COUNTING THE INVISIBLE: HEALTH SYSTEM FACTORS INFLUENCING STILLBIRTH MEASUREMENT AND REPORTING

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Declaration of work

I, Nana Afriyie Mensah Abrampah, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: [redacted] Date: 21 August 2024

Abstract

Background

Stillbirths represent a global public health crisis, affecting nearly two million babies annually. Progress in reducing stillbirth rates worldwide has been slow, primarily due to limited data availability and poor data quality, which hinder advocacy and planning. This constraint has stalled the prioritization of stillbirths in global and national public health agendas. The foundational components of health systems, including governance and leadership, health workforce, financing, data/health information systems, essential commodities, and service delivery, form the basis for producing, analyzing, interpreting, and disseminating high-quality, reliable, and timely health data, including data related to stillbirths.

Objectives

The thesis aims to investigate health system factors influencing stillbirth recording and reporting. Three key objectives were pursued to achieve this aim. Objective 1 reviews the legislative policy environment in countries to understand stillbirth recording and reporting. Objective 2 seeks to understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of the district health management team. Objective 3 aims to gain insights into practices and challenges related to stillbirth recording and reporting from the perspective of health workers in public health facilities in the Ashanti Region of Ghana.

Methods

Two distinct methodological approaches were employed. For objective one, a systematic three-step policy review process analyzed country responses to the 2018-2019 WHO Reproductive, Maternal, Neonatal, Child, and Adolescent Health policy survey across 155 countries. Additionally, over 800 national policies relevant to stillbirths were examined across 66 countries. Descriptive quantitative analysis was applied to examine the findings.

For objectives 2 and 3, semi-structured qualitative interviews were conducted at the sub-national level, with 15 district health officers and 28 facility-level health workers involved in maternity

services or stillbirth data in the Ashanti Region of Ghana. Thematic analyses were performed using an a priori framework.

Results

At the policy level, fewer than one-fifth of countries have an established stillbirth rate target. Only 45.5% of reviewed national policy documents mention registering stillbirths, while 43.9% of countries have national policies requiring stillbirths to be reviewed. Interviews at the country level suggested a disconnect between policy and practice. Five areas were identified to close the policy and practice gap for stillbirth data: 1) Standardizing stillbirth definitions and sensitizing health workers to the definition; 2) Ensuring effective assessment of stillbirth types using international classification; 3) Avoiding blame from the individual level to the wider organizational health system level; 4) Addressing errors contributing to misclassifications, omissions, and under-reporting; and 5) Integrating information across data systems.

Conclusion

Defining and implementing stillbirth policies, strengthening and empowering health workers, and establishing robust data/ health information systems play critical roles in improving stillbirth data by ensuring the availability, accessibility, timeliness, and quality of data. This is essential for monitoring and tracking stillbirth trends, identifying the magnitude and distribution of stillbirths, and ultimately working toward achieving the global goal of 12 stillbirths or fewer per 1,000 total births in every country.

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Abbreviations

ANC	Antenatal care
BMC	BioMed Central
CDC	Centers for Disease Control and Prevention
CRVS	Civil Registration and Vital Statistics
DHD	District Health Directorate
DHIMS-2	District Health Information Management System 2
DHMIS	District Health Management Information System
DHMT	District Health Management Team
DHS	Demographic and Health Surveys
ENAP	Every Newborn Action Plan
FCV	Fragile, Conflict-Affected and Vulnerable
GHS	Ghana Health Service
HMIS	Health Management Information Systems
ICD	International Classification of Diseases
IJHPM	International Journal for Health Policy and Management
LMICs	Low-and Middle-Income Countries
LSHTM	London School of Hygiene and Tropical Medicine
MCS	Medical Certificates of Stillbirth
MDG	Millennium Development Goals
MDSR	Maternal Death Surveillance Review
MICS	Multiple Indicator Cluster Survey
MITS	Minimally Invasive Tissue Sampling

MNCH	Maternal, Newborn and Child Health
MPDSR	Maternal and Perinatal Death Surveillance and Response
NMR	Neonatal Mortality Rate
RHD	Regional Health Directorate
RMNCAH	Reproductive, Maternal, Child and Adolescent Health
SARAH	Stillbirth Advocacy and Research in Africa Hub
SBR	Stillbirth Rate
SDGs	Sustainable Development Goals
U5M	Under-Five Mortality
U5MR	Under-Five Mortality Rate
UN-IGME	UN Inter-Agency Group for Child Mortality Estimation
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Glossary

Term	Definition
Measurement	Within the context of this thesis, measurement refers to the counting, recording, and reporting of stillbirths. Throughout the thesis, recording and reporting are used interchangeably with measurement.
Stillbirth	Stillbirth is the complete expulsion or extraction from a woman of a fetus, following its death prior to the complete expulsion or extraction, at 22 or more completed weeks of gestation.*
Health systems	A health system consists of all organizations, people, and actions whose primary intent is to promote, restore, or maintain health. † A health system has six main elements, as defined by WHO, service delivery, health workforce, data/health information systems, essential commodities, financing, and leadership/ governance.
Health workers	Health workers in this thesis refer to all individuals involved in the various aspects of promoting, maintaining, or restoring health. This includes healthcare workers engaged in the direct clinical care of people (such as doctors, nurses, midwives, physician assistants etc.), as well as those involved in health management and broader public health functions (such as district health officers, health information managers, surveillance officers, etc.).

* World Health Organization, ICD-11 for Mortality and Morbidity Statistics 2024, World Health Organization: Geneva
† World Health Organization. Monitoring the Building Blocks of Health Systems: A Handbook of Indicators and Their Measurement Strategies. Geneva, Switzerland: WHO Press (2010)

1 Chapter 1 Research Rationale

1.1 Summary

This section introduces the rationale for the research and the importance of counting stillbirths. It provides an overview of the neglected burden of stillbirths, acknowledging the progress made in other related areas, such as neonatal and child health mortality. Additionally, the chapter reviews the limited focus on stillbirth indicators within global measurement efforts. The first chapter ends with an overview of the study aims, objectives and an outline of the thesis structure.

My interest in the research area was informed by a literature review, conversations with experts in stillbirth measurement, and my professional engagement with the Network for Improving Quality of Care for Maternal, Newborn, and Child Health (Quality of Care Network). Through my involvement with the Quality of Care Network, I gained a foundation to further review the literature, ultimately informing the development of this thesis.

1.2 Background

Globally, progress in child health has improved. An estimated 1 in 27 children died before reaching age five in 2022 compared to 1 in 11 in 1990. [1, 2] Similarly, in 2020, 17 deaths per 1,000 live births were observed in the first month of a child's life compared to 37 deaths per 1,000 live births in 1990. [3] A closer look at broader child health indicators reveals that progress is fragmented and unequal across specific components of child health. While the global prevalence of stillbirths remains substantial, [4, 5] the stillbirth rate (SBR) has decreased by only 2.3% annually over the last twenty years. However, a stillbirth occurs every 16 seconds, nearly 4 every minute, over 200 every hour, 5,400 every day, 164,000 every month, and nearly 2 million a year. [6] Despite this high prevalence, stillbirths remain an invisible, underfunded, and marginalized topic due to the challenges reported in stillbirth measurement, causing them to be absent from national and global tracking efforts. [7]

Both national and global level discussions lack attention to the burden and counting of stillbirths. The Millennium Development Goals (MDGs) failed to address the issue of stillbirths, as stillbirths were excluded from the monitoring of MDG-related targets. [5] This lack of focus on stillbirths persisted into the Sustainable Development Goals (SDGs) era in 2015, where stillbirths were neglected, as there was a greater focus on child mortality and the associated monitoring indicators of under-5 mortality rate (U5MR) and neonatal mortality rate (NMR). [8] However, the slow progress to curb stillbirths, [6] has resulted in calls for increased investment at the global and national levels. Several bodies of work have emerged on stillbirths to amplify and accelerate progress toward reducing stillbirths. These include the *Every Newborn Action Plan (ENAP)* [9, 10], a global initiative and action plan launched in 2014 aimed at reducing preventable deaths and improving the health of newborns and mothers; the *Global Strategy for Women and Child Health* [11], a framework that outlines a roadmap for improving the health and well-being of women, children, and adolescents around the world by 2030; the *Network for Improving Quality of Care for maternal, newborn, and child health* [12], a collaborative initiative that aims to enhance the quality of healthcare services for mothers, newborns, and children globally; and the *UN Inter-Agency Group for Child Mortality Estimation (UN-IGME) Core Stillbirth Estimation Group*, a dedicated group primarily focused on estimating child mortality rates globally and providing up-to-date and accurate data on stillbirths. [13]

Across global measurement efforts, the stillbirth rate (SBR) has been featured as part of the WHO Global Reference List of 100 Core Health Indicators, a global compilation of key health indicators widely used for monitoring and assessing health trends at the global, regional, and national levels. Additionally, as part of ENAP, a prominent target is for countries to achieve stillbirth rates of 12 or fewer per 1,000 total births by 2030. Table 1 shows the progress made on the inclusion of stillbirths in reproductive, maternal, child, and adolescent health (RMNCAH) measurement efforts, with gaps reported, particularly in the measurement efforts related to the SDGs and the Universal Health Coverage monitoring agenda. [14]

Table 1: Inclusion of stillbirth rate in global measurement efforts.

Global agenda	**Stillbirth included**	**Indicator**
Global indicator framework for the SDGs and targets for the 2030 Agenda for Sustainable Development **[8]**	No	Not included
Universal Health Coverage: Global Health Observatory‡ **[15]**	No	Not included
WHO Core 100 indicators **[16]**	Yes	Stillbirth rate
Every woman, Every child **[17]**	Yes	Stillbirth rate
Every newborn action plan **[10, 18, 19]**	Yes	Stillbirth rate
Quality of Care Network for Maternal, Newborn and Child Health **[20]**	Yes	Institutional stillbirth rate (disaggregated by fresh and macerated)

Challenges related to stillbirth measurement include under-reporting of stillbirths, omissions of events, misclassification between stillbirths and other related areas such as neonatal death or a miscarriage, weak health management information systems (HMIS), and persistent data quality issues. [21-25] Additional challenges related to non-standard definitions, health workforce knowledge and skills, tools, assessments, and stigma and blame have also been reported, affecting the reliability of data on stillbirths. In response to these challenges and to ensure the comprehensive counting of every stillbirth, a call has been issued by the above-mentioned global initiatives and

‡ Stillbirth rate is included within the broader indicators in the Global Health Observatory but not within the thematic area on universal health coverage.

groups for rapid and urgent improvements in health systems strengthening, focusing on enhancing the accuracy of stillbirth data and its measurement. [6, 7, 26]

Accurate data on stillbirths relies on strong health systems. [7] Acknowledging this importance, in 2020, the WHO and the United Nations Children's Fund (UNICEF) global report on stillbirths issued a call for countries to urgently improve health systems. [6] The WHO defines health systems as the organizations, people, and actions whose primary intent is to promote, restore, or maintain health. [27]. A health system has six key building blocks, including leadership and governance, health workforce, service delivery, financing, essential commodities, and data/health information systems. These building blocks provide the foundation for the production, analysis, interpretation, and dissemination of high-quality, reliable, and timely data for health, including stillbirths. [27, 28] Within this thesis, leadership and governance, alongside the health workforce, serve as a lens that allows for a deeper investigation to understand the additional building blocks, notably data/health information systems. [29]

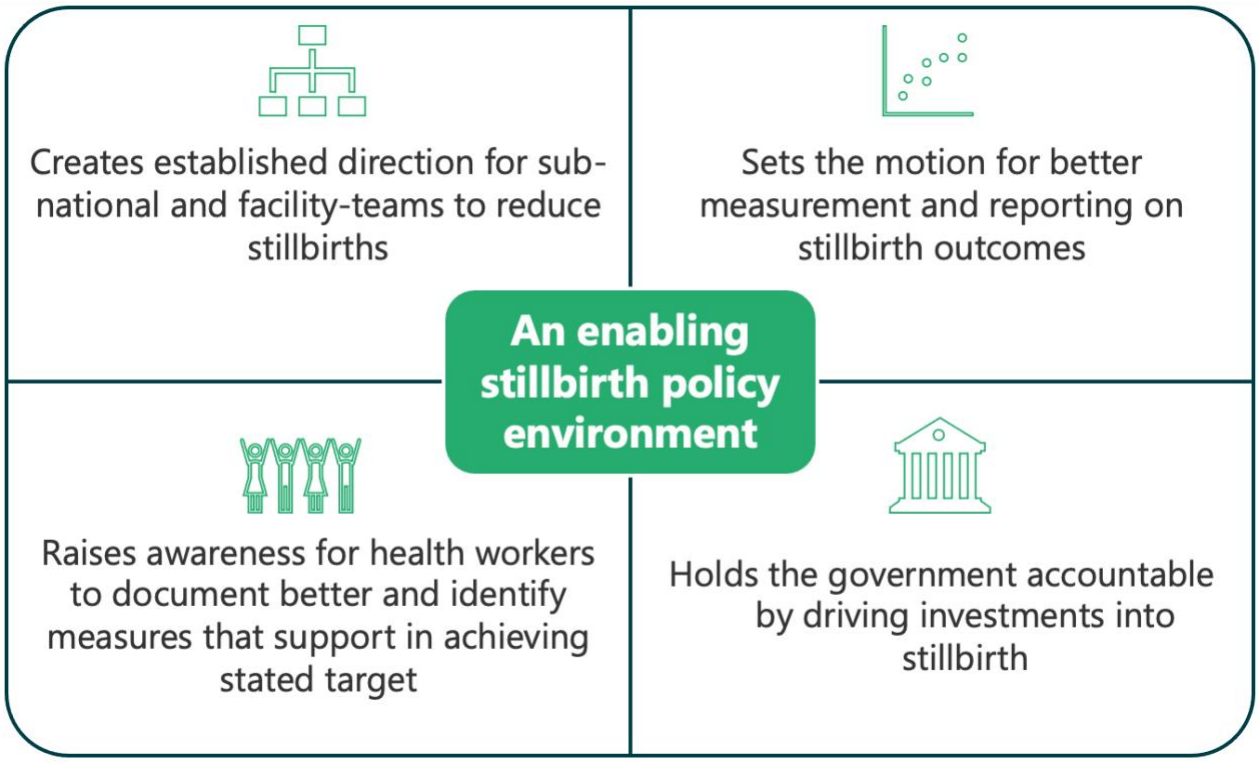
The justification for using leadership and governance, alongside the health workforce, as the starting point to examine the building blocks is explained below.

Health system governance refers to the processes, structures and institutions that oversee and manage the health system within a country. [30] The governance of a health system is crucial for understanding the relationships among various actors in the system, including government agencies, health providers, patients and their families, individuals and communities, civil society organizations, and private sector entities. Further, governance ensures that policies exist with clear oversight, regulation and accountability to improve the well-being of populations. The availability of policies sets the importance and outlines a mechanism to guide, monitor, evaluate, and review the health system's performance and relevant indicators, including stillbirths.

Governments are responsible for the stewardship and governance of a health system. [27] National health sector policies and plans, formulated by governments, guide the roles of various actors and outline the necessary steps for progress in specific technical areas. These areas may include defined national targets for stillbirths or the local stillbirth definition or thresholds. Within the framework

of ENAP, governments are urged to review and sharpen national strategies, policies, and guidelines for RMNCAH. [19] Setting a national target for the stillbirth rate provides established direction for sub-national and facility teams, drives the identification of measures to achieve the stated target, and holds the government accountable. The inclusion of the stillbirth rate and its prioritization within national plans and subsequent sub-national actions allows for improved reporting and measurement of the neglected burden of stillbirth. Additionally, the inclusion of stillbirth in national policies and plans, as well as sub-national actions, increases awareness for health workers to document better and drive increased investments in stillbirth measurement and reporting infrastructure. The importance of an enabling policy environment for stillbirth is captured in Figure 1.

Figure 1: Benefits of an enabling stillbirth policy environment.



Health systems cannot function without health workers. Equally, there is no data without health workers. The availability, accessibility, and quality of stillbirth data depends on the health workers.

[7, 31, 32] Health workers play a key role in the classification of a stillbirth and are responsible for the accurate recording and completion of any associated reporting form/medical records for stillbirths into routine hospital and health information systems. A trained health worker is critical throughout a woman's pregnancy, providing the quality care needed to ensure safe delivery for both mother and baby, and documenting the birth outcome. From the moment a stillbirth occurs, a health worker is responsible for recording the birth outcome at the health facility or community-level, and appropriately channeling the report to sub-national authorities, who then share the data with the national-level. Generally, stillbirth knowledge amongst health workers remains sub-optimal [33] with many studies focusing on mothers, clinical management, and care outcomes. [31, 34-42] In 2023, recognizing the acute importance of the health workforce, WHO/UNICEF called on governments to invest in health workers to improve birth outcomes. [7] The development of health worker skills to report fetal deaths and complete perinatal audits is an identified strategy to strengthen stillbirth data quality and availability. [31, 32]

Very few studies have focused on stillbirths, their measurement, and health workers [25, 43], with one study reporting that health worker attitudes and beliefs remain a perceived barrier to stillbirth measurement.[21] There is little known information on the extent of the health workforce knowledge on stillbirth recording and reporting. There is, therefore, a need to understand how health workers perceive recording and reporting of stillbirths.

Ending preventable deaths and ensuring that every stillbirth is counted requires understanding the health system factors that facilitate or hinder stillbirth measurement. Strengthening health systems to count every stillbirth has positive implications for the global and local health community. [44]Stillbirths are preventable when quality data is produced and analyzed by health workers to understand timing and the associated conditions. Stillbirth policies and standards informed by data drive the delivery of quality care; and finally, the monitoring of stillbirths is critical to determine the burden of stillbirth rates by geography, place of residence, socio-economic background, or age.

1.3 Study aims and objectives

This research aims to investigate health systems factors influencing stillbirth recording and reporting, as well as provide recommendations to improve stillbirth recording and reporting.

The overall aim is achieved through the following objectives:

- Objective 1: Review the legislative[§] environment in countries to understand stillbirths recording and reporting.

- Objective 2: Understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of the district health management team (DHMT).

- Objective 3: Gain insights into practices and challenges related to stillbirth recording and reporting from the perspective of health workers in public health facilities in the Ashanti Region of Ghana.

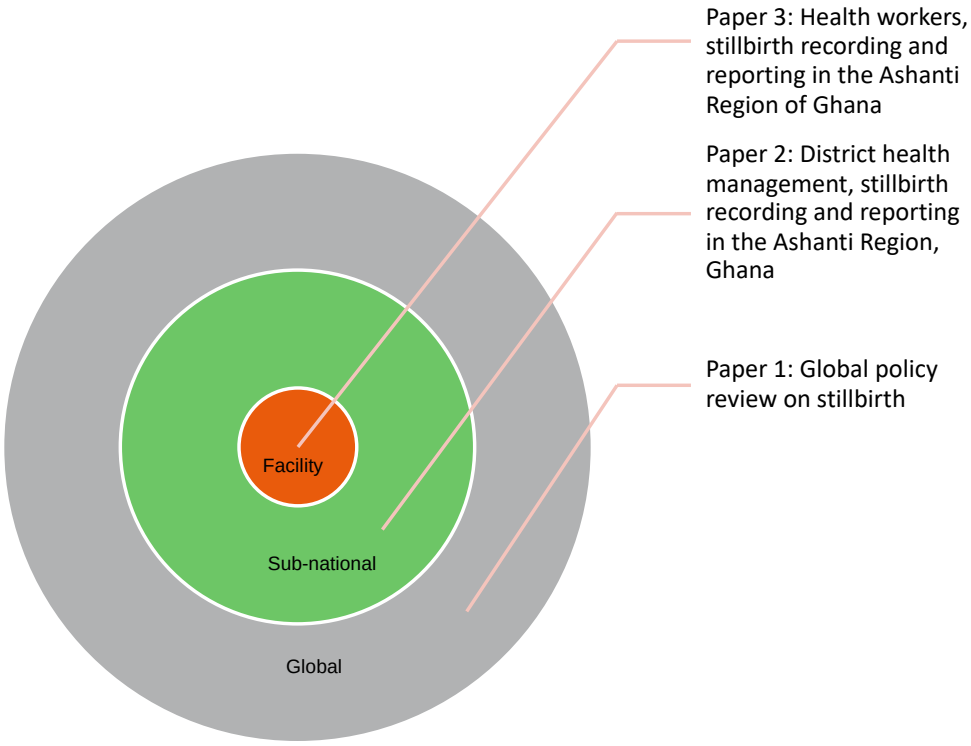
The selection of the three objectives was deliberate. Objective 1 enabled an understanding of the policy context shaping how countries address stillbirths at the operational sub-national level. Objectives 2 and 3 focused on a high-mortality stillbirth setting such as Ghana, aiming to understand how policy is translated at the sub-national district-level for stillbirth measurement. The three objectives are discussed across three papers. Figure 2 provides an overview of the three research papers, grounding the three objectives.

It is important to highlight that examining the clinical care dimensions of stillbirths and clinical practice of health workers is beyond the scope of this thesis. Similarly, the thesis does not review clinical guidelines and their application in countries for stillbirth, considering that these areas are related to service delivery. Per the outlined objectives, the thesis aims to examine the health systems building blocks, particularly governance and leadership, health workforce,

[§] The legislative environment refers to polices, strategies, laws, plans and guidelines.

essential commodities, data/ health information systems and finance, and how they influence the recording and reporting of stillbirths.

Figure 2: Overview of PhD objectives and papers



1.4 Thesis Structure

The thesis follows the research-paper style format. Two papers have been published in peer-reviewed journals; namely, the International Journal for Health Policy and Management (IJHPM), a premier journal focused on publishing recent evidence on health policy and management research for decision-makers, health policymakers and managers; and the BMC (BioMed Central) Pregnancy and Childbirth, a leading journal concerned with all aspects of pregnancy and childbirth. A third paper has been submitted to a peer-reviewed journal and is currently undergoing the peer-review process. The thesis is divided into eight chapters:

Chapter 1 provides the **rationale** as well as the **study objectives and aim of the research.**

Chapter 2 presents a **literature review** of the stillbirth measurement context relevant to policies. Furthermore, it provides an overview of the criteria commonly used in policies and strategies to assess stillbirth, including gestational age. The chapter also discusses common data sources used to inform stillbirth policies and strategies, such as Civil Registration and Vital Statistics (CRVS) systems, health management information systems (HMIS), and demographic and population surveys. Additionally, the chapter explores challenges and barriers to stillbirth recording and reporting by health workers, including issues of omissions, under-reporting, misclassifications, and data quality problems. The importance of the health workforce in the context of stillbirth recording and reporting is also elaborated upon. Finally, the chapter concludes with a focused examination of the stillbirth environment in the study country, Ghana. This includes an outline of the policy context and a review of past stillbirth studies conducted in Ghana.

Chapter 3 provides a detailed overview of the **research methodology** undertaken for each of the three objectives, data collection, and analysis techniques, along with discussions on data reliability, validity, and potential limitations. This is followed by a description of the study site and study population, as well as the rationale for selecting the study site.

Chapter 4 comprises a **global policy review of stillbirth** across 155 countries, involving the examination of over 800 national policy documents. It presents findings on how stillbirths are positioned within national policies, which dictate the prioritization of stillbirths and counting processes within countries. Recommendations and implications for action are included to inform the 2030 SDG goal agenda. The section addresses objective 1 of the thesis and is the first published paper in a peer-reviewed journal.

Chapter 5 focuses on **district health management and stillbirth data**. The section discusses the district health management teams (DHMTs) that translate national health policies into action. DHMTs also manage the district health management information systems (DHMIS). Specific to Ghana, the DHMIS is referred to as the District Health Information Management system 2 (DHIMS-2). The DHIMS-2 serves as the electronic data system for capturing stillbirth related

indicators in health facilities in Ghana. DHMTs are responsible for overseeing, planning, and budgeting, human resource management, monitoring, and resource allocation to support health facilities. The section addresses objective 2 of the thesis. It is the second published paper from this thesis, in a peer-reviewed journal.

Chapter 6 focuses on **facility health workers and stillbirth data**. Health workers are responsible for initially recording and reporting stillbirth data. This data shapes what gets counted and how it is counted. The data collected by health workers influences stillbirth prioritization and the global and national-level discourse on stillbirths. This section discusses health worker knowledge and practices related to stillbirth recording and reporting in the Ashanti Region, Ghana. This section addresses objective 3 of the thesis.

Chapter 7 provides a **summary** and **critical discussion** on the policy and practice of recording and reporting stillbirths. The summary offers an overview of the findings across all three papers/objectives. Building on Chapters 4-6, the critical discussion section puts forth a theory of change for enhancing stillbirth measurement by improving health systems.

Chapter 8 reflects on the recommendations and implications of the thesis for the broader maternal and child health community.

1.5 Thesis Outline

Chapter	Objectives	Research themes/question	Methods
Chapter 1 Introduction.	Provide an overview of the research.	• Rationale for the focus on stillbirth recording, reporting and health systems.	Targeted literature review. Conversations with experts. General reading on the subject.
Chapter 2 Literature Review.	Review the literature to understand stillbirth measurement.	• How are stillbirths defined globally? • What indicators are associated with stillbirth? • What are the common challenges related to stillbirth reporting and recording? • What data sources are used to record and report stillbirths? • What health worker challenges exist for recording and reporting stillbirth? • What is the stillbirth context in Ghana?	Targeted review of literature to provide background and situate the research/thesis.
Chapter 3 Methods.	Detailed methodology explaining the approach for the PhD, including the specific methodology applied for each research paper.	• Elaborate on the methodology undertaken for the three research papers. • Strengths and limitations of the research methodology approach.	
Chapter 4 Global Stillbirth Policy Review.	Review the legislative environment in countries to understand stillbirths recording and reporting.	• Understand the governance related to stillbirths. • Assess processes established for maternal deaths, stillbirths, and neonatal deaths.	Policy Review. Descriptive quantitative analysis.

