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PERSPECTIVE

# 'Silent Losses–Silent Data': Reviewing Stillbirth Data Quality in Low- and Middle-Income Countries Using Data Quality Dimensions

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## ABSTRACT

Precise data is crucial for policy decision-making, especially in sensitive outcomes like stillbirth, where each data element have significant effects. Following years of advancement in the healthcare domain, there is a pressing need to improve data-based policymaking by addressing both the social context and emotional dimensions. This holds true for any healthcare condition including stillbirth, which demands the attention of healthcare managers, researchers and policymakers. Conditions such as stillbirth signify more than a birth devoid of vital signs. A mother endures months of discomfort and excruciating labour pain and faces the devastating reality that her baby is no longer alive. The absence of her child's initial cry disrupts her life, causing her to struggle with confusion and sadness on the factors that may have led to this catastrophe. In spite of this significant loss, we typically perceive it as merely one death, often neglecting to acknowledge it adequately. Significant advancements in averting stillbirths can be achieved by viewing it as a loss of life, rather than only perceiving it as the birth of a lifeless infant. Examining stillbirth data and comprehending its causes can aid in formulating strategies to avert future incidents. This publication seeks to compile information on the principal issues associated with the reporting and recording of stillbirths in low- and middle-income countries (LMICs) from the perspective of data quality aspects. Furthermore, it also proposes strategies to enhance each aspect of data quality like harmonising stillbirth definitions, linking routine data systems with surveys, facility audits for better data capture, and increasing funding for stillbirth-related research etc.

## 1 | Introduction

Following years of advancement in the healthcare business, there is an urgent necessity to improve data-driven decision-making. Stillbirth is characterised by the death of a foetus prior to birth or the delivery of a neonate exhibiting no signs of life. Stillbirth remains a global burden with almost every 1 of 70 births reported as stillbirth during 2023 globally. Annually, around 1.9 million stillbirths happen worldwide (≥ 28 weeks of gestation), implying 1 stillbirth/17 s in 2023 [1]. Since 2000, around 53 million births have been stillborn, with about 80% occurring in sub-Saharan Africa (SSA) and Southern Asia (SA) [2, 3] which remained stagnant at 79% during 2023 [1]. Lower-middle-income countries (LMICs)

**Highlights**

- Progress in stillbirth prevention needs robust data for informed decision making.
- Concerns in LMIC stillbirth data: no targets, misclassification, fear, stigma etc.
- Study recommends better data capture via audits, system links and funding.

account for 56% of all global stillbirth and 49% of all live births. Over 98% of global stillbirths (~ 2.6 million) occurred in low- and middle-income countries (LMICs) during 2015, with approximately 60% occurring in rural regions [4]. The reduction in SBR (Stillbirth rate) and NMR (Neonatal mortality rate) has been more gradual than that of other maternal and child health indicators. The worldwide yearly decline in the stillbirth rate (SBR) was calculated at 2.3% from 2000 to 2019, with an SBR of 13.9 per 1000 total births in 2019 [5].

There have been marked disparities in the global stillbirth burden. In 2019, discrepancies in regional stillbirth rates were reported, ranging from 22.8 in West and Central Africa to 2.9 in Western Europe per 1000 total births [6], with rural areas exceeding urban regions. Marked disparities in stillbirth rates persist across many countries. Women in SSA and SA encounter the greatest risk of stillbirth [7], equating to over 77% of global stillbirths, with nearly 1.5 million occurrences in these regions during 2021 [8]. Between 2000 and 2019, South Asia's proportion of stillbirths decreased from 44.3% to 33.1%, indicating a notable regional reduction in these negative consequences. Over one-third (34%) of all global stillbirths occurred in India (17.3%), Pakistan (9.7%), and Nigeria (8.7%), indicating India's predominant contribution to the global burden (0.34 million of approximately 2 million global stillbirths in 2019) [6]. In India, stillbirth rate reporting exhibits significant discrepancies between the Sample Registration System (SRS [9]) 2020 (4 per 1000 births) and the Health Management Information System (HMIS [10]) 2019–2020 (12.4 per 1000 births), which are the two primary data sources from the country. Additionally, there are significantly varied reports of burden between States/UTs [10, 11], underscoring the difficulty associated with reliable data availability and reporting for policy decision-making.

