forceps delivery / vacuum extraction<br>4. caesarean delivery<br>5. precipitate delivery<br>6. preterm labour and delivery<br>7. other complications of labour and delivery |
| M4: Maternal medical and surgical conditions; noxious influences | 1. pre-eclampsia / eclampsia<br>2. gestational hypertension<br>3. other hypertensive disorders<br>4. renal and urinary tract diseases<br>5. infectious and parasitic disease<br>6. circulatory and respiratory disease<br>7. nutritional disorders<br>8. injury<br>9. surgical procedure<br>10. other medical procedures<br>11. maternal diabetes including gestational diabetes<br>12. maternal anaesthesia and analgesia<br>13. maternal medication<br>14. tobacco / alcohol / drugs of addiction<br>15. nutritional chemical substances<br>16. environmental chemical substances<br>17. unspecified maternal condition |
| M5: No maternal condition | 1. no maternal condition identifed (healthy mother) |

# Annex 1b. Guidance for completing the Stillbirth and Neonatal Death Case Review Form

**Purpose of form**: To assist perinatal death review (also known as "perinatal mortality audit") meetings/committees in reviewing a perinatal death, to provide information about the death, and to identify critical delays and modifiable factors that can be targeted with interventions to prevent future deaths. The form is designed so that the "normal" answers appear on the left and the "abnormal" answers appear on the right, making it easier to identify problem areas.

**Time of completion**: Sections 1–4 should ideally be completed by a committee in advance of the perinatal death review meeting, for discussion during the meeting. In some settings it may be completed during the meeting itself. If this is the case, ensure that all relevant files and patient notes are available at the meeting.

Section 5 should be completed and discussed at the review meeting.

## Section 1: Identification

1.1: Mother's ID: Put an identifier for the mother here. Include ID numbers that are used by your health-care facility. If there are potential legal ramifications linked to audit records, do not use this identifier and instead just number the cases discussed sequentially.

1.2: Baby's ID: Include ID numbers that are used by your health-care facility. If no standard ID numbers are used, put the baby's name instead. If the baby has no name, put mother's name + "boy" or "girl". If there are multiple babies for the same mother, add "boy No. 1" or "girl No. 1" as needed.

1.3: Facility name: Put the name of the facility where the stillbirth or neonatal death took place. If it is being reviewed at a different facility, add "reviewed at facility: _____" to clarify.

1.4: Type of care available: Circle the type of care available at the time the woman presented for care.

Type of care is defined according to the World Health Organization classification of basic emergency obstetric care (BEmOC) and comprehensive emergency obstetric care (CEmOC).

To classify care as "basic", it must provide all of seven essential interventions:

1. administration of parenteral antibiotics to treat infection
2. administration of magnesium sulfate for treatment of eclampsia and pre-eclampsia
3. administration of oxytocin for postpartum haemorrhage
4. manual removal of the placenta
5. assisted or instrumental vaginal delivery
6. removal of retained products of conception
7. neonatal resuscitation.

To classify care as "comprehensive", it must provide the seven essential interventions listed above and the following two additional interventions:

1. blood transfusion
2. surgery (i.e. caesarean section).

1.5: District name: Put the name of the district where the facility at which the mother delivered is located. This may not be the district that the woman is from.

1.6: Referred:

- Circle "not referred" if the woman or baby presented from home;
- If the woman or baby were referred from another hospital, health centre or clinic, write the name of that facility on the line for "referred in from".
- If the woman or baby were referred out to another hospital or other facility, write the name of that hospital or other facility on the line for "referred out to".

## Section 2: Pregnancy progress and care

### 2.1: Obstetric history:

- For "all pregnancies", put the total number of *pregnancies,* irrespective of gestational age, including the most recent pregnancy. Pregnancies with twins or other multiples are counted as one pregnancy.
- For "all births" put the *total number of deliveries the woman has had of babies of gestational age 28 weeks or more*. Include the delivery of the fetus or neonate being discussed. Deliveries of twins or other multiples are counted as one delivery.
- For "total live births", put the total number of *live births* the woman has had. Include the delivery of the fetus or neonate being discussed. If both were born alive, twins are counted as two living children, with the same for higher-order multiples.
- For "dead", put the number of the mother's *deceased children*. Include the fetus or neonate being discussed. If both are deceased, twins are counted as two deceased children.
- For "stillbirths", put the number of the mother's *stillbirths* of gestational age of 28 weeks or more. Include the fetus or neonate being discussed. If both are deceased, twins are counted as two deceased babies.
- For "neonatal deaths", put the number of the mother's *deceased babies that died within 28 days of life*.
- For "abortions", put the total number of *abortions* for the woman, whether induced or spontaneous. If a stillbirth is being discussed, include this stillbirth in the number.

2.2: Mother's age: Put the woman's age in completed years. For example, a woman of 23 years and 10 months of age would be entered as "23".

2.3: Type of pregnancy: Circle the type of pregnancy with the fetus or neonate being discussed:

- "singleton" if a pregnancy with one fetus;
- "twin" if a pregnancy with two fetuses;
- "higher multiple" if more than two fetuses (if more than two fetuses, put the number of fetuses next to the equals sign);

- "unknown" if the total number of fetuses is/was not known.

2.4: Antenatal care: Circle the total number of antenatal care visits the woman had during her pregnancy with the fetus or neonate being discussed: 4 or more; 3; 2; 1; no visits; unknown.

2.5: Malaria prophylaxis: Circle the number of intermittent preventive treatments (IPT) for malaria the woman received during her pregnancy with the fetus or neonate being discussed:

- "not needed" if malaria prophylaxis was not medically indicated due to lack of malaria in her residence during pregnancy;
- "IPT3+" if she received at least three treatments;
- "IPT2" if she received only two treatments;
- "IPT1" if she received only one treatment;
- "not received" if she did not receive any IPT in an area where it is indicated;
- "unknown" if there is no information on her receipt of treatments.

2.6: Tetanus toxoid vaccination: Circle the number of TT doses the woman received during her pregnancy with the fetus or neonate under discussion:

- "TT2+" if she received at least two TT doses in this pregnancy or at least 5 TT doses in her lifetime;
- "TT1" if she received one dose;
- "not received" if she did not receive any TT doses;
- "unknown" if there is no information on her receipt of TT doses.

2.7: HIV status: Circle to indicate the woman's HIV status:

- "HIV-negative" if she was tested and found to be negative;
- "HIV-positive" if she was tested and found to be positive, or was known to be positive prior to pregnancy (and proceed to 2.7.1 below);
- "not done" if no HIV testing was performed during pregnancy;
- "unknown" if the HIV status and testing status are unknown.

2.7.1: If the woman was found to be HIV-positive or known to be HIV-positive prior to pregnancy, circle to indicate what action was taken:

- "NVP" if she received nevirapine prophylaxis for delivery
- "HAART" if she received highly active antiretroviral therapy during her pregnancy
- Next to "other", write whether:
  - any additional treatment was received for HIV or its complications
  - no treatment was received
  - treatment was received but the type was unknown.

Do not complete line 2.7.1 for any woman who was not known to be HIV-positive.

2.8: Syphilis test: Indicate the status of the woman's syphilis test:

- "negative" if she was tested for syphilis and found to be negative
- "syphilis-positive" if she was tested and found to be positive
- "not done" if no syphilis testing was performed during pregnancy
- "unknown" if the syphilis status and testing status are unknown.

## Section 3: Labour and birth

3.1: Mother's LMP: Enter the date of the woman's last menstrual period here, or circle "unknown".

3.2: Date of birth: Record the date of the birth here, whether live or stillborn.

3.3: Gestational age: Enter in weeks and days at the time of birth (live or stillbirth), using the LMP.

Choose gestational age to record in this order:

1. If there is a gestational age based on early ultrasound, enter this.
2. If there is no gestational age based on early ultrasound, enter the estimated gestational age according to woman's recollection of her LMP.
3. If there is no gestational age estimate either based on ultrasound or the woman's recollection, circle "unknown" (DO NOT enter gestational age based on late ultrasound or estimated by size at delivery).

3.3.1: Method of determination: Circle the method by which this gestational age was calculated. Additionally, circle "sure" or "unsure" for the LMP dates, depending on the woman's stated level of certainty. If the woman's certainty is not stated, or if another method was used, write this in the "other, specify" box.

3.4: Place of delivery. If delivery was at a facility, enter the facility's name on this line.

3.4.1: Attendant at delivery:

- Circle "midwife" if delivery was attended by a trained midwife.
- Circle "nurse" if delivery was attended by a nurse with midwifery skills.
- Circle "doctor" if delivery was attended by a physician.
- If the delivery was attended but none of the provided options fit, write in the type of attendant in the "other" box (e.g. traditional birth attendant, community health worker, relative).
- Circle "no one" if no one other than the woman was present at the delivery.
- Circle "unknown" if delivery attendance is not known.

3.5: Onset of labour: Circle to indicate the appropriate information:

- "spontaneous" if labour began without artificial aid
- "induced" if labour was brought on with the use of drugs
- "c/s before onset" if a caesarean section was done before the onset of labour
- "unknown" if unsure.

3.6: Fetal heart sounds on admission:

- If fetal heart sounds (fetal heart tones) were auscultated on admission and were not present, circle "no".
- If fetal heart sounds (fetal heart tones) were auscultated on admission and were present, circle "yes" and write what they were recorded as on admission.

- If fetal heart sounds were not auscultated on admission or if this information is not available, circle "unknown".

3.7: Partograph used: Circle to indicate the appropriate information:

- "no" if a partograph was not used during delivery;
- "yes" if a partograph was used during delivery, and write any relevant additional comments (e.g., write "incomplete" if it was used for only a portion of delivery or does not include all standard information on a partograph);
- "unknown" if this information is not available.

3.8: Mode of delivery: Circle to indicate the appropriate information for the fetus or neonate being discussed.

- "CVD" for cephalic vaginal (or normal) delivery
- "assisted vaginal delivery" if vacuum and/or forceps were used
- "caesarean" if indicated
- "other" if indicated, and describe (e.g. breech delivery)
- "unknown" if this information is not available.

More than one answer can be chosen, as appropriate (e.g. failed use of vacuum or forceps followed by a caesarean section).

3.9: Time between the decision for action and the birth: If mode of delivery was anything other than "CVD", circle the amount of time it took from making the decision that a normal delivery is not longer possible/appropriate to achieving the actual birth by way of assisted/surgical delivery. If delivery was "CVD", circle "n/a" for not applicable.

3.10: Apgar score: Record the scores at 1 and at 5 minutes. Next to these, circle "6 or more" or "5 or less" as indicated by the score. If either of these scores is not available, circle "unknown" for that score.

3.11: Circle to indicate actions related to resuscitation:

- "not needed" if not indicated by Apgar scores or clinical state;
- "bag + mask" if performed;
- "not done" if resuscitation was indicated but not performed;
- "other" and record whether the following forms of resuscitation were performed:
  - stimulation
  - suction
  - intubation
  - CPR
  - other forms of resuscitation (record);
- "unknown" if this information is not available.

3.12: Sex of baby: Circle "male", "female" or "unknown" as indicated.

3.13: Birth weight: Record the total birth weight, and circle the appropriate category of birth weight, or "unknown" if birth weight is not available. The acronyms stand for:

- LBW: Low birth weight (1500–2499 g)

- VLBW: Very low birth weight (1000–1499 g)
- ELBW: Extremely low birth weight (< 1000 g)

## Section 4: Details of the death

4.1 and 4.1.1: Record the date and time of death.

4.2: Type of death: Circle to indicate the appropriate category based on the following definitions.

- "Neonatal death" is the death of a baby born alive but who died within the first 28 days of life.
- "Intrapartum stillbirth" is the death of a fetus who was alive at the onset of labour but who died before delivery. This can be determined by the presence of fetal heart sounds (fetal heart tones) on admission or prior to delivery, or by appearance of a "fresh" stillbirth (intact skin and fetus on delivery).
- "Antepartum stillbirth" is the death of a fetus before the onset of labour. This can be determined by "macerated" appearance of the fetus upon delivery, in combination with absence of fetal heart sounds on admission.
  - Absence of fetal heart sounds on admission does not necessarily indicate an antepartum stillbirth, if the woman was admitted with labour already in progress.
  - Presence of fetal heart sounds on admission of a labouring woman does exclude the possibility of an antepartum stillbirth.
- "Stillbirth, unknown timing" should be circled if it is not possible to tell the time of death of the fetus.

4.3: Main maternal condition: Enter in writing the main maternal condition followed by the letter and number code corresponding to it, found on the maternal conditions reference page. If unknown circle "unknown".

4.4: Cause of death: Identify the relevant cause of stillbirth or neonatal death by circling the appropriate letter below this item (a–g). For infections (e), circle the most appropriate response.

After choosing a main cause of stillbirth or neonatal death, indicate the maternal condition in the relevant M1–M5 category, using the numbers provided on the accompanying reference page. If the mother was healthy, enter 1 in the M5 column corresponding to the cause of stillbirth or neonatal death. Check "other" if none of the maternal conditions codes fit, and check "unknown" if the mother's condition is unknown.

## Section 5: Critical delays and modifiable factors

5.1: Critical delays: Circle any delays in care that are recognized during the review of the case, as described below.

- Delay 1: Delay in the **decision** to seek care (e.g., a woman may labour at home for too long because she and/or her family are afraid to come for care, are concerned about the cost of care, or do not recognize developing problems).

- If a "delay 1" is present, circle "delay 1" and describe the delay at the end of this line.
- If no delay 1 is identified, circle "not identified".

- Delay 2: Delay in **reaching** care (e.g., a labouring woman may not be able to find or afford expedient transportation to a care facility).
  - If a "delay 2" is present, circle "delay 2" and describe the delay at the end of this line.
  - If no "delay 2" is identified, circle "not identified".

- Delay 3: Delay in **receiving** adequate care (e.g., a labouring woman may arrive at a hospital where no clinicians are available to provide any care to her, or her transfer between lower- and higher-level facilities may take too long to provide effective care and prevent stillbirth).
  - If a "delay 3" is present, circle "delay 3" and describe the delay at the end of this line.
  - If no "delay 3" is identified, circle "not identified".

5.2: Modifiable factors: This section relates to modifiable factors in terms of levels of system failure. These may be helpful to identify interventions to prevent future deaths.

- Family-level factors: Did the family of a victim of neonatal death not understand when to seek care for their infant? Should families in their community receive any educational campaign, or resources to help get them to a health-care facility sooner?
  - If a family-level modifiable factor is present, circle "family-related" and describe the factor(s) next to "specify".
  - If no family-level modifiable factor can be identified, circle "none identified".

- Administration-level factors: Was transfer between lower- and higher-level facilities inhibited by administrative barriers? Was there a stock out of any needed drugs or equipment?
  - If an administration-level modifiable factor is present, circle "administration-related" and describe the factor(s) next to "specify".
  - If no administration-level modifiable factor can be identified, circle "none identified".

Provider-level factors: Was a provider unable to give adequate resuscitation? Are there needs for training or additional resources for provider use?

- If a provider-level modifiable factor is present, circle "provider-related" and describe the factor(s) next to "specify".
- If no provider-level modifiable factor can be identified, circle "none identified".

## Actions to address critical delays and avoidable factors:

This section is the least structured part of the form, but potentially the most important.

Participants in the perinatal death review should work together to highlight the critical delays and avoidable factors that can be targeted by interventions to avoid similar deaths in the future. It is particularly helpful to ask the question: What could actually be done to prevent a critical delay or avoidable factor?

The group should generate and write down specific actions required to mitigate these critical delays and avoidable factors in future cases, attaching additional pages as needed.