		• Identify health information systems commonly used for data collection on maternal and perinatal mortality. • Understand the availability of essential commodities for maternal and perinatal services. • Explore national health workforce policies for stillbirth reporting. • Examine national-level policies and processes on death registration and stillbirths.	
Chapter 5 District health management and stillbirth recording and reporting.	Understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of DHMTs.	• Explore the experiences, perceptions, and attitudes of DHMTs on stillbirth recording and reporting. • Understand stillbirth data flow and how stillbirth data is used by DHMTs. • Explore leadership and support mechanisms available from the district-level to facilitate stillbirth recording and reporting at the facility-level.	Qualitative Research. Purposive sampling.
Chapter 6 Facility health workers, stillbirth recording and reporting.	Gain insights into their practices and challenges related to stillbirth recording and reporting from the perspective of health workers in public health facilities in the Ashanti Region of Ghana.	• Explore the experiences, perceptions, and attitudes of health workers toward stillbirth recording and reporting. • Understand barriers related to stillbirth recording and reporting among health workers. • Identify support mechanisms available to health workers to enable stillbirth recording and reporting.	Qualitative research. Purposive sampling to identify facility health worker cadres. Convenience sampling once at the study site.

Chapter 7 Critical discussion – Summary	Summary of findings from three papers	• What do we know about health systems factors influencing stillbirth recording and reporting: a summary of the research findings.	
Chapter 7 Critical discussion – Framework	Provide a critical discussion of the three papers, proposing a way forward on what is required to strengthen health systems for better stillbirth measurement.	• Critical discussion of the three papers. • Proposed framework for enhancing stillbirth measurement.	
Chapter 8 Conclusion		• Overall recommendations and practical implications going forward.	

2 Chapter 2 Literature Review

2.1 Policy environment for stillbirths

2.1.1 Global perspectives: defining stillbirths

In understanding the policy environment for stillbirths, we first need to understand how it is defined both globally and nationally.

The definition of stillbirth is a key factor influencing prioritization. Establishing a standardized stillbirth definition is critical for comparing stillbirth rates and directing attention to areas with the greatest burden. A standard stillbirth definition is also essential for consistent stillbirth reporting in health facility registries, health management information systems, civil registration and vital statistics systems, and population-based surveys [45]. Table 2 presents the updated definition of stillbirths from WHO, issued in 2022 as part of the International Classification of Diseases (ICD) 11th edition. [46] The updated definition recognizes stillbirths as the *complete expulsion or extraction from a woman of a fetus, following its death prior to the complete expulsion or extraction, at 22 or more completed weeks of gestation*. Previously, the ICD 10th edition defined stillbirths as a fetal death at 500g or 22 completed weeks or more and recommended using the threshold of 1000g or 28 completed weeks, for international comparisons. [47]

As part of ICD-11, gestational age has been prioritized over birth weight in many settings for both clinical and reporting purposes, and the length cut-off is rarely used. Gestational age, measured from the first day of the last normal menstrual period, was maintained at 22 weeks for stillbirth recording (and national comparisons where relevant). When information on gestational age is unavailable for stillbirth, ICD-11 encourages the use of birth weight less than 500 grams as the criteria. Countries with the ability to report stillbirths of 22 or more completed weeks of gestation (early stillbirth) are recommended to do so. For international reporting, it is recommended to report stillbirths of 28 or more completed weeks (late stillbirth) of gestation and all deaths following live birth. The specific mention of 28 weeks for international comparison is due to several reasons,

including the fact that the inclusion of fetal deaths and live births at extremely low gestational ages disrupts the validity of international comparisons and is therefore not recommended. [48] Further, definitions and reporting criteria concerning the lower limit for fetal deaths may differ depending on different national legislation. [49]

Using 28 weeks or more as a benchmark for international comparison allows for the assessment and comparison of stillbirth rates across high, middle, and low-income countries (with many low and middle-income countries aligning behind the 28-weeks definition), each with different levels of health system maturity and varying capabilities for counting and recording stillbirths. This standardized approach ensures that stillbirth data is potentially more comparable, despite the differences among countries. By using this consistent gestational age threshold across countries, it becomes feasible to identify and analyze stillbirth rates more accurately.[50, 51] Using 28 weeks or 1000g threshold for international comparison is beneficial for many low- and middle-income countries, including Ghana, the country of this study. This enables these countries, many of which have developing health systems, to accurately count stillbirths and identify the most appropriate interventions to prevent them.

In addition, WHO has further defined associated areas for stillbirth, including the related areas of fetal death and the timing of the stillbirth. These associated terminologies are reflected in Table 2. All the definitions are extracted from the WHO ICD-11 database. [46]

Table 2: Associated terminologies for stillbirth

Area	*Definition*
Fetal death	*Fetal death is the death of a fetus prior to its complete expulsion or extraction from a woman, irrespective of the duration of pregnancy.*
Antepartum fetal death	*Antepartum fetal death is a fetal death before the onset of labor. If the vital status of the fetus at the onset of labor is unknown, consider it was antepartum if there is the presence of signs of maceration at the time of delivery.*

Maceration	*Maceration describes the degenerative changes that occur in stillbirths retained in utero after death, and the earliest signs are in the form of discoloration and peeling of the skin, leaving regions of raw tissue.*
Intrapartum fetal death	*Fetal death during labor. If the vital status of the fetus at the onset of labor is unknown, consider it was intrapartum if there is fresh skin appearance or no signs of maceration at the time of delivery.*
Stillbirth	*Stillbirth is the complete expulsion or extraction from a woman of a fetus, following its death prior to the complete expulsion or extraction, at 22 or more completed weeks of gestation.*
Antepartum stillbirth	*Complete expulsion or extraction from a woman of a fetus following an antepartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more.*
Intrapartum stillbirth	*Complete expulsion or extraction from a woman of a fetus following an intrapartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more.*
Fresh stillbirth	*Complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin showing no signs of maceration (fresh appearance).*
Macerated stillbirth	*Complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin showing signs of maceration.*

Neonatal death	*A neonatal death is defined as a death during the first 28 days after live birth (days 0-27). An early neonatal death is a death during the first 7 days after live birth (days 0 – 6)*

A fetal death is described as the death of a fetus prior to its complete expulsion or extraction from a woman, irrespective of the duration of pregnancy. The WHO ICD-11 further describes fetal death as a death that may be diagnosed in utero by the absence of fetal heart sounds or, upon delivery, the absence of signs of life. Fetal death before the onset of labor, and if the vital status of the fetus is unknown before delivery, is referred to as antepartum fetal death. Antepartum fetal death is also associated with maceration around the time of delivery. Maceration depicts the degenerative changes that take place in fetuses retained in the uterus after death. The initial indications of maceration manifest as discoloration and peeling of the skin, revealing areas of exposed and raw tissue. Fetal death during labor is commonly referred to as intrapartum fetal death. Intrapartum fetal deaths show no signs of maceration.

Stillbirths are differentiated from earlier pregnancy losses, such as miscarriages, using thresholds based on gestational age or birth weight (Table 3). Gestational age describes the duration of pregnancy measured from the first day of the last normal menstrual period. Gestational age at birth is therefore the duration measured from the first day of the last menstruation period to the day of birth. [6] Gestational age is critical for monitoring the status of the fetus and determining the appropriate interventions should risks be identified. Previously, the WHO ICD-10 used birth weight first (and only if not available, did they use gestational age). Birth weight is defined as the first measured weight of a baby after birth. If possible, this weight should be measured immediately in the hours after birth, prior to the onset of postnatal weight loss. Body length, which refers to the crown-to-heel length of a baby, has also been used in describing stillbirths. In reviewing the three areas of gestational age, birth weight, and body length, the UN-IGME placed an importance on gestational age over birth weight or body length. This recommendation is also aligned with the latest definition of stillbirths by the ICD-11, emphasizing gestational age at 22 weeks. Table 3 provides an overview of gestational age, birth weight, and body length.

Table 3: Gestational age, birth weight and length

Stillbirth marker	Definition
Gestational age	Duration of pregnancy measured from the first day of the last normal menstrual period. Gestational age at birth is therefore the duration measured from the first day of the last menstruation period to the day of birth.
Birth weight	Birth weight is defined as the first measured weight of a baby after birth. This weight should be measured as soon as possible in the hours after birth prior to the onset of postnatal weight loss.
Length	Crown-to-heel length of a baby

Figure 3 provides an overview of the stillbirth-related pregnancy outcomes.

Figure 3: Pregnancy outcomes

Adapted from Lawn et al., (2011) [58]

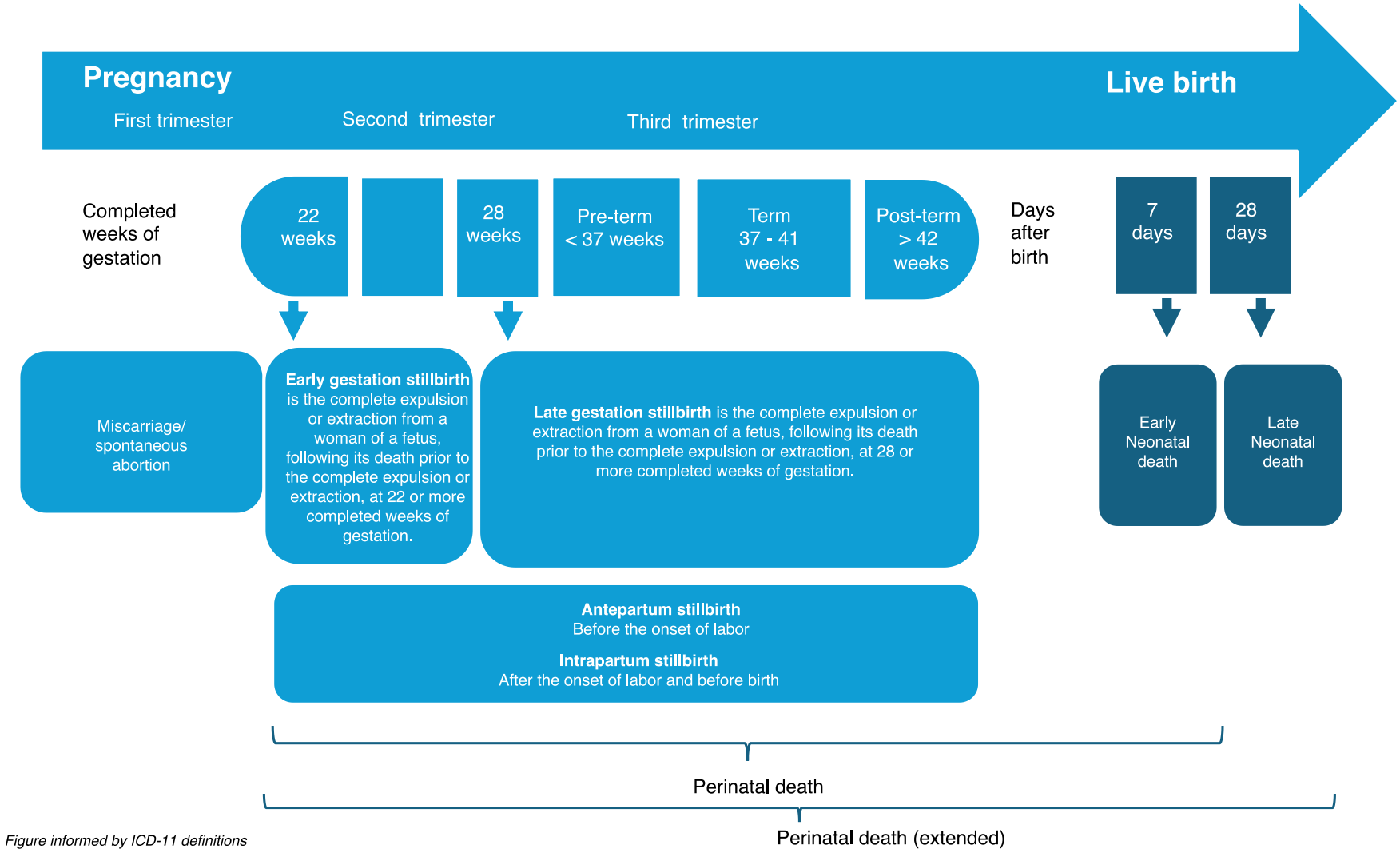


Figure informed by ICD-11 definitions

2.1.2 National policies: defining stillbirths

Inconsistent application of the stillbirth terminology exists across countries. [31, 52] The varying cut-offs used in gestational age and birth weight affect how we record, interpret, count, report, and act upon stillbirths, including their prioritization in national policies and global strategies.[4] [6]

For example, Australia defines stillbirth as a fetal death prior to the birth of a baby of 20 or more completed weeks of gestation or 400 grams or more in birth weight. [53] Across the European region, variations also exist. [54] Ireland defines stillbirth as a fetus born without any signs of life at 24 weeks gestation or more, or with a birth weight of at least 500 grams. [55] Romania aligns with a gestational age of 28 weeks and more, and 1,000 grams or more for birth weight.[56] Greece and Lithuania align their definition of stillbirth with a gestational age threshold of over 22 weeks. Additionally, Lithuania includes a birth weight criterion of 500 grams or more in their definition. [57] In the Middle East, Kuwait defines stillbirth as fetal deaths at or over 28 weeks of gestation. [5] In the Americas, Panama defines stillbirth as a fetal death over 7 months and Guatemala describes stillbirths as fetal deaths at or over 20 weeks. [5, 58] Additionally, even within countries, variations on the stillbirth definition may differ depending on the administrative region. In the United States, for example, the stillbirth definition differs by state. [59, 60]

In summary, approaches to assessing stillbirths differ across countries. While some countries base their assessments solely on gestational age, others consider both gestational age and birth weight. Some countries also utilize either gestational age or birth weight independently. Moreover, countries frequently employ diverse thresholds for gestational age and birth weight, ranging from 20 to 28 weeks for gestational age, and at or over 400 grams for birth weight. This array of approaches introduces numerous combinations and variations, thereby significantly constraining the comparability of stillbirth data across regions, and sometimes within countries. [6] Understanding these variations is important for interpreting and comparing stillbirth data globally and underscores the importance of harmonizing definitions to enable effective policy development aimed at reducing stillbirth rates.

2.1.3 Indicators commonly used in national-level policies/strategies for stillbirths

Incorporating stillbirth measurement into policies allows the global and national public health communities to review and prioritize successful interventions for reducing the stillbirth burden. Once mandated in national legislation, the measurement of stillbirth becomes more feasible, enabling the monitoring and assessment of the overall stillbirth burden in a country. Two indicators are commonly used in national policies and strategies for stillbirth measurement – one, the total stillbirth number, and two, the stillbirth rate.

The total number of stillbirths is described as the absolute number of stillbirths observed in a setting. This total number reflects the overall stillbirth number in a country.

The stillbirth rate, on the other hand, is the proportion of stillbirths per 1,000 total births. Using the recent ICD-11 definition of stillbirths, the stillbirth rate is defined as:

$$\frac{\text{The number of babies born with no signs of life at 22 weeks or more of gestation}}{\text{per 1,000 total births (including live births plus stillbirths).}}$$

Using the stillbirth definition of 22 weeks and greater, allows for the inclusion of early gestation stillbirths as well as late gestation stillbirths (defined as stillbirths starting at 28 weeks).

Table 4 provides an overview of the stillbirth indicators. Throughout this thesis, neonatal mortality, perinatal mortality, under-5 mortality and maternal mortality are presented as related indicators to stillbirth due to the similar underlying pathways, determinants and solutions needed to avert deaths. Avoiding stillbirths, promoting newborn health, and preventing maternal deaths are intrinsically linked. The same interventions required to prevent maternal deaths are the same ones needed to end preventable newborn deaths and stillbirths. This includes scaling up quality of care interventions before conception, and during pregnancy as part of antenatal care (ANC) and across the life course continuum. [6, 26] Women who receive quality midwifery care and regularly attend ANC are 16% less likely to lose their baby and 24 % less likely to experience preterm delivery.

[61] The WHO recommends that pregnant women see a health provider at least eight times. This recommendation is due to the recent evidence suggesting that an increased frequency of antenatal care contacts in the third trimester is linked to a lower probability of stillbirths. [62, 63]

Table 4: Associated indicators for measuring stillbirths

Indicator	Definition
Number of stillbirths	Absolute number of stillbirths.
Stillbirth rate	Number of stillbirths per 1,000 total births.
Number of intrapartum stillbirths	Number of stillbirths where the death occurs after the onset of labor but before birth.
Number of antepartum stillbirths	Number of stillbirths where the death occurs before the onset of labor.
Proportion of stillbirths that are intrapartum[**][64, 65]	Number of stillbirths that are intrapartum divided by total number of stillbirths.
Number of neonatal deaths	Number of children who die during the first 28 completed days of life.
Neonatal mortality rate	Number of neonatal deaths during the first 28 completed days of life per 1,000 live births.
Perinatal mortality	Perinatal mortality is defined as the number of fetal deaths at 22 or more completed weeks of pregnancy, plus the number of deaths among live-born children up to 7 completed days of life, per 1000 total births (live births and stillbirths).
Under-5 mortality rate	The probability a newborn would die before reaching exactly 5 years of age, expressed per 1,000 live births.
Maternal mortality ratio	The number of maternal deaths during a given time period per 100,000 live births during the same time period.

[**] From a policy and quality of care perspective, the intrapartum proportion is important due to its impact on maternal and neonatal outcomes during labor and delivery. [60,61]

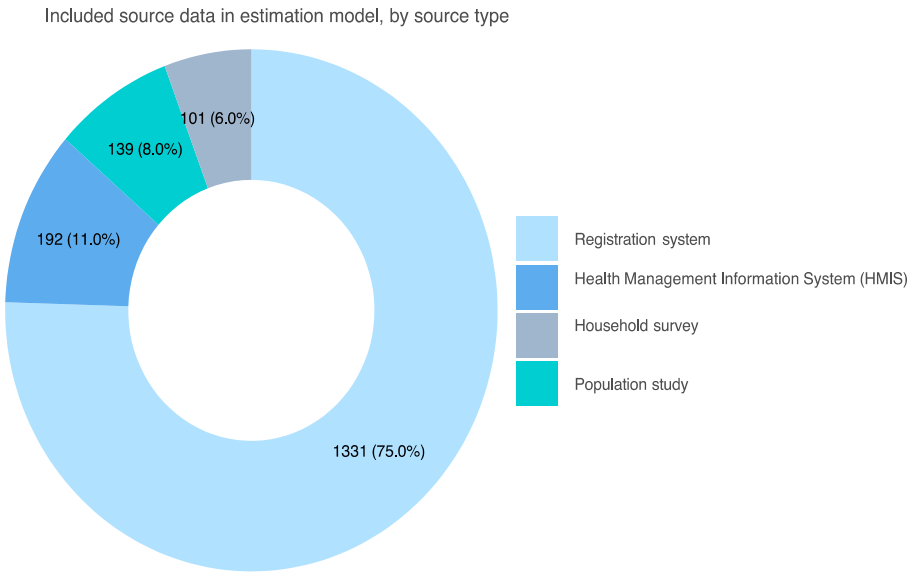
2.1.4 Sources of stillbirth data to inform the stillbirth policy environment

Data sources are important for providing information and tracking reductions in stillbirths over time. These data sources support data collection on prioritized health service indicators which then inform how policies and strategies are developed for stillbirths. The information produced from data sources is used in programme planning, implementation, management, and monitoring of stillbirths. [27] In 2021, data collation conducted by the UN Inter-agency Group for Child Mortality Estimation to inform national, regional, and global stillbirth estimates revealed that vital registration systems, surveys, Health Management Information Systems (HMIS), and a combination of data sources were key in informing stillbirth measurement in countries (see Figure 4). [66]

Generally, there is a lack of data availability for stillbirths across data systems, particularly in sub-Saharan Africa. In cases where data were accessible, substantial challenges in data quality limited the usability of much of the collected data, especially from sub-Saharan Africa (see Figure 5). [66]

Figure 4: Sources of stillbirth data used to inform stillbirth estimations in 2021.

Figures 4 and 5 are adapted from *the 2022 UN Inter-agency Group for Child Mortality Estimations*. [66]



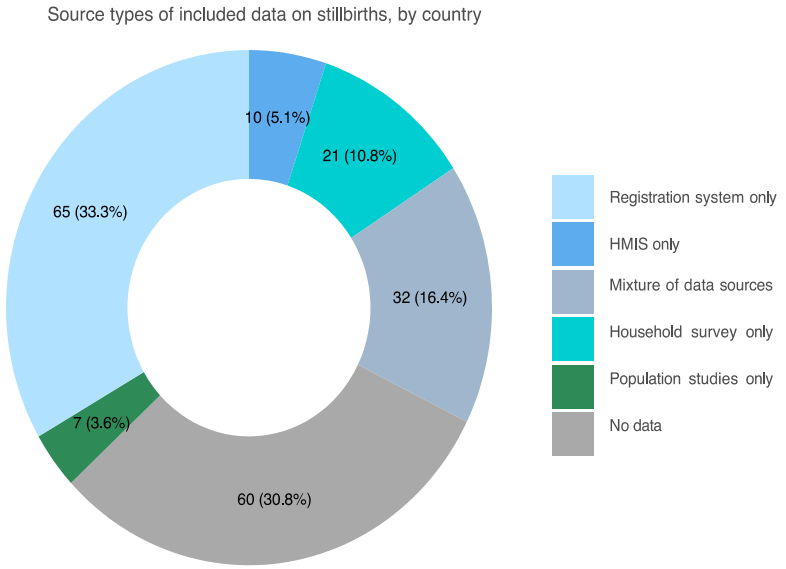
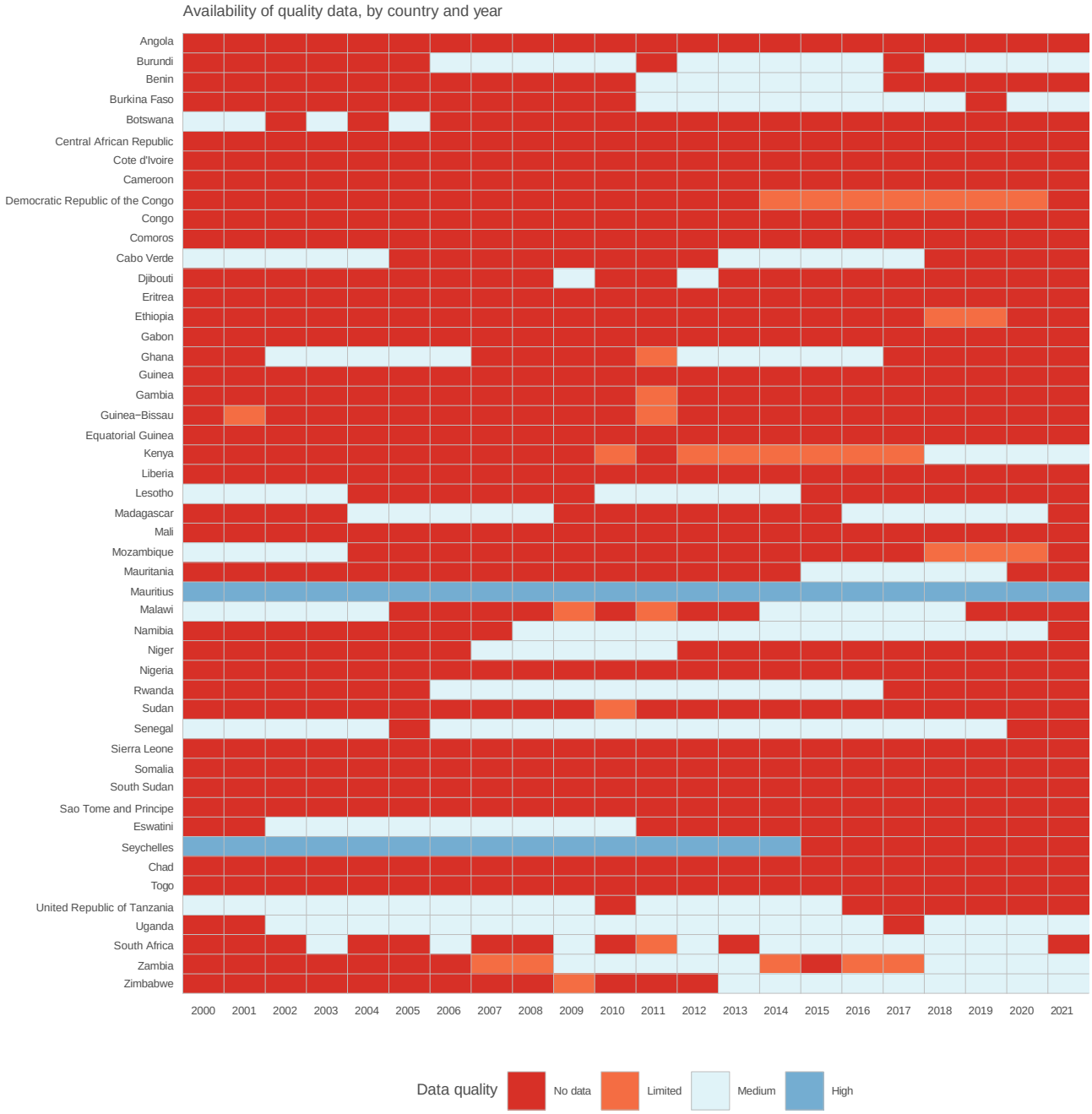


Figure 5: Stillbirth data availability across sub-Saharan Africa.

Adapted from *the 2022 UN Inter-agency Group for Child Mortality Estimations*. [66]



The widely used data sources for stillbirths, including the civil registration and vital statistics system (CRVS), health management information system (HMIS), and population surveys are summarized in Table 5. [6]

The coverage of data systems in Table 5 varies. In many high-income countries, particularly those in Europe and North America, CRVS systems are widely used. Most high-income countries have over 90% coverage for birth and death registration rates, while lower percentages are recorded in LMICs. [67] In the African region, which comprises many LMICs, approximately 40% of countries have less than 50% coverage of birth registration, while about 60% have no data available for birth and death registration. [67]

On the contrary, in LMICs, population surveys are commonly used. [21] Information regarding stillbirths in LMICs is mainly informed by household surveys, particularly the Demographic and Health Surveys (DHS). However, challenges such as timeliness (DHS is conducted every five years), data quality, omission, and under-reporting have been reported in its use. [5, 68, 69]

As more women opt for deliveries in health facilities, health management information systems are becoming critical. Over a period of 20 years, between 2001-2007 and 2015-2021, global deliveries in health facilities increased from 51% to 80%, respectively. [70] Within the same time period, West and Central Africa reported a 15% increase, while Eastern and Southern Africa reported a 26% increase. As a result, facility-based data collection systems, such as HMIS are increasingly playing a key role in stillbirth data and measurement [71] Additionally, in many LMICs where the CRVS registration is lagging, it is recommended that the health system informs the CRVS directly on stillbirth outcomes. [71]

Table 5: Data sources for stillbirth

Data sources for stillbirth	Summary
Administrative data	The CRVS system registers all births and deaths in a country. Many countries also include provisions for stillbirth registration. Health management information systems (HMIS) collect data in health facilities. Few HMIS systems currently report exact gestational age and/or birth weight data on stillbirths. The District Health Management Information System is the most common HMIS data platform.
Household survey and surveillance data	Nationally representative population-based household surveys collect data through pregnancy histories or reproductive calendars, demographic and health surveys, or demographic surveillance. Surveys support in identifying women who may have had a stillbirth and never contacted the health system.

