# WEBINAR

# HEALTHY NEWBORN NETWORK

Stillbirths: Reducing preventable deaths and improving care for every affected family

Thursday, 20 Jul 2023 Interprétation simultanée en français







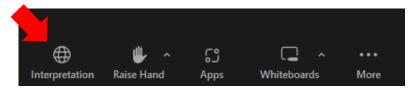




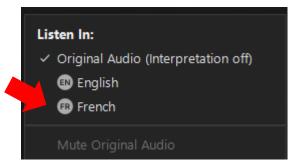


# A écouter en français

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# Agenda

Topic	Speaker
Welcome and introductions	<b>Theresa Shaver</b> - Senior Maternal and Newborn Health Advisor, USAID
The situation of stillbirth around the globe	<b>Lucia Hug</b> – Statistics Specialist, Data and Analytics, UNICEF
Introduction to the Stillbirth Advocacy and Implementation Guide	<b>Dr. Paula Quigley</b> – Chair, International Stillbirth Alliance
Raising voices	Claire Storey – Director of Bereavement, Community & Parent Voice, International Stillbirth Alliance
What's next and Q&A	<b>Theresa Shaver</b> - Senior Maternal and Newborn Health Advisor, USAID
Closing	<b>Dr. Hannah Blencowe</b> – Associate Professor, Co- Programme Director MSc Public Health for Development, MARCH Centre, LSHTM

# STILLBIRTHS

Reducing preventable deaths and improving care for every affected family













### **Speakers**

**Theresa Shaver** - Senior Maternal and Newborn Health Advisor, USAID

Lucia Hug - Statistics Specialist, Data and Analytics, UNICEF

Paula Quigley – Chair, International Stillbirth Alliance

Claire Storey – Director of Bereavement, Community & Director of Bereavement, Communi

**Dr. Hannah Blencowe** – Associate Professor, Co-Programme Director MSc Public Health for Development, MARCH Centre, LSHTM

### **Definitions**

Stillbirth: A baby born following a fetal death (22 weeks) or more of gestation

Early gestation stillbirth: A stillbirth at (22 to 27 weeks)

Late-gestation stillbirth: A stillbirth at (greater than 28 weeks)

Intrapartum stillbirth: A stillbirth following intrapartum fetal death

Preventing and Addressing STILLBIRTHS

Along the Continuum of Care:

A Global Advocacy and Implementation Guide





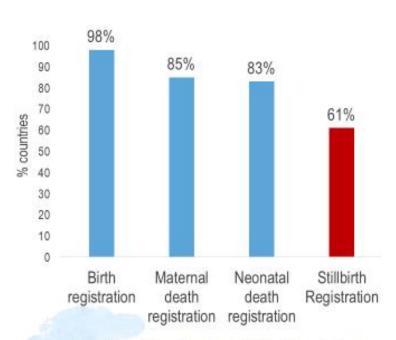




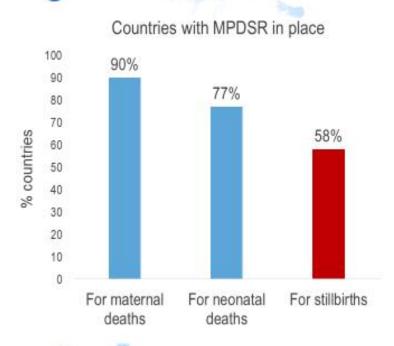




## Focus on stillbirths missing at all levels



Countries with policy for birth/death registration



MPDSR by each component

### Parents as experts, Parents as allies



**Ending preventable still** A renewed call for collective

21 October 2020, 8-10 a.m. EDT

experts. Give them a local or national platform to call for change. https://www.youtube .com/watch?v=kedm5 4zBVXc

Parents are the

#### Opening Remarks



Dr Tedros Adhanom Ghebrevesus Director General, WHO



Dr Osagie Ehanire Minister of Health, Nigeria

#### Current Status and The Way Forward



Dr Mark Hereward Associate Director, Data & Analytics, UNICEF



Dr Anshu Banerjee Director, Department of MNCAH and Ageing, WHO

Mrs Istiyani Purbaabsari

Registered Midwife

#### xperiences of Bereaved Parents and Midwives



Mrs Akindovin Oyeleye Parent, Nigeria

Ms. Diana Jepkosgei

Lead Psychologist and



Ms Christine Wangechi Parent,



Hilma Shikwambi Chairperson IMANA. Namibia

#### **Perspective of Country Representatives**



Dr Ghutai Sadeg Yagubi Acting Director, RMNCAH, Ministry of Public Health, Islamic Republic of Afghanistan



Dr Bhim Singh Tinkari Director, FWD, Ministry of Health and Population, Nepal



#### Dr Salma Ibrahim Anas-Kolo Director, Family Health Department, Federal Ministry of Health, Nigeria

#### Engagement of Partners



Dr Amy Pollack Director of MNCH. The Bill & Melinda Gates Foundation



Mr Darren Welch Director for Policy, Foreign, Commonwealth and Development Office, UK