Form completed by: Adding a contact name here, as well as contact information, can be very helpful to future people reviewing the forms in the future.

Date: Add the date on which the review was completed.

**Abbreviations**: c/s: caesarean section; CVD: cephalic vaginal delivery; ELBW: extremely low birth weight; EmOC: emergency obstetric care; HAART: highly active antiretroviral therapy; HIV: human immunodeficiency virus; IPT: intermittent preventive treatment; LBW: low birth weight; LMP: last menstrual period; NVP: nevirapine prophylaxis; TT: tetanus toxoid; VLBW: very low birth weight

# Annex 2: Births and Deaths Summary Form
## (and guidance for completion)

## Annex 2a: Births and Deaths Summary Form

**Section 1: Identification**

1.1 Data collected at (facility name):

1.2 Data for the month of:

1.3 District name:

1.4 Births

| | Total births (incl deaths) | Stillbirths (SB) | | | Neonatal deaths | |
|---|---|---|---|---|---|---|
| | | Antepartum SB | Intrapartum SB | Unknown SB | Early | Late |
| < 1000 g | | | | | | |
| 1000–1499 g | | | | | | |
| 1500–1999 g | | | | | | |
| 2000–2499 g | | | | | | |
| 2500 g+ | | | | | | |

1.5 Multiple pregnancies ☐ babies from ☐ pregnancies

1.6 Born before arrival ☐ total

1.7 Mode of delivery

| | | | | |
|---|---|---|---|---|
| CVD | vacuum | forceps | caesarean | unknown |

1.8 Gestational age

| | | | | | |
|---|---|---|---|---|---|
| term | post-term | ext preterm | very preterm | mod preterm | unknown |

1.9 HIV status

| | | |
|---|---|---|
| negative | positive | unknown |

1.10 Syphilis serology

| | | |
|---|---|---|
| negative | positive | unknown |

1.11 Maternal age

| | | | | |
|---|---|---|---|---|
| 20–34 y | > 34 y | 18–19 y | < 18y | unknown |

## Section 2: Cause of death

| 2.1a Cause of death: antepartum stillbirths | M1 | M2 | M3 | M4 | M5 | other | unknown |
|---|---|---|---|---|---|---|---|
| a. congenital | | | | | | | |
| b. antepartum complications | | | | | | | |
| c. intrapartum complications | | | | | | | |
| d. complications of prematurity | | | | | | | |
| e. infection | | | | | | | |
| f. other | | | | | | | |
| g. unknown/unspecified | | | | | | | |

| 2.1b Cause of death: intrapartum stillbirths | M1 | M2 | M3 | M4 | M5 | other | unknown |
|---|---|---|---|---|---|---|---|
| a. congenital | | | | | | | |
| b. antepartum complications | | | | | | | |
| c. intrapartum complications | | | | | | | |
| d. complications of prematurity | | | | | | | |
| e. infection | | | | | | | |
| f. other | | | | | | | |
| g. unknown/unspecified | | | | | | | |

| 2.1c Cause of death: neonatal deaths | M1 | M2 | M3 | M4 | M5 | other | unknown |
|---|---|---|---|---|---|---|---|
| a. congenital | | | | | | | |
| b. antepartum complications | | | | | | | |
| c. intrapartum complications | | | | | | | |
| d. complications of prematurity | | | | | | | |
| e. infection | | | | | | | |
| f. other | | | | | | | |
| g. unknown/unspecified | | | | | | | |

CVD: cephalic vaginal delivery

# Annex 2b. Guidance for completing the Births and Deaths Summary Form

Purpose of form: To assist a facility to document births and perinatal deaths.

Responsibility for completion: Once per month by the facility data clerk or statistics department. Additionally, numbers generated on this form can be compared between months to obtain trends. At every perinatal death review meeting/committee meeting, these data can be reviewed to identify similarities in cases reviewed and overall trends. This may help guide prioritization of actions or interventions recommended by the perinatal death review committee/meeting.

## Section 1: Identification

1.1: Write facility name here.

1.2: Write the month and year for which these data were collected.

1.3: Write the name of the district where the facility is located.

1.4: Births

Column 1: Total Births: Write the total number of births in each of the categories, including both live and stillbirths (including any live births of neonates who later died).

Column 2: Stillbirths: Write the total number of stillbirths (SB) in each category, as defined here:

- "Antepartum SB" is the death of a fetus before the onset of labour.
  - This can be determined by "macerated" appearance of the fetus upon delivery (i.e. tissue degeneration, starting with skin changes), in combination with absence of fetal heart sounds (fetal heart tones) on admission.
    - Absence of fetal heart sounds on admission does not necessarily indicate an antepartum stillbirth, if the mother was admitted with labour already in progress.
    - Presence of fetal heart sounds on admission of a labouring woman does exclude the possibility of an antepartum stillbirth.
- "Intrapartum SB" is the death of a fetus who was alive at the onset of labour but who died before delivery.
  - This can be determined by the presence of fetal heart sounds (fetal heart tones) on admission or prior to delivery, or by "fresh" appearance of a fetus upon delivery (i.e. intact skin and fetus on delivery).
- "Unknown SB" is the category for those stillborn fetuses for whom it is not possible to tell the timing of the death.

1.5: Multiple pregnancies:

In the "pregnancies" box, write the total number of pregnancies of at least two fetuses (e.g. twins, triplets).

In the "babies" box, write the total number of fetuses or neonates who resulted from these pregnancies. Include those born alive as well as stillborn.

For example, suppose that in one month a hospital delivered 10 women who had pregnancies with more than one fetus. Suppose that of these 10 women, 8 delivered live twins, 1 delivered stillborn twins, and 1 delivered live triplets. In this example, the "pregnancies" box would have the number "10" and the "babies" box would have the number "21".

1.6: Born before arrival: Enter the total number of stillbirths and live births that occurred before arrival at the facility.

1.7: Mode of delivery: Write in each box the total number of deliveries by cephalic vaginal delivery (CVD), vacuum-assisted, forceps-assisted, caesarean and unknown mode.

1.8: Gestational age: Write in each box the total number of:

- term deliveries: deliveries at gestational ages 37–42 weeks
- post-term deliveries: deliveries at gestational ages > 42 weeks
- extremely preterm deliveries ("ext preterm"): deliveries at gestational ages < 28 weeks
- very preterm deliveries: deliveries at gestational ages 28–32 weeks
- moderate-to-late preterm deliveries ("mod preterm"): deliveries at gestational ages 32–37 weeks.

1.9: HIV status: Record the numbers of HIV-negative mothers, HIV-positive mothers, and mothers of unknown HIV status served by the facility in the past month.

1.10: Syphilis serology: Record numbers of syphilis-negative mothers, syphilis-positive mothers, and mothers of unknown syphilis status served by the facility in the past month.

1.11: Maternal age: Record the numbers of mothers served by the facility in the past month within each of the age groups shown on the form, as well as number of mothers for whom age group was unknown.

## Section 2: Cause of death

2.1a Cause of death – antepartum stillbirths: Tally the number of causes of antepartum stillbirths in each of the listed categories in the past month at this facility. If M1–M5 designations were used, total each of those. If M1–M5 designations were not used, enter all in the "other" column provided. Tally any unknowns in the "unknown" column.

If a facility has stillbirths for which antepartum versus intrapartum status is unknown, record these separately in the empty space to the right of the antepartum deaths list, along the same rows.

2.1b: Cause of death – intrapartum stillbirths: Tally the number of causes of intrapartum stillbirths in each of the listed categories in the past month at this facility. If M1–M5 designations were used, total each of those. If M1–M5 designations were not used, enter all in the "other" column provided. Tally any unknowns in the "unknown" column.

2.1c: Cause of death – neonatal deaths: Tally the number of causes of neonatal deaths in each of the listed categories in the past month at this facility. If M1–M5 designations were used, total each of those. If M1–M5 designations were not used, enter all in the "other" column provided. Tally any unknowns in the "unknown" column.

# Annex 3: Minimum set of perinatal indicators to collect for all births and perinatal deaths (and guidance for completion)

## Annex 3a: Minimum set of perinatal indicators to collect for all births and perinatal deaths

**Section 1: Identification**

| | | |
|---|---|---|
| 1.1 | ID # mother | |
| 1.2 | ID # baby | |
| 1.3 | Facility name: | |
| 1.4 | District name: | |

**Section 2: Pregnancy progress and care**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 2.1 | Obstetric history | | all pregnancies | total live births | dead | | | | | |
| 2.2 | Mother's age | | | | y | | | | | |
| 2.3 | Type of pregnancy | | | singleton | twin | higher multiple = | | | | unknown |
| 2.4 | Antenatal care number of visits | | | 4 or more | 3 | 2 | 1 | no visits | | unknown |
| 2.5 | HIV status | | | HIV-negative | HIV-positive | | | not done | | unknown |
| 2.5.1 | HIV-positive action | | | | NVP | HAART | other: | | | |

**Section 3: Labour and birth**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 3.1 | Mother's LMP | DD | MM | YYYY | | | | | | |
| 3.2 | Date of birth | DD | MM | YYYY | | | | | | |
| 3.2.1. | Time of birth | : | h | | | | | | | |
| 3.3 | Gestational age | | | weeks | | | | | | |
| 3.3.1. | Method of determination | sure LMP dates | | | unsure LMP dates | | other, specify | | | |
| | | early ultrasound | | | late ultrasound | | | | | |
| 3.4 | Place of delivery | | | facility | home | road | other, specify | | | unknown |
| 3.5 | Attendant at delivery | midwife | nurse | doctor | other, specify | | | no one | | unknown |
| 3.6 | Mode of delivery | | | CVD | assisted vaginal | caesarean | other, specify | | | unknown |
| 3.7 | Sex of baby | male | | female | | | | | | unknown |
| 3.8 | Birth weight | | g | ≥ 2500 g | 1500–2499 g | 1000–1499 g | < 1000 g | | | unknown |
| | | | | | LBW | VLBW | ELBW | | | |

**Section 4: Details of the death**

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 4.1 | Date of death | DD | MM | YYYY | | | | |
| 4.2 | Time of death | : | h | | | | | |
| 4.2 | Type of death (circle one) | | | | neonatal death | intrapartum stillbirth | antepartum stillbirth | stillbirth, unknown timing |

CVD: cephalic vaginal delivery; ELBW: extremely low birth weight; HAART: highly active antiretroviral therapy; HIV: human immunodeficiency virus; LBW: low birth weight; LMP: last menstrual period; NVP: nevirapine prophylaxis; SB: stillbirth; VLBW: very low birth weight

# Annex 3b. Guidance for collecting the minimum set of perinatal indicators for all births and perinatal deaths

**Purpose of form**: To identify the minimum elements that should be collected on every birth and death that occurs in the health-care facility. The form does not have to be used in addition to routine data collection if all of these elements are already being captured in another place (e.g. the register or electronic health management information system).

**Time of completion**: The form should be completed as close to the time of birth and discharge/death as possible. This information is to be compiled before or at the initiation of the perinatal death review meeting (also known as "perinatal mortality audit meeting") if not possible in advance of the meeting.

## Section 1: Identification

1.1: Mother's ID: Put an identifier for the mother here. Include ID numbers that are used by your health-care facility. If there are potential legal ramifications linked to audit records, do not use this identifier and instead just number the cases discussed sequentially.

1.2: Baby's ID: Include ID numbers that are used by your health-care facility. If no standard ID numbers are used, put the baby's name instead. If the baby has no name, put mother's name + "boy" or "girl". If there are multiple babies for the same mother, add "boy No. 1" or "girl No. 1" as needed.

1.3: Facility name: Put the name of the facility where the stillbirth or neonatal death took place. If it is being reviewed at a different facility, add "reviewed at facility:____" to clarify.

1.4: District name: Put the name of the district where the facility at which the mother delivered is located. This may not be the district that the mother is from.

## Section 2: Pregnancy progress and care

2.1: Obstetric history:

- For "all pregnancies", put the total number of *pregnancies*, irrespective of gestational age, including the most recent pregnancy. Pregnancies with twins or other multiples are counted as one pregnancy.
- For "total live births", put the total number of *live births* the woman has had. Include the delivery of the fetus or neonate being discussed. If both were born alive, twins are counted as two living children, with the same for higher-order multiples.
- For "dead", put the number of the mother's *deceased children*. Include the fetus or neonate being discussed. If both are deceased, twins are counted as two deceased children.

2.2: Mother's age: Put the woman's age in completed years. For example, a woman of 23 years and 10 months of age would be entered as "23".

2.3: Type of pregnancy: Circle the type of pregnancy with the fetus or neonate being discussed:

- "singleton" if a pregnancy with one fetus;
- "twin" if a pregnancy with two fetuses;
- "higher multiple" if more than two fetuses (if more than two fetuses, put the number of fetuses next to the equals sign);
- "unknown" if the total number of fetuses is/was not known.

2.4: Antenatal care: Circle the total number of antenatal care visits the woman had during her pregnancy with the fetus or neonate being discussed: 4 or more; 3; 2; 1; no visits; unknown.

2.5: HIV status: Circle to indicate the woman's HIV status:

- "HIV-negative" if she was tested and found to be negative;
- "HIV-positive" if she was tested and found to be positive, or was known to be positive prior to pregnancy (and proceed to 2.5.1 below);
- "not done" if no HIV testing was performed during pregnancy;
- "unknown" if the HIV status and testing status are unknown.

2.5.1: If the woman was found to be HIV-positive or known to be HIV-positive prior to pregnancy, circle to indicate what action was taken:

- "NVP" if she received nevirapine prophylaxis for delivery
- "HAART" if the mother received highly active antiretroviral treatment during her pregnancy
- Next to "other", write whether:
  - No treatment was received
  - Any additional treatment was received for HIV or its complications
  - Treatment was received but the type was unknown.

Do not complete line 2.5.1 for any woman who was not known to be HIV-positive.

## Section 3: Labour and birth

3.1: Mother's LMP: Enter the date of the woman's last menstrual period (LMP) here, or circle "unknown".

3.2: Date of birth: Record the date of the birth here, whether live or stillborn.

3.3: Gestational age: Enter in weeks and days at the time of birth (live or stillbirth), using the LMP.

Choose gestational age to record in this order:

1. If there is a gestational age based on early ultrasound, enter this.
2. If there is no gestational age based on early ultrasound, enter the estimated gestational age according to woman's recollection of her LMP.

3) If there is no gestational age estimate either based on ultrasound or the woman's recollection, circle "unknown" (DO NOT enter gestational age based on late ultrasound or estimated by size at delivery).

3.3.1: Method of determination: Circle the method by which this gestational age was calculated. Additionally, circle "sure" or "unsure" for the LMP dates, depending on the woman's stated level of certainty. If the woman's certainty is not stated, or if another method was used, write this in the "other, specify" box.

3.4: Place of delivery: Circle to indicate the place. If delivery was at a facility, enter the facility's name on this line.

3.5: Attendant at delivery:

- Circle "midwife" if delivery was attended by a trained midwife.
- Circle "nurse" if delivery was attended by a nurse with midwifery skills.
- Circle "doctor" if delivery was attended by a physician.
- If the delivery was attended but none of the provided options fit, write in the type of attendant in the "other" box (e.g. traditional birth attendant, community health worker, relative).
- Circle "no one" if no one other than the woman was present at the delivery.
- Circle "unknown" if delivery attendance is not known.

3.6: Mode of delivery: Circle to indicate the appropriate information for the fetus or neonate being discussed.

- "CVD" for cephalic vaginal (or normal) delivery
- "assisted vaginal delivery" if vacuum and/or forceps were used
- "caesarean" if indicated
- "other" if indicated, and describe
- "unknown" if this information is not available.