2.1.4.1 Civil registration and vital statistics system

Civil registration includes recording the occurrence and characteristics of vital events, such as births, deaths, marriage, and divorce, pertaining to the population and the community. The vital events internationally recommended to capture, include stillbirths. [72] Civil registration enables individuals and families to document and identify civil status and family relations; claim social, economic, and political rights; and access multiple socio-economic benefits. [73] Civil registration promotes efficient government planning, effective use of resources and aid, and more accurate monitoring of the progress made toward achieving the national and global development goals. [74]

Across countries, different governance arrangements for CRVS are used. [75, 76] In sub-Saharan Africa, according to the UNICEF CRVS country profiles, 27 out of 45 countries include information on fetal death registration in their legal frameworks, whereas 13 countries do not register fetal deaths at all, and 5 countries have no information. [74] Figure 6 provides an overview of the countries.

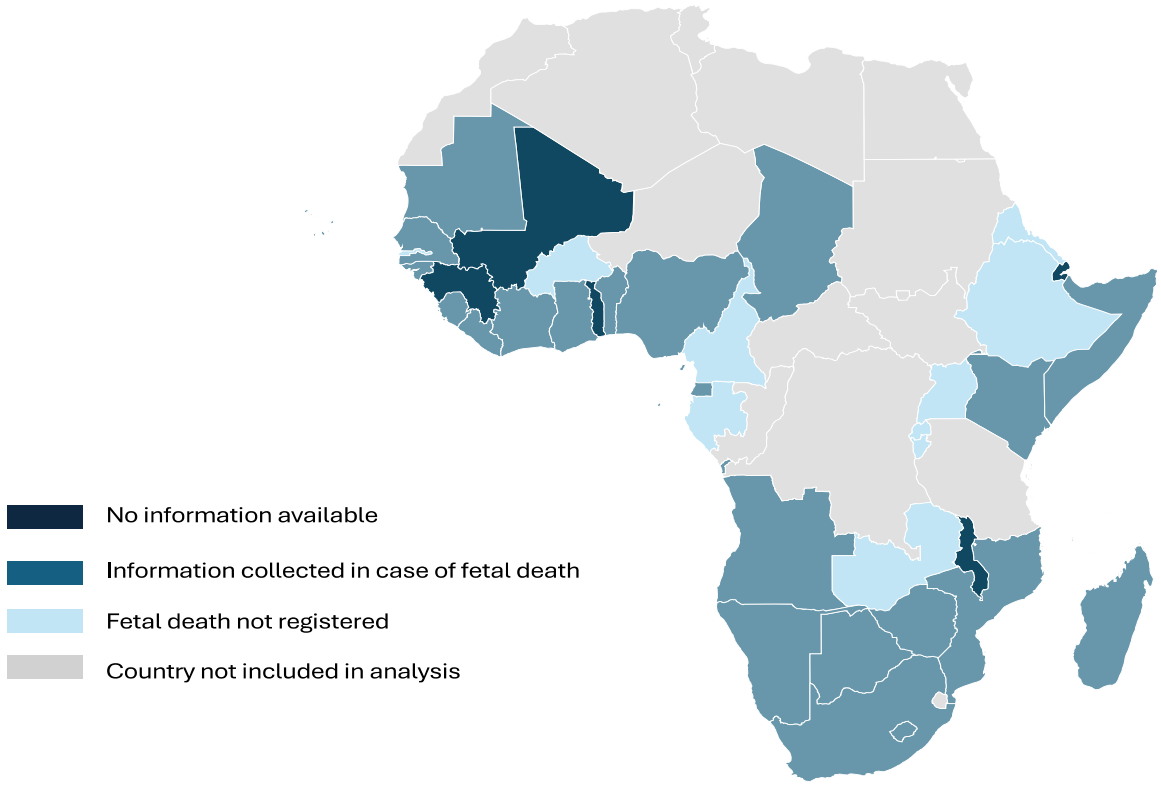


Figure 6: Fetal death registration in national legal frameworks

Even when laws exist, the implementation of these laws is variable between countries with challenges reported in enforcing the law. [74, 77] Specific to stillbirths, its registration in CRVS has lagged compared to the increased registration of vital events including other deaths and live births, which has resulted in gains reported in these areas within the CRVS. [78, 79] For example, in the Kintampo Health and Demographic Surveillance Site of Ghana, despite 72.9% of reported stillbirths occurring in facilities, only around 1% of stillbirths at the community level were reported to be registered in the CRVS. [77]

Known challenges for accurately recording deaths in the CRVS are similar in many data systems. These include insufficient coverage, the accurate counting of the numbers, and a lack of accuracy or completeness of the data. [74] Additionally misreporting of age at death, under-reporting, and

omission or misclassification of deaths have also been reported. [80] Existing data within CRVS systems may only cover part of the population and have incomplete information for deaths (for example, missing information or lack of information on registration details and the cause of death) outside the health facility. [81]

2.1.4.2 Health management information systems

Health management information systems (HMIS) are routine health facility data and management systems that include key information regarding service coverage and utilization. [27] The process includes recording, storing, retrieving, and processing data from the lowest level of health facilities to the national level.

Challenges noted for rolling out HMIS infrastructure and software include human resources i.e., lack of knowledge of health workers in operating the information system, and poor engagement and understanding of senior managers to support and use such systems. [82] The availability of quality data influencing data analysis for decision-making is also a documented challenge. [82] Gaps are also reported in data completeness, timeliness of data reporting and over-reporting on certain indicators from health facilities to the HMIS system. [83]

The HMIS does generally record information on stillbirths. [83, 84] This information is, however, only limited to stillbirths that occur at the health-facility and excludes stillbirths from the community. Further, information on birth weight and gestational age, intrapartum and antepartum, and fresh and macerated stillbirth may be limited in HMIS data. [40, 84] For each birth, generally information on maternal age, place of delivery, mode of delivery, birth weight, gestational age, and birth outcome are to be collected in the HMIS. [19]

The district health management information system (DHMIS) is a type of HMIS system designed to support electronic data collection and analysis. The purpose of DHMIS is to aggregate routinely collected data across all public health facilities in a country, facilitate analysis, forecast required services, and evaluate the performance of healthcare workers. [82, 85-87] The challenges reported for DHMIS are similar to those reported for HMIS.

2.1.4.3 Population-Based Surveys: Demographic and Health Surveys and Multiple Indicator Cluster Surveys

Population health surveys, particularly demographic and health surveys (DHS), are major sources for population data on stillbirths. [88] In settings without high coverage of CRVS, population health surveys are used to gather data on important vital events. Surveys are sources for adverse pregnancy outcome data including stillbirths, and miscarriages. [89] Specific to maternal and child health, the multiple indicator cluster survey (MICS), administered by UNICEF is a household survey designed to collect key household information specifically on women and children to understand the current situation in the country. [90] The MICS serves as a major source of data for stillbirth and neonatal deaths.

Data is often gathered by health cards or memory recall for stillbirths in population health surveys. When information is not available on a health card, maternal recall based on the last menstrual cycle or length of pregnancy, is used to determine gestational age. [89] Recall from mothers, which is one of the main methods of data collection, suffers from the limited awareness by mothers of the importance of gestational age and birth weight during pregnancy. Furthermore, at the community-level, without the presence of a skilled birth attendant, it is difficult for mothers to determine signs of life at birth to report a still or live birth. Socio-cultural and spiritual beliefs in some countries are identified barriers for mothers under-reporting stillbirths. [91, 92]

2.2 Health workers and stillbirth measurement

This section elaborates on the intersection of health workers and stillbirth measurement, exploring the key role played by health workers in such measurements. Additionally, common challenges faced by health workers, including misclassifications and omissions are examined, as they contribute to the under-reported burden of stillbirths.

Health workers serve as the backbone of service delivery and are key in the concerted effort to eliminate preventable stillbirths. The role of a well-trained health worker, along with essential supplies, is seen throughout the entire period of a woman's pregnancy. At the onset of labor, health workers provide the essential quality care necessary to ensure a safe delivery for both the mother and child, including documenting the birth outcome. All associated documentation forms for stillbirth e.g. stillbirth notification forms, labor ward registers, admission books etc., are completed by the attending health worker. Additionally, the entry of stillbirth related data into data collection systems such as CRVS notification, and HMIS, is carried out by a health worker. In some countries, this is done by a doctor, physician assistant, midwife, or nurse in health facilities. At the community level, this is normally a community health worker or a skilled birth attendant. The information is then processed by a health information officer, relevant statistician, statistic officer, or monitoring/surveillance officer.

Figure 7 outlines the importance of a health worker along the data flow process for stillbirths. [93]

Figure 7: Generic process for stillbirth registration.

CHW is a community health worker and MCCD refers to the medical certificate cause of death. Figure 7 is reproduced with permission (see Annex 14*)*. [93]

While numerous studies have discussed the emotional toll experienced by mothers and the care provided by health workers following stillbirths, a significant gap exists in the literature regarding the critical role played by health workers in ensuring the generation of high-quality data for stillbirths. [43, 91, 94-97] This aspect of health worker involvement remains largely unexplored, even though the recording and reporting of stillbirths heavily depend on health worker skills. Figure 5 highlights how data on stillbirth in sub-Saharan Africa is largely absent in many countries. Many of the issues reported on stillbirth data such as missing values, incomplete information, and measurement errors, are due to human errors in data entry and computation. [98] Furthermore, indicated barriers to the recording and reporting of stillbirths by health workers have included limited staff capacity and knowledge of a stillbirth, fear of being held accountable, lack of understanding in the value of recording a stillbirth, data management and use (interpretation, analysis, and planning), and no available systems for regular data review. [23, 73, 99] The health worker-to-patient ratio can also affect stillbirth measurement, where understaffing can lead to lapses in the care provided.

In cases where stillbirth data is captured, health workers are again at the center of all efforts. Stillbirth data accuracy remains substantially worse than adult and child death certificate accuracy. [100-102] Issues such as non-standard definitions, under-reporting, or misclassification of stillbirths, and other data quality issues may render the data unusable. [6] A study from the United Kingdom found that almost 80% of Medical Certificates of Stillbirth (MCS) in the country contained errors and 55.9% had a major error that would alter MCS interpretation. [100] Data availability and quality issues are further aggravated by issues surrounding health workforce knowledge and training, available commodities, and understanding administrative processes to collect and enter information into routine systems. The availability and use of other essential commodities and infrastructure including power/energy, calculators, and computers, can also hinder the compilation, transfer, and utilization of information into routine health information management systems by health workers. [83]

Without information on the location, type, frequency, and timing of stillbirth, health facilities and national level-leaders will face difficulty in prioritizing areas of improvement. National-level data is needed to provide an accurate picture of the stillbirth realities in all countries, improve pregnancy

and childbirth, and increase national and global-level investment to address the most urgent needs in stillbirth. When accurately recording and reporting a stillbirth, the right skills, competencies, health worker engagement, motivation level, and teamwork skills are needed, in addition to supportive supervision, protocols, training and equipment. [26, 35, 103]

2.2.1 Stillbirth misclassifications between antepartum and intrapartum

Half of all stillborn babies begin labor alive but die before birth. [10, 18, 104] In 2021 alone, intrapartum stillbirths[††] accounted for 42 % of the global stillbirth burden, with higher percentages recorded for the two regions that experience a high stillbirth burden, sub-Saharan Africa and Central/Southern Asia. In these high-burden settings, one in two stillbirths are intrapartum. [7] Intrapartum stillbirths can be prevented with attention to quality of care, focusing on labor monitoring availability linked to timely action. [105] However, gaps have been reported in the literature due to health facilities not providing accurate data. [7] In cases where data on stillbirths are collected, unreliable information is shared, thereby affecting appropriate clinical interventions. Specifically concerning antepartum and intrapartum stillbirths, in some contexts, fresh and macerated skin appearance is used to classify and report intrapartum/antepartum stillbirths. [25] The use of fetal skin appearance as the sole measurement proxy is challenging.

Fetal appearance based on skin assessment coupled with gestational age and birth weight can be used to describe stillbirth. A fresh stillbirth is described as the complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin showing no signs of maceration (fresh appearance). A macerated stillbirth is described as the complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin

[††] Antepartum stillbirth deals with the complete expulsion or extraction from a woman of a fetus following an antepartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more. Intrapartum stillbirth involves the complete expulsion or extraction from a woman of a fetus following an intrapartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more.

showing signs of maceration. In reviewing the literature, using skin appearance alone is not an accurate proxy for stillbirth classification due to the subjective nature applied by the attending health worker. [99, 106, 107] Studies have found provider descriptions of fresh or macerated stillbirths to be inaccurate compared to the actual time since fetal death. [22, 25] The UN-IGME and the WHO, as part of the ICD-11 release, are encouraging countries to use gestational age and birth weight in addition to monitoring of fetal heart activity on auscultation or ultrasound on admission to the labor ward. [13, 46]

The terminology used to characterize deaths occurring around the time of birth is prone to misclassification. [45] Properly classifying a stillbirth is essential to improve understanding of when a death occurred and is important to guide clinical intervention for quality service delivery. Globally, 42% of all stillbirths are intrapartum. [6] Distinguishing between an intrapartum and antepartum stillbirth can be difficult. Studies have recorded high misclassification of antepartum and intrapartum stillbirths. [22, 23] Reasons cited in the reviewed studies include lack of knowledge amongst staff on clinical data, an understanding of terminology, fear of punitive measures when complications occur during childbirth, and a lack of understanding the value in recording true antepartum or intrapartum stillbirths. Additionally, antepartum stillbirths have been linked to the quality of care received during pregnancy whereas intrapartum care is associated with the quality of care provided during labor. [24, 105] Furthermore, as previously mentioned, using fresh or macerated skin appearance to determine the timing of stillbirth, can also contribute to misclassification. [25, 99]

2.2.2 Misclassifications with spontaneous abortions; early gestation stillbirth and late gestation stillbirth

It is estimated that one in five pregnancies will result in a miscarriage. [108-110] Both stillbirth and spontaneous abortions (also referred to as miscarriages) relate to the loss of a fetus. The differentiating factor is the timing of the loss, informed by the gestational age of the pregnancy. Work by the UN-IGME Core Stillbirth Estimation Group, recognizes stillbirth as pregnancy losses at 22 weeks and over [13], whereas miscarriages can be classified as spontaneous pregnancy losses

before 22 weeks. [5] Correctly classifying a fetal death as a miscarriage versus a stillbirth will depend on maternal recall of the last menstrual cycle or gestational age of the fetus and available clinical tools, such as early ultrasound. Moreover, the gestational age limit defined in a country for stillbirths and abortions, may not be practiced by health workers, therefore contributing to misclassification. [111]

Closely related, differentiating between intentional late term induced abortion and stillbirth also poses a challenge. [112] In the case of late-term induced abortions where women deliver at home and then present to a health facility with post-abortion complications, these cases are sometimes incorrectly classified as a stillbirth. [113]

Misclassification also occurs between early and late gestation stillbirth. Early gestation stillbirth, involving stillbirths at 22 weeks or more of gestation could be misclassified by health workers who are not able to distinguish between early gestation stillbirth (at 22 to 27 completed weeks of gestation) and late gestation stillbirth (at 28 or more completed weeks of gestation). [46, 71]

2.2.3 Misclassifications with neonatal deaths

The first 28 days of a child's life, also known as the neonatal or newborn period, are the most vulnerable. Progress has been made in newborn health with the number of newborn deaths declining from 5.0 million in 1990 to 2.4 million in 2019. [61] In 2020, research by WHO revealed that 47% of deaths under five years old occur in the first 28 days of life. [114] Within those 28 days, a greater number (75%) of neonatal deaths occur in the first 7 days (first week). Early neonatal deaths that occur within the first 7 days of life alongside stillbirths are referred to as perinatal deaths. [115] Most newborn deaths are preventable and treatable. The most common causes of newborn death are due to prematurity, intrapartum-related deaths (including birth asphyxia), and neonatal infections. [18] However, these outcomes can be averted. Quality of care, skilled birth attendance, and postnatal care for mothers and babies are recognized as priority strategies to reduce neonatal mortality.

Misclassifications have been reported for stillbirth and neonatal death. [25, 116-118] In some settings where neonatal death is seen as a quality of care issue, there is a tendency among health workers to avoid blame by recording neonatal deaths as intrapartum stillbirths. [23, 25] A study in Nepal across 12 public hospitals reported that 46% of documented intrapartum stillbirths were potentially misclassified when in actuality they were newborn deaths. Of this number, all the documented stillbirths had a fetal heart sound on admission, and 95% had a fetal heart sound 15 minutes before birth. However, neonatal resuscitation was not initiated at birth. Misclassifications are likely to occur following complications during delivery, or when a preterm birth or low birth weight baby is delivered. [23] Further, misclassifications of early neonatal death and stillbirths have been reported in the CRVS systems. [119] This is done to avoid reporting both a death and a birth, within days, sometimes often moments between the two. From a monitoring and measurement perspective, this hinders the development of both clinical and non-clinical interventions aimed at addressing reported gaps for stillbirth in the health system.

2.2.4 Omissions of stillbirths

The recording of stillbirths may be entirely absent from a data system. This could be due to several reasons, including inadequate awareness of a stillbirth and the related thresholds used within a particular country. For example, a lack of uniformity in the definition of stillbirths can lead to omissions. Similarly, in settings where blame is prevalent within the health system, health workers may under-report or forgo recording and reporting stillbirths out of fear of punishment. A study from India found that child deaths were under-reported due to fear of punitive actions. [120] Additionally, a culture of blame and the application of punitive actions against health workers were widely acknowledged to discourage accurate reporting of stillbirth, as the full account of the circumstances surrounding death is often not shared when blame is prevalent. [121, 122] Furthermore, research has shown that stillbirths are sometimes not reported to conceal errors in healthcare provision.[123]

The absence of active involvement and engagement of health workers in documenting and reporting stillbirths can further perpetuate the under-reporting and omissions of stillbirth occurrences. This lack of engagement may stem from various factors, including a lack of

awareness, inadequate training, and the absence of standardized protocols and tools for recording and reporting stillbirths within healthcare facilities. [5, 124]

Finally, limitations in the data coverage of deaths may not present a full account of the stillbirth burden. [71] This is especially true for stillbirths that occur at the community-level where stigma and blame can lead to unreported stillbirths. [92, 125]

2.2.5 Perinatal death audits and stillbirth measurement

For health workers, and the health system at large, mortality audits are a crucial learning component for understanding death causes and identifying process gaps within the health system to improve and make every birth count. The concept surrounding mortality reviews for mothers and babies has evolved over the past decades. The maternal death surveillance review (MDSR) launched in 2012 is a continuous learning cycle that investigates the causes of maternal deaths and acts on the weaknesses identified. The primary goal of MDSR is to reduce preventable maternal mortality through continuous action and a surveillance cycle of identification, quantification, notification, and review of maternal deaths followed by the interpretation of the aggregated information and recommended actions to prevent future deaths. [126] Over the years of implementing MDSR, there was acknowledgment to approach the review through a holistic lens incorporating perinatal health. The maternal and perinatal death surveillance and response (MPDSR) is similar to MDSR and includes a focus on identifying causes of death for mothers and babies. [46]

A significant component of MDSR and MPDSR are reviews or audits, with the terms used interchangeably. For this thesis, audits are used. Audits are quality assurance (internal checks) and control (external evaluation) tools used to monitor progress and ensure that processes and systems function how they are intended to function. According to WHO, there are six processes for the audit cycle: (1) identifying cases; (2) collecting information; (3) analyzing information; (4) recommending solutions; (5) implementing solutions; and (6) evaluating both the process and the outcomes, and refining the process as indicated. [127]

For stillbirth measurement, mortality audits are critical to understanding the absolute number and associated contextual elements such as time of death, type of stillbirth, frequency, and stillbirth markers (gestational age, birth weight, and length). Mortality audits have implications for stillbirth measurement and reporting, for both the health worker and the overall health system. An adapted summary table is provided in Table 6. [127]

Table 6: Influence of health facility audits on stillbirth measurement and reporting

Implications	Identification of a death	Recording/ reporting of the death	Team-based collaborative learning review	Learning and responding with action
Health worker	Build capacity and empower health workers to count and report stillbirths	Classification and accurate completion of any associated reporting form/medical records for noted stillbirths	Identify issues and solutions for stillbirth without fear of blame or litigation	Translate review into health workforce strategies to improve stillbirth measurement and reporting
Health systems	Increased coverage of routine health information systems	Ability to track mortality trends	Use of objective measures to review and learn from the process to improve the quality of care	Improve service delivery for both mother and health worker

2.3 Stillbirths in Ghana

Three in four stillbirths occur in sub-Saharan Africa or Southern Asia. In sub-Saharan Africa alone, the collective stillbirth rate of 21.0 per 1,000 total births is seven times higher than the countries found in the northern hemisphere. If action is not taken, many countries in Africa will miss the ENAP target of 12 or fewer stillbirths per 1,000 total births by 2030. This is particularly alarming as the continent's portion of the global number of stillbirths has increased from 26% in 2000 to 45% in 2021. [6]

Ghana, a country in sub-Saharan Africa, defines stillbirth as a baby delivered with no signs of life (gasping, heartbeat, or limb movements) after 28 completed weeks of pregnancy. [128] The country is a signatory to the ENAP and has developed a National Newborn Health Strategy and

Action Plan, aiming to reach a SBR of 12 or fewer stillbirths per 1,000 total births by 2030. Currently, though improvements have been made in stillbirth reduction (between 2017 and 2018, the SBR decreased from 15 to 13.9 per 1,000 total births), the SBR for Ghana stagnated from 12.7 to 12.8 per 1,000 total births between 2019 and 2021. [129] The increase in the SBR can be attributed to lack of skilled attendants, inadequate emergency obstetric services and inadequate health infrastructure.[130] Similarly, disruptions in essential health service provision during the COVID-19 Pandemic between 2019-2021 led to reductions in care-seeking behavior for maternal health. [131, 132] At the community level, stillbirth data remains fragmented and varied. Information from the latest publicly accessible DHS conducted in 2014, indicates that out of 9,396 women aged 15-49 who participated in the survey, the estimated stillbirth rate was 14 stillbirths per 1,000 total births. [133] The number may underestimate the true population-level stillbirth rates due to biases introduced through omission and misclassification.

Most stillbirths in Ghana occur in the third trimester of pregnancy, commonly referred to as late gestation stillbirths. This is not surprising as few early gestation stillbirths are reported, if at all. A recent study from a district in Ghana revealed that most stillbirths are fresh (about 56.7%) and 43.3% of stillbirths are macerated. [134] Other studies have also reported higher percentages of fresh stillbirths compared to macerated stillbirths. [130, 135] Unexplained intrauterine fetal death (18.4%), prolonged or obstructed labor (14.9%), hypertensive disease (9.9%), and malaria in pregnancy (8.5%) were the leading causes of stillbirth in a reported study from Ghana. [134] Concerning the number of institutionalized versus non-institutionalized deliveries, across Ghana, most deliveries (56%) occur in a health facility. Looking closely at the type of health facility, 54% of deliveries occur in a government hospital or polyclinic, 26% in a government health center or health post, and 20% in a private clinic or maternity home. [35] Additionally, a study conducted in a 123-bed secondary referral hospital in the northern part of Ghana, serving a population of about 165,000 people, and receiving referrals from numerous health facilities in the area, including private clinics, outlined the most common delivery methods. These included spontaneous vaginal delivery (82.6%), with a cesarean section being the next most frequent (12.5%), followed by assisted or instrumental deliveries (5.0%). [130]

Within the Ghanaian context, many stillbirths can be averted. Interventions such as labor monitoring, improved peri-conceptual health and nutrition, and high-quality antenatal and delivery care can prevent stillbirths. [35, 130] However, due to limitations of the health system, some stillbirths are not prevented. Shortages have been reported with health facilities being understaffed and some facilities lacking essential equipment. The limited number of health workers has led to instances where women are admitted in labor with live fetuses but end up delivering stillbirths due to insufficient monitoring during labor, failing to identify issues and prompt appropriate interventions. [35]

2.4 Conclusion

The literature review focused on the main areas relevant to this research: 1) the policy environment for stillbirths, and 2) health workers and stillbirth measurement.

In the policy environment section, an overview of how stillbirths are defined was provided along with an examination of how stillbirths are positioned across countries, including the variability in definitions. The review investigated the indicators commonly used in national-level policies/ strategies on stillbirths and the sources of stillbirth data used to inform the stillbirth policy environment.

In the section on health workers and stillbirth measurement, the review explored issues such as omissions, under-reporting, and misclassification of stillbirths, commonly experienced by health workers responsible for collecting stillbirth data.

Finally, the review examined the stillbirth environment in Ghana.

3 Chapter 3 Research Methodology

This chapter of the thesis presents the research methodology used for the three papers/objectives. It provides an additional overview of the methodology captured in Chapter 4 (global stillbirth policy review), Chapter 5 (District Health Management Team (DHMT)) and Chapter 6 (facility health workers).

The methodology for objective 1/paper 1 is presented individually, while objective 2/paper 2 and objective 3/paper 3 are presented as an integrated methods approach since similar qualitative research processes were used.

All methods were approved by the relevant academic and in-country ethical committees.