Stillbirths are categorized to explain potential causes as Intrapartum stillbirths (fresh), indicating that the foetus died during labour, characterized by the intact skin appearance of the deceased foetus. Macerated stillbirth happens when the foetus dies prior to the commencement of labour—often regarded as Antepartum stillbirth [12]. Research indicates that more than 40% of stillbirths happen during labour, a loss linked to multiple factors that could be mitigated by various interventions throughout pregnancy and labour [2, 3].

In 2014, the World Health Assembly endorsed Every Newborn Action Plan (ENAP), establishing a global objective to limit third-trimester stillbirths to 12 or fewer per 1000 total births by 2030. By 2021, 139, predominantly developed nations have attained this objective. Nevertheless, 56 nations may fail to achieve the ENAP objective by 2030 without focused, additional interventions [2, 3]. In line to the same, the India Newborn Action Plan (INAP) also aims to decrease the SBR in India to single digit by 2030 [13]. This necessitates expedited efforts to comprehend the barriers within the existing health system processes and the competencies of healthcare personnel and address the issue. The initiative demands addressing community attitudes towards stillbirths and their involvement in program interventions aimed at alleviating this maternal-foetal tragedy [13–16].

Inequalities in SBR are evident, with disadvantaged women experiencing approximately double the risk of stillbirth compared to their affluent counterparts [17]. Factors affecting stillbirths, both immediate and distal, in LMICs, exhibit similarities: extremes of age and parity, inadequate quality of antenatal care, poor early detection, management and timely referral of high-risk pregnancies, and substandard intrapartum care [18]. Additional factors encompass problems during gestation and delivery, including extended pregnancy, maternal infections (malaria, syphilis, HIV), maternal health disorders (hypertension, diabetes), and foetal growth restriction. Congenital defects may possibly represent one of the contributing factors (10% of cases in high-income countries); nevertheless, due to diagnostic difficulties, their prevalence remains ambiguous. Additional causes and risk factors included in the UNIGME report, 2022, include access to healthcare facilities, socioeconomic determinants, environmental influences, maternal fertility-related conditions, and behavioural variables [8]. Comprehending the principal determinants of these negative outcomes and for further action necessitates a comprehensive data system to ascertain the causes, risk factors, and essential areas that demand intervention.

A report indicates that a veil of silence envelops the subject of stillbirths [8]. Despite the alarming prevalence of these fatalities, stillbirth is hardly addressed in personal or public discourse, nor is it acknowledged as a worldwide public health issue. Data about stillbirths is predominantly lacking in worldwide monitoring systems, and preventive measures are frequently omitted from maternal health policies and programs, despite the fact that numerous losses may be averted. This disregard is especially evident while comparing the rate of decline for stillbirth as compared to that of other maternal-foetal conditions. Another study asserts that substantial advancements in reducing stillbirths can be attained by its social acceptance [19]. The necessity for a comprehensive data system to accurately account for every stillbirth has been reiterated in a research by Kerber K et al. [20].

Given the obstinate nature of this issue, we endeavoured to objectively assess the weaknesses in the stillbirth data systems of LMICs utilizing Data Quality (DQ) Dimensions. A comprehensive examination of the existing literature was performed to identify areas for enhancement or deficiencies in the current data system represented by DQ dimension heads. We have reached additional conclusions along with recommendations and a planned course of action for each aspect of data quality.

