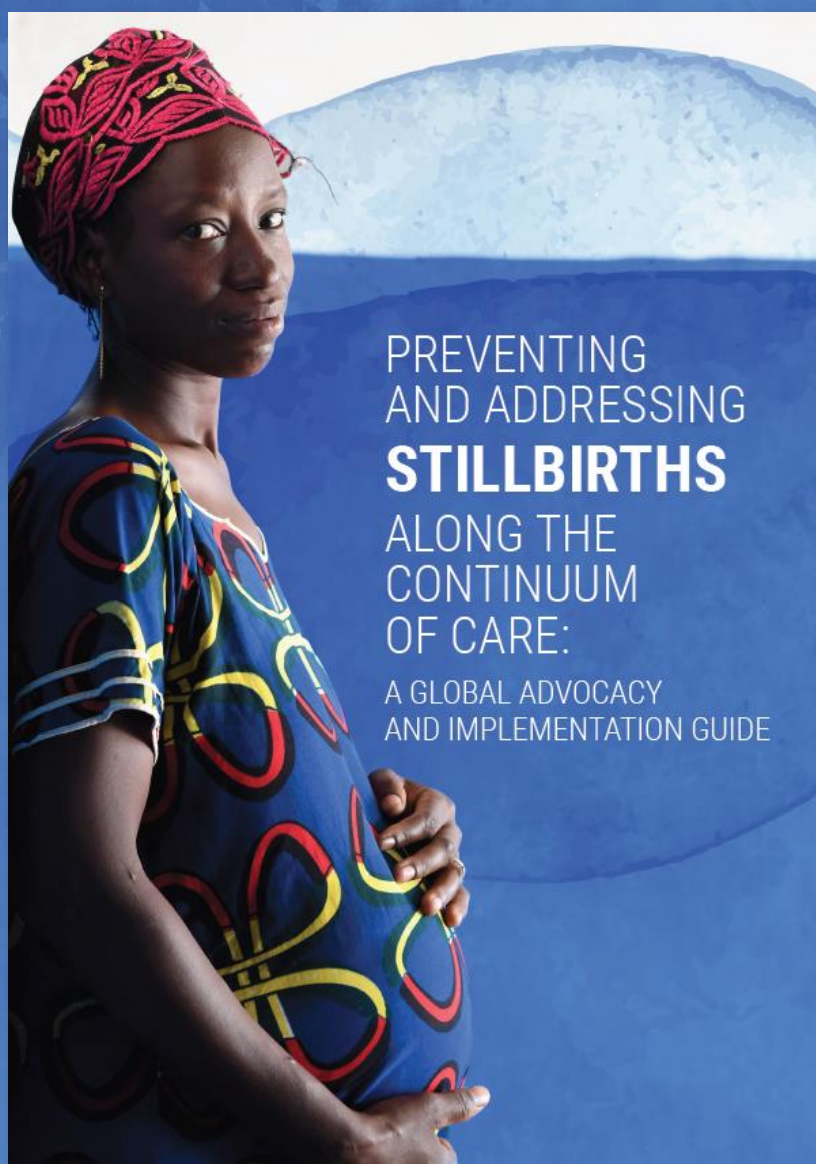


# ONLINE REPOSITORY

Additional case studies for



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*Note. The case studies in this online repository reflect the perspective of the author(s) alone; they do not necessarily represent the views of the International Stillbirth Alliance or any collaborating organizations or partners for the Global Stillbirth Advocacy and Implementation Guide. Some of the case studies in this online repository have been shared by individuals and/or organizations and have not been meaningfully altered prior to inclusion.*

Preventing and addressing stillbirths along the continuum of care: a global advocacy and implementation guide is available at [www.stillbirthalliance.org/global-guide](http://www.stillbirthalliance.org/global-guide)

# Advocacy

## Technical advocacy: prioritization of stillbirth prevention at the national level – Uganda

In Uganda, maternal and newborn health stakeholders capitalized on increased global momentum for stillbirths, stemming from [The Lancet Ending Preventable Stillbirths Series](#) and [Every Newborn Action Plan](#), to advocate for incorporation of a stillbirth target and related interventions into the national health policy. The stakeholders, organized through the Maternal and Child Health cluster, ensured that key evidence was shared. They then vetted and refined recommendations to support the adoption of the target and related interventions. Factors that helped in the success of this advocacy work included targeted funding and technical support for various projects in Uganda that included stillbirths such as through the [Global Financing Facility](#).