3.1 Review the legislative environment in countries to understand stillbirths recording and reporting

3.1.1 Rationale for research approach

Objective 1 reviewed country responses and national policy documents submitted to the WHO Reproductive, Maternal, Newborn, Child, and Adolescent Health (RMNCAH) Policy Survey. The approach taken for this stillbirth policy review is aligned with the systematic process developed and validated by WHO for the broader RMNCAH policy survey review. [136] The WHO RMNCAH policy review process included a careful examination of national responses against the content of national source documents, and communications with Ministries of Health to validate survey responses.

3.1.2 Objectives

Using responses submitted by countries as part of the WHO RMNCAH Policy Survey (2018-2019) and submitted national documents, the stillbirth policy review aimed to review the legislative

environment in countries to understand stillbirth recording and reporting and facilitate focused stillbirth recommendations for country implementation ahead of the 2030 agenda. Specific objectives included:

1. Understand the governance related to stillbirths.
2. Assess processes established for reporting maternal deaths, stillbirths, and neonatal deaths.
3. Identify health information systems commonly used for data collection on maternal and perinatal mortality.
4. Understand the availability of essential commodities for maternal and perinatal services.
5. Explore national health workforce policies for stillbirth reporting.
6. Examine national-level policies and processes on death registration and stillbirths.

The legislative and policy documents in this study are used to describe policies, strategies, laws, plans, and guidelines.

3.1.3 Overview

The WHO RMNCAH Policy Survey is a comprehensive policy survey designed to assess the adoption of WHO recommendations in national health policies and guidelines in the areas of sexual, reproductive, maternal, newborn, child, and adolescent health. The survey aims to evaluate strides made by countries toward the commitment to improve outcomes for women, children, and adolescents through the inclusion of WHO recommendations in national legislation and policies. [137] The survey outlines key questions requiring responses by countries to understand the depth and breadth of national policies and guidelines on sexual, reproductive, maternal, newborn, child, and adolescent health. The survey, communicated to all 194 Member States or countries of WHO to complete, covers 6 modules, namely cross-cutting, maternal and newborn health, child health, adolescent health, reproductive health, and gender-based violence. Member States do not need to complete the survey. For the global stillbirth policy review, the research focused on two modules that have relevance to stillbirth, namely: the cross-cutting RMNCAH module, and two, the maternal and newborn health module.

In total, 155 countries responded to the WHO RMNCAH Policy Survey held in 2018-2019. The survey was conducted by WHO from August 2018 through May 2019. The depth of completing the survey varied between countries. The survey had around 331 primary questions, many of which had sub-questions relating to the primary question. All survey questions required a categorical or a numeric data response. Categorical data responses for this survey consisted of only two or binary categories. For example, "is there a national policy/law that requires every death to be registered, yes or no." Numeric data responses for the survey require a counted or measured quantity. For example, "has your country developed a national target for stillbirth, include the target and year." In addition to the responses, countries were requested to submit national-level documents which could be used to substantiate submission responses.

For each country, the WHO country office or other assigned country focal point was responsible for coordinating with the Ministry of Health and/or other United Nations agencies to complete the survey. An online portal administered by WHO was used to collect responses to the survey, alongside any accompanying/associated documentation.

3.1.4 Process

Approval to review country responses to the broader WHO RMNCAH policy survey was provided by WHO (refer to Annex 1 for the WHO approval). The London School of Hygiene and Tropical Medicine (LSHTM) Ethics Committee also approved the study (reference number 26502 – refer to Annex 2). Advanced academic training in research ethics was completed (see Annex 3).

WHO conducted a systematic data validation for the entire RMNCAH policy survey. This process included reviewing the national documents that countries submitted against the survey question response and indicating if there was a match or mismatch between the content of the national documentation and the submitted responses by countries (national documents were required as part of country responses for each question). An additional validation exercise was also conducted to categorize the national documentation submitted by countries to the relevant associated question. However, it is important to highlight that the broader validation done by WHO did not

systematically focus on or critically review stillbirths. The validation exercise conducted by WHO focused broadly on RMNCAH. Therefore, the purpose within this thesis was to assess national policies to understand their implications for stillbirths.

The process outlined for the stillbirth policy review involved a systematic three-step process which is captured in Chapter 4 and further elaborated below:

Step 1: Reviewed all the survey questions (and associated sub-questions) in the two modules of interest to this study. This included 160 questions from the cross-cutting module as well as the maternal and newborn modules. The review of the questions was guided by the inclusion criteria.

- All questions that specifically mention stillbirth.
- Relevant health systems building block questions related to perinatal care services – legislation and governance, financing, service delivery, health workforce, data/health information, and essential medicines and equipment. These are essential facilitators for creating an enabling environment for stillbirth reduction.
- Other questions related to stillbirth. For example, neonatal and maternal deaths are important signals that can help us assess the magnitude of stillbirth in countries.

Questions that did not mention stillbirth or its associated areas (neonatal and maternal deaths) and references made to RMNCAH without mention of stillbirth were not examined. Further, questions relating to broader clinical interventions and preventive measures for child health and maternal health were outside the scope of this exercise. From the inclusion criteria, I was able to narrow down the list of survey questions relevant to my study to 24.

- Step 2: Following step 1, a request was submitted to WHO to obtain the country responses for the 24 questions and all national documents submitted by countries to those questions. In the response from WHO, some data quality issues were flagged for 8 questions. These included: 3 questions that required verification in the national health information management system, 2 questions on the frequency of death review panel meetings, and 5 questions that addressed general human resources. The human resources questions were excluded for more focused

questions on human resources for stillbirths. From this step, 16 questions were relevant to the study. The rationale for excluding the 8 questions is reflected in Table 7.

Table 7: Rationale for excluding the eight questions for Objective 1

	ID	Thematic Area	RMNCAH Policy Question	Rationale for excluding
1	MN_23	Childbirth Policy	Does the country have a national policy/guideline on the right of every woman to have access to skilled care at childbirth?	Focused question on human resources for stillbirths
2	CC_57	Surveys and health management information systems	Does your national health information system (HIS) collect and report on the following data?	Requires verification in national health management information systems
	CC_57e		Number or rates of live births	
	CC_57f		Number or rates of stillbirths	
	CC_57g		Number or rates of newborn deaths?	
	CC_57h		Causes of newborn death?	
3	MN_68	Human Resources Policy	Are there national policies/guidelines that set forth a competency framework for maternal and/or newborn health care?	Focused question on human resources for stillbirths
4	MN_69	Human Resources Policy	Is there a continuous professional education system in place for primary health-care clinicians and/or nurses to receive maternal and/or newborn-specific training?	Focused question on human resources for stillbirths
5	MN_70	Human Resources Policy	Is there a national policy/guideline on education of midwifery care providers based on International Confederation of Midwives (ICM) competencies?	Focused question on human resources for stillbirths
6	MN_71	Human Resources Policy	Is there a national policy/guideline on regulation of midwifery care providers (doctors, nurses, and midwives) based on ICM competencies?	Focused question on human resources for stillbirths
7	MN_88	Maternal deaths	How often does the national panel (committee) meet?	Frequency of death review panel meetings
			Monthly	
			Quarterly	
			Semi-annually	
			Annually	
			Unknown	
8	MN_89	Maternal deaths	When did the panel last meet?	

The list of included 16 questions comprised of: a question relating to national targets for SBR, U5MR, and NMR; 4 questions on policies for death registration processes (birth registrations were not accounted for in this study as the term is used to refer to registration of live births, not stillbirths or fetal deaths); 2 questions on essential medicines and equipment; a question on surveys and health information management systems; and 8 questions on death reviews. From the 16 questions, original country responses to 12 questions submitted by the 155 responding countries in all languages were included for the global stillbirth policy review. For the remaining 4 questions, the questions were adjusted because though the question is relevant to stillbirth, stillbirth is not directly mentioned within the framing of the question. For example, one of the original survey questions states: "is there a national policy/law that requires every death to be registered?" The question has direct relevance to stillbirth, but stillbirth is not directly mentioned. Therefore, the question is reframed/adjusted to "is there a national policy/law that requires every death including [stillbirth or fetal death] to be registered?" The complete list of questions is reflected in Table 8.

Table 8: List of included survey questions for Objective 1

	ID	Thematic Area	RMNCAH Policy Survey Original Question	This study adjusted question	Associated study objective
Module 1: Cross-cutting					
1	CC_11b	Introductory	Has your country developed a national target for any of the following indicators? [Under-five mortality rate]	Not applicable	Objective 1
			Target [per 1000 live births]		
	CC_11c	Introductory	Has your country developed a national target for any of the following indicators? [Neonatal mortality rate]	Not applicable	Objective 1
			Target [per 1000 live births]		
	CC_11d	Introductory	Has your country developed a national target for any of the following indicators? [Stillbirth rate]	Not applicable	Objective 1
			Target [per 1000 live births]		
2	CC_51	Policies on death registration processes	Is there a national policy/law that requires every death to be registered?	Is there a national policy/law that requires every death including [stillbirth or fetal death] to be registered?	Objective 6

3	CC_52	Policies on death registration processes	Does the policy/law require cause of death registration to be in line with ICD-10?	Does the policy/law require cause of death registration [for stillbirth or fetal death] to be in line with ICD-10?	Objective 6
4	CC_53	Policies on death registration processes	Is there a policy/law that requires routine audit and/or review of death certification for maternal, perinatal, neonatal and/or child deaths?	Is there a policy/law that requires routine audit and/or review of death certification for [stillbirth or fetal death]?	Objective 6
5	CC_54	Policies on death registration processes	Does the policy/law that requires routine audit and/or review of death certification do any of the following?	Not applicable	Objective 4 Objective 6
	CC_54a		Require the issuance of medical certificates of cause of death?	Require the issuance of medical certificates of cause of death for [stillbirth or fetal death]?	
	CC_54b		Recommend training health workers in filling out death certificates using the International Classification of Diseases (ICD)?	Recommend training health workers in filling out death certificates using the ICD-classification for stillbirth?	
	CC_54c		Require death data recorded at health facilities or by community health workers (CHWs) to be provided to the national statistics office, civil registration system, or equivalent bodies?	Require death data recorded on [stillbirth or fetal death] at health facilities or by community health workers to be provided to the national statistics office, civil registration system or equivalent bodies	
	CC_54d		Require sharing individual death records within the health system and between central and district/regional levels?	Require sharing of individual death records on [stillbirth or fetal death] within the health system and between central and district/regional levels?	
	CC_54e		Recommend verbal autopsy on community deaths for determining cause of death?	Recommend or use verbal autopsy on [stillbirths or fetal death] at the community level for determining cause of deaths?	
6	CC_59	Surveys and health management	What are the three most commonly used data sources to compare maternal, newborn, child, and	Not applicable	Objective 3

		information systems	adolescent mortality rates in your country to mortality rates in other countries? National Health Statistics Civil Registration and Vital Statistics Population-based survey WHO website or reports UNICEF website or reports UN SDG website or reports WB website or reports UNDP website or reports UNFPA website or reports Institute for Health Metrics Global Burden of Disease Countdown to 2030 website or reports Other		
Module 3: Maternal and Newborn Health					
7	MN_75	Essential Medicines and Equipment	Are there national policies/guidelines on essential medicines and equipment?	Not applicable	Objective 4
8	MN_77	Essential Medicines and Equipment	Are any of the following supplies and equipment included in the national list of commodities indicated for use of pregnancy, childbirth and postpartum care? Obstetric ultrasound machine? Self-inflating bag (newborn size) with neonatal and pediatric masks of different size and valve? Oxygen supply? Pulse oximeter? Blood and blood products? Vacuum aspiration?	Not applicable	Objective 4
9	MN_84	Maternal deaths	Is there a national panel (committee) to review maternal deaths in place?	Not applicable	Objective 2
10	MN_87	Maternal deaths	Does this national panel (committee) include stillbirth or neonatal death reviews? [Y/N]	Not applicable	Objective 2
11	MN_90	Maternal deaths	Is/are there a subnational panel(s) (committee(s)) to review maternal deaths in place?	Not applicable	Objective 2
12	MN_92	Stillbirths	Is there a national policy/guideline/law that requires stillbirths (fresh or macerated) to be reviewed?	Not applicable	Objective 2
13	MN_93	Stillbirths	Is there a facility stillbirth review process in place?	Not applicable	Objective 2

14	MN_95	Neonatal death	Is there a national policy/guideline/law that requires neonatal deaths (0-28 days) to be reviewed?	Not applicable	Objective 2
15	MN_96	Neonatal death	Is there a national policy requiring classification of the causes of stillbirths and neonatal deaths according to the ICD-PM (WHO application of ICD-10 to deaths during the perinatal period) classification?	Not applicable	Objective 2
16	MN 97	Neonatal death	Is there a facility neonatal death review process in place?	Not applicable	Objective 2

- Step 3: Reviewed national documents to extract key information on the adjusted questions. In total, over 6,500 national-level documents were submitted by countries for the full survey, spanning all the official UN languages (English, French, Spanish, Russian, Chinese, and Arabic). 4,700 of these documents were policies, strategies, laws, plans, and guidelines. 2,817 documents were pertinent to the scope of this study. 885 documents were in English. National documents not written in English were excluded. Table 9 provides an overview of the different documents across the UN languages.

The purpose of the national document review was to identify relevant national policies, guidelines, and legislative instruments on stillbirths across countries, and review the national documents with a stillbirth lens, informed by the key search terms. Search terms used for this analysis included: still, stillbirth, still birth, fetal, foetus, fetus, foetal. The systematic process undertaken to review the national documents is captured in Annex 4.

Table 9: Distribution of national documents pertinent to objective 1

WHO Region	Arabic	Chinese	English	French	Not Official Language	Russian	Spanish	Grand Total
Europe			98	30	689	50	15	882
Americas			77	14	52		464	607

Africa			211	205	47			463
Eastern Mediterranean	91		175	32				298
Western Pacific		24	174		99			297
South-East Asia			150		120			270
Grand Total	91	24	885	281	1007	50	479	2817

3.1.5 Data analysis

The data was analyzed using the WHO Health Systems Building Blocks Framework. [27] The health systems framework was most appropriate as the topic of the research aimed to understand stillbirth measurement through a health systems lens. Moreover, the framework allowed for the description of various organizations, institutions, resources, and stakeholders that work together to reduce stillbirth rates. [138, 139]

A descriptive analysis approach was used to analyze the country data. Regional groupings using the WHO regional office categorization, alongside the World Bank country income classification and the fragile, conflict-affected, and vulnerable (FCV) country classification were also used.

- The WHO regional office categorization presented chronologically includes the African Region, Eastern Mediterranean Region, Southeast Asian Region, European Region, Western Pacific Region and Region of the Americas.
- The World Bank income classification includes low-income, low-middle-income, upper-middle-income, and high-income countries.
- The World Bank's fragile, conflict-affected, and vulnerable country classification includes high-intensity conflict, medium-intensity conflict, and high institutional and social fragility (including non-small and small states).

Categorization by region indicates where the most significant legislation and governance gaps exist and can shed light on potential regional contextual factors facilitating or hindering stillbirth outcomes. Classification by income level offers complementary perspectives on resourcing implications for stillbirth. Grouping by fragility level helps to understand how stillbirth is prioritized in settings where health systems are disrupted by humanitarian crises. [140, 141]

STATA 16 software was used for data analyses. R software was used for visualization.

3.1.6 Data reliability and validity

An extensive data validation process was conducted by WHO for the full RMNCAH policy survey. This broad validation done by WHO did not systematically focus on, and critically review stillbirths. The stillbirth policy review undertook a second layer of validation specific to stillbirth, informed by the earlier WHO approach to review the national documents.

The review of country documents for the stillbirth policy review was conducted by three individuals. A systematic approach was developed to validate and ensure that a standard approach was used. The systematic data validation protocol is captured in Annex 4. Country responses and STATA/R data cleaning and analyses were reviewed by a member of the supervisory committee.

3.2 Practices and challenges related to stillbirth recording and reporting in public health facilities in the Ashanti Region

3.2.1 Objective

Objectives 2 and 3 aimed to understand stillbirth recording and reporting amongst health workers who attend to deliveries in public/government health facilities, and the health management teams who provide support, monitor health services, and collect data on stillbirth across health facilities at the district-level of the Ashanti Region in Ghana.

To achieve the stated aim, at the facility level, the experience, perception, and attitude of health workers on stillbirth recording and reporting were assessed. Furthermore, the support mechanisms and barriers for health workers in stillbirth recording and reporting were examined. The focus on facilities is important because when a stillbirth occurs at the facility level, data is generated by the health worker at the point of care at the primary, secondary and tertiary levels. [142, 143] The primary care level is the first point of contact that many individuals have with the health system. [142, 143] The primary care often refers up to the secondary and tertiary level to provide specialized care. [144]

At the district level, the experiences, perceptions, and attitudes of both the regional health directorate (which oversees the district health management team) and the district health management teams regarding stillbirth recording and reporting were explored. In addition, given that a key role of district health management teams is routine data collection, an investigation was conducted on the use of data on stillbirth at the district level. The available leadership and support mechanisms to facilitate stillbirth recording and reporting were also examined. The focus on the district level is important because data collected at the facility level is transferred to the district level, entered into HMIS at the sub-national level, and reported to relevant national authorities. Coordination and collaboration across all levels of the health system, from the facility level and sub-national district level to the national level, are essential for measurement. [27]

At the health facility level, specific objectives were to:

- Explore the experiences, perceptions, and attitudes of health workers toward stillbirth recording and reporting.
- Understand barriers related to stillbirth recording and reporting among health workers.
- Identify support mechanisms available to health workers to enable stillbirth recording and reporting.

At the district level, specific objectives were to:

- Explore the experiences, perceptions, and attitudes of DHMTs on stillbirth recording and reporting.
- Understand stillbirth data flow and how stillbirth data is used by DHMTs.

- Explore leadership and support mechanisms available from the district level to facilitate stillbirth recording and reporting at the facility level.

3.2.2 Overview:

Qualitative research using a semi-structured interview guided the methodology for objective 2 and objective 3 of the research. This section presents further details of the methodology applied for the two objectives.

3.2.3 Study country – why Ghana?

Ghana currently has an enabling environment for reducing its SBR. This includes –

- The country is a signatory to the *Every Newborn Action Plan (ENAP)*. [10, 18, 104] As part of ENAP, participating countries agree to reduce the SBR target to 12 or fewer stillbirths per 1,000 total births.
- Ghana is also a founding member of the Quality of Care Network. [12]
- There is a system in place to ensure that stillbirths are adequately captured within the health management information system. Currently, stillbirths are included in the district health information management system (DHIMS-2) in Ghana. [74]
- The Ghana Health Service (GHS) plays a key role in processing the stillbirth data collected in health facilities. Data processing begins at the facility-level where stillbirth data is collected and collated, then forwarded to the district and regional level, and finally to the national level.

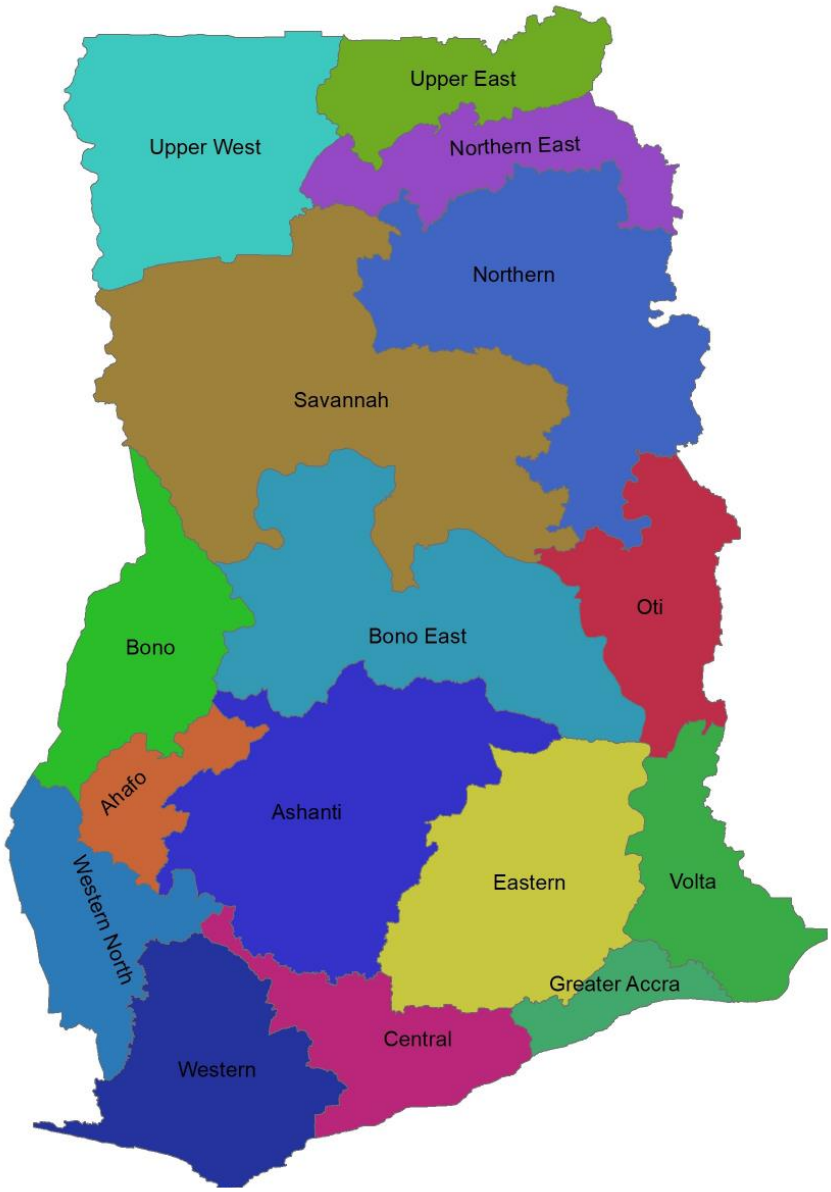
Despite the enabling environment, a national report from Ghana published in 2022 revealed that between 2019 and 2021, no significant changes were reported in stillbirth-related indicators. Rates in 2019 and 2021 were 12.7 and 12.8 stillbirths per 1,000 total births; 7.3 and 7.6 neonatal deaths per 1,000 live births; 9.8 and 10.7 under-5 deaths per 1,000 live births, respectively. [129] If current trends continue, Ghana is at risk of missing the ENAP SBR target by 2030.

Gaps have been reported in stillbirth data collection systems globally and in Ghana [4]. The 2014 Demographic and Health Survey of Ghana recorded several data quality issues for childhood mortality, including stillbirth. [133] This included omission, or failure to report births that did not survive. Similarly, within routine health management information systems, variations were reported in the completeness and accuracy of data transfer at the facility to the district levels. The underlying reasons provided for the variation included the manual nature of the reporting by health workers. [145]

3.2.4 Selection of study region – why Ashanti Region?

The study was conducted in the Ashanti Region, the most populous of Ghana's sixteen regions (refer to Figure 8 for the map of Ghana). According to national documents, though lower than the reported national average, the Ashanti Region has a high stillbirth rate of 12.2 per 1,000 total births, and the highest total stillbirth number across all regions, (1580 stillbirths recorded for the year 2020) reflecting the size of the region and number of births. Additionally, other related indicators, including maternal mortality remain high for the region. As a result of the large number of births in the region, the number of maternal deaths remains high at 124 (second highest nationally). The region reported that 97.6% of all maternal deaths in the region are audited through maternal death surveillance reviews. All reported numbers are from 2020. [146] Finally, the institutional neonatal mortality rate in the region was reported to decrease from 13.59 live births in 2017 to 6.49 in 2021. [129]

Figure 8: Map showing the sixteen administrative regions of Ghana.



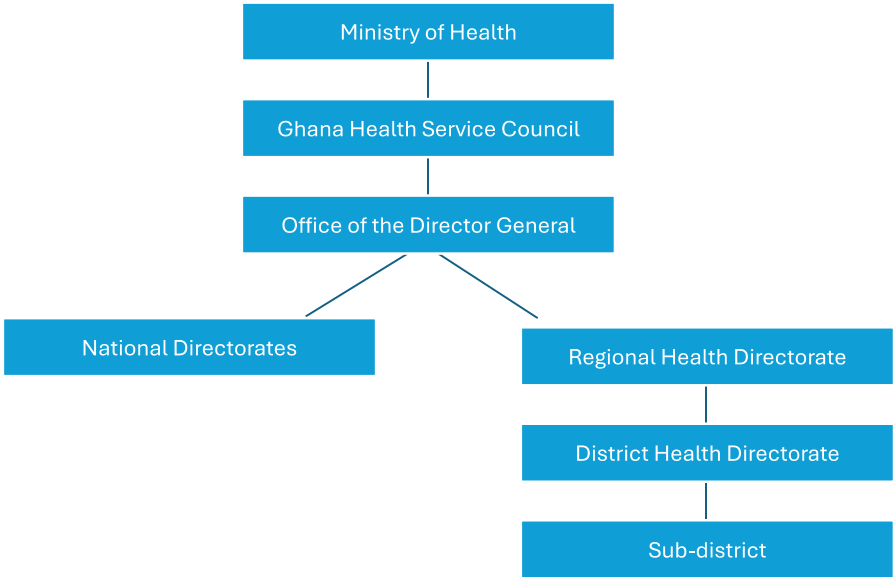
3.2.5 Health governance of the Ashanti Region

The Ashanti Region has one Regional Health Directorate (RHD) and 43 District Health Directorates (DHDs; also known as the district health management teams). [147] RHDs represent the administrative apex of health service delivery at the sub-national level. They champion the implementation of health policies formulated by the Ministry of Health for implementation by Ghana Health Service (GHS) at the regional level (see Figure 9 for the structure of the regional health directorate). DHDs are established in each district of the region. DHDs provide leadership,

supervision, management, and technical support to their sub-districts. They champion the implementation of health policies and programmes of GHS in the districts. In the Ashanti Region, there are 1,654 health facilities comprising Community-based Health Planning and Services facilities (1,120), clinics (29), maternity homes (71), health centers (165), polyclinics (5), district hospitals (26), other hospitals (125), regional hospital (1), university hospital (1) and a teaching hospital (1). [148]

Figure 9: Health governance of the Ashanti Region.

Adapted from *Ghana Health Service. Administrative Structure and Reporting Relationships (2022).* [147]



3.2.6 Selection of Ashanti Regional Health Directorate sample

Study participants from the district level included the RHD and the DHD/district health management team (DHMT). At the regional level, interviews were conducted with the leadership team including directors.

