Stillbirth Definition and Data Quality Assessment for Health Management Information Systems (HMIS)

A Guideline

IGME

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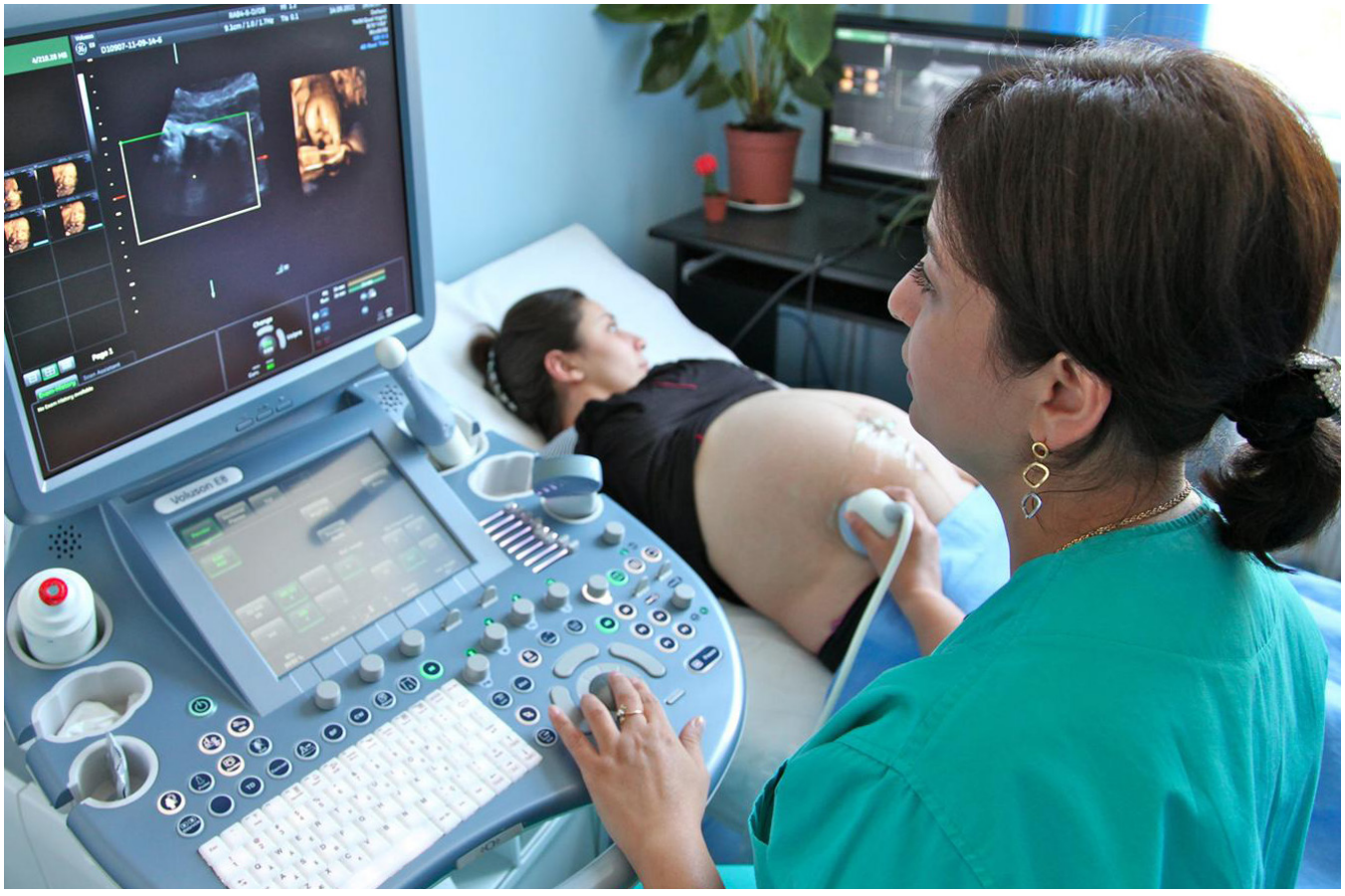

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BACKGROUND

There were an estimated 2 million stillbirths in 2019. The importance of these deaths, both in terms of their overall number and their impact on women, families, health professionals and wider society, is increasingly being recognized (1, 2). It has also been widely accepted that stillbirths are largely preventable when women have improved access to high quality care along the continuum from pre-conception to childbirth. This information led to important national commitments in 2014, when 194 countries committed to the Every Newborn Action Plan (ENAP) target to reduce stillbirths to 12 or fewer per 1,000 total births by 2030 (3). ENAP also flags the imperative to count every newborn – live births and stillbirths – to drive progress towards Sustainable Development Goal child mortality targets.

While most governments now recognize that stillbirths are preventable, large gaps exist in national- and global-level data on stillbirth. In order to end these unnecessary deaths by 2030, urgent investments are needed to improve the data on this often overlooked aspect of child mortality.

Data and stillbirth

Stronger data allow us to better understand the distribution of the burden of stillbirth and of the closely related burdens of maternal and newborn morbidity and mortality, and to target interventions accordingly. Improvements are not only needed in the collection of data to count and classify these deaths – including birthweight, gestational age and vital status at birth – but also in data that capture the contextual conditions that contribute to stillbirths (4).

High quality comparable data can be utilized in many important ways: They can facilitate review of progress in reducing stillbirths that occur during deliveries at health facilities, allow regional and international comparisons to be made, improve clinical practice and epidemiological and health surveillance, and focus limited programmatic and research funds. Collecting information on timing of stillbirths -- whether antepartum or intrapartum – is also an important quality-of-care indicator.

Challenges with data

Several challenges stand in the way of quality and comparable data on stillbirths, including omission of events and misclassification. With regards to omission, stillbirths may be missing from a data system completely, in cases, for instance, where no attempt is made to capture this information. In data systems that seek to reflect information on all births – both live births and stillbirths – births can still be missed for various reasons. These may include low levels of understanding and engagement in stillbirth reporting among health care workers and a failure of data systems to cover birth events among the most marginalized, especially when deliveries take place outside a health facility.

Misclassification of stillbirths as miscarriages[1] or neonatal deaths is common. These errors may be inadvertent or deliberate, to avoid blame or additional paperwork, for example. In addition, inconsistent application of stillbirth definitions

[1]A spontaneous pregnancy loss before 22 weeks gestation.

can also contribute to misclassification and thus impact comparability of stillbirth data.

Including all births, whether live or stillborn, in a single data system is important in light of the substantial misclassification between stillbirths and very early neonatal deaths; while the underlying risk factors, cause of death, and public health interventions to address these deaths are similar, stillbirths are additionally associated with increased maternal morbidity and health care needs that may differ to those of very early neonatal deaths.

Scope of this guideline

While national-level information on stillbirths may be collected in a number of data systems, including civil registration and vital statistics (CRVS) systems and nationally representative population-based household surveys, this guideline focuses on the collection and data quality assessment of stillbirth data within Health Management Information Systems (HMIS).

One rationale for this approach is that many high-mortality settings have historically relied on household surveys for information on stillbirths; yet these surveys have substantial data quality issues for stillbirths. With more and more deliveries taking place at health facilities, facility-based data collection systems now have the potential to be an increasingly important source of population-level data on stillbirths – especially in places where most births occur in public facilities or where HMIS also collect data from the private sector.

