6. MEASUREMENT OF PROGRESS

Where to start

Making progress towards stillbirth reduction and equity targets requires research and data. This chapter provides resources and data on causes of death, alongside guidance on tracking progress and why it is crucial to count all stillbirths.



RESOURCES

- <u>UN-IGME</u> publishes regular estimates of neonatal mortality and stillbirth rates. Find the <u>latest data and modelled estimates</u> and trends.
- Data for your context may be available from your national maternal perinatal death surveillance and response or vital statistics systems.

DATA HIGHLIGHTS

National and global estimates of cause of death for live born babies in the first month after birth (neonatal death) are available (95). Important causes of neonatal death in all settings include preterm birth complications, childbirth complications (also called intrapartum-related) and infectious causes. In low-mortality contexts, congenital abnormalities are increasingly important contributors.

There are currently no comparable national and global estimates for causes of stillbirth, but important causes include pregnancy complications (including maternal conditions such as hypertensive disorders and antepartu

such as hypertensive disorders and antepartum haemorrhage) and childbirth complications associated with fetal hypoxia and infection (such as syphilis, malaria and group B streptococcus).

Tracking progress

- Find out: Does your country have a stillbirth reduction target? This may be included as part of its ENAP or other national plans.
- → If not, use the ENAP target, which is to reduce late-gestation stillbirths (stillbirths at 28 weeks or more) to 12 or fewer per 1,000 total births by 2030, while also reducing inequities.
- **Find out**: Is progress towards this target being tracked?
- → If not, use local data (see <u>Resources</u>) or <u>national estimates</u> to track progress.

Achieving ENAP targets in all settings will require high-quality care along the continuum. Tracking progress for stillbirth prevention and care therefore requires an understanding of wider maternal newborn health care in any given context. This includes coverage of care along the continuum and related health indicators, such as maternal mortality.

RESOURCES



- Other indicators related to wider maternal newborn health along the continuum, such as antenatal care, skilled birth attendance, and caesarean section rate, are available from <u>UNICEF</u>, <u>WHO-Global Health</u> <u>Observatory</u> and <u>Healthy Newborn Network</u>.
- See the <u>Health Equity Assessment Toolkit</u> for more details and resources on equity.
- Countdown to 2030 also produces excellent country profiles and equity profiles that can be a useful tool for action.



Counting stillbirths

Every baby – whether live born or stillborn –should be included in every data system capturing births, with information on the baby's birthweight and gestational age. These data are needed to measure stillbirth rates accurately and track progress towards stillbirth rate reduction targets. While there are many myths remaining around counting stillbirths (see Box 6.1), capturing data on stillbirths is possible in all settings (see Sharing what works). The following section provides information and resources to improve and effectively use these data.

Sharing what works

Wide variation in reported stillbirth rates is a key challenge in addressing stillbirths in Mali. With around three in five babies born at home, gaps in data reporting at the community level are an important barrier to obtaining accurate data. To improve reporting of these deaths, the Malian Ministry of Health and Social Affairs created the Perinatal and Neonatal Audit Guide with surveillance reporting standards in 2019. Even knowing that cultural and health-seeking challenges were resulting in stillbirth underreporting, public health researchers in the region were stunned by the high number of stillbirths reported weekly. Aware that this was just a small fraction of the overall number of stillbirths, with the many babies who are stillborn at home remaining hidden, these researchers are now aiming to strengthen community-based perinatal mortality surveillance. At the village level, community health workers are being trained to use an electronic tool to collect, record and report real-time data on perinatal deaths in two health districts. If the tool is beneficial, this system will be implemented in other districts in the region.



REFLECTION

Are data on stillbirths recorded in all relevant data systems in your context? Are these data of adequate quality (96)? Have they been reported in dashboards, reports or other platforms to inform action? If so, are the data disaggregated appropriately to provide sufficient data for action? Are the data being used to track progress towards ENAP targets in your context?

BOX 6.1: BUSTING MYTHS AROUND COUNTING STILLBIRTHS

- MYTH: There are no standard definitions of stillbirth.
- FACT: WHO has standard definitions as part of the <u>International Classification</u> of Diseases (ICD).
- MYTH: It is not possible to capture information on stillbirths in routine data systems in LMIC settings.
- FACT: Stillbirths can be included in all data systems that capture live births.
- MYTH: It is not important to count stillbirths.
- FACT: Stillbirths matter to women and families and ending preventable stillbirths requires data to target action and track progress. Stillbirth rates are also important markers of access to high-quality antenatal and intrapartum care and are closely linked with maternal mortality and health. Due to substantial misclassification between stillbirths and neonatal deaths, especially around the thresholds of viability, counting stillbirths is also critical to tracking neonatal mortality.

Definitions and indicators

Standard definitions for stillbirths are included in the <u>International Classification of Diseases (ICD-11)</u>:

Live birth: the complete expulsion or extraction from a woman of a fetus, irrespective of the duration of the pregnancy, which, after such separation, shows signs of life.

Fetal death: the death of a fetus prior to the complete expulsion or extraction from a woman. It may be diagnosed in utero by the absence of fetal heart sounds, confirmed by imaging techniques where available, or at delivery by absence of signs of life at birth or after attempted resuscitation.

Stillbirth: A baby born following a fetal death at 154 days (22⁺⁰ weeks) or more of gestation.

Early gestation stillbirth: A stillbirth at 154–195 days of gestation (22⁺⁰ to 27⁺⁶ weeks).

Late-gestation stillbirth: A stillbirth at 196 or more days of gestation (≥28⁺⁰ weeks).

Intrapartum stillbirth: A stillbirth following intrapartum fetal death (occurring during labour or the birthing process).