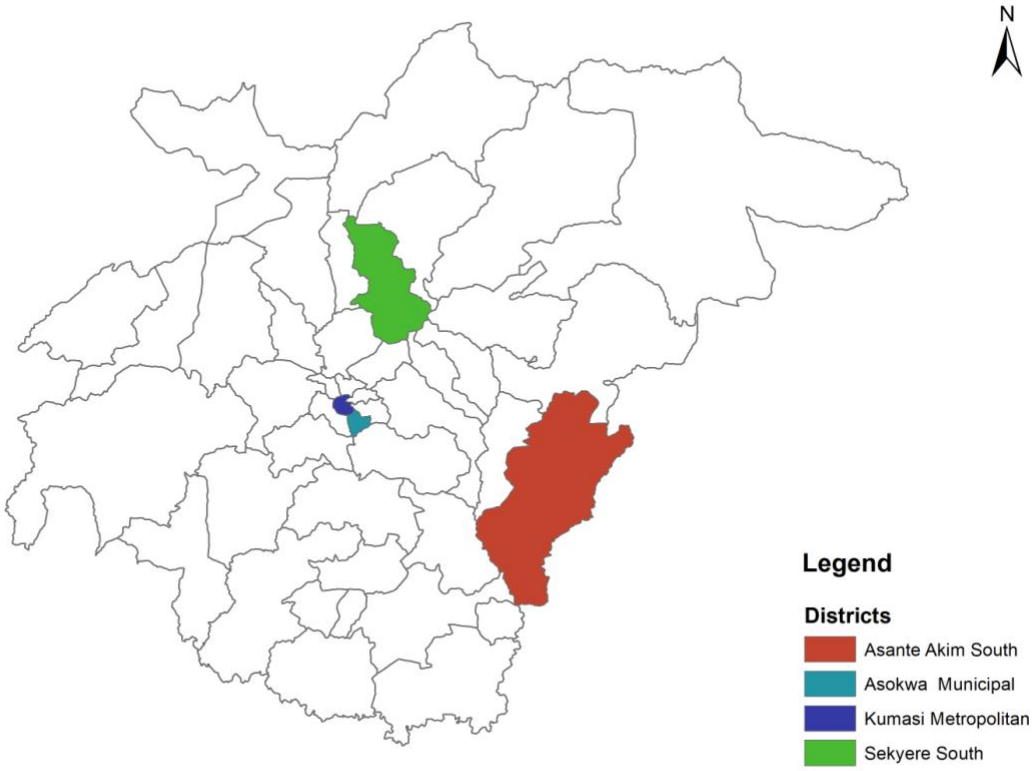
3.2.7 Selection of study districts

The selection of districts was informed by the data available in the DHIMS-2. Based on the criteria presented below, four study districts with variations across the criteria were selected.

- Total volume of deliveries: Total number of all deliveries, including live and stillbirths.
- Level of skilled deliveries: Total number of deliveries attended to by a skilled health worker - midwife, nurse, doctor, etc.
- Absolute number of stillbirths or stillbirth rate: Number of stillbirths per 1,000 total births (or absolute number of stillbirths).
- Absolute numbers of neonatal deaths or neonatal mortality rate: Number of neonatal deaths during the first 28 completed days of life per 1,000 live births (or number of children who die during the first 28 completed days of life).
- Absolute numbers of maternal deaths or maternal mortality ratio: annual number of female deaths from any cause related to or aggravated by pregnancy or its management during pregnancy and childbirth or within 42 days of termination of pregnancy, expressed per 100,000 live births; or number of maternal deaths during a given period per 100,000 live births during the same period.
- Availability of perinatal audit.

Based on this criteria, four districts in the Ashanti Region were selected: Asante Akim South, Sekyere South, Asokwa and Kumasi Metropolitan. The rationale for the selected regions is reflected in Chapter 5. The selected districts are highlighted in Figure 10.

Figure 10: Selected districts for Objective 2



3.2.8 Selection of sample at district level

Once the study districts were identified, the selection of study participants from the district-level was purposive and included members of the district health management team who focus on management and RMNCAH, particularly, those who interacted with maternity services or stillbirth data. These included the monitoring and evaluation officers, surveillance officers, clinical officers, and district health managers/officers. An overview of the profile and sample size of key informant interviews are described in Table 10.

Table 10 Profile of study sample at district-level

Level	Number	Name	Profile of health workers	Sample	Interview Size
Region where the identified health facilities /district operate	1	Ashanti Region	Ashanti Regional Health Directorate Leadership Team	Leadership team of the Regional Health Directorate: Regional Health Director (1). All four Regional Deputy Directors – Public Health, Clinical Care, Health Administration and Support Services, Finance.	5
Districts where the identified health facilities operate	4	District 1-4	District health management officers monitoring RMNCAH outcomes	-District Health Managers/ -Monitoring and Evaluation/Health Information Officers -Surveillance Officers - Public Health Nurse	16 (4 members of each district health management team x 4 districts), until saturation

3.2.9 Selection of study facilities

Within the selected districts, focus was on the secondary-care level (hospitals) and primary-care level (health centers) government health facilities. The tertiary level was not examined as there is only one teaching hospital in the Ashanti Region and many researchers have previously published studies on stillbirths in that facility. [35, 149, 150] Private health facilities, faith-based health organizations and partly owned government health institutions were excluded. This was primarily done because additional in-country clearance processes would have been required, which would have significantly delayed the study being conducted. Further, some of these facilities, particularly the private facilities are also autonomous.

Based on the criteria presented below, two health facilities (one each in the primary and secondary levels of care) per the four study districts were selected. Selected health facilities had variation across the criteria. The criteria for facility selection included:

- Total number of deliveries.
- Total number of stillbirths.
- Total number of neonatal deaths.
- Total number of maternal deaths.
- Number of health workers attending to pregnancy.

The selected facilities and the rationale for their selection are captured in Chapter 6.

3.2.10 Selection of sample at facility-level

Purposive sampling of health workers who attend to deliveries and/or deal with stillbirth data was used to identify study participants (Table 11).

Table 11: Profile of study sample at facility-level

	Level	Number	Type	Profile of health workers	Sample	Interview Size
Facility	Primary Care	4	Health Center	Health workers attending to deliveries or dealing with stillbirth data	-Midwives -Doctors -Health Information Officers -Physician Assistants	4 health workers x 8 facilities = 32 health workers or until saturation
	Secondary Care	4	Hospital			

3.2.11 Ethics

Ethical approval was provided by the two relevant institutions: Ghana Health Service (GHS, Reference: GHS-ERC 025/07/22, refer to Annex 5) and the London School of Hygiene and Tropical Medicine (LSHTM, Reference: 28017, refer to Annex 6). Approval was also granted by one of the study hospitals, functioning as a regional referral hospital (KSH./RESH-50, refer to Annex 7).

3.2.12 Data collection

A semi-structured interview guide was developed informed by the literature review from Chapter 2. Conversations with experts in the field of stillbirth measurement, the Ghana context and data systems also informed the data collection exercise. Additionally, the results published from the stillbirth policy review were used to inform the development of the interview guide. [151] To ensure that questions were understood in the Ghanaian context, the guide underwent testing with experts in Ghana to confirm comprehension of the questions.

All interviews were conducted in English or the local language, Asante Twi. English is the official working language in Ghana, although some health workers preferred to speak in Twi. Given that I am fluent in both English and Ashanti Twi, a conversational and interactive approach was applied to encourage the study participants to speak openly on the subject and explore further areas needing investigation through probing. Three interview guides were developed: Regional Health Directorate, District Health Directorate and Health Facility (see Annex 8 and 9).

Interviews with the RHD and DHD were held virtually via Zoom, a highly suitable platform for collecting qualitative interview data. [152] Zoom was utilized for several reasons: namely, in-country COVID-19 protocols at the time of the research, time, and cost-effectiveness. Additionally, this approach ensured that all the necessary information for the facility-level selection was identified before the in-country presence.

Facility-level interviews were held in person at the premises of the identified health facilities in a comfortable environment for the health worker. Once at the facility level convenience sampling was applied, based on health worker availability at the time of the interviews.

All interviews were recorded with notes taken during the interview. All participants were made aware of the recording, and I conducted all interviews, with durations ranging from 30 to 45 minutes, in either Twi, the native language of the Ashanti Region, or English. Responses were

paraphrased and reiterated to enhance data validation and credibility. All interviews were recorded, transcribed verbatim, translated, and securely stored in a password-protected computer.

3.2.13 Data analysis and synthesis

Thematic analyses were used for analyzing the data for objectives/papers 2 and 3. The thematic analyses used the approach of reviewing, identifying, analyzing, and reporting themes, informed by the Braun and Clark 6-step approach. [153] The steps are further elaborated below.

- Familiarization with the data: This element entailed listening to the recorded interviews, transcribing the interviews, and reading the written transcripts.
- Generating codes: This next step involved systematically coding features of the data and gathering data pertinent to each code.
- Searching for themes: The third step of the approach included generating themes aligned to the identified codes and the relevant data.
- Reviewing themes: This step involved reviewing the themes to ensure that they are aligned with the extracted codes and data.
- Defining and naming themes: This fifth step involved refining the generated themes and ensuring that identified data and codes align. A key element of this step was the engagement of the supervisory team in reviewing the data collected and the generated themes to ensure agreement on the themes selected. At least 30% of all generated transcripts, codes and themes, for objectives 2 and 3 were randomly selected and reviewed by the supervisory team to ensure that the themes selected were accurate.
- Producing the report: Developing a convincing report, with appropriate data/quotes selected to ground the inclusion of themes.

The software NVivo 14 was used both for data management and data analysis. The data management plan is captured in Annex 10.

3.2.14 Rationale for using thematic analysis

Thematic analysis forms the basis or is included as a critical step in many qualitative research approaches, including interpretative phenomenological analysis and grounded theory. [154-157] Thematic analysis is a qualitative research method concerned with generating themes and patterns from a data set, [153] while interpretative phenomenological analysis focuses on understanding people's everyday experiences in detail, an approach commonly used in social science to understand experience or demand of care. [158-161] Grounded theory aims to generate a theory or concept, grounded in data. It utilizes an inductive approach to generate theories, while comparing and analyzing data as it is collected. Thematic analysis is more flexible, allowing researchers to use it without committing to the specific theoretical constructs.

Thematic analysis was most appropriate for objectives 2 and 3 because it facilitated comprehensively reviewing the data and the shared perspectives of health workers, in order to identify broad themes emerging from the data. [162] Similarly, this approach allowed to validate earlier findings from the literature review process, as well as generate new ideas that may not have been known. [163] Using both an inductive and deductive approach, for objectives 2 and 3, an a priori framework was developed informed by literature to guide the selection of the major themes captured in Chapters 5 and 6. Sub-themes were developed based on the new insights shared by health workers.

3.2.15 Data validity and trustworthiness

The Pope and Mays Framework [164] served as a guide to improve the validity of research findings.

- **Triangulation of the research data** was critical to ensure comprehensiveness and encourage a more reflexive analysis of the data. At the facility level, interviews were conducted with different cohorts of health workers including both clinical as well as non-clinical staff. At the district level, interviews were conducted with the regional health directorate and the district health management teams.

- **Respondent validation** during the interview process was facilitated, as responses from study participants were repeated or paraphrased to ensure that a true account of the health worker perspective was captured.

- **Clear exposition of the data collection methods and analysis** was provided through a detailed information leaflet, along with a clear account of the process of data collection and analysis. This was shared with study participants (refer to Annex 11). A consent form was also provided to study participants to read and sign, or it was verbally read to them, and consent was verbally sought before interviews commenced (see Annex 12). Ethics protocols including the information leaflet detailing the overview, objectives, risks, and benefits, alongside privacy and confidentiality of the research were made available to the facility health worker and regional/district health officers. The information leaflet was shared in advance of the interview and read verbally to the health worker during the day of the interview. Any questions were clarified during the day of the interviews. The consent form and information leaflet used simple language tailored to the country context, ensuring that facility health workers and district health officers could easily understand them. For interviews conducted over Zoom, a leaflet on using the online platform was also provided (Annex 13).

- **Reflexivity** is defined as the way the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience, which can influence the research outcomes. [164] Reflexivity involves introspection on the role of subjectivity in the research process. It is a continuous practice where researchers reflect on their values and recognize, examine, and understand how their social background, location, and assumptions influence their research activities. [165-168] Throughout the qualitative component of the thesis, literature reviews and conversations with stillbirth measurement experts may have influenced the research interpretation. Additionally, being viewed as an "outsider" i.e. an external researcher, by those who participated in the qualitative research interviews, may have influenced the responses provided by study participants.

- **Attention to negative cases**, as part of the data collection process, emerging data that were outliers were further investigated and probed during interviews.

- **Fair dealing** was achieved as the study interviewed diverse health workers from the regional health directorate, district management teams, and health workers attending to pregnancy or dealing with stillbirth data to understand stillbirth recording and reporting in the Ashanti Region of Ghana.

3.3 Overall limitations to research approach

Limitations for specific objectives/papers are discussed in Chapters 4-6. Limitations to the overall PhD research approach are summarized below.

- **Country Focus**

Objectives 2 and 3 of the study focused on one country. This might limit the generalizability of the findings. However, throughout this research, I worked with the Stillbirth Advocacy and Research in Africa Hub to ensure that the tools and resources produced as part of this study, are informing similar studies in other countries i.e. Namibia, Ethiopia, Uganda, Malawi, and Tanzania. Furthermore, the approach utilized for the research is being considered for a similar study by a doctoral student at LSHTM for Liberia.

- **District Focus**

Objective 2 focused on one of the sixteen regions of Ghana. This scope of the findings may be constrained, potentially limiting their applicability to a broader context. To address this limitation, I am currently working with the Ashanti Regional Health Directorate and the Ghana Health Service on a capacity-building three-day workshop programme on stillbirth measurement. The objective of the three-day workshop programme is to bring RHD/DHD and facility health workers together to undergo training in stillbirth terminology, types, appropriate measurement, and stillbirth recording and reporting. Initially, the workshop will be conducted in the Ashanti Region, before

scaling up to other regions of Ghana. Resources to support the operationalization of the three-day programme are being discussed with donors/funders working in Ghana.

- **Influence of researcher presence**

Responses by health workers and district health officers may have been influenced by the presence of the researcher. Health workers and officers may have answered affirmatively to questions without fully understanding their depth. To address this, an inquiry-based learning approach using probing techniques was employed to gather insights from health workers. Ensuring confidentiality and asking neutral questions were strategies used to enhance trustworthiness.

- **Availability of comprehensive secondary data**

In Ghana, the DHIMS-2 was used as the source data to inform the selection of districts and health facilities. Given the outlined gaps summarized in this thesis regarding stillbirth data, it is undeniable that data may have been compromised, leading to under-reporting, over-reporting, or missing values. This potential compromise in data accuracy may have influenced the selection of the study sites and participants for this research.

Similarly, country responses to the WHO RMNCAH survey may have been subjective, depending on the perspectives of the government officials responsible for completing the information at the time of the survey.

4 Chapter 4 Global Stillbirth Policy Review – Outcomes and Implications ahead of the 2030 Sustainable Development Goal Agenda

This chapter provides an in-depth look at how stillbirths are positioned within national level policies on reproductive, maternal, newborn, adolescent and child health (objective 1). It provides an analysis of the methodology used as well as key findings, discussion, and recommendations to ensure that stillbirths are prioritized ahead of the 2030 SDG agenda deadline. Implications of the findings for research, policymakers and the public are also expanded upon.

This chapter was published on August 15, 2023 in the International Journal for Health Policy and Management (IJHPM). The manuscript and associated supplementary document are available here: https://www.ijhpm.com/article_4486.html. The manuscript was published under a creative commons license (CC BY-NC-ND 4.0) and the published manuscript is included in full below.

4.1 List of Figures

4.2 Citation

Mensah Abrampah NA, Okwaraji YB, You D, Hug L, Maswime S, Pule C, Blencowe H, Jackson D. Global Stillbirth Policy Review – Outcomes And Implications Ahead of the 2030 Sustainable Development Goal Agenda. Int J Health Policy Manag. 2023 Aug 15;12:7391. doi: 10.34172/ijhpm.2023.7391.

4.3 Research Paper

The research paper is presented with cover sheet on the next page.

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RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	1805521	**Title**	Ms
First Name(s)	Nana Afriyie		
Surname/Family Name	Mensah Abrampah		
Thesis Title	Counting the invisible: health system factors influencing stillbirth measurement and reporting		
Primary Supervisor	Debra Jackson		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	The International Journal for Health Policy and Management as: Mensah Abrampah NA, Okwaraji YB, You D, Hug L, Maswime S, Pule C, Blencowe H, Jackson D. Global Stillbirth Policy Review – Outcomes And Implications Ahead of the 2030 Sustainable Development Goal Agenda. Int J Health Policy Manag. 2023 Aug 15;12:7391. doi: 10.34172/ijhpm.2023.7391.		
When was the work published?	August 2023		
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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I led the conceptualization of the study jointly with my supervisory team. I led the data curation, formal analysis, investigations, methodology development, review and validation of national documents, and the overall development and editing of the manuscript. The first and subsequent drafts of the paper included review inputs from the supervisory team and co-authors.

SECTION E

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Date	29 April 2024

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Original Article

Global Stillbirth Policy Review – Outcomes And Implications Ahead of the 2030 Sustainable Development Goal Agenda

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Abstract

Background: Globally, data on stillbirth is limited. A call to action has been issued to governments to address the data gap by strengthening national policies and strategies to drive urgent action on stillbirth reduction. This study aims to understand the policy environment for stillbirths to advance stillbirth recording and reporting in data systems.

Methods: A systematic three-step process (survey tool examination, identifying relevant study questions, and reviewing country responses to the survey and national documents) was taken to review country responses to the global 2018-2019 World Health Organization (WHO) Reproductive, Maternal, Neonatal, Child and Adolescent Health (RMNCAH) Policy Survey. Policy Survey responses were reviewed to identify if and how stillbirths were included in national documents. This paper uses descriptive analyses to identify and describe the relationship between multiple variables.

Results: Responses from 155 countries to the survey were analysed, and over 800 national policy documents submitted by countries in English reviewed. Fewer than one-fifth of countries have an established stillbirth rate (SBR) target, with higher percentages reported for under-5 (71.0%) and neonatal mortality (68.5%). Two-thirds (65.8%) of countries reported a national maternal death review panel. Less than half (43.9%) of countries have a national policy that requires stillbirths to be reviewed. Two-thirds of countries have a national policy requiring review of neonatal deaths. WHO websites and national health statistics reports are the common data sources for stillbirth estimates. Countries that are signatories to global initiatives on stillbirth reduction have established national targets. Globally, nearly all countries (94.8%) have a national policy that requires every death to be registered. However, 45.5% of reviewed national policy documents made mention of registering stillbirths. Only 5 countries had national policy documents recommending training of health workers in filling out death certificates using the International Classification of Diseases (ICD)-10 for stillbirths.

Conclusion: The current policy environment in countries is not supportive for identifying stillbirths and recording causes of death. This is likely to contribute to slow progress in stillbirth reduction. The paper proposes policy recommendations to make every baby count.

Keywords: Stillbirths, Fetal Death, Perinatal Health, Measurement, Health Policies, Health Systems

Citation: Mensah Abrampah NA, Okwaraji YB, You D, et al. Global stillbirth policy review – outcomes and implications ahead of the 2030 Sustainable Development Goal agenda. *Int J Health Policy Manag.* 2023;12:7391. doi:10.34172/ijhpm.2023.7391

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Background

Stillbirth is a global health crisis that affects millions of families each year. Globally, 1 in 72 babies are stillborn, amounting to around 2 million stillbirths annually.[1] Over the last twenty years, the stillbirth rate (SBR) has declined by only 2.3% compared annually to a 2.9% reduction in neonatal mortality, 4.3% in mortality among children aged 1–59 months and 2.9% for maternal mortality.[1] The stagnating trend has resulted in calls for increased investment at global and national levels. Several global publications, initiatives and networks have emerged to amplify and accelerate progress on reducing stillbirths. These include the *Every Newborn Action Plan (ENAP)*[2,3]; *Global Strategy for Women and Child Health*[4]; *the Network for Improving Quality of Care (QoC) for maternal, newborn, and child health (MNCH)*[5]; and the *Core Stillbirth Estimation Group of the United Nations Inter-agency Group for Child Mortality Estimation (UN IGME).*[6] SBR is also part of the World Health Organization (WHO) *Global Reference List of 100 Core Health Indicators.* Within ENAP, a prominent target is for countries to achieve SBRs of 12 or fewer stillbirths per 1000 total births by 2030 and to close equity gaps.

There is an acknowledgment that the unequal gains witnessed in stillbirth compared to other MNCH outcomes require further investment.[1,2,7] Many stillbirths are preventable through improved peri-conceptual health and nutrition, high quality antenatal and delivery care, and improved

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Key Messages

Implications for policy makers

National policy-makers should:

- Establish a standard national definition for stillbirths and include stillbirth registration as part of strategies to accelerate progress to end preventable stillbirths.
- Undertake reviews of reproductive, maternal, newborn, child and adolescent health plans and guidelines, and include specific reference to the training of health workers to record and register stillbirths and their causes according to internationally recognized standards.
- Improve the reporting infrastructure at country level with clear protocols for health workers and ensure data on stillbirths is shared between different actors and health system levels.
- Consider joining global initiatives that aim to reduce stillbirth rates (SBRs) such as the *Every Newborn Action Plan (ENAP)* and the *Quality of Care (QoC) Network for Maternal, Newborn and Child Health (MNCH)*.
- Ensure policies do not remain detached from frontline efforts by including adequately financed implementation plans at the facility and district levels.

The highlighted recommendations are applicable to health providers and stakeholders involved in stillbirth prevention. It is essential to ensure that policies, training and reporting infrastructure on stillbirth are available and sensitized within countries.

Implications for the public

Findings from 155 countries and over 800 national policy documents reveal stillbirths remain invisible in national policies. Countries that responded to the survey prioritized child health mortality indicators (such as under-five mortality rate [U5MR] and neonatal mortality rate [NMR]), three-times more than stillbirths. The regions with the highest burden of stillbirth, Africa and South-East Asia, accounted for more than half of all established stillbirth rate (SBR) targets. 40.6% of reporting countries in Africa and 21.9% of reporting countries in South-East Asia had established SBR targets. Greater than half of all reporting countries with established SBR targets are middle-income, with gaps reported in countries facing fragility, vulnerability, and conflict. Overall, more countries reported review processes for maternal (65.8%) and neonatal deaths (67.7%) compared to stillbirth (43.9%). Improving the policy environment which directs how stillbirths are acted upon at country-level is an essential step in creating the enabling environment needed to make every baby count.

health systems.[7] Health systems also provide the foundations needed to deliver quality care.[8] Health systems building blocks including leadership and governance are required to drive action and investment at the point of care. Information systems allow for evidence-informed decision-making. Financing arrangements remove barriers to health service access. Essential commodities and a skilled, motivated health workforce support the delivery of QoC interventions.

As a critical function of health systems, leadership and governance are vital roles governments play in the stewardship of health systems. The central role of governments is to provide policy guidance underpinned by oversight, collaboration and coalition, regulation, and accountability.[8] ENAP has issued a call to action to governments to review and sharpen national strategies, policies, and guidelines for newborns and stillbirths. Prioritizing and establishing national targets for SBR reduction provides direction to sub-national and facility teams for better reporting and measurement on the neglected burden of stillbirth, drives the identification of measures to achieve the stated target, and holds governments accountable. Prioritization of stillbirths within national plans also creates awareness for health workers to document better and can drive increased investments into stillbirth measurement and reporting infrastructure.

This paper seeks to provide an overview of the policy environment in countries to understand stillbirths recording and reporting. The policy instruments used in this paper refer to policies, strategies, laws, plans, and guidelines. Specifically, we aimed to: understand the governance related to stillbirths; assess processes established for maternal deaths, stillbirths, and neonatal deaths; identify health information systems commonly used for data collection on maternal and perinatal mortality; understand availability of essential commodities for maternal and perinatal services; explore national health workforce policies for stillbirth reporting; and finally, examine national-level policies and processes on death registration and stillbirths. The selection of objectives was informed by the WHO Health Systems Framework.[8]

Methods

Design

The continuum of services across reproductive, maternal, neonatal, child and adolescent health (RMNCAH) is key for QoC in a country. Country responses to the global 2018-2019 WHO RMNCAH Policy Survey were reviewed to understand the policy environment for stillbirth.[13,14] The survey, distributed to all 194 Member States of WHO via email, tracked country progress in adopting WHO recommendations in national health policies, strategies and guidelines related to RMNCAH.[13] The survey was communicated by WHO, with an indicated timeframe, for WHO country offices to complete with relevant Ministry of Health and other United Nations (UN) agencies. Country responses to the survey were validated against national documents submitted by countries to WHO, with the required follow-up done by WHO. WHO conducted an analysis and published the results of the broader RMNCAH survey in the *International Journal of Health Policy and Management*.[15] This report did not systematically focus on, or review critically stillbirths.

Survey Question Selection – Inclusion and Exclusion Process

The policy survey was modular and included 331 questions and associated sub-questions. Thematic areas for the survey included cross-cutting RMNCAH issues, maternal and newborn health, child health, adolescent health, reproductive health, and gender-based violence.[16]

For inclusion in this review, the two survey modules with content on stillbirths were examined: firstly, the cross-cutting RMNCAH module, and secondly, the maternal and newborn health module.

From the two relevant survey modules, a systematic three-step process was conducted to determine study questions to be included in the study. In the first step, we (the authors of this paper) reviewed all 160 questions and sub-questions captured within the cross-cutting, and maternal and newborn health modules of the RMNCAH policy survey questionnaire. We identified questions related to stillbirth or influencing stillbirth outcomes using three perspectives. For inclusion, first, all questions that specifically mention stillbirth. Second, questions related to health systems building blocks that are essential facilitators for creating an enabling environment for stillbirth reduction[8]; and finally, questions on stillbirth-related areas such as neonatal and maternal deaths which are highly correlated to SBR. We excluded questions about clinical interventions and preventive measures for perinatal and maternal health. Twenty-four questions were identified from this step (Figure 1).