A second rationale for the focus on HMIS is that while efforts are underway in some countries to improve CRVS systems' capacity to capture stillbirths (5, 6), in countries where there is no legal status to the registration requiring parents' involvement, it is recommended that the health system notifies all stillbirths directly to the CRVS system. Therefore, improving stillbirth registration data requires efforts to develop frontline health care workers' capacity to collect stillbirth data at facilities. Where stillbirth data are collected as part of the CRVS system, once the health sector notifies the system of these stillbirths, the data must then be accurately collated and integrated into reporting mechanisms, scorecards and other data trackers.

This guideline seeks to support two specific audiences: (1) **health care workers,** to provide guidance on the data elements and indicators needed to collect high quality stillbirth data and (2) **data managers/public health professionals at local, regional and national level,** to provide guidance on the data required to assess current stillbirth data quality and to execute relevant improvements to these data, thus driving informed policies to end preventable deaths.

This document complements existing guidance, including ongoing ENAP work to improve newborn and stillbirth indicators (EN-MINI) (7–12). Some previous relevant guidance did not explicitly include stillbirths; this guidance takes the existing data quality principles and applies them specifically to stillbirth measurement.

DEFINITIONS AND INDICATORS

Definitions

The following section contains details of the relevant International Classification of Diseases (ICD) definitions required for the collection of stillbirth data (13). ICD definitions have recently been updated for ICD-11 and reflect minor changes from the ICD-10. The updated definitions are provided here.

Live birth is 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[2]

Gestational age is the duration of gestation estimated based on the best obstetric estimate of gestation, which is usually expressed in completed weeks with additional days, or in completed days[3]

Birthweight is the first weight of the fetus, stillbirth or neonate obtained after birth. For live births, birthweight should preferably be measured within the first hour of life before significant postnatal weight loss has occurred

Fetal death is 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[4] where available, or at delivery by absence of signs of life at birth or after attempted resuscitation

Antepartum fetal death is a fetal death before the onset of labour or the birthing process
Intrapartum fetal death is a fetal death during labour

Stillbirth: A baby born following a fetal death at 154 days (22^{+0} weeks) or more of gestation[5]
- **In-facility stillbirth:** A stillbirth who was known to be alive on admission to the facility
- **Early gestation stillbirth:** A stillbirth between 154–195 days of gestation (22^{+0}–27^{+6} weeks)[6]
- **Late gestation stillbirth:** A stillbirth at 196 or more days gestation (≥28^{+0} weeks)[7]
- **Antepartum stillbirth:** A stillbirth following antepartum fetal death (i.e., occurring before onset of labour)
- **Intrapartum stillbirth:** A stillbirth following intrapartum fetal death (i.e., occurring during labour or the birthing process)[8]

Total births is the number of live births plus stillbirths

Neonatal death is a death during the first 28 completed days after a live birth (days 0–27)[9]
- **Early neonatal death:** A death during the first 7 completed days after a live birth (days 0–6)

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[2] Signs of life at birth include breathing, beating of the heart, pulsation of the umbilical cord and definite movement of voluntary muscles whether or not the umbilical cord has been cut or the placenta is attached. Fleeting reflex activity observed only in the first minute after birth does not warrant classification as a sign of life.
[3] For example: 22 completed weeks is written as 22+0 weeks (154 days), the gestational age 4 days later would be 22+4 weeks (158 days).
[4] Such as visualization of the fetal heart with absence of cardiac activity.
[5] Or if gestational age is not available, born with a birthweight of ≥500g.
[6] Or if gestational age is not available, born with a birthweight of ≥500g but <1,000g.
[7] Or if gestational age is not available, born with a birthweight of ≥1,000g.
[8] Skin appearance is a poor proxy for stillbirth timing and is recommended to be used only when the vital status of the baby at the onset of labour, or admission to the facility is not known. Every effort should be made to assess all women presenting in labour to the health facility, and the vital status of the fetus should be assessed and recorded at this time.
Macerated stillbirth is stillbirth with presence of signs of maceration at the time of delivery and is used as a proxy for antepartum stillbirth. **Fresh stillbirth** is stillbirth with fresh skin appearance and no signs of maceration at the time of delivery and is used as a proxy for intrapartum stillbirth.

Late neonatal death: A death occurring 7–27 days after a live birth
Predischarge neonatal death: A death of a baby (day 0–27) born at a health facility but not yet discharged home

Perinatal death includes late gestation stillbirths and early neonatal deaths. Predischarge perinatal death includes late gestation stillbirths and predischarge neonatal deaths

Note: Spontaneous pregnancy loss at $<22^{+0}$ weeks gestation

Indicators

Stillbirth rate is the number of stillbirths per 1,000 total births.

As this guidance relates to HMIS, facility-based denominators are used for the calculation of the following indicators.

Late gestation stillbirth rate in a health facility:

$$\textit{Health facility late gestation stillbirth rate} = \frac{\textit{Number of late gestation stillbirths}^{10}}{\textit{Total live births and late gestation stillbirths}} \times 1{,}000$$

Percentage of late gestation stillbirths that are intrapartum:[11]

$$\%\ \textit{of late gestation stillbirths that are intrapartum} = \frac{\textit{Number of late gestation stillbirths that are intrapartum}}{\textit{Total late gestation stillbirths with known timing}} \times 100$$

Percentage of late gestation stillbirths that are antepartum:[11]

$$\%\ \textit{of late gestation stillbirths that are antepartum} = \frac{\textit{Number of late gestation stillbirths that are antepartum}}{\textit{Total late gestation stillbirths with known timing}} \times 100$$

Predischarge neonatal mortality rate:[12]

$$\textit{Health facility predischarge neonatal mortality rate} = \frac{\textit{Number of predischarge neonatal deaths}}{\textit{Number of live births}} \times 1{,}000$$

Predischarge perinatal mortality rate:

$$\text{Health facility predischarge perinatal mortality rate} = \frac{\textit{Late gestation stillbirths plus predischarge neonatal deaths}}{\textit{Total live births and late gestation stillbirths}} \times 1{,}000$$

[9] Neonatal death definitions are included in view of their potential for misclassification with stillbirth.
[10] Using the ICD-11 definition for international comparison above where possible. In addition, information on stillbirths using alternative definitions may be collected where relevant.
[11] Indicator can also be calculated for early gestation stillbirths or other definitions as required.
[12] Where follow-up data are collected on all live births in the facility up to at least 28 days of age, then neonatal mortality rates for early deaths (0–6 days of life/live births) and late deaths (7–27 days of life/live births) can also be calculated.

WHAT DATA TO COLLECT?

Two types of data on stillbirths can be collected by the health system:

1) **Data required to measure stillbirth rates accurately and track progress towards stillbirth rate reduction targets**
2) **Data to understand contextual/ contributing factors and/or cause of death**

This guidance primarily focuses on data required to measure stillbirth rates accurately. High-level information is also provided on data to understand contextual/contributing factors and/or cause of death, with links to further resources where available.