## 2 | DQ Dimensions

For data-based decision making, it is crucial to comprehend various dimensions of data quality that facilitate the evaluation

of data's suitability for its intended purpose. Dependence on one dimension is inadequate; thus, a multifaceted approach yields a more thorough assessment. The Data Management Association UK (DAMA - UK) identifies six essential dimensions: accuracy, completeness, uniqueness, consistency, timeliness, and validity, together referred to as DQ Dimensions [21]. Table 1 attempts to provide an explanation to each data quality dimensions. To identify the associated challenges in maintaining quality levels and later address each component of data quality, we examined existing literature and identified opportunities for improvement in the current data system.

The global data tracking systems predominantly overlook stillbirths, hiding the actual burden of stillbirth [22]. The UN Interagency Group for Child Mortality Estimation (UNIGME), 2022, indicates that approximately 63% of LMICs lack reliable data on stillbirths, as this information is frequently omitted from public health strategies and policy-making frameworks [8]. In LMICs, significant discrepancies are observed between reported and actual SBR due to multiple factors, necessitating the evaluation of the timeliness, accuracy, completeness, and consistency of information.

## 3 | From Mandate to Meaning: Is Policy Alone Enough?

Prior to examining the implementation status of policies, it is crucial to confirm their availability. Numerous countries lack both a target for reducing stillbirths and a strategy for their prevention, failing in accountability for action [1, 8]. A study assessed availability of stillbirth reduction targets in 155 nations. Of the 32 countries with targets, 40.6% were classified as LMICs. This signifies a substantial disparity in availability of policies

**TABLE 1** | Data quality dimensions and the associated challenges in per maintaining quality levels.

| DQ dimension | Definition used for assessment | Quality maintenance challenges | Evidence as 2023 UNIGME report [1] |
|---|---|---|---|
| Timeliness | Evaluates the availability of data at the required moment. | • Suboptimal governance on data availability.<br>• Lack of national targets and legal frameworks. | Average age of most recent stillbirth data point is 3.3 years *for 2023 UNIGME estimation, of these* ~ 50% countries have most recent data before 2022. Further over 75% have data from last 5 years. |
| Completeness | Denotes the possession of all requisite information, including the availability of parameters like gestational age (GA), birth weight (BW), foetal hearth rate (FHR) etc. | • Insufficient clinical information in routine data, survey based and vital registration system.<br>• Healthcare professional's competencies in identifying and reporting. | Of 200 countries assessed—50 countries have reported a poor-quality data, of these 56% are from low- and lower-middle-income groups. |
| Accuracy | Guarantees that data accurately represents reality, including the definitions employed for identifying stillbirth and the under-reporting attributable to various factors. | • Lack both a target and strategy for reducing stillbirths' burden.<br>• Ambiguous criteria for stillbirth documentation<br>• Fear of punitive actions, cultural stigma, and knowledge gaps. | Increase in countries using 28-week definition (2000–2005 to 2020–2023) from 67% (71 of 106 countries) to 83% (101 of 121 countries). |
| Uniqueness | Assesses the lack of duplication in data sets. | • Limited timing/cause-of-death data due to lack of diagnostic capacity. | Of 200 countries assessed - 28% countries use clinical assessment; 51% rely on skin appearance; 21% method unknown. |
| Consistency | Guarantees that data remains non-conflicting across data sets, hence improving the capacity to triangulate information from diverse sources. | • Absence of an effective vital registration system.<br>• Suboptimal HMIs data quality.<br>• Variability in stillbirth definitions.<br>• Misclassification of early newborn deaths. | Of 200 countries assessed - only 12 of the 51 LMICs report CRVS data for stillbirth, 41% data come from HMIS, household surveys accounts to 21% data and population studies—23%. Even this available information was not used due to data quality concerns. |
| Validity | Pertains to data adhering to anticipated formats and ranges, facilitating seamless automated procedures. | • Lower direct investment in research.<br>• Close association with negative social and economic determinants of health. | Countries with substandard quality of data contributes to 23% of global stillbirths. Exclusion rate of stillbirth data due to quality issues 70% in low- and lower-middle-income countries. |