→ [Read more in this BMC article](#)

→ [Read the Global Financing Facility's Roadmap for Improved Stillbirth Reporting and Response](#)

## Political advocacy: how legislators can help after stillbirth – USA

A bereaved mother in Washington state in the US realized that her son Keegan, who was stillborn, would not be granted a birth certificate and therefore his existence would not be recognized by the state. Working with a coalition of other bereaved parents, she made a case, met with politicians, engaged lobbyists and pushed for a bill to issue birth certificates to stillborn children in her state. The informal group was met with ignorance and much of their work involved educating legislators about stillbirths and the impact of stillbirth on parents and families. After two years of advocacy, with the bill failing on its first attempt, it was finally passed by the Washington state legislature.

→ [Read more in this post from the Stillbirth Advocacy Working Group stillbirth series](#)

## Awareness raising or voice advocacy: Still A Mum – Kenya

Launched in Kenya in 2015, [Still a Mum](#) has supported over 5,000 moms and dads who have lost a baby through miscarriage, stillbirth or infant loss throughout Africa. It was founded by Wanjiru Kihusa after she lost two unborn babies and realized that there was gap in care for and support of affected families in Kenya. Wanjiru started blogging about her experience and offered advice on how to support someone who has lost a baby. Her blog posts and social media posts created connections with other parents who had also experienced child loss and wanted support.

→ [Read more in this Nation Africa article](#)

## Still A Mum Parent Voices Initiative – Kenya

[Still A Mum](#) is an organization that is passionate about maternal mental health. Launched in Kenya in 2015, we have supported over 5,000 moms and dads who have lost a baby through miscarriage, stillbirth and infant loss throughout Africa. Apart from psychosocial support, we have championed for education and advocacy on matters perinatal loss through working with companies and government to audit HR policies and laws pertaining to maternal mental health. For instance, we are involved in the amendment of the Employment Act to allow parents who lose a baby or those that get premature babies to get maternity and paternity leave.

The Parents Voices Initiative (PVI) Kenya, in collaboration with International Stillbirth Alliance Stillbirth Advocacy Working Group and the London School of Hygiene & Tropical Medicine, funded by the Partnership for Maternal, Newborn and Child Health, gave us an opportunity to empower parents bereaved by stillbirth in matters advocacy with the aim of improving bereavement care.

It was encouraging to notice the zeal among bereaved parents to take the lead in bereavement support, educating the society on bereavement care and engaging the government at the policy level as well. Self-advocacy and group advocacy have been the common tools among our community of bereaved parents. From the workshops, we gathered that organizational culture has also been influenced by parents who advocated for bereavement leave, while other parents advocated for separate rooms from the nursing ward at the hospital.

These are just few examples of encouraging advocacy efforts made by bereaved parents. The PVI workshops and the [toolkit](#), allowed us to gather valuable data, reflect on parents' advocacy experiences and to contribute to a more compassionate culture of bereavement care and stillbirth prevention in the maternal health system, especially in our context where stigma and shame is still prevalent.