More than one answer can be chosen, as appropriate.

3.7: Sex of baby: Circle "male", "female" or "unknown" as indicated.

3.8: Birth weight: Record the total birth weight, and circle the appropriate category of birth weight, or "unknown" if birth weight is not available. The acronyms stand for:

- LBW: Low birth weight (1500–2499 g)
- VLBW: Very low birth weight (1000–1499 g)
- ELBW: Extremely low birth weight (< 1000 g)

## Section 4: Details of the death

This section is only applicable in the case of death. If the baby was discharged alive, this section will not be completed.

4.1 and 4.2: Record the date of death and time of death.

4.3: Type of death: Circle to indicate the appropriate category based on the following definitions.

- "Neonatal death" is the death of a baby born alive but who died within the first 28 days of life.
- "Intrapartum stillbirth" is the death of a fetus who was alive at the onset of labour but who died before delivery. This can be determined by the presence of fetal heart sounds (fetal heart tones) on admission or prior to delivery, or by appearance of a "fresh" stillbirth (intact skin and fetus on delivery).
- "Antepartum stillbirth" is the death of a fetus before the onset of labour. This can be determined by "macerated" appearance of the fetus upon delivery, in combination with absence of fetal heart sounds on admission.
  - Absence of fetal heart sounds on admission does not necessarily indicate an antepartum stillbirth, if the woman was admitted with labour already in progress.
  - Presence of fetal heart sounds on admission of a labouring woman does exclude the possibility of an antepartum stillbirth.
- "Stillbirth, unknown timing" should be circled if it is not possible to tell the time of death of the fetus.

**Abbreviations**: CVD: cephalic vaginal delivery; ELBW: extremely low birth weight; HAART: highly active antiretroviral therapy; HIV: human immunodeficiency virus; LBW: low birth weight; LMP: last menstrual period; NVP: nevirapine prophylaxis; SB: stillbirth; VLBW: very low birth weight

# Annex 4. Approaches for classifying modifiable factors

A modifiable factor is something that may have prevented the death if a different course of action had been taken.

Many modifiable factors are due to missed opportunities within the health system. These represent potential for positive change. Documenting these modifiable factors is a very important priority of perinatal death review (also known as "perinatal mortality audit").

Modifiable factors are often discussed in terms of delays in care and in levels of system failure. Modifiable factors are often analysed using a root cause analysis, including fish-bone diagrams.

Participants in the perinatal death review should work together to highlight the critical delays and avoidable factors that can be targeted by interventions. It is particularly helpful to ask the question: What could actually be done to prevent a critical delay or avoidable factor?

## Instructions, part 1: Three delays model

The "three delays" model describes three types of delays in getting adequate care:

**Delay 1**: Delay in the *decision* to seek care. For example, a woman may labour at home for too long because she and/or her family are afraid to come for care, are concerned about the cost of care, or do not recognize developing problems. Participants in the perinatal death review meeting should write down any type 1 delays they can identify on the Stillbirth and Neonatal Death Case Review Form (Annex 1a).

**Delay 2**: Delay in *reaching* care. For example, a labouring woman may not be able to find or afford expedient transportation to a health-care facility. The perinatal death review meeting participants should write down any type 2 delays they can identify on the Stillbirth and Neonatal Death Case Review Form (Annex 1a).

**Delay** 3: Delay in *receiving* adequate care. For example, a labouring woman may arrive at a hospital without any clinicians available to provide care to her, or transfer between lower- and higher-level facilities may take too long to provide effective care and prevent stillbirth. Participants in the perinatal death review meeting should write down any type 3 delays they can identify on the Stillbirth and Neonatal Death Case Review Form (Annex 1a).

## Instructions, part 2: Patient–provider–administration model

Discussion of modifiable factors in terms of levels of system failure may be helpful to guide interventions. Typically three levels are discussed:

1. **Family level**: Did the family of a victim of neonatal death not understand when to seek care for their infant? Should families in their community be targeted with an educational campaign or provided with resources to help them get to care sooner? Family-level modifiable factors can be recorded on the bottom of the Stillbirth and Neonatal Death Case Review Form (Annex 1a), to help develop the comments and the root cause analysis.

2. **Administrative level**: Was transfer between lower- and higher-level facilities inhibited by administrative barriers? Was there a stock-out of any needed medicines or equipment? Administrative-level modifiable factors can be recorded on the bottom of the Stillbirth and Neonatal Death Case Review Form (Annex 1a), to help develop the comments and the root cause analysis.

3. **Provider level**: Was a health-care provider unable to give adequate resuscitation? Are there needs for additional training or resources for providers? Provider-level modifiable factors can be recorded on the bottom of the Stillbirth and Neonatal Death Case Review Form (Annex 1a), to help develop the comments and the root cause analysis.

For example, if a baby dies of congenital syphilis, and the mother did not attend antenatal care, then the modifiable factor would most likely have been related to family- or patient-level factors. However, if the mother attended the antenatal clinic but the health worker failed to screen her for syphilis or failed to collect the result and treat her, then the avoidable factor would have been provider related. Finally, if the mother attended antenatal clinic, and the health worker wanted to screen her for syphilis but either transport or the facilities to perform the test were not available, then the modifiable factor would have been administration related.

Some modifiable factors can be clearly identified as being the cause of a death, while other avoidable factors may have contributed to the death more distally. Therefore, avoidable factors can be further divided into “probable” and “possible” factors.

Only when the specific avoidable factor or missed opportunity has been identified can steps be taken to prevent similar deaths in the future. If it is not clear why the care was substandard, it is very difficult to solve the problem. Identifying modifiable factors is an important step in improving care.

## Instructions, part 3: Root cause analysis

A root cause analysis helps to identify all of the problems that led to or contributed to an event. In this case, the event is the stillbirth or neonatal death under review. This analysis may help facilitate the formulation of integrated strategies and recommendations.

There are multiple tools available for completing a root cause analysis. One of the most helpful is called an Ishikawa diagram, which is also known as a "fishbone" diagram, because a completed diagram can look like the skeleton of a fish (see Figure A4–1).

Steps for a group to complete a root cause analysis through a fishbone diagram:

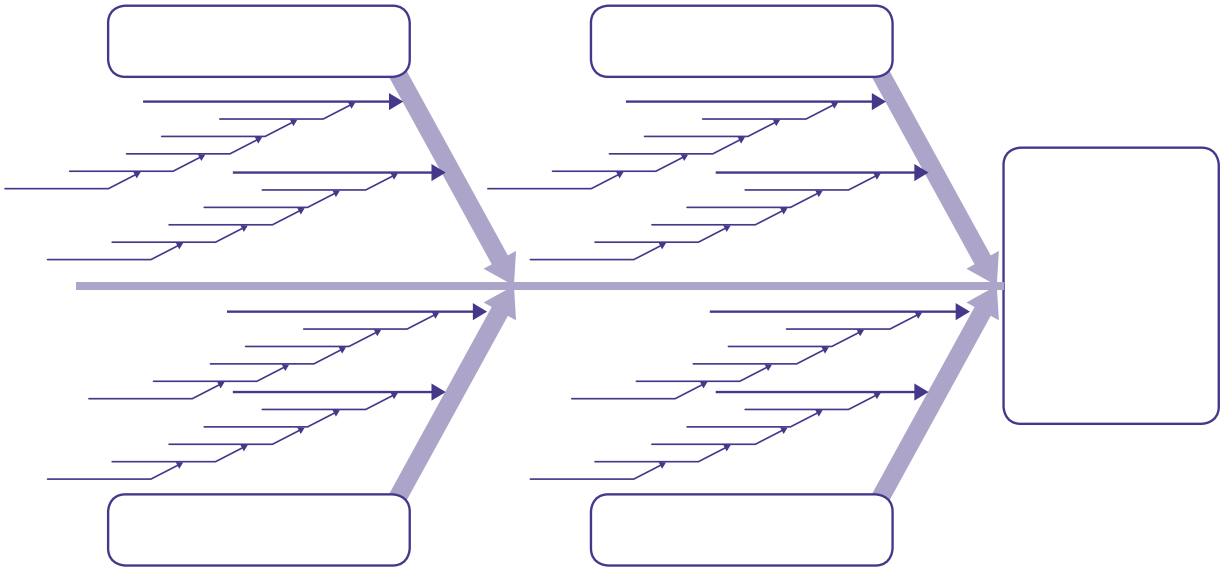
## Step 1: Record the event at the head

The first step is to identify the problem or event – for example, a death with a specific cause, such as an intrapartum-related perinatal death in a full-term baby. Write this problem in a box on the far right-hand side of a large sheet of paper as the "head" of the fish, to represent the event that is under investigation for contributing problems and factors, and then draw a line across the paper horizontally from the box as the "spine" of the fish.

## Step 2: Brainstorm contributing factors

Next, draw lines as "bones" off the spine of the fish with a box at the end of each line/bone in which to write down the contributing factors. The group then attempts to identify the problems and factors that led to the perinatal death. These may be problems at different levels of the health systems, or system building blocks such as staffing, equipment, information, etc. Identifying the contributing factors is typically done through open brainstorming, with every person in the group contributing out loud everything that they can think of that contributed to the occurrence of this death. Alternatively, instead of contributing out loud, groups may choose to have participants write down what they think the contributing factors to the death were and then submit them anonymously to a discussion leader who can read them out loud.

FIGURE A4–1. Fishbone diagram



The National Health Service (NHS) of England has developed a list of potential contributing factors which is is provided to participants in its National Patient Safety Agency to assist them when brainstorming circumstances around adverse patient events, in the course of completing fishbone diagrams. These factors include:[9]

- Team factors: role congruence, leadership, team cultural factors, team support factors;
- Organizational and strategic factors: organizational structure, organizational priorities, and culture of safety;
- Communication factors: verbal, written, non-verbal, and communication between management and staff;
- Working condition factors: administrative, design of physical environment, environment, staffing, workload, hours, and time;
- Task factors: guidelines, procedures, protocols, decision aids, task design;
- Equipment and resources: displays, integrity, positioning, usability;
- Individual staff factors: physical issues, psychological issues, social issues, personality, cognitive factors;
- Education and training factors: competence, supervision, availability, accessibility, appropriateness;
- Patient factors: clinical condition, physical factors, social factors, psychological factors, interpersonal relationships.

### Step 3: Record the contributing factors at the end of the bones

After brainstorming, the next step is to write down each contributing factor in a box at the end of a bone leading to the head of the fish (the event).

*Steps 4 through 6 are best performed one contributing factor – or one "bone" – at a time, until each step has been completed for each bone before moving on to step 7.*

### Step 4: Brainstorm contributing causes within each bone

The next step is to repeat the brainstorming process with each of the bones (each of the contributing factors), to identify possible contributing causes. What problems or factors contributed to that specific problem or factor written at the end of the bone?

### Step 5: Record contributing causes on the veins

Again after this round of brainstorming, the next step is to write down these possible contributing problems or contributing causes as shorter lines or "veins "coming off each bone of the diagram.

### Step 6: Brainstorm contributing subcauses on the subveins

For each contributing cause that is large or complex, it may be best to break it down into sub-causes, working from proximal to distal causes below. Therefore, further brainstorming is undertaken for each of the contributing problems or causes written on the veins.

---

[9] The list of contributing factors is adapted from Root cause analysis investigation tools: contributory factors classification framework. NHS National Patient Safety Agency; 2009 (http://www.nrls.npsa.nhs.uk/resources/?entryid45=75605, accessed 25 July 2016). This contributing factors list is not meant to be comprehensive, but to assist brainstorming.

What problems or factors (subcauses) contributed to the specific contributing problem or cause? These subcauses – as well as any additional problems or factors that contributed to their occurrence – are entered onto the fishbone diagram as the "subveins" coming off each vein or cause line.

## Step 7: Create action targets and develop actionable solutions

By this stage of the root cause analysis exercise, the fishbone diagram should show many possible causes, problems and factors that likely contributed to the perinatal death (see Figure A4–1). From here, the team should be able to develop actionable solutions. There may be many problems and solutions that can be explored, but teams may choose to focus on gaps that are actionable within their sphere of influence in the short term, while advocating for more long-term systemic change.

To be most effective, a perinatal death review meeting can take this fishbone diagram one step further and circle the contributing causes and subcauses that will be targeted with action. These items are called action targets. **Only causes and subcauses that can be addressed by participants in the perinatal death review may be designated as action targets.** For example, "poverty" may be listed as a contributing factor on one of the bones. Causes written on veins for that bone may include "lack of income", "family poverty" and "cost of health care". Subveins for "cost of health care" may include "delivery fees", "hospital debt" and "cost of gloves". Of all these causes and subcauses, participants in the perinatal death review should only circle those things that they believe they can address through intervention. For example, "cost of gloves" may be circled as an action target if there is a programme or nongovernmental organization that may be approached for free gloves. Alternatively, "delivery fees" may even be circled as an action target if one of the participants is an administrator with the power to reduce or eliminate those fees. In contrast, "lack of income" should never be circled, because the perinatal death review participants have no way to intervene in that particular issue. To provide an even more extreme example, "poverty" itself should never be circled as an action target: this would unfortunately be unrealistic.

## Step 8: Create action spears

The perinatal death review meeting participants can then add arrows or "action spears" to the fishbone diagram that point to these action target circles and specify on the end of these spears:

1. *who* will take the action
2. *what* action will be taken
3. *when* will the action be taken.

These action spears represent the power to prevent future perinatal deaths.

# Annex 5. Setting up a mortality audit steering committee

The role of a steering committee in mortality audit is to organize and oversee the review process and, when it is time to act on the findings, help develop and implement the recommendations. The primary purpose of mortality audit is action, and without the support of key stakeholders, recommendations cannot be turned into actions. Key stakeholders are the people who have the responsibility and authority to achieve actions. These actions can include community- or facility-based interventions, the development and introduction of guidelines, improving access to services or health system reform. Thus, the importance of the support of local community leaders, facility directors, or national or state government entities for such audits cannot be overemphasized. Also, to ensure sustainability, since many good programmes come to an end when project funding ends for new initiatives, governments and other key stakeholders need to be involved from the beginning of the facility-based death review process, informed of progress and, as appropriate, invited to attend meetings or sit on steering committees.

Steering committee members for the facility-based death reviews (also known as "mortality audit") should have an interest in neonatal and maternal health. The committee should include a diverse group of members, as appropriate. Members may include representatives from the district health office, the facility administration, the departments of neonatology/paediatrics, obstetrics, midwifery/nursing, anaesthesia, pathology, pharmacy and statistics, as well as a community liaison.

The key roles of the steering committee are to:

- help initiate the case review and mortality audit process and decide on the approach and its scope;
- oversee data collection, analysis and case selection for review meetings, including assigning responsibility for this task if not included in existing job descriptions;
- develop a schedule for the audit meetings, invite participants and ensure adequate facilitation;
- assist with dissemination of recommendations and advocate for their implementation.

At the national level, a stillbirth and neonatal mortality audit steering committee would have similar composition and roles as described above, but would likely be led by the national ministry of health, with official representation from health professional associations, and with more opportunity for diversity of membership, including epidemiologists, staff of nongovernmental organizations, development partners and high-level policy-makers.

# Annex 6. Sample mortality audit meeting code of practice declaration

To foster an environment of collaboration rather than blame, it might be helpful if a written code of practice is established by the mortality audit (also known as "death review") steering team, and agreed through discussion with facility staff and management. For the written code of practice, use of wording specific to each team is encouraged, but a suggested short text is provided below, which can be signed by each individual before each review meeting.