#### Critical Actions



Dr Luwei Pearson Acting Associate Director and Chief of Health tramme, UNICEF



Closing Remarks



Henrietta Fore Executive Director, UNICEF

We need to create awareness ...

are lost every year

We need to emnower these mums

**Christine**, stillbirth mom from Kenya:

It's alarming... almost 2 million babies

Credit: Susannah Hopkins Leisher, former chair, International Stillbirth Alliance (stillbirthalliance.org)















# The situation of stillbirth around the globe











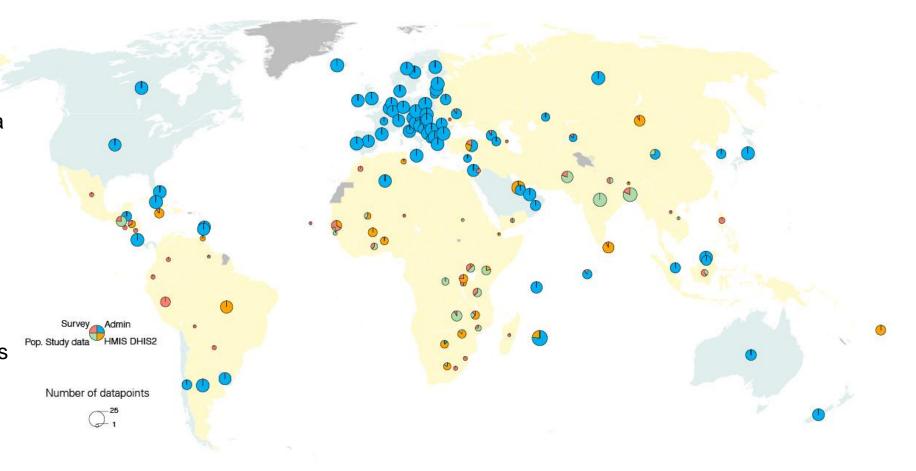


### **Substantial data gaps**

60 countries have no stillbirth data or quality data available

Almost half (40%) of countries in sub-Saharan Africa have no stillbirth data or quality data available

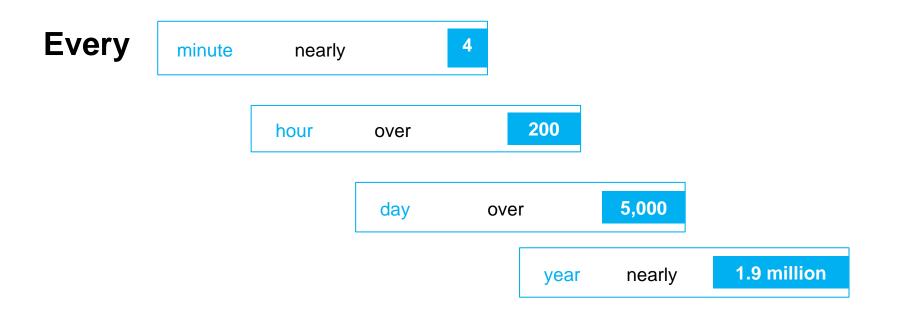
Lack of data at subnational level obscures marginalized populations



Note: Map does not reflect a position by UN IGME agencies on the legal status of any country or territory or the delimitation of any frontiers.

### **Enormous loss**

### 1 in 72 births is a **stillbirth**



babies are stillborn

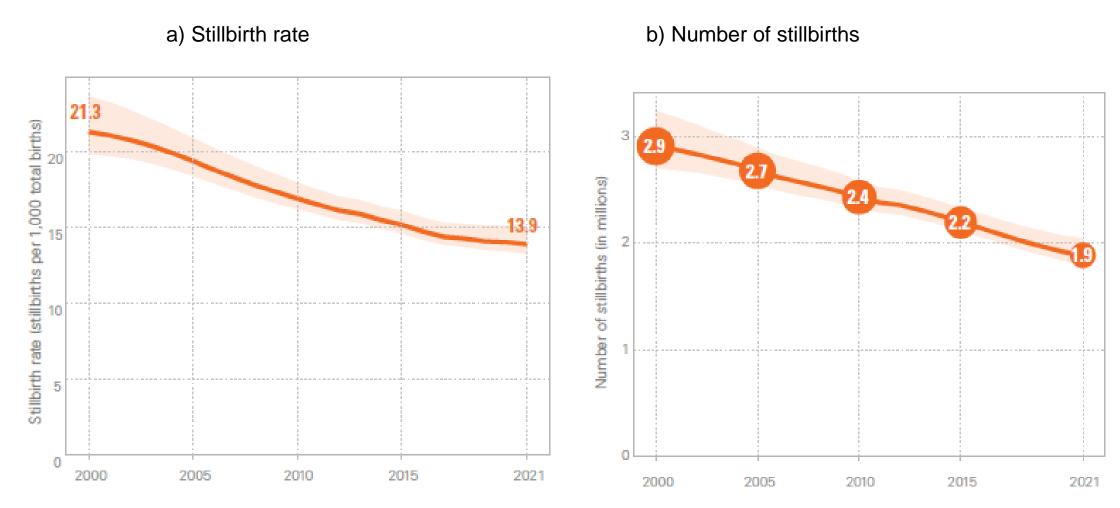
Unnecessary
Unseen
Unrecognized
Uncounted
Unprioritized
Underfinanced