### **Christine Wangeci (bereaved mom)**



*“The workshops equipped me greatly for advocacy work. I have been following up with two mums from the support group, who had cases of preeclampsia and one is now 30 weeks pregnant and healthy, and the other mum, we are continuing to trust God for the fruit of the womb. The Parents Voices Initiative workshop has enlightened and equipped me adequately on the tools of advocacy that has made my advocacy activity more targeted”.*

## Establishment of the Centre of Research Excellence in Stillbirth – Australia

The efforts of the Australian stillbirth community of parents, researchers, policymakers and healthcare providers in advocating for change to address stillbirth was boosted by the alarming data in [The Lancet Ending Preventable Stillbirths Series](#) showing Australia's rate of late-gestation stillbirth was much higher than similar countries. A subsequent successful bid to the [National Health and Medical Research Council \(NHMRC\)](#) saw the establishment of the [Centre of Research Excellence in Stillbirth \(Stillbirth CRE\)](#) in 2017 and, in 2018, Australia's first-ever [Parliamentary Senate Inquiry into Stillbirth](#) was undertaken. The Inquiry was spear-headed by a politician who had experienced stillbirth and was overseen by a committee with members who had also been affected by stillbirth. This Inquiry included six public hearings where the voices of parents were instrumental in driving action, resulting in a [National Stillbirth Action and Implementation Plan](#) for Australia in 2020. This plan aims to reduce stillbirth rates by 20% over the following five years, reducing the disparity in stillbirth rates between advantaged and disadvantaged communities, and improving care for all families who experience this loss. A major prevention initiative has been the national [Safer Baby Bundle](#) for antenatal care, which has been rolled out across the country (2020-2022). Initial data indicates the goal of a 20% reduction in stillbirths may become a reality. Parent support and advocacy organisations ([Stillbirth Foundation Australia](#) and [Red Nose](#)) have played a critical role in ensuring the experiences of parents are at the heart of the program to address stillbirth in Australia, including a public awareness campaign in 2020/21.

## Advocacy and implementation support to address stillbirth – Afghanistan

Afghanistan has one of the highest rates of stillbirth in the surrounding region, with a rate of 25.7 per 1,000 total births in 2021. Despite a 27.4% decline between 2000 and 2021, the rate of reduction needs to be accelerated by more than five times to meet [Every Newborn Action Plan \(ENAP\)](#) stillbirth target by 2030. To address the high rate of stillbirth in the country, USAID has supported implementation of several high impact and low-cost interventions such as improving antenatal care, intrapartum care and postnatal care, focusing on competency/skill of healthcare providers on emergency obstetric and newborn care along the continuum of care at the facility and community level in rural and urban settings.

To improve intrapartum care, WHO recommends a comprehensive package for positive childbirth which includes respectful maternity care, emotional support, effective communication, pain management, continuity of care, regular monitoring, skilled birth attendants and a safe physical environment. USAID has continued to translate these recommendations into local languages and hold orientation sessions for clinical specialists and midwives to improve quality of care and reduce stillbirths, with a focus on midwife-led maternity care and a safe caesarean section. Moreover, USAID is supporting Maternal and Newborn Death Surveillance and Response (MNDSR) activities under the Urban Health Initiative (UHI) project to improve access and quality of essential health services, focusing on women and children. The UHI project supports the establishment and revitalization of MNDSR committees in public and private health facilities through:

- review of maternal and newborn deaths to identify gaps and develop action plans;
- provision of technical support;
- organization of orientation sessions for clinical specialists, midwives and other healthcare providers;
- arrangement of virtual workshops and translation of MNDSR scorecard and
- progress markers for health facilities in local languages, with plans to assess the facilities.

Advocacy for integrating stillbirth in the MNDSR national guidelines is ongoing. Through these initiatives, Afghanistan aims to meet the ENAP stillbirth targets and improve the quality of care for newborns and reduce the stillbirth rate.

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## Group B Strep International – USA

Co-founded in 2006 by two parents whose daughters were stillborn due to Group B streptococcus (GBS), the mission of [Group B Strep International \(GBSI\)](#) is to promote awareness and prevention of GBS disease in babies not only at birth, but before birth through several months of age. We are grateful to the many parents worldwide who have shared their experiences surrounding GBS infection in their babies. Not only does this help other families learn from their experiences and be alert as to how to help protect their baby, but it also helps us and others to better advocate for babies' health by being able to identify potential gaps in GBS and perinatal care which can vary around the world.