An attendance sheet could also be signed at the end of the meeting, so that those who were there to sign in at both the beginning and end of the meeting can be credited for staying and participating throughout the meeting.

**Code of practice**

To show respect for the babies and families we are responsible for looking after, we, the staff of _____ [name of facility], agree to respect the rules of good conduct during meetings where cases of deaths that have occurred in our facility are reviewed. We understand and appreciate that the results of these meetings will not result in punitive measures. The rules of our stillbirth and neonatal mortality audit meetings include:

- arrive on time to the audit meetings;
- participate actively in discussions;
- respect everyone's ideas and ways of expressing them;
- accept discussion and disagreement without resorting to verbal abuse;
- respect the confidentiality of the discussions that take place during the meetings;
- agree not to hide useful information or falsify information that could provide insight into the case(s) under review; and
- try as much as possible (recognizing that it is not easy) to accept that your own actions can be questioned.

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

# Annex 7: Sample calculations for reporting

This form provides dummy data and formulas for calculating simple indicators that can be used to complete the Meeting Minutes and Action Items Form found in Annex 8.

| | | | |
|---|---|---|---|
| | **Facility name:** | | |
| | **Period under review:** | | |
| | **Numbers** | | |
| A | Number of deliveries | | 1000 |
| B | Number of live births | | 880 |
| C | Number of stillbirths* | | 20 |
| D | Number of intrapartum stillbirths | | 12 |
| E | Number of antepartum stillbirths | | 8 |
| F | Early neonatal deaths (1–7 days) | | 14 |
| G | Neonatal deaths (1–28 days) | | 18 |
| H | Maternal deaths | | 2 |
| I | Number of caesarean section deliveries | | 150 |
| J | Number of assisted deliveries | | 100 |
| K | Number of babies born weighing < 2500 g | | 200 |
| L | Number of babies born < 37 weeks gestational age | | 140 |

*specify definition in use at the health-care facility

**Rates**

| | | |
|---|---|---|
| Stillbirth rate | (C/A)*1000 | 20.0 |
| Percentage of stillbirths that are antepartum | (D/C)*100 | 60% |
| Early neonatal mortality rate | (F/B)*1000 | 15.9 |
| Perinatal mortality rate | ((C+F)/A)*1000 | 34.0 |
| Neonatal mortality rate | (G/B)*1000 | 20.5 |
| Maternal mortality ratio | (H/B)*100 000 | 227.3 |
| Caesarean section rate (all births) | (I/A)*100 | 15% |
| Assisted delivery rate (all births) | (J/A)*100 | 10% |
| Low birth weight rate (live births) | (K/B)*1000 | 23% |
| Preterm rate (live births) | (L/B)*100 | 16% |

# Annex 8: Stillbirth and Neonatal Mortality Audit – Meeting Minutes and Action Items Form

## Annex 8a: Stillbirth and Neonatal Mortality Audit – Meeting Minutes and Action Items Form

**Institution:** _____

**Date of meeting:** _____ **Start time:** _____ **End time:** _____

**Chairperson:** _____

**Month and year being reviewed:** _____

**Statistics:**

Number of women delivered: _____ Number of babies born: _____

Preterm birth rate (< 37 weeks): _____% Low birth weight rate (< 2500 g): _____%

Caesarean section rate: _____% Assisted delivery rate: _____%

Antepartum stillbirth rate: _____ Intrapartum stillbirth rate: _____

Neonatal mortality rate: _____

**Cases discussed**

**Main causes of antepartum stillbirths:**

1. _____

2. _____

3. _____

**Main causes of intrapartum stillbirths:**

1. _____

2. _____

3. _____

**Main causes of neonatal deaths:**

1. _____

2. _____

3. _____

**Modifiable factors identified:**

1. _____

2. _____

3. _____

**Action plans**

| Modifiable factor identified | Specific actions to address modifiable factor | Responsible person | Time frame | Follow-up (this section to be completed at the next meeting) |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

**Date of next meeting:** _____

**Date minutes ratified:** _____

**Proposed by:** _____ **Seconded by:** _____

**Chairperson's signature:** _____

# Annex 8b. Guidance for completing the Stillbirth and Neonatal Mortality Audit – Meeting Minutes and Action Items Form

## Steps for minute-taking at perinatal mortality audit meetings (also known as perinatal death review meetings):

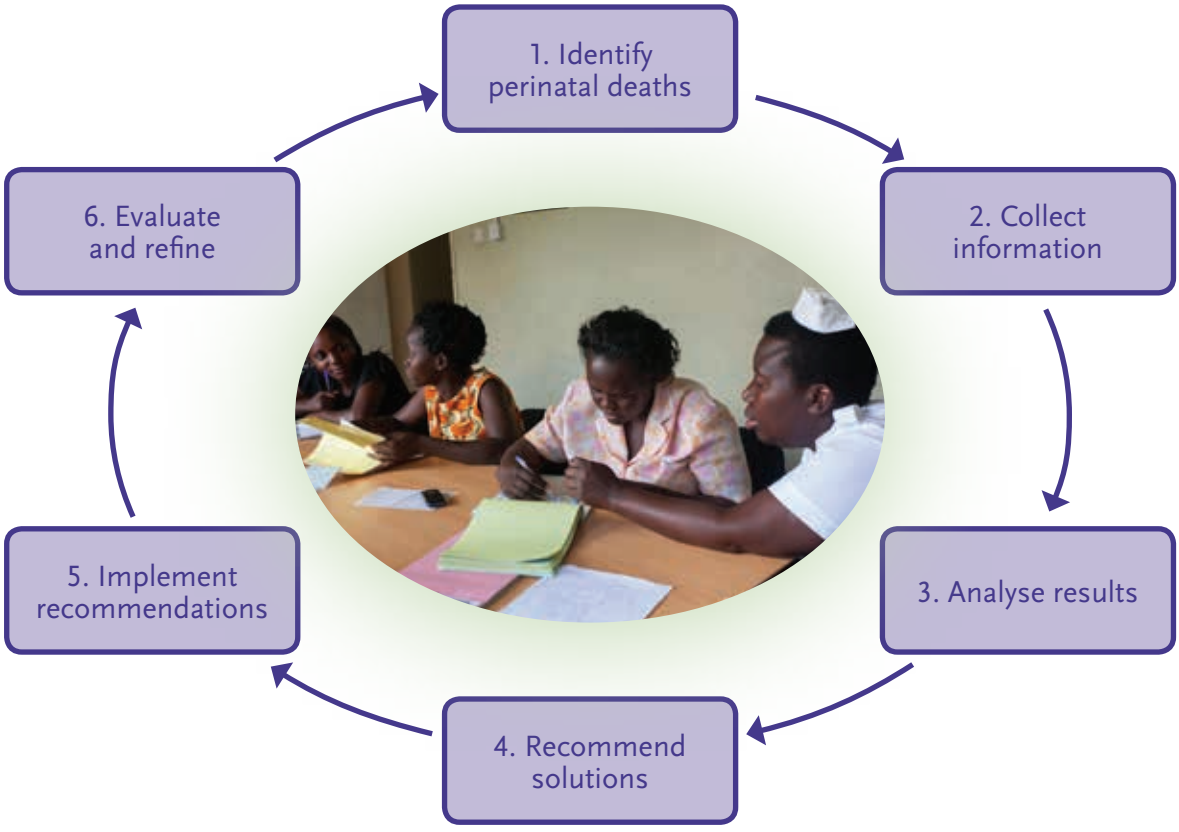
1. Use this form to capture the minutes, which should be accompanied by the code of practice declaration signed before each meeting (see Annex 6) and the attendance register signed at the end of each meeting.
2. The meeting chairperson is responsible for ensuring that the minutes are taken, and that the form is filled in at the end of the meeting. **Do not leave the filling of the form for a later time. For the minutes to be a functional document, the filling of the form needs to be part of the meeting process.**
3. The statistics can be filled in on the form during preparations in advance of the meeting. If more extensive statistics are presented at the meeting, it is optional to attach a copy of the presentation as an addendum to the minutes.
4. Enter a one-line summary about each case presented. For example: "Case X.N., No. 45368, intrapartum stillbirth 2.5 kg, ruptured uterus". It is not necessary to include a full case report. If requested, case presentations can be attached as an addendum to the minutes.
5. The chairperson should allocate at least 5 minutes at the end of the meeting to summarize the key problems that have been identified during the meeting, based on the presentation of statistics or the cases discussed, or both.
6. Based on these problems, action plans can be drawn up, as outlined on the table on the second page of the form. The task list should be clearly allocated and agreed upon at the meeting.
7. At the end of the meeting, the chairperson should ensure that the minutes form is fully complete, either on paper or electronically. Only the follow-up section of the table should be left blank.
8. Within 72 hours of the meeting, paper-based minutes should be typed up and stored electronically. This should not be a long task if the format of the template is adhered to. The typed minutes should be verified by the chairperson, and then circulated as draft minutes by email to all members on the attendance list for the meeting, other interested stakeholders and anyone with responsibility for one of the tasks in the action plan. The distribution of the draft minutes should be completed within a week of the date of the meeting.
9. At the following perinatal mortality audit meeting, the chairperson should allocate some time for reviewing the draft minutes of the previous meeting, preferably at the start of the meeting. If a task has not been completed, this should be noted in the follow-up column and the task can be carried over into the action plans table for the current meeting. Once the follow-up column from the minutes of the previous meeting has been filled in, those final minutes can be ratified, with a proposer and a seconder.
10. The meeting can then proceed with new statistics and/or case presentations.

# Annex 9. Steps for establishing a mortality audit for stillbirths and neonatal deaths

Mortality audit (also known as "death review") is a process to document the medical causes of each death and the contributing systemic failures across many cases, to identify solutions and to take action.

It is not a solution in itself.

It is a systematic way of improving quality of care by collecting and analysing data, linking solutions to identified problems, and ensuring accountability for changes to improve care.



## Steps

1. Understand the steps of the perinatal mortality audit cycle and underlying principles.
2. Establish or strengthen any local, regional or national stillbirth and neonatal mortality audit steering committee to oversee the process.
3. Ensure confidentiality and a legal and ethical framework.
4. Identify data and map all existing data and services.
5. Plan data collection:
    i. Obtain permission and engage the local community in the review process.
    ii. Set up the mortality audit steering committee.
    iii. Plan how you will identify cases.
    iv. Decide how to select a subset of identified cases for detailed review.
    v. Decide which data to collect on each case.
    vi. Pilot-test and refine data collection instruments.
    vii. Plan review of cases – who will do it and how.
    viii. Plan data analysis.
    ix. Educate and sensitize health-care staff.
    x. Set ground rules for review meetings.
6. Implement the system:
    i. Identify cases.
    ii. Collect the data.
    iii. Supervise data collectors.
    iv. Prepare data for review.
    v. Hold mortality audit meeting to review data.
    vi. Analyse the results.
    vii. Use findings to create a list of possible actions (during the review meeting).
    viii. Develop, prioritize and disseminate recommendations.
    ix. Forward data, case notes and recommendations to the next review level.
    x. Publish the results.
    xi. Evaluate and improve the system.
7. Assess the achievements of the perinatal mortality audit cycle, and expand and improve linkages.

# Annex 10: Verbal and social autopsy tool for stillbirth and neonatal death audits in the community

## Verbal and Social Autopsy Form
## Stillbirths and Neonatal Deaths (1–28 days)

*Adapted for audit purposes from the 2014 WHO Verbal Autopsy Instrument*[10,11]

*Instructions to interviewer: Introduce yourself and explain the purpose of your visit. Ask to speak to the mother or to another adult caregiver who was present during the illness that led to the death. If this is not possible, arrange a time to revisit the household when the mother or caregiver will be home. Before interviewing the person, explain to him/her that participation in the interview is voluntary; s/he can refuse to answer any question and s/he can stop the interview at any time. Explain to him/her that the information provided is only for research purposes and will be confidential.* ***Leave the signed top page (copy of informed consent) with the interviewee.***

[10] Verbal Autopsy Standards: 2014 WHO Verbal Autopsy Instrument: Geneva: World Health Organization 2014.

[11] The adaptation of the WHO 2014 Verbal Autopsy Instrument has been expanded for audit purposes with questions on social factors and questions specific to the perinatal period.

**INFORMED CONSENT FORM (INTERVIEWEE COPY)**

## Informed Consent Form for verbal autopsy (VA) interviews (for stillbirths and decedents 1–28 days)

Hello. My name is _____ and I am working with _____ (AGENCY) a partner of the Ministry of Health. We are conducting a survey in this district that asks about health issues of newborn babies.

I am asking you to take part in this survey because I am trying to learn more about stillbirths and the causes of death among newborn babies. We are asking all households in this district that reported a stillbirth or death to a newborn baby since _____ to participate in this survey. The government and its stakeholders have been improving access to health care and the provision of health services in this district. The information that you provide will help us understand health challenges faced by newborns.

I am visiting you today because we were informed about the death of (your baby). I am here now to ask you about the circumstances that led to his/her death. This information will help the government and its stakeholders to understand better ways through which they can improve neonatal health services and help us know whether the improvements in health care planned for your district are helping. The interview will take between 30 and 45 minutes to complete. Whatever information you provide will be kept strictly confidential and will not be shown to other persons.

Participation in this interview is voluntary, so if we should come to any question you don't want to answer, just let me know and I will go to the next question; or you can stop the interview at any time. You should be aware that your answers about the deceased may say something about your own health. However, we hope that you will participate in this survey since your views are important. The information that you provide is strictly confidential. At this time, do you want to ask me anything about the information we are collecting or the survey?

May I begin the interview now?

☐ No, consent for participation not given  Interviewer signature: _____

☐ Yes, consent for participation given  Interviewer signature: _____

☐ Yes, consent for participation given  Respondent signature: _____

OR Respondent thumb print:

Date _____

If you have any questions about this survey, please contact:
Name (Principal investigator)
Institutional affiliation
Telephone

If you ever have questions about your rights or ethics as a participant in this study, please contact:
Name (Principal investigator)
Institutional affiliation
Telephone

**INFORMED CONSENT FORM (INTERVIEWER COPY)**

## Informed Consent Form for verbal autopsy (VA) interviews (for stillbirths and decedents 1–28 days)

Hello. My name is _____ and I am working with _____ (AGENCY) a partner of the Ministry of Health. We are conducting a survey in this district that asks about health issues of newborn babies.

I am asking you to take part in this survey because I am trying to learn more about the causes of death among stillbirths and newborn babies. We are asking all households in this district that reported a stillbirth or death to a newborn baby since _____ to participate in this survey. The Government and its stakeholders have been improving access to health care and the provision of health services in this district. The information that you provide will help us understand health challenges faced by newborns.

I am visiting you today because we were informed about the death of your baby. I am here now to ask you about the circumstances that led to his/her death. This information will help the government and its stakeholders to understand better ways through which they can improve neonatal health services and help us know whether the improvements in health care planned for your district are helping. The interview will take between 30 and 45 minutes to complete. Whatever information you provide will be kept strictly confidential and will not be shown to other persons.

Participation in this interview is voluntary, so if we should come to any question you don't want to answer, just let me know and I will go to the next question; or you can stop the interview at any time. You should be aware that your answers about the deceased may say something about your own health. However, we hope that you will participate in this survey since your views are important. The information that you provide is strictly confidential. At this time, do you want to ask me anything about the information we are collecting or the survey?

May I begin the interview now?