Taboo Stigma Misconception

### **Trends**

### Globally, nearly 2 million babies are stillborn

Global stillbirth rate and number of stillbirths, 2000-2021



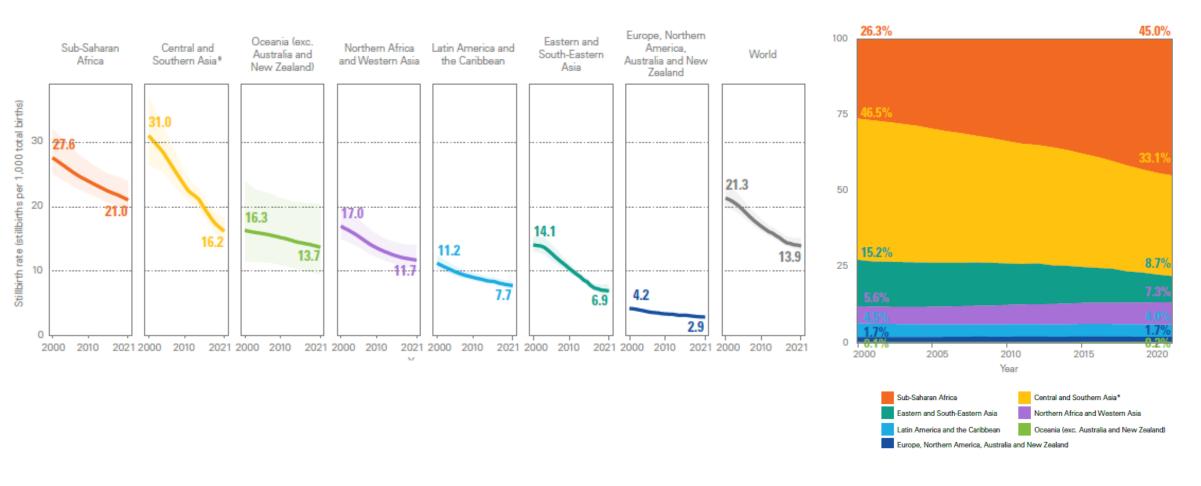
Source: United Nations Inter-agency Group for Child Mortality Estimation 2023 (UN IGME 2023).

### **Burden**

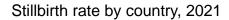
### The share of stillbirths is growing in sub-Saharan Africa