We submitted a data sharing request form to WHO outlining the scope and intended output of the research. We obtained from WHO, secondary data including the original country responses to the 24 questions, catalogued national policy documents submitted by countries to validate and substantiate the survey responses, protocols for validation of country survey responses against national documents, and information from WHO on any data quality concerns relating to these questions.

As a second step, once the data was received for the 24 questions, data verification was undertaken. Three questions for which responses could not be verified through the national documents were excluded. These included a question that required verification in the national health management information system and two questions on the frequency of death review panel meetings. Five questions that addressed general human resources were dropped, as more focused responses were available in a specific question on human resources for stillbirths (See Table S1 of Supplementary file 1). National documents were reviewed to ensure that countries that indicated "yes" to established stillbirth targets had stated targets.

Overall, 16 questions (See Table S2 of Supplementary file 1) were included in this study: one question relating to national targets for SBR, under-five mortality rate (U5MR), and neonatal mortality rate (NMR); four questions on policies for death registration processes (birth registrations were not accounted for in this study as the term is used to refer to registration of live births, not stillbirths or fetal deaths[17]); two questions on essential medicines and equipment; one question on surveys and health management information systems; and eight questions on death reviews. From the 16 questions, original country responses to 12 questions submitted by the 155 responding countries in all languages were included for the global review. For the remaining four questions, the questions had relevance to stillbirth, but stillbirth was not directly mentioned, for example, "is there a national policy/law that requires every death to be registered?" These four questions were adjusted to make them stillbirth specific eg, "is

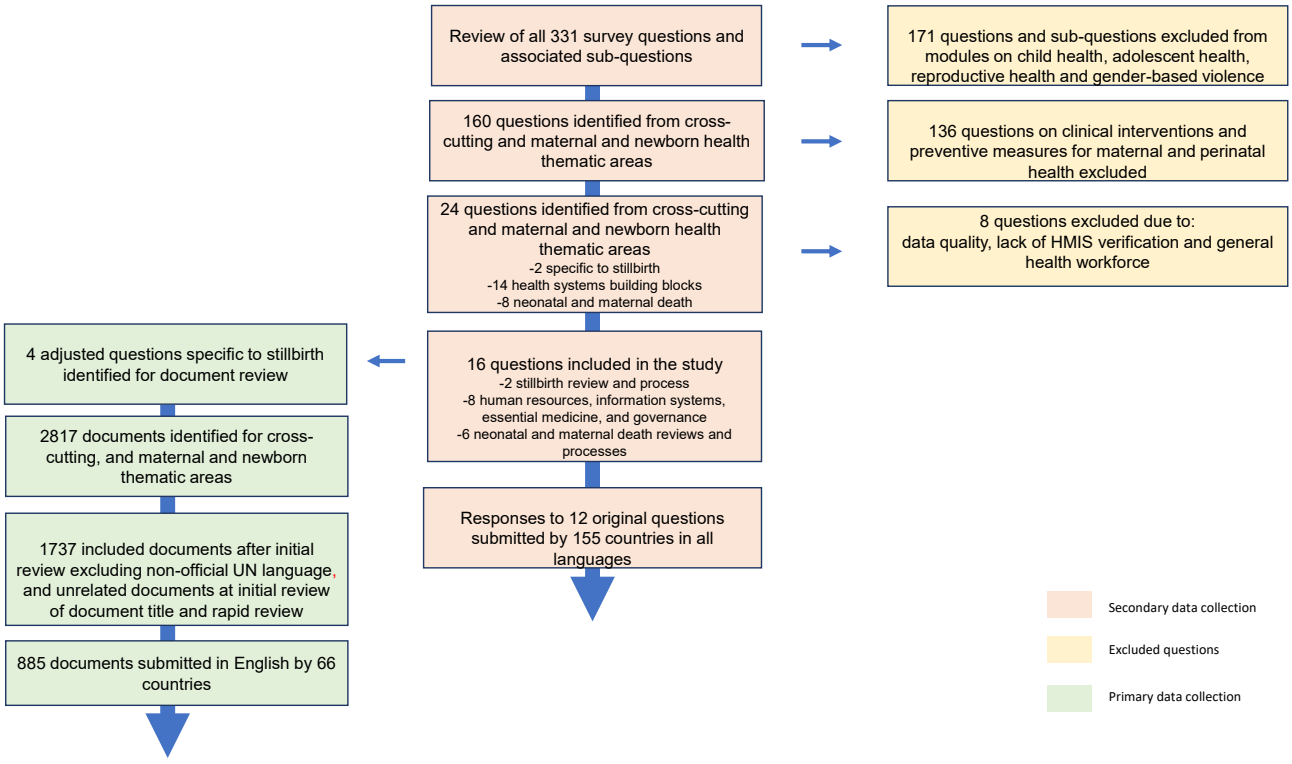

Figure 1. Methodology Flow Chart. Abbreviations: Abbreviations: UN, United Nations; HMIS, Health Management Information Systems.

there a national policy/law that requires every death including [stillbirth or fetal death] to be registered?"

For the third step, national documents for the sixty-six countries who submitted documents in English (Table S3, Supplementary file 1) were then examined to answer the four adjusted questions (Table S2, Supplementary file 1) using a defined search protocol. A response to the adjusted questions was then recorded. Responses to these four questions served as primary data. Search terms used for this analysis included: still, stillbirth, still birth, fetal, foetus, fetus, and foetal. Associated definitions for the search terms are reflected in Table S4 of Supplementary file 1.

Limitations to this approach are further expanded upon in the limitations section.

Analysis

The WHO Health Systems Framework was most appropriate to our study as it allows for a description of the various organizations, institutions, resources and people that work together to reduce SBRs. Past studies have also highlighted the usefulness of applying this framework to achieve health goals.[18-20] The WHO Health Systems Framework guided the framing of study objectives and presentation of results. Country responses were recorded for each objective in a data tracking sheet to determine if stillbirth was addressed (Table S2, Supplementary file 1). These responses were then analysed using the WHO regional groupings as the primary level of analysis. Countries also identified as fragile, conflict-affected, and vulnerable (FCV) settings, and the 2021 World Bank country income classification were used as an additional level of analysis.[21,22] STATA 16 was used for data cleaning and analyses. Descriptive analyses were used to identify and describe the results across regions.

Results

A Global Perspective on National Stillbirth Policy Environment

The following results were obtained from 155 countries (80% of WHO Member State countries) who responded to the wider RMNCAH survey. This captured 95.2% of the current burden of stillbirths in 2019.

Governance for Stillbirths: Mortality Targets

A national target for SBR was developed in 32 countries (21.9%). No established SBR target was reported in 114 countries and 9 countries did not respond to the question (Figure 2). Two regions accounted for over 60% of countries with a national target for SBR (Africa 40.6% [n = 13] and South-East Asia 21.9% [n = 7]). This is partly due to the large number of reporting countries in the African region.

In comparison, three quarters of countries (n = 110) reported having set a national target for U5MR, and 68.5% (n = 102) reported a national NMR target (Figure 3). Results from the survey indicate that for countries with an established SBR target, 28.1% (n = 9) had set these greater than the ENAP target of 12 or fewer stillbirths per 1000 total births. Nearly half of all countries with identified NMR and U5MR targets, these were set at greater than the ENAP target of 12 or fewer deaths per 1000 live births and the Sustainable Development Goal target of 25 or fewer deaths per 1000 live births, respectively.

Of the 32 countries reporting having a national target for SBR, 15.6% (n = 5) are high-income, 18.8% (n = 6) are upper-middle-income, 40.6% (n = 13) reported as lower-middle-income, and 25.0% (n = 8) are classified as low-income countries. Among the 39 globally recognized FCV countries, 29 completed the survey. A third of FCV countries who responded to the survey, reported having set a SBR target.

Review Processes (eg, Panels or Committees) Established for Maternal Deaths, Neonatal Deaths, and Stillbirths

Review Processes Established for Maternal Deaths Including Stillbirths

Maternal death review panels provide an opportunity to learn from the circumstances surrounding the death of a woman. Two-thirds of countries reported a national maternal death review panel or committee, and no information was available for 8.4% (n = 13) (Figure 4). Of the 102 countries with maternal death review, over half (59.8%, n = 61) reported that stillbirth and neonatal death reviews were integrated in

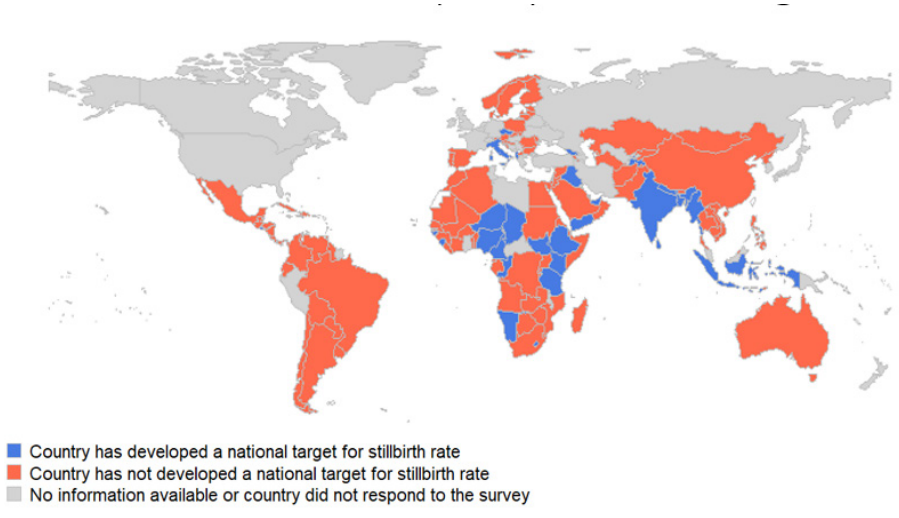

Figure 2. Countries That Have Developed a National Target for Stillbirth Rate, as Reported on the 2018-2019 RMNCAH Policy Survey. Abbreviation: RMNCAH, Reproductive, Maternal, Neonatal, Child and Adolescent Health.

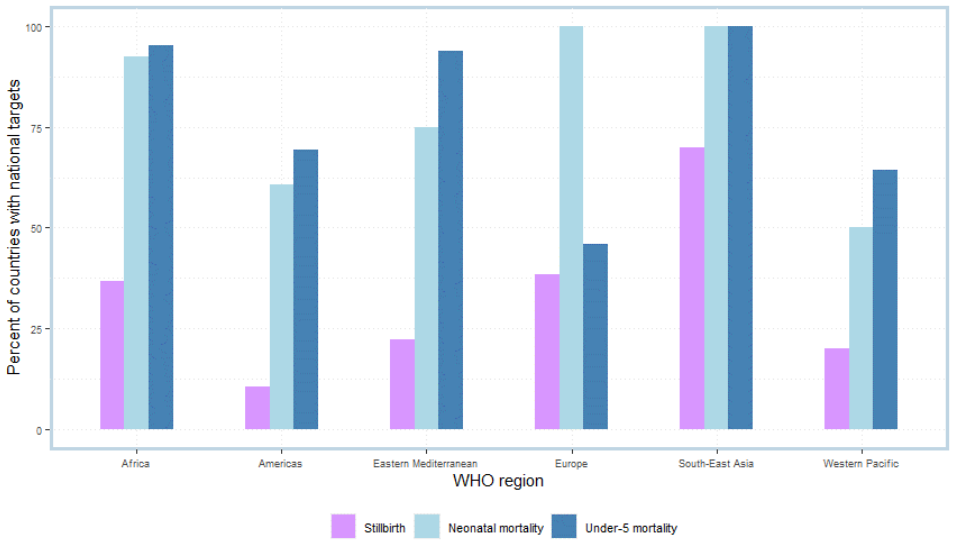

Figure 3. Countries That Have Developed a National Stillbirth Rate Target Compared to Neonatal Mortality Rate and Under-Five Mortality Rate Targets, Grouped by WHO Region. Abbreviation: WHO, World Health Organization.

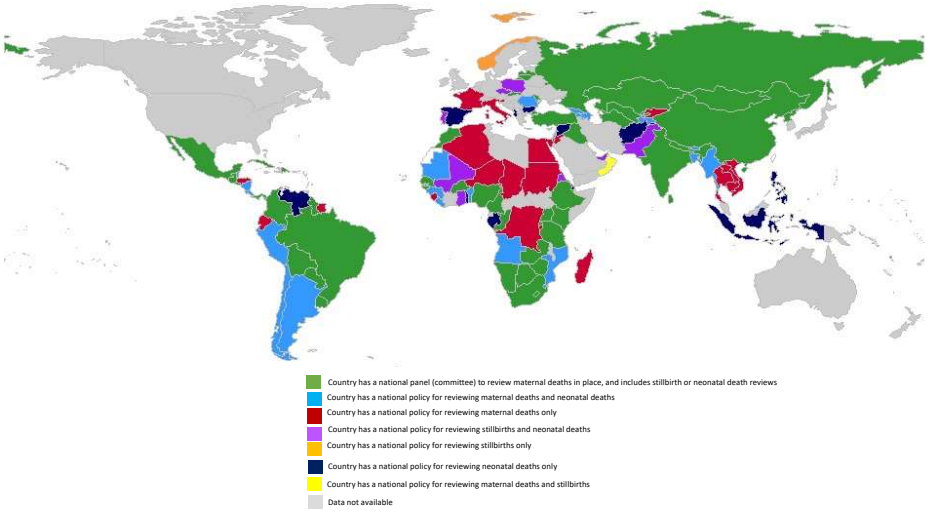

Figure 4. National Review Processes Established for Maternal Deaths, Stillbirths and Neonatal Deaths, as Reported on the 2018-2019 WHO RMNCAH Policy Survey. Abbreviation: RMNCAH, Reproductive, Maternal, Neonatal, Child and Adolescent Health.

the system. Integrated systems, defined as the investigation into a stillbirth or neonatal death should they have occurred alongside with a maternal death, were most common in Africa (39.3% of countries, n = 24), the Americas (23.0%, n = 14), Europe (13.1%, n = 8), and South-East Asia (13.1%, n = 8).

Review Processes Established Specifically for Stillbirths

A little less than half (n = 68) of countries have a national policy that requires stillbirth causes to be reviewed. Of this number, 62 countries have a policy requiring stillbirth review supported by an established operational facility-level review process. This approach was more common in Africa and the Americas compared to other regions. A further six countries reported having a national policy to review stillbirths but no facility-level review processes in place. No national policy was available in 43.9% (n = 68) of countries, however, facility-level review mechanisms exist in 13 of these countries. Only 3.9% (n = 6) of countries reported unknown or no information.

Review Processes Established Specifically for Neonatal Deaths

Two-thirds of countries (n = 105) have a national policy requiring review of neonatal deaths. Of this number, 95 countries have a national policy/guideline/law requiring neonatal death reviews alongside a facility neonatal death review process. This was common in Africa, the Americas and Europe compared to other regions. A national policy requiring neonatal death review was available in 10 countries, but no facility-level processes exist. No national policy for neonatal death review was reported in 5.2% (n = 8) of countries, however facility review processes existed. Only 3.9% (n = 6) of countries responded having no information.

Health Information Systems Commonly Used for Data Collection on Maternal and Perinatal Rates

The relevant survey question on health information systems looked into data sources for comparison. Across countries, the four most used data sources to compare maternal,

newborn, child, and adolescent mortality rates, in descending order were: WHO websites and reports; national health statistics databases; national population-based surveys (eg, Demographic and Health Surveys and Multiple Indicator Cluster Surveys); and civil registration and vital statistics systems (Figure 5).

Essential Commodities for Quality of Care for Maternal and Perinatal Services

Globally, more than 90.3% of countries had a national policy or guideline for essential medicines and equipment. Over 80% of countries had key commodities including oxygen supply, blood and blood products, self-inflating bag with neonatal and paediatric masks of different size, for pregnancy and childbirth care which are required for stillbirth prevention and resuscitation of babies who are apnoeic at birth and would otherwise be classified as a 'fresh stillbirth.'

A Focused Perspective on National Policy Documents and Stillbirth

The following results are obtained from the document review of the 66 countries (out of 155) that submitted documents in English on content relevant to stillbirths, using the four stillbirth-specific adjusted questions. 885 documents (31.4% of those submitted for the cross-cutting, and maternal and newborn thematic areas) were examined as part of the primary data review.

Among national policies reviewed, 45.5% (n = 30) mention registering stillbirths, according to established national guidelines or protocols. Just 12.1% (n = 8) of countries reported a national policy/law that requires the cause of death registration for stillbirth or fetal death to be in line with the WHO International Classification of Diseases (ICD)-10.[23] When cause of death was mentioned for stillbirths, ICD-10 was rarely referenced. 24.3% (n = 16) of countries have a policy/law that requires a routine audit and review of death certification for stillbirth or fetal death. Across countries, when certificates were mentioned in the context of stillbirths, countries did not differentiate between death or medical certificates.

Training of health workers in filling out death certificates using ICD-10 classification for stillbirths was reported in 5 out of the 66 countries. When training of health workers was mentioned, it generally entailed communication and counselling to the mother/family after a stillbirth.

Between national agencies, 32% (n = 21) of countries require death data recorded on stillbirth at health facility or at the community-level be provided to the national statistics office, civil registration system, or equivalent bodies. 30.3% (n = 20) of countries required sharing individual death records on stillbirth between central and district/regional health directorate levels. Reporting stillbirth data that occurred in private facilities was mentioned by two countries in national documents.

Discussion

In the post Millennium Development Goals era, focus on stillbirth has improved.[24] A coalition of agencies and initiatives including the *Network for improving QoC for MNCH, the UN IGME, ENAP,* and *the Global Strategy for Women and Child Health* are coordinating action by providing guidance on stillbirth reduction. These initiatives have exerted influence on the political priority for stillbirth.[2,3,7,25-28] Since its launch in 2014, countries who signed onto the ENAP,[29] committed to end preventable newborn mortality and stillbirths. ENAP is further underpinned by periodic monitoring processes to ensure countries are on track to achieve the 12 per 1000 total births goal by 2030.[30] The success made by ENAP is clear, countries who actively report to ENAP have established stillbirth targets. Similarly, the eleven countries who are the

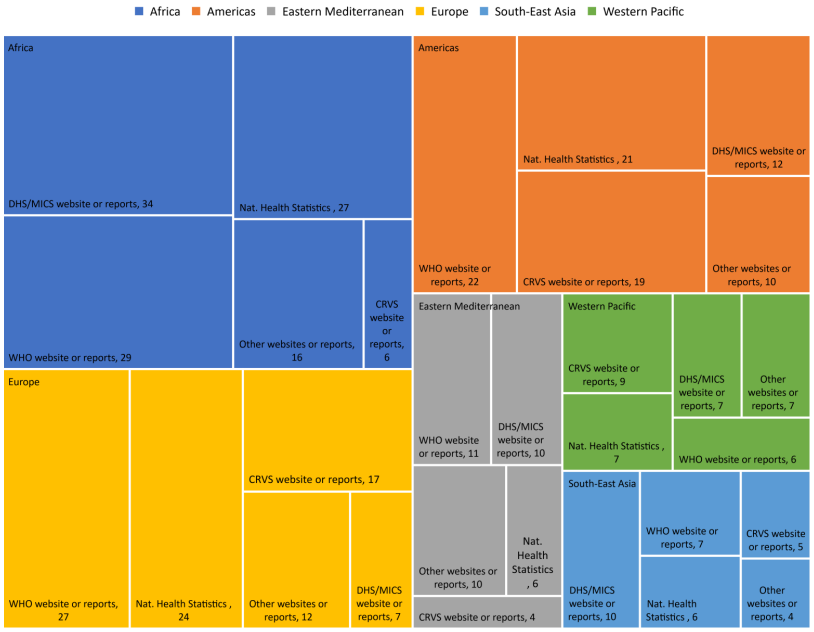

Figure 5. Top Five Data Sources Used by Countries to Compare Child and Maternal Mortality Rates. Each box is proportional to its value, meaning that bigger boxes have bigger proportions. Abbreviations: WHO, World Health Organization; DHS, Demographic and Health Surveys; MICS, Multiple Indicator Cluster Surveys; CRVS, Civil Registration and Vital Statistics; Nat Health statistics, National Health Statistics.

founding members of the QoC Network for MNCH, all have established SBR targets.[5]

In October 2020, with the launch of the global report on *A Neglected Tragedy: The global burden of stillbirths*[1] by the UN IGME, there was consensus and acknowledgement by international agencies and networks that further work is required to include stillbirths in all relevant maternal and newborn health policies. Implementing the actions shared in the global report will require involvement of actors at the country and local levels to make sustainable improvements.

Stillbirths are not prioritized in most countries when compared to other child health indicators.[10,12,31] Only 21.9% of countries have established a national target for SBR (compared to 68.5% for NMR and 73.8% for U5MR), and less than half of countries have a national policy for stillbirths to be reviewed. This lower proportion of countries signals that stillbirths continue to be relegated to a "not now" agenda. Though in 2019, an estimated 2.0 million babies were stillborn roughly similar to the number of neonatal deaths.[1] The gains reported in child health[10,12] (2.9% reduction in neonatal mortality and 4.3% among children aged 1–59 months annually over the last 20 years) are consistent with findings from this policy review and align with the historical increase in global calls for standardized and improved measurement on newborns.[32] An increased number of countries have established a national NMR target (and a higher number of countries reported neonatal death review processes at national and facility-level) and U5MR target.

Some factors that play a role in why stillbirth prioritization lags at the country-level compared to other child health areas. First, definitions for stillbirths vary. Whilst standard definitions for stillbirth are included in WHO's ICD, including a standard definition for international comparison, these definitions are not consistently applied.[33] Universal application of these definitions is essential to enable accurate comparisons between countries and within countries over time and to identify where the need is greatest. Second, the literature on stillbirth has predominately focused on clinical interventions[34-38] with very little information positioning the stillbirth agenda in a way that is understood by and attracts attention of policy-makers, rather than just clinicians.[7] This affects how stillbirths are portrayed and prioritized internally within the policy community.[39] Third, culture, taboo and misconception about stillbirths remain a big barrier.[40]

Contextual factors play a role in how stillbirth policies and strategies are acted upon at country-level. Few (15.6%) high-income countries have established a SBR target. This may be due to increased focus being placed on low- and middle-income countries where overall national SBRs frequently remain greater than the 12 per 1000 total births ENAP targets.[1] However, ENAP targets also include a requirement to close equity gaps in SBR in all contexts. This will require focus on the highest risk groups in every country in terms of improving equity of access and use of essential health services to end preventable deaths.[3] In low-income countries where the risk of stillbirth is on average 7.6 times higher than in high-income countries,[1] 25% of low-income countries in this study have set a SBR target. This is likely due in part to more active engagement in ENAP and active WHO and the United Nations International Children's Emergency Fund (UNICEF) support of country implementation and monitoring of ENAP in high mortality settings, including support for target setting.[3,27,28] For low-income countries that have not set a stillbirth target, these countries could benefit from increased investments into stillbirth policy setting and data strengthening. Further, national policies and strategies to reduce stillbirths would benefit from scaling up QoC interventions, which are often the same interventions to reduce maternal and neonatal mortality and improve well-being.[1,7]

In FCV settings where health systems face complexity with service delivery resourcing, organization, access, and use,[22,41,42] 29 countries responded to the survey. The 10 countries classified as FCV settings with an established SBR target are all signatories to the ENAP, signaling commitment by national governments to prevent newborn deaths and stillbirths. Some FCV settings do not have an established stillbirth target. This can be attributed to the significant health and development needs, competing priorities, service delivery disruption, and unpredictable resourcing streams witnessed in such settings.[41-43] To achieve the global target of 12 or less stillbirths per 1000 total births by 2030, careful attention will need to be given to FCV settings, which account for significant health burden globally.[43] This will require accelerating access to essential quality care[44]; improving health workforce competencies[45]; addressing systems redesign, infrastructure and essential commodities in health facilities and at the community level[41-43]; and improving data on stillbirths to address inequities in these settings.

National policies need to be grounded by operational mechanisms at the sub-national and facility-level to facilitate the achievement of national goals.[46,47] Setting a national approach to review stillbirths is a step in the right direction by countries, with 40% of all countries indicating that they have national policies to review stillbirth grounded by facility-level review processes to understand the causes and address gaps in service delivery, to improve QoC. A small number of countries (n = 13) indicated that there are facility-level review processes but no national policies. Contributing factors to the differences reported within countries could include varying forms of decentralized health planning and management systems within countries, which may result in greater delegation of power, community participation, and flexibility in planning to address urgent health needs in a local community[47,48]; extended time to translate policies into practice[49]; sub-national commitment and ownership to curb SBRs; and funding from global-level initiatives and point-of-care efforts to improve SBRs.[50]

Globally, 56 countries are off track to meet the SBR ENAP target by 2030.[51] At the country-level, several challenges remain to record and report a stillbirth: First, due to the varied definitions on stillbirths, countries use different criteria, including gestational age and birthweight for stillbirth measurement.[37,52] Second, misclassification of antepartum and intrapartum stillbirths,[53,54] differentiating between intentional late term induced abortion and stillbirth,[55] and distinguishing stillbirth and early neonatal death,[11,56-58] further compromises

data quality of stillbirth reporting. Third, challenges persist in reporting stillbirths within health information systems. Only 32% of surveyed countries require death data recorded on stillbirths at health facilities or by community health workers be provided to the national statistics office, civil registration system, or equivalent bodies. This finding warrants further research at country-level to understand and close the evidence-gap on how the policy environment affects reporting of stillbirths into health information systems. When data is reported on stillbirth, noted challenges include under-reporting, omission or misclassification of deaths in civil registration systems,[59] and limited information on birthweight, gestational age, and stillbirth type in the health management information systems.[60,61] Further, socio-cultural and spiritual beliefs in some countries are identified barriers for mothers underreporting stillbirths or hindering families to register a stillbirth in demographic health surveys.[40,62]

A key intervention proposed to improve stillbirth recording and reporting are death reviews. Maternal and perinatal death surveillance and response (MPDSR) has expanded in recent years,[63-66] with a view to learning about causes and promoting successful partnerships at different levels that can lead to real change for communities and nations. Globally, only 39.4% of countries have identified the inclusion of stillbirth or neonatal death reviews as part of national committees on maternal death reviews, resulting in missed opportunities for an efficient and integrated review process alongside identifying the high-yield QoC intervention packages to save both mother and baby. Further missed opportunities were reported where very few countries had mechanisms to review causes of death for stillbirth. Some reasons for countries reporting no review or lack of an integrated review process may include policy and planning environment, resource support, historical focus by external actors on the implementation of MPDSR, political prioritization, pressures to implement, and the level of connectedness and networks between health system levels.[64,66]

Stillbirths remain invisible in most national documents. Less than half of reviewed national policy documents made mention of registering stillbirths and just 12.1% made mention of identifying stillbirth causes according to ICD-10. A systematic classification[67,68] such as ICD-10, supports national tracking, provides in-depth investigation, grounds research, and identifies areas of greatest need. Low utilization of classification systems in facilities may be due to scarce national resourcing thereby affecting coverage and lack of required data.[68] Several studies have called on training of health workers on management related to stillbirth[40,69,70] to address the gaps related to health worker skills for perinatal death reviews. Properly identifying the causes of stillbirth is important for women to know why their baby died, to reduce blame and stigma and take positive action for the next pregnancy.[71]

Limitations

This study has some limitations. The study is a policy review and does not assess the level of implementation of the various policies. Additionally, the document reviews were conducted only in English. Documents submitted in the other five official UN languages were excluded, in addition to those in local national languages. Though the document reviews, were only conducted in English, this was the highest share of documents submitted in official UN languages. We recommend that further reviews in other UN official languages be conducted to augment these findings.

