

PREVENTING  
AND ADDRESSING  
**STILLBIRTHS**

ALONG THE  
CONTINUUM  
OF CARE:

A GLOBAL ADVOCACY  
AND IMPLEMENTATION GUIDE

# PREVENTING AND ADDRESSING **STILLBIRTHS** ALONG THE CONTINUUM OF CARE:

## A GLOBAL ADVOCACY AND IMPLEMENTATION GUIDE

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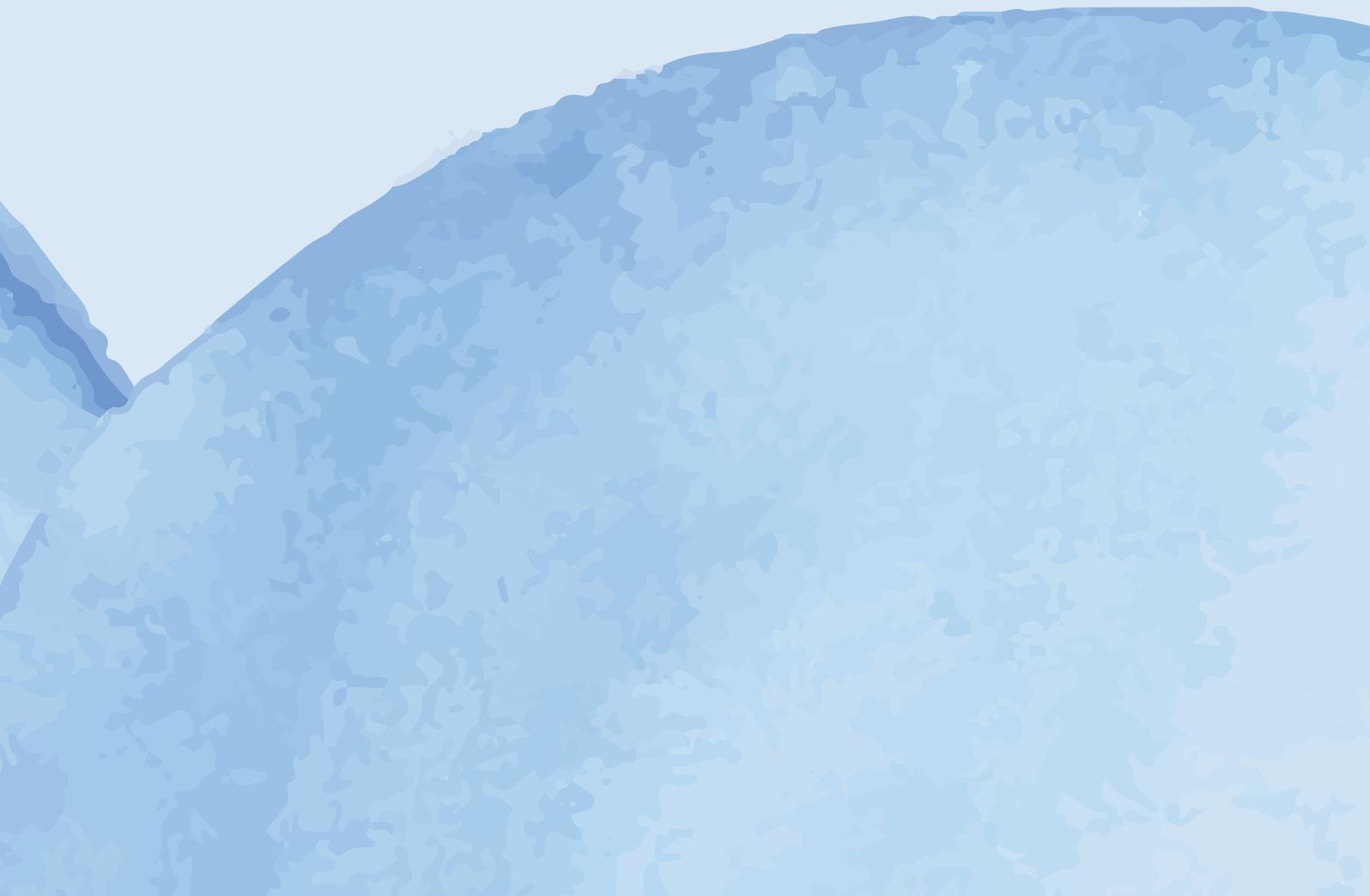
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# CONTENTS

<b>THE VISION</b>	<b>IV</b>	<b>4. ADVOCACY</b>	<b>19</b>
<b>FOREWORD</b>	<b>V</b>	Introduction to stillbirth advocacy	19
<b>JOINT MESSAGE FROM COLLABORATING ORGANIZATIONS</b>	<b>VI</b>	Fundamentals of advocacy	19
<b>ACKNOWLEDGEMENTS</b>	<b>VII</b>	Guidance for developing an advocacy strategy	22
<b>ACRONYMS</b>	<b>VIII</b>	<b>5. PROGRAMME IMPLEMENTATION ALONG THE CONTINUUM OF CARE</b>	<b>32</b>
<b>USING THIS GUIDE</b>	<b>IX</b>	Access to care	32
<b>1. BACKGROUND</b>	<b>1</b>	Leadership	40
The toll of stillbirth	1	Infrastructure, equipment and supplies	44
Underlying risk factors associated with stillbirth	6	Health workforce	47
<b>2. OPPORTUNITIES TO OVERCOME CHALLENGES IN ADDRESSING STILLBIRTH</b>	<b>8</b>	<b>6. MEASUREMENT OF PROGRESS</b>	<b>55</b>
What are the challenges?	8	Where to start	55
Opportunities along the continuum of care	11	Counting stillbirths	56
<b>3. BEREAVEMENT CARE IS ESSENTIAL</b>	<b>15</b>	<b>7. ACHIEVING THE GOAL</b>	<b>61</b>
What is respectful and supportive bereavement care?	15	Action needed at the country level	61
		Progress can be made	66
		<b>8. REFERENCES</b>	<b>68</b>
		<b>9. ANNEXES</b>	<b>74</b>

## THE VISION

We envision a world in which preventable stillbirths no longer occur, and care for families and health workers after stillbirth is compassionate, high quality and culturally appropriate.



## FOREWORD



When a baby is stillborn, the impact on parents, their families and the health-care professionals who have cared for them can be devastating. The resulting grief is as strong as that for the loss of any child, yet poor acknowledgement of their birth and the pregnancies that resulted in a stillbirth, combined with stigma, blame and silence, continue to limit acceptance and legitimization of these tragic experiences across the globe. Inadequate quality of care during pregnancy, labour and birth impacts stillbirth prevention. The shared vision of the International Stillbirth Alliance and our members is to improve access to quality care across the continuum of maternity and newborn care. This includes support for parents and families, as well as those who care for them, across a range of health-care and community settings.

As many of us contributing to this foreword have lived experience of bereavement following the death of a baby, we welcome this guide and extend our thanks to the Bill & Melinda Gates Foundation for overarching funding and to the authors and contributors who have devoted their time and expertise to bring this guide to fruition.

Central to this guide are the voices, experiences and images of many bereaved parents who have collaborated each step of the way to co-produce

a unique document. To those parents and their babies, we also extend our deepest gratitude and thanks.

We hope this guide will be read and utilized by all those working to integrate stillbirth prevention and care into national, subnational and health-care facility programmes and policies – because every pregnancy and every baby counts. By taking a holistic and collaborative approach to policy development and implementation, and by including and listening to bereaved families, it is possible to ensure that all women and babies experience the quality, safe and respectful care they deserve throughout the continuum of care.

A handwritten signature in black ink, appearing to read 'Claire Storey'.

**Claire Storey**, Director of Bereavement, Community and Parent Voice, on behalf of the International Stillbirth Alliance Board

**Marti Perhach**, CEO and Co-founder of Group B Strep International

**Grace Mwashigadi**, Research Coordinator, Aga Khan University, Kenya

# JOINT MESSAGE FROM COLLABORATING ORGANIZATIONS

Every day, over 5,000 babies are stillborn, affecting nearly 2 million families every year. Two out of five of these deaths occur during labour, most of which are preventable with high-quality maternity care. While some progress has been made in reducing the global stillbirth rate, substantial disparities persist between and within regions and countries, with the most vulnerable groups continuing to experience disparities in all countries. Timely care and support can mitigate the known impacts of stillbirths on women, families, communities and health workers. Yet such support is only sparsely available, and little progress has been made to close these gaps in access. Despite previous calls for action, progress has been slow.

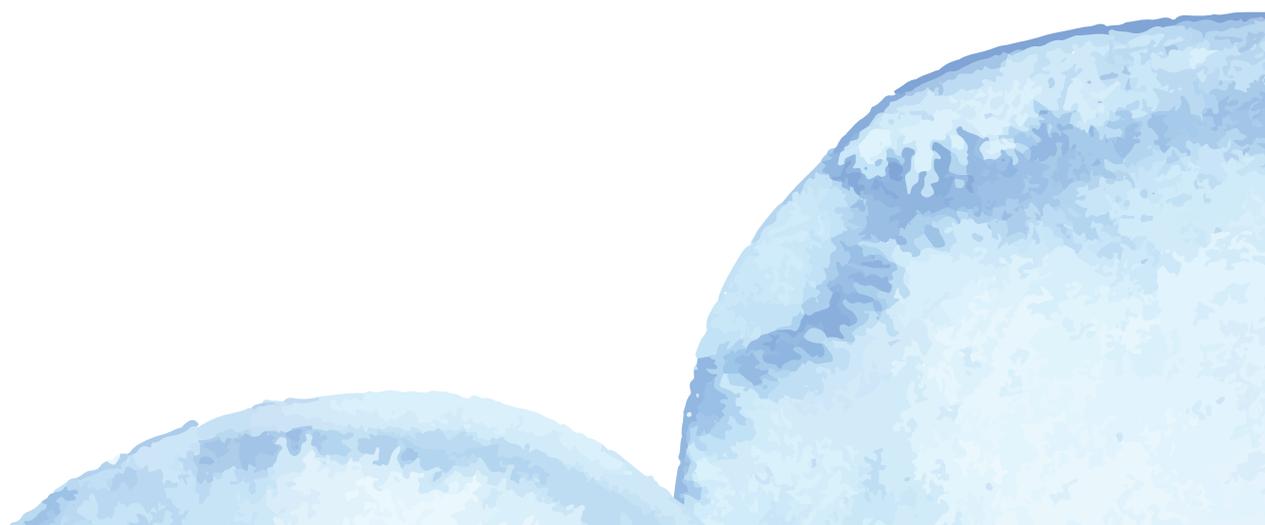
## **We can and must do better.**

In its latest report, *Never Forgotten: The Situation of Stillbirth Around the Globe*, The United Nations Inter-agency Group for Child Mortality Estimation describes the dire situation of stillbirths around

the globe. It makes clear that, to drive change in preventing stillbirths, there must be sound policies and targeted investments along the continuum of care.

From the team of volunteers representing United Nations organizations, donors, academics, professional associations, facility directors, administrators, clinicians, parent organizations and others who have been working on this global stillbirth advocacy and implementation guide, we hope to aid and empower readers to use this guide to inspire the change needed to end preventable stillbirths and ensure respectful and supportive care for every woman and family after stillbirth. By taking immediate action as a global community of champions, we can ensure quality and respectful maternal and newborn care along the continuum of care and make the vision of this guide a reality.

## **We hope you will join us.**



# ACKNOWLEDGEMENTS

## Technical working group

Hannah Blencowe, Susannah Hopkins Leisher, Joolan Saroor, Theresa Shaver, Claire Storey and Aleena Wojcieszek.

## Lead writer

Aleena Wojcieszek

## Parent voice lead

Claire Storey

## Writing team section leads

Bethany Atkins, Hannah Blencowe, Aliko Christou, Alka Dev, Asheber Gaym, Alexander Heazell, Caroline Homer, Susannah Hopkins Leisher, Lucia Hug, Olga Joos, Lennie Kamwendo, Mary Kinney, Tomomi Kitamura, Rebecca Levine, Margaret Murphy, Anne Rerimoi, Francesca Sadler, Theresa Shaver and Aleena Wojcieszek.

## Writing team co-contributors

Neelam Aggarwal, Elena Ateva, Sarah Bar-Zeev, Amy Boldosser-Boesch, Kel Currah, Rakhi Dandona, Alka Dev, Vicki Flenady, Mandy Forrester, Anna Gruending, Gagan Gupta, Tsakane Hlongwane, Bo Jacobsson, Salome Maswime, Lori McDougall, Allisyn Moran, Margaret Murphy, Lyudmila Nepomnyashchiy, Inês Nunes, Monica Oguttu, Robert Pattinson, Emma Sacks, Joolan Saroor, Bharti Sharma, Sue Steen, Claire Storey, Marleen Temmerman and Petra ten Hoop-Bender.

## Case studies

Mohamed Afifi, Neelam Aggarwal, Mamadou Berthé, Billie Bradford, Vicki Flenady, Mandy Forrester, Karima Gholbzouri, Clea Harmer, Marc Harder, Tsakane Hlongwane, Kristi Izod, Diana Jepkosgei, Wanjiru Kihusa, Tomomi Kitamura, Farzana Maruf, Monica Oguttu, Marti Perhach, Neena Raina, Bharti Sharma, Khalid Siddeeg, Ilana Siegal, Modibo Soumaré, Sue Steen and Lorena Suárez-Idueta.

## Advisory committee

Caroline Homer (Burnet Institute); Carole Kenner (Council of International Neonatal Nurses; International Council of Nurses); Bo Jacobsson, Cornélie Martin, Wanda Nicholson, Inês Nunes and Monica Oguttu (International Federation of Gynecology and Obstetrics); Mandy Forrester (International Confederation of Midwives); Fitsum Belay and Anne Rerimoi (International Pediatric Association); Paula Quigley (International Stillbirth Alliance); Lori McDougall (Partnership for Maternal, Newborn and Child Health); Gagan Gupta, Tedbabe Degefie Hailegebriel, Lucia Hug, Tomomi Kitamura and Danzhen You (United Nations Children's Fund [UNICEF]); Sarah Bar-Zeev and Petra ten Hoop-Bender (United Nations Population Fund [UNFPA]); Chandani Anoma Jayathilaka, Allisyn Moran and Neena Raina (World Health Organization [WHO]); Lennie Kamwendo (White Ribbon Alliance); and Mary Ellen Stanton (consultant).

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# ACRONYMS

**CRVS** Civil registration and vital statistics

**EmOC** Emergency obstetric care

**EmONC** Emergency obstetric and newborn care

**ENAP** Every Newborn Action Plan

**EPMM** Ending Preventable Maternal Mortality

**HIC** High-income country

**ICD** International Classification of Diseases

**ICM** International Confederation of Midwives

**IMPROVE** Improving Perinatal Mortality Review and Outcomes Via Education

**ISA** International Stillbirth Alliance

**ISA-SAWG** International Stillbirth Alliance Stillbirth Advocacy Working Group

**LMIC** Low- and middle-income country

**MOH** Ministry of Health

**MPDSR** Maternal perinatal death surveillance and response

**NBCP** National Bereavement Care Pathway

**PMNCH** Partnership for Maternal, Newborn and Child Health

**PVI** Parent Voices Initiative

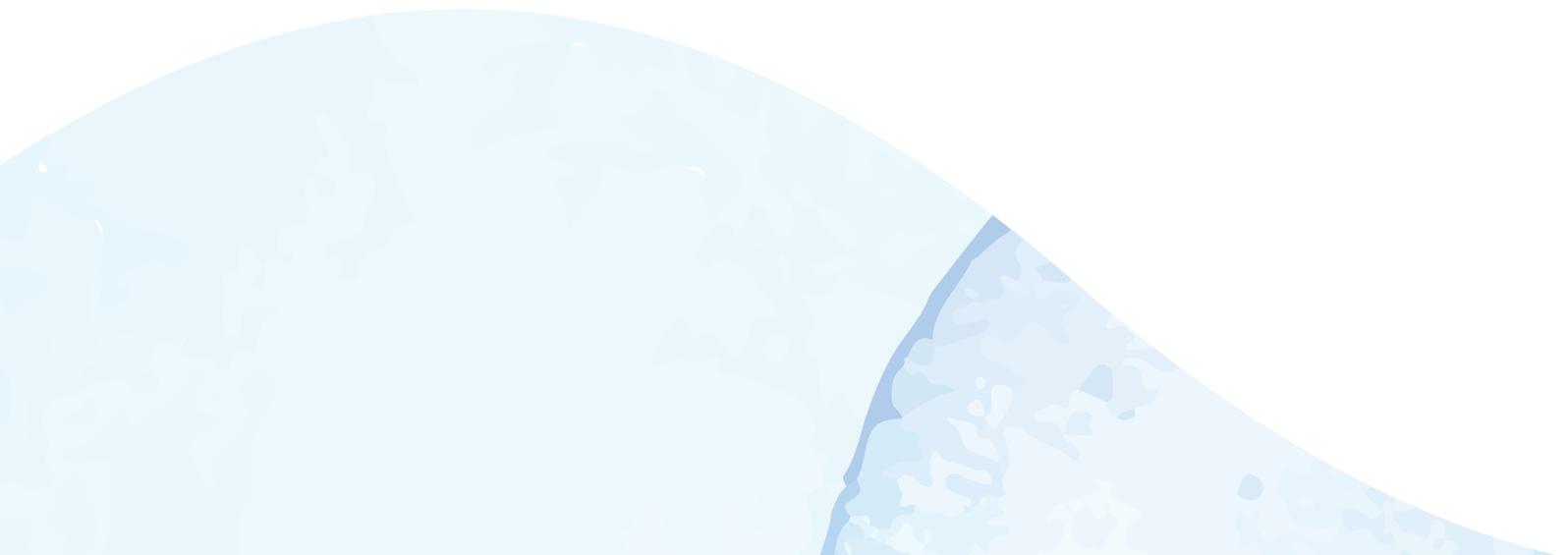
**RMNCAH** Reproductive, maternal, newborn, child and adolescent health

**UN-IGME** United Nations Inter-agency Group for Child Mortality Estimation

**UNFPA** United Nations Population Fund

**UNICEF** United Nations Children's Fund

**WHO** World Health Organization



## USING THIS GUIDE



### Purpose of the guide

This guide is intended to provide technical resources and practical guidance for stillbirth advocacy and programme planning at national and subnational levels. The guide does not present new information but rather brings together existing resources, global guidance and toolkits in one place to inform planning, investments and programmes aimed at ending preventable stillbirths and improving care for all women and families who experience stillbirth. In doing so, gaps in available resources are also highlighted.



### Target audience

The target audience of this guide includes:

- Country-level and subnational governments and stakeholders, including ministries of health, civil registration authorities and national statistics offices.
- Health-professional organizations including national medical, midwifery and nursing associations and other relevant bodies.
- Hospital and health facility directors, managers and administrators.

It is anticipated that the guide will also be useful for parents, parent organizations, community leaders, individual clinicians and others who advocate for stillbirth prevention and respectful and supportive care after stillbirth to be integrated along the continuum of maternal and child health care.



### Stakeholder level definitions

The content in this guide is sometimes aimed at specific stakeholder levels. The following definitions have been used:

- **Policy level:** Includes those who work in ministries or United Nations agencies in-country and make or directly influence policy.
- **Mid-level:** Includes those who work in ministries or United Nations agencies in-country but do not make or directly influence policy.
- **Local level:** Includes those who do not work in ministries or United Nations agencies, whose work is based in communities (villages, cities, towns).



### Types of resources included

Included in this guide are links to global guidelines, toolkits, key initiatives, training resources, data sources and publications about stillbirth and care along the continuum of maternal and child health. Case studies from a wide range of geographical contexts are also included to illustrate what can be achieved.

A colour-coded system has been used to organize specific features of the guide:

- Blue boxes: reflections, definitions of key terms and key data and their sources (the latter presented as “Data highlights”).

- Large lavender boxes: case studies, often presented as “Sharing what works”.
- Green boxes: resource links, presented as “Resources”
- Aqua boxes: links for further information, presented as “Learn more”.
- Orange boxes: content specific to bereavement care.



## Navigating the document

This guide includes hyperlinks to external web resources, as well as internal hyperlinks to specific sections of the guide itself. To return to your place

in the guide when using internal hyperlinks, press *ALT+left arrow* (PC) or *Command+left arrow* (Mac) on your keyboard.



## Feedback and updates

The International Stillbirth Alliance Stillbirth Advocacy Working Group (ISA-SAWG) welcomes feedback on this guide, as well as suggestions for additional resources to be included in future updates, to [sawg@stillbirthalliance.org](mailto:sawg@stillbirthalliance.org).