For example, in Trinidad, [Divyashri](#) passed away the same day she was born, being resuscitated at birth as she was already infected with GBS. Although GBS can infect babies before labour starts and water breaks, had her mother been tested for GBS and tested positive, her mother could have been given intravenous antibiotics for GBS during labour and birth, which could have changed the outcome for Divyashri. A mother in the UK reiterates a common concern among stillbirth parents who contact us, which is that her membranes were stripped in the days just prior to her baby's stillbirth. She was not encouraged to have an autopsy for her stillborn daughter [Faith](#), being told that an autopsy would most likely give no answers. She was also told that GBS is only a danger to the baby upon delivery and as her baby was dead before she was born this would not in any way have caused her death.

According to WHO, at least [46,000 babies](#) are stillborn due to GBS each year (WHO & LSHTM, 2021).

Please visit [GBSI's website](#) for more info on prenatal-onset GBS disease including knowledge-based strategies which may help prevent unborn babies becoming infected by GBS and/or enable better outcomes with prompt medical intervention.

### **Additional links:**

- Recognize the [signs of GBS infection](#) in babies
- Read more [parent stories](#) on the GBSI website
- Learn about GBSI's [WAVES Study](#) to help identify gaps in GBS care and communication
- Download [GBS awareness materials](#) to share in your community

### **References:**

World Health Organization and London School of Hygiene & Tropical Medicine. Group B streptococcus vaccine: full value of vaccine assessment. Geneva: World Health Organization; 2021.

## Programme implementation

### Screening for placental insufficiency in low-risk pregnant women – South Africa

The WHO guideline group recommend that the value of single Doppler ultrasound assessment of the fetal blood vessels during the third trimester needs more rigorous evaluation, particularly in low- and middle-income countries, to address the value of screening pregnancies with Doppler ultrasound with respect to changes in perinatal outcomes and should focus on preventing deaths.

A team in South Africa explored the prevalence of abnormal umbilical Dopplers in low-risk pregnant women using a continuous wave Doppler device called [Umbiflow™ device](#). Umbiflow™ is a mobile, low-cost continuous-wave Doppler ultrasound (CWDU). The device measures the resistance index (RI) in the umbilical artery and plots it against the estimated gestational age (GA) to identify the fetus at risk of fetal growth restriction (FGR). The advantage of CWDU is that it is considerably less expensive than pulsed-wave Doppler ultrasound, which must be performed in conjunction with imaging ultrasound. CWDU detects all movement in the line of the ultrasound wave and gives the classic pattern which allows measurement without requiring imaging ultrasound.

A study done in Mamelodi, a township in the east of Pretoria looked at screening and use of CWDU in a low-risk pregnant population. A low-risk pregnancy was defined in all these studies as a pregnant woman attending non-specialist antenatal care clinics and classified as “low-risk” according to local clinical guidelines at the time of recruitment, based on their obstetric and clinical assessment. CWDU was performed in 2,868 women at primary health care between 28 and 32 weeks’ gestation. Pregnancy outcomes were available for 2,539 fetuses (88.5%); 297 fetuses (11.7%) were regarded as having abnormal umbilical artery RI. Absent end diastolic flow (AEDF) – which represents end stage placental function and is associated with adverse outcomes – was found in 1.5% of the screened low-risk population. The prevalence of AEDF in this low-risk population was 10 times higher than reported in existing literature. There were 29 perinatal deaths in the CWDU group. The perinatal mortality rate for 12,168 women attending primary health care antenatal clinics draining to the referral hospital who did not have an umbilical artery RI was 21.3/1,000 births, significantly higher than in the CWDU group (11.4/1,000 births) (RR 0.58, 95% CI 0.42 - 0.81). Use of umbilical artery RI, with a standard management protocol, in this low-risk population demonstrated a significant reduction in perinatal mortality.