Antepartum stillbirth: A stillbirth following antepartum fetal death (occurring before onset of labour).

Total births: the number of live births plus stillbirths.

Stillbirth rate: $\left(\frac{Number of stillbirths}{Number of total births}\right) X 1,000$

WHO recommends that information on all stillbirths is collected in national data systems and that data for late-gestation stillbirths are reported for global comparisons.



Collecting actionable data

Data for stillbirths can be captured in all national systems collecting information on births, including civil registration and vital statistics (CRVS) and routine health information systems. The reporting of stillbirths in a CRVS system should ensure that all stillbirths are reported to the statistical office compiling and disseminating vital statistics, whether the stillbirths are registered through civil registration or reported, without registration, to the MOH. All United Nations Member State countries should have a legal framework that defines the continuous, permanent, compulsory and universal registration of live births and registration or reporting of stillbirths to civil registration or health systems, respectively, in line with globally agreed recommendations (97). Stillbirth data can also be captured via household surveys, but underreporting and data quality issues are common with this method (96, 98).

To ensure all relevant data to accurately measure stillbirth rates are collected, WHO recommends a standard minimum perinatal data set to be recorded by the health system for every birth at the point of care (see Annex 9). Accurate recording of these data, including vital status at the start of labour and at birth, gestational age and birthweight, is essential to correctly classify birth outcomes. "Macerated" and "fresh" skin appearance should not be used to classify the time of death (98). Instead, the time of death assessed by last time of fetal heartbeat or movement should be used for classification.

Common challenges with stillbirth data management include omission of events and misclassification between miscarriages and stillbirths (requiring accurate gestational age assessment and application of standard definitions) and between stillbirths and neonatal deaths (requiring accurate assessment of vital status at birth and attempted resuscitation of all non-macerated babies who do not breathe at birth). Data quality assessments/audits should be routinely undertaken to detect and address these challenges. For household survey data, followon verbal autopsy tools can be helpful to assess potential misclassification between stillbirth and neonatal deaths (99).

Including all babies – live born and stillborn – in a single data system is important, considering the substantial misclassification between stillbirths and very early neonatal deaths. While the underlying risk factors, causes of death and public health interventions to address stillbirths and very early neonatal deaths are similar, stillbirths are associated with increased maternal morbidity and health-care needs that may differ to those of very early neonatal deaths.

Where possible, information on contextual and contributing factors and causes of death should also be collected to guide targeted interventions for common drivers of preventable stillbirths. WHO recommends recording a cause of death for each stillbirth using the international form of medical certification of cause of death (MCCD). Perinatal audit (100), maternal perinatal death surveillance and response (MPDSR) (101) systems and verbal

autopsy also provide important information on causes of death and contributory factors, especially in settings without universal coverage of stillbirths in CRVS.

Using data for action

While data for stillbirths are collected in most settings, these are not always included in relevant reporting platforms or available to inform action.

Disaggregating data helps to identify geographical locations and population groups that have a higher stillbirth burden. Disaggregation of data permits resources to be directed to the populations in the greatest need. Relevant disaggregation will vary by context, but examples include by sex, gestational age, birthweight, maternal age, urban/rural location, geographical region and facility type.

Sharing what works

The WHO Regional Office for South-East Asia (WHO SEARO) established a regional Technical Advisory Group in 2015 to provide guidance on stillbirth reduction, including setting national and subnational targets, addressing inequities and developing national action plans. Its recommendations have been included in the Regional Strategic Framework for Accelerating Universal Access to Sexual and Reproductive Health in the South-East Asia Region (2020–2024) as key strategies to reduce stillbirth in the region. Six of 11 countries in the region have achieved the ENAP 2030 country target and all countries in the region have included stillbirth prevention as part of the country's ENAP, while seven countries have identified country targets for 2020 and 2025. WHO SEARO has also established a hospital-based registry, supported national MPDSR guidelines and training packages in several countries and developed a virtual maternal death surveillance and response capacity-building training programme in partnership with the MOMENTUM Country Global Leadership, UNFPA and UNICEF.

RESOURCES

CRVS

Stillbirth is one of the 10 vital events that should be captured through continuous, permanent, compulsory and universal CRVS.

- A <u>WHO and UNICEF report</u> (102) provides operational guidance for health sector managers, civil registrars and development partners to improve health sector reporting of stillbirths to civil registration authorities.
- Chapter 5 of the <u>Civil Registration</u>, <u>Vital Statistics and Identity Management</u>
 (<u>CRVSID</u>): <u>Legal and Regulatory Review Toolkit</u> (103) is also helpful.
- UNFPA has provided specific guidance on integrating CRVS and MPDSR for development and humanitarian response settings in its report Reinforcing Civil Registration and Vital Statistics and Maternal and Perinatal Death Surveillance and Response Systems Interlinkages (104).

ROUTINE HEALTH INFORMATION SYSTEMS

The UNICEF <u>Stillbirth Definition and</u>
 <u>Data Quality Assessment for Health</u>

 <u>Management Information Systems</u> (96)
 provides practical guidance on data
 collection, assessing data quality and improving data for action.

AUDIT AND OTHER RESOURCES

- The WHO Maternal and Perinatal Death
 Surveillance and Response (101), Making
 Every Baby Count Audit Guide (100) and
 The WHO Application of ICD-10 to Deaths
 During the Perinatal Period: ICD-PM (105)
 each provide useful reference materials to
 support their implementation.
- For deaths occurring outside a health facility, verbal and social autopsy can also be used, although verbal autopsy has limited validity in assessing cause of stillbirth. For specific guidance, refer to the Institute for Health Metrics and Evaluation (IHME) verbal autopsy tool and Annex
 10 of the Making Every Baby Count Audit Guide (100).