Data required to accurately measure stillbirth rates

To ensure all relevant data needed to accurately measure stillbirth rates are collected, WHO recommends a **standard minimum perinatal dataset** to be recorded by the health system for every birth as part of the 'Making Every Baby Count – Audit Guide' and 'The WHO application of ICD-10 to deaths during the perinatal period: ICD-PM' (14, 15). This dataset contains the recommended data elements to be recorded for every birth at the point of care (see Annex 1).

Accurate recording of these elements in a data system, including **vital status at birth** (collected under details of death), **gestational age** and **birthweight**, is essential to correctly classify birth outcomes.

These minimum data items are important both for local purposes (e.g., facility-based audits) and for aggregating up the data system. In contexts where induced abortion (termination of pregnancy (TOP)) is legal, it is recommended that TOPs be recorded separately from stillbirths. This differentiation is important as stillbirths and TOPs have different underlying causes and require different public health approaches to address. For example, most late TOPs are associated with congenital anomalies, compared to fewer than 10 per cent of spontaneous fetal deaths.

Data to understand contributing factors and cause of death

Where possible, a cause of death for each stillbirth should be recorded using the international form of Medical Certification of Cause of Death (MCCD) (see Annex 2). WHO now recommends that this form is used for deaths at all ages, including stillbirths (16). Data for both stillbirth and neonatal deaths should be reported according to ICD-PM to standardize information from a variety of settings, thus improving availability of consistent information around the critical time of childbirth (14). At minimum, all countries should collect information on timing of stillbirth (antepartum or intrapartum), even if collecting detailed information on cause of death is not possible at the time of the event.

DATA COLLECTION

Accurately measuring the key variables required to classify a death as a stillbirth is an essential first step. These variables include assessing vital status at birth, gestational age and/or birthweight.

Measuring required variables

Vital status at birth

In order to apply the ICD definition to distinguish between live births and stillbirths, the delivery attendant or health care worker must be able to accurately distinguish babies with signs of life at birth, e.g., breathing, beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, from those without these signs. In cases where the baby is vigorous and crying, there is no doubt of the vital status. However, when the baby is very preterm, under the influence of maternal drugs, or compromised, for instance, by fetal hypoxia, detecting signs of life can be more challenging.

The delivery attendant or health care worker should assess every baby and attempt neonatal resuscitation in most non-macerated babies who are not breathing at birth unless fetal death was confirmed in utero, or a prior decision was made not to initiate active survival-focused care. This may occur in the case of an extremely preterm baby at the threshold of survival[13] or a baby with a congenital malformation not compatible with life[14].

All babies with any signs of life at birth or after resuscitation should be recorded as a live birth, even if the baby dies shortly after birth. Babies that show any signs of life – even if only for a few minutes – are not stillbirths.

Gestational age

The best obstetric estimate of gestation is based on the birth attendant's final estimate of gestation, calculated from the time elapsed since the first day of gestation. The first day of gestation is usually determined by:

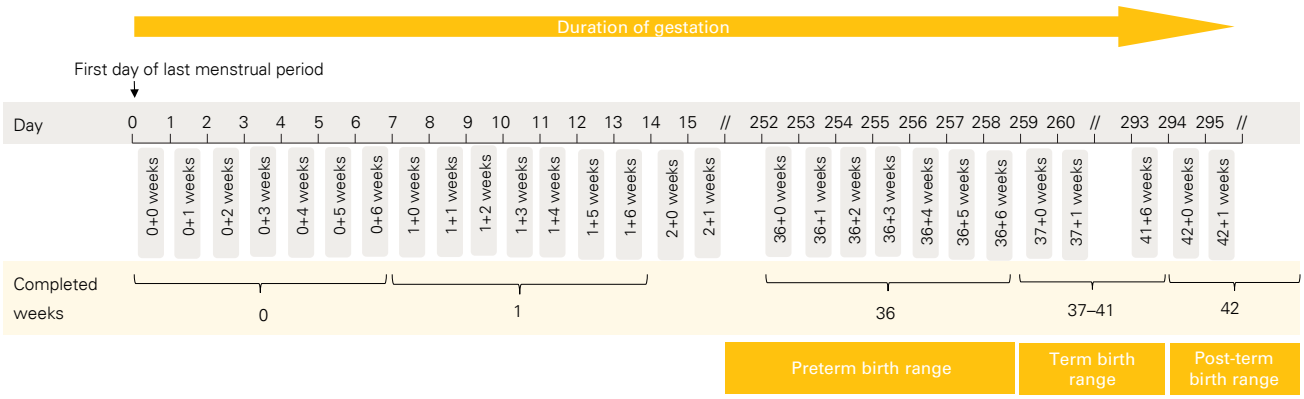
1) first day of the last menstrual period (LMP),[15] if confirmed by results of early ultrasound scan,
2) early ultrasound scan, where LMP and results of early ultrasound scan differ, or
3) LMP and/or the clinical postnatal estimate of gestational age, where no early ultrasound scan is available.

In cases of assisted reproduction when the date of embryo transfer is known, an offset of 14 days is added to calculate gestational age.

Gestational age is counted by calendar days where day zero (Day 0) refers to the first calendar

[13] Limits of viability or survival vary across different settings and are dependent on availability of neonatal intensive care. In high-resource settings, a 22-week threshold may be used and in lower-resource settings a 28-week threshold is more common.
[14] E.g., anencephaly.
[15] Conceptional age, the true fetal age from the time of conception, is measured, for example, in cases of assisted fertility interventions. However, for the purpose of comparison, gestational age measured from LMP as detailed above should be used.

Figure 1. Duration of gestation in weeks and days



Source: Adapted from Liauw et al. (17). Preterm birth is birth prior to 37^{+0} weeks of gestation, term birth is birth between 37^{+0} to 41^{+6} weeks and post-term is birth after 42^{+0} weeks.

day of gestation and Day 1 for the second calendar day. In other words, the first day of gestation, or Day 0, corresponds to gestational age 'zero completed weeks' with zero additional days (gestational age 0^{+0} weeks), and six days later would be gestational age 0^{+6} weeks.

The number of completed weeks is calculated as the number of days since the first day of gestation divided by seven, presented as a whole integer plus a remainder. For example, Day 8 after gestation is 1^{+1} weeks, Day 252 corresponds to 36^{+0} weeks and Day 258 would be 36^{+6}.

Data on gestational age should be retrieved from antenatal cards or records where available, but also confirmed with the woman. Relying on maternal recall or card information alone could introduce errors.

Gestational age should be reported in days where possible. This minimizes confusion that commonly surrounds the interpretation of 'completed weeks'. If gestational age is recorded in number of weeks rather than days, two columns should be included in the register: the first detailing the number of complete weeks and the second detailing the number of days the pregnancy had advanced into the next incomplete week.

Birthweight

Accurate birthweight measurement requires the weighing of the baby (whether live or stillborn) naked as soon as possible after birth (ideally within the first hour), using an electronic weighing scale graduated to 10g; calibrated at least once a year (or more often if moved); placed on a level, hard surface and tared to zero.

To facilitate accurate measurements for all babies, suitable, well-maintained and calibrated weighing scales should be readily available in labour wards, close to resuscitation areas and in the community for home births.