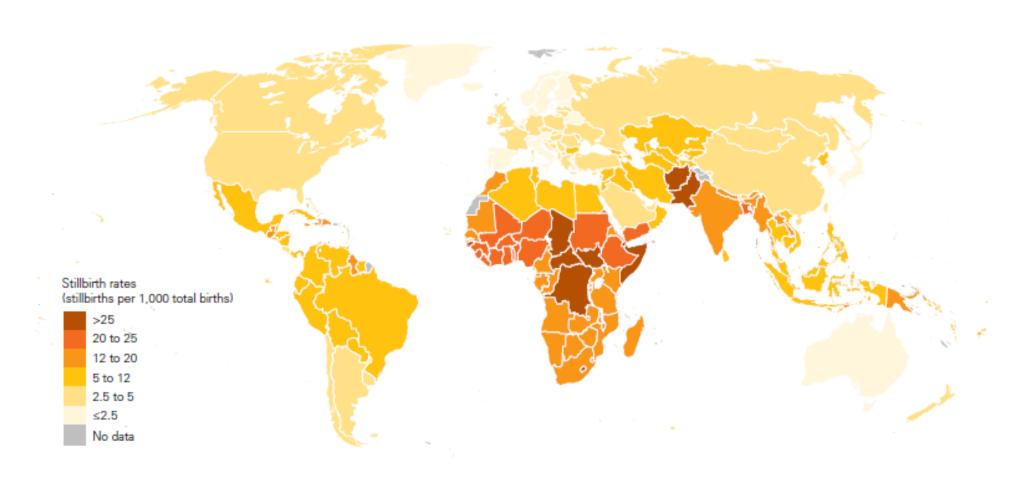
Stillbirth rates, 2000-2021

Number of stillbirths and regional share, 2000-2021



### Large disparities



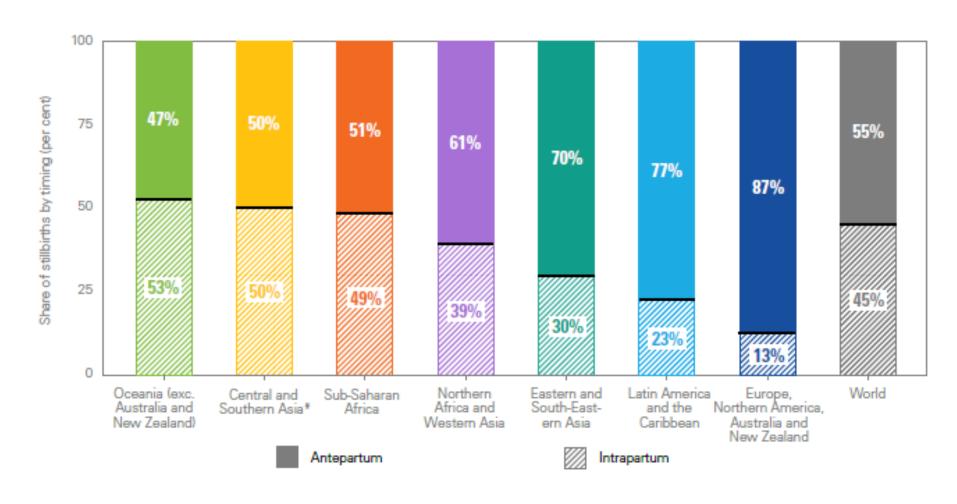


# A 20-fold difference in the stillbirth rates across countries

### **Timing**

### Almost half of stillbirths occur during labour

Proportion of intrapartum and antepartum stillbirths in 2021 (%)



Source: United Nations Inter-agency Group for Child Mortality Estimation 2023 (UN IGME 2023).

### **Slow progress**

### **Progress is slower than in child mortality**



Annual rate of reduction (ARR) in stillbirth rate, 2000–2021

2.0%



ARR in under-five mortality rate, 2000–2021 **3.3%** 



ARR in stillbirth rate

2000–2010 2011–2021

2.3% 1.7%

# Stillbirths are an increasingly important global public health problem

Share of stillbirths out of total stillbirths and under-five deaths (%)



### **Urgent action**

### We must do better and faster



16 million babies are projected to be stillborn in the next decade, if trends observed between 2000 and 2021 in reducing the stillbirth rate continue



**56 countries are at risk to miss the ENAP target** of 12 or fewer stillbirths per 1,000 total births by 2030

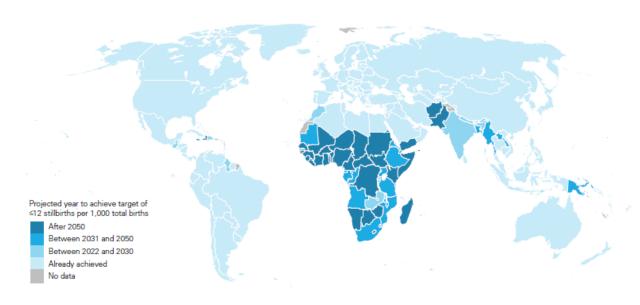


**35 countries** will only meet the ENAP stillbirth target after 2050



**46 countries** need to more than double their progress in reducing stillbirths in order to achieve the ENAP target

### Projected year to achieve the 2030 stillbirth target



Note: Map does not reflect a position by UN IGME agencies on the legal status of any country or territory or the delimitation of any frontiers.

### **COVID-19** pandemic threatened additional lives

#### A majority of countries have not shown deviation from expected number of stillbirths

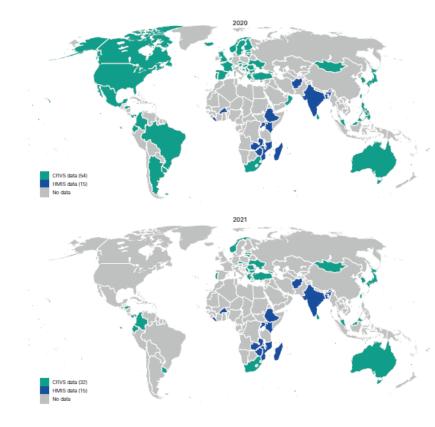
Proportion of countries with significant excess stillbirths in CRVS data for 2020 and 2021



The effects of COVID-19 on pregnancy and childbirth are not yet fully understood

A decrease in prenatal care visits and strained health care infrastructure could have further increase stillbirth risks

Stillbirth data availability for the years 2020 and 2021 in HMIS and registration



### Progress is possible and data gaps can be closed



Using the health system to strengthen the data collection on stillbirths



Standardize stillbirth definition and measures to align with international standards