# 1. BACKGROUND

## The toll of stillbirth

### Stillbirth rates

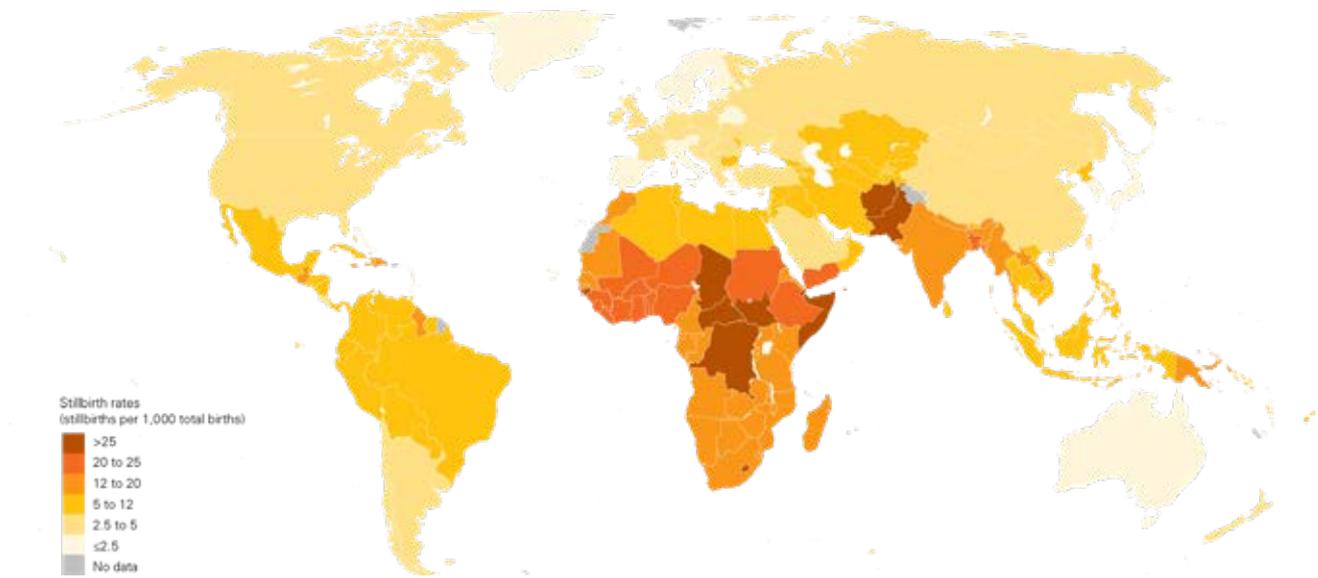
Stillbirth, when a baby dies in the latter stages of pregnancy or during birth, is a devastating pregnancy outcome. One stillbirth occurs every 17 seconds worldwide – equating to around 1.9 million babies stillborn in 2021. These are babies whose mothers and families expected them to be born alive. Over three quarters of stillbirths occur in sub-Saharan Africa and South Asia ([Figure 1.1](#)). Low- and lower-middle-income countries account for 89% of all stillbirths, but only 71% of all live births. Forty-five per cent of all stillbirths occur

after the onset of labour. Many of these stillbirths occur in full-term babies, and they are preventable with equitable access to high-quality pregnancy and childbirth care [\(1\)](#). Over the past two decades, progress in lowering stillbirth rates has not kept pace with achievements in saving mothers' lives, nor with progress in preventing deaths of newborns in the first 28 days after birth. Between 2000 and 2021, the annual rate of reduction in the global stillbirth rate was just 2%, compared with a 2.7% reduction in neonatal mortality (deaths in the first month after birth) and 3.9% among children aged 1 month to 59 months [\(1\)](#). Meanwhile, between 2000 and 2020, the global maternal mortality ratio (MMR) decreased by 2.1% per year [\(2\)](#).

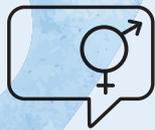
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Nadège Ndi Rose, 20, is in labour in the maternity ward of Saint Luc Hospital, a privately run hospital in the town of Mbalmayo (Cameroon). Two health workers attend to her. Ms. Rose will deliver her fifth premature, stillborn baby. She has never received a prenatal consultation.



**FIGURE 1.1: STILLBIRTH RATES, BY COUNTRY (2021)**

Source: [Never Forgotten: The Situation of Stillbirth Around the Globe](#). Report of the United Nations Inter-agency Group for Child Mortality Estimation, 2022. Note: Map does not reflect a position by UNICEF, or any collaborating organizations on this guide, on the legal status of any country or territory or the delimitation of any frontiers. The most recent national stillbirth rates for 195 countries are available at [www.childmortality.org](http://www.childmortality.org).



### A note on terminology around gender

*This guide recognizes gender diversity among pregnant and birthing individuals. The terms “woman” and “mother” have been used throughout for brevity. The guide is intended to be inclusive of all pregnant and birthing individuals, even though some may not identify as a woman or as a mother (3).*

Stillbirth is an increasingly critical global health problem. In 2000, stillbirths accounted for 23% of all under-5 deaths and stillbirths. By 2021, this figure had increased to 27% (1). In sub-Saharan Africa, the estimated number of stillbirths increased from 765,000 in 2000 to 847,000 in 2021, as the growth in total births outpaced the decline in the region’s stillbirth rate (1). In some high-income countries (HICs), there are more stillbirths than neonatal deaths, and the number of stillbirths surpasses that of even infant deaths (deaths of children from 1 month to 12 months of age).

In 2014, 194 Member States endorsed the [Every Newborn Action Plan](#) (ENAP) (4) at the Sixty-seventh World Health Assembly. The ENAP set a target of 12 or fewer stillbirths per 1,000 total births in every country by 2030. More than 45 countries must more than double their current progress to meet this target (1). ENAP also aimed to close equity gaps, meaning differences in stillbirth rates between the most and least advantaged groups. But few countries – even those with low overall mortality – have made progress in using data and targeted action to close these gaps.

## Emotional and psychological toll

The experience of having a stillborn baby is a life-changing event with extensive and complex psychological, psychosocial and emotional impacts on parents and families (5). For many parents, the unexpected loss of their child – and the care experienced following that loss – affects their approach to life and death, self-esteem and identity (6).



No one ever tells you that you're going to lose all context of yourself. Your life, your identity, your interests, your relationships – everything feels like you're figuring it out again for the first time.” – Alex, mother of stillborn son Robin

Source: [whatsyourgrief.com/loss-of-identity-after-stillbirth](https://whatsyourgrief.com/loss-of-identity-after-stillbirth)

While the mental health impacts of stillbirth vary in severity and manifestation, common emotional themes among bereaved individuals include shock, guilt, blame, a profound need to understand the cause of death and to remember the birth, and irrational and terrifying thoughts (7). Multiple studies show that while these impacts appear to be most frequent and intense in the first few months following stillbirth, there are long-lasting, complex emotional and psychological impacts on birthing women and their partners. These long-lasting impacts include increased psychological morbidity in subsequent pregnancies and increased risk of severe mental health disorders (8).



The loss of my baby changed so many things about me. Telling people was so shameful. People [said] it was my fault that the baby died, and I started blaming myself too, telling myself that I was not careful enough. I went home [from work] everyday crying.” – Oyele, Nigeria

Source: [blogs.unicef.org/evidence-for-action/shrouded-in-silence-the-untold-story-of-stillbirths](https://blogs.unicef.org/evidence-for-action/shrouded-in-silence-the-untold-story-of-stillbirths)

Research also shows that the emotional aftermath of having a stillborn baby is often significantly influenced by social and cultural norms and contexts. In some cultures, stillbirth is perceived as the fault of the woman, resulting in public shaming and future discrimination. In other cultures, stillbirths are not recognized at all or are considered so-called “non-events”, which may considerably impact the capacity of an individual to grieve (9, 10). Studies have also found that, in certain contexts, the cheery, bustling environment of the labour and birthing ward is an extremely painful place for parents and families who have had a stillborn baby, and that well-intentioned attempts of health-care workers to provide comfort often have the opposite effect (11).

While nothing can prevent the pain and grief of having a stillborn baby, the availability of culturally appropriate, person-centred care and psychosocial support may help to reduce the severity, magnitude and duration of its psychological and emotional toll on women and families.



Crystal and LP Nielsen say goodbye to their daughter Aleia Nielsen following her funeral on July 8, 2020. Aleia is their only daughter.

Source: Stacey Fletcher



### What do we mean by culturally appropriate care?

*This guide defines culturally appropriate care as care that is informed by, respectful of and aligned with the woman's particular cultural beliefs and norms, while also adhering to accepted global norms on human rights and respectful maternity care, such as the [International Declaration on Human Rights](#) and the [Respectful Maternity Care Charter](#).*

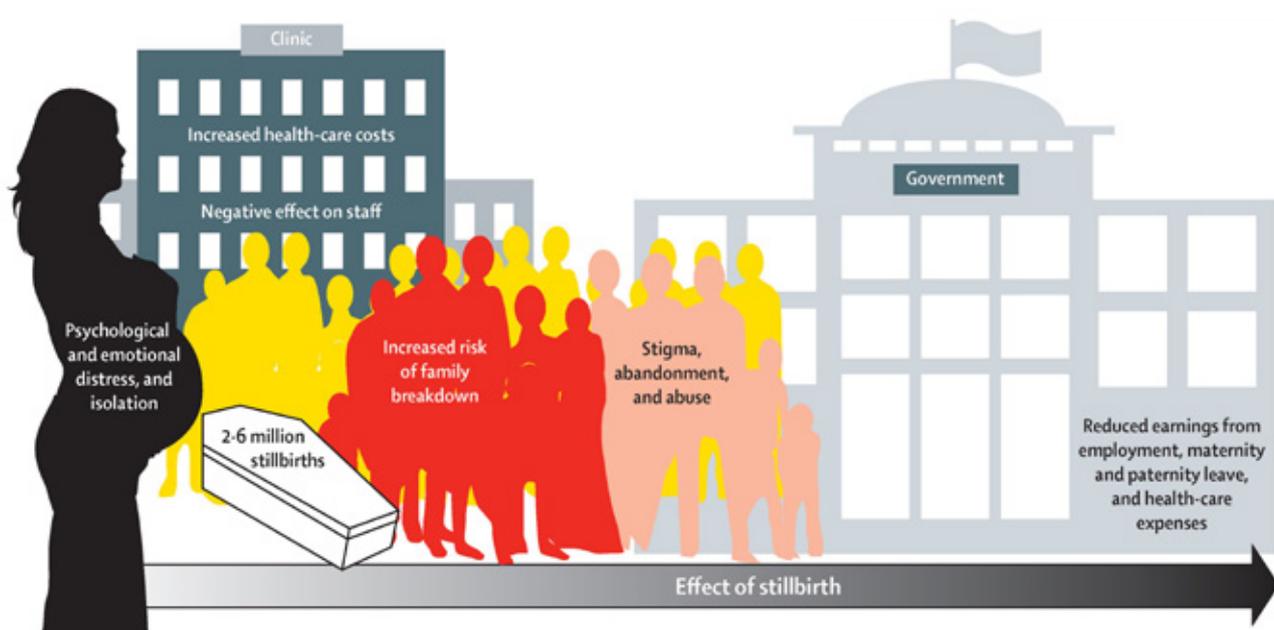
## Financial and societal toll

Estimating the economic and societal toll of stillbirth is challenging, but it is necessary to understand the cost-effectiveness of interventions to prevent stillbirth and to improve care after a baby dies. The losses attributed to stillbirth can be difficult to estimate because they include direct costs (the financial cost of health service use when a baby dies), indirect costs (the cost of loss of

productivity or human resources) and intangible costs (the non-monetary costs that largely reflect the emotional impact of stillbirth) (12). [Figure 1.2](#) depicts the effect of stillbirth including direct, indirect and intangible costs associated with the baby, mother, family, health services, society and governments.

In 2018, Campbell and others estimated the mean direct cost per stillbirth to be £802. Inflated to 2022 values, and converted to US dollars for global comparison, this is approximately US \$1,000 per stillborn baby (13). The direct cost of parental anxiety and depression was approximately US \$820 per stillborn baby (10). Costs of care in subsequent pregnancies varied depending on the cause of the stillbirth, and it was greatest for unexplained stillbirths, approximately US \$5,500 per case (14). In addition to its effect on parents, the death of a baby has a negative impact upon staff, estimated to be US \$900 per case (13).

**FIGURE 1.2: THE EFFECT OF STILLBIRTH ORIGINATING WITH THE DEATH OF THE BABY, AFFECTING MOTHER, FAMILY, HEALTH SERVICES, SOCIETY AND GOVERNMENT**



Source: Reprinted from The Lancet, Vol. 387, Heazell, Siassakos, Blencowe, et al., Stillbirths: economic and psychosocial consequences, pages 604–616, Copyright (2016), with permission from Elsevier. Note. 2.6 million stillbirths each year reflects the estimate at the time of publication of the figure (2016); the 2021 estimate is 1.9 million stillbirths.

A systematic review grouped the intangible costs of stillbirth into eight themes: profound grief, depression, social isolation, relationship issues, sibling issues, return to normality, need for support, and life-changing event (12). These extensive intangible costs are experienced by mothers, as well as fathers/partners, siblings, grandparents and other family members. These intangible costs may lead to financial costs, which are frequently met by parents alone and are likely much greater than the direct and indirect costs.

Few countries provide maternity or paternity leave following stillbirth, leading to loss of earnings or presenteeism (being present at work, but with lowered productivity) (10). Taking the impact of stillbirth into account, the investment required for effective interventions to save babies' lives is reduced to US \$2,143 per life saved, compared with \$3,994 if neonatal deaths are considered alone (10). Capturing all these aspects of the stillbirth burden indicates the large economic cost of stillbirth that is ultimately borne by governments and societies.

## Impact on health-care providers

Health-care providers are at risk of developing professional burnout due to the psychological impact of working through stressful events, including being with women who experience stillbirth (15). For health-care providers, significant negative impacts of caring for families after stillbirth include personal distress, feelings of overwhelm, trying to "hold it together", difficulty concentrating and difficulty returning to work after the event (16-20). Secondary traumatic stress and symptoms of post-traumatic stress disorder have also been reported among health-care providers

attending traumatic births, including stillbirths (21). A study in Kenya and Uganda showed sadness, frustration, guilt and shame were commonly experienced, and health-care providers exhibited blame, fear and negative behaviours such as passing the responsibility of communication with families to others (22). Another study from Papua New Guinea showed health-care providers felt at risk of physical violence from angry relatives after caring for a woman who had a stillborn baby (23).



Any time I care for a woman who has had a stillbirth, it is devastating for the woman and her family but also for me as the caregiver. I have to deal with my own grief and that of the woman and her family, and yet culturally it is not acceptable to grieve in public since the society does not consider the stillborn as a human being..." – Midwife from Malawi

Source: Homer, Malata, ten Hoop-Bender (2016) (24)

However, there is evidence of some positive impacts, especially when health-care providers feel they can provide quality bereavement care. Caring for families can be rewarding when health-care providers are able to connect with families, offer opportunities to create special memories, listen to – and share – grief and make a positive difference (25).

© UNICEF/UNI59991/Nesbitt

A woman unpacks baby clothes and blankets in her home in Lusaka (Zambia). She has just returned following the stillbirth of her baby. She believes her baby was stillborn due to complications related to her diabetes and HIV-positive status.

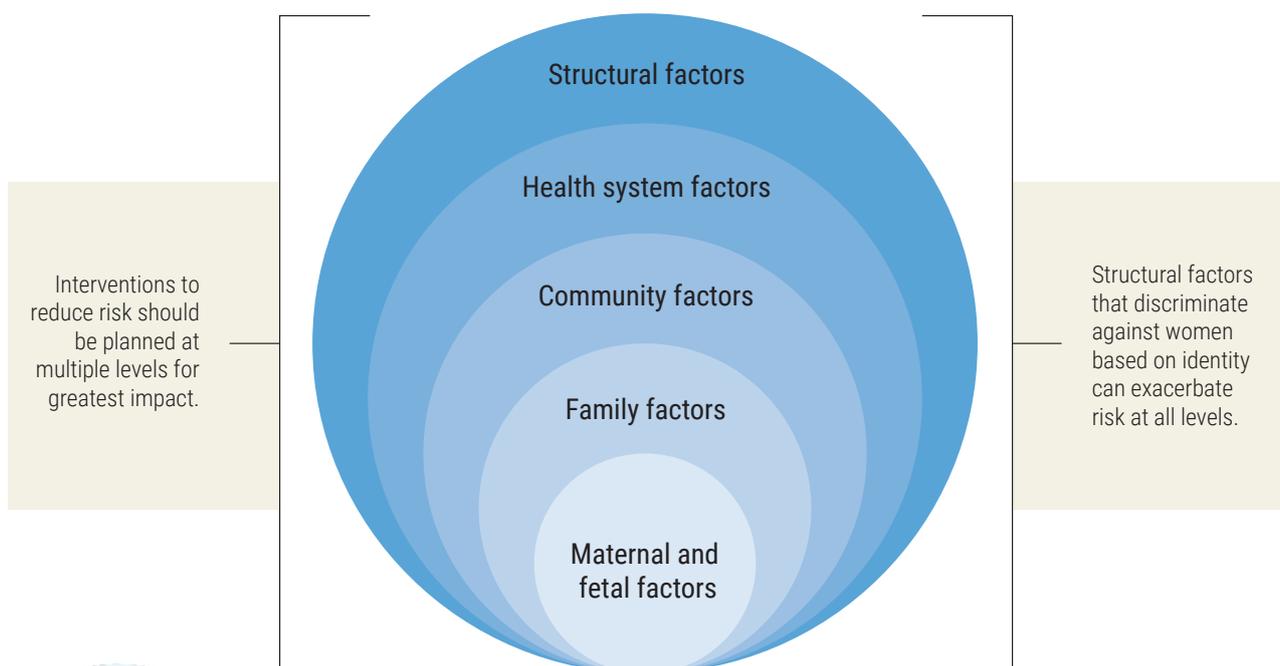


## Underlying risk factors associated with stillbirth

Risk factors are conditions or characteristics that increase a person’s risk or chance of developing a disease, or of experiencing an adverse health outcome such as stillbirth. These risk factors may act directly or indirectly, by increasing the risk of other, more direct causes of death. For instance, infection is a risk factor that can directly cause death, while lack of skilled providers is an indirect risk factor that could contribute to a death. Risk factors for stillbirth commonly increase the risk of other adverse birth outcomes as well, including preterm birth, low birthweight and neonatal death. [Figure 1.3](#) depicts one model of stillbirth risk (called the social ecological model) and the multilayered

risk factors that impact stillbirth, including maternal, family, community, health system and structural risk factors. Examples of specific risk factors are shown in [Table 1.1](#), in accordance with this model. The table provides a list of example risk factors, but it is not exhaustive. It is important to note that such risk factors may interact with one another in complex ways, potentially amplifying risk (26).

**FIGURE 1.3: SOCIAL ECOLOGICAL MODEL OF STILLBIRTH RISK**



**TABLE 1.1:** STILLBIRTH RISK FACTORS ACCORDING TO THE SOCIAL ECOLOGICAL MODEL

Model component	Examples of risk factors
<b>STRUCTURAL RISK FACTORS</b>	
Discrimination and inequity	Based on race, ethnicity, religion, sexual orientation, gender identity or other characteristic
	Denial of services or poor quality of care; lack of respectful care
	Lack of policies protecting reproductive health
<b>HEALTH SYSTEM RISK FACTORS</b>	
Health workforce	Lack of skilled care providers, especially for night shifts and in rural areas
	Lack of initial training and continuing education on risk management
	Poor supervision and accountability
Quality of care	Lack of continuity along the care continuum
	Substandard care factors including (but not limited to) failure of care providers to recognize and manage risk, failure to follow clinical practice guidelines, and poor communication
	No/delayed referral for high-risk pregnancies
	Missing or poor-quality obstetric care during labour and birth
Health infrastructure and supplies	Lack of health infrastructure, such as clean water, electricity, medical supplies
	Poor supply chain for essential supplies such as oxygen and anaesthesia
<b>COMMUNITY RISK FACTORS</b>	
Long travel distance and poor access to care	Lack of specialty care in rural areas
	Long distances, lack of road and transport infrastructure, cost of travel
Unsafe neighbourhoods	High levels of crime, violence and insecurity on the street
Environmental exposures	Lack of clean water and sanitation services; indoor and outdoor air pollution
<b>FAMILY RISK FACTORS</b>	
Family structures and dynamics	Emotional and physical abuse
	Lack of autonomy over health and health-care decision-making
<b>MATERNAL AND FETAL RISK FACTORS</b>	
Financial, emotional and interpersonal stress	Poverty or low income and associated food or housing insecurity
	Lack of social or family support
Remoteness and rurality	Lack of access to transportation
	Lack of access to and availability of emergency obstetric services
Lack of self-efficacy	Low health literacy leading to a poor understanding of health information
Physiological or biomedical	Maternal age 35 years or older
	High body mass index/obesity
	Pre-existing conditions such as hypertensive disorders, malaria, HIV infection
	Poor nutritional intake; substance use such as tobacco, alcohol, opiates
Placental/fetal	Fetal growth restriction; pre-eclampsia/eclampsia; infection
	Antepartum or intrapartum haemorrhage

Note: This list provides examples of risk factors; it is not intended to be exhaustive.

## 2. OPPORTUNITIES TO OVERCOME CHALLENGES IN ADDRESSING STILLBIRTH

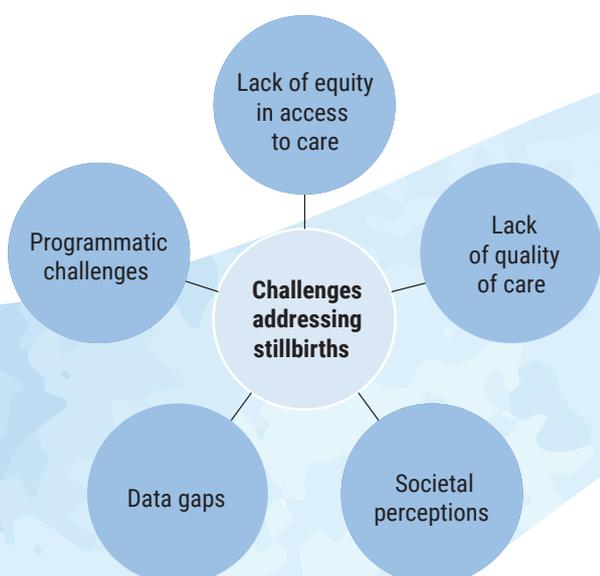
### What are the challenges?