and objectives regarding stillbirths, especially in LMICs [23]. Further, only 24.3% ($n$ = 16) of nations possess rules or legislation mandating regular audits and evaluations of death certifications for stillbirths. Countries frequently failed to differentiate between death certificates and medical certifications [23]. Another study indicates that disparities in legislation among nations, divergent policies on viability at gestational age extremes, and factors such as fatalism and insufficient accountability could be a reason to under-reporting [24]. The 2023 UNIGME report highlights that the 23% of global stillbirths are from 50 countries with poor data quality implying better data quality reported from countries with lower stillbirth rates. In most low- and lower-middle-income countries, early gestation stillbirths remain underreported. *Despite these arguments, mere existence of a policy does not guarantee its effective implementation, policies often remain aspirational rather than actionable. This can further be argued that getting a consensus on common use of definitions and having a robust policy might pose systemic level challenges.*

## 4 | Are We on the Same Page?

Different organizations suggest different definitions of stillbirth, classifying them based on GA and BW [25]. The Centre for Disease Control (CDC) defines stillbirth as death of foetus ≥ 20 weeks of gestation or BW < 350 g. The WHO/ICD (International Classification of Diseases) categorises stillbirths as fatalities occurring > 22 weeks of gestation or BW < 500 g, but the international classification stipulates a requirement of either 1000 g or 28 weeks. The European Medicines Agency equates stillbirth with late foetal mortality occurring beyond 22 weeks of gestation. The American College of Obstetricians and Gynaecologists (ACOG) defines stillbirth as occurring at 20 weeks and 400 g, while the United Kingdom considers 24 weeks. The UNIGME, 2022, issued a report based on gestations of 28 weeks or longer. A recent publication from Globan Burden of Disease (GBD) Study 2021 [7] clearly indicates a significant undercount of stillbirths when using the 28-week threshold. Further, as presented in Table 2, it presents the information from the UNIGME 2022 data [8], implying that there is a huge variation in the adopted cutoff values across data points from different countries.

## 5 | Which Data System to Rely on?

Research indicates a significantly low completeness of stillbirth data within the operational vital registration system [8, 26]. There is a lack of functional vital registration systems. The necessity for a data system to enhance reporting and documentation is underscored by a suggestion in a WHO report [2]: 'Most stillbirths do not receive a birth certificate and are not registered'. Enhancing mechanisms for documenting births and neonatal fatalities is a human rights issue and essential for decreasing stillbirths. Furthermore, it is essential to enhance regular health information systems to precisely document and report stillbirths for the purpose of monitoring and elevating the quality of care. The UNIGME, 2022, reported the utilization of vital registration data from 107 countries; however, none from

**TABLE 2** | Variation in cut-off criteria across data points.

| Sr. No | Classification system | Classification by week/birth weight | Percentage of contribution to total dataset analysed for UNIGME 2022 |
|---|---|---|---|
| 1. | Classification based on gestational week alone | 20 weeks | 1% |
| | | 22 weeks | 6% |
| | | 24 weeks | 2% |
| | | 26 weeks | < 0.5% |
| | | 28 weeks | 64% |
| 2. | Classification based on months of pregnancy | 7 months | 7% |
| 3. | Classification based on gestational week along with birth weight | 500 g or 22 weeks | 2% |
| | | 1000 g or 28 weeks | 1% |
| | | 500 g or 20 weeks | 1% |
| 4. | Classification based on birth weight only | 500 g | 1% |
| | | 1000 g | 8% |
| 5. | Others | Any | 2% |
| | | Not defined | 4% |

LMICs fulfils the quality standards [8]. The data in the Health Management Information System (HMIS) is of substandard quality [27]. The UNIGME 2022, utilised just 38% of the HMIS data on stillbirths from LMICs. Conversely, just 43% of data pertaining to stillbirths were incorporated in study from LMICs [8]. An initial assessment of quality of DHS data of India resulted in an information in which stillbirth is reported in first trimester of pregnancy also, implying a suboptimal quality of data.