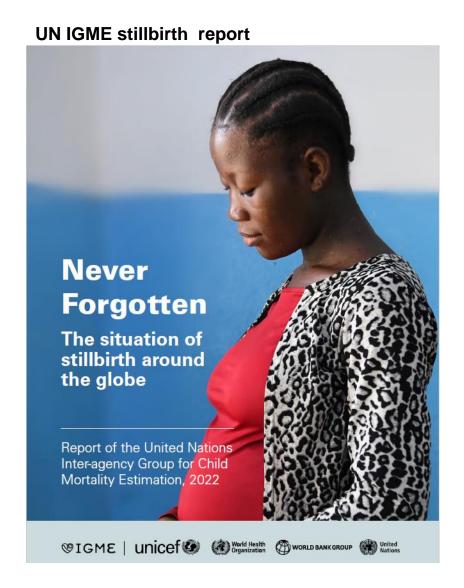


With sound policy, investment and programs, 21 countries – including 7 low- and lower-middle income countries – cut their stillbirth rate by more than half (2000-2021)



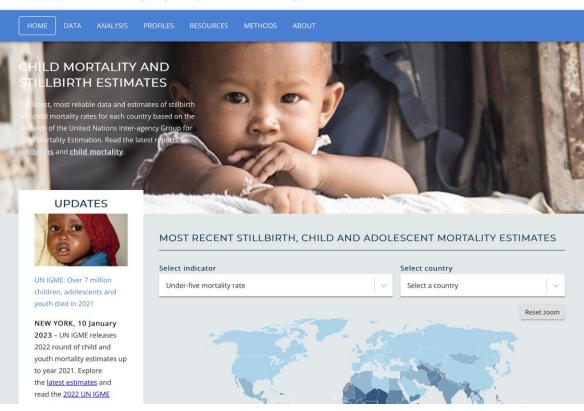
Over 40% of stillbirths occur after the onset of labour

### More information available at:

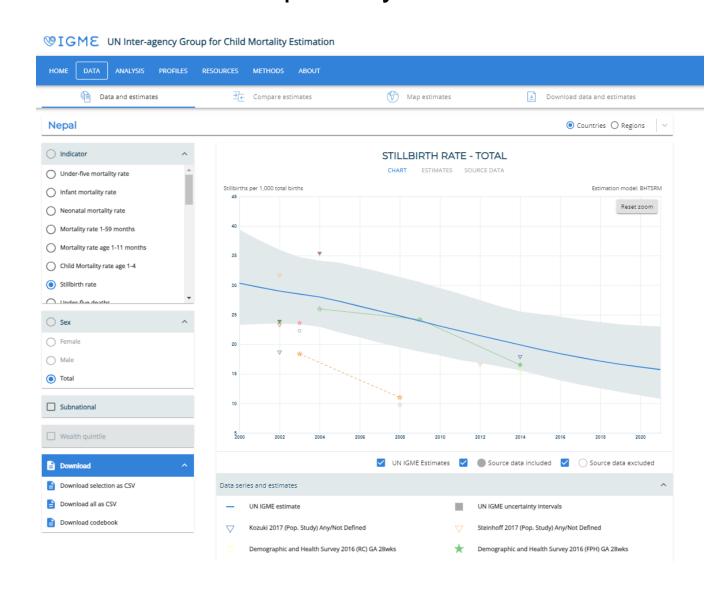


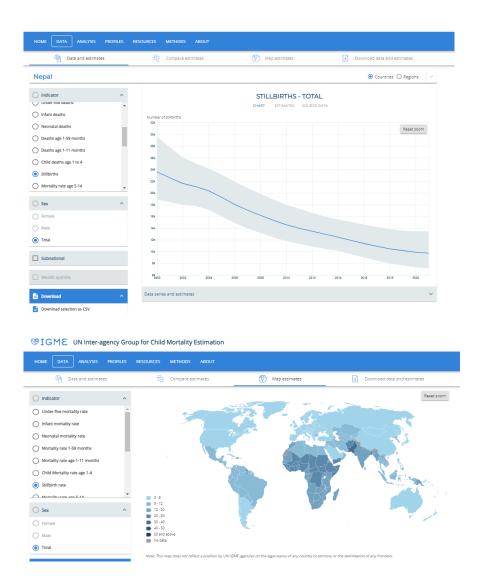
#### UN IGME data portal – <u>www.childmortality.org</u>