A second larger prevalence study was conducted including over 7,000 low-risk women screened with CWDU between 28- and 34-weeks' gestation in nine different sites across eight provinces in South Africa. Researchers recorded pregnancy outcomes in 6,536 women (92.2%). The study found a similarly high prevalence of abnormal umbilical artery RI (13%) and AEDF (1.2%). There were 66 stillbirths, resulting in a stillbirth rate (SBR) in the group screened with CWDU of 10.1/1,000 births while, in the control group of 10,832 women, it was 17.8/1,000 births. Hence, screening pregnant women with CWDU resulted in a decrease in the SBR of 43% (RR 0.57, 95% CI 0.29-0.85).

Furthermore, if all women in the control group who developed subsequent antenatal complications were excluded, there were 9,811 women and 152 stillbirths, giving a SBR of 15.5/1,000 births, which was 35% higher than the CWDU-screened group (RR 0.65, 95% CI 0.36-0.94). The caesarean section rate remained the same between the CWDU and the control groups, but there was an increase in the number of low-birthweight infants. However, despite the increase in the use of neonatal services, the neonatal mortality rate did not increase, thus the fetuses who were at risk of stillbirth were not transferred to neonatal deaths.

Screening using CWDU is an effective tool that detects abnormal umbilical artery RI and when the information is used, it opens an opportunity to identify the fetus at risk and allows for appropriate intervention when necessary and prevent stillbirths.

## Strengthening antenatal care through antenatal care checklists – South Africa

Some antenatal stillbirths occur, despite the best antenatal care being available for that setting (particularly in low- and middle-income countries). In low- and middle-income countries, most antenatal care is performed at primary health care clinics with limited resources and a severely limited ability to detect fetal growth restriction (FGR), which is the cause of approximately half of antenatal stillbirths. Routinely used techniques aimed at detecting FGR have not been shown to effectively prevent stillbirths (including symphysis-fundal (SF) height measurement and fetal movement counting and recently, a two-step imaging ultrasound in low- and middle-income country settings failed to show any reduction in perinatal mortality or morbidity). There is a need to methodically identify and stratify patients in need of expert care as many interventions are dependent on timely identification and intervention.

In November 2016, WHO released the comprehensive [WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience](#), prioritizing person-centred care and well-being as well as prevention of mortality and morbidity. WHO envisions that “every pregnant woman and newborn infant receives good quality care throughout pregnancy, childbirth and the postnatal period”, where quality refers to provision and experience of care from a health systems perspective, enabling a positive pregnancy experience. The recommendations include a minimum of eight contacts in the course of the pregnancy, since recent empirical evidence has shown that eight contacts suffice for uncomplicated pregnancies and may assist to identify previously missed complications that resulted in adverse outcomes in the low-risk pregnant women. The recommendations also recognize there are gaps in our knowledge and thus include research areas and priorities.

The [South African National Department of Health](#) included maternal and perinatal health care amongst its priorities in healthcare service provision and adopted the WHO antenatal recommendations and termed it Basic antenatal care plus (BANC Plus). They developed antenatal guidelines and checklists to improve the content, and quality of antenatal care. Since the countrywide scale-up of BANC Plus in April 2017 there has been a sustained increase in the number of antenatal contacts and a reduction in stillbirths and perinatal deaths due to hypertensive disorders of pregnancy.

**References:** World Health Organization. WHO recommendations on antenatal care for a positive pregnancy experience. Geneva: World Health Organization; 2016.

## CLEVER Maternity Care – South Africa

CLEVER Maternity Care is a multicomponent intervention package that focuses on achieving respectful obstetric care and better-quality pregnancy outcomes. The acronym CLEVER stands for Clinical care and obstetric triage; Labour ward management to resolve the withholding of care; Eliminate barriers to meet basic human needs; Verify care with monitoring, evaluation and feedback to reach reflective practice; Emergency obstetric simulation training (EOST) to create autopilot sequences during emergencies; and Respectful care to improve birthing women’s experiences. The implementation of CLEVER Maternity Care has contributed to improved women’s experiences of childbirth and improved maternal and perinatal morbidity and mortality.