Despite recent progress in including stillbirths in global data tracking for child mortality (1), stillbirths remain hidden in terms of social recognition, investment and programmatic action, due to failures in five broad categories (27): lack of equity in access to care; lack of quality of care; societal perceptions; data gaps; and programmatic challenges (Figure 2.1). These broad categories describe why preventable stillbirths – which can be avoided via the actions of health systems – continue to occur. They also underscore why quality care after stillbirth is often lacking. Examples of specific challenges are shown in Annex 1.

### Lack of equity in access to care

Equity in maternal health means all women have access to – and can utilize – the right care at the right time, regardless of their race, social status, ethnicity, religion, age, sexuality or other individual characteristics. Health-care authorities must take steps to ensure maternal health services are available to all women, and especially those most likely to need them but least likely to use them. These include migrant women, refugees and women and families living in fragile and humanitarian response settings.

**FIGURE 2.1: FRAMEWORK OF THE CHALLENGES IN ADDRESSING STILLBIRTHS**



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In 25 July 2014 in the State of Palestine, Soha Mosleh lies on a cot as she recovers in the maternity ward of Al-Shifa Hospital in Gaza. On the second day of the recent escalation of violence between Israel and Gaza, Ms. Mosleh, who was in her ninth month of pregnancy, left her home in Zeitoun district in search of a safer place to take refuge. "It felt like a stone," she says of vaginal pain she began to experience. Once in hospital, she gave birth to a stillborn baby girl. According to her doctors, the stillbirth was caused by stress the conflict induced.



Poverty devastated me; I had four stillbirths in a row. Most people are illiterate and poor here. They are conservative; they do not allow their women to go for check-ups. But rich women do not face such issues; they have more freedom than us.”

Source: Zakar, Zakar, Mustafa, et al. (woman in Pakistan, 2018) (28)

## Lack of quality of care

The stillbirth rate is a key indicator of quality of care during pregnancy and childbirth.



*Quality of care is defined by WHO as “the extent to which health-care services provided to individuals and patient populations improve desired health outcomes ... health care needs to be safe, effective, timely, efficient, equitable and people-centred” (29).*

Evidence shows that a higher frequency of antenatal visits by women and adolescent girls is associated with a reduced likelihood of stillbirth. This reduced risk is due in large part to increased opportunities for health-care professionals to detect and – together with women – manage potential complications. Compared with four contacts, eight or more contacts for antenatal care can reduce perinatal deaths (stillbirths and newborn deaths) by up to 8 per 1,000 births (30). But there remain many barriers to providing high-quality antenatal care. Barriers to providing quality intrapartum care also exist, and approximately half of all stillbirths result from complications during labour and birth (31). There are many challenges to improving quality of care relating to emotional, informational and system factors such as staffing and funding issues (32).

## Societal perceptions

The significant loss of life due to stillbirth is frequently unrecognized and hidden from view. Common challenges countries and societies face include persisting stigma and taboos that keep stillbirth hidden (33), as well as the limited recognition of and provision for stillbirths within the legal framework in many countries. There is also a need for greater community awareness of the grief and trauma of stillbirth and how to respond to it, as this is a crucial step towards reducing the isolation, grief and stigma that many parents experience (see [Chapter 1](#) and [Suppression of grief: a case study from India](#)).



Our society finds it very difficult to talk about death and finds it very difficult to talk about intense emotion, and the death of a little baby or a child is such a painful and confronting area for people.”

– Deborah de Wilde, volunteer, Stillbirth Foundation Australia

Source: [Senate Select Committee on Stillbirth Research and Education. 2018 Report](#)

## Suppression of grief: a case study from India

Mrs S, a 29-year-old woman, was enjoying her first pregnancy in 2019. In her eighth month of pregnancy, a routine growth scan showed swelling in the baby's head with destruction of brain matter (gross hydrocephalus with very thin cerebral cortex). Both parents were counselled, and the prognosis of the baby was explained. Family support helped Mrs S as she waited for spontaneous labour. After nine months of pregnancy, a beautiful baby boy was born still. Mrs S was asked if she would like to see and hold her baby. The baby had been dressed nicely with head cap in place (to conceal the procedure marks), but Mrs S refused. She asked her obstetrician to take a picture of her baby in case she ever wanted to see the picture in the future. At the time, there was no apparent grief expression.

After the death of their baby, the couple were so distressed that they left their jobs and went abroad, in the hope of escaping painful memories. Mrs S conceived again and gave birth to a healthy baby girl. After almost two and a half years, Mrs S called her previous obstetrician and requested the pictures of her lost son. She shared that, at the time of her son's death, she had been under intense sociocultural pressure to avoid seeing him. Her family had been supportive, but they thought that the baby was a bad omen and that seeing him may bring bad luck for her next pregnancy. When the obstetrician shared the pictures with Mrs S, she started crying. She had not cried over her son until this point, which led to a build-up of self-guilt over the course of her delayed grieving. The obstetrician understood her situation and told her that it's normal to cry. The obstetrician suggested she seek counselling for ongoing support.

## Data gaps

One of the challenges in conducting epidemiological studies of stillbirth – and for developing and implementing evidence-based interventions, training programmes and health policies to reduce stillbirth – has been the lack of precise, high-quality and complete data on stillbirths. Lack of attention to the issue coupled with inadequate funding and human resources have contributed to these gaps. Failure to disaggregate data has led to lost opportunities to prevent stillbirths. For example, without disaggregated data by timing of death, there is no capacity to monitor intrapartum stillbirths, which are largely preventable.

Many stillbirths are not recorded due to social stigma, or where there are no legal requirements to do so. Even where data are available, their use has been frequently hampered by lack of effective communication to the public, national governments, funders, health-care providers and others on the emotional and financial cost of stillbirth (10, 31).

Data are also required to address specific actions to prevent stillbirth and monitor care after death. Data that are already routinely collected to track intrapartum and antenatal care, including content, quality, coverage and equity, could be better used to inform stillbirth prevention. More data are needed to quantify all stillbirth-related direct and indirect costs (see [Chapter 1](#)).

## Programmatic challenges

Programmatic gaps, such as a failure to provide clear local protocols for diagnostic investigation into the causes of stillbirth ([Annex 1](#)), exacerbate challenges in addressing stillbirth. Such gaps may reflect a lack of organizational and political commitment to stillbirth prevention and to providing respectful and supportive care to families after stillbirth, as well as the inaccurate belief that stillbirth is not preventable. Policies and guidance for programmatic approaches to care after stillbirth (including bereavement care and care in subsequent pregnancies) are crucial and require multilevel [leadership](#).

## Opportunities along the continuum of care

The continuum of care refers to the continuity of individual care that is necessary throughout the life cycle, from birth to death and between places of care provision, to ensure survival and good health. It has become a primary focus of efforts to reduce maternal, newborn and child deaths and stillbirths, and to improve quality of care globally ([34, 35](#)). The continuum of care involves provision of comprehensive services, including clinical care, outpatient services and community-based care, provided by midwives, nurses, obstetricians, gynaecologists, paediatricians, neonatologists, general medical practitioners, community health workers, allied health workers and others. It spans adolescence, preconception, pregnancy, childbirth, the postnatal period and the early childhood period, as well as following death – with an emphasis on reducing inequities ([34](#)). Integration between programmes and across stages of the continuum is key to ensuring quality of care so that no woman, baby or child falls through the cracks ([34](#)).

## Guidelines and best practice

Existing guidelines from WHO provide a comprehensive summary of interventions along the continuum of care. While not aimed specifically at stillbirth prevention, many of the recommended interventions for preconception, antenatal and intrapartum care will help to prevent stillbirths. Selected recommendations for postnatal care are applicable for the physical care of women who have given birth to a stillborn baby. **However, there are no dedicated WHO guidelines specific to care after stillbirth.**



### Preconception care

- [WHO Preconception Care to Reduce Maternal and Childhood Mortality and Morbidity \(36\)](#)

### Antenatal care

- [WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience \(30\)](#)

### Intrapartum care

- [WHO Recommendations: Intrapartum Care for a Positive Childbirth Experience \(37\)](#)
- [WHO Managing Complications in Pregnancy and Childbirth: A Guide for Midwives and Doctors – 2nd Edition \(38\)](#)
- [WHO Labour Care Guide: User's Manual \(39\)](#)

### Postnatal care

- [WHO Recommendations on Maternal and Newborn Care for a Positive Postnatal Experience \(3\)](#)

### WHAT YOU CAN DO:

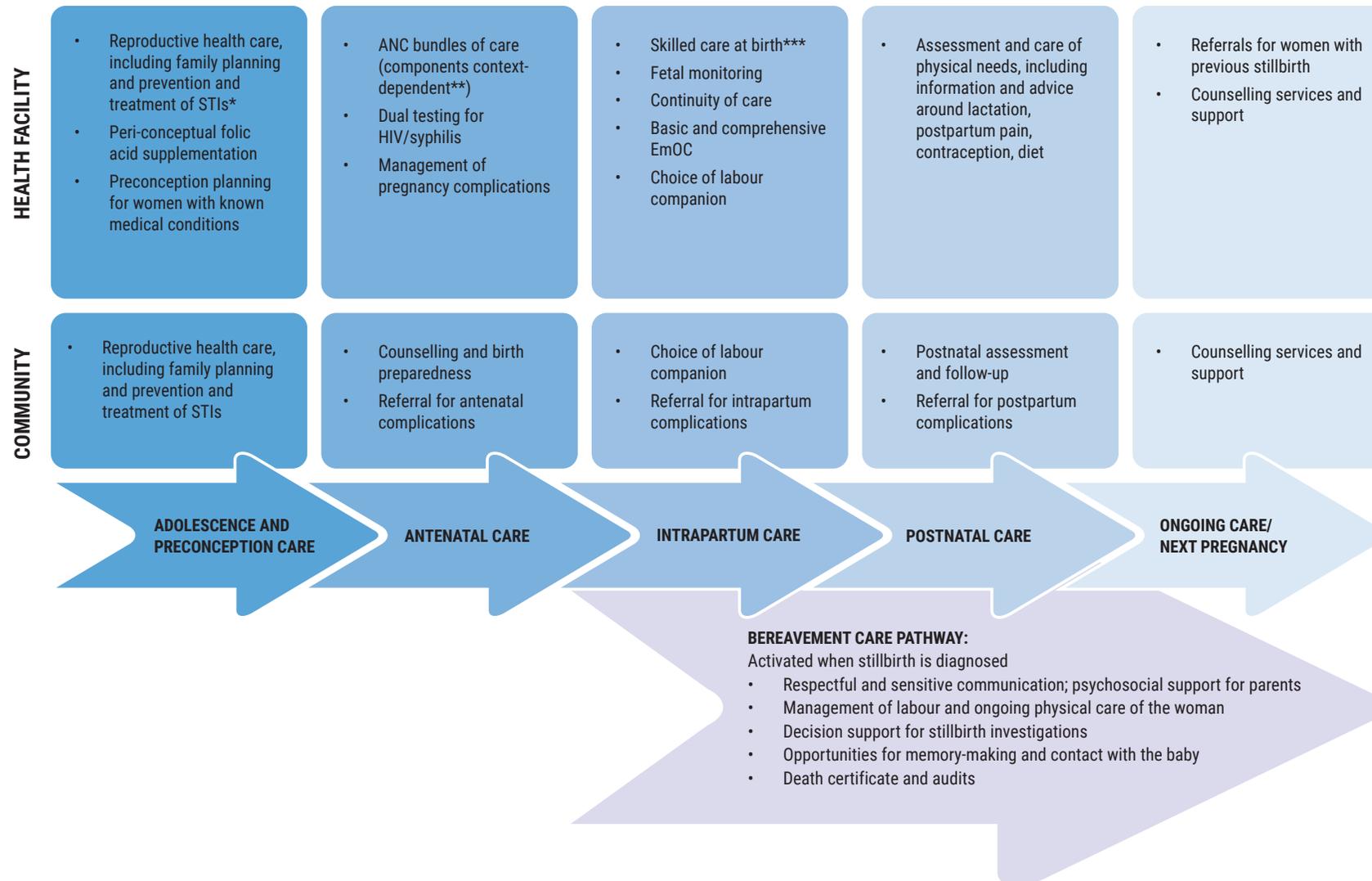
- **Local level:** Ensure access to relevant and up-to-date clinical practice guidelines; implement the recommended interventions.
- **Mid-level:** Link with local politicians to develop a campaign to raise women's awareness of the services to which they are entitled, and to hold government and health-care workers accountable for their performance.
- **Policy level:** Secure funding for implementation and adaptation of guidelines in your setting.
- Take action using the advocacy guidance provided in [Chapter 4](#).

## What about stillbirth, specifically?

Delivered by skilled providers in an enabling environment, the continuum of care approach is critical to stillbirth prevention and care when stillbirth occurs, through improving the health of every woman and every baby. [Figure 2.2](#) shows actions for stillbirth prevention and care at each point along the continuum of care, drawing from existing guidelines and best practice. Essential elements of bereavement care are included, with further detail in [Chapter 3](#).

[Box 2.1](#) outlines essential elements of physical care, which should not be lost in bereavement support, especially as stillbirth is often associated with maternal health conditions. It is critical that physical care of the woman is provided with sensitivity and compassion.

**FIGURE 2.2: THE CONTINUUM OF CARE: ACTIONS FOR STILLBIRTH PREVENTION AND CARE**



ANC: antenatal care; EmOC: emergency obstetric care; STI: sexually transmitted infection

\* Plus other public health measures to improve the general health and well-being of all women of reproductive age.

\*\* May include interventions such as umbilical artery doppler ultrasound screening, maternal smoking cessation and awareness of fetal movements, maternal vaccinations, environmental precautions (such as mosquito netting), informed decision-making around timing of birth, group B streptococcus testing and others.

\*\*\* Includes monitoring of labour progress and maternal status, as per the [WHO Labour Care Guide: User's Manual \(39\)](#).

### BOX 2.1: ESSENTIAL ELEMENTS OF PHYSICAL CARE OF WOMEN AFTER DIAGNOSIS OF STILLBIRTH

#### Labour and birth

- Sensitive shared decision-making on options for timing and mode of birth (vaginal or caesarean birth)
- Discussion of options for pain relief and management of the third stage of labour (for vaginal births)
- Planning for a birthing companion, according to the woman's preferences
- Treatment for any maternal conditions

#### Postnatal care

- Comprehensive postnatal physiological assessment
- Management of postpartum perineal and uterine pain following vaginal birth
- Pain management and wound care following caesarean birth
- Dietary advice and information for preventing constipation
- Lactation management, including lactation suppression where required
- Treatment of breast engorgement and prevention of mastitis
- Comprehensive contraceptive information and services
- Ongoing treatment for any maternal conditions and counselling around subsequent pregnancy planning



© UNICEF/UNI48209/Khemka

A doctor checks Hameeda Abdul, 25, who lies in bed following a Caesarean section at Qatar Hospital in the port city of Karachi. Hameeda's baby was stillborn, and Hameeda almost died due to complications from severe anaemia, low blood pressure and Hepatitis C. This was her eighth pregnancy; she has four surviving children. All her previous deliveries were conducted at home. Doctors said they were lucky to save her life.

## 3. BEREAVEMENT CARE IS ESSENTIAL

Quality, respectful and supportive bereavement care – which spans antenatal, intrapartum and postnatal care – is essential for all bereaved parents and families everywhere. This chapter introduces and defines bereavement care and outlines principles of respectful bereavement care. It also provides links to available guidelines and lists additional considerations for bereavement care, as voiced by parents. More guidance on bereavement care is presented throughout the programme implementation chapter ([Chapter 5](#)), highlighted in orange boxes, as shown below.

For more information and guidance on bereavement care, see [Chapter 5](#).

### What is respectful and supportive bereavement care?

Stillbirth bereavement care encompasses holistic clinical, social and psychological care from the first signs of concern about a baby's well-being through diagnosis, labour and birth and the extended postnatal period. Bereavement care includes care of the woman, partner, baby and family members. Midwives, nurses, obstetricians, community health workers and general practitioners are instrumental in providing bereavement care, alongside support organizations and lay professionals, such as doulas specializing in bereavement.

### Principles of respectful bereavement care

Eight globally applicable principles of bereavement care for women, babies and families have been developed, as follows ([40](#)):

1. Reduce stigma
2. Provide respectful care
3. Support shared, informed decision-making
4. Make every effort to investigate and provide an acceptable explanation for the death of the baby
5. Acknowledge the depth and variety of grief responses and offer support
6. Offer information and postnatal care to address physical, practical and psychological needs
7. Provide information about future pregnancy planning at appropriate time points
8. Enable high-quality care through workforce training and support (see [Chapter 5](#))



Adam and JC Unferdorfer hold their daughter Emmalee. She is their only child and was stillborn on September 30, 2017. Source: Stacey Fletcher

The International Stillbirth Alliance (ISA) Bereavement Working Group is currently working to build on these principles to ensure they fully incorporate the experience and voice of affected parents and health-care providers, especially those from low- and middle-income countries (LMICs).

## Guidelines for bereavement care following stillbirth

Bereavement care guidelines must support culturally appropriate care, recognizing the specific needs of minority and marginalized groups, while ensuring that all parents are given choices. While there are WHO guidelines for care at other stages along the continuum ([Chapter 2](#)), there are currently no global bereavement standards or guidelines. Some HICs have developed national guidelines, and several other guidelines provide relevant advice. Below is an annotated list of these resources in order of publication:

- [WHO: Managing Complications in Pregnancy and Childbirth: A Guided for Midwives and Doctors, 2nd Edition.](#) (2017) (38). This guide addresses care to be provided to a woman and her family at the time of and after stillbirth, with emphasis on emotional need, memory-making, naming, avoidance of sedation of the woman, and arranging a discussion with the woman and her partner about the stillbirth and possible preventive measures for subsequent pregnancies.
- [Sands Australian Principles of Bereavement Care](#) (Australia, 2018) (41). This guide describes 10 bereavement care principles following miscarriage, stillbirth and newborn death: individualized bereavement care; good communication; shared decision-making; recognition of parenthood; acknowledging a partner's and family's grief; acknowledging that grief is individual; awareness of burials, cremations and funerals; ongoing emotional and practical support; health-care professionals trained in bereavement care; health-care professionals with access to self-care.
- [Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death](#) (2020) (42). This guideline includes a dedicated chapter on respectful and supportive care following stillbirth or newborn death. It describes 10 foundations for care and an organizing framework that sets out four overarching goals of care: good communication; shared decision-making; recognition of parenthood; and effective support, including in subsequent pregnancies.
- [Management of Stillbirth](#) (American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine, 2020) (43). This guideline describes the recommended management of stillbirth, including bereavement care principles adapted from the Sands Australia principles of bereavement care.
- [National Bereavement Care Pathway \(NBCP\)](#) (UK, 2022). A parent-led bereavement care plan is recommended for women and their families to provide quality bereavement care following miscarriage, ectopic pregnancy, molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months. The pathway also emphasizes bereavement care training for health-care providers. Read about the development and implementation of the NBCP in [Sharing what works](#) in [Chapter 4](#).
- [National Standards for Bereavement Care](#) (Ireland, 2022) (44). These national standards are built around four central themes related to pregnancy loss and perinatal death: bereavement; the hospital; the baby and parents; and the staff.
- [Parent Voices Initiative toolkits](#) (India/Kenya, 2022). The purpose of the Parent Voices Initiative (PVI) is to raise the voice and participation of parents bereaved by stillbirth to

strengthen advocacy for stillbirth prevention and bereavement support. See [Sharing what works](#).

- [NEST360 UNICEF newborn kit](#) (Kenya, Malawi, India, 2022). Family-centred bereavement care is advocated by NEST360. Family-centred care revolves around a mutual relationship between the family and health-care providers, in the care of a well, sick or dying child.

Across all these documents is a consistent message: the need for effective communication and respectful bereavement care for every woman and family.



### REFLECTION

*The evidence base for best practice bereavement care in LMICs is very limited. Given this fact, what can you do in the short and medium term to improve bereavement care in your setting?*

## Additional considerations

In the absence of global guidelines for bereavement care, action can still be taken to help ensure that women and families receive respectful care after stillbirth. Along with the resources listed in this chapter, recommendations and considerations from affected parents are invaluable. Some of these recommendations and considerations are evidence-based, while others are informal, reflecting insufficient research into bereavement care. All could be incorporated into caregiver training, health facility policy or stillbirth advocacy initiatives. These include:

- **What to say to parents** when they are told their baby has died. See [Box 3.1](#) for a list of suggested phrases, and what not to say.
- The value of parental closure in **seeing, holding and photographing** their baby. Many parents find that creating memories and keepsakes helps in the grieving process.

- The power of **peer-to-peer support** and finding other families who have experienced similar losses. The [ISA Global Registry of Stillbirth Support Organizations and Individuals](#) is a registry of organizations that provide support to those affected by stillbirth. Many local and national support organizations sponsor support meetings at community level. These services could reach even more affected parents with increased awareness and integration into postnatal bereavement care at the facility level.
- The importance of **follow-up care**. Families often experience shock while in the health facility after learning of their baby's death, and they require follow-up care weeks, months or even years later. Referrals and following through with additional resources such as psychiatric care is essential and can be life-saving. Health-care providers need to understand that parents do not quickly "get over" grief, and that women and their partners often require additional emotional and physical support during subsequent pregnancies (see [Box 3.2](#)).
- **Burial, cremation and memorial rituals**. While not universal practices, burial, cremation and memorial rituals are common in some settings and are often of great comfort to families.