Stillbirth timing (antepartum/intrapartum)

Stillbirths where intrauterine fetal death is diagnosed prior to the onset of labour should be recorded as antepartum (occurring prior to the onset of labour). In all other cases, the fetal heart rate should be assessed at labour admission and recorded in the clinical notes. In cases where fetal heart sounds are absent on admission in early labour, fetal death should be confirmed by ultrasound where feasible and recorded as antepartum stillbirths. Stillbirths where the fetus was confirmed to be alive (by the presence of fetal heart sounds) at any point during labour should be recorded as intrapartum stillbirths.

In cases where the vital status was not assessed in early labour, signs of maceration at the time of delivery can be used as a proxy for antepartum stillbirths and absence of such signs as a proxy for intrapartum stillbirth. However, these are poor proxys, and every effort should be made to assess vital status where feasible.

Table 1. Data input validation rules for key stillbirth data variables in individual records

	Variable details	Missing data	Ranges[16]	Other validation rules
Vital status at birth	Select one of these options: - live birth - non-live birth/stillbirth	If value missing – red flag to check data and confirm that vital status is not known	Not applicable	Check recorded Apgar scores: In stillbirth, both 1- and 5-minute Apgar should be = 0. If either Apgar score is >0, then code as live birth
Birthweight	4-digit integer in grams, e.g., 0960 or 3,125	If value missing – red flag to check data and confirm that birthweight is missing	0300–7,000	Check for implausible birthweight-gestational age combinations[17]
Gestational age (Option 1)	3-digit integer in days, e.g., 226 days[18]	If value missing – red flag to check data and confirm that gestational age is missing	140–315	Check for implausible birthweight-gestational age combinations[10]
Gestational age (Option 2)	Two separate variables: 1) Completed weeks (2-digit integer), e.g., 32 2) Additional days (1-digit integer), e.g., 2	If value missing – red flag to check data and confirm that gestational age is missing	20–45 0–7	Check for implausible birthweight-gestational age combinations[10]

It is recommended that a column to indicate stillbirth timing (antepartum/intrapartum) be included in all labour ward registers to collect this information.

Recording data

As detailed in the minimum perinatal dataset above, the same information should be recorded for all births – whether live births or stillbirths – in a comparable way. Where possible, this should be in the same register or data collection form. If local policy requires a separate register, comparable information should be captured in both registers, including all components of the minimal perinatal dataset.

All live births should be recorded, regardless of gestational age at birth. Lower gestational age or birthweight thresholds may be applied for the recording of fetal deaths/stillbirths in a data system, e.g., where directives are in place to record only fetal deaths at 20^{+0} or more weeks. Please refer to local guidance for information on thresholds. Where no local guidance is available, it is advised to collect the minimum perinatal dataset on all fetal deaths at 20^{+0} or more weeks.

Electronic data capture systems and data quality

Where data are recorded using an electronic data collection form, in-built validation rules can be set to improve data quality.

Completeness of key variables

If the electronic checks above are not integrated into the data collection system, the completeness of the key variables should be checked prior to calculation of stillbirth indicators (see Annex 3). The goal is for key variables to be >95 per cent complete. If >5 per cent of stillbirths have missing information on both birthweight and gestational age, or timing of stillbirth (antepartum or intrapartum), this is likely to impact the accuracy of the calculated stillbirth indicators. When reporting stillbirth indicators at a district, regional or national level, if data are not available for all health facilities in the geographical area, the geographic coverage should be clearly documented at the time of reporting.

[16] Suggested plausible minimum and maximum values are provided.
[17] Implausible birthweight-gestational age combinations can be checked using relevant growth charts or applications, e.g., Intergrowth-21st see http://intergrowth21.ndog.ox.ac.uk. A birthweight-gestational age combination ≥5 S.D. from the mean requires further checking of both birthweight and gestational age entry.
[18] Example given for a birth at 32^{+2} weeks.

DATA REPORTING

Calculating indicators

The following stillbirth indicators should be collected in every health facility:

1) **Late gestation stillbirth rate**
2) **Percentage of late gestation intrapartum stillbirths**

If >5 per cent of stillbirths have missing information on both birthweight and gestational age in addition to the *'late gestation stillbirth rate'*, also calculate *'total stillbirth rate'* (stillbirths at 154 days or more (22^{+0} weeks) gestation plus those of unknown gestation)/total live and stillbirths).

See 'Indicators' (p. 7) for details on calculations and additional indicators.

Ensuring timeliness

Reporting of stillbirth data should be timely as these data are important for monitoring trends in stillbirths and to inform prevention programmes. Data should be reported monthly or quarterly, in line with national HMIS reporting. Where HMIS is the main source of reporting for vital statistics in a country (i.e., no reporting takes place through the civil registration system), stillbirths should be reported to the national CRVS system within 30 days of the event.

Prioritizing disaggregation

Disaggregating data helps identify geographical locations and population groups with poor stillbirth outcomes. This permits resources to be directed to populations in greatest need.

Efforts should be made to allow stillbirth data to be disaggregated by:

- sex – male, female, unknown or indeterminate
- gestational age group (see Annex 4)
- birthweight group (see Annex 5)
- maternal age group[19]

At the district level, the following can also be considered:

- facility type: private/public and level of facility
- urban/rural geographical region

[19] Other demographic categories for disaggregation can be considered, such as birth order, birth intervals (<12 months, 12–<18 months, 18–<24 months, 24–<36 months, ≥24 months).

DATA QUALITY ASSESSMENT FOR AGGREGATE STILLBIRTH DATA

Assessing quality of stillbirth data follows a similar approach as other HMIS data quality assessments. Key questions to ask include: Are the data complete? Are they collected on time? Are they correct? Therefore, assessing these data should be integrated into wider efforts to improve the quality of HMIS data.

As with all data, there are many factors that can reduce the quality of stillbirth data. Challenges with the initial information collected may include unclear definitions and a range of staffing issues: too much data to collect (challenges balancing clinical or other duties with data collection, which can lead to rushed reporting, typos or "shortcuts"), duplication of information due to fragmented systems, or insufficient training in the fields being completed in the data collection form or register. Other challenges can occur at the stage where data are collated from initial forms or registers – including illegible handwritten entries, incorrect transcribing, and summing/mathematical errors. In addition, when data collectors are unsure that the information they are collecting and collating will be used, they may not invest the appropriate amount of time and attention to detail to ensure data quality.

The following indicators have been adapted for use in stillbirth data collection from the data quality dimensions detailed in WHO's *Data Quality Review: A toolkit for facility data quality assessment* (7). The proposed data quality indicators relate primarily to internal consistency. They could be used alone to assess stillbirth data quality specifically, or integrated into wider maternal, newborn and child health data quality assessment work.

Identifying outliers

An outlier is defined as a value in a series of values that is extreme in relation to the other values in the series. Outliers can be suggestive of data quality problems and extreme values should be identified and investigated.

Consistent with recommended HMIS data quality assessment, stillbirth data values (numbers or rates) greater than two standard deviations from the mean are considered moderate outliers, while those identified as greater than three standard deviations from the mean are considered extreme and should be investigated for possible data quality issues (7–9).

Example 1. Outliers and annual late gestation stillbirth rates
Table shows illustrative example. Red indicates an extreme outlier.