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## Bereavement care in the **United Arab Emirates**: context and case examples

The United Arab Emirates (UAE) is representative of a diverse cultural and socioeconomic community and a predominantly private healthcare setting. For the large expatriate demographic community (approximately 88.5%) maternity care is predominantly obstetrician-led within a private hospital setting via company sponsored medical insurance. Government hospitals provide subsidized maternity care for Emirati nationals and typically offer a more financially obtainable option to expatriate families with lower income/level of health insurance. There is currently no nationwide, standardized bereavement care pathway when it comes to stillbirth and parent experience may be influenced by the hospital policies and individual care provider's own cultural perspectives, their experience and training.

### **Example 1 - Mother, 40 years or age, 4th Child. Nationality: Filipino**

“My husband and I lost our jobs during the pandemic and could not return home or find new employment. I was pregnant and because I had no employment, I did not have the necessary ID or medical insurance, nor could I afford to pay out of pocket. One clinic offered us one free prenatal scan and our baby was found to be small, but we could not afford the follow up care they recommended. At 40 weeks I felt pain and went to hospital to be told my baby had no heartbeat. They suspected she had died days earlier due to complications from maternal hypertension. The hospital staff wanted to take her from me right away, but I was supported by one very kind and compassionate nurse who encouraged me to hold and spend some moments with my daughter. The time with her was very precious and all I have to remember her by. I asked the hospital to keep my daughter's body and I would return to claim her as soon as I could find a way to pay my medical bills. When I returned a few days later I learned my daughter had already been buried without me being present in a cemetery near the hospital that I am unable to visit. The care of the nurse who supported me to have those precious moments with my daughter and the memory box I have since received from the Love Through Loss community are very precious moments in what otherwise continues to be a deeply traumatic experience.”

### **Example 2 - Mother, 40 years of age, 4th Child. Nationality: Irish**

“When considering moving overseas, I don't think anyone considers the 'what if?' scenarios of stillbirth. The UAE is perceived as a glamorous and progressive city, and I assumed the hospital care I would receive would be on a par with Ireland and the UK. Having previously toured the private hospital and NICU where I was to give birth and met with the midwives, I had felt so confident that

my baby and I would receive good quality perinatal care. At a scan at 30 weeks, I was told my baby had no heartbeat. I soon realized that the hospital had no clear bereavement care pathway, access to a Cuddle Cot or even a comprehensive understanding of the UAE system so they could discuss what to expect. After 23 hours of labour, I was allowed to spend 3 hours with my daughter before she was taken to the mortuary. It was 2am and I was assured that my baby could come back to my room the following morning for memory making. Shortly after this the police arrived to open a criminal case which they assured us was routine, but we were shocked and upset.

The following morning when we requested to have our baby back with us, we were refused. I spoke to the management team, but nobody was willing to allow this, they felt that visiting her in the mortuary was adequate. First a priest came and we said prayers with her in a cardboard box, inappropriate. Later we had arranged with the Love Through Loss team (whose memory boxes the hospital provided us with) remembrance photography and hand imprints, which both were done in the mortuary. It felt intimidating and traumatising in the mortuary being watched by security, management and a nurse; devastating to only be able to spend supervised time with our baby girl. I wanted my older children to meet her, but I couldn't bring them into a mortuary. It was so disappointing and they still question why they couldn't meet her, it makes me feel so guilty but I was in such disbelief about the whole situation that I did not have the energy to do more. It is my feeling that there needs to be proper training to support families and a clear care plan. I was not offered any follow up care or support by the hospital who advertised themselves as providing individual, compassionate patient care but we did not see or feel any of that. It was only in finding the Love Through Loss community we found places to turn and proper information."