## 6 | From Clinical Angle to Stigma

The absence of proven GA assessment methodologies, inadequate intrapartum FHR monitoring, and misclassification between neonatal and intrapartum stillbirths are exacerbated by the absence of quality data [22, 25, 28]. Furthermore, insufficient clinical information frequently constitutes the primary reason for the failure to identify causes of mortality, particularly in LMICs, where access to diagnostic tests is restricted [4, 29]. Inadequate recall and the related shame are a significant problem, particularly in communities where stillbirth is linked to cultural and familial taboos [30–32]. According to a UNICEF report, in many cultures, stillbirths are attributed to maternal responsibility, leading to public shaming and personal sentiments of guilt or shame that hinder public mourning of the loss. The absence of a platform for public mourning may lead to stillbirths being perceived as 'non-events' [3]. Social taboos, stigmas, and prejudices frequently silence families and hinder the acknowledgement and mourning of stillbirths, so

contributing to their invisibility. Lawn et al. also identified cultural stigma and definitional difficulties with stillbirths as significant obstacles to enhancing stillbirth reporting [33]. The stigma associated with stillbirth remains predominantly unacknowledged, especially for women in LMICs. Stillbirths remain neglected, leading to considerable consequences for parents, healthcare professionals, and communities [24].

## 7 | Beyond Constraints: Why Can't We?

A study by Stanton C et al. indicated that countries with the highest stillbirth rates experience a scarcity of acceptable data, with significant under-reporting [1, 34]. A recent publication has reiterated the paucity of relevant data concerning stillbirth across various locations [7]. Anecdotal evidence from India indicates that fear substantially contributes to the under-reporting of stillbirths (evidence from an ongoing study in India by the authors). Numerous recorded stillbirths are inaccurately classified as macerated, so attributing responsibility to the mother or family rather than categorising them as fresh stillbirths. Similarly, fresh stillbirths are often categorised as early neonatal deaths again shifting the responsibility onto the family. This misreporting continues despite research indicating that 40% of stillbirths occurred during labour [8]. Nevertheless, the current stillbirth reporting system in LMICs fails to differentiate between fresh and macerated stillbirths. This complicates the identification of the definitive factors contributing to stillbirths [35, 36] (Table 3).

A Cochrane analysis indicated that no intervention exists to improve the identification and accurate reporting of stillbirth causes [37]. Numerous studies have underscored the necessity to improve data reporting and the overall quality of data collection methods [6, 17, 22, 38, 39]. Research indicates that stillbirths are significantly linked to adverse social and economic determinants of health [28]. Consequently, numerous stillbirths remain undocumented, especially those occurring outside of healthcare institutions [37]. Community-level births are frequently underreported due to many factors, including discrepancies in the understanding of definitions and prevalent beliefs [40, 41]. A new meta-analysis also indicates insufficient financing for stillbirth research in both LMICs and high-income nations [42].

## 8 | Striving Forward: Potential Recommendations

To attain ENAP objectives, stringent efforts are required. Identified challenges and potential recommendations are summarised further (Figure 1). The UNIGME, 2022, indicated that 56 nations will fail to fulfil the target, with over half projected to fall short by 2050, predominantly in sub-Saharan Africa. Consequently, efforts to address future demands, are essential [43]. Research has provided numerous proposals for enhancing data reporting which are further categorised as '*short-term operational measures*' and '*long-term systemic improvements*'.

### 8.1 | Short-Term Operational Measures

1. Establishing national targets, legal frameworks, and accountability mechanisms.
2. Harmonising stillbirth definitions across countries.
3. Training healthcare workers to accurately identify and report stillbirths.
4. Refining DHS survey questions to ask about stillbirths separately from abortions using clear definitions and other clinical parameters.