	Late gestation stillbirth rate in district/ 1,000 total births				Notes/actions
	D1	D2	D3	D4	
2015	18.9	24.3	24.3	20.1	
2016	19.1	24.2	24.3	20.2	
2017	19.3	24.5	24.8	19.9	
2018	18.8	24.4	42.1	20.0	D3 district stillbirth rate much higher than trend in other years. Investigation required.
2019	18.9	24.1	23.9	19.8	
2020	18.7	24.2	24.0	19.7	

Assessing internal consistency

The ratio of the number of stillbirths reported in the current year should be compared to the average of the preceding three to five years. In settings with improving health care and a constant number of births, the ratio would be expected to be less than 1. If ratios greater than 1 are observed in such settings, this likely points to a data issue and further investigation is needed: For instance, has the national definition of stillbirth changed? Have training, new software or other factors led to an increase in reporting of events?

In settings where the number of births is fluctuating, an alternative indicator would be the ratio of the stillbirth rate reported in the current year compared to the average of the preceding three years.

Bar charts detailing the number of stillbirths reported each quarter over the preceding three to five years can be used to assess consistency of the reported number of stillbirths by season and to check for patterns of seasonal variation.

Visual inspection of figures depicting trends in the number of stillbirths (overall and by timing – antepartum and intrapartum) and trends in the stillbirth rate can also be used to identify consistency over time and any outliers in reported stillbirth data.

Assessing consistency between related indicators

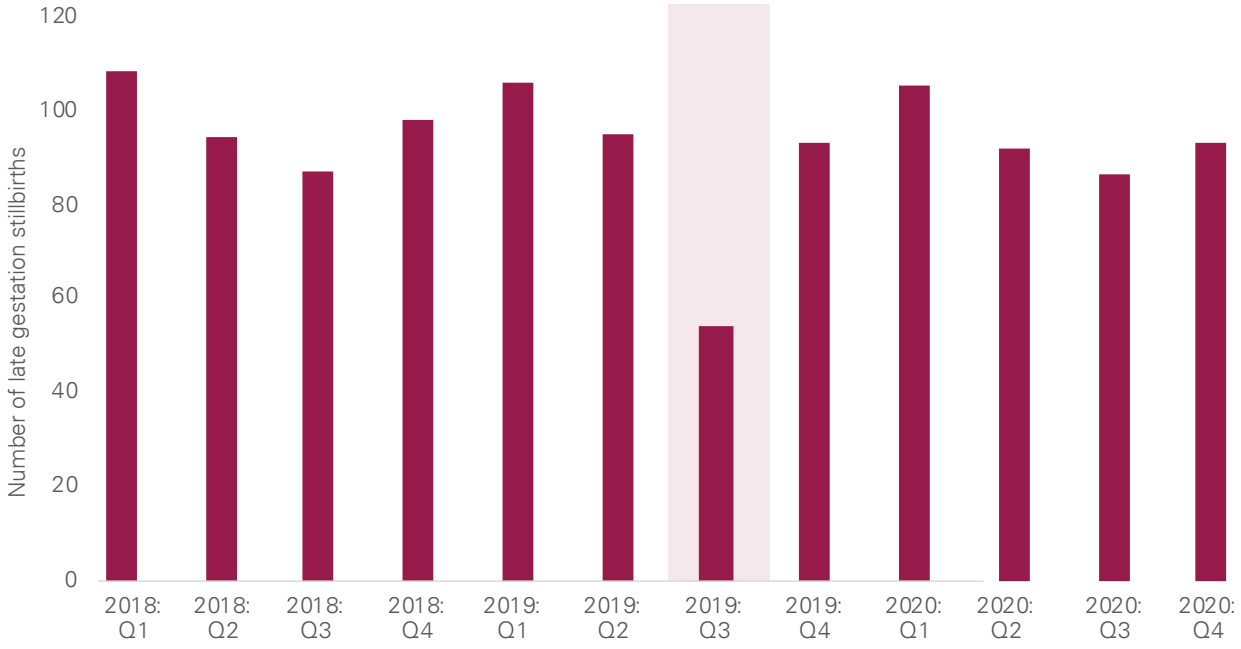
This metric is used to assess the extent to which two related indicators follow a predictable pattern. Deviations from this pattern may be indicative of data quality issues.

Stillbirth: predischarge neonatal mortality ratio

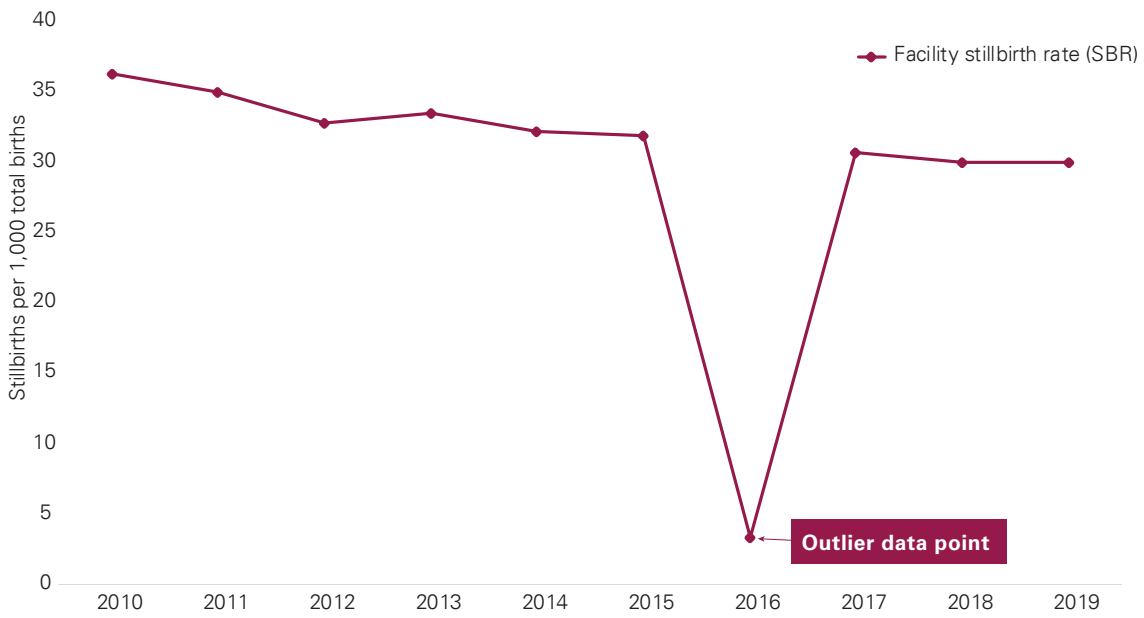
The relationship between late gestation stillbirth ($\geq 28^{+0}$ weeks) and neonatal mortality rates in settings with high quality data has previously been shown to be relatively stable across different mortality settings, with late gestation

Example 2. Outliers and quarterly data on number of stillbirths

Overall evidence of a seasonal pattern is observed, with the highest number of stillbirths reported in Q1 in each year. In 2019 Q3, fewer stillbirths were reported than expected based on previous patterns – further investigation of potential data issues is warranted.