Ruthie Mae Unkovic was stillborn on September 16, 2020. Her mother is Rachel Unkovic. Source: Stacey Fletcher



**BOX 3.1: COMMUNICATING WITH PARENTS****What you can say to parents:**

- ✓ "I cannot find your baby's heartbeat. Your baby is not alive. I am sad to say that your baby has died. I am sorry for your loss."
- ✓ "I am saddened by the loss you have to bear. We will do some investigations to try to find out the reasons for your baby's death."
- ✓ "Have you thought of a name for the baby? (if yes) Would you allow me to use that name to talk about your baby?"
- ✓ "Many women have found it helpful to see and hold their stillborn baby after she or he is born. Would you like to do this?"

**What you should never say to parents:**

- ✗ "Do not worry, it was only a girl child."
- ✗ "This happened because you came late for delivery."
- ✗ "At least you know you can get pregnant again."
- ✗ "This baby was sick. It is good that the baby died."
- ✗ "It was your fault: you were late for your check-up."
- ✗ "There might have been something wrong with it."
- ✗ "It's for the best."

Adapted from the Raising Parent Voices Advocacy Toolkit – India Providers' Version

**BOX 3.2: CARE IN SUBSEQUENT PREGNANCIES**

Most women conceive again after having a stillborn baby, often within the following 12 months (45). These women face an increased risk of stillbirth, as well as heightened anxiety, fear and stress during subsequent pregnancies. There is a lack of evidence on how best to provide care to these women and families (46), but consensus on 12 key recommendations has been reached. These recommendations highlight the importance of meeting psychosocial needs and the value of peer support.

Access the consensus statement:

[No. 369-Management of Pregnancy Subsequent to Stillbirth \(47\)](#).

## 4. ADVOCACY

### Introduction to stillbirth advocacy

Ending the tragedy of preventable stillbirths and ensuring respectful and supportive care after stillbirth – including bereavement care and care in subsequent pregnancies – will not happen through programmes and interventions alone; it will require addressing systemic causes, increasing awareness, changing policy and making investments to redress inequities and improve quality of care. This level of change requires advocacy.

This chapter provides a foundation level of knowledge about advocacy plus guidance on the development of advocacy strategies for stillbirth prevention and support. It includes fundamentals of advocacy, how to determine the priorities for stillbirth advocacy and how to build a strategy for stillbirth advocacy. Alongside are case studies, suggested messaging and examples of policy instruments that can be used in building a concrete argument for action. Additional case studies are provided in an [online repository](#). The list of topics addressed in these case studies is presented in [Annex 2](#).

### Fundamentals of advocacy

Advocacy is the process of influencing decision makers to adopt or change policies or other measures to better achieve a desired objective – usually to solve a problem. Advocacy action can range from direct political lobbying to petitions, large rallies and more. An advocate is a person who argues for, recommends or supports that objective through advocacy. Many people engage in advocacy in their work and daily lives, whether it is convincing a health minister to adopt a new programme or to invest in a new area of work, or arguing for better water supply in the local community.

### Types of stillbirth advocacy

For stillbirth prevention and support, there are three main types of advocacy: technical, political and awareness-raising (or “voice”). Each type has a different purpose, requires engagement with different actors and demands different tactics – but all three are needed to make stillbirths important on the political agenda. [Table 4.1](#) describes the types of advocacy, with target audiences, and example tactics and tools to use for each approach. More examples are provided in the [online repository](#).



Wilson Center’s Maternal Health Initiative and the UNFPA for a discussion on the role that midwives play in achieving Universal Health Coverage (UHC). The event will highlight the barriers to UHC, the contribution of midwives to sexual, reproductive, maternal, and newborn health, and strategies to fill the service gaps worldwide. Source: White Ribbon Alliance

**TABLE 4.1:** TYPES OF ADVOCACY WITH TARGET AUDIENCES, EXAMPLE TACTICS AND TOOLS FOR EACH APPROACH

TYPE	AIM	TARGET AUDIENCES	EXAMPLE TACTICS
<b>VOICE</b>	<p>Raise awareness of stillbirth prevention and support; increase demand for action from key stakeholders</p>	<ul style="list-style-type: none"> <li>• Politicians or influencers</li> <li>• Media</li> <li>• Affected parents</li> <li>• Community leaders</li> </ul>	<ul style="list-style-type: none"> <li>• Develop strong, culturally relevant messages to fight stigma and deliver messages through inspiring champions.                             <ul style="list-style-type: none"> <li>→ Use the <a href="#">Parent Voices Initiative advocacy toolkits</a></li> </ul> </li> <li>• Partner with affected parents and leverage their powerful voices to advocate for change. Elevate parents’ voices by creating a platform to share their experience and expertise (op-eds, panels, conversations, meetings with officials). Support parent education and training on advocacy and integrate them into health policy planning and implementation. Facilitate anonymous sharing of stories where required (e.g. via online submissions).                             <ul style="list-style-type: none"> <li>→ Identify parent groups through <a href="#">the Parent Voices Registry</a></li> </ul> </li> </ul>
<b>TECHNICAL</b>	<p>Introduce or improve implementation of a relevant policy or measure – such as including new data points for stillbirths, using data to identify populations with disproportionate stillbirth risk, adjusting health workforce training programmes to incorporate stillbirth awareness</p>	<ul style="list-style-type: none"> <li>• Staff in ministries (such as health, finance, education) and departments of civil registration and statistics)</li> <li>• Local government</li> <li>• Other relevant institutions</li> </ul>	<ul style="list-style-type: none"> <li>• Request a meeting with officials to share data through presentations or briefs.                             <ul style="list-style-type: none"> <li>→ Consider using the UNICEF <a href="#">stillbirth profiles</a></li> </ul> </li> <li>• Suggest possible changes or interventions, such as inviting officials on a learning visit to a clinic that has implemented key measures.                             <ul style="list-style-type: none"> <li>→ Draw from recommendations in the <a href="#">Every Newborn Action Plan (ENAP)</a></li> </ul> </li> <li>• Make an investment case.                             <ul style="list-style-type: none"> <li>→ Build from <a href="#">The Lancet Ending Preventable Stillbirths Series</a></li> </ul> </li> </ul>
<b>POLITICAL</b>	<p>Increase government prioritization of and funding for stillbirths; mobilize the apparatus of government to support action on stillbirth prevention and support</p>	<ul style="list-style-type: none"> <li>• Politicians</li> <li>• Decision makers who set the political agenda or approve budgets</li> </ul>	<ul style="list-style-type: none"> <li>• Present decision makers with evidence of demand for action.                             <ul style="list-style-type: none"> <li>→ Consider using national commitments to <a href="#">Every Women Every Child</a></li> </ul> </li> <li>• Ensure ownership of and accountability to international agreements (such as the <a href="#">ENAP</a> or the <a href="#">Sustainable Development Goals</a>) in relation to the current state of progress at the national level. Clarify that the government is responsible for meeting agreed global targets.                             <ul style="list-style-type: none"> <li>→ Use national strategies and targets relating to stillbirths</li> </ul> </li> </ul>

## Sharing what works

The [UK National Bereavement Care Pathway \(NBCP\)](#) was successfully developed and implemented through key advocacy strategies. Below are the critical steps and how they were achieved:

- **Demonstrate the scale of the problem:** The NBCP core group used reports such as [annual Sands audits](#) to provide evidence of inconsistent and suboptimal bereavement care. Subsequent parent listening events were held, profiling the real stories of parents. Regular data collection points emphasized how many families are affected, and an independent evaluation helped to demonstrate the ongoing needs.
- **Outline the direction of a solution:** The NBCP core group formulated a nationally agreed pathway and gained the support of charities and national professional organizations. Awareness-raising through [Baby Loss Awareness Week](#) and other initiatives kept quality, respectful bereavement care on the agenda.
- **Outline how you can help implement the solution:** [Sands UK](#) offered to chair the NBCP core group, lead on behalf of the collaboration and be the main voice back to the government.

**More information:** The NBCP for pregnancy loss and the death of a baby provides guidance and resources for health-care professionals working with families who have experienced miscarriage, termination for fetal anomaly, stillbirth, neonatal death or the sudden unexpected death of an infant. The pathway has been adopted by over 100 hospital trusts in England and is being piloted in Scotland.

## Priorities for stillbirth advocacy

The priorities and focus of advocacy will depend on the main problems identified, the context, the available resources and other situation-specific factors. However, one framework to help in setting priorities for stillbirth advocacy is [The Lancet Ending Preventable Stillbirths Series](#) call to action (27), presented in [Annex 3](#) and summarized in [Box 4.1](#). This call to action includes targets and milestones to end preventable stillbirths, close equity gaps and improve bereavement support after stillbirth.

#### BOX 4.1: SUMMARY OF THE LANCET ENDING PREVENTABLE STILLBIRTHS SERIES CALL TO ACTION (27)

##### Mortality targets by 2030

- National stillbirth rate: 12 stillbirths or fewer per 1,000 total births in every country
- Equity: All countries set and meet targets to close equity gaps and use data to track stillbirths

##### Universal health care coverage by 2030

- Sexual and reproductive health care: Universal access to services and integration into national strategies and programmes
- Antenatal care: Universal comprehensive quality antenatal care
- Care during labour and birth: Universal effective and respectful intrapartum care

##### Milestones by 2025 (updated)

- Milestones in [Every Newborn Action Plan \(ENAP\) \(4, 48\)](#) and [Ending Preventable Maternal Mortality \(EPMM\) \(49, 50\)](#)
- Respectful care, which includes global consensus on a package of care after death in pregnancy or childbirth
- Reduce stigma: All countries should acknowledge the effect of stillbirths and identify mechanisms to reduce associated stigma

## Guidance for developing an advocacy strategy

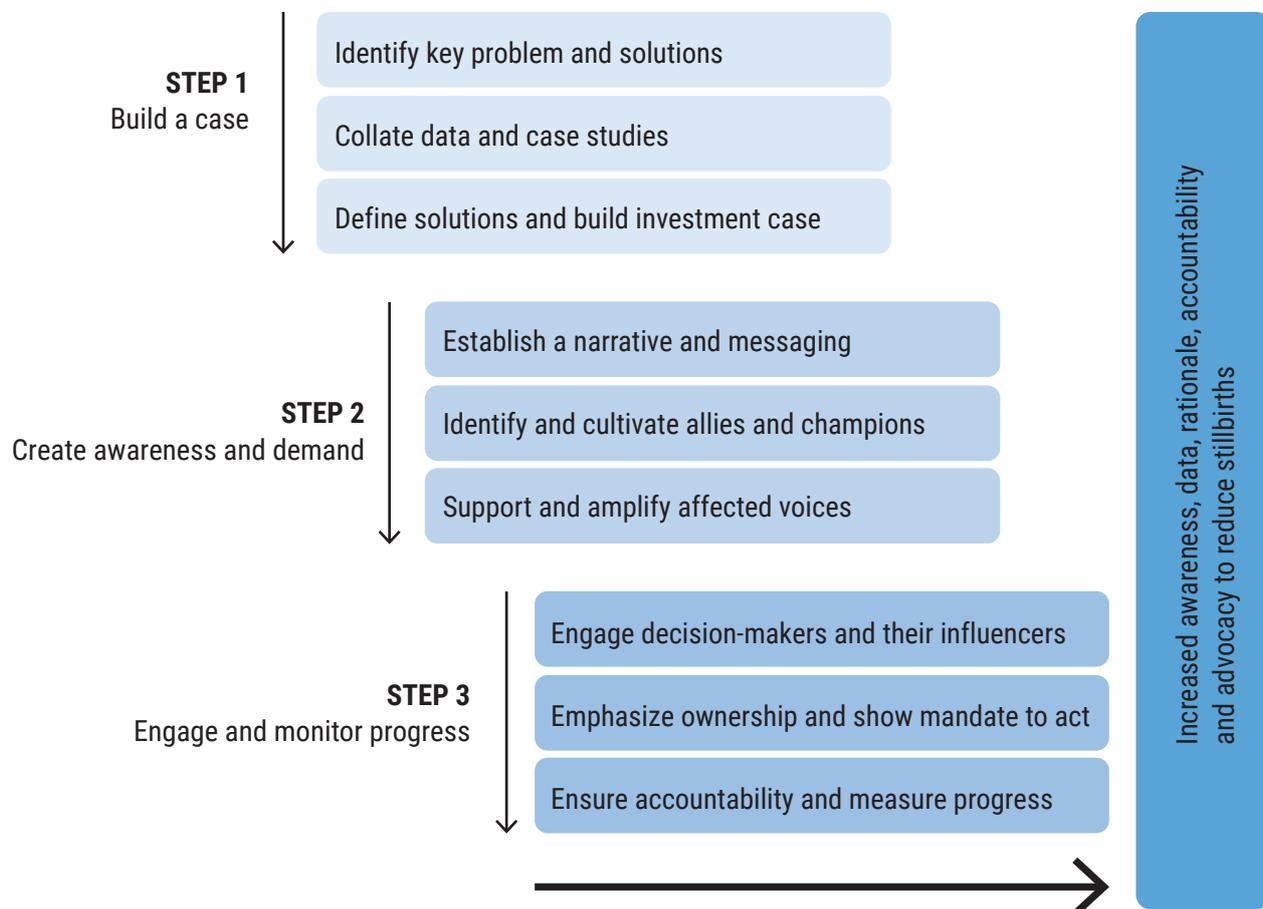
In this section, advocacy is broken down into its component steps, to provide a clear understanding of what goes into making a compelling case for change.

Regardless of the length of the strategy, it is helpful to consider these questions: *What's the problem? What's the solution? Who makes the decisions that can solve the problem? What do these decision makers need to do and by when? How can they be influenced to make it happen?*

Creating an advocacy strategy is an iterative process. Even though the steps are presented here in a specific order, they can be carried out in a different order or done simultaneously. Also, certain steps can be repeated or skipped.

Effective advocacy must build a case, create awareness and demand and engage decision makers and monitor progress ([Figure 4.1](#)). However, as advocacy is an iterative and continuous process, these steps may not be linear. For example, it may be helpful to map actors before building a case, so that actors can help to build the case.

**FIGURE 4.1:** STEPS FOR EFFECTIVE ADVOCACY



Advocacy can also be used to pursue smaller goals, such as obtaining an invitation for a stillbirth parent to speak at a national health conference, as a means of tackling bigger goals, such as adding a stillbirth target to a national health strategy. However, even smaller goals such as this will require funding, including for travel and incidentals, and support for the stillbirth parent (as they address relived trauma).

### Step 1: Build a case

ASK:	ACT:
What is the problem?	Conduct a situation analysis
What is the goal?	Identify key objective(s) for solving the problem
What information is available to explain the problem and build a case for change?	Gather evidence, including collating data and case studies Define solutions that will help support the call for action Build an investment case, including key asks for decision makers

## Identify problems and possible solutions

Stillbirth prevention and support is multifaceted, involving many actors, challenges and opportunities (see [Chapter 2](#)). It can be difficult to identify a single problem to centre an advocacy strategy, as there are likely several interrelated problems. Identify these problems and break them down into smaller, actionable objectives. Setting out which objectives need to be tackled first will help to define the “asks” – the specific actions that the decision makers will need to take. A situation analysis can help.

To carry out a situation analysis, it is important to consider the specific problems in each setting and what information is available. Some issues might be data limitations, lack of awareness about stillbirth, unheard voices of those affected, limited funding allocation and weak strategies to quantify and address the causes of stillbirths.

It is crucial to partner with affected parents in the process of developing a situation analysis and as the key asks are being defined.



Group Work National Dialogue – Pakistan.  
Source: White Ribbon Alliance

## Collate data and case studies

Collating data and case studies involves compiling key data related to the problem identified and analysing and presenting the data in a way that can be understood by – and influence – decision makers. It is helpful to use real-world examples or case studies to illustrate the problem, as data alone are unlikely to lead to action. Politicians and decision makers see large amounts of data every day, so case studies and data must be accompanied by specific asks.



### REFLECTION

*What are the common problems for stillbirth prevention and support in your setting? Do the examples given here apply? Are there others as well? Consider equity: do any of the problems systematically affect any population group(s) more than others?*



### RESOURCES

- [Every Newborn Toolkit](#) Section V: Situation analysis tools: Country examples and lessons learnt (51)
- [ISA webpage on advocacy](#)

### RESOURCES

- [United Nations Inter-agency Group for Child Mortality Estimation \(UN-IGME\) country and regional profiles](#)
- [Guidance for how to develop case studies](#)



## Finalize solutions, build investment case

To define solutions to the problem, the policy opportunities and gaps must be identified. This means understanding a country’s policies and targets related to stillbirths. Global initiatives for stillbirths and newborn deaths can also be used to leverage country and subnational action. There

are two key global initiatives in which stillbirths are embedded:

1. [Every Newborn Action Plan \(ENAP\) \(4, 48\)](#) adopted as a World Health Assembly resolution (WHA 67.10) in 2014, which focuses on ending preventable stillbirths and newborn deaths.
2. [Ending Preventable Maternal Mortality \(EPMM\) \(49, 50\)](#), launched in 2015, which aims to end preventable maternal deaths.

ENAP and EPMM include global and national targets for mortality and coverage (meaning access to quality health care throughout the continuum), as well as recommendations for how countries can reduce mortality and morbidity and close subnational equity gaps with harmonized workplans coordinated by WHO. [Annex 4](#) presents the ENAP and EPMM mortality and coverage targets along with guiding questions to consider in creating an advocacy strategy. In reviewing these global initiatives, ask the following questions:

[Does your country/district/facility have national or subnational stillbirth targets?](#)

- If yes, what are they? Do they align with ENAP and EPMM national and subnational targets? Use the [UN-IGME latest data](#) to determine different scenarios for reaching these targets by 2030.

[Does your country/district/facility have national and subnational maternal and newborn health coverage targets?](#)

- If yes, what are they? Do they align with ENAP and EPMM national and subnational targets?
- If there are no targets for stillbirth, maternal and newborn health, consider incorporating the development of these targets in the advocacy strategy.

[Has your country/district/facility set targets to close equity gaps?](#)

- If yes, what are they? If there are no equity targets, consider incorporating these in the advocacy strategy.

Finally, the solution(s) will also need to address any challenges that could stand in the way of success. It will be important to identify and map objectives to achieve the solutions, and to note possible challenges. If the objectives are very long term, unpack them into subobjectives with more short-term, interim targets.

## RESOURCES

- [The Lancet Ending Preventable Stillbirths Series](#) presents a case for a triple return on investment in stillbirth prevention that also prevents maternal and newborn deaths and improves health outcomes. Find the triple return argument in [The Lancet \(52\)](#).



## Step 2: Create awareness and demand

ASK:	ACT:
How can I explain and share my objectives?	Establish a narrative and develop core messages based on the evidence
Who can address the problem? Who can make the decisions to solve the problem?	Identify and map key targets and audiences (allies and champions) and cultivate them
Who influences them? Who can be a champion?	Undertake a power analysis
How to support and engage affected voices?	Identify and engage champions, including affected families and health workers

### Establish a narrative and messages

Once the problem and advocacy objectives have been identified, it is time to develop advocacy messages that will convey the urgency, extent and impact of the issue.

These messages will highlight the depth of the problem and set the tone of the advocacy initiative. Advocacy strategies often have a single overarching message, along with up to four supporting messages. Possible stillbirth messages – which can be adapted to specific contexts – include:

- **Every stillbirth is a tragedy.** There are an estimated [ADD HERE the latest data before using this guide] stillbirths annually, many of which are preventable, and most of which occur during labour and birth.
- **Stillbirths are overlooked** in many ways – to the detriment of progress, and to the detriment of grieving parents. Stillbirths are undercounted in routine data, and health systems are often not equipped to support bereaved women and families.
- **Women from disadvantaged groups face at least double the risk of stillbirth** when compared with more advantaged groups.

Targeted policies and programmes can help to redress inequities and reduce stillbirths.

- **Progress on reducing stillbirths is too slow,** but our experience shows that it is possible to reduce stillbirths with strong leadership and the right investments.
- **Leaders, policymakers and advocates must urgently seize the opportunity to raise the visibility of stillbirths** and to better integrate stillbirths within women’s and children’s health policies and programmes. These actions have the potential to save millions of lives.
- **At all levels of society, we need increased advocacy and awareness** to confront the harmful taboos and fatalism surrounding stillbirths, to reduce stigma and to ensure that bereaved women and families are supported.

For information on what leaders can do, see the [Leadership](#) section in [Chapter 5](#).



## RESOURCES

- Panel 2: Debunking myths about stillbirths in [deBernis et al. 2016 \(27\)](#) is a useful starting point to help guide messaging about stillbirth facts.
- The [message mapping template, worksheet and checklist](#) created by Agency for Toxic Substances and Disease Registry may help.

### Identify and cultivate allies and champions

When drafting a stillbirth advocacy strategy, it is important to identify the target audience, allies and champions and individuals or groups to be influenced. A power analysis can help in understanding the decision-making and policymaking processes, identify stakeholders involved and define to what extent they can influence the outcome (the changes we would like to see).

To conduct a power analysis, consider three key questions:

- Who can change the current situation? These are *targets* or key individuals who are in a position or have the power to bring about changes.
- Who are the *influencers*? These individuals have some influence on the targets and can use this influence for or against the changes we would like to see.
- What do they care about – what will motivate them to agree to a call to action (the “asks”)?