☐ No, consent for participation not given  Interviewer signature: _____

☐ Yes, consent for participation given  Interviewer signature: _____

☐ Yes, consent for participation given  Respondent signature: _____

OR Respondent thumb print:

Date _____

If you have any questions about this survey, please contact:
Name (Principal investigator)
Institutional affiliation
Telephone

If you ever have questions about your rights or ethics as a participant in this study, please contact:
Name (Principal investigator)
Institutional affiliation
Telephone

SIGNATURE OF VA SUPERVISOR: _____

VA SUPERVISOR CODE: _____ ☐☐☐

SEQUENTIAL NUMBER

**GPS CODES:** (of village) DECIMAL DEGREES

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## SECTION 1. INTERVIEW AND DEMOGRAPHIC INFORMATION

### SECTION 1.1 INTERVIEWER VISITS

| | 1 | 2 | 3 | FINAL VISIT |
|---|---|---|---|---|
| DATE | | | | DAY / MONTH / YEAR |
| INTERVIEWER'S NAME | | | | INTERVIEWER # |
| RESULT* | | | | RESULT |
| TAKE NOTES HERE IF FOLLOW-UP IS NEEDED (e.g. TELEPHONE, DIRECTIONS ETC) | | | | |
| NEXT VISIT: DATE | | | | TOTAL NUMBER OF VISITS |
| TIME | | | | |

* RESULT CODES:

1 COMPLETED 2 NOT AT HOME 3 POSTPONED 4 REFUSED

5 PARTLY COMPLETED 6 NO APPROPRIATE RESPONDENT FOUND 7 OTHER (SPECIFY) _____

### SECTION 1.2 ADDITIONAL DEMOGRAPHIC INFORMATION (PLEASE USE CORRECT SPELLING FROM LIST)

**To be filled by data entry**

DISTRICT _____

HEALTH SUBDISTRICT _____

SUBCOUNTY _____

PARISH _____

VILLAGE/LOCALITY _____

HOUSEHOLD NUMBER (HHN) _____

NAME OF DECEASED BABY _____

NAME OF THE BABY'S MOTHER _____

NAME OF HOUSEHOLD HEAD

| WHAT IS THE PRIMARY LANGUAGE OF THE INTERVIEW? | ENGLISH ..... 1<br>OTHER (SPECIFY) _____ 2 |
|---|---|

| SECTION 2. BASIC INFORMATION ABOUT THE RESPONDENT | | | | |
|---|---|---|---|---|
| 2.1 | *RECORD THE TIME AT THE START OF THE INTERVIEW* | HOURS ☐☐ AND ☐☐ MINUTES | | |
| 2.2 | What is your name?<br>*RECORD THE NAME OF THE RESPONDENT* | NAME _____ | | |
| 2.3 | What is your relationship to the deceased baby?<br>*RECORD THE RELATIONSHIP OF THE MAIN RESPONDENT TO THE DECEASED BABY* | MOTHER ..... 1<br>FATHER ..... 2<br>SIBLING ..... 3<br>OTHER RELATIVE _____ 4<br>(SPECIFY)<br>NEIGHBOUR ..... 5<br>FAMILY FRIEND ..... 6<br>OTHER _____ 7<br>(SPECIFY) | →3.1 | |
| 2.4 | Is the mother of the deceased alive? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | →2.8<br><br>→2.8 | |
| 2.5 | Did she die during or after delivery? | DURING DELIVERY ..... 1<br>AFTER DELIVERY ..... 2<br>DON'T KNOW ..... 8 | →2.8<br><br>→2.8 | |
| 2.6 | How long after delivery did the mother die?<br>*ENTER TIME INTERVAL IN MINUTES OR HOURS OR DAYS* | MINUTES ..... 1 ☐☐<br>**OR**<br>HOURS ..... 2 ☐☐<br>**OR**<br>DAYS ..... 3 ☐☐<br>2 OR MORE MONTHS ..... 777<br>DON'T KNOW ..... 998 | | |
| 2.7 | What do you think was the primary cause of the mother's death? | _____<br>_____<br>_____ | | |
| 2.8 | Did you live with the deceased baby in the period leading to his/her death? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8<br>REFUSE ..... 9 | | |

| SECTION 3. INFORMATION ON THE DECEASED AND DATE/PLACE OF DEATH | | | | |
|---|---|---|---|---|
| 3.1 | Was the baby named? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→3.3<br>→3.3 | |
| 3.2 | What was the name of the baby who died?<br>*RECORD THE NAME OF THE BABY AND USE THROUGHOUT THE INTERVIEW* | NAME _____ | | |
| 3.3 | What was the sex of the baby? | FEMALE ..... 1<br>MALE ..... 2<br>UNDETERMINED ..... 3<br>DO NOT KNOW ..... 8 | | |
| 3.4 | In what day, month and year was the baby born?<br>*RECORD "98" IF DON'T KNOW DAY OR MONTH*<br>*RECORD "9998" IF DON'T KNOW YEAR* | DAY ..... ☐☐<br>MONTH ..... ☐☐<br>YEAR ..... ☐☐☐☐ | | |
| 3.5 | In what day, month and year did the baby die?<br>*RECORD "98" IF DON'T KNOW DAY OR MONTH*<br>*RECORD "9998" IF DON'T KNOW YEAR* | DAY ..... ☐☐<br>MONTH ..... ☐☐<br>YEAR ..... ☐☐☐☐ | | |
| 3.6 | How old was the baby when he/she died?<br>*ENTER NEONATAL DEATH AGE IN MINUTES, HOURS OR DAYS*<br>*IF THE BABY WAS STILLBORN, ENTER "00" FOR MINUTES* | MINUTES ..... 1 ☐☐<br>**OR**<br>HOURS ..... 2 ☐☐<br>**OR**<br>DAYS ..... 3 ☐☐<br>DON'T KNOW ..... 998 | | |
| 3.7 | *INTERVIEWER, CHECK AGE AT DEATH (PROBE IF THE BABY DIED BEFORE OR AFTER 28 COMPLETED DAYS OF LIFE)* | 1. AGE BETWEEN 1 AND 28 DAYS ..... 1<br>2. AGE 28 DAYS OR MORE ..... 2<br>3. DON'T KNOW ..... 8 | <br>→**END** | |
| 3.8 | Was the baby a resident in this village, or was he/she brought home for illness or burial? | RESIDENT IN THE VILLAGE ..... 1<br>HOME COMING SICK ..... 2<br>BODY BROUGHT HOME FOR BURIAL ..... 3<br>DON'T KNOW ..... 8 | | |
| 3.9 | Where did the baby die? | OWN HOME ..... 01<br>TBA'S WORK AREA/HOME ..... 02<br>ENROUTE TO HOSPITAL/HEALTH FACILITY ..... 03<br>**PUBLIC SECTOR HEALTH CARE**<br>GOVERNMENT HOSPITAL ..... 04<br>GOVERNMENT HEALTH CENTRE ..... 05<br>OTHER PUBLIC SECTOR (SPECIFY) _____ 06<br>**PRIVATE SECTOR HEALTH CARE**<br>PRIVATE HOSPITAL/CLINIC ..... 07<br>OTHER PRIVATE SECTOR (SPECIFY) _____ 08<br>OTHER (SPECIFY) _____ 10<br>DON'T KNOW ..... 98<br>REFUSE ..... 99 | →3.9.2<br>→3.9.2<br><br><br><br><br><br><br>→3.9.2<br>→3.9.2<br>→3.9.2 | |
| 3.9.1 | What was the name of the health-care facility where the baby died? | NAME : _____ | | |

| | | | | |
|---|---|---|---|---|
| 3.9.2 | Was the baby taken to any (other) health-care facility for treatment prior to his/her death? | YES .....1<br>NO .....2<br>DON'T KNOW .....8<br>REFUSE .....9 | | |
| 3.9.3 | What was the name of the health-care facilities where he/she received treatment?<br>*REVIEW LIST PROVIDED*<br>*PROBE: "ANY OTHER FACILITY?"* | NAME : _____<br>NAME : _____<br>NAME : _____ | | |

TBA: traditional birth attendant

## RESPONDENT'S ACCOUNT OF ILLNESS/EVENTS LEADING TO DEATH

*Instructions to interviewer: Allow the respondent to tell you about the illness in his or her own words. Do not prompt except for asking whether there was anything else after the respondent finishes. Keep prompting until the respondent says there was nothing else. While recording, underline any unfamiliar terms.*

**ASK THE RESPONDENT:**

Could you tell me about the illness that led to the baby's death?

**PROBE FOR:**

**Recognition in the home** – *first symptoms recognized, other symptoms, when did the family realize it was severe, who recognized the first symptoms and the severity of the symptoms.*

**Timing** – *how long did it take from first symptoms to become severe.*

**Actions taken in the 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: Include the 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, if care was sought outside the home** – *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.*

**ASK THE RESPONDENT:**

Do you feel the death could have been avoided somehow? Please explain:

*PROBE FOR: What could have been done at the household level? What could have been done to improve access to health care outside the house? What could have been done to improve care after reaching a health-care facility? What could have been done to improve referral to higher levels of care? etc.*

_____

_____

_____

_____

_____

_____

_____

_____

***ASK THE RESPONDENT:*** What do you think was the primary or basic cause of death?

**OR** Based on our conversation, what would you say is the primary cause of death?

PRIMARY CAUSE OF DEATH ACCORDING TO RESPONDENT

***ASK THE RESPONDENT:*** In addition to this primary cause, do you think there are any additional or secondary causes of death?

**OR** Based on our conversation, what would you say are the secondary causes of death?

SECONDARY CAUSE OF DEATH ACCORDING TO RESPONDENT

## SECTION 4. PREGNANCY HISTORY AND CARE

I would like to ask you some questions concerning the mother and symptoms that the deceased had/showed at birth and shortly after. Some of these questions may not appear to be directly related to the baby's death. Please bear with me and answer all the questions. They will help us to get a clear picture of all possible symptoms that the deceased had.

*IF THE RESPONDENT IS THE MOTHER, ADJUST LANGUAGE TO REFLECT THAT BY ADDRESSING THE WOMAN.*

| | | | | |
|---|---|---|---|---|
| 4.1 | What was the age of the mother at the time the baby died? | YEARS ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 4.1.1 | What was her occupation – that is, what kind of work did the mother **mainly** do? | _____ ☐☐☐<br>_____ | | |
| 4.1.2 | What was the **highest level** and year (step/grade) of formal education the mother attended?<br>*CIRCLE ONE CODE IN "LEVEL" COLUMN AND ONE CODE IN "YEARS" COLUMN* | Level / Years in level<br>NONE ..... 0<br>PRIMARY ..... 1 — 1<br>SECONDARY ..... 2 — 2<br>TERTIARY ..... 3 — 3<br>4<br>5<br>6<br>7<br>DON'T KNOW ..... 8 — 8<br>REFUSE ..... 9 — 9 | | |
| 4.2 | Did the mother receive any antenatal care during the pregnancy? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→4.5<br>→4.5 | |
| 4.3 | How many antenatal visits did the woman have during the pregnancy?<br>*IF RESPONDENT DOESN'T KNOW, ASK IF SHE HAD ATTENDED AT LEAST 4 VISITS* | VISITS ..... ☐☐<br>AT LEAST 4 ..... 77<br>DON'T KNOW 4 ..... 98 | | |
| 4.4 | How many weeks or months pregnant was the woman at her first antenatal visit?<br>*ENTER IN WEEKS OR MONTHS* | WEEKS ..... 1 ☐☐<br>**OR**<br>MONTHS ..... 2 ☐☐<br>DON'T KNOW ..... 998 | | |
| 4.4.1 | When the woman became pregnant with this pregnancy, was she using any form of family planning?<br>*MULTIPLE ANSWERS ARE ALLOWED; SELECT ALL THAT APPLY* | NO METHOD ..... 00<br>LACTATIONAL AMENORRHOEA METHOD ..... 01<br>RHYTHM METHOD ..... 02<br>WITHDRAWAL ..... 03<br>PILL ..... 04<br>IUD ..... 05<br>INJECTABLES ..... 06<br>IMPLANTS ..... 07<br>CONDOM ..... 08<br>FEMALE CONDOM ..... 09<br>DIAPHRAGM ..... 10<br>FOAM/JELLY ..... 11<br>OTHER MODERN (SPECIFY) _____ 12<br>OTHER TRADITIONAL (SPECIFY) _____ 13<br>DON'T KNOW ..... 98 | | |

| | | | | |
|---|---|---|---|---|
| 4.4.2 | **Before** the woman became pregnant with this pregnancy, how many times per week was she drinking alcoholic beverages? | 4 TIMES OR MORE /ALMOST DAILY ..... 1<br>1–3 TIMES ..... 2<br>LESS THAN ONCE PER WEEK ..... 3<br>NEVER ..... 4 | | |
| 4.4.3 | How many times per week was she drinking alcoholic beverages **during** pregnancy? | 4 TIMES OR MORE /ALMOST DAILY ..... 1<br>1–3 TIMES ..... 2<br>LESS THAN ONCE PER WEEK ..... 3<br>NEVER ..... 4 | | |
| 4.5 | Did the baby's mother receive any tetanus vaccination during the pregnancy? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→4.6<br>→4.6 | |
| 4.5.1 | How many doses? | NUMBER OF DOSES ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 4.6 | Did the mother receive IPTp (IPTp-SP, Fansidar or equivalent) for malaria prevention during the pregnancy? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→4.7<br>→4.7 | |
| 4.6.1 | How many doses of IPTp did she receive during the pregnancy? | NUMBER OF DOSES ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 4.7 | Did the mother take iron supplements? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 4.7.1 | Did the mother take folic acid? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 4.8 | Did the mother take deworming tablets? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 4.9 | Did the mother sleep under a bed net during the pregnancy? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 4.10 | Was the mother ever tested for HIV/AIDS? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→4.15<br>→4.15 | |
| 4.11 | Was she HIV-positive or HIV-negative? | POSITIVE ..... 1<br>NEGATIVE ..... 2<br>DON'T KNOW ..... 8 | <br>→4.15<br>→4.15 | |
| 4.12 | How long ago had she been diagnosed as HIV-positive?<br>*IF LESS THAN 1 YEAR, NOTE NUMBER OF MONTHS;*<br>*IF GREATER THAN 12 MONTHS, NOTE NUMBER OF YEARS* | WEEKS AGO ..... 1 ☐☐<br>**OR**<br>MONTHS AGO ..... 2 ☐☐<br>**OR**<br>YEARS AGO ..... 3 ☐☐<br>DON'T KNOW ..... 998 | | |
| 4.13 | At the time of delivery, was she taking ARVs or Septrin for HIV or was she not taking HIV treatment? | ARVS ..... 1<br>ARVS + SEPTRIN ..... 2<br>SEPTRIN ..... 3<br>NOT TAKING TREATMENT ..... 4<br>DON'T KNOW ..... 8<br>REFUSE ..... 9 | <br><br>→4.15<br>→4.15<br>→4.15<br>→4.15 | |