Reliability of country responses can be a problem as this is based on the knowledge of the individuals reporting the data at country-level. The situation in the country may have changed since the time of the survey with new guidelines having been released from WHO on MPDSR (2021) and the COVID-19 pandemic. The nature in which questions were framed within the WHO RMNCAH survey may have influenced the responses by country. For example, "what is the target" does not indicate if it is a current or future target.

Recommendations

The following recommended actions for policy-makers could improve prioritization of stillbirths within national policies and plans, ahead of the 2030 Sustainable Development Goal deadline. First, close the large gaps in stillbirth registration by using a standard definition for stillbirths and explicitly incorporating stillbirth into RMNCAH policies and plans. The WHO ICD-11 (released 2022) is now updated with a revised standard definition for stillbirth.[72] Where stillbirth is not included, include stillbirth registration as part of plans for stillbirth reduction. Second, undertake reviews of RMNCAH plans and guidelines, with a specific reference to the training of health workers to record and register stillbirths and their causes according to internationally recognized standards such as ICD-11. This action should apply to all health facilities including public and private facilities and at the community-level. Third, develop simple communication and advocacy materials making the case for stillbirth policy improvements for policy-makers. Fourth, improve the reporting infrastructure at the country level with clear protocols for health workers and ensure data on stillbirths is shared between different actors. Data is needed to develop sound policies. Finally, ensure policies do not remain detached from frontline efforts by including adequately financed implementation plans at the facility and district levels.

At the global level, we suggest improvements to the WHO RMNCAH policy survey to address the urgent need for stillbirth reduction and better reporting, including a dedicated thematic area on stillbirth. Integration of the additional four adjusted questions on stillbirth into the WHO RMNCAH policy survey could provide a better picture of the policy landscape for stillbirths and allow for useful information for policy tracking in addition to the data collected by the ENAP. We suggest that international agencies increase investments in stillbirth by expanding upon countries participating in global initiatives (such as ENAP and the QoC Network) to advance the stillbirth agenda. We also urge global and implementing partners to provide guidance and training for how governments can incorporate stillbirths in national policies and plans on RMNCAH and strengthen data systems to record and report on stillbirths.

Conclusion

Networks and global initiatives play a key role in supporting the policy environment to reduce stillbirths. The findings from this global policy review highlight great gaps exist in setting national direction for stillbirth reduction. Without improving the policy environment which directs how stillbirths are acted upon at country-level, the global goal of reducing the SBR to 12 or less stillbirths in every country per 1000 total births will remain aspirational.

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Ethical issues

Ethics approval was received from the London School of Hygiene and Tropical Medicine to conduct the policy review. Additionally, we submitted a data sharing request form to WHO outlining the scope and intended output of the research. Approval was obtained and we received from WHO all national policies and documents submitted to the global 2018-2019 WHO RMNCAH Policy Survey.

Competing interests

Authors declare that they have no competing interests.

Authors' contributions

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Methodology: Nana A. Mensah Abrampah.
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Validation: Nana A. Mensah Abrampah.
Visualization: Yemisrach B. Okwaraji and Nana A. Mensah Abrampah.
Writing-original draft: Nana A. Mensah Abrampah.
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Supplementary files

Supplementary file 1 contains Tables S1-S4.

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5 Chapter 5 District health management and stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

This chapter, to the best of my knowledge, provides the first analysis of district health management and stillbirth measurement (objective 2). It provides a review of the applied methodology as well as the insights shared by the district health management teams. Implications of the findings are discussed as well as the recommendations for action.

This chapter was published on 24 January 2024 in the BMC Pregnancy and Childbirth journal. The manuscript and associated supplementary document can be found at the link provided below: https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-024-06272-x. The manuscript was published under a creative commons license (CC BY-NC-ND 4.0) and the published manuscript is included in full below.

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5.1 List of Figures

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5.3 Research Paper

The research paper is presented with cover sheet on the next page.

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Student ID Number	1805521	**Title**	Ms
First Name(s)	Nana Afriyie		
Surname/Family Name	Mensah Abrampah		
Thesis Title	Counting the invisible: health system factors influencing stillbirth measurement and reporting		
Primary Supervisor	Debra Jackson		

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SECTION E

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Date	29 April 2024

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Date	30 April 2024

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RESEARCH

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District health management and stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

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Abstract

Background Despite global efforts to reduce maternal and neonatal mortality, stillbirths remain a significant public health challenge in many low- and middle-income countries. District health systems, largely seen as the backbone of health systems, are pivotal in addressing the data gaps reported for stillbirths. Available, accurate and complete data is essential for District Health Management Teams (DHMTs) to understand the burden of stillbirths, evaluate interventions and tailor health facility support to address the complex challenges that contribute to stillbirths. This study aims to understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of DHMTs.

Methods The study was conducted in the Ashanti Region of Ghana. 15 members of the regional and district health directorates (RHD/DHD) participated in semi-structured interviews. Sampling was purposive, focusing on RHD/DHD members who interact with maternity services or stillbirth data. Thematic analyses were informed by an a priori framework, including theme 1) experiences, perceptions and attitudes; theme 2) stillbirth data use; and theme 3) leadership and support mechanisms, for stillbirth recording and reporting.

Results Under theme 1, stillbirth definitions varied among respondents, with 20 and 28 weeks commonly used. Fresh and macerated skin appearance was used to classify timing with limited knowledge of antepartum and intrapartum stillbirths. For theme 2, data quality checks, audits, and the district health information management system (DHIMS-2) data entry and review are functions played by the DHD. Midwives were blamed for data quality issues on omissions and misclassifications. Manual entry of data, data transfer from the facility to the DHD, limited knowledge of stillbirth terminology and periodic closure of the DHIMS-2 were seen to proliferate gaps in stillbirth recording and reporting. Under theme 3, perinatal audits were acknowledged as an enabler for stillbirth recording and reporting by the DHD, though audits are mandated for only late-gestational stillbirths (> 28 weeks). Engagement of other sectors, e.g., civil/vital registration and private health facilities, was seen as key in understanding the true population-level burden of stillbirths.

Conclusion Effective district health management ensures that every stillbirth is accurately recorded, reported, and acted upon to drive improvements. A large need exists for capacity building on stillbirth definitions and data

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use. Recommendations are made, for example, terminology standardization and private sector engagement, aimed at reducing stillbirth rates in high-mortality settings such as Ghana.

Keywords Health systems, District health management, District health management teams, Stillbirths, Fetal deaths, Data systems, Quality of care

Background

Every year, 1.9 million babies are stillborn [1]. Despite this number, stillbirths are rarely discussed in global and national conversations on improving reproductive, maternal and newborn outcomes [2, 3]. The World Health Organization (WHO) *International Classification of Diseases (ICD), Edition 11* defines stillbirth as a baby born with no signs of life at 22 or more completed weeks of gestation [4]. Stillbirths are categorized by timing of fetal death in relation to the onset of labour [4]. Most intrapartum fetal deaths, occurring during labor, and many antepartum fetal death, before the onset of labor, can be prevented with strong health systems [2]. While strengthening health systems broadly is key, increased attention needs to be placed on the health workforce [5–9]. Involving health workers in stillbirth recording and reporting is fundamental for collecting accurate data, understanding causes and risk factors and driving effective public health interventions.

The district health system has long been seen as the foundation of strong health systems [10]. In the realm of public health, District Health Management Teams (DHMTs) play a pivotal role as drivers of health initiatives. DHMTs are responsible for effectively planning and budgeting, human resource management, monitoring service quality, and resource allocation to support health facilities and meet needs of the population within their comunities [11]. The dedication of DHMTs to ensuring the well-being of their communities extends to the comprehensive recording and reporting of health indicators, including the critical aspect of stillbirths [12].

DHMTs serve as the cornerstone of data collection, analysis, and reporting mechanisms within their respective districts [12]. In many low- and middle-income countries (LMICs), including Ghana, information on stillbirth is collected at the facility-level and entered into routine health information systems at the district-level. Common bottlenecks reported for using maternal and newborn health data have included weak staff capacity for data management and use (interpretation, analysis, and planning) [13]. Specifically related to stillbirths, existing literature highlights the challenges that impede the quality and availability of stillbirth data. These factors relate to omission and classification of stillbirth, low levels of understanding and engagement on stillbirth issues, and inconsistent application of stillbirth definitions [14].

With the release of the global stillbirth report by the United Nations Children's Fund (UNICEF) and WHO, evidence suggests that measures to improve accuracy of stillbirth data are needed now more than ever [2]. The UNICEF/WHO report urges countries to report and review stillbirth data locally at the facility and district, and reduce incentives for misreporting outcomes, and to monitor potential misclassification. This paper, the first in-depth analysis of district health management and stillbirths, is the first of two-papers looking at the role of DHMTs and facility-level health workers in stillbirth recording and reporting. The overall aim of this study is to understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of DHMTs.

Methods

Aim

Based on literature reviews conducted, specific objectives of the paper include: to explore the experiences, perceptions, and attitudes of DHMTs on stillbirth recording and reporting; to understand stillbirth data flow and how stillbirth data is used by DHMTs; and to explore leadership and support mechanisms available from the district-level to facilitate stillbirth recording and reporting at the facility-level.

Region selection and study participant characteristics

The 2020 Ghana Health Service (GHS) Family Health Division Annual Report reported the stillbirth rate (SBR) for Ghana at 12.3 per 1 000 total births [15]. The SBR declined in most regions except for four regions including the Ashanti Region. The Ashanti Region reported a SBR of 12.2 per 1 000 total births, and the highest total stillbirth number across all regions (1580 stillbirths recorded for year 2020) [15]. Additionally, stillbirth related indicators, including maternal and neonatal deaths remain high for the region [15, 16].

Within the Ashanti Region, we selected study participants from the public/government sector. Namely, the Regional Health Directorate (RHD) and four out of the 43 District Health Directorates (DHD) were selected to represent different levels of stillbirth reporting (Fig. 1). The RHD champions the implementation and monitoring of health policies formulated by the Ministry of Health.

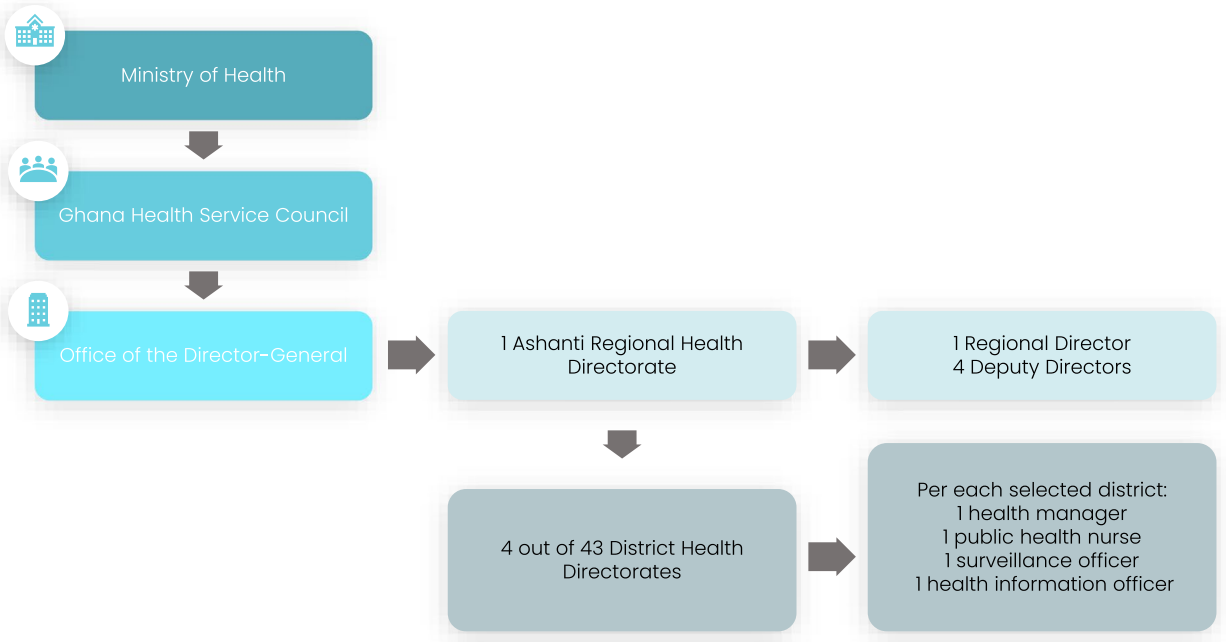

Fig. 1 RHD/DHD organization and participants of interest to the study

DHDs provide leadership, supervision, management, and technical support to their sub-districts and facilities.

Selection of participants from the study region and districts (Fig. 2) was purposive aiming to include viewpoints from a variety of RHD/DHD cadres. All five members of the leadership team at the regional level were invited to participate. At the district level, we focused on members who interacted with maternity services or stillbirth data; aiming for each district to interview one district health manager, one public health nurse, one surveillance officer

District	Stillbirth rate (SBR)	Stillbirth number	Total volume of deliveries in the district	Neonatal mortality rate (NMR)	Maternal mortality rate (MMR)	Level of skilled deliveries	Availability of perinatal audit	Rationale for district selection
Asante Akim South	1.6	5	3401	1.2	31.1	68.8	Yes	Reporting low SBR and low NMR with adequate levels of skilled birth attendants
Asokwa	19	69	3537	14.1	56.3	70.4	Yes	Second highest NMR rate in the district following Kumasi. The NMR is greater than the Every Newborn Action Plan (ENAP) target of 12 per 1 000 live births. The district has an increased number of skilled deliveries and second highest SBR (> ENAP target of 12 per 1000 total births)
Kumasi	28.7	571	20003	24.9	542.4	112.6	Yes	High stillbirth rate (> ENAP target of 12 per 1 000 total births), high total volume of deliveries, high MMR, high NMR(> ENAP target of 12 per 1 000 live births) and high level of skilled deliveries
Sekyere South	13.6	46	3343	3.9	29.9	69.6	Yes	High stillbirth rate(> ENAP target of 12 per 1 000 total births), though low NMR, adequate levels of skilled birth attendance, high volume of deliveries

Fig. 2 Selection criteria for study districts in the Ashanti Region, as reported in the 2021 DHIMS-2 system from the Ashanti Region

and a health information officer. In total, 21 participants were of interest to the study.

Procedure

Semi-structured interviews were conducted to explore the experiences, perceptions, and attitudes on stillbirth recording and reporting; stillbirth data; and leadership and support mechanisms, using an interview guide (Supplementary document 1). A visual aid was developed to further elicit perspectives on stillbirth types (Supplementary document 2). The interview guide was jointly developed by the authorship team using insights gathered from the WHO reproductive, maternal, neonatal, child, and adolescent health policy survey stillbirth review [17], an analysis of existing literature, and conversations with stillbirth measurement experts. The guide was tested with the in-country team in Ghana to ensure that the questions were understood in this context. Interviews were conducted over Zoom in English by the first author, due to in-country protocols for COVID-19, time and cost-effectiveness. All interviews were recorded on Zoom, transferred into the London School of Hygiene and Tropical Medicine (LSHTM) password secured drive of the first author and transcribed verbatim. Consent forms (Supplementary document 3) were shared with participants ahead of interviews and verbal consent was obtained during interviews. Interviews were between 45 min to an hour long.

Data collection and analysis

Thematic analyses were used for the study. This was guided by the Braun and Clark 6-step approach: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and report production [18].

All interviews were coded by the first author, and a random 30% reviewed by a second and third coder. When there was discrepancy between the coders, a discussion was held to address and agree on a way forward. Inductive and deductive approaches were applied. The literature review informed the selection of three major a priori themes (experiences, perceptions, attitudes on stillbirth recording and reporting; stillbirth data; and leadership and support mechanisms). Sub-themes were identified and derived from the interviews. The authorship team had access to the blinded interview transcripts to facilitate agreement on identified themes. NVivo software was used to manage and code the data.

Perspectives shared by study participants were taken at face value to highlight the realist approach to the research. The study followed the consolidated criteria for reporting qualitative studies (COREQ) guidelines [19].

Results

Fifteen interviews were conducted (out of a total of 21), including: 3 senior managers from the regional health directorate, 4 district health managers, 3 district public health nurses, 3 district health information officers and 2 district surveillance officers. Two senior regional managers declined to participate in the interviews as they did not work directly on stillbirths. We received no responses to participate in the interview from 2 surveillance officers and 1 health information officer. One district, Asante Akim South, did not have a Public Health Nurse at the time of the interviews. The 15 study participants interviewed represented 8 women and 7 men, with an average of 10 working years.

Data saturation was achieved after 15 interviews with the following themes emerging. Ten sub-themes were identified from the interviews across the three a priori major themes. For experiences, perceptions and attitudes, sub-themes relating to preventability, stillbirth definition, and quality of care were identified. For stillbirth data, recurring themes included data quality, audits, and the district health information management system (DHIMS-2). Themes relating to leadership and support mechanisms touched on available support mechanisms, funding constraints, DHIMS-2, and private sector engagement. Figure 3 provides an overview of the major and sub-themes from the study.

Experiences, perceptions, and attitudes on stillbirth reporting and recording

Preventability

All respondents were aware of the importance of preventing a stillbirth. Notably, antenatal care (ANC) and health worker skills were flagged as being critical to end preventable stillbirths.

> *"We educate women to come for ANC and to report any danger signs during pregnancy...there are times also when we organize in-service or refresher trainings for the midwives... (Public Health Nurse #12)."*

The importance of recording stillbirths to inform interventions and course-correct actions was shared:

> *"The recording helps us know how we are progressing or retrogressing so that the necessary steps can be taken to correct the errors (Public Health Nurse #6)."*

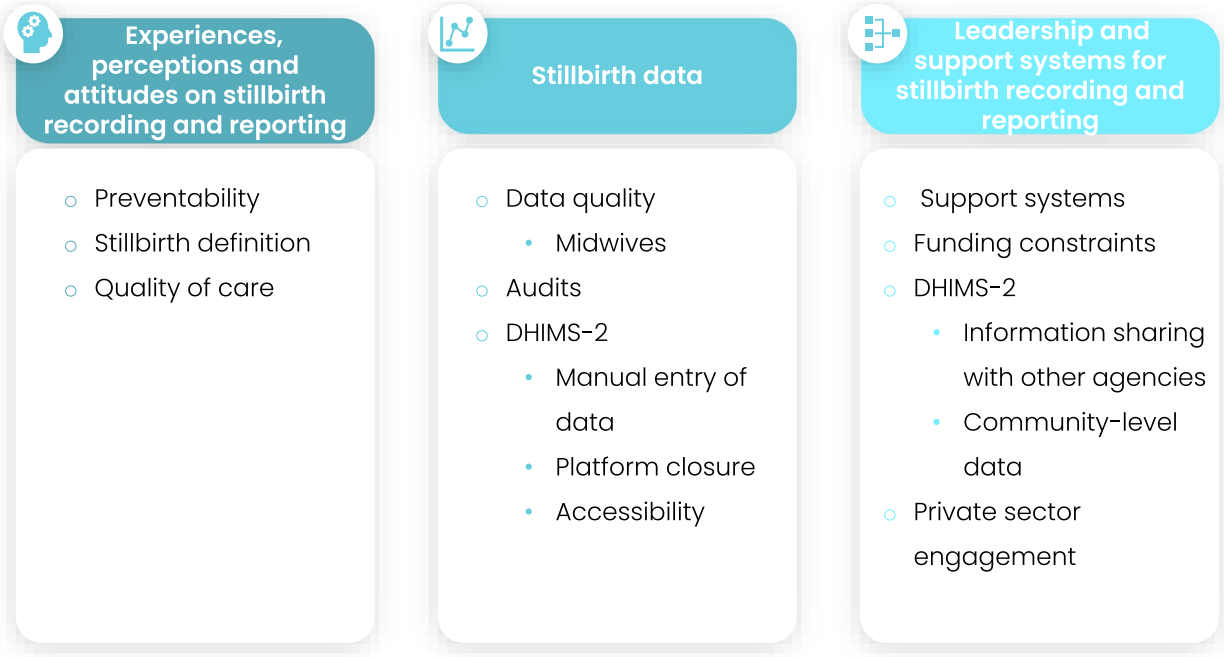

Fig. 3 Major and sub-themes from interviews

Stillbirth definition

Most respondents were aware of what a stillbirth entails, describing it as the death of a baby before or during delivery. Respondents highlighted that health facilities within the region align with the Ghana Health Service institutional definition of stillbirths.

> *"That one, we are working within the national Ghana Health Service. So, the definition for Ghana Health Service is what we use; we don't have different definition (Health Information Officer #7)."*

When probed further on the gestational age threshold in weeks for defining a stillbirth in Ghana, there was variation with 20 weeks (about 4 and a half months) and 28 weeks (about 6 and a half months) were commonly referenced.

> *"Stillbirth is a death or end of pregnancy after the 20th week. After the 20th week, if the pregnancy is terminated, it is stillbirth but if it is less than 20 weeks, it becomes a miscarriage (District Health Manager #8)."*

> *"So, for us as a country, if you have a baby that is not born alive after 28 weeks of gestation, we consider it as stillbirth (Deputy Director #4)."*

Other respondents characterized stillbirth as fresh or macerated, with little reference made to the gestational age of the fetus.

> *"The fresh is immediately the death occurs even before delivery but within the delivery process. For macerated, the child may die for let say some few days before the mother reports to the facility (Public Health Nurse #12)."*

Quality of care

A few respondents with background in clinical care (i.e., public health nurses and members of the regional health directorate) described stillbirth in terms of antepartum and intrapartum stillbirth. Respondents equated antepartum stillbirth to before labor reflecting the quality of antenatal care and intrapartum stillbirth to during delivery reflecting the quality of delivery care.

> *"The antepartum (stillbirth), I will say will reflect the quality of antenatal care whilst the intrapartum (stillbirth) reflects the quality of the delivery care (Deputy Director #2)."*

Some respondents linked the outcome of stillbirth to health systems failure and health workforce skills.

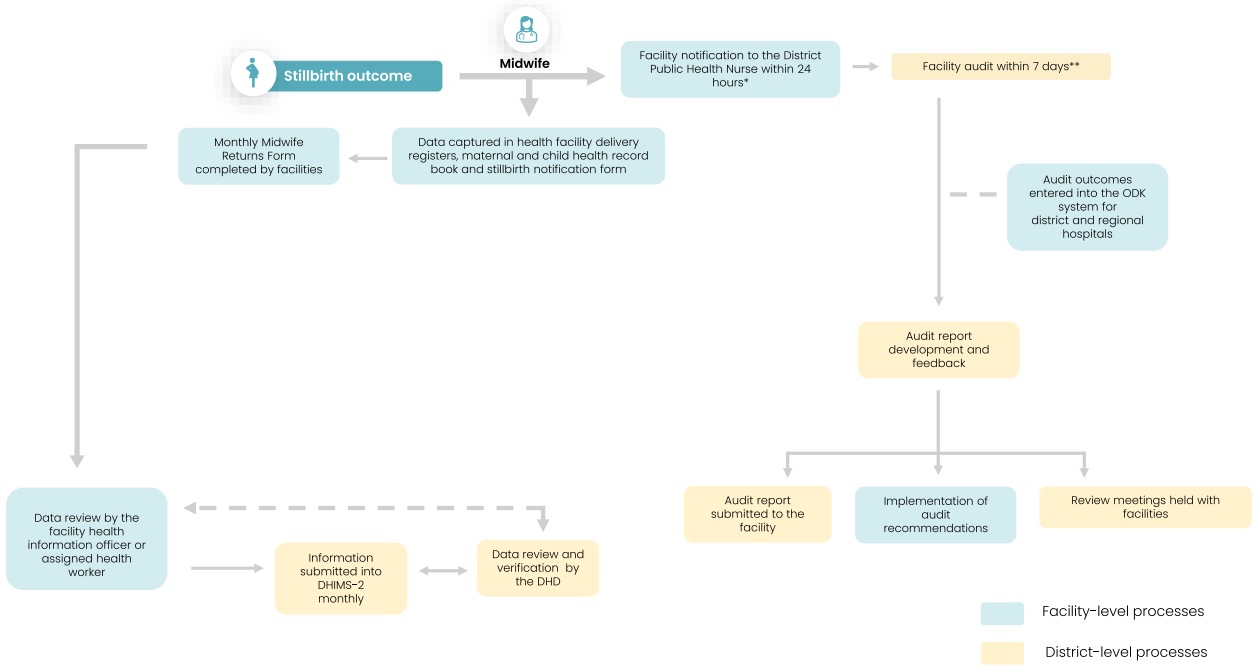

Fig. 4 Stillbirth data flow as reported by respondents

*Except for the regional hospital where an email is sent per Electronic Perinatal Death Surveillance and Response (ePDSR) system

** Performed by a multi-disciplinary team, including health workers at the facility and the DHD

> *"We have two types of stillbirths; we have fresh and macerated stillbirth. The fresh one has to do with technicality of the midwife in assisting the woman to deliver …. When it is macerated, we consider that it was a system problem (District Health Manager #11)."*

Stillbirth data

Figure 4 illustrates the flow of stillbirth data from the facility-level to the district-level as described by the respondents.