Key targets for stillbirth advocacy include:

- Senior health policymakers in government and United Nations agencies (decision makers/ influencers)
- Programme officers and senior policymakers in other agencies outside the health sector
- Parliamentarians (focused on budget allocation, accountability, representation)
- Civil society, including affected parent organizations (to encourage outside pressure on government to act)
- Donor agencies
- Non-government organizations
- Professional associations for obstetricians and other doctors, midwives, nurses and other health professionals (to shape guidelines and protocols and work with government to act)
- Media (for evidence-based message dissemination)

[Table 4.2](#) provides examples of advocacy targets and possible tactics.

## RESOURCES

- [Stakeholder power analysis](#)
- [Power analysis briefing](#)



**TABLE 4.2:** IDENTIFYING AND UNDERSTANDING ADVOCACY TARGETS

TARGET	WHO INFLUENCES THEM	WHAT THEY CARE ABOUT	POSSIBLE TACTICS
<b>Ministry official</b>	Department ministers, think tanks and universities, prominent former ministers and staff, donors, development and implementing partners	Creating good policy, strong evidence to justify action	Produce a report co-authored by a leading institution; organize a meeting with health-care professionals and affected parents to present an investment case and solutions
<b>National politician</b>	The media, other legislators, important constituents, regional politicians and peers	Getting re-elected, their image – what the electorate thinks of them	Organize a meeting with other sympathetic legislators; write a letter signed by significant national champions; put an op-ed in the media
<b>Local politician</b>	Community leaders, faith leaders, voters, the media	A vibrant community, re-election	Write an op-ed in the local paper co-authored by a parent and a faith leader

### Support and amplify affected voices

The role of champions – affected parents or prominent people who care about an issue – can be very influential and helpful to the success of an advocacy strategy. This is the case particularly for stillbirths, given the associated strong cultural taboos and stigma. Engaging and supporting a champion to speak out and talk to the target audience directly or through other modes, such as the media, can help raise awareness of the issue and reduce some of the stigma that hampers progress. Politicians are often influenced by real examples of the issue, and messages conveyed

in meetings between champions and decision makers can be very effective. The ISA PVI provides recommendations on how to achieve this (see [Sharing what works](#)).

#### RESOURCES

- [Saving Newborn Lives Champions Toolkit, 2nd edition and Toolkit Forms \(editable\)](#)
- [Raising Parents’ Voices Stillbirth Advocacy Toolkit: Parents’ Version – Kenya](#)
- [Raising Parent Voices Advocacy Toolkit – India Providers’ Version](#)



## Sharing what works

The ISA Parent Voices Initiative (PVI) aims to raise the voice and participation of parents bereaved by stillbirth to strengthen advocacy for stillbirth prevention and bereavement support. Its two advocacy toolkits provide brief, simple advocacy training for stillbirth parent support organizations and health-care workers. In Kenya, the [advocacy toolkit for parents](#) who have experienced stillbirth aims to help parents advocate for themselves and other affected parents among providers, family and friends, and community leaders for quality care. In India, the [advocacy toolkit for health-care providers](#) in health facilities aims to raise their awareness about stillbirths, improve care after stillbirth and foster champions, paving the way for parents to advocate on their own behalf.

## Step 3: Engage and monitor progress

ASK:	ACT:
What is the best tactic or combination of tactics to achieve maximum influence?	Engage decision makers and their influencers  Determine the type of engagement: meetings, forums, reports and papers, petitions, mobilization
What actions need to take place by when to implement these tactics?	Develop an action plan with clear targets and responsibilities; make sure to emphasize ownership and show mandate to act
When are good opportunities to implement tactics?	Set out the timeline – use relevant events, anniversaries and other “hooks” that will help emphasize the objectives
How do we monitor progress and determine next steps?	Document actions through reports, blogs, event summaries, social media reports and feedback to relevant stakeholders

### Engage decision makers and their influencers

The next stage of an advocacy strategy is engaging the decision makers, either directly or through their influencers or issues they care about. Use the investment case together with the increased awareness built through messaging to pressure decision makers to act. [Annex 5](#) presents example activities to engage decision makers and their influencers.

Remember the target: it is key to tailor the “ask” to what the decision maker can do. For example, a health official cannot decide the government’s health budget, which is up to the finance minister. A legislator cannot solve the issue of stillbirths, but they can ask questions of the ministers to push ministries to collect better data or organize a government review of stillbirths.

Once messages are developed, champions identified and tactics defined, put together a messaging grid that identifies the medium

for specific messages. Such platforms might include social media (such as Twitter, Instagram, Facebook), a policy brief or an op-ed in the press ([Table 4.3](#)). Consider the timing of the messages. For example, it may be best to build the case over time, using many steps.

#### RESOURCES



- [Launch Toolkit](#) for The Lancet Ending Preventable Stillbirths Series.
- ISA Stillbirth Advocacy Working Group (ISA-SAWG) **Ending Preventable Stillbirths scorecard** – tracking global progress against The Lancet call to action. See the 2018 scorecard published on pages 88–89 of the [2019 Every Newborn Progress Report \(53\)](#).
- [Joint technical brief](#) on the Stillbirth Situation and Way Forward in the Middle East (read more about how this brief was developed in [Sharing what works](#)).

TABLE 4.3: EXAMPLE OF A MEDIA GRID

OBJECTIVE	AGENT	MESSAGE CONTENT	DELIVERY METHOD	TIMING AND FREQUENCY
<b>Increase awareness and urgency on stillbirth reduction</b>	Affected parents Health-care professionals	Stillbirths are overlooked and progress is slow (include data)	Series of tweets, Instagram posts, Facebook posts, TikTok videos (and/or other social media platforms)	Once – at launch of advocacy strategy
<b>Increase awareness of inequities leading to increased stillbirth risk</b>	Academic institutions Professional organizations	(For example) Stillbirth disproportionately affects families living in rural and remote areas	Reports, infographics, radio or TV interview, social media	Once – at launch of advocacy strategy
<b>Reduce stigma around stillbirth</b>	Affected parents Health-care professionals	We cannot reduce stillbirths if we cannot talk about them	Radio or TV interview, social media, inclusion of parent panels in community and religious events	At launch of advocacy strategy and in the six months leading up to new MOH budget

MOH: Ministry of Health

## Sharing what works

The [WHO Regional Office for the Eastern Mediterranean \(WHO EMRO\)](#), [United Nations Population Fund Arab States Regional Office \(UNFPA ASRO\)](#), [United Nations Children’s Fund \(UNICEF\) Headquarters](#) and [Regional Office for the Middle East and North Africa \(UNICEF MENARO\)](#) have jointly developed the [Technical Brief on Stillbirth Situation and Way Forward](#) to raise voices as one. In the combined regions of the Eastern Mediterranean, Arab States, and the Middle East and North Africa, around 380,000 babies are stillborn every year, with a rate of 19 stillbirths per 1,000 total births, which is higher than the global average of 14 per 1,000 total births. UNICEF Headquarters has contributed with data consolidation and analysis as the countries covered by three organizations in the region are slightly different. Due to the COVID-19 pandemic, virtual meetings and discussions have been held between the three agencies, and a regional webinar was organized by the three agencies to raise awareness of the stillbirth situation, the main challenges and the way forward. The brief is available in English, Arabic and French [on the UNICEF website](#).

## Ensure accountability and measure progress

An advocacy strategy should tell a story. It should show how planned activities will bring about desired changes. Identify these and include milestones to track progress. [Annex 6](#) provides an action plan template. Review this action plan and milestones and set indicators for each objective. Through discussion and feedback on which messages and tactics are working and which are not, the strategy can be improved.

Finally, at the end of the process, take time to evaluate the strategy – the outcomes achieved, effort involved and lessons learned, to help inform the next strategy. Advocacy work is not easy; celebrating even small achievements can keep momentum going and signify that efforts are making a difference.

## RESOURCES



- The [Global Health Advocacy Incubator](#) provides a wide range of advocacy guidance and tools.
- The [Partnership for Maternal, Newborn and Child Health](#) (PMNCH) has mapped various advocacy toolkits – including some specifically for stillbirth – which provide further guidance and ideas for how to do advocacy. See [Annex 7](#).
- The Australian [National Stillbirth Action and Implementation Plan \(54\)](#) is another highly useful resource. (Read about its development in the [online repository](#).)



Honorable Jenister Mhagama, a Parliamentarians Group for Safe Motherhood (PGSM) chairperson – Tanzania. Source: White Ribbon Alliance

## 5. PROGRAMME IMPLEMENTATION ALONG THE CONTINUUM OF CARE



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Awa Sonta sits on a bed at the regional hospital in Djenne District, Mopti Region (Mali). She is recovering from delivery complications that resulted in the stillbirth of her baby. She had experienced three days of painful labour before being taken to a rural health centre in the village of Mougna, 15 kilometres from her home, on a cart pulled by two bulls – the only transportation available. An ambulance then transported her from the health centre to the regional hospital. By the time she arrived, her uterus had ruptured, and the baby had died.

Ending preventable stillbirths and providing respectful and supportive care after stillbirth – including bereavement care and care in subsequent pregnancies – requires implementation of programmes across the continuum of care. This chapter outlines and describes strategies for, and essential elements of, such programme implementation. The chapter is structured around four action areas:

- ACCESS TO CARE
- LEADERSHIP
- INFRASTRUCTURE, EQUIPMENT AND SUPPLIES
- HEALTH WORKFORCE

Additional guidance for bereavement care, which was introduced in [Chapter 3](#), is highlighted throughout this chapter in orange boxes, as shown below. This structure has been adopted to convey the important message that bereavement care is not an optional or additional element, but a crucial component of the continuum of care for families whose baby is stillborn.

Throughout this chapter, look out for more guidance specific to bereavement care as signified by these orange boxes.

### Access to care

To prevent stillbirth, every woman must have access to health care from preconception through to the postnatal period. This requires the removal of physical, socioeconomic and cultural barriers to services. Ensuring access to care will help to achieve a “more than triple return on investment” [\(52\)](#): fewer newborn and maternal deaths, fewer stillbirths and improved child development and lifelong health.

## Six strategies along the full continuum of care

### STRATEGY 1: Strengthen community-based health systems and interventions

Community-based health systems bring services geographically close to women and help to remove other barriers to service.

#### WHAT YOU CAN DO:

- Engage formal and informal community-based providers as key allies in increasing demand for and supply of health services. Include Indigenous midwives, doulas, community health workers, traditional birth attendants, village health volunteers, community-based birth attendants and companions. These providers can help reduce inequities in access to care (55-57).
  - **Local level:** Facilitate communication between health facility staff and community-based health workers.
  - **Policy level:** Where appropriate, explore how to integrate traditional birth attendants into health systems, so they are better equipped to link women with formal health facilities and provide support. [This BMC article \(58\)](#) may help.
- Foster an enabling policy environment to strengthen integration of community-based providers into the health system.
  - **Mid-level:** Meet with community-based providers to learn what blockages stand in the way of their integration into the health system.
  - **Policy level:** Include community-based provider representatives in regular progress reviews and development of new, more inclusive policies. Systematically check in with community-based providers to assess the effectiveness of the improved policies.
- Invest in mobile clinics and outreach services. These services provide crucial links between the community and the health system, particularly in remote areas. See [Sharing what works](#).
- Engage community and religious leaders to foster demand for health care and stillbirth support groups, deliver key health messages and help reduce stigma and misconceptions about stillbirth.
  - **Local level:** Invite leaders to talk about stillbirth on public radio.
  - **Mid-level:** Identify influential leaders and include them in stillbirth prevention campaigns.
- Partner with parents and communities, learning how to collaborate with them, giving them a place at the table and ensuring the necessary power balance to co-produce meaningful, accessible programmes of work and services.

#### LEARN MORE

- Read about [community-based models to improve maternal health outcomes and promote health equity \(59\)](#) in the USA.
- Read about [community-based care to improve maternal, newborn and child health in low-income settings \(60\)](#).
- Review the [Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings \(61\)](#).
- Read [about a study \(62\)](#) demonstrating an example of mobile outreach services for mothers and children in conflict-affected Afghanistan.
- Access the [WHO Guideline on Health Policy and System Support to Optimize Community Health Worker Programmes \(63\)](#).



## Sharing what works

In Kenya, community health volunteers work directly with households in their villages. They identify and refer cases as needed and educate women on services available, including Kenya's [Linda Mama \(Protect a Mother\) programme](#). This programme provides free basic maternity services and has improved health-seeking behaviour during pregnancy and birth.

→ [Read more about Linda Mama](#)

In addition, integrated mobile outreach services serve hard-to-reach communities through public–private and community partnerships, overcoming access barriers including inability to pay for transport and long queues at facilities. These services allow ministries of health and non-governmental organizations to collaborate to expand the reach of both types of partners to meet maternal health targets. Partnerships facilitate a holistic approach by filling service gaps or providing technical assistance where services are limited. Joint work planning is encouraged to ensure well-coordinated outreach. → [Read more about Kenya's mobile outreach services](#).

### STRATEGY 2: Establish clear referral and escalation pathways

Pathways for referral and escalation (for when there is concern about an acute pregnancy complication) are crucial to minimize delays in connecting women with the services they need as quickly as possible. This includes linkages with specialist services that may be outside the scope of midwives' work, as well as transportation to enable implementation of these pathways.

#### WHAT YOU CAN DO:

→ Find out: Does your MOH have a quality of care package? Ensure that it includes a policy for referral and escalation. If not, help to develop one and support its inclusion in the package.

→ Strengthen referral linkages:

- **Local level:** Post, discuss and implement referral guidelines. If you cannot implement them, identify and report bottlenecks.
- **Policy level:** Ensure referral linkages are part of your quality of care policy.

→ Strengthen community-based transportation strategies and systems. Particularly when coupled with mobile-based interventions, these strategies and systems can reduce delays in care-seeking and increase facility-based care (see [Sharing what works](#)).

Asma Begum, a pregnant woman who goes to the hospital for health services–Bangladesh. Source: White Ribbon Alliance.



## Sharing what works

In Kenya, escalation policies are clearly integrated with health services. To reduce delays, most counties are strengthening public–private partnerships and reverse referrals (when the doctor moves to the referring facility for timely management of the complication). Some counties also have inter-facility (public to private) referrals (when the doctor moves with the patient to the new facility if the original facility lacks the necessary supplies or a functional operating theatre).

→ Watch [this short clip](#) and read [this newsletter article](#) for more information.

### STRATEGY 3: Develop a minimum package of health-care messaging for women

Ensuring that women know the services to which they have a right is key to increasing demand, improving quality of care and, ultimately, reducing stillbirths.

#### WHAT YOU CAN DO:

- Identify and integrate key messages into health education and health promotion packages delivered as part of bundles of care or through mHealth (see [Strategy 4](#)).
- Promote a self-care approach by ensuring women know what actions they can take to manage and support their own health (see [Learn more](#)).
- Be sure to integrate stillbirth-specific messages into health messaging. See [“Establish a narrative” in Chapter 4](#).

#### LEARN MORE

- When used appropriately, self-care interventions can increase access to care and improve health outcomes. The [WHO Guideline on Self-Care Interventions for Health and Well-Being, 2022 Revision \(64\)](#) includes self-care in the antenatal, intrapartum and postnatal periods and for family planning.
- The [Safer Baby Bundle](#) is a national initiative to reduce stillbirth rates in Australia. Read about how the Safer Baby Bundle was implemented in a regional Australian hospital in [Sharing what works](#).



## Sharing what works

The [Safer Baby Bundle](#) is a nationwide initiative in Australia incorporating five evidence-based elements to reduce late-gestation stillbirth rates. In Townsville, Australia, one of the greatest challenges the Safer Baby Bundle project team anticipated was relaying the important Safer Baby Bundle health messaging to the wider community. The Townsville Hospital and Health Service covers a very broad geographical area, including regional and remote communities. To ensure that the messaging was clear and consistent throughout the region, the team began with a local launch, including a parent with a lived experience of stillbirth, hospital public affairs and the State health minister. The launch was successful in reaching the wider Townsville community and promoting the Safer Baby Bundle. To aid implementation, the team sourced a TV for the antenatal clinic waiting room, which displayed educational content provided by the [Australian Centre of Research Excellence in Stillbirth](#). Other promotional materials were sourced, including banners, posters and magnets outlining the Safer Baby Bundle care elements. Promotional material was distributed to antenatal clinics and to women and their families. The launch and ongoing promotion of the Safer Baby Bundle created conversations around stillbirth, reducing the stigma of stillbirth and educating women and their extended families on how to reduce their risk.

→ [Read more about the Townsville Safer Baby Bundle launch](#)

### STRATEGY 4: Adopt innovative mHealth strategies to facilitate access to care

Innovative service delivery models including mHealth and other technologies can help to overcome key barriers to accessing care at the community level.



*mHealth is the use of mobile devices to improve population health, for example through delivering health messages, collecting health data, monitoring biomarkers or even delivering health care itself.*

### DATA HIGHLIGHTS

Stillbirth rates are highest among the poorest and most marginalized groups and in the most rural and remote regions (31). Even in HICs, **women from disadvantaged groups face at least double the risk of stillbirth when compared with more advantaged groups (65).**

### WHAT YOU CAN DO:

- Figure out how to integrate mHealth into the care provided in your setting (see [Sharing what works](#)).
- Adapt mHealth to provide information for and reminders to marginalized groups. Partner with leaders to ensure appropriate adaptation for these groups.

## Sharing what works

The Kenya MOH is progressively adopting a digital health platform that connects women with life-saving advice and referrals to care. Women receive reminders via bulk messaging about clinic days, pregnancy danger signs and actions required. These SMS prompts have driven key behaviour changes such as improved antenatal care attendance and uptake of breastfeeding, family planning and infant vaccination. Improved referral and triage of urgent cases has also occurred, connecting women and their babies who face life-threatening illness to the closest well-equipped facility.

### STRATEGY 5: Ask women what they want

Underpinning these first four strategies must be open dialogue with women about their experiences, needs and expectations in accessing care.

#### Bereavement care

Asking women and families what they want is crucial for respectful, supportive bereavement care (see [Sharing what works](#) for a case study related to seeing and holding the stillborn baby).

#### WHAT YOU CAN DO:

- Ensure women are treated as experts in identifying bottlenecks to accessing care as well as possible solutions. One way is to include women in reviews of draft policies.
- Use the White Ribbon Alliance [What Women Want](#) demands to guide priorities for service provision (see [Learn more](#)).
- Include women who have had a stillborn baby or newborn death in identifying ways to ensure access to care. Their voices and experiences can inform improvements to care, including ensuring care is respectful, both during and following death.
- [Contact ISA](#) to connect with women who have experienced stillbirth in your region.

#### LEARN MORE

- The White Ribbon Alliance [What Women Want](#) campaign asked 1.3 million women from over 115 countries to state their demands in relation to quality reproductive and maternal care. Their top five requests were:

1. **Respectful and dignified care**
2. Availability of water, sanitation and hygiene
3. Availability of medicines and equipment
4. Availability of midwives and nurses, and better support for them
5. Close, fully functioning health facilities



## STRATEGY 6: Address unconscious bias in interactions between health-care providers and women

A final key strategy for increasing access to care is addressing implicit bias among health-care providers.

Implicit bias occurs when unconsciously held beliefs and assumptions about race, social status, ethnicity, religion, age, sexuality or other individual characteristics influence one person's judgment of and interactions with another person. These potentially harmful beliefs and assumptions contribute to inequalities in health care that lead to worse health outcomes among specific populations (66). Such biases are not only held by individuals; they are also entrenched within institutions, manifested as institutional policies and practices that can result in lower quality and inadequate uptake of health services (67).

### WHAT YOU CAN DO:

→ Integrate learning about unconscious bias into institutional policies.

- **Local level:** Roleplay with health providers to learn how bias might affect treatment. Discuss your observations. [Introduce training.](#)
- **Mid-level:** Review relevant policies with representatives of marginalized populations to see how policies may inadvertently enable implicit bias. Brainstorm revisions.

### LEARN MORE

- Read about the [law in California](#) that addresses implicit bias in maternity care.



## Sharing what works

In LMICs, seeing or holding a stillborn baby is culturally inappropriate – is this true? An obstetrician's perspective in India.



A mother holds her stillborn baby in PGIMER Chandigarh, India. Her eyes have been concealed on request. Image shared by Bharti Sharma, Consultant WHO SEARO Project, Department of Obstetrics and Gynecology, with permission.

As an obstetrician working in a busy labour room, I never thought seeing or holding a stillborn baby would help a mother in coping. Memory-making in this situation seemed to be inappropriate – something that could exacerbate trauma. But increasing evidence has shown that seeing and holding a stillborn baby can be beneficial for bereaved parents. Due to limited evidence and huge burden in our setting, a stillborn baby is usually wrapped and handed to the family members. Decisions about the stillborn baby and mother are primarily left to the family; mothers are not usually involved. I recently cared for a woman who had a stillborn baby. When we asked the mother and her family directly whether they wanted to see or hold the baby, the family agreed. So, in place of wrapping the stillborn baby with a cloth, the baby was cleaned and dressed properly, as we do for a live born baby. After holding the baby, both parents were content and expressed their gratitude to health-care providers.

Since then, other women have agreed to see and hold, and spend quality time with, their stillborn baby. These mothers have taught me that the grief of a mother following a stillbirth is not country-specific: it is the same worldwide. Contact and quality time with a stillborn baby is powerful, and every parent – no matter where they live – deserves this opportunity. As health-care providers, it is our moral responsibility to provide such opportunities, and to respect the preferences of bereaved parents.