**♥IGME** UN Inter-agency Group for Child Mortality Estimation

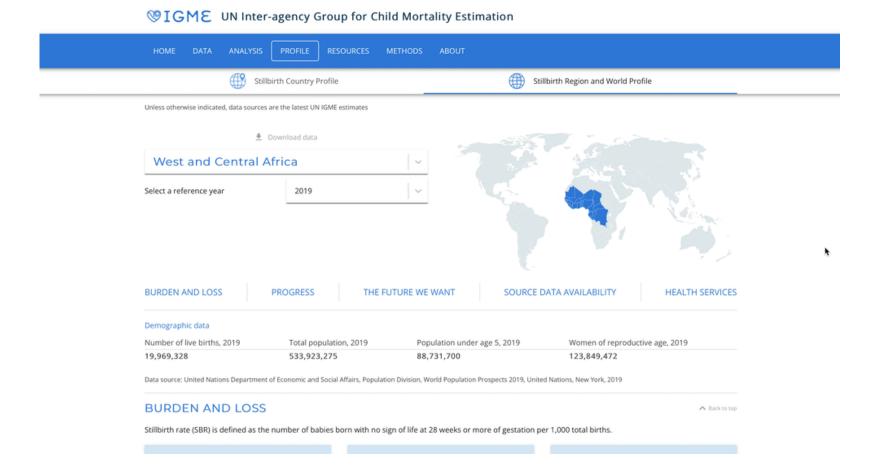


# Stillbirth estimates and source data on UN IGME data portal – to disseminate evidence and transparency





# Country, regional and global Stillbirth Profiles on UN IGME data portal – to bridge data and estimates with programmatic and advocacy efforts and

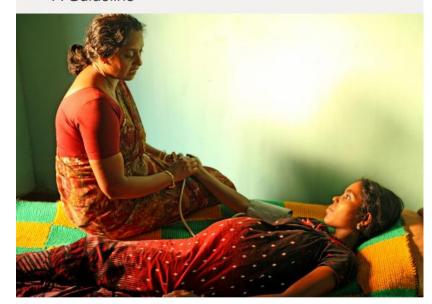


- Guide and inform advocacy and action around stillbirths
- Interactive charts on burden and loss, progress, future we want, data availability and health interventions with data to download

# Guidelines to improve health sector data and understanding the factors that contribute to stillbirths

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

A Guideline











## Stillbirth in Low- and Middle-Income Countries A conceptual framework











#### What data to collect



• Completed weeks= number of days since the first day of gestation/7

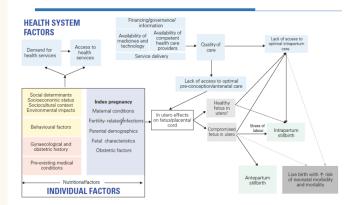
#### Rirthweight

 As soon as possible after birth and using suitable, well-maintained and calibrated weighing scales

#### Timing (Antepartum/Intrapartum)

· Assessment of fetal heartbeat, skin appearance as poor proxy

#### High-level Framework - drilling deeper





## **THANK YOU!**

UNICEF
On behalf of SIGME



Preventing and Addressing **STILLBIRTHS**Along the Continuum of Care:

A Global Advocacy and Implementation Guide



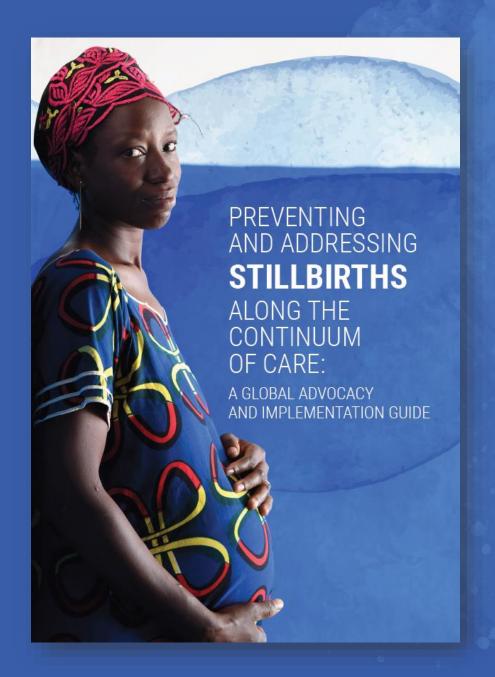
















#IMNHC2023 #GlobalStillbirthGuide #EndStillbirths #RespectfulCare #BereavementSupport #Advocacy #Implementation #ContinuumOfCare

# Purpose and target audience



## Purpose

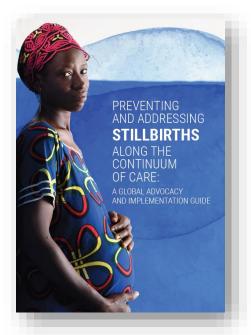
To bring together existing technical resources and practical guidance in one place to inform national and subnational planning, investments and programmes aimed at ending preventable stillbirths and improving care for all women and families who experience stillbirth.



# **Target audience**

- 1. National and subnational governments, civil registration authorities, national statistics offices, health-professional organizations, health facility directors, managers and administrators.
- 2. Parents, parent organizations, community leaders, individual clinicians, and others

# Chapters









OPPORTUNITIES
TO OVERCOME
CHALLENGES



BEREAVEMENT CARE IS ESSENTIAL

### Parent, community, and clinician voice!

- → The toll of stillbirth
- → Underlying risk factors associated with stillbirth
- → What are the challenges?
- → Opportunities along the continuum of care
- → What is respectful and supportive bereavement care?

# Chapters (cont'd)





PROGRAMME IMPLEMENTATION



MEASUREMENT OF PROGRESS



ACHIEVING THE GOAL

Resource links, case studies, reflections, where to learn more

Parent, community, and clinician voice!