| | | | | |
|---|---|---|---|---|
| 4.14 | How long has she been taking ARVs for HIV?<br>*IF LESS THAN 1 YEAR, NOTE NUMBER OF MONTHS; IF GREATER THAN 12 MONTHS, NOTE NUMBER OF YEARS* | WEEKS ..... 1 ... ☐☐<br>MONTHS ..... 2 ... ☐☐<br>**OR**<br>YEARS ..... 3 ... ☐☐<br>DON'T KNOW ..... 998 | | |
| 4.15 | During the pregnancy was the mother told by a health-care provider that she suffers from any of the following known illnesses:<br>**READ ALL OPTIONS:**<br>1 HIGH BLOOD PRESSURE?<br>2 HEART DISEASE?<br>3 DIABETES?<br>4 EPILEPSY/CONVULSION?<br>5 MALNUTRITION<br>6 MALARIA<br>7 TB<br>8 ANAEMIA<br>9 SICKLE CELL ANAEMIA<br>10 SYPHILIS<br>11 RUBELLA<br>12 OTHER SEXUALLY TRANSMITTED INFECTIONS (EXCLUDING HIV)<br>13. DID SHE SUFFER FROM **ANY OTHER** MEDICALLY DIAGNOSED ILLNESS? (SPECIFY ILLNESS) | **YES NO DON'T KNOW**<br>High blood pressure ..... 1 2 8<br>Heart disease ..... 1 2 8<br>Diabetes ..... 1 2 8<br>Epilepsy/convulsion ..... 1 2 8<br>Malnutrition ..... 1 2 8<br>Malaria ..... 1 2 8<br>TB ..... 1 2 8<br>Anaemia ..... 1 2 8<br>Sickle cell anaemia ..... 1 2 8<br>Syphilis ..... 1 2 8<br>Rubella ..... 1 2 8<br>STI ..... 1 2 8<br>Other (specify) _____ 1 2 8<br>_____ | | |
| 4.16 | During **the last 3 months of pregnancy** but before labour, did the mother have any of the following symptoms:<br>**READ ALL OPTIONS:**<br>1 HEAVY VAGINAL BLEEDING?<br>2 FOUL SMELLY VAGINAL DISCHARGE?<br>3 SWELLING OF FINGERS, FACE, LEGS?<br>4 HEADACHE?<br>5 BLURRED VISION?<br>6 CONVULSION?<br>7 FEBRILE ILLNESS?<br>8 SEVERE ABDOMINAL PAIN THAT WAS NOT LABOUR PAIN?<br>9 PALLOR AND SHORTNESS OF BREATH (BOTH PRESENT)?<br>10 YELLOW DISCOLOURATION OF THE EYES?<br>11 DID SHE SUFFER FROM ANY OTHER ILLNESS? (SPECIFY ILLNESS) | **YES NO DON'T KNOW**<br>Vaginal bleeding ..... 1 2 8<br>Smelly vaginal discharge ..... 1 2 8<br>Swelling fingers, face, legs ..... 1 2 8<br>Headache ..... 1 2 8<br>Blurred vision ..... 1 2 8<br>Convulsion ..... 1 2 8<br>Febrile illness ..... 1 2 8<br>Severe abdominal pain ..... 1 2 8<br>Pallor/shortness of breath (both) ..... 1 2 8<br>Yellow discolouration of the eyes ..... 1 2 8<br>Other illness (specify) _____ 1 2 8<br>_____ | | |
| 4.16.1 | It is common for women during and after pregnancy to feel down or depressed.<br>During **the last 3 months of pregnancy** but before labour, how often did **(you** – if mother is the respondent; or **the mother** – if other respondent) have little interest or pleasure in doing things? | NOT AT ALL ..... 1<br>SEVERAL WEEKS ..... 2<br>MORE THAN HALF OF THE TIME (OF 3 MONTHS) ... 3<br>NEARLY EVERY DAY ..... 4<br>DON'T KNOW ..... 8 | | |

| | | | | |
|---|---|---|---|---|
| 4.16.2 | During the last 3 months of pregnancy but before labour, how often were **(you** – if mother is the respondent; or **the mother** – if other respondent) down, depressed or hopeless? | NOT AT ALL ..... 1<br>SEVERAL WEEKS ..... 2<br>MORE THAN HALF OF THE TIME (OF 3 MONTHS) ... 3<br>NEARLY EVERY DAY ..... 4<br>DON'T KNOW ..... 8 | | |
| 4.17 | How many births, including stillbirths, did the mother have **before this baby**?<br>*COUNT ALL BABIES BORN ALIVE OR DEAD AT OR AFTER 7 MONTHS OF PREGNANCY;* **DO NOT COUNT THE BIRTH OF THE BABY WHO DIED** | NUMBER OF BIRTHS ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 4.18 | How many of these previous births were stillbirths?<br>*BORN DEAD AFTER 7 MONTHS OF PREGNANCY* | NUMBER OF STILLBIRTHS ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 4.19 | Now, let's talk about the birth of the baby who died. How many weeks or months was the mother pregnant when the baby was born?<br>*TRY TO RECORD IN WEEKS, WHENEVER POSSIBLE* | WEEKS ..... 1 ☐☐<br>**OR**<br>MONTHS ..... 2 ☐☐<br>DON'T KNOW ..... 998 | | |
| 4.20 | Was the baby born before expected? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→4.21<br>→4.21 | |
| 4.20.1 | How many days, weeks or months was the baby born before the expected date of delivery?<br>*ENTER IN DAYS OR WEEKS OR MONTHS* | DAYS ..... 1 ☐☐<br>**OR**<br>WEEKS ..... 2 ☐☐<br>**OR**<br>MONTHS ..... 3 ☐☐<br>DON'T KNOW ..... 998 | | |
| 4.21 | Was the baby a single or multiple birth? | SINGLETON ..... 1<br>TWIN ..... 2<br>TRIPLET OR MORE ..... 3<br>DON'T KNOW ..... 8 | →4.21.2<br><br><br>→4.21.2 | |
| 4.21.1 | What was the birth order of the baby that died, in the case of a multiple birth? | FIRST ..... 1<br>SECOND ..... 2<br>THIRD ..... 3<br>OTHER (SPECIFY) _____ 4<br>DON'T KNOW ..... 8 | | |
| 4.21.2 | Before the birth of this baby (babies, if twin delivery), when did the woman have her previous pregnancy (dd/mm/yyyy)?<br>*RECORD "98" IF DON'T KNOW DAY OR MONTH*<br>*RECORD "9998" IF DON'T KNOW YEAR*<br>*RECORD "77" FOR MONTH AND "7777" FOR YEAR IF NO PREVIOUS PREGNANCY* | DAY ..... ☐☐<br>MONTH ..... ☐☐<br>YEAR ..... ☐☐☐☐ | | |
| 4.21.3 | What was the outcome of the last pregnancy before this baby?<br>*CIRCLE "7" IF THE BABY WHO DIED WAS THE FIRST PREGNANCY* | SINGLE LIVE BIRTH ..... 1<br>MULTIPLE BIRTH (ALL ALIVE) ..... 2<br>MULTIPLE BIRTH (ONE ALIVE) ..... 3<br>MULTIPLE BIRTH (ALL DEAD) ..... 4<br>SINGLE STILLBIRTH ..... 5<br>ABORTION ..... 6<br>NO PREVIOUS PREGNANCY ..... 7<br>DON'T KNOW ..... 8 | | |

| SECTION 5. DELIVERY HISTORY | | | | |
|---|---|---|---|---|
| 5.1 | Where was the baby born? | OWN HOME ..... **01**<br>TBA'S WORK AREA/HOME ..... **02**<br>ENROUTE TO HOSPITAL/HEALTH FACILITY ..... **03**<br>**PUBLIC SECTOR HEALTH CARE**<br>GOVERNMENT HOSPITAL..... **04**<br>GOVERNMENT HEALTH CENTRE ..... **05**<br>OTHER PUBLIC SECTOR (SPECIFY) _____ 06<br>**PRIVATE SECTOR HEALTH CARE**<br>PRIVATE HOSPITAL/CLINIC..... **07**<br>OTHER PRIVATE SECTOR (SPECIFY) _____ 08<br>OTHER (SPECIFY) _____ 77<br>DON'T KNOW ..... 98 | | BORN |
| 5.1.1 | How soon after labour started did she receive assistance with labour and delivery?<br>*IF THE ANSWER IS IN DAYS: ESTIMATE NUMBER OF HOURS* | HOURS..... ☐☐<br>DID NOT RECEIVE ASSISTANCE..... 20<br>INDUCTION OF LABOUR FOR FETAL DEATH ..... 55<br>INDUCTION OF LABOUR/ POSTDATE BABY ..... 66<br>NO LABOUR, PLANNED C-SECTION..... 77<br>DON'T KNOW ..... 98 | | |
| 5.2 | Who assisted the delivery? | DOCTOR..... 1<br>CLINICAL OFFICER/MEDICAL ASSISTANT..... 2<br>NURSE..... 3<br>MIDWIFE ..... 4<br>TRADITIONAL BIRTH ATTENDANT..... 5<br>RELATIVE ..... 6<br>MOTHER BY HERSELF ..... 7<br>OTHER (SPECIFY) _____ 8<br>DON'T KNOW ..... 9 | | ASSI |
| 5.3 | How many hours or days was she in labour before delivery?<br>*IF LESS THAN 1 HOUR, RECORD "00" IN HOURS*<br>*IF RESPONDENT DOESN'T KNOW, ASK IF THE MOTHER HAD BEEN IN LABOUR > 24 HOURS BEFORE DELIVERY.* | HOURS..... 1 ☐☐<br>**OR**<br>DAYS..... 2 ☐☐<br>MORE THAN 24 HOURS ..... 777<br>DON'T KNOW ..... 998 | | HLAB |
| 5.3.1 | Was the mother given any medication during labour to stimulate contractions?<br>If yes, please specify | YES (SPECIFY) _____ 1<br>NO..... 2<br>DON'T KNOW..... 8 | | |
| 5.3.2 | Do you know whether the mother used local herbs during pregnancy, labour and delivery, or after delivery (in relation to this last pregnancy)?<br>*READ ALL RESPONSE OPTIONS EXCEPT "DON'T KNOW"* | DURING PREGNANCY BUT BEFORE LABOUR ..... **1**<br>DURING LABOUR AND DELIVERY ..... 2<br>AFTER DELIVERY..... 3<br>DURING PREGNANCY AND LABOUR/DELIVERY..... 4<br>DON'T KNOW..... 8 | | |
| 5.4 | When did the water break?<br>*READ OPTIONS* | Before labour started?..... 1<br>**OR**<br>During labour? ..... 2<br>DON'T KNOW ..... 8 | →5.7 | |

| | | | | |
|---|---|---|---|---|
| 5.5 | How many hours or days passed between her water breaking and birth?<br>*IF LESS THAN 1 HOUR, RECORD "00" IN HOURS*<br>*IF RESPONDENT DOESN'T KNOW, ASK IF THE WATER BROKE > 24 HOURS BEFORE DELIVERY.* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>MORE THAN 24 HOURS .....777<br>DON'T KNOW .....998 | | |
| 5.5.1 | What colour was the water? | CLEAR .....1<br>YELLOW/GREEN .....2<br>GREEN/BROWN.....3<br>DARK RED .....4<br>BRIGHT RED .....5<br>DON'T KNOW.....8 | | |
| 5.6 | Was the water foul smelling? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.7 | Was there excessive bleeding before, during or after delivery? | NO.....1<br>BEFORE DELIVERY.....2<br>DURING DELIVERY .....3<br>AFTER DELIVERY.....4<br>BOTH BEFORE AND AFTER.....5<br>DON'T KNOW.....8 | | |
| 5.8 | Did she have convulsions before, during or after delivery? | NO.....1<br>BEFORE DELIVERY.....2<br>DURING DELIVERY .....3<br>AFTER DELIVERY.....4<br>BOTH BEFORE AND AFTER.....5<br>DON'T KNOW.....8 | | |
| 5.9 | Did she have fever before, during or after delivery? | NO.....1<br>BEFORE DELIVERY.....2<br>DURING DELIVERY .....3<br>AFTER DELIVERY.....4<br>BOTH BEFORE AND AFTER.....5<br>DON'T KNOW.....8 | | |
| 5.10 | Did the baby stop moving in the womb? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→5.11<br>→5.11 | WOMB |
| 5.10.1 | When did the baby stop moving in the womb? | BEFORE LABOUR STARTED .....1<br>DURING LABOUR .....2<br>DON'T KNOW.....8 | | WWOM |
| 5.11 | Did a birth attendant listen for fetal heart sounds during labour with an electric device (Doppler) or cone-shaped stethoscope placed on the abdomen?<br>*DESCRIBE THE USE OF A CONE-LIKE INSTRUMENT* | YES, DOPPLER.....1<br>YES, STETHOSCOPE .....2<br>NO .....3<br>DON'T KNOW .....8 | <br><br>→5.11.2<br>→5.11.2 | HSOU |
| 5.11.1 | Were fetal heart sounds present? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | HPRE |
| 5.11.2 | Was an ultrasound scan done just before labour started or during labour? | JUST BEFORE LABOUR STARTED.....1<br>DURING LABOUR .....2<br>NEITHER JUST BEFORE NOR DURING LABOUR .....3<br>DON'T KNOW.....8 | <br><br>→5.12<br>→5.12 | |

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| 5.11.3 | Did the scan show any fetal heart beats? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.12 | What type of delivery was it? | NORMAL VAGINAL DELIVERY .....0<br>FORCEPS/VACUUM .....1<br>CAESAREAN SECTION .....2<br>ASSISTED BREECH DELIVERY .....3<br>OTHER (SPECIFY) _____ 4<br>DON'T KNOW .....8 | →5.13 | TDEL |
| 5.12.1 | After the baby was delivered, was any injection given to **(you** – if mother is the respondent; or **the mother** – if other respondent) to help the uterus to contract? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.13 | Which part of the baby came first? | HEAD.....1<br>BOTTOM .....2<br>FEET .....3<br>ARM/HAND.....4<br>CORD.....5<br>OTHER (SPECIFY) _____ 6<br>DON'T KNOW .....8 | | PART |
| 5.14 | Did the umbilical cord come out before the baby was born? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | UMBI |
| 5.15 | Was the cord wrapped more than once around the neck of the baby? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.15.1 | Was there a cord knot? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.15.2 | What colour was the cord? | NORMAL WHITE/GREY COLOR .....1<br>RED/BROWN.....2<br>GREEN/YELLOW .....3<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW .....8 | | |
| 5.15.3 | Was there anything else about the cord that was different? | SPECIFY _____ | | |
| 5.16 | Was the placenta different from the normal red/blue in colour, soft in consistency, circular normal placenta? | YES (SPECIFY) _____ 1<br>NO .....2<br>MOTHER DIED WITH PLACENTA INSIDE HER .....3<br>DON'T KNOW .....8 | | |
| 5.16.1 | Was the placenta foul smelling? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.17 | What was the birth weight in grams?<br>*IF ANSWERED IN KILOGRAMS, MULTIPLY BY 1000 AND RECORD IN GRAMS* | ☐☐☐☐ GRAMS<br>DON'T KNOW ..... 9998 | | |
| 5.18 | Would you say the baby's size at birth was smaller than normal, normal or bigger than normal? | SMALLER THAN NORMAL.....1<br>NORMAL .....2<br>BIGGER THAN NORMAL .....3<br>DON'T KNOW.....8 | | |

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| 5.19 | On what surface did the mother deliver? | LABOUR BED.....1<br>MATTRESS ON THE FLOOR.....2<br>FLOOR WITH MACKINTOSH/PLASTIC COVER .....3<br>MAT ON THE FLOOR.....4<br>DIRECTLY ON THE FLOOR .....5<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW.....8 | | |
| 5.20 | Did the birth attendant wash his/her hands before examining the mother? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.21 | Did the birth attendant use gloves? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.22 | Was anything applied to the umbilical cord stump after birth? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→5.23<br>→5.23 | |
| 5.22.1 | What was applied to the umbilical cord stump after birth? | CLORHEXIDINE .....1<br>METHYLATED SPIRITS OR IODINE .....2<br>HERBS.....3<br>DUNG.....4<br>ASHES .....5<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW .....8 | | |
| 5.23 | What tool was used for cutting the cord? | NEW RAZOR BLADE.....1<br>OLD RAZOR BLADE .....2<br>SCISSORS.....3<br>OTHER (SPECIFY) _____ 4<br>DON'T KNOW .....8 | | |
| 5.24 | What material was used for tying the cord? | CLEAN PIECE OF THREAD.....1<br>UNCLEAN PIECE OF THREAD .....2<br>CORD CLAMP.....3<br>OTHER (SPECIFY) _____ 4<br>DON'T KNOW .....8 | | |
| 5.25 | Were there any bruises or signs of injury on the baby's body after birth? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→5.26<br>→5.26 | |
| 5.25.1 | Where were the injury marks? | <br>SPECIFY _____ | | |
| 5.26 | Was there any sign of paralysis? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 5.27 | Did the baby have any major malformation at birth? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→5.28<br>→5.28 | |