## Leadership

Good leadership fosters and catalyses efforts towards a common goal.



*Leadership brings people and resources together, inspiring and supporting and enabling people to achieve a common goal as a united team. Leadership is about empowering and serving others to a point where people develop an “ownership mindset” (68).*

### What does leadership for stillbirth prevention and support look like?

#### At the community level

Women who experience stillbirth are members of a family and of a community. Leadership at community level is therefore crucial for stillbirth prevention and care.

Community leaders can play an important role in disseminating health messages to community members and community health workers. Doing so empowers communities to demand access to health services and to quality and respectful care.

#### RESOURCE

- The White Ribbon Alliance [Power On: A Toolkit for Community Organizing \(69\)](#) can help guide community level action around health and health rights and respectful maternity care.



#### WHAT YOU CAN DO:

- Identify community leaders to [advocate](#) at various levels of care to ensure that no woman or family are left behind.
- Provide community leaders with health information as it relates to stillbirth prevention and care. See these [Australian Centre of Research Excellence in Stillbirth examples of stillbirth prevention information resources in various languages](#).



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Esther Achieng, the Village Health Team member (VHT) and mobilizer arriving at a homestead in Olibai village and using her megaphone to mobilize mothers and caregivers in the community to gather for the monthly immunization outreach.

- With community leaders, encourage women to attend antenatal care for the health and well-being of themselves and their babies.
- Consider establishing outreach clinics where they are not available (read more in [Access to care](#)).

#### LEARN MORE

- Leadership efforts must reflect an understanding of the structural determinants of health. Read about how [systems thinking helps solve challenges in global health \(70\)](#), including stillbirth.

## At the clinical care level

Mid-level leaders need to ensure appropriate deployment of midwives who are not only competent but also interested in providing quality and respectful midwifery care. Clear and consistent leadership and accountability can contribute to the reduction of stillbirths.

#### WHAT YOU CAN DO:

- Ensure that those caring for women along the continuum are educated, qualified and licensed to provide midwifery care. This requires training, supporting and enabling more midwives.
- Ensure that more experienced staff are always available to support less experienced staff.

#### LEARN MORE

- Increased leadership and accountability can save lives. [Read about the hospital in Zimbabwe \(71\)](#) that showed a reduction in intrapartum stillbirths following deployment of competent midwives and timely caesarean sections.

Effective leadership at the clinical level can facilitate stillbirth surveillance and response, as is done for maternal deaths. This means identification of stillbirth causes, contributing factors and practice changes.

#### WHAT YOU CAN DO:

- Promote collaboration among health-care professionals in maternity units and with women using the services.
- Promote openness among staff in relation to the concerns of parents and families. Give parents the option to be included in review at the health facility level of their baby's death (perinatal mortality review).
- Collaborate with educational institutions for pre-service skills development and continuing or in-service education, where deemed necessary based on surveillance.
- Monitor and evaluate quality of care. Use findings to inform practice change.

#### LEARN MORE

- Leadership should provide continuous and consistent support as well as positive, motivating feedback to health-care workers. [Read more about how investing in midwives and midwifery \(72\)](#) offers a cost-effective approach to reducing stillbirths and improving other maternal and newborn health outcomes.

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A social awareness meeting about maternal death, infant mortality, stillbirth and other health issues is conducted by the Ministry of Health and Family Welfare in Pirganj, Thakurgaon (Bangladesh) on 8 September 2014.

## At the policy level

To have an impact at the policy level, it is valuable to have a designated individual to provide overall leadership in stillbirth prevention and care.

### WHAT YOU CAN DO:

- Use your networks to identify an individual who is knowledgeable on maternal, newborn and child health issues, as well as government and non-governmental politics. This individual should be someone who has the capacity to forge collaborative relationships with local and international organizations, to pull financial and human resources together for greater impact.
- Educate them on your country's or region's stillbirth prevention needs. Brainstorm a list of policy asks for which to advocate.
- Again, ensure parents have a platform to share their stories; these stories can be very powerful in driving action at the policy level. Make sure to engage interested parents beyond storytelling, to help inform policy and practice through their expertise.



### TIP

- A women's health ambassador can sit at the table of policymakers and push for strategies for stillbirth prevention and care.
- Read about the role and impact of the Kyrgyzstan chief midwife in [Sharing what works](#).



### REFLECTION

*Do you know of someone in your region or setting who has pushed for change in women's and children's health? What do you think it would take for them to also push for stillbirth prevention and care?*



Finally, efforts to prevent or reduce the incidence of stillbirths will require advocacy. The designated leader's role is partly to ensure that the voices of advocates are heard. This includes the voices of relevant professional organizations, which represent the health workforce.

### RESOURCE



- This [Advocacy Toolkit for Midwives \(73\)](#), developed by the International Confederation of Midwives (ICM), includes information and guidance on advocating for increased resources for midwives, raising awareness about health issues, increased rights and protections for midwives and more.

### WHAT YOU CAN DO:

- Revisit [Chapter 4](#) for guidance on making an impact at different levels, including at the policy level.
- Use the resources and tips provided in the upcoming section on [Health workforce](#) to guide and support leadership efforts.
- Work to develop clinical care standards for your setting to show key areas for quality improvement. The [Australian Stillbirth Clinical Care Standard \(74\)](#) is one example, which describes 10 quality statements and seven indicators to reduce stillbirth and improve care following stillbirth, including in subsequent pregnancies.

## Sharing what works

In 2016, ICM worked with the Kyrgyz Alliance of Midwives (KAM), the Kyrgyzstan MOH and other stakeholders to introduce the [Midwifery Services Framework](#). Work plans were developed to strengthen midwifery education, regulation and KAM, including the appointment of a chief midwife by the MOH. Asel Orozalieva became the second chief midwife in 2022. The chief midwife promotes and supports midwives and midwifery in Kyrgyzstan by advocating for the profession politically at the level of the MOH of the Kyrgyz Republic. She is visible by her participation in conferences, workshops and seminars held by the MOH and other development partners. As a midwifery leader, the chief midwife has had a positive impact on relationships with development partners and stakeholders. She actively promotes midwives by nominating them for MOH awards. Since the role was introduced, there has been improvement of the regulatory and legal framework of midwives in the Republic. In 2018, the MOH approved competencies for midwives adapted from [ICM Essential Competencies of Midwifery Practice](#). The autonomous practice of midwives has improved in the regions where they independently provide services for the management of pregnancy, as well as childbirth and the postnatal period.

→ Read more about the Midwifery Services Framework in the [Health workforce](#) section at [Models of care](#).

## Bereavement care

Organizational support within a health facility helps to ensure quality of bereavement care by creating the necessary structures, processes and conditions across the health service that facilitate supportive and respectful care. Here is what health facility directors can do:

- Seek out relevant evidence-based policies, protocols and guidelines and make them accessible to all staff.
- Identify local champions to lead on the development and implementation of bereavement support initiatives.
- Advocate for all staff – including students and new graduates – to receive training to deliver best practice perinatal bereavement care.
- Informal and formal support mechanisms such as debriefing should also be available (see [Health workforce](#)). Promote clinical mentoring and supervision to build staff capacity and sustainability for high-quality care.
- Make available dedicated spaces for provision of bereavement care (see [Infrastructure](#)).
- Establish data-collection processes for monitoring quality of bereavement care.
- Establish local partnerships and referral mechanisms in the community (such as parent support groups).
- Identify and work with community leaders such as traditional leaders, women's cooperatives, parent organizations and religious groups.

Sónia Felizberto Camilo, 24 years old, is a mother of twins, Junito and Junior, who are 9 months old. The twins were born at the Ramiane Health Centre (RHC) after the construction of the new water and sanitation facilities. Their older children were born while these facilities did not yet exist and they were two very different experiences.



## Infrastructure, equipment and supplies

Infrastructure, equipment and supplies are required for stillbirth prevention and care. Fully resourcing health facilities to provide quality care along the continuum – including as part of stillbirth prevention and care – requires innovation, education, investment and political will.

### Infrastructure

Infrastructure needs for stillbirth prevention and care include (but are not limited to):

- Roads to facilitate access, referrals and supply delivery
- Electricity for functioning facilities and equipment
- Clean water supply for care provision
- Emergency medical services
- Established referral routes
- Pathology and diagnostic services

Ensuring that the required infrastructure is available requires a dedicated department(s) or organization(s) at the national level to be accountable for identification and prioritization of needs, as well as data collection and planning, implementation and maintenance of the infrastructure itself. The department must also have the authority to coordinate infrastructure needs with other government sectors and non-governmental organizations at national, district and local levels.

#### REFLECTION

*Which government department is accountable for infrastructure needs related to stillbirth prevention in your setting? Is there more than one? How could you connect with someone at this department to plan for improvements?*

#### WHAT YOU CAN DO:

- Collaborate with colleagues to identify local issues with infrastructure, equipment and supplies. [Try this problem-solving tool](#).
- Lobby (if you work at the **local** or **mid-level**) or secure funding (if you work at the **local** or **policy level**) to adopt new tools, technology and delivery strategies to extend the reach of the health service to overcome infrastructure shortcomings. The guidance under [Strategy 4: Adopt innovative mHealth strategies to facilitate access to care](#) in Chapter 4 may help.
- Promote collaboration between the different government ministries responsible for ensuring that stillbirth-related infrastructure needs are met:
  - **Local level:** Invite local authorities to a forum to discuss infrastructure successes and challenges.
  - **Mid-level:** Organize a round table of peers in other ministries to share feasible solutions to challenges in infrastructure provision.

#### RESOURCE

- The [Ethiopia Health Sector Transformation Plan \(75\)](#) describes a five-year strategic plan to ensure the health system provides excellence in health service delivery, quality improvement and assurance, leadership and governance and health system capacity. Seek out and use existing documentation like this to inform infrastructure planning.



## Bereavement care

Key recommendations for the preparation of the physical environment for respectful and supportive bereavement care include identifying a dedicated space for delivering bad news and carrying out all discussions with parents. These spaces should be:

- Private and quiet
- Large enough for extended family/support people to gather
- Where appropriate, free of medical equipment or other materials that could be confronting or upsetting to bereaved parents (balancing emotional needs with any postnatal clinical needs)
- Conducive to unrushed and uninterrupted time for personalized care
- Separated from other families, either in separate rooms or, in low-resource settings, curtained-off areas

## Equipment and supplies

[Table 5.1](#) shows examples of critical equipment and supplies along the continuum of care. Whether it is cataloguing what is missing from this list and identifying bottlenecks or lobbying your peers to budget for availability of these essential supplies, you can take action no matter the level at which you work.

### RESOURCES

- Refer to the [Pregnancy, Childbirth, Postpartum and Newborn Care Guide for Essential Practice](#). Section L, “Equipment, supplies, drugs, and laboratory tests”, contains detailed lists of supplies for antenatal, intrapartum and postnatal care (76).
- The WHO guidelines on [intrapartum \(37\)](#) and [postnatal \(3\)](#) care may also be helpful. These guidelines contain main resource requirements tables with equipment and supply needs for specific interventions.



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Midwife Paulina Chepkumun of Kartita Health Centre III packing baby resuscitating equipment in the maternity ward. “UNICEF mentoring programme has meant a lot for me. I was trained, I now have the skill. I save lives of many babies. I used to try resuscitating a baby for 10 minutes then I would give up. Now I can do up to 40 minutes and the baby gets back to life” she said.

**TABLE 5.1:** CATALOGUING EXAMPLES OF EQUIPMENT AND SUPPLIES NEEDED ALONG THE CONTINUUM OF CARE

WHAT'S NEEDED	WHAT'S AVAILABLE	WHAT'S MISSING
<b>Preconception period</b>		
Comprehensive family planning equipment and supplies		
Supplies to facilitate diagnosis and treatment of non-communicable and sexually transmitted infections		
<b>Antepartum period</b>		
Supplies to enable dual testing for serious infections such as HIV and syphilis		
Prophylactic medications such as iron and folic acid supplementation, calcium and aspirin		
Blood pressure measuring equipment and urine dipstick to identify proteinuria		
Other supplies depending on context and needs, such as mosquito netting, maternal vaccinations		
<b>Intrapartum period</b>		
Equipment for monitoring of maternal and fetal well-being		
Birth kits with sterile cord clamps, bag and mask devices, partograph and neonatal suction tubing		
Vital medications such as antibiotics, IV fluids, synthetic oxytocin and drugs to treat hypertension		
Surgical equipment to facilitate caesarean sections		
<b>Postpartum period</b>		
Supplies and equipment for adequate postnatal physical assessment, including blood pressure cuffs, thermometers, infant weighing scales		
Medications and supplies for pain management, such as oral paracetamol and cooling packs, and life-saving medications such as antibiotics to treat infection		
Supplies for HIV and TB testing and iron supplementation		

HIV: human immunodeficiency virus; IV: intravenous, TB: tuberculosis

## Health workforce

High-quality care is founded on a competent, educated, motivated and well-supported health workforce. Health workforce strategies for stillbirth prevention and care along the continuum of care should cover staffing, training, models of care and support.

### Staffing

#### Along the full continuum of care

Availability of [skilled health personnel \(77\)](#) is key, including midwives, nurses, obstetricians, gynaecologists, paediatricians, anaesthetists, pathologists, allied health workers and others. Midwives are especially critical because they provide many services across the reproductive health and childbirth continuum.

#### RESOURCES

- Investments in nursing and midwifery are vital. [The State of the World's Midwifery 2021 \(78\)](#) highlights a global shortage of sexual, reproductive, maternal, newborn and adolescent health workers – mainly midwives. It outlines critical investments to ensure midwives can achieve their potential. Similarly, [The State of the World's Nursing 2020 \(79\)](#) highlights the case for investment in nursing education, jobs and leadership.
- Investing in midwifery means building an enabling environment. [Building the Enabling Environment for Midwives: A Call to Action for Policymakers \(80\)](#) sets out policies to ensure midwives can perform their full scope of practice with autonomy and accountability, while working in a safe, fair, well-functioning health-care system.

- Critical shortages of surgeons, obstetrician-gynaecologists and anaesthesiologists contribute to inadequate access to and quality of obstetric and surgical care in LMICs (81). The [WHO Global Health Observatory](#) tracks data on the numbers of licensed and qualified surgeons, obstetricians and anaesthetists actively working in countries.
- Bringing health-care workers to rural and remote areas can improve care in underserved settings. The [WHO Guideline on Health Workforce Development, Attraction, Recruitment and Retention in Rural and Remote Areas \(82\)](#) sets out key policies on education, regulation, incentives and support to build the rural and remote health workforce.
- Action in LMICs is a must. [Human Resource Strategies to Improve Newborn Care in Health Facilities in Low- and Middle-income Countries \(83\)](#) provides strategies to better equip health-care workers in LMICs to provide high-quality maternity care through national-level workforce policies.

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Dimple Ghetia is a Nurse practitioner Midwifery works with the midwife led labour room. She has also received supportive training by UNICEF. Location: PDU Civil Hospital, Rajkot, India.



## WHAT YOU CAN DO:

- Use the template in [Annex 8](#) to map relevant policies and recommendations against what is available in your own setting.

## Training

### Along the full continuum of care

All women and babies have the right to respectful and dignified health care, with no disrespect or abuse of women during pregnancy and childbirth. This requires training.



### RESOURCES

- The [RESPECT Toolkit \(84\)](#) includes practical guidance on how to run workshops to train health workers to provide respectful maternity care. These workshops can help health-care workers better understand what is meant by respectful maternity care (see [Box 5.1](#)) and how to respond to challenging practice situations.
- The March of Dimes training programme [Awareness to Action: Dismantling Bias in Maternal and Infant Healthcare](#) offers specific education and training to better recognize and reflect on ingrained, harmful stereotypes and other implicit biases that reduce equitable care. Read more in Chapter 5 at [Strategy 6: Address unconscious bias in interactions between health-care providers and women](#).
- Provision of respectful care can be especially strained in fragile and humanitarian response settings. The Inter-Agency Working Group on Reproductive Health in Crises has developed the brief: [Approaching Implementation of Respectful Maternity Care in Humanitarian Settings \(85\)](#) with useful information and links.

### BOX 5.1: SEVEN RIGHTS OF CHILDBEARING WOMEN FROM THE [RESPECT TOOLKIT \(84\)](#)

1. Be free from harm and ill treatment
2. Information, informed consent and refusal, and respect for her choices and preferences, including companionship during maternity care
3. Privacy and confidentiality
4. Be treated with dignity and respect
5. Equality, freedom from discrimination, equitable care
6. Health care and the highest attainable level of health
7. Liberty, autonomy, self-determination and freedom from coercion

## WHAT YOU CAN DO:

- Consider running a workshop on respectful maternity care in your setting.
- Incorporate implicit bias training and awareness into health provider training curricula.

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Mother, Uyalkan Abibila kyzy and father, Jamshidbek uulu Altynbek with their baby girl Tolgonay in the family yurta (tent), who survived a difficult birth thanks to the skilled intervention of an obstetrician and a midwife trained by UNICEF. Kyrgyzstan



## DATA HIGHLIGHTS

To be effective in stillbirth prevention, care providers must believe that it is possible to reduce stillbirth rates. [The Lancet Ending Preventable Stillbirths Series](#) showed that, even in HICs, **only around one third of care providers agreed with the statement “Many stillbirths are preventable” (65)**. Better education and training may combat providers’ fatalistic views about the inevitability of stillbirth. Success stories can also help reinforce the message that stillbirths can be reduced through improved care.

## WHAT YOU CAN DO:

- Identify a success story from your own setting and share it with colleagues in your network.
- Reach out to your network for success stories from their settings and consider how a similar approach could be implemented where you work.

## During antenatal and intrapartum care

Training and education on effective communication and teamwork is vital to promote and support well-functioning multidisciplinary maternity teams.

## RESOURCES

- [Each Baby Counts + Learn & Support](#) (EBC L&S) aims to improve clinical escalation practices through promoting excellence in teamwork and better communication. Three interventions – Team of the Shift, Teach or Treat and Advice Inform Do (AID) – aim to create a supportive workplace culture, enhance psychological safety among staff and reduce hierarchical decision-making.
- [PROMPT](#) programmes aim to reduce preventable harm to mothers and babies through practical obstetric multi-profession training. Training focuses on enhancing teamwork through improving communication, team roles and leadership and situational awareness.



## Sharing what works

Essential Steps in Managing Obstetric Emergencies (ESMOE) is a skills and simulation drills training programme implemented nationwide in South Africa. It was developed to train obstetricians to combat the high rate of maternal and neonatal morbidity and mortality in prevalent South African conditions. ESMOE aims to improve the quality of care for women suffering from obstetric emergencies, encourage best practice, retain skills and knowledge by building the capacity and confidence of health-care workers and achieve better maternal and neonatal outcomes.

→ [Read more about ESMOE](#)

## WHAT YOU CAN DO:

- Work with colleagues, health administrators and other key decision makers to promote effective communication and teamwork through evidence-based training.
- For specific clinical obstetric skills, implement context-based training sessions and drills (see [Sharing what works](#)).

## During postnatal care

Training to provide supportive and respectful bereavement care following stillbirth remains crucial. Providing sensitive, individualized physiological care and advice, including for lactation management, pain management and wound care, is also imperative.

As part of comprehensive best practice care following stillbirth or neonatal death, the [IMproving Perinatal Mortality Review and Outcomes Via Education \(IMPROVE\) workshop](#) includes training on management of physiological symptoms in the context of post-stillbirth care. Read more about the IMPROVE workshops in [Sharing what works](#).

## Bereavement care

Bereavement care is typically provided by nurses and midwives, especially in inpatient settings. Depending on the particular setting, obstetricians, community health workers and others may also provide bereavement care.

A list of formal bereavement care training programmes is provided in [Resources](#). Such programmes are typically available in high-resourced countries, but it is possible to adapt them for other settings.

## RESOURCES

- [Learn more about IMPROVE eLearning and workshops](#)
- [Read about Resolve Through Sharing Bereavement Training](#)
- [Access the SANDS UK stillbirth and neonatal death support training](#)
- [Visit the UK National Bereavement Care Pathway website](#)



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Kadiatu Sama, who has had no prenatal care and whose child was stillborn, is comforted by a woman nurse in the maternity ward of the government hospital in the southern town of Bo (Sierra Leone).

## Sharing what works

IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) is an interactive workshop providing training in best practice care following stillbirth or neonatal death, developed and run by the [Perinatal Society of Australia and New Zealand](#) and the [Australian Centre of Research Excellence in Stillbirth](#). The workshop is available to all relevant medical, nursing, midwifery and allied health workers (including ultrasonographers, social workers and others). Following a short introductory lecture, small groups of participants rotate around six learning stations – each facilitated by an experienced educator – before completing a formal assessment. The IMPROVE learning stations cover: communicating with parents about perinatal autopsy; autopsy and placental examination; investigation of stillbirths; examination of babies who die in the perinatal period; institutional perinatal mortality audit and classification; and respectful and supportive bereavement care (including breaking bad news and care in subsequent pregnancies). The workshop is aligned with the [Australia and New Zealand Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death](#), but it can be adapted for international contexts with the assistance of ISA. IMPROVE workshops have been run in sites across Australia, as well as in Fiji, Ireland, the Netherlands, Spain, Vancouver and Vietnam.