- → Introduction to stillbirth advocacy
- → Fundamentals of advocacy
- → Guidance for developing an advocacy strategy

- → Access to care
- → Leadership
- → Infrastructure, equipment and supplies
- → Health workforce

- → Where to start
- $\rightarrow$  Counting stillbirths
- → Action needed at the country level
- → Progress can be made

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

As an obstetrician working in a I never thought seeing or hold would help a mother in coping in this situation seemed to be something that could exacer increasing evidence has sho and holding a stillborn baby o for bereaved parents. Due to and huge hurden in our setting is usually wrapped and handed members. Decisions about the st mother are primarily left to the fami usually involved. I recently cared for a a stillborn baby. When we asked the moth directly whether they wanted to see or hold the

agreed. So, in place of wrapping the stillborn baby wit was cleaned and dressed properly, as we do for a live born baby. After hold parents were content and expressed their gratitude to health-care providers

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

PROGRAMME IMPLEMENTATION ALONG THE CONTINUUM OF CARE

#### 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 p nurses and midwives, especially settings. Depending on the part obstetricians, community health others may also provide bereav

A list of formal bereavement ca programmes is provided in Res programmes are typically availa resourced countries, but it is po adapt them for other settings.

#### RESOURCES

- Learn more about IMPROVE and workshops
- · Read about Resolve Through Bereavement Training
- · Access the SANDS UK stillbirt neonatal death support training
- Visit the UK National Bereave Pathway website

#### → With community leaders, encourage women to attend antenatal care for the health and well-

PROGRAMME IMPLEMENTATION ALONG THE CONTINUUM OF CARE

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:

LEARN MORE

- → 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.



#### 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 based on surveillance.
- Monitor and evaluate quality findings to inform practice c

health outcomes.

#### LEARN MORE

· Leadership should provide and consistent support a motivating feedback to h workers. Read more abo WHAT YOU CAN DO: effective approach to reand improving other mat

#### PROGRAMME IMPLEMENTATION ALONG THE CONTINUUM OF CARE

A social awareness meeting about maternal death, infant montaity, stillbirth and other health issues is conducted by the Ministry of Health and Fernily Welfere 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.

- → 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 force 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 evpertise



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.



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?

MEASUREMENT OF PROGRESS

#### RESOURCES

#### CRVS

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

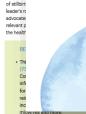
- A WHO and UNICEF report (102) provides operational guidance for health sector managers, civil registrars and development partners to improve health sector reporting of stillbirths to civil registration authorities.
- Chapter 5 of the <u>Civil Registration</u>, <u>Vital</u> Statistics and Identity Management (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

 The UNICEF Stillbirth Definition and Data Quality Assessment for Health provides practical guidance on data collection, assessing data quality and

improving data for action. AUDIT AND OTHER RESOURCES

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



Finally, ef

- → Revisit <u>Chapter 4</u> 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



b UNICEF/UNI32026/Pirozzi adiatu Sama, who has had no prenatal care and whose child was stillborn, is omforted by a woman nurse in the maternity ward of the government hosp the southern town of Bo (Sierra Leone).

# **Funding**

# BILL&MELINDA GATES foundation

Thank you to the Bill & Melinda Gates Foundation for overarching funding for this guide.



Thank you to UNFPA for funding and support for design and layout.