Example 3. Outliers and stillbirth rate over time



stillbirth to neonatal mortality ratios (SBR:NMR) of >1 commonly observed. Reported ratios of late gestation stillbirth to early neonatal mortality are commonly slightly higher (>1.2), and ratios to predischarge neonatal mortality may be expected to be slightly higher still.[20]

The SBR:NMR ratio seeks to detect where stillbirths are under-reported compared to neonatal deaths or where substantial misclassification between stillbirths and neonatal deaths is present. As HMIS data systems may only capture very early neonatal deaths before discharge and not later neonatal deaths occurring after discharge, 'predischarge neonatal mortality' is recommended as a proxy.

The ratio facility late gestation SBR predischarge NMR should be calculated for each year of data. As stillbirth is a relatively rare event, large fluctuations can be seen when calculating the ratio using monthly or quarterly figures. Years with ratios of <0.75 may be suggestive of possible omission and/or misclassification and should be further investigated for possible data quality concerns.

At minimum, the late gestation stillbirth to predischarge or early neonatal mortality ratio should be reviewed in all settings and systems. Where data are also collected on early gestation stillbirths, an additional indicator – all stillbirths (≥22^{+0} weeks) to predischarge or early neonatal mortality ratio – can be considered. It should be noted that this ratio would be expected to be higher than the late gestation stillbirth to predischarge or early neonatal mortality ratio.

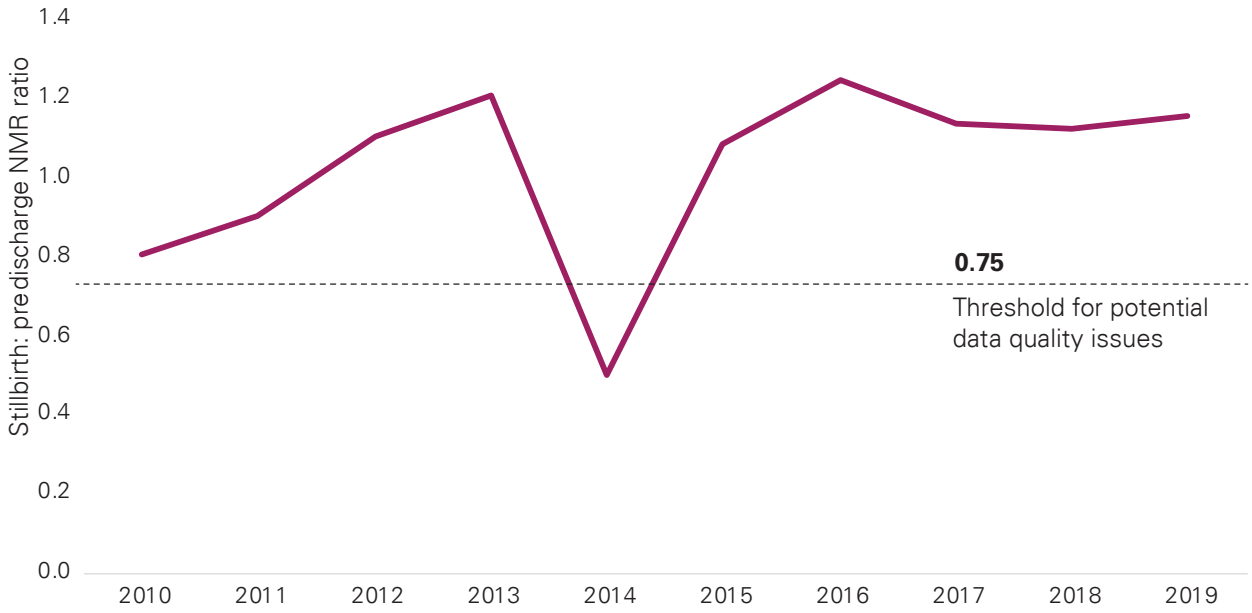
Additional stillbirth data quality indicators

Gestational age-specific mortality

The gestational age-specific mortality rate is the number of stillbirths at a given gestation, divided by all births (live and stillbirths) at that gestation. Given the relatively small number of stillbirths in most data systems, it is recommended that this is calculated annually using gestational age groups (22^{+0}–27^{+6}, 28^{+0}–31^{+6}, 32^{+0}–36^{+6}, 37^{+0}–41^{+6}, 42^{+0} or more weeks). Stillbirth risk is highest for births at the earliest gestations, lowest for births at 37+0–41+6 weeks, and shows a very slight

[16] SBR:NMR will be affected by the definition threshold used for stillbirths: where all stillbirths from 22^{+0} weeks are included, the ratio would be expected to be even higher than the ratio using late gestation stillbirths (≥28^{+0} weeks only).

Example 4. Outliers and stillbirth rate:predischarge neonatal mortality ratio over time



increase at 42+0 weeks or more. If annual figures in a health facility or a district have a different pattern with lower neonatal mortality risk for early gestations, this may suggest missing data for early gestation births (see Annex 4).

Birthweight-specific mortality

Birthweight-specific mortality rate is the number of stillbirths within a birthweight group, divided by all births (live and stillbirths) within the birthweight group. Stillbirth risk is expected to be highest for births with the lowest birthweights (<1,000g), lowest for births with normal birthweight (2,500–3,999g), and shows a very slightly higher level for those born at 4,000g or more. If annual figures in a health facility or a district have a different pattern with lower neonatal mortality risk for very low birthweight babies, this may suggest missing data regarding these births (see Annex 5).

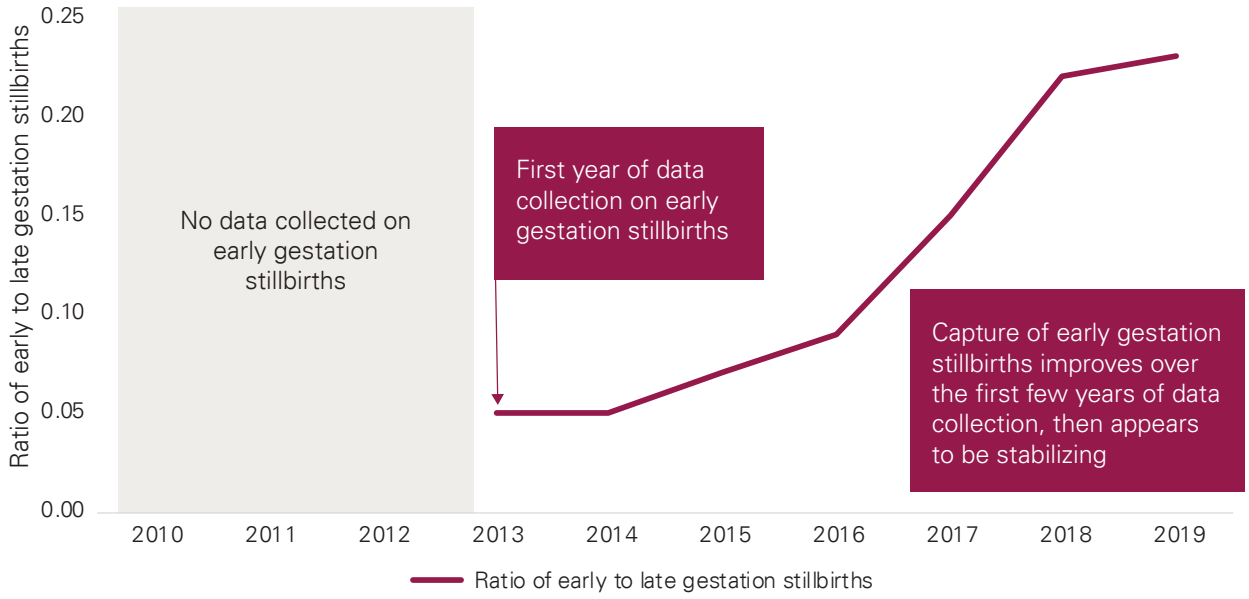
Assessing potential under capture of stillbirths around the thresholds of survival