→ [Learn more about IMPROVE eLearning and workshops](#)

→ Read the [formal evaluation of the IMPROVE workshop by Gardiner and colleagues \(86\)](#)

→ [Contact ISA](#) to enquire about setting up an IMPROVE workshop in your region

Even if you work in a setting where there are no formal bereavement care programmes, components of bereavement care can be implemented with minimal additional resources. These components include sensitive, respectful communication with parents, as outlined in the [Raising Parent Voices Advocacy Toolkit – India Providers' Version](#) (see [Box 3.1](#) and [Sharing what works](#)).

### TIP

- Develop local guidelines for communication, ensuring privacy of parents, enabling space for family and chosen support people, and respectful handling of the baby's body.
- No matter what your setting, offer opportunities to see and hold the stillborn baby and support parents' preferences (revisit [Sharing what works](#)).



## Sharing what works

In Uganda, a 30-year-old woman and her husband came for a 20-week check-up. This couple had suffered a miscarriage before and were notably anxious. They felt that things were not right. After bereavement care training, the nurse knew to listen carefully to what this couple was saying and to acknowledge their fears. She made eye contact with the couple and told them that we would do a thorough exam to see how the baby was progressing. Upon auscultation, no heartbeat was found. The parents began to cry. While she empathized with their pain, the nurse wanted to be truthful, and she told them that the baby had died. The couple continued to cry and she gave them some time alone. The nurse then discussed options about how to birth the baby, as well as other decisions to make. The nurse's training helped her to realize that being actively present, listening to and acknowledging concerns and communicating clearly and respectfully helped both the family and the nurse cope with this most difficult situation. Letting the family grieve, taking time and supporting the couple through decision-making empowered them to be active in caring for their baby. The nurse felt better able to cope knowing that she gave them the best possible care while supporting them as a family.

## Models of care

### During antenatal, intrapartum and postnatal care

Midwife-led continuity of care models – where a primary/named midwife is assigned to every woman from the start of the pregnancy,

coordinating collaboration with other health professionals when necessary (87) – are recommended by WHO from antenatal through to postnatal care in settings with well-functioning midwifery programmes (3, 30, 37). Evidence has shown specifically that women who are cared for under midwife-led continuity models of care are less likely to experience stillbirth and neonatal death (88).

## Sharing what works

In New Zealand, midwife-led continuity of care is the national standard of care with [93.5% of pregnant women booking with a midwife lead maternity carer](#). Midwifery care is publicly funded, largely provided in the community and supported by a nationally agreed referral guideline that ensures access to secondary and tertiary level hospital services when required. Because midwives are embedded in the community, they develop relationships with – and become known and trusted by – not just women, but often their extended families as well.

→ [Read more about continuity of midwifery care in Aotearoa, New Zealand](#)

## DATA HIGHLIGHTS

**Stillbirth rates among Indigenous women in Canada, the USA and Australia are 1.5–2 times higher than their non-Indigenous counterparts (89-91).** But in New Zealand – where midwifery continuity of care is the standard – **rates of stillbirth at 20 weeks’ gestation or more among Māori women are similar to their New Zealand European counterparts (5.50 versus 5.15 per 1,000 births) (92).** These data are not readily explained by variations in social determinants of health, which raises the possibility that midwife-led continuity of care could be mitigating some of the adverse effects of disparity for Indigenous mothers in New Zealand. Read more in [Sharing what works](#).

## WHAT YOU CAN DO:

- If midwife-led continuity of care is feasible in your setting, start by increasing the number and quality of practising midwives in your region. Use the [Midwifery Services Framework](#) to help.
- If midwife-led continuity of care is not feasible in your setting, increase continuity through other care providers to improve quality of care.

## RESOURCES

- The [Midwifery Services Framework](#) serves as a tool to guide countries through the process of developing and strengthening their midwifery services.
- For a quick summary, watch [this video](#) describing the Midwifery Services Framework journey.

## Care in pregnancies subsequent to stillbirth

Specialist services, including multidisciplinary clinics, can offer an individualized approach to care in pregnancies subsequent to stillbirth, with medical and psychosocial care tailored to the unique needs of women and families (93).

## WHAT YOU CAN DO:

- If feasible in your setting, build a case for a dedicated service providing care in pregnancies subsequent to stillbirth. See examples of such services in [Learn more](#).
- If a dedicated service is not available or feasible, invest in training for individual health-care providers for pregnancy-after-loss care. The IMPROVE workshop is one example (revisit [Sharing what works](#) in the [Training](#) section).

## LEARN MORE

- Read about the [Rainbow Clinic](#) at St Mary’s Hospital in Manchester, UK.
- Read about the [Stillbirth and Reproductive Loss \(STAR\)](#) and [Integrated Support After Infant Loss \(iSAIL\)](#) clinics in Melbourne and Sydney, Australia.
- Read about the [Subsequent Pregnancy Program](#) at Sunnybrook Health Sciences Centre in Toronto, Canada.



## Supporting the health workforce

### Along the full continuum of care

Supporting the health workforce requires global recognition of the importance of reproductive, maternal, newborn and child health and its role in shaping society at large.

#### WHAT YOU CAN DO:

- **Advocate** for appropriately respected and remunerated health service roles, with opportunities for continuing development and career progression.
- Carry out public awareness and education initiatives to communicate the importance of reproductive, maternal, newborn and child health and highlight career pathways.

### During antenatal, intrapartum and postnatal care

As described in [Chapter 1](#), the adverse psychological effects of stillbirth are felt by health-care workers as well as women and families (94). Failure to support health-care workers, particularly midwives as those providing social and emotional support to families (24), will exacerbate existing workforce shortages. Specific attention to individuals' well-being is also crucial.

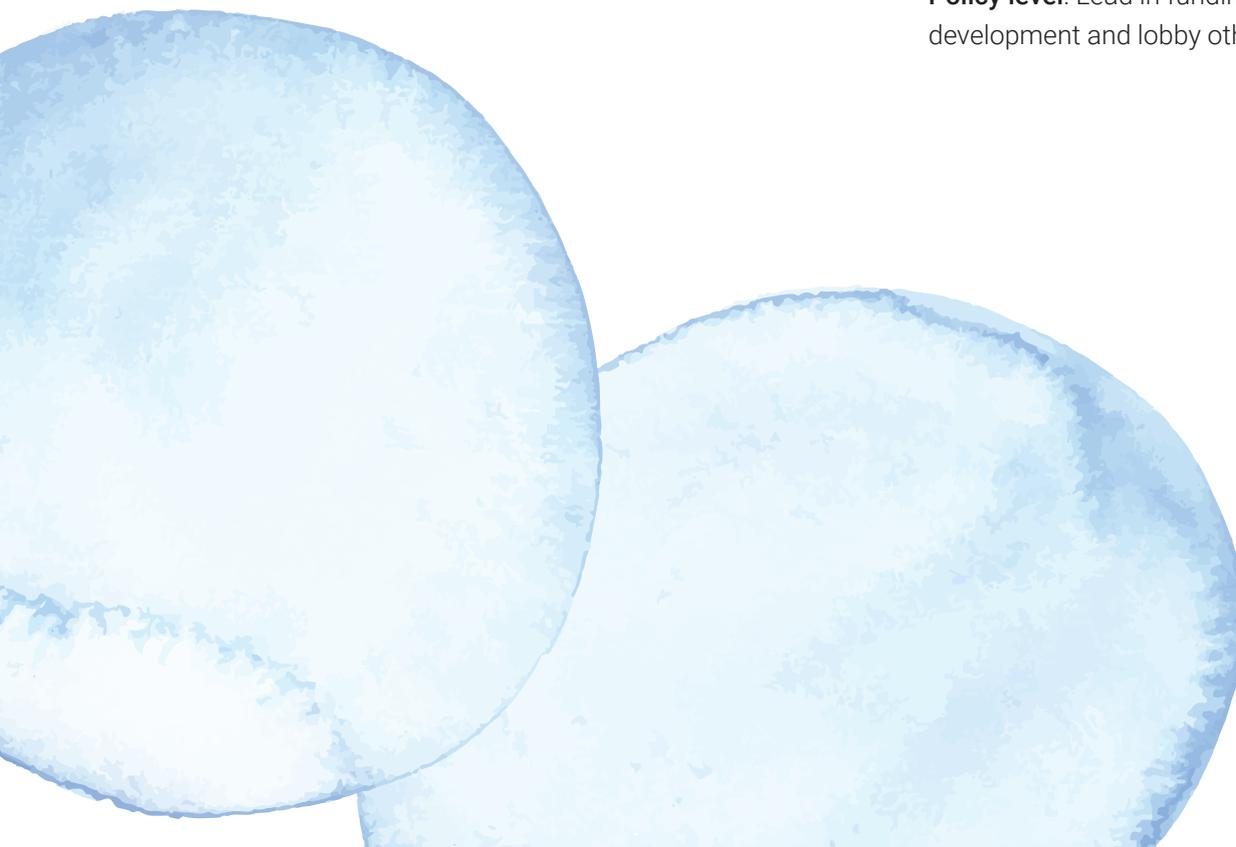
#### WHAT YOU CAN DO:

- Promote a workplace culture that enables and supports self-care through modelling, education and training.

Remember, whatever level you work at and whatever the initiative, you can take action.

Examples include:

- **Local level:** Garner support from colleagues, work with community leaders and engage in formal [advocacy](#).
- **Mid-level:** Contribute to case-making and planning and advocate upward.
- **Policy level:** Lead in funding and policy development and lobby other ministers.



## 6. MEASUREMENT OF PROGRESS

### Where to start

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



#### RESOURCES

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

#### DATA HIGHLIGHTS

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

**There are currently no comparable national and global estimates for causes of stillbirth,** but important causes include pregnancy complications (including maternal conditions such as hypertensive disorders and antepartum haemorrhage) and childbirth complications associated with fetal hypoxia and infection (such as syphilis, malaria and group B streptococcus).

### Tracking progress

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

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

#### RESOURCES

- The [Ending Preventable Newborn Deaths and Stillbirths by 2030 report](#) provides revised ENAP coverage targets for 2020 to 2025 (48).
- Other indicators related to wider maternal newborn health along the continuum, such as antenatal care, skilled birth attendance, and caesarean section rate, are available from [UNICEF](#), [WHO-Global Health Observatory](#) and [Healthy Newborn Network](#).
- See the [Health Equity Assessment Toolkit](#) for more details and resources on equity.
- Countdown to 2030 also produces excellent [country profiles](#) and [equity profiles](#) that can be a useful tool for action.



## Counting stillbirths

Every baby – whether live born or stillborn – should be included in every data system capturing births, with information on the baby's birthweight and gestational age. These data are needed to measure stillbirth rates accurately and track progress towards stillbirth rate reduction targets.

While there are many myths remaining around counting stillbirths (see [Box 6.1](#)), capturing data on stillbirths is possible in all settings (see [Sharing what works](#)). The following section provides information and resources to improve and effectively use these data.

## Sharing what works

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



### REFLECTION

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

### BOX 6.1: BUSTING MYTHS AROUND COUNTING STILLBIRTHS

**✘ MYTH:** There are no standard definitions of stillbirth.

**✔ FACT:** WHO has standard definitions as part of the [International Classification of Diseases \(ICD\)](#).

**✘ MYTH:** It is not possible to capture information on stillbirths in routine data systems in LMIC settings.

**✔ FACT:** Stillbirths can be included in all data systems that capture live births.

**✘ MYTH:** It is not important to count stillbirths.

**✔ FACT:** Stillbirths matter to women and families – and ending preventable stillbirths requires data to target action and track progress. Stillbirth rates are also important markers of access to high-quality antenatal and intrapartum care and are closely linked with maternal mortality and health. Due to substantial misclassification between stillbirths and neonatal deaths, especially around the thresholds of viability, counting stillbirths is also critical to tracking neonatal mortality.

## Definitions and indicators

Standard definitions for stillbirths are included in the [International Classification of Diseases \(ICD-11\)](#):

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

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

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

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

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

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

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

**Total births:** the number of live births plus stillbirths.

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

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

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Deepak Kumar plays a very important role as the data operator at the Special Newborn Care Unit (SNCU) of Prabhawati Hospital, Gaya, Bihar (India). Deepak is responsible for collecting, collating and analysing data he gathers from every case that comes into the SNCU each day, that he translates into hard data used by doctors and staff to respond to cases as need be.



## Collecting actionable data

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

To ensure all relevant data to accurately measure stillbirth rates are collected, WHO recommends a standard minimum perinatal data set to be recorded

by the health system for every birth at the point of care (see Annex 9). Accurate recording of these data, including vital status at the start of labour and at birth, gestational age and birthweight, is essential to correctly classify birth outcomes. “Macerated” and “fresh” skin appearance should not be used to classify the time of death (98). Instead, the time of death assessed by last time of fetal heartbeat or movement should be used for classification.

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

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

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

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

## Using data for action

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

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

## Sharing what works

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

## RESOURCES

### CRVS

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

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

### ROUTINE HEALTH INFORMATION SYSTEMS

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- The UNICEF [Stillbirth Definition and Data Quality Assessment for Health Management Information Systems \(96\)](#) provides practical guidance on data collection, assessing data quality and improving data for action.

### AUDIT AND OTHER RESOURCES

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

## 7. ACHIEVING THE GOAL

This final chapter details the country-level actions needed now, by 2025 and by 2030 to end preventable stillbirths and ensure respectful care for women and families when stillbirth occurs. It concludes by restating the vision of this advocacy and implementation guide, including voices from the field.

### Action needed at the country level

Ending preventable stillbirths does not necessarily require new interventions. Rather, countries need to ensure quality and respectful antenatal and intrapartum care for every woman, child and family, along the continuum of care. This can be achieved through strengthening existing health systems, as described. Strengthening of health systems will also enable scale-up of effective support and bereavement care for all affected by stillbirth, including families of stillborn babies and their carers (1).

### Actions to implement NOW

#### Identify national leaders, champions, allies

While it is possible for a few individual champions to lead and adopt a national stillbirth target in their country, strong and intentional leadership is needed to bring about sustained change for neglected health issues, such as stillbirth (106). Effective stillbirth leadership can facilitate situation analysis, agenda setting and prioritization, and formulation of health policies and guidance (106). These steps provide the required foundations for implementation of interventions and monitoring and evaluation to ensure accountability towards national and global milestones and targets (see Chapter 4).

#### Raise voices

Bereaved parents and families must be supported to bring their voices into policy formulation and actions. This will help to:

- Understand and remove social taboos, stigma and misconceptions that silence families.
- Facilitate opportunities for women and families to demand and receive high-quality, respectful maternity and newborn care including for stillborn babies.
- Ensure families' views are considered in child death reviews.
- Ensure national-level actors, governments and global organizations include stillbirths in relevant reproductive, maternal, newborn, child and adolescent health (RMNCAH) investments, policies and programmes.
- Improve availability and quality of data on the burden of, causes of and risk factors for stillbirths (1).



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Harriet Karij, a 27 year old UNICEF-supported midwife, attends to Monica John in the delivery room at Malakal Teaching Hospital, South Sudan on 26th October 2020. Monica's last two babies tragically died during childbirth so – following abdominal pain a week ago – she decided to come to the hospital's maternity ward where, according to Monica (28 years old), she knew she "would be closely monitored and receive superior care".

## Increase awareness

As described in [Chapter 2](#), stillbirths are often excluded from the public health agenda at the country level. Stigma, taboo and fatalism have contributed to this lack of attention, which has been perpetuated by a lack of accurate, timely data on numbers and causes of stillbirth (1). To increase accountability for stillbirths, data systems must be strengthened in their capacity to collect, analyse and promote the use of timely, quality and disaggregated data, with information on causes of death, risk factors and inequities (1, 27) (see [Chapter 6](#) and [Box 7.1](#)).

### BOX 7.1: ACTIONS FOR DATA SYSTEM STRENGTHENING (1)

- Align stillbirth definitions and measures with international standards
- Integrate stillbirth-specific components within relevant plans for data system strengthening and improvement
- Record stillbirths in all relevant RMNCAH programmes (registers, monthly reporting forms and routine health management information systems)
- Improve health-care workers' skills related to reporting of fetal deaths and perinatal audits
- Provide training and support to include stillbirths within CRVS
- Include information on timing of stillbirth (ante-partum or intra-partum) in all settings and record causes of and contributing factors to stillbirth where possible
- Report and review stillbirth data locally at the facility or district level – together with data on neonatal deaths

## Set the agenda

The [Millennium Development Goals](#) and the [Global Strategy for Women's, Children's and Adolescents' Health \(2016–2030\)](#) (107) show that acceleration of country-level actions for maternal and newborn health is possible (106). Further progress could be achieved by setting clear goals and nationalizing or localizing stillbirth targets (1, 48, 106, 108).

## Formulate policy

The health agenda and prioritized actions must be supported by strong political will and sustained investments at the country level. Countries need to facilitate integration of stillbirths into policies for RMNCAH across the continuum of care, as well as policies for monitoring and data collection linked to strong accountability mechanisms (1, 27).

## Implement programmes

[Table 7.1](#) shows high-impact stillbirth prevention interventions and corresponding WHO guidance along the continuum of care. As 45% of all stillbirths occur during labour, it is vital to improve provision of and access to high-quality intrapartum care for every woman and baby, everywhere (1, 31). Stillbirth and neonatal death must also be considered for country preparedness in fragile settings and during humanitarian crises such as natural disasters, pandemics and conflict (see [Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings](#)) (61).

**TABLE 7.1:** GUIDANCE AND HIGH-IMPACT INTERVENTIONS ALONG THE CONTINUUM OF CARE

CONTINUUM STAGE	WHO GUIDANCE AND HIGH-IMPACT INTERVENTIONS
<b>Adolescent and preconception care</b>	<p><b>WHO guidance:</b> <a href="#">Preconception Care to Reduce Maternal and Childhood Mortality and Morbidity (36)</a></p> <p>High-impact interventions:</p> <ul style="list-style-type: none"> <li>• Family planning and birth spacing (including for adolescents)</li> <li>• Iron and folic acid supplementation</li> <li>• Prevention/testing/management of infectious diseases (such as STIs, HIV)</li> </ul>
<b>Antenatal care</b>	<p><b>WHO guidance:</b> <a href="#">WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience (30)</a></p> <p>High-impact interventions:</p> <ul style="list-style-type: none"> <li>• Antenatal care models with a minimum of eight contacts</li> <li>• Iron and folic acid supplementation</li> <li>• Prevention of infectious diseases (malaria, HIV)</li> <li>• Screening and management of maternal illness and risk factors (GDM, HIV, TB, tobacco and substance use)</li> </ul>
<b>Intrapartum care</b>	<p><b>WHO guidance:</b> <a href="#">WHO Recommendations: Intrapartum Care for a Positive Childbirth Experience (37)</a>, <a href="#">WHO Managing Complications in Pregnancy and Childbirth: A Guide for Midwives and Doctors, 2nd edition (38)</a> and <a href="#">WHO Labour Care Guide: User's Manual (39)</a></p> <p>High-impact interventions:</p> <ul style="list-style-type: none"> <li>• Basic and comprehensive emergency obstetric care</li> <li>• Facility childbirth with a skilled birth attendant</li> <li>• Assessment of fetal well-being on labour admission (Doppler ultrasound device or Pinard fetal stethoscope)</li> <li>• Assisted vaginal delivery and caesarean section for fetal indication</li> <li>• Functional referral systems</li> </ul>

GDM: gestational diabetes mellitus; STI: sexually transmitted infection; TB: tuberculosis

Raising awareness is critical for increasing demand for services, while integration of interventions for stillbirth prevention into community-based and primary health care will aid access to these services.

As addressed in [Chapter 5](#), to provide quality and respectful care, countries must have functional health facilities with adequate infrastructure, equipment and supplies, and round-the-clock referral systems with adequate numbers of

competent health-care providers [\(1, 109\)](#).

Health-care providers need further education and professional support, particularly in relation to psychosocial care and respectful communication with families after stillbirth [\(10\)](#). Health-care providers also need their own support to mitigate the adverse psychological impacts of caring for families experiencing stillbirth (see [Chapter 1](#)).

## Actions to implement by 2025

### Engage communities

Communities can be further mobilized by parents, families and national champions and allies in response to the activities proposed at [Raise voices](#) and [Increase awareness](#). Complacency and fatalism within communities related to pregnancy and childbirth must be addressed, and countries should identify mechanisms to reduce stigma among key stakeholders at the community level **(1)**. Community-based interventions are one method of changing norms and should be piloted for scale-up **(27)**.

### Formulate policy

Ongoing effort is needed to identify, understand and redress inequities through comprehensive situation analyses. In addition to policy formulation to integrate stillbirths into policies for RMNCAH, countries should also develop standards related to stillbirth, including integrating family support and counselling into national health strategies, with reference to the [Principles of respectful bereavement](#) care outlined in [Chapter 3](#).

### Scale up interventions, monitor and evaluate

Monitoring and evaluation of care and services must follow implementation of immediate interventions. The quality of care framework **(108)** and assessment tools describe eight domains of quality of care that should be monitored within the health system. Innovative approaches should also be considered, including digital health interventions. Countries could seek collaboration with professional associations and the private sector to improve the competency of health-care workers and provision of care, as well as with academia to update the research agenda for stillbirth prevention and care, including filling knowledge gaps through research.

## Actions to implement by 2030

### Revise the agenda, reprioritize actions

Based on the outcomes of monitoring, evaluation and ongoing research, health agenda and priority actions should be revised where needed.

### Formulate policy

Countries must ensure that stillbirth prevention is integrated into national health policy. ENAP and EPMM mortality and universal health care coverage targets are key, alongside respectful care and reduction of stigma. Further policies to support parents and families should be considered, including those beyond the health sector. Important areas include paid leave from employment and financial support, such as support for funeral costs **(10)**.