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| 5.27.1 | What kind of malformation did the baby have? | SWELLING/DEFECT ON THE BACK ..... 1<br>VERY LARGE HEAD ..... 2<br>VERY SMALL HEAD ..... 3<br>DEFECT OF LIP AND/OR PALATE ..... 4<br>EXTRA FINGER/TOES ..... 5<br>INTESTINES PROTRUDING THROUGH ABDOMEN .... 6<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW ..... 8 | | |
| 5.28 | What was the colour of the baby at birth? | NORMAL/PINK ..... 1<br>PALE ALL OVER ..... 2<br>BLUE ALL OVER ..... 3<br>PALE/BLUE HANDS AND FEET ..... 4<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW ..... 8 | | |
| 5.28.1 | Was there any green/brown material or substance on the baby's skin? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.28.2 | Were the baby's hands or feet swollen? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.29 | Did the baby ever cry after birth, even a little? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→5.31<br>→5.31 | |
| 5.30 | How many minutes after birth did the baby first cry? | ☐☐ MINUTES<br>LESS THAN ONE MINUTE ..... 77<br>DON'T KNOW ..... 98 | | |
| 5.30.1 | Did the baby stop being able to cry? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.30.2 | How long before death did the baby stop crying? | MINUTES ..... 1 ☐☐<br>**OR**<br>HOURS ..... 2 ☐☐<br>**OR**<br>DAYS ..... 3 ☐☐<br>DON'T KNOW ..... 998 | | |
| 5.31 | Did the baby breathe after birth, even a little?<br>*PROBE FOR PRESENCE OF ANY CHEST MOVEMENT; CIRCLE 'YES" EVEN IF ONLY SMALL OR IRREGULAR MOVEMENTS WERE PRESENT* | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.32 | Was the baby given assistance to breathe?<br>*MULTIPLE ANSWERS ARE ALLOWED; READ ALL OPTIONS* | **YES NO DON'T KNOW**<br>STIMULATION ..... 1 2 8<br>RUBBING THE BACK ..... 1 2 8<br>BAG AND MASK ..... 1 2 8<br>SUCTION ..... 1 2 8<br>INTUBATION ..... 1 2 8 | | |
| 5.32.1 | Was the baby given any oxygen? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |

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| 5.33 | Did the baby ever move, even a little? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | →5.33.2 | BMOV |
| 5.33.1 | Were the arms and legs limp, or did they have some flexing? | LIMP ARMS AND LEGS ..... 1<br>FLEXED ARMS AND LEGS ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.33.2 | Did the baby have any heartbeats? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| **5.34** | *CHECK QUESTIONS 5.29, 5.31, 5.33 AND 5.33.2: IF ALL ARE "NO", CONTINUE* | **IF ALL "NO"** ☐↓ **IF ANY "YES"** ☐ **→ 5.37** | | |
| 5.35 | If the baby did not cry, breathe or move, and had no heartbeats, was he/she born dead? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→5.37<br>→5.37 | BDED |
| 5.36 | Was the baby macerated; that is, skin peeling or showing signs of decay?<br>*ASK ONLY IF THE BABY WAS BORN DEAD* | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | →9.1<br>→9.1<br>→9.1 | MACE |
| 5.37 | Was the baby ever breastfed? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→5.40<br>→5.40 | |
| 5.38 | How soon after birth was breastfeeding initiated?<br>*IF LESS THAN 1 HOUR, RECORD "00" IN HOURS* | HOURS ..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 5.39 | Was the breastfeeding exclusive? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.40 | Were any other feeds administered before breast-milk flow started? | YES (SPECIFY) _____ 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.40.1 | Was the baby dried immediately after birth? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.40.2 | Was the baby kept warm immediately after birth? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→5.42<br>→5.42 | |

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| 5.41 | How was the baby kept warm on the first day after birth?<br>*MULTIPLE ANSWERS ARE ALLOWED; READ ALL OPTIONS* | **YES NO DK**<br>PLACED SKIN-TO-SKIN IMMEDIATELY AFTER BIRTH ..... 1 2 8<br>WRAPPED ..... 1 2 8<br>COVERED WITH BLANKET ..... 1 2 8<br>PLACED IN INCUBATOR. ..... 1 2 8<br>OTHER (SPECIFY) ..... 1 2 8<br>DON'T KNOW. ..... 1 2 8 | | |
| 5.42 | How was the baby cleaned on the first day after birth? | BATHING WITH COLD WATER ..... 1<br>BATHING WITH WARM WATER ..... 2<br>WIPING WITH FABRIC ..... 3<br>NOT CLEANED ..... 4<br>OTHER (SPECIFY) _____ 5<br>DON'T KNOW ..... 8 | | |

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| 5.43 | How many hours or days after birth was the baby examined by a health worker?<br>*ENTER IN HOURS OR DAYS* | HOURS ..... 1 ☐☐<br>**OR**<br>DAYS ..... 2 ☐☐<br>NOT EXAMINED ..... 777<br>DON'T KNOW ..... 998 | <br><br><br>→5.49<br> | |
| 5.44 | Was the baby ever admitted to the neonatal intensive care unit? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br><br> | |
| 5.45 | How soon after birth was the baby discharged?<br>**IF THE MOTHER DELIVERED AT HOME, ASK:** When did the baby first come in contact with a health worker after delivery?<br>*ENTER IN HOURS OR DAYS* | HOURS ..... 1 ☐☐<br>**OR**<br>DAYS ..... 2 ☐☐<br>DIED BEFORE DISCHARGE ..... 777<br>DON'T KNOW ..... 998 | <br><br><br>→5.50<br>→5.50 | |
| 5.46 | Did the mother receive any counselling by a health worker before discharge?<br>*IF THE MOTHER DELIVERED AT HOME, ASK:* Did the mother receive any counselling by a health worker after delivery? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→5.48<br>→5.48 | |
| 5.47 | What was the mother counselled on?<br>*MULTIPLE ANSWERS ARE ALLOWED; READ ALL OPTIONS* | **YES NO DON'T KNOW**<br>BREAST FEEDING ..... 1 2 8<br>IMMUNIZATION ..... 1 2 8<br>POST-NATAL CARE ATTENDANCE ... 1 2 8<br>DANGER SIGNS ..... 1 2 8<br>FAMILY PLANNING ..... 1 2 8<br>OTHER (SPECIFY) ..... 1 2 8<br>_____ | | |
| 5.48 | Was the mother given vitamin A just before or after delivery? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 5.49 | Was the baby given any of the following vaccines in the first week of life?<br>*MULTIPLE ANSWERS ARE ALLOWED; READ ALL OPTIONS* | **YES NO DON'T KNOW**<br>BCG (TB) ..... 1 2 8<br>OPV (POLIO) ..... 1 2 8<br>HEPATITIS B ..... 1 2 8 | | |
| 5.50 | Did the baby sleep under a bed net? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |

| SECTION 6. NEONATAL ILLNESS HISTORY | | | | |
|---|---|---|---|---|
| 6.1 | How old was the baby when the fatal illness started?<br>*ENTER IN HOURS OR DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |
| 6.2 | Was the baby ever able to suckle or bottle-feed? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.4<br>→6.4 | |
| 6.3 | Did the baby stop suckling or bottle-feeding? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.4<br>→6.4 | |
| 6.3.1 | How many days after birth did the baby stop suckling or bottle-feeding?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW .....98 | | |
| 6.4 | Did the baby have a fever? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.5<br>→6.5 | |
| 6.4.1 | How many hours or days after birth did the fever start?<br>*ENTER IN HOURS OR DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |
| 6.4.2 | How many hours/days did the fever last?<br>*ENTER IN HOURS OR DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |
| 6.5 | Did the baby's body feel cold when touched? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.6<br>→6.6 | |
| 6.5.1 | How many hours or days after birth did the baby become cold to the touch? | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |
| 6.6 | Did the baby have a cough? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.7<br>→6.7 | |
| 6.6.1 | How many days after birth did the baby start to cough?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW .....98 | | |
| 6.7 | Did the baby have fast breathing? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→6.8<br>→6.8 | |
| 6.7.1 | How many hours or days after birth did the baby start breathing fast?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |

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| 6.7.2 | For how many days did the fast breathing last? | DAYS ☐☐<br>DON'T KNOW 98 | | |
| 6.8 | Did the baby have any difficulty in breathing? | YES 1<br>NO 2<br>DON'T KNOW 8 | <br>→6.12<br>→6.12 | |
| 6.8.1 | How many hours or days after birth did the baby start having difficulty in breathing?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | HOURS ☐☐ 1<br>**OR**<br>DAYS ☐☐ 2<br>DON'T KNOW 998 | | |
| 6.8.2 | For how many days did the difficulty breathing last? | DAYS ☐☐<br>DON'T KNOW 98 | | |
| 6.9 | Did the baby have indrawing of the chest? | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.10 | Did the baby have noisy breathing (grunting or wheezing)?<br>*DEMONSTRATE WHEEZING* | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.11 | Did the baby have flaring of the nostrils?<br>*DEMONSTRATE FLARING OF THE NOSTRILS* | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.12 | Did the baby have convulsions? | YES 1<br>NO 2<br>DON'T KNOW 8 | <br>→6.13<br>→6.13 | |
| 6.12.1 | How many hours/days after birth did the convulsions start?<br>*ENTER IN HOURS OR DAYS* | HOURS ☐☐ 1<br>**OR**<br>DAYS ☐☐ 2<br>DON'T KNOW 998 | | |
| 6.13 | Did the baby's body become stiff and arched backwards? | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.14 | Did the baby become unresponsive or unconscious? | YES 1<br>NO 2<br>DON'T KNOW 8 | <br>→6.15 | |
| 6.14.1 | How many hours or days after birth did the baby become unresponsive or unconscious?<br>*ENTER IN HOURS OR DAYS* | HOURS ☐☐ 1<br>**OR**<br>DAYS ☐☐ 2<br>DON'T KNOW 998 | →6.16<br><br>→6.16<br>→6.16 | |
| 6.15 | Did the baby become lethargic after a period of normal activity? | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.16 | During the illness that led to death, did the baby have sunken fontanelles? | YES 1<br>NO 2<br>DON'T KNOW 8 | | |
| 6.16.1 | During the illness that led to death, did the baby have a bulging or raised fontanelle? | YES 1<br>NO 2<br>DON'T KNOW 8 | | |

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| 6.17 | Did the baby have a swollen stomach (abdomen)? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→6.18<br>→6.18 | |
| 6.17.1 | How many days after birth did the baby develop a swollen stomach?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.18 | Did the baby vomit? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→6.19<br>→6.19 | |
| 6.18.1 | How many days after birth did vomiting start?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.18.2 | When the vomiting was most severe, how many times did the baby vomit in a day? | TIMES..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.18.3 | Did the baby vomit blood? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW NO ..... 8 | | |
| 6.19 | Did the baby have diarrhoea (more frequent or more liquid stools than usual)? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→6.20<br>→6.20 | |
| 6.19.1 | How many days after birth did the baby have diarrhoea?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.19.2 | On the day when the diarrhoea was most severe, how many times did he/she pass stools in a day? | TIMES..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.20 | At any time during the final illness was there blood in the stool? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 6.21 | Did the baby have redness around, or drainage from, the umbilical cord stump? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 6.22 | During the illness that led to death, did the baby have a skin rash? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 6.22.1 | During the illness that led to death, did the baby have skin ulcer(s) or pits? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 6.23 | Did the baby have yellow palms or soles? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→6.24<br>→6.24 | |
| 6.23.1 | How many days after birth did the yellow palms or soles begin?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.23.2 | For how many days did the baby have yellow palms or soles?<br>*IF LESS THAN 1 DAY, RECORD "00" IN DAYS* | DAYS..... ☐☐<br>DON'T KNOW ..... 98 | | |
| 6.23.3 | Did the baby have yellow discoloration of the eyes? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |

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| 6.24 | During the illness that led to death, did the baby bleed from anywhere? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 6.25 | After birth, was the baby growing normally? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 6.26 | Did the baby appear to be healthy and then just die suddenly? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | | |
| 6.27 | *LIST SYMPTOMS IN CHRONOLOGICAL ORDER AND RECORD AT HOW MANY DAYS AFTER BIRTH WAS THE ONSET OF EACH SYMPTOM. THE DAY WHEN BIRTH OCCURED IS DAY "0".*<br>*PROBE THE SEQUENCE OF OCCURENCE OF EACH SYMPTOM ALREADY MENTIONED IN SECTION 6.* | **SYMPTOM**<br>1:.....<br>2:.....<br>3:.....<br>4:.....<br>5..... | **DAY AFTER BIRTH**<br>DAY:<br>DAY:<br>DAY:<br>DAY:<br>DAY: | |
| 6.28 | How long after the first symptom was recognized did the baby die?<br>*ENTER IN HOURS OR DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW ..... 998 | | |

| SECTION 7. HISTORY OF INJURIES/ACCIDENTS | | | | |
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| 7.1 | Did the baby die from an injury or accident? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→7.2<br>→7.2 | |
| 7.1.1 | What kind of injury or accident? | ROAD TRAFFIC ACCIDENT ..... 1<br>FALL ..... 2<br>DROWNING ..... 3<br>POISONING ..... 4<br>BURNS ..... 5<br>VIOLENCE/ASSAULT (HOMOCIDE/ABUSE) ..... 6<br>OTHER (SPECIFY) _____ 7 | | |
| 7.1.2 | Was the injury or accident inflicted by someone else? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | | |
| 7.2 | Did the baby suffer from any animal/insect bite that led to her/his death? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→8.1<br>→8.1 | |
| 7.2.1 | What kind of animal/insect? | DOG ..... 1<br>SNAKE ..... 2<br>INSECT ..... 3<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW ..... 8 | | |

| SECTION 8. TREATMENT AND HEALTH SERVICE USE FOR THE FINAL ILLNESS | | | | |
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| 8.1 | Did the baby receive any treatment before s/he died? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | →8.3<br><br>→8.3 | |
| 8.2 | Why did the baby not receive any treatment? | _____ | →9.1 | |
| 8.3 | How was the baby treated at home? | WITH DRUGS ..... 1<br>WITH HERBS ..... 2<br>NO HOME TREATMENT ..... 3<br>OTHER (SPECIFY) _____ 7<br>DON'T KNOW ..... 8 | <br>→8.5<br>→8.6<br>→8.5<br>→8.6 | |
| 8.4 | What type of treatment was given to the baby at home? | **YES NO DON'T KNOW**<br>MALARIA DRUG (SPECIFY) _____ 1 2 8<br>SEPTRIN ..... 1 2 8<br>OTHER ANTIBIOTIC (SPECIFY) _____ 1 2 8<br>PARACETAMOL ..... 1 2 8<br>ORS ..... 1 2 8<br>ARVs ..... 1 2 8<br>OTHER (SPECIFY) _____ 1 2 8 | | |
| 8.5 | How many hours or days after onset of the illness that led to death was care initialized at home? | HOURS ..... 1 ☐☐<br>**OR**<br>DAYS ..... 2 ☐☐<br>DON'T KNOW ..... 998 | | |
| 8.5.1 | As far as you know, was anyone aware that the baby needed medical help before the baby died? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | <br>→8.6<br>→8.6 | |
| 8.5.2 | How long before the baby's death was the illness or health problem recognized? | HOURS ..... 1 ☐☐<br>**OR**<br>DAYS ..... 2 ☐☐<br>DON'T KNOW ..... 998 | | |
| 8.6 | Was the baby brought outside the home for care during the illness that led to death? | YES ..... 1<br>NO ..... 2<br>DON'T KNOW ..... 8 | →8.8<br><br>→9.1 | |