Stillbirths around the threshold of viability or survival (the earliest stage of fetal maturity when extrauterine survival is feasible) are more frequently omitted from data systems than stillbirths at later gestations. The threshold of viability or survival varies by context from around 22 to 28 weeks depending on the availability of neonatal intensive care. Ratios of early to late gestation stillbirths range from around 0.2 to 0.4, depending on context. Potential omission of early gestation stillbirths can be assessed by comparing the ratio of early gestation stillbirths to late gestation stillbirths over time. Ratios of <0.1 in any single year or outlier years more than 2 standard deviations from the mean ratio could suggest potential omission.

Stillbirth sex ratio

The sex ratio for stillbirths (number of male stillbirths number of female stillbirths) is expected to be around 1.1 and could be used as a potential indicator if there are concerns about quality of sex data for stillbirths. The sex ratio for stillbirths is typically slightly higher than the sex ratio for live births, as male fetuses have around a 10 per cent increased risk of stillbirth compared to female fetuses (18). Annual stillbirth data with a greater number of female than male stillbirths could be an indication of a data quality issue.

Example 5. Ratio of early to late gestation stillbirths over time and consistency issues



Geographic variation

Comparing stillbirth rates between geographical regions can be used to detect potential data quality issues. Stillbirth rates would be expected to be higher in economically disadvantaged geographical districts or states than richer areas; any deviation from this pattern could indicate data quality issues. High stillbirth rates are highly correlated with lack of access to timely high quality obstetric care, therefore higher rates may be expected in rural areas compared to urban areas.

Demographic variation

Higher stillbirth rates are expected at the extremes of maternal age – girls younger than 17 or women older than 40; thus, examining maternal age-specific stillbirth rates can provide an additional data quality check.

NEXT STEPS: IMPROVING STILLBIRTH DATA FOR ACTION

The above steps highlight issues with stillbirth data already collected by a data system. While improving stillbirth data quality is a long-term task and likely part of wider actions to improve data quality, many of the measures are organizational in nature. There are more immediate steps that can be taken by health care workers (and their managers) and data collectors, data managers and public health practitioners.

Data quality should be integrated into any data system. Key quality improvement measures across all data collection include reviewing and harmonizing data forms, developing and implementing data quality checks, and providing training in data quality (for both the data recorder – commonly a health care worker – and the data collator).

The following section highlights some examples of stillbirth-specific data improvement measures.

Closing gaps in recording stillbirths at health facilities

Accurate assessment of vital status at birth, gestational age and/or birthweight is required for proper categorization of stillbirths. In health facilities, these is most commonly carried out by health care workers. Currently, many births that are reached by the data system are not accurately assessed and key data items are not properly recorded. Closing this measurement gap will require improvements in knowledge, understanding and technical ability among frontline health care workers.

Improving assessment and recording of vital status at birth

For births occurring with a skilled attendant, training health care workers in neonatal resuscitation is an effective way to both improve survival and reduce misclassification between fresh stillbirths and early neonatal deaths in the delivery room, hence reducing measurement error of vital status at birth. This training should be coupled with an enabling environment, including non-blame perinatal audit, to reduce misreporting.

Next steps to consider

Review environment for vital status reporting

- Is the labour ward/theatre an enabling environment for accurate reporting of vital status at birth? For instance, is equipment such as bag and mask and stethoscope available?
- Is there a neonatal resuscitation training programme in place?

Consider further consultation with frontline workers

- What might incentivize misreporting of vital status at birth in this context? For instance, is more paperwork/investigation required for a neonatal death compared to a stillbirth? Are health care workers perceived as exposing themselves to blame if they report a stillbirth? Do parental influences impact health care workers' reporting behaviour? For instance, does the psychological impact on parents play a role, or financial costs of funeral or access to maternity/paternity pay, if different for live/stillbirth?

Improving assessment and recording of gestational age

The assessment of gestational age is challenging in settings without routine early dating ultrasound scans. Information on gestational age, both from ultrasound scans and last menstrual period, should be retrieved from antenatal cards or records where available but confirmed with the woman. Relying on maternal recall or card information alone could introduce errors.

Next steps to consider

Capturing gestational age

- What format is used?
- Undertake a review of data collection tools, including labour ward registers
- If gestational age is collected in weeks, are the number of days the pregnancy had advanced into the next 'incomplete' week also recorded consistently?

Data completeness on gestational age for non-live births

- **DATA CHECK: Calculate gestational age completeness for non-live births:**

$$\frac{\textit{Number of stillbirths with gestational age recorded}}{\textit{Total number of stillbirths}} * 100$$

- How does this compare to gestational age completeness for live births?

Consider further consultation with frontline workers

- How common are early ultrasound dating scans?
- What is current practice for obtaining an estimate of gestational age on arrival in labour?
- What are the barriers to completing gestational age accurately?
- How can these barriers be overcome?

Improving assessment and recording of birthweight

Accurate birthweight measurement and recording should be feasible for all facility births. All health facilities should ensure that a functional, suitable and calibrated weighing scale is available for every birth. Weighing scales should be able to accurately measure birthweights to the nearest 20g, although where possible, accuracy to the nearest 10g is preferable. In addition, training, standards, guidelines and support are required to improve the quality of recorded birthweight data and to reduce heaping.

Next steps to consider

Availability of accurate scales

- Are functional weighing devices available in all facilities in this context?
- Are there guidelines for scale calibration? Are these adhered to?

Capturing birthweight

- Undertake a review of data collection tools, including labour ward registers
- If collected in kilograms, are the number of grams also reported consistently and to how many decimal places?

Data completeness on birthweight for non-live births

- **DATA CHECK: Calculate birthweight completeness for non-live births:**

$$\frac{\textit{Number of stillbirths with gestational age recorded}}{\textit{Total number of stillbirths}} * 100$$

- How does this compare to birthweight completeness for live births?

% of birthweights heaped on multiples of 500g

- **DATA CHECK: Calculate % of birthweights heaped on multiples of 500g:**

$$\frac{\textit{Number of stillbirths with birthweights on multiples of 500g}}{\textit{Number of stillbirths weighed}} * 100$$

Consider further consultation with frontline workers

- For example, if there is a gap for birthweight specifically for stillbirths compared to live births, what are the barriers to weighing a stillborn baby? If a high per cent of birthweights are heaped on multiples of 500g, what could explain this? For instance, is an imprecise weighing device being used? Are health care workers rounding birthweights?

Closing gaps in collation and use of stillbirth data

Though frontline health care workers are required to record information on all stillbirths in most settings, these data are not always reported in aggregated data. Stillbirth rate is an important marker of maternal health and quality of care and should be collated in all HMIS. Once stillbirth data are collated, ensuring these data are used for action will require that they are accessible to both frontline health care workers and policymakers and that they are understood, valued and perceived as useful. Closing this gap requires greater understanding of how data are currently used and of current barriers and enablers to more widespread use.