#### 8.1.1 | Evidence

Negandhi et al. [44] advocated for the establishment of definitions and categories for stillbirths to achieve uniformity across healthcare facilities. Educating healthcare practitioners on these

**TABLE 3** | Key stillbirth indicators across regions.

| Regions | Overall data quality* | Number of stillbirths in thousand (rate) | Share of stillbirth (%) | Annual rate of reduction in stillbirth rate (2015–2023) | Proportion of antepartum and intrapartum stillbirths |
|---|---|---|---|---|---|
| Sub-Saharan Africa | Limited | 912 (22.2) | 47.7% | 1.2 | 51%–49% |
| Oceania (exc. Australia and New Zealand) | Limited | 6 (17.3) | 0.3% | 0.6 | 40%–60% |
| Central and Southern Asia | Average | 616 (15.5) | 32.3% | 3.3 | 49%–51% |
| Northern Africa and Western Asia | Average | 139 (11.7) | 7.3% | 0.5 | 67%–33% |
| Eastern and South-Eastern Asia | Average | 139 (6.7) | 7.3% | 2.4 | 67%–33% |
| Europe, Northern America, Australia and New Zealand | High | 30 (2.8) | 1.6% | 1.5 | 88%–12% |

*Note:* *Author's discretion based on substantial data quality gaps by data source and region—UNIGME report [1].
*Source:* UNIGME report 2023 [1].