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| 8.7 | What were the reasons the baby was not taken to care outside the home?<br>*CIRCLE ALL MENTIONED*<br>*PROBE:* Any other reason? | **MENTIONED** / **NOT MENTIONED**<br>BABY DIED SUDDENLY.....1 2<br>DID NOT RECOGNIZE HOW SERIOUS ILLNESS WAS .....1 2<br>DID NOT KNOW WHERE TO GO.....1 2<br>HAD NO ONE TO TAKE CARE OF OTHER CHILDREN.....1 2<br>TRANSPORT WAS NOT AVAILABLE....1 2<br>TRANSPORT WAS TOO EXPENSIVE...1 2<br>FAMILY LACKED MONEY FOR HEALTH CARE .....1 2<br>HEALTH FACILITY IS TOO FAR AWAY.....1 2<br>DID NOT TRUST QUALITY OF HEALTH CARE .....1 2<br>STAFF MAY BLAME MOTHER FOR HOME DELIVERY .....1 2<br>PROVIDER REFUSE TO WAKE DURING THE NIGHT.....1 2<br>FEAR TO BE SCOLDED OR SHOUTED AT BY THE STAFF.....1 2<br>OTHER (SPECIFY) _____1 2 | 9.1 | |
| 8.8 | How many hours or days after onset of the illness that led to death was treatment initiated outside the home?<br>*ENTER IN HOURS OR DAYS* | HOURS.....1 ☐☐<br>**OR**<br>DAYS.....2 ☐☐<br>DON'T KNOW .....998 | | |
| 8.9 | At what place was treatment sought?<br>*CIRCLE ALL THAT APPLY*<br>*PROBE: Anywhere else?*<br>*INCLUDE ALL PLACES THAT WERE VISITED WHILE SEEKING CARE FOR THE ILLNESS THAT LED TO DEATH* | **YES** **NO** **DON'T KNOW**<br>HOSPITAL.....1 2 8<br>HEALTH CENTRE.....1 2 8<br>PRIVATE CLINIC .....1 2 8<br>DRUG SHOP/PHARMACY.....1 2 8<br>TRADITIONAL HEALER.....1 2 8<br>OTHER (SPECIFY) _____ 1 2 8<br>DON'T KNOW.....1 2 8 | | |
| 8.10 | LIST CARE SOUGHT IN CHRONOLOGICAL ORDER, STARTING WITH THE FIRST PLACE WHERE CARE WAS SOUGHT; USE CODES BELOW FOR THE LEVEL THAT BEST DESCRIBES THE PLACE<br>RECORD THE MAIN PROVIDER AT EACH PLACE (USE CODES LISTED BELOW)<br>RECORD THE NUMBER OF DAYS AFTER ILLNESS STARTED AT THE TIME OF VISITING EACH PLACE | | | |

| PLACE NAME | LEVEL: | PROVIDER: | WHEN? |
|---|---|---|---|
| 1: _____ | _____ | _____ | DAY : _____ |
| 2: _____ | _____ | _____ | DAY : _____ |
| 3: _____ | _____ | _____ | DAY : _____ |
| 4: _____ | _____ | _____ | DAY : _____ |

| CODES FOR LEVEL | CODES FOR TYPE OF PROVIDER | | |
|---|---|---|---|
| 1. HOSPITAL<br>2. HEALTH CENTRE IV<br>3. HEALTH CENTRE III/II<br>4. PRIVATE CLINIC<br>5. TBA PLACE<br>6. TRADITIONAL HEALER PLACE<br>7. PHARMACY<br>8. CHURCH<br>9. OTHER | 1. DOCTOR<br>2. NURSE/MIDWIFE<br>3. TBA<br>4. TRADITIONAL HEALER<br>5. PHARMACY, DRUG SELLER, STORE<br>6. RELIGIOUS LEADER<br>8. OTHER | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 8.11 | What kind of treatment was given to the baby outside the home? | | **YES** | **NO** | **DON'T KNOW** | | |
| | | ORS | 1 | 2 | 8 | | |
| | | ARVS | 1 | 2 | 8 | | |
| | | SEPTRIN | 1 | 2 | 8 | | |
| | | OTHER ANTIBIOTIC (SPECIFY) _____ | 1 | 2 | 8 | | |
| | | BLOOD TRANSFUSION | 1 | 2 | 8 | | |
| | | IV FLUID | 1 | 2 | 8 | | |
| | | OXYGEN | 1 | 2 | 8 | | |
| | | NG TUBE FEEDING | 1 | 2 | 8 | | |
| | | SURGERY | 1 | 2 | 8 | | |
| | | NO TREATMENT | 1 | 2 | 8 | | |
| | | OTHER (SPECIFY) _____ | 1 | 2 | 8 | | |
| 8.12 | Did a health worker tell you or anyone the cause of the baby's death? | YES | | | | 1 | |
| | | NO | | | | 2 | →8.14 |
| | | DON'T KNOW | | | | 8 | →8.14 |
| 8.13 | What did the health worker say? | _____ | | | | | |
| 8.14 | What means of transportation were used to get the baby to the first place of care?<br>*CIRCLE "1" FOR ALL THAT APPLY* | | **YES** | **NO** | **DON'T KNOW** | | |
| | | PRIVATE CAR | 1 | 2 | 8 | | |
| | | BICYCLE | 1 | 2 | 8 | | |
| | | MOTORCYCLE | 1 | 2 | 8 | | |
| | | TAXI | 1 | 2 | 8 | | |
| | | ON FOOT | 1 | 2 | 8 | | |
| | | OTHER (SPECIFY) _____ | 1 | 2 | 8 | | |
| | | DON'T KNOW | 1 | 2 | 8 | | |
| 8.15 | How much total transportation time did it take to reach the first place of care?<br>*ENTER IN MINUTES OR HOURS OR DAYS* | MINUTES | 1 | | | | |
| | | **OR** | | | | | |
| | | HOURS | 2 | | | | |
| | | **OR** | | | | | |
| | | DAYS | 3 | | | | |
| | | DON'T KNOW | 998 | | | | |
| 8.15.1 | Did you have difficulties when you sought help care for the baby at the facility? | YES | | | | 1 | |
| | | NO | | | | 2 | →8.16 |
| | | DON'T KNOW | | | | 8 | →8.16 |

| | | | | |
|---|---|---|---|---|
| 8.15.2 | What difficulties did you have when you sought health care for the baby at the facility?<br>*CIRCLE "1" FOR EACH DIFFICULTY HAD WHEN THEY SOUGHT HEALTH CARE AT THE PLACE OF CARE.* | **MENTIONED** **NOT MENTIONED**<br>DID NOT HAVE DIFFICULTY BEING GIVEN CARE ..... 1 2<br>HAD BEEN TURNED AWAY ..... 1 2<br>WAITED LONG TO BE SEEN ..... 1 2<br>LACK OF QUALIFIED STAFF ..... 1 2<br>LACK OF EQUIPMENT ..... 1 2<br>LACK OF SUPPLIES ..... 1 2<br>LACK OF MEDICATION ..... 1 2<br>NO ELECTRICITY ..... 1 2<br>TREATED POORLY/DISRESPECTED .. 1 2<br>TREATMENT NOT AVAILABLE, TOO COMPLEX ..... 1 2<br>DELAYED REFERRAL FOR BETTER CARE ..... 1 2<br>COST/DENIED TREATMENT FOR FEES ..... 1 2<br>OTHER (SPECIFY) _____ 1 2<br>DIED WITHOUT BEING GIVEN CARE ..... 1 2 | | |
| 8.16 | How much time passed between when the baby arrived at the first place of care and treatment was given?<br>*ENTER IN MINUTES OR HOURS* | MINUTES ..... 1 ☐☐<br>**OR**<br>HOURS ..... 2 ☐☐<br>NO CARE RECEIVED ..... 777<br>DON'T KNOW ..... 998 | | |
| 8.17 | Was the baby ever referred/transferred to another place of care during the final illness? | YES ..... 1<br>NO ..... 2 →8.23<br>DON'T KNOW ..... 8 →8.23 | | |
| 8.18 | Where was the baby referred or transferred? | HOSPITAL ..... 1<br>HEALTH CENTRE ..... 2<br>PRIVATE CLINIC ..... 3<br>DRUG SHOP ..... 4<br>TRADITIONAL HEALER ..... 5<br>OTHER (SPECIFY) _____ 6<br>DON'T KNOW ..... 8 | | |
| 8.19 | What was the reason for the referral/transfer? | LACK OF EQUIPMENT ..... 1<br>FOR BETTER CARE ..... 2<br>LACK OF BLOOD ..... 3<br>LACK OF DRUGS ..... 4<br>LACK OF OXYGEN ..... 5<br>OTHER (SPECIFY) _____ 6<br>DON'T KNOW ..... 8 | | |
| 8.20 | Did the baby reach the place where he/she was referred/transferred? | YES ..... 1<br>NO ..... 2 →8.22<br>DON'T KNOW ..... 8 →8.22 | | |

| | | | | |
|---|---|---|---|---|
| 8.21 | What means of transportation were used to get the baby to the place of referral/transfer? | **YES NO DON'T KNOW**<br>PRIVATE CAR ..... 1 2 8<br>BICYCLE..... 1 2 8<br>MOTORCYCLE..... 1 2 8<br>TAXI ..... 1 2 8<br>ON FOOT ..... 1 2 8<br>OTHER (SPECIFY) _____ 1 2 8<br>DON'T KNOW ..... 1 2 8 | →8.23 | |
| 8.22 | Why did the baby not reach the place of referral/transfer? | BABY DIED BEFORE REACHING PLACE OF REFERRAL.. 1<br>FAMILY THOUGHT IT WASN'T NECESSARY ..... 2<br>FAMILY HOPED/WAITED FOR IMPROVEMENT..... 3<br>LACK OF MONEY ..... 4<br>LACK OF TRANSPORT..... 5<br>OTHER (SPECIFY) _____ 6<br>DON'T KNOW ..... 8 | | |
| 8.23 | Altogether, how much did you pay for transport during the illness that led to death? | ☐☐☐☐☐☐☐ UGS<br>NO COST..... 7777777<br>DON'T KNOW..... 9999998 | | |
| 8.24 | Altogether, how much did you pay for treatment and other costs related to care of the baby (including fees for admission, consultation, lab tests, consumables, etc.)? | ☐☐☐☐☐☐☐ UGS<br>NO COST..... 7777777<br>DON'T KNOW..... 9999998 | | |
| 8.25 | Altogether, how much did you pay for other costs (including accommodation, feeding, etc.)? | ☐☐☐☐☐☐☐ UGS<br>NO COST..... 7777777<br>DON'T KNOW..... 9999998 | | |

| SECTION 9. DATA ABSTRACTED FROM RECORDS | | | | |
|---|---|---|---|---|
| 9.1 | Do you have a death certificate for the deceased? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→9.2<br>→9.2 | |
| 9.1.1 | Can I see the death certificate?<br>*COPY THE DAY, MONTH AND YEAR OF DEATH FROM THE DEATH CERTIFICATE* | ☐☐ ☐☐ ☐☐☐☐<br>DAY MONTH YEAR | | |
| | *RECORD THE CAUSE OF DEATH ON THE FIRST LINE (TOP) OF THE DEATH CERTIFICATE:* | _____ | | |
| | *RECORD THE CAUSE OF DEATH ON THE SECOND LINE OF THE DEATH CERTIFICATE* | _____ | | |
| | *RECORD THE CAUSE OF DEATH ON THE THIRD LINE OF THE DEATH CERTIFICATE:* | _____ | | |
| | *RECORD THE CAUSE OF DEATH ON THE FOURTH LINE OF THE DEATH CERTIFICATE:* | _____ | | |
| | *RECORD THE CONTRIBUTING CAUSE(S) OF THE DEATH FROM THE CERTIFICATE (PART 2):* | _____ | | |
| | *WRITE THE OUTCOME AS PER THE DEATH CERTIFICATE* | ANTEPARTUM (MACERATED) STILLBIRTH.....1<br>INTRAPARTUM STILLBIRTH .....2<br>NEONATAL DEATH.....3 | →9.3<br>→9.3 | |
| | | AGE AT DEATH ..... ☐☐ | | |
| 9.2 | Do you have an immunization card for the baby? | YES .....1<br>NO .....2<br>DON'T KNOW .....8 | <br>→9.3<br>→9.3 | |
| 9.2.1 | *ASK TO SEE THE IMMUNIZATION CARD AND RECORD THE DATE OF BCG AND OPV1; USE CODE "98" FOR MISSING INFORMATION* | BCG ☐☐ ☐☐ ☐☐☐☐<br>DAY MONTH YEAR<br>OPV1 ☐☐ ☐☐ ☐☐☐☐<br>DAY MONTH YEAR<br>DON'T KNOW .....98 | | |
| 9.3 | *RECORD THE CAUSE OF DEATH FROM THE POST-MORTEM RESULTS* | _____ | | |
| 9.4 | *RECORD THE CAUSE OF DEATH FROM THE BURIAL PERMIT* | _____ | | |
| 9.5 | *RECORD RELEVANT INFORMATION FROM THE MCH/ANC CARD* | _____ | | |
| 9.6 | *RECORD RELEVANT INFORMATION FROM THE HOSPITAL PRESCRIPTION FORM/ TREATMENT CARDS* | _____ | | |

| | | | | |
|---|---|---|---|---|
| 9.7 | *RECORD RELEVANT INFORMATION FROM HOSPITAL DISCHARGE FORMS, INCLUDING DIAGNOSIS*<br>*RECORD THE DATE OF THE MOST RECENT (LAST VISIT); THE LAST BUT ONE VISIT (SECOND TO LAST); THE DATE OF TH LAST NOTE IN THE HEALTH RECORDS; RECORD THE WEIGHT IN GRAMS AT THE LAST VISIT; RECORD THE WEIGHT IN GRAMS AT THE SECOND TO LAST VISIT*<br>*IF ANSWERED IN KILOGRAMS MULTIPLY BY 1000* | _____<br>_____<br>LAST VISIT ..... ☐☐☐☐ GRAMS<br>DON'T KNOW ..... 9998<br>SECOND TO LAST VISIT ..... ☐☐☐☐ GRAMS<br>DON'T KNOW ..... 9998 | | |
| 9.8 | *RECORD RELEVANT INFORMATION FROM OTHER HOSPITAL DOCUMENTS* | _____ | | |
| 9.9 | *RECORD RELEVANT INFORMATION FROM LABORATORY RESULTS* | _____ | | |

# END OF INTERVIEW

## THANK RESPONDENT FOR THEIR COOPERATION

| | |
|---|---|
| *RECORD THE TIME AT THE END OF THE INTERVIEW* | HOURS ☐☐ AND ☐☐ MINUTES |

Date: ☐☐ DAY ☐☐ MONTH ☐☐☐☐ YEAR

Interviewer comments and observations:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

VA Supervisor comments and observations:

_____

_____

_____

_____

_____

Signature of the Supervisor

World Health Organization

For more information, please contact:

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