### Implement programmes

Long-term strategies and interventions should be considered, such as integrating stillbirth education and care into pre-service education for health-care workers, social workers and other cadres. Setting up centres of excellence to support mentoring and coaching, detailed death review and genetic counselling could also be considered. A summary of actions is presented in [Table 7.2](#).



**TABLE 7.2:** SUMMARY OF COUNTRY ACTIONS

ACTORS	ACTIONS		
	Now	By 2025	By 2030
<b>GOVERNMENTS</b>	<ul style="list-style-type: none"> <li>Identify national leadership, champions and allies in maternal, newborn and child health</li> <li>Set or review national (and subnational) stillbirth targets</li> <li>Conduct rapid situation analysis on stillbirth programme, policy, guidelines, data system, training, health facility readiness</li> <li>Revise the legal framework for civil registration of stillbirths or reporting to the health sector, and strengthen information systems for capture of stillbirth data</li> <li>Integrate stillbirth into RMNCAH strategy and related working groups</li> <li>Identify key strategies based on the country situation (health facility and health-care workers)</li> </ul>	<ul style="list-style-type: none"> <li>Integrate stillbirth into national health strategy (financing, human resources, quality of care framework, etc.) with a clear target</li> <li>Integrate stillbirth into RMNCAH: supportive supervision, information systems (HMIS, MPDSR, CRVS, surveys), communication framework, guidelines, pre- and in-service training, monitoring and evaluation</li> <li>Strengthen primary-level and community-based services to include stillbirths</li> <li>Seek collaboration with professional associations, academia and the private sector to strengthen competency of service providers and monitoring and evaluation, including research</li> <li>Carry out further situation analysis on equity to identify priority geographical areas and population groups</li> </ul>	<ul style="list-style-type: none"> <li>Ensure stillbirth is being included in all relevant national health policies, strategies, guidelines and training</li> <li>Consider multisectoral support for mothers and families</li> <li>Identify centres of excellence for mentoring, coaching, death review, genetic testing and other core areas for stillbirth prevention and support</li> </ul>
<b>WOMEN, FAMILIES AND COMMUNITIES</b>	<ul style="list-style-type: none"> <li>Raise voices; share knowledge and experience</li> <li>Engage with the health sector to receive essential care along the continuum</li> <li>If not realized, demand high-quality, respectful and equitable maternity and newborn care</li> </ul>	<ul style="list-style-type: none"> <li>Demand high-quality, respectful care closer to home, including community-based interventions</li> <li>Demand support for families and counselling</li> <li>Demand action on reducing inequities</li> </ul>	<ul style="list-style-type: none"> <li>Demand high-quality, respectful care along the continuum and universal health coverage</li> <li>Demand support for women and families beyond the health sector</li> </ul>
<b>SERVICE PROVIDERS</b>	<ul style="list-style-type: none"> <li>Adhere to national guidance on quality and respectful care along the continuum</li> <li>Share information about stillbirth with women, families and communities</li> <li>Participate in pre- and in-service training, including for bereavement care</li> </ul>	<ul style="list-style-type: none"> <li>Collaborate with the MOH, professional associations, academia and the private sector to strengthen competency and share information and lessons learned</li> </ul>	<ul style="list-style-type: none"> <li>Update evidence-based care through refresher training and networking with centres of excellence</li> </ul>

CRVS: civil registration and vital statistics; HMIS: health management information system; MPDSR: maternal perinatal death surveillance and response; RMNCAH: reproductive, maternal, newborn, child and adolescent health

## Progress can be made

Across the world, a stillbirth occurs every 17 seconds. This translates to about 1.9 million babies stillborn every year – and tragically, most of these deaths could have been avoided with high-quality care during the antenatal and intrapartum periods (1).

The ISA-SAWG has a clear vision for “*A world in which preventable stillbirths no longer occur, and care for families and health workers after stillbirths is compassionate, high quality and culturally appropriate*”. This vision aligns well with The Lancet Ending Preventable Stillbirths Series, ENAP, The Lancet Every Newborn Series and the report by UNICEF, WHO, the World Bank Group and the United Nations *Never Forgotten: The Situation of Stillbirth Around the Globe* (1). Providing respectful care and reducing stigma are key components of this vision, as specifically highlighted in the final paper of The Lancet Ending Preventable Stillbirths Series (27). The vision is attainable but will require urgent action with international collaboration.

Presented throughout this guide are the essential components for addressing stillbirth, including: advocacy; programme implementation around access to care, leadership, infrastructure and the health workforce; bereavement care; and data collection, monitoring and evaluation. The guidance includes the voices of women, parent groups and families across the continuum of care.

To capture voices from professionals – including members of the target audience of this guide – a survey was conducted in early September 2022. A total of 178 professionals from seven countries responded, predominately from a global array of organizations including government, intergovernmental and non-governmental organizations, donor agencies, professional organizations, academic and research institutions, public and private facilities and civil society.

Many of the challenges for stillbirth prevention identified from country responses to the survey echo those outlined in previous sections of this advocacy and implementation guide. The survey results show that:

- Health-care workers are not trained in bereavement counselling.
- Excessive workload and major fatigue have been compounded by the COVID-19 pandemic.
- There remains a lack of funding for infrastructure, health system strengthening and delivery of service to rural communities.
- Poor transport to and care on the way to facilities increase the “three delays”: delay in the decision to seek care, delay in arrival at a health facility and delay in the provision of adequate care (110). This also includes the challenges related to financial commitments for follow-up care.
- There remains an overall lack of psychosocial support for health-care providers, women and their families after a baby is stillborn.

The survey results showed a clear need for stillbirth support, including community resources, peer-to-peer support, empathy, grief care, and privacy and confidentiality. The survey participants consistently and clearly identified key country priorities and actions that can be implemented now to address stillbirth (Box 7.2).

The Lancet Ending Preventable Stillbirths Series emphasized that leadership is needed at all levels, but it will be crucial to improve technical skills as well as programmatic data to close quality and equity gaps.

Progress on the hidden tragedy of stillbirth can be made globally, but it must be given greater priority so that we can move forward with clear actions, as highlighted throughout this advocacy and implementation guide.

We know that most stillbirths are preventable, particularly intrapartum stillbirths. As a global community, and with our growing government partnerships, let's ensure evidence and data are widely visible, and that our financial commitments and investments are aligned and linked to accountability at the country and global levels.

The time to act is now! Please see this guide as a tool and work with us to ensure its use as a living document for catalytic change throughout the continuum of care. Together as a global community with learning agendas set by ENAP and EPMM, we work to end these preventable deaths.

#### **BOX 7.2: KEY COUNTRY ACTIONS TO ADDRESS STILLBIRTH, ACCORDING TO SURVEY RESPONDENTS**

- Improve the quality of antenatal and intrapartum care
- Establish policies and procedures for managing stillbirths in health facilities
- Provide accessible and affordable care for family planning and reproductive health
- Provide quality medicines, equipment and services
- Expand primary health care
- Increase capacity for stillbirth audits
- Improve the focus on health-care workers, including midwives
- Better health education and psychosocial support for families



A smiling mother and her baby in India.  
Source: White Ribbon Alliance

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## 9. ANNEXES

<b>Annex 1:</b> Challenges in addressing stillbirth	75
<b>Annex 2:</b> Additional case studies available in online repository	76
<b>Annex 3:</b> The Lancet Ending Preventable Stillbirths Series call to action (updated)	77
<b>Annex 4:</b> ENAP and EPMM mortality and coverage targets	78
<b>Annex 5:</b> Example activities to engage decision makers and their influencers	80
<b>Annex 6:</b> Template for advocacy action plan	81
<b>Annex 7:</b> Advocacy toolkits for women's, children's and adolescents' health	82
<b>Annex 8:</b> Template for mapping of relevant policies and recommendations	84
<b>Annex 9:</b> WHO minimum perinatal data set	85

# ANNEX 1

## CHALLENGES IN ADDRESSING STILLBIRTH

CATEGORY	EXAMPLES OF KEY ISSUES
EQUITY AND ACCESS TO CARE	Triad: low socioeconomic status, illiteracy and inadequate antenatal care
	Wealth inequality
	Discrimination in health care
QUALITY OF CARE	Inadequate information on recommended healthy practices in pregnancy
	Lack of respectful care
	Inaccessible interventions for women's health promotion and disease prevention, screening and timely diagnosis
	Lack of infrastructure and equipment/supplies to provide good-quality care
	Lack of personnel to provide adequate care (such as lack of midwife-led continuity of care, leading to few contacts and potentially poor-quality care)
	Inadequate funding and resources for essential monitoring tools (such as women's handheld or digital notes)
SOCIAL PERCEPTIONS	Lack of bereavement care
	Stigma and ostracism of mothers after a stillbirth (in some regions, women are blamed, mistreated and dishonoured through divorce)
	Hidden mourning practices for stillbirths embedded in diverse cultural contexts (such as where fathers are prevented from grieving)
DATA GAPS	Taboos, fatalism and false beliefs (such as that witchcraft or evil spirits cause stillbirth)
	Failure to consistently include global targets or indicators for stillbirth in post-2015 initiatives
	Limited availability of reliable population-based surveillance data
	Lack of indicators to measure impact and monitor progress
	Lack of data disaggregation, including by timing, cause and for marginalized groups
	Lack of programmatic coverage indicators
	Lack of accurate measurement of stillbirths, including omission of events and misclassification between stillbirths and early neonatal deaths
Inconsistent classification – stillbirth definitions vary across settings and over time, limiting comparability for the assessment of accurate data	
PROGRAMMATIC CHALLENGES	Lack of implementing policies/guidance on stillbirths
	Insufficient training of the workforce on appropriate management guidelines
	Insufficiently organized and structured methodology for stillbirth investigations
	Failure to guarantee specialized personnel are included in management policies (such as failure to guarantee that trained pathologists – including trained placental pathologists – carry out the appropriate diagnostic investigations/examinations)

## ANNEX 2

# ADDITIONAL CASE STUDIES AVAILABLE IN ONLINE REPOSITORY

View the online repository at:

[www.stillbirthalliance.org/global-guide](http://www.stillbirthalliance.org/global-guide)

### Advocacy

- Technical advocacy: prioritization of stillbirth prevention at the national level

**Uganda**

- Political advocacy: how legislators can help after stillbirth

**USA**

- Awareness-raising or voice advocacy: Still A Mum

**Kenya**

- Still A Mum Parent Voices Initiative

**Kenya**

- Establishment of the Centre of Research Excellence in Stillbirth

**Australia**

- Advocacy and implementation support to address stillbirth

**Afghanistan**

- Group B Strep International

**USA**

### Programme implementation

- Screening for placental insufficiency in low-risk pregnant women

**South Africa**

- Strengthening antenatal care through antenatal care checklists

**South Africa**

- CLEVER Maternity Care

**South Africa**

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

### Measurement of progress

- Using data to reduce preventable deaths of babies and children

**Mexico**

# ANNEX 3

## THE LANCET *ENDING PREVENTABLE STILLBIRTHS* SERIES CALL TO ACTION

(UPDATED)

### MORTALITY TARGETS BY 2030

- National stillbirth rate: 12 stillbirths or fewer per 1,000 total births in every country
- Equity: All countries set and meet targets to close equity gaps and use data to track stillbirths

### UNIVERSAL HEALTH CARE COVERAGE BY 2030

- Sexual and reproductive health care: Universal access to services and integration into national strategies and programmes
- Antenatal care: Universal comprehensive quality antenatal care
- Care during labour and birth: Universal effective and respectful intrapartum care including: high-quality intrapartum monitoring; timely and appropriate obstetric interventions, including caesarean section; and adequate, context-appropriate clinical and respectful management of stillbirth

### MILESTONES BY 2025 (UPDATED)

- Milestones in the [Every Newborn Action Plan \(ENAP\)](#) and [Ending Preventable Maternal Mortality \(EPMM\)](#)
- Respectful care, which includes global consensus on a package of care after death in pregnancy or childbirth (of a mother, newborn or stillborn baby) for the affected family, community and caregiver in all settings
- Reduce stigma: All countries should acknowledge the effect of stillbirths and identify mechanisms to reduce associated stigma for all stakeholders, including health workers and communities

Meeting these targets will require that the global health community, country leaders and individuals collaborate more effectively in support of:

- Deliberate leadership at global and country levels, especially from policymakers
- Increased voice, especially of women, to break the silence and reduce stigma and taboo surrounding stillbirths
- Implementation of integrated interventions across the maternal and child health continuum, with investment that is commensurate with the scale of the global burden of stillbirth
- Definition and use of indicators to measure progress and quality of care
- Investigation of gaps in knowledge on stillbirth prevention and bereavement support

# ANNEX 4

## ENAP AND EPMM MORTALITY AND COVERAGE TARGETS

TARGET	ENAP	EPMM
<b>MORTALITY TARGETS TO 2030</b>	<p>All countries to have 12 or fewer stillbirths per 1,000 total births and to continue to improve equity</p> <p>All countries to have 12 or fewer newborn deaths per 1,000 live births and to continue to reduce death and disability, ensuring that no newborn is left behind (SDG 3.2 target)</p>	<p>The global MMR to be reduced to less than 70 per 100,000 live births, with no country having an MMR more than 140 per 100,000 live births (SDG 3.1 target)</p>
<b>GLOBAL COVERAGE TARGETS TO 2025</b>	<p><b>Care in pregnancy</b> 90% global coverage of four or more antenatal care contacts</p> <p><b>Care at birth</b> 90% global average coverage of births attended by skilled health personnel</p> <p>At least 60% of the population able to physically access the closest EmONC health facility within two hours of travel time (EPMM only)</p> <p><b>Postnatal care and newborn care</b> 80% global coverage of early postnatal care</p> <p>80% of countries to have a national implementation plan that is being implemented in at least half the country, with an appropriate number of functional level-2 inpatient units linked to level-1 units to care for small and sick newborns, with family-centred care (ENAP only)</p> <p><b>Social determinants</b> 65% of women making their own informed and empowered decisions on sexual relations, contraceptive use and reproductive health care (EPMM only)</p>	
<b>NATIONAL COVERAGE TARGETS TO 2025</b>	<p><b>Care in pregnancy</b> 90% of countries to have &gt;70% coverage of four or more antenatal care contacts</p> <p><b>Care at birth</b> 90% of countries to have &gt;80% coverage of births attended by skilled health personnel</p> <p>80% of countries to have &gt;50% of the population able to physically access the closest EmOC health facility within two hours of travel (EPMM only)</p> <p><b>Postnatal care and newborn care</b> 90% of countries to have &gt;60% coverage of early postnatal care</p> <p>80% of districts (or equivalent subnational unit) to have at least one level-2 inpatient unit to care for small and sick newborns, with respiratory support, including provision of continuous positive airway pressure (ENAP only)</p> <p><b>Social determinants</b> 80% of countries to enact legal and policy changes that guarantee full and equal access to women and men aged 15 years and older to sexual and reproductive health care, information and education (EPMM only)</p>	

**SUBNATIONAL COVERAGE  
TARGETS TO 2025****Care in pregnancy**

80% of districts to have &gt;70% coverage of four or more antenatal care contacts

**Care at birth**

80% of districts to have &gt;80% coverage of births attended by skilled health personnel

**Postnatal care and newborn care**

80% of districts to have &gt;60% coverage of early postnatal care (within two days)

EmOC: emergency obstetric care; EmONC: emergency obstetric and newborn care; ENAP: Every Newborn Action Plan; EPMM: Ending Preventable Maternal Mortality; MMR: maternal mortality ratio; SDG: Sustainable Development Goal

# ANNEX 5

## EXAMPLE ACTIVITIES TO ENGAGE DECISION MAKERS AND THEIR INFLUENCERS

<b>“ASK” FOCUSED ON...</b>	<b>POSSIBLE WAYS TO ENGAGE</b>	<b>TARGET</b>
<b>DATA</b>	Propose pilot projects to support better data collection in facilities  Propose a system to include outcomes of pregnancies in surveys	Think tanks and professional bodies  Ministry officials
<b>INTERVENTIONS</b>	Work with the relevant authority to develop specific guidelines on stillbirth  Create and disseminate clear, simple stillbirth interventions  Share learnings of reports or studies in easily digestible ways	Health professionals  Ministry officials  Academia
<b>INVESTMENT</b>	Propose stillbirth rate as an indicator for quality of care	Health officials  Ministry officials
<b>MESSAGING</b>	Set up panels and events on stillbirths – include stillbirth speakers in panels and round tables – spark debate	The media  The public, including parents
<b>CHAMPIONS</b>	Create opportunities for sharing experiences as well as impact of effective interventions – round tables, dialogues, media	The media  Government officials  Academia, health professionals
<b>STIGMA</b>	Engage with parent groups on lessons learned	The media
<b>OWNERSHIP</b>	Push relevant authorities to recognize the issue and take ownership of stillbirths  Show interconnectedness of stillbirths to government targets, objectives, etc.	Local and national politicians  Government leaders
<b>ACCOUNTABILITY</b>	Partner with a think tank or credible agency to measure stillbirths – publish progress report	Government leaders  Ministers
<b>MANDATE</b>	Use parents’ and allies’ voices to show politicians that they have a mandate to act  Build a strong coalition of NGOs, professional associations and foundations to undertake joint advocacy to show depth of solidarity	Local and national politicians  Government leaders and ministers

NGO: non-government organization

Note. Listed activities are not comprehensive; these are provided to give an idea of the range of approaches available



# ANNEX 7

## ADVOCACY TOOLKITS FOR WOMEN'S, CHILDREN'S AND ADOLESCENTS' HEALTH

Developed by Kelly Thomson, Partnership for Maternal, Newborn and Child Health (PMNCH)

TOOLKIT	ORGANIZATION	FOCUS AREAS
<a href="#">Advocating for Change for Adolescents! A Practical Toolkit for Young People to Advocate for Improved Adolescent Health and Well-being</a>	PMNCH and Women Deliver	Adolescents and young people; health for all; mental health; sexual and reproductive health services
<a href="#">Power On: A Toolkit for Community Organizing</a>	White Ribbon Alliance	Health and health rights; respectful maternity care charter: universal rights of mothers and newborns
<a href="#">Demystifying Data: Using Evidence to Improve Young People's Sexual Health and Rights – Workshop and Toolkit</a>	Guttmacher Institute	Young people's sexual and reproductive health rights; using data to address issues; developing an advocacy strategy
<a href="#">ICM Advocacy Toolkit for Midwives</a>	International Confederation of Midwives	Increased resources for midwives; raising awareness about health issues; increased rights and protections for midwives
<a href="#">Every Newborn: An Advocacy Toolkit and Guidance Manual for Ending Preventable Deaths</a>	WHO and UNICEF	Practical tools for country programmes and stakeholders to support advocacy for improving newborn and maternal health and preventing stillbirths
<a href="#">Health for All Advocacy Toolkit</a>	Civil Society Engagement Mechanism for UHC2030	Broadly on achieving universal health coverage, but includes reference to maternal health
<a href="#">The Young Advocates' Guide on SRHR Advocacy and Intersectionality</a>	Right Here Right Now and YUWA	Adolescent sexual and reproductive health rights; digital advocacy
<a href="#">Every Mother Counts Advocacy Toolkit</a>	Every Mother Counts	Maternal health and health equity; US maternal health crisis
<a href="#">Raising Parent Voices Advocacy Toolkit – India Health Providers</a>	ISA	Stillbirths; parent voices

TOOLKIT	ORGANIZATION	FOCUS AREAS
<a href="#">Raising Parent Voices Advocacy Toolkit – Kenya Parents' version</a>	ISA	Stillbirths; parent voices
<a href="#">Breastfeeding Advocacy Toolkit</a>	UNICEF and WHO	Breastfeeding
<a href="#">Health Budget Literacy, Advocacy and Accountability for UHC</a>	UHC2030 and PMNCH	Health budget literacy; universal health coverage; accountability
<a href="#">Mobilising Communities on Young People's Health and Rights: An Advocacy Toolkit for Programme Managers</a>	Family Care International	Young people's sexual and reproductive health and rights
<a href="#">Black Mamas Matter: Advancing the Human Right to Safe and Respectful Maternal Health Care</a>	Black Mamas Matter Alliance and Center for Reproductive Rights	Maternal mortality in the US; access to reproductive health care; quality care; respectful maternal care

## ANNEX 8

# TEMPLATE FOR MAPPING OF RELEVANT POLICIES AND RECOMMENDATIONS

RESOURCE	POLICIES AND RECOMMENDATIONS RELEVANT TO MY SETTING	STATUS IN MY SETTING
<a href="#">Building the Enabling Environment for Midwives: A Call to Action for Policymakers</a>	Example 1: Safety and security in the workplace and when travelling to and from	For example, "in place", "lacking", "in progress"
<a href="#">WHO Guideline on Health Workforce Development, Attraction, Recruitment and Retention in Rural and Remote Areas</a>	Example 2: Scholarships, bursaries or other education subsidies to health workers with agreements for return of service	For example, "in place", "lacking", "in progress"
	User complete	User complete

## ANNEX 9

# WHO MINIMUM PERINATAL DATA SET

### THE FOLLOWING INFORMATION SHOULD BE COLLECTED ON 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 and time of birth:

Gestational age (weeks) and 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 THE BABY HAS DIED, THE FOLLOWING ADDITIONAL INFORMATION SHOULD BE COLLECTED:

Date and time of death:

Type of death: neonatal, intrapartum stillbirth, antepartum stillbirth, stillbirth of unknown timing

# Partners

BILL & MELINDA  
GATES *foundation*