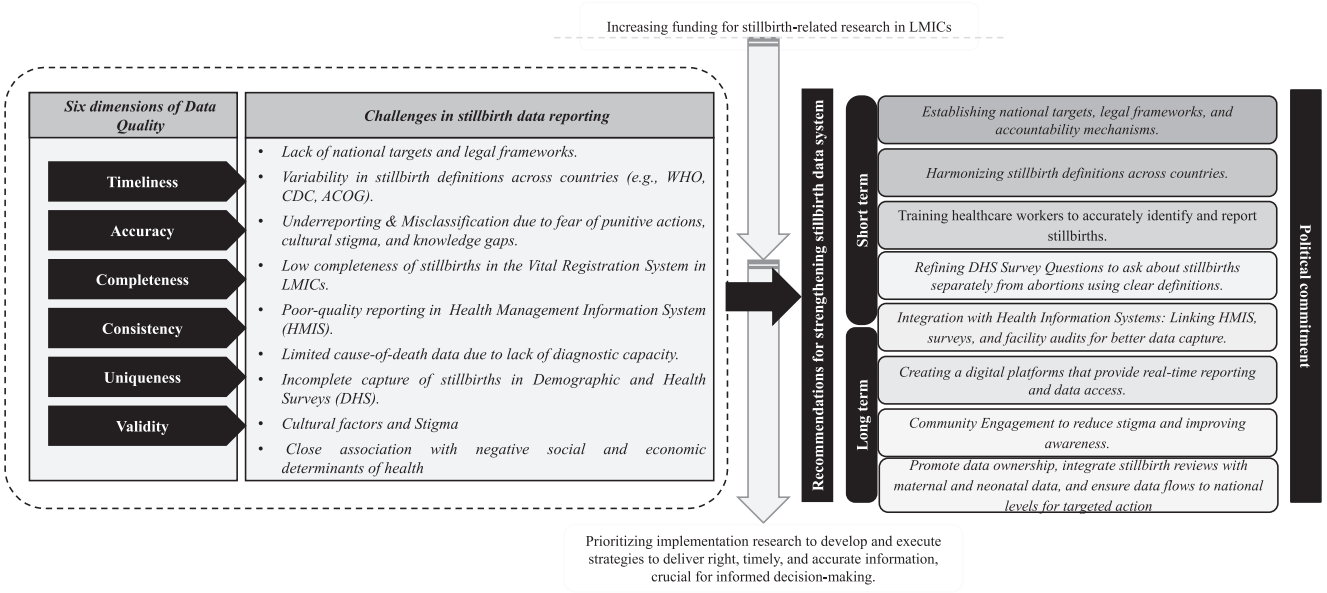


**FIGURE 1** | Identified challenges in each DQ dimensions and potential directions.

principles can reduce misclassification and enhance data accuracy. Incorporating stillbirth reporting into current health information systems can enhance data collection efficiency. This integration must encompass the creation of intuitive digital platforms that provide real-time reporting and data access. Fostering a culture of transparency and accountability is vital. Promoting the reporting of stillbirths by healthcare personnel without the apprehension of stigma or punitive repercussions can enhance the accuracy of data collection. Moreover, community involvement programs can enhance awareness regarding the significance of reporting stillbirths, underscoring that precise data is essential for formulating effective preventative strategies. Regular audits and evaluations to identify challenges and opportunities for improvement are essential for the ongoing advancement of reporting processes. Lawn et al. [33] similarly recommended enhancing the availability of data through house-to house surveys or through facility-level audits, as well as necessary advancements in vital registration.

## 8.2 | Long-Term Systemic Improvements

1. Promote data ownership, integrate stillbirth reviews with maternal and neonatal data, and ensure data flows to national levels for targeted action.
2. Integration with Health Information Systems: Linking HMIS, surveys, and facility audits for better data capture.
3. Creating a digital platform that provides real-time reporting and data access.
4. Community Engagement to reduce stigma and improve awareness.

### 8.2.1 | Evidence

Dandona et al. [45] asserted the necessity of increasing validation of available data systems, improving the data quality by training and teaching healthcare professionals to correctly identifying and recording data in a timely manner and strengthening governance and addressing the financial aspects involved. Moreover, improving medical recording of delivery timing, gestational age, weight of stillbirth, and foetal heart rate monitoring, is essential for accurately evaluating the type of stillbirths (to prevent early neonatal deaths from being misclassified as stillbirths), which can guide targeted interventions. Conducting a mortality audit cycle to investigate the circumstances of these deaths is an established quality improvement technique that can uncover weaknesses in clinical care and processes at the district level, thereby reducing missed opportunities to avert similar tragedies. Ali et al., in their publication [46] provided a methodology for the accurate identification and reporting of stillbirths utilising DHS data. However, India encounters considerable challenges in implementing these methodologies due to the lack of high-quality data necessary for applying appropriate adjustment metrics [47]. These findings align with those proposed by Bhutta et al. [48], who underscored the necessity of acknowledging the facts and, importantly, the political commitment required for the broader implementation of these techniques. Furthermore, the UNIGME, 2022, advocated improving data accessibility regarding the timing and paths to stillbirth across various contexts. Moreover, it is imperative to enhance household surveys for accurately capturing the requisite data items, as these surveys serve as the primary data source in most LMICs [8].

## 8.3 | Authors Recommendation

Direct investment in research led by LMICs, particularly in implementation studies, could expedite the global advancement in stillbirth prevention and neonatal survival. Monitoring all pregnant women in designated geographic areas on a pilot basis to assess pregnancy outcomes may yield dual benefits of improved estimations and strengthened health systems for long-term advantages. Further research is also needed to identify

context-appropriate, scalable interventions tailored to different health system settings for correct GA assessment methodologies. Authors recommended prioritising implementation research to develop and execute strategies to deliver right, timely, and accurate information, which is crucial for informed decision-making. Employing the innovative theory of change (TOC) methodology to devise and assess strategies aimed at enhancing documentation of stillbirths may serve as an additional way to address this difficulty. Systematic improvement requires a multi-pronged approach like - strengthening routine data systems (like HMIS and CRVS), integrating digital platforms for real-time entry and validation, ensuring regular training and supervision of frontline workers, and establishing audit-feedback loops for error detection and correction. Embedding these mechanisms at both facility and community to track and report both intrapartum and antepartum stillbirths can create a more robust and reliable system for stillbirth data reporting and use. The authors also recommend placing greater emphasis on overall perinatal mortality, due to the frequent misclassification of these deaths and the need for more accurate tracking of progress.


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### Ethics Statement

The authors have nothing to report.

### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

The authors have nothing to report.

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