**Example 3 - Mother, 33, 1st Child, Nationality: British**

"Losing a baby is something you never expect to happen to you. Our first baby died in utero at 35 weeks. At first I thought I would be scared to hold him but once I saw him I loved him immediately. The midwife caring for us was extremely competent and compassionate in creating a makeshift cool cot in our room with ice packs and fiercely protected our time together with him when hospital management wanted to take our son to the mortuary after a brief time. The hospital provided a memory box which meant we had access to remembrance photography, hand and footprints and bereavement support resources which are not provided by the hospital. The time we got to spend with him in the hospital is without doubt the most special and treasured memory of my whole life and I am so grateful to the midwife for her care, compassion and confidence in guiding us during that time. Every family should have access to care like this, supported to have time with their baby

and guided to make memories in the way that feels right for them. We had never considered this could happen to us, let alone what we would have wanted to do or were in the headspace to investigate for ourselves. The memory box and the care of our midwife have meant we have such precious memories of his birth and items we will cherish always.”

## Measurement of progress

### Using data to reduce preventable deaths of babies and children – Mexico

Mexico has joined the global commitment to reduce preventable deaths of babies and children by 2030 (1). During the last two decades, the Government has strengthened the nationwide collection of individual-level datasets of livebirths and fetal deaths through the National Subsystem of Livebirths and the National Subsystem of fetal deaths, respectively. Notification of livebirths and fetal deaths is mandatory through medical certificates of births and causes of death across the 32 states in the country; both datasets include information on mothers (age, parity, educational attainment, place and mode of delivery), newborns (birthweight, gestational age, sex), and institutions (2, 3). Cause of death is reported according to the International Classification of Diseases and information on stillbirth timing, using fresh or macerated skin appearance as a proxy, has been collected since 2013 (4).

Variable	Livebirths		Stillbirths	
	number of records	%	number of records	%
Number of births	14,471,221	100	105,324	100
Male	7,368,825	50.9	55,238	52.4
Female	7,090,522	49.0	48,270	45.8
Missing sex of the baby	11,874	0.1	1,816	1.7
Missing gestational age	25,999	0.2	0	0.0
Missing birthweight	795,123	5.5	602	0.6
Missing birthweight & gestational age	3,144	0.0	0	0.0
Missing skin appearance (fresh/ macerated) as proxy for stillbirth timing	N/A	N/A	5,225	5.0
Birthweight heaped on multiple of 500g	13,676,098 with birthweight recorded	8.2	13,011 with birthweight recorded	12.4

Table 1. Number of records, heaping and missing values for key variables among livebirths and stillbirths collected in Mexico from 2013 to 2019.

To maximize their utility to inform action to reduce preventable deaths, stillbirth data need to be of high quality. Using UNICEF new guidance on stillbirth data quality assessment (5), we reviewed information on 14,471,221 livebirths and 105,324 stillbirths  $\geq 22+0$  weeks captured in Mexico's publicly available datasets from 2013 to 2019 to assess quality of stillbirth data. Missing values for

key variables were overall low (<5%) with stillbirths having lower levels of missingness than livebirths of birthweight (0.6% vs 5.5%) and gestational age (0.0% vs 0.2%) but higher missing sex (1.7% vs 0.1%) (Table 1). Birthweight heaping was higher for stillbirths (12.4%) than for livebirths (8.2%). Disaggregated data confirmed the expected pattern that gestation-specific stillbirth rates (per 1000 total births) were the highest among earliest gestations (583.2 from 22+0 to 27+6 weeks, 184.6 from 28+0 to 31+7 weeks, 25.8 from 32+0 to 36+6 weeks) lowest for births at 37+0 to 41+6 weeks (2.2) and showed a slight increase (8.3) for those born 42+0 and over.

Overall, data completeness is high for core variables. Improving data quality should include the accurate recording of birthweight and stillbirth timing. Closing this gap requires greater engagement with admin users and frontline care workers.

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