At minimum, information on the number of stillbirths overall and by timing (antepartum/intrapartum) should be collated and aggregated to the subnational and national level. These figures should be

included alongside the number of live births in all birth reporting captured by the data system, such as vital statistics or health statistics reports and, where relevant, web-based health statistics portals. Annual subnational and national estimates of the stillbirth rate among total births included in the data system should also be estimated and reported. Further disaggregation of data may also be presented depending on the context (see p. 14).

Next steps to consider

- Are stillbirth data currently collated in the HMIS?
- Are stillbirth data collated in a standard way consistent with the guidance in this document? Are there steps that could be taken now to standardize collation of data to improve data comparability?
- Are stillbirth indicators included in district, regional and national tracking of RMNCH outcomes, e.g., dashboards, scorecards and regular reporting structures?
- Are stillbirths being included in national initiatives to improve routine health data quality?
- Are these being used to inform policy and finance planning?
- Are these being communicated effectively to frontline health care workers and other stakeholders?

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ANNEX

Annex 1: Minimum perinatal dataset (WHO)

All births:

ID # mother:
ID # baby:
Facility name:
District name:
Obstetric history: Number of pregnancies, number of live births
Mother's age:
Type of pregnancy: singleton, twin, higher multiple
Number of antenatal care visits:
HIV-status:
Mother's last menstrual period:
Date of birth – time of birth:
Gestational age (weeks) – method of determination:
Place of delivery:
Birth attendant: midwife, nurse, doctor, other, unknown
Mode of delivery: cephalic vaginal, breech vaginal, caesarean section
Sex of baby:
Birthweight (grams):

If deceased, the following additional information should be collected:

Date of death – time of death:
Type of death: neonatal, intrapartum stillbirth, antepartum stillbirth, stillbirth unknown timing

Annex 2: Medical Certificate of Cause of Death (MCCD)

The Medical Certificate of Cause of Death (MCCD) is the internationally accepted template form for the reporting of deaths through the health sector. Doctors or trained health staff are required to complete Frame A of the form, which requires the listing of both the immediate and underlying causes of death (Part 1), as well as any contributory causes of death (Part 2), expressed in terms that can be coded to statistical categories in accordance with the rules of the International Classification of Diseases (ICD) (16).

Administrative Data (can be further specified by country)																
Sex	☐ Female								☐ Male				☐ Unknown			
Date of birth	D	D	M	M	Y	Y	Y	Y	Date of death	D	D	M	M	Y	Y	Y	Y

***Frame A*: Medical data: Part 1 and 2**			
1 Report disease or condition directly leading to death on line a		Cause of death	Time interval from onset to death
	a		
Report chain of events in due to order (if applicable)	b	Due to:	
	c	Due to:	
State the underlying cause on the lowest used line	d	Due to:	
2 Other significant conditions contributing to death (time intervals can be included in brackets after the condition)			

Frame B of the MCCD includes questions relevant to fetal or infant deaths, including birthweight, gestational age, whether it was a multiple pregnancy, and age of the mother.

Fetal or infant Death									
Multiple pregnancy			☐ Yes	☐ No	☐ Unknown				
Stillborn?			☐ Yes	☐ No	☐ Unknown				
If death within 24h specify number of hours survived			Birth weight (in grams)						
Number of completed weeks of pregnancy			Age of mother (years)						
If death was perinatal, please state conditions of mother that affected the fetus and newborn									

The MMCD form and further instructions on completion can be found at https://icd.who.int/icd11refguide/en/index.html#2.17.2DataSourceIntlDeathCertificate|data-source-the-international-death-certificate|c2-17-2.

Annex 3: Assessing completeness of key variables

The completeness of the following key variables should be assessed prior to calculating the stillbirth indicators.

Variable	Live births	Stillbirths	Birth type not recorded
Number of births	A	B	C
Sex of baby: Male Female			
Missing sex of baby	D	E	F
% missing sex of baby	D/A x 100	E/B x 100	F/C x 100
Number gestational age not recorded	G	H	I
% missing gestational age	G/A x 100	H/B x 100	I/C x 100
Number birthweight not recorded	J	K	L
% missing birthweight	J/A x 100	K/B x 100	L/C x 100
Number with neither birthweight nor gestational age recorded	M	N	O
% missing both birthweight and gestational age	M/A x 100	N/B x 100	O/C x 100
Number missing information on stillbirth timing (antepartum or intrapartum)	NA	P	NA
% missing information on stillbirth timing	NA	P/B x 100	NA

Annex 4: Disaggregation by gestational age groups

Gestational age groups and mortality

Gestational age group	Number stillbirths	Number live births	Number predischarge neonatal deaths	Number outcome at discharge unknown	GA-specific mortality rates	
					Stillbirth per 1,000 total births	Neonatal deaths per 1,000 live births
<22^{+0} weeks (<154 days)	N/A	A	B		Not applicable	B/A x 1,000
22^{+0} – 27^{+6} weeks (154 - <196 days)	C	D	E		C/(C+D) x 1,000	E/D x 1,000
28^{+0}-31^{+6} weeks (196-223 days)	F	G	H		F/(F+G) x 1,000	H/G x 1,000
32^{+0}-36^{+6} weeks (224-258 days)	I	J	K		I/(I+J) x 1,000	K/J x 1,000
37^{+0}-41^{+6} weeks (259-293 days)	L	M	N		L/(L+M) x 1,000	N/M x 1,000
42^{+0} weeks and over (294 days and over)	O	P	Q		O/(O+P) x 1,000	Q/P x 1,000

Gestational age-specific stillbirth and predischarge neonatal mortality rates are expected to be highest for births at the earliest gestations, lowest for births at 37^{+0} – 41^{+6} weeks, and show a very slight increase for those born at 42^{+0} weeks or more. If annual figures in a health facility or a district have a different pattern with lower neonatal mortality rates for early gestations, this may suggest missing data for early gestation births.

Annex 5: Disaggregation by birthweight groups

Birthweight groups and mortality

Birthweight group	Number stillbirths	Number live births	Number predischarge neonatal deaths	Number outcome at discharge unknown	Birthweight-specific mortality rates	
					Stillbirth per 1,000 total births	Neonatal deaths per 1,000 live births
<1,000g	Z	A	B		Z/(Z+B) x1,000	B/A x1,000
1,000–1,499g	C	D	E		C/(C+D) x1,000	E/D x1,000
1,500–1,999g	F	G	H		F/(F+G) x1,000	H/G x1,000
2,000–2,499g	I	J	K		I/(I+J) x1,000	K/J x1,000
2,500–3,999g	L	M	N		L/(L+M) x1,000	N/M x1,000
4,000g or more	O	P	Q		O/(O+P) x1,000	Q/P x1,000

Stillbirth risk and predischarge neonatal mortality is expected to be highest for births with the lowest birthweight, lowest for births with normal birthweight (2,500–3,999g), and shows a very slightly higher level for those born at 4,000g or more. If annual figures in a health facility or a district have a different pattern with lower neonatal mortality risk for very low birthweight babies, this may suggest missing data regarding these births.


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