# **Partners**

























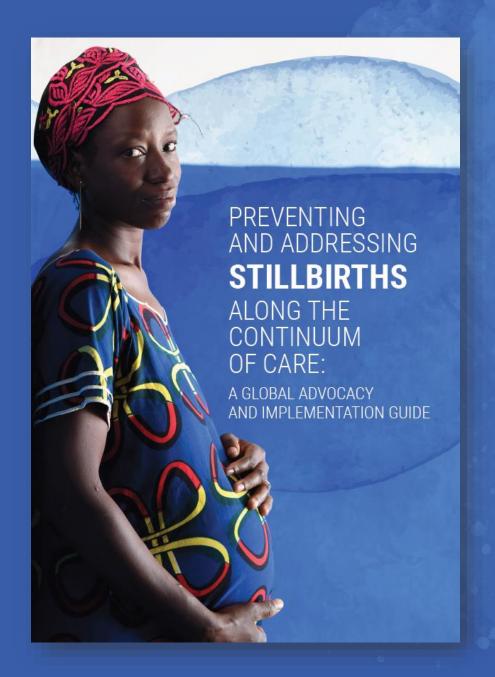












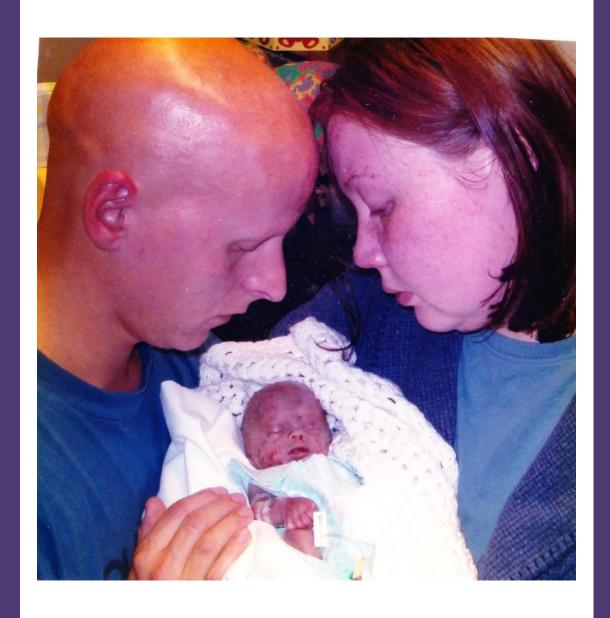




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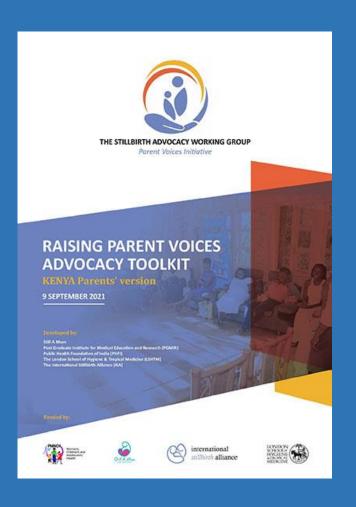


Raising Parent Voices







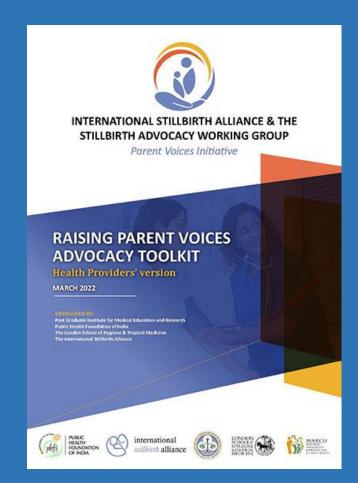


## Purpose

To reduce stigma and strengthen bereavement care post-stillbirth in developing countries

# Target audience

- Healthcare providers (Health Providers' version)
- Parents & parent organizations (Parent version)







# **Toolkit for Parents**

This version provides a simple advocacy training toolkit for stillbirth parent support organizations in places with large numbers of stillbirths. The aim is:

- To introduce the concept and aims of advocacy related to stillbirth
- To provide guidance
- To support parents to learn about how to raise their voices to help ensure their views and needs are heard within their country's health goal-setting agendas

This toolkit provides parents information on:

- Stillbirths overview, causes and risk factors
- The impact of stillbirth on parents
- Advocacy as a tool for change in stillbirth prevention and bereavement care
- Ways of advocating for change in stillbirth prevention and bereavement care
- Coping strategies for advocacy-related stress



# **Toolkit for Healthcare Providers**

This version provides information and suggested approaches for deeper and more open communication with parents after a stillbirth, including:

- Delivering the news
- Acknowledging parents' grief
- Talking with parents about how and why their baby may have died
- Making room for them to express their need for support
- Discussing a safe plan for future pregnancies
- Providing respectful bereavement care to parents

The toolkit will help healthcare providers to:

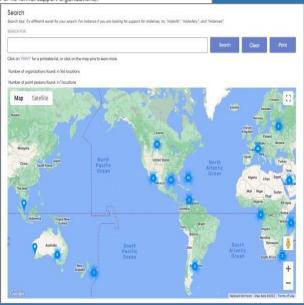
- Raise awareness and educate women and their families about stillbirth
- Advocate for increased resources for stillbirth bereavement support
- Amplify the voices and needs of affected parents and with fellow providers related to stillbirth bereavement support





Keep checking back! We are ISA does not endorse the au

emergency care providers in



# **Objective**

To address global gaps in respectful bereavement care by:

- Identifying organizations and individuals that provide support to parents and families following a stillbirth
- Investigating key challenges related to support provision
- Identifying potential ways to overcome those challenges

# Methodology

- Systematic online & snowball searches of support providers worldwide
- Online survey and in-depth
   interviews with a subset of
   providers to understand the
   challenges that they face and how
   these could be overcome



stillbirthalliance.org/isa-registry-map



# The Global Registry

- 621 support providers from 75 countries:
  - 510 organizations
  - (485 from 63 countries, 25 unknown)
  - 111 point persons
- Big gaps in high burden settings:
  - In the six countries with the highest stillbirth burden we found only eight support providers –Six in India and two in Nigeria
  - None in China, Ethiopia, Pakistan, or the DRC

If you are a representative of such an organization we hope that you will **join the Registry!** There is no fee for joining, and access to the Registry is free for all.





# Thank you!