When a stillbirth occurs, notification is sent to the district public health nurse. Data capture for stillbirth is manually entered into a maternity registry. At the end of the month, stillbirth data at the facility is tallied and entered into the paper-based Midwife Returns Form (also known as Form A), a form which captures key data on pregnancy outcomes. The information on the Midwife Returns Form is then transferred into the electronic data management system, DHIMS-2, the database for storing health service data in Ghana. For the district and regional hospitals, stillbirth data is also captured into the Open Data Kit (ODK) system. The ODK system is the national maternal/perinatal audit form translated into an online form. The ODK system requires health workers to provide further information on the circumstances surrounding a stillbirth.

Most respondents shared that data quality checks, audits, and the DHIMS-2 data entry and review, are primary functions played by the district health management teams.

Data quality

Data quality checks occur both at the facility and district-level. Respondents shared that data validation meetings with health facilities help to ensure that data being processed is accurate.

> *"We invite the facility heads for data validation meetings at the DHD every month. During the validation meetings, we do analysis of the data (Health Information Officer #7)."*

When inconsistencies are reported in the data, the DHD schedules a meeting with the facility to review the paper-source documents and make corrections where needed.

> *"It should not be less or more. Once it is less or more, there is a data quality issue, which means*

that one is omitted or an additional one is smuggled. We need to go back to the facility and look at the data and make the necessary correction (Surveillance Officer #5)."

Inaccurate reporting linked to internet connectivity for DHIMS-2 was also reported.

"Sometimes the DHIMS-2 can also go off temporarily. If you do not follow up to see that what you have entered, it will not be recorded (District Health Manager #10)."

Midwives

The majority of respondents flagged that midwives were responsible for many data quality gaps in stillbirth data. These were reported to be both deliberate omissions, for example to avoid blame:

"The midwife will decide not to capture a stillbirth because sometimes, maybe they are running from their responsibility... maybe the death was due to the inaction of the health worker. That is what I can say (Health Information Officer #4)."

Or from errors in classification:

"We realize that certain deaths are captured as stillbirths, meanwhile the baby was out for some period before the baby passed out and that is certainly not a stillbirth. So that misjudgment on the part of the midwife recording is there (District Health Manger #9)."

Lack of recording may also occur due to increased workload:

"…For example, the midwife may be busy and forget to call when a stillbirth happens, and it is only during data verification that we discover (Surveillance Officer #14)."

Audits

The importance of audits was highlighted strongly by all respondents. Some respondents shared that audits take place if the fetus is over 28 weeks.

"Of course, if you are born at 27 weeks and you make it, we take you but if you are below 28 weeks and you do not make it, nobody will audit that death. You are not required by the service (GHS) to audit that death because the health system is not robust to be able to take care of such babies (Deputy Director #4)."

District health information management system-2

The importance of the online DHIMS-2 for review and analysis of stillbirth data was universally shared. Respondents mostly discussed gaps when the DHIMS-2 was discussed.

Manual entry of data

Stillbirth data is originally captured on paper before being transferred into the DHIMS-2, which was reported to lead to potential data entry errors. With manual entry, respondents reported that the midwife attending to the labor records the birth outcome on paper before it is transmitted by the facility/district health information officer to the DHIMS-2.

"The midwife will do the recording on the paper, then send to HI (Health Information) Officer. As to whether the HI is entering the real data into DHIMS-2, we are not sure. I think that one is a challenge for us (Public Health Nurse #12)."

A lack of understanding the terminology associated with stillbirths was also flagged:

"During review meetings, the midwives will say no this is a wrong figure. Sometimes, the health information officer may not understand some of our midwifery terms. The health information officer may enter it wrongly (District Health Manager #8)."

Platform closure

At the end of each month, DHIMS-2 is closed 60 days after that month ends. This is done for data verification at the district level. Health facilities do not have access to record or review the data in DHIMS-2 after 60 days when locked. If a facility failed to input the data before DHIMS-2 is locked, some respondents reported they experienced health facilities adding the data to the next month.

"If a particular month, a facility is to report, and DHIMS-2 is locked… In DHIMS-2, you realize this facility did not have any stillbirth for that month. You call the facility, and you realize that yes, they (health workers) recorded a stillbirth in their register, but it wasn't entered in the DHIMS-2 because DHIMS-2 was closed. The following month when DHIMS-2 is open, they(health workers) add it to the new month (District Health Manager #10)."

Accessibility

Accessing the information in the DHIMS-2 is only available to health information officers, and senior managers within the public health system. Respondents shared this limits engagement of health workers in stillbirth data use.

> *"It is only the health information officer in the district who has access to the DHIMS-2. I think it is very challenging. Ideally even the midwife who is using the data should be able to access and engage with DHIMS-2 … (Public Health Nurse #12)."*

Leadership and support mechanisms

Support systems

All respondents shared that the RHD/DHD are committed to improving stillbirth recording and reporting. Specifically, over half of interviewed respondents mentioned the role of audits as a sign of leadership commitment to reducing stillbirths.

> *"Yes, we are committed because whenever you record any stillbirth you have to find out from the midwives, is it really a stillbirth? That is why we have the audit….we are committed to reducing stillbirths (Health Information Officer #7)."*

Additionally, feedback and introduction of the DHIMS-2 and the ODK system were seen by respondents as a sign of leadership commitment to stillbirth recording and reporting.

Specifically, the ODK system is a regional initiative introduced by the RHD to obtain timely information on stillbirth and the mother following an audit.

> *"The ODK …is a regional initiative. It captures everything that was supposed to be captured for the perinatal audit, just that it is electronic. By the time a facility has finished their perinatal audit, the region already has a soft copy (Deputy Director #3)."*

Feedback loops through audits, informal telephone communications, and more formalized supportive supervision and training were seen as available support systems to facilities.

> *"We have our planned quarterly supervision visits and supportive supervision visits…We do our best to visit some of the facilities. We are fortunate our current public health nurse is also a midwife, so she has that skill to coach and mentor newly posted midwives to do the right thing (District Health Manager#9)."*

Funding constraints

Limited funding was highlighted as the major bottleneck to improving stillbirth recording and reporting. When funding is available, it is often from donors and earmarked.

> *"Funding is a big challenge. All our funding is from programmes so if a donor doesn't have interest and all the money coming in is for vaccination, nutrition …, you will come up with priorities for the year and you will have perinatal and maternal death at the top, but we may go through the year and we would have done little to achieve the stated objectives because the funding was not there (Deputy Director #15)."*

Funding limitations, respondents noted affects training, supportive supervision, coaching, and essential equipment. Most importantly, limited funds affect the frequency of stillbirth audits.

> *"…even moving from one facility to another for the stillbirth audit, the district will have to get fuel. Looking at the current situation, the district does not have any funds for those services. So sometimes you have to go on your own (Public Health Nurse #12)."*

DHIMS-2

Information sharing with other agencies.

Information captured in DHIMS-2 is only available to health information managers and senior officials within the public health sector. Other agencies such as statistical services or civil and vital registration, who play important roles in stillbirth monitoring do not have access to the DHIMS-2.

> *"Other agencies don't have automatic access to the data. You need to be assigned an account before you can access the DHIMS-2. Often, it is Ghana Health Service who assigns, and it is not for everybody in the Service. It is specifically for data officers, health information officers and maybe managers of the health system who have access to it (Deputy Director #2)."*

> *"…… every data from GHS is in the DHIMS-2, it is sensitive information. If the national statistical service will need it, they will have to put it officially in writing (Deputy Director #4)."*

Community-level data

Currently the DHIMS-2 only captures information at the public health facility level. Some respondents flagged the importance of moving to a system that captures information from the community-level. Three respondents noted this is important for planning and delivering interventions within the peripheral of the district health system.

> *"The vital registration and statistics are not directly under the district health, so this is difficult to under-*

stand what is happening at the community level to plan interventions which we help deliver. DHIMS-2 could help with this (District Health Manager #10)."

Private sector engagement

The theme of private sector engagement was expressed by several of the RHD/DHD respondents. In Ghana, private facilities are autonomous. Though, they are mandated to report health data, including mortalities to the DHD, this is not always the case.

"*In the event of a stillbirth, most private facilities do not report to the DHD meaning, a lot of stillbirth cases and other cases are missed (Deputy Director #2)."*

One respondent flagged that in terms of data sharing on stillbirth, there were some challenges getting private sector facilities to submit monthly reports to the district-level. These challenges include staff attrition, limited skilled workforce and reporting does not bring profits.

"Since submitting reports does not generate revenue for the (private) facilities, sometimes you go to a facility, and they don't even have a record officer who will submit reports. That is always a challenge (Health Information Officer #3)."

Discussion

In understanding the experiences, perceptions, and attitudes of the RHD/DHD on stillbirth recording and reporting, we found that respondents understood the importance of stillbirth prevention and quality care, though there was varied understanding on what a stillbirth entails. Stillbirths were classified as fresh or macerated with limited references made to antepartum or intrapartum stillbirths. Data quality and DHIMS-2 were recurring themes for stillbirth data use. Support systems, funding constraints, sharing of data with other agencies and community-level data inclusion in DHIMS-2 were identified as enablers and barriers. Private sector engagement was a noted priority for respondents.

Experiences, perceptions and attitudes

Leaders at the RHD/DHD were keenly aware of the importance of quality of care interventions such as ANC attendance and a skilled workforce in preventing stillbirths [20]. This finding was in line with other health workforce studies reported in Ghana and other similar settings [21–24]. An understanding of the importance of stillbirth prevention is crucial for district health mangers. District health managers who understand the significance of stillbirth prevention are more likely to prioritize data collection, analysis, and utilization, resulting in better-informed strategies and policies.

With the release of the WHO ICD-11, stillbirth is now defined as a baby born with no signs of life at 22 or more completed weeks of gestation [4]. The Ghana Health Service defines stillbirth as a baby delivered with no signs of life (gasping, heart beat or limb movements) after 28 completed weeks of pregnancy (Fig. 5) [25]. Interviews with the RHD and the DHD highlighted diverse understanding, within and between the different RHD/DHD cadres, on the definition of stillbirth. The lack of a universally understood definition of stillbirth affects how stillbirths are accurately recorded into routine health information management systems at the district-level

	Global	Ghana
Stillbirth Definition	2023 Definition: Stillbirth is the complete expulsion or extraction from a woman of a fetus, following its death prior to the complete expulsion or extraction, at 22 or more completed weeks of gestation. Stillbirths are distinct from cases of induced abortion. When information on gestational age is unavailable use birthweight less than 500 grams as the criteria (1)	2015 Definition: A stillbirth is a baby delivered with no signs of life (gasping, heartbeat or limb movements) after 28 completed weeks of pregnancy (2)
Audit Recommendation	2016 Recommendation: WHO's recommended threshold of 28 completed weeks is appropriate for mortality audits in low- and middle-income settings(3)	2016 Recommendation: A perinatal death audit occurs for any death occurring between twenty-eight completed weeks gestation and seven days after delivery (4).

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1. World Health Organization. *ICD-11 for Mortality and Morbidity Statistics*. Geneva, 2023.
2. Ministry of Health Ghana. *Standard Operating Procedures for Maternal and Child Health Services*. Accra, Ghana 2015.
3. World Health Organization. *Making every baby count: audit and review of stillbirths and neonatal deaths*. Geneva: World Health Organization; 2016.
4. Ministry of Health Ghana. *Perinatal Death Audit Guidelines* Accra, Ghana: Ministry of Health 2016.

Fig. 5 Stillbirth definition and audit recommendation in Ghana and globally

and reported in national-level documents [26]. Further, non-standard application of the stillbirth definition has resulted in challenges in assessing stillbirth rates [2], thereby influencing prioritization, resourcing allocation and strategic planning based on gaps, and informing regional and district health management team support to health facilities.

Historically, classifying stillbirths in many LMICs has relied on fetal appearance based on assessment by the attending health care worker [27–29]. We found similar perspectives among regional and district health management teams in this study. Study participants classified stillbirth as macerated or fresh stillbirth with little reference to the timing around labor. Macerated stillbirth shows changes in skin i.e., soft-tissue changes, while fresh stillbirth does not. A study conducted at a tertiary hospital in the Ashanti region of Ghana found that using skin appearance is not an accurate proxy for stillbirth classification due to its subjective nature [27, 30, 31]. Misclassifications are likely to occur when a standard criterion is not applied between health care workers. The United Nations Inter-agency Group for Child Mortality Estimation (UN-IGME) and the WHO, as part of the ICD-11 release, are encouraging countries to move away from traditional visual assessments for timing of stillbirth, and towards a more accurate classification using absence of fetal heart activity on auscultation or ultrasound on admission to labour ward [4, 32]. This is intended to standardize the stillbirth definition and avoid misclassification.

Globally, 42% of stillbirths are intrapartum, with up to 50–70% in LMICs [2, 9]. Most stillbirths are preventable with quality of care interventions, which was well recognized by the RHD/DHD. Interventions such as monitoring mothers throughout pregnancy can prompt timely delivery of at-risk pregnancies [14] and improved intrapartum monitoring linked to timely action can avoid adverse pregnancy outcomes, including stillbirth [33]. Improving the accuracy of recording of fetal death, and including information around timing, will allow regional and district health teams to plan and track appropriate quality of care interventions to avert preventable stillbirths.

Stillbirth data

DHIMS-2, an electronic data management system in Ghana, was established to aggregate routinely collected data across all public health facilities in the country, facilitate analysis, forecast required services, and evaluate performance of health care workers [34–37]. Information gathered from the DHIMS-2 is also used to formulate policies, evaluate programmes and allocate resources [38]. We discovered that when the national-level periodically shuts down DHIMS-2, health workers tend to report stillbirths by adding data from the previous month to the new month, leading to an increase in reported cases. This finding aligned with the known challenges on over-reporting of certain indicators from health facilities into health information management systems [39]. Similarly, in the absence of a universal online platform accessible by all health facilities, manual entry of data into health information management systems can be time-consuming, has shown to increase errors and has potential to decrease data quality which influences data analysis [37]. All these factors can impact decision-making, leading to ill-informed resource allocation and planning inefficiency at the regional and district level [40].

Early gestational stillbirth is defined as stillbirths occurring between 22 and 27 weeks. Late gestational stillbirths are fetal deaths occurring after 28 weeks. Some RHD/DHD members described the national mandate to conduct audits only if the fetus is over 28 weeks [41]. In Ghana, this is done due to the capacity of the health system to investigate third-trimester stillbirths or late fetal deaths. This national audit recommendation is aligned to global guidance from WHO, using an audit threshold of 28 completed weeks as appropriate for mortality audits in LMIC settings (Fig. 5) [42]. When audit thresholds start at 28 weeks, early gestational stillbirths are excluded. Whilst it may not be feasible to audit all stillbirths, excluding early gestational stillbirths may result in these deaths being perceived as having less value, which may result in them being missed from being counted in the data system [14]. This can potentially lead to underreporting of the true burden of stillbirths in the routine health information management systems [43].

Literature surrounding blame of midwives and other health care workers in stillbirths is widely documented [44–47]. There were similar findings in this study with some RHD/DHD members blaming omission or gaps reported in stillbirth data on midwives. The trauma and guilt associated with stillbirth can cause health care workers to forgo recording and reporting stillbirth.

Leadership and support mechanisms

Efforts to accurately record and report stillbirth data are often hampered by limited resources [2]. We found that funding constraints affect the frequency of audits, a systematic process to prevent future stillbirths [45]. Insufficient resourcing has been extensively documented as a barrier to audit implementation [48]. This hinders the monitoring, review and learning processes grounding perinatal audits; limits improvements to be made post-audits and contributes to gaps reported in routine health information management systems on the circumstances surrounding a death.

A recent study found that 21 countries (out of 66) required data on stillbirth at health facility or at the community-level be provided to the national statistics office, civil registration system, or equivalent bodies [17]. In exploring this further, we found that information captured within the DHIMS-2 is not easily accessible to other national agencies. Agencies requiring information from the DHIMS-2 need to undergo a formal process/request to GHS for the information. Understanding the magnitude of the stillbirth burden at country level, requires collaboration and triangulation of information across various data sources including the DHIMS-2, civil registration and vital statistics systems (CRVS) and the birth or death registries. With CRVS, the health sector can be a powerful ally in providing insights into births as well as the circumstances surrounding a death [49]. Ensuring timely access to information on stillbirth in DHIMS-2 can facilitate greater prioritization of the stillbirth agenda across agencies, foster inter-agency collaboration and drive investments into stillbirth reduction.

Over 70% of stillbirths in LMICs occur in community settings [50, 51]. Triangulating information from the community-level on stillbirths with information from health facilities provides a holistic picture of the true population burden of stillbirths. Interviewed RHD/DHD members flagged the importance of an integrated health information management systems which includes data on stillbirths from the community and the health facility level. Taking forward an integrated system was reported to optimize data timeliness and completeness though challenges were also reported on network connectivity and support systems for community health workers to report the data [52].

Private health facilities are increasingly becoming the first point of contact for the health system for many LMIC families including for maternal and child health service delivery, accounting for around 40% of antenatal and childbirth care contacts [53, 54]. In Ghana, private health facilities make up 40.2% of all health facilities, while government facilities (53.8%) and faith-based facilities (6%) complete the spectrum of service delivery actors [55]. In this study, although private health sector facilities within the Ashanti Region are mandated to report stillbirth data to the DHD, this did not always occur. Even when policies are in place, there are gaps in reporting from the private sector – a situation likely to be worse in the majority of countries without even a policy. This can potentially lead to under-reporting of stillbirths in DHIMS-2 and under-estimating the real burden of stillbirths since information from the private sector is not captured. Improving stillbirth data requires equal attention to public as well as private health facilities [2].

Implications for practice

The findings from this study provide important information to inform improvements in stillbirth recording and reporting in the Ashanti Region of Ghana.

Immediate priorities for action include: first, the Ashanti RHD should organize a workshop for all DHD members within the region to sensitize the district health management teams on stillbirths and the types of stillbirths aligned to the national definition for stillbirths. This will facilitate consistent application of the stillbirth definition for recording and reporting. Second, revisit the national definition for stillbirths in Ghana, in light of the recent classification by WHO using the 22-week threshold. This ensures that all stillbirths are counted. Finally, review emerging global guidance on audit implementation to inform policy reforms.

Three long-term recommendations are proposed. These include the need to move towards a holistic digitalized DHIMS-2 for all health facilities. Two, integrate community-level data into DHIMS-2 to understand and manage district and regional-level support on stillbirths. Finally, whilst it is mandated that private sector facilities report data on stillbirth, measures should be put in place to ensure reporting by private facilities. This allows us to understand the scale, reach and true burden of stillbirths in the region.

Limitations

Though Zoom is a highly suitable platform for collecting qualitative interview data, [56] we experienced some internet connectivity issues with some participants. The study was conducted in one of the four regions of Ghana not experiencing a decline in SBR. This might limit the generalizability of the findings. However, RHD/DHDs are regularly on rotation to different regions within the health system of Ghana. Additionally, findings from this study have been shared with the Ghana Health Service to ensure that recommendations in this study are scaled up to the rest of the country. Responses of the RHD/DHD may have been influenced by the presence of the first author. To address this, questions were asked repeatedly in a neutral manner and confidentiality was respected.

The first author has policy expertise in district health management, alongside an understanding of the issues on stillbirth recording and reporting. This may have influenced the thematic analyses.

Conclusion

This study explored the critical role that DHMTs play in stillbirth recording and reporting. By understanding the importance of stillbirth recording and reporting, DHMTs can pave the way for evidence-informed decision-making, implement effective interventions, and deliver

actions needed to achieve the global goal of 12 or fewer stillbirths per 1000 total births by 2030.

Abbreviations

ANC	Antenatal care
CRVS	Civil registration and vital statistics
COREQ	Consolidated criteria for reporting qualitative studies
DHD	District health directorate
DHIMS-2	District health information management systems 2
DHMT	District health management team
GHS	Ghana health service
ICD	International classification of diseases
LMICs	Low-and middle-income countries
LSHTM	London School of Hygiene and Tropical Medicine
MMR	Maternal mortality rate
NMR	Neonatal mortality rate
ODK	Open data kit
RHD	Regional health directorate
SBR	Stillbirth rate
UNICEF	United Nations Children's Fund
UN-IGME	United Nations inter-agency group for child mortality estimation
WHO	World Health Organization

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12884-024-06272-x.

Additional file 1.

Additional file 2.

Additional file 3.

Additional file 4.

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Authors' contributions
Conceptualization: NAMA, YBO, HB, DJ. Formal Analysis: NAMA. Investigation: NAMA. Methodology: NAMA, YBO, HB, DJ. Supervision: YBO, HB, DJ. Validation: NAMA, HB, DJ. Visualization: NAMA. Writing-original draft: NAMA. Writing–review & editing: DJ, HB, YBO, KFO, EKA, RLR.

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Availability of data and materials
The datasets used and/or analyzed during the study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Ethical approval for the study was gained from the appropriate ethical committees, including the Ghana Health Service (GHS, Reference: GHS-ERC 025/07/22) and the London School of Hygiene and Tropical Medicine (LSHTM, Reference: 28017).
Study participants were provided with a consent form (Supplementary document 3) and an information sheet (Supplementary document 4) outlining the intended scope of the research. Informed consent was obtained from all subjects.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Publisher's Note

6 Chapter 6 "If there is no data, how do we improve?" Exploring health workers, stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

This chapter, to the best of my knowledge, is the first study looking at the critical role of health workers in stillbirth recording and reporting (objective 3). It provides a review of the approaches and methodology applied and the perspectives shared by midwives, doctors, physician assistants and health information officers on the counting of stillbirths.

The paper was submitted to the BMC Pregnancy and Childbirth Journal on 18 November 2023 and is currently undergoing review and revision.

6.1 List of Figures

6.2 List of Tables

6.3 Text Boxes

6.4 Research Paper

The research paper is presented with cover sheet on the next page.

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RESEARCH PAPER COVER SHEET

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SECTION A – Student Details

Student ID Number	1805521	**Title**	Ms
First Name(s)	Nana Afriyie		
Surname/Family Name	Mensah Abrampah		
Thesis Title	Counting the invisible: health system factors influencing stillbirth measurement and reporting		
Primary Supervisor	Debra Jackson		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?			
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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	BMC Pregnancy and Childbirth
Please list the paper's authors in the intended authorship order:	Nana A. Mensah Abrampah; Yemisrach B. Okwaraji; Kenneth Fosu Oteng; Ernest Konadu Asiedu; Rita Larsen-Reindorf; Hannah Blencowe; Debra Jackson
Stage of publication	**Undergoing revision**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I led the conceptualization of the study jointly with my supervisory team. I developed the ethics documentation protocol, research questions and guides, conducted and analyzed the interviews and wrote the manuscript. The first and subsequent drafts of the paper included review inputs from the supervisory team and co-authors. Further, my supervisory team provided reviews of all developed tools and protocols.

SECTION E

Student Signature	Nana Afriyie Mensah Abrampah
Date	29 April 2024

Supervisor Signature	Prof Debra Jackson
Date	30 April 2024

"If there is no data, how do we improve?" Exploring health workers, stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

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Abstract

Background

Health workers play a critical role in documenting the estimated 2 million stillbirths that occur annually. From the moment a stillbirth occurs, a health worker is responsible for recording the birth outcome. The reliability of stillbirth data for informing global and national-level strategies on stillbirths depends on the information recorded by the health worker at the point of care. This study aimed to gain insights into their practices and challenges related to stillbirth recording and reporting.

Methods

The study explored the experiences, perceptions, and attitudes; barriers; and support mechanisms available to health workers for stillbirth recording and reporting. Semi-structured interviews were conducted with 28 health workers, including midwives, medical officers, physician assistants and health information officers. The study was conducted across four secondary-care and four primary-care level health facilities in the Ashanti Region of Ghana. All health facilities are government owned. Thematic analyses were conducted using a priori framework.

Results

Inconsistent definitions were used to describe stillbirths. Health workers described stillbirths using various gestational age thresholds, including 24-,28-,36- and 38-weeks. However, some health workers did not reference gestational age when describing stillbirths. Pre-service education shaped knowledge on stillbirths and its recording, with limited opportunities for in-service training. The motivation to record stillbirths was influenced by both intrinsic, driven by the moral imperative to do what is right, and extrinsic factors, influenced by district-level standards. Misclassifications and omissions of stillbirths occurred due to a higher workload, a large volume of forms requiring completion, limited knowledge and experience, and a deliberate effort to minimize facility mortality rates, especially in cases of macerated stillbirths. Midwives reported that blame was evident at three levels: blame from the wider health system, blame within the organizational facility, and individual-level blame. The failure to implement audit recommendations was identified as a bottleneck that perpetuating negative attitudes toward collecting stillbirth data.

Conclusion

To obtain reliable national data on stillbirths, we first need to understand the health worker experiences, perceptions and attitudes that underpin stillbirth data. The study suggests several recommendations, including reviewing audit protocols and improving coordination and communication on stillbirth definitions.

Background

In the last twenty years, progress has been made on maternal and child health outcomes with annual rate declines reported at 2.9% for both neonatal mortality and maternal mortality.[6] However, stillbirths, a related dimension of the maternal and child health life course, continues to remain a global public health issue with nearly 2 million babies stillborn after 28 weeks of gestation each year. Several low-and-middle income countries including Ghana are at risk of missing the global target of 12 stillbirths per 1 000 total births by 2030. Currently the stillbirth rate for Ghana is 12.3 per 1 000 total births.[146] To advance efforts in ending preventable stillbirths, a key strategy identified by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) is to improve health worker skills on recording and reporting of fetal deaths.[6]

Health workers are the foundation of high-quality data. The critical role played by health workers involves collecting and reporting accurate and complete data on stillbirths at the point of care, which informs national and global level actions. This reliable information is also key to close the implementation and knowledge gaps on quality of care needed to end preventable maternal and neonatal deaths. From the moment a stillbirth occurs, a health worker is responsible for recording the birth outcome. Gaps have been reported in the ability of health workers to properly document a stillbirth.[31, 32, 169] These challenges relate to knowledge, limited training and a lack of supportive work environment.[39] Further, blame, fear of being held accountable and a lack of understanding the value of recording a stillbirth are additional reported barriers for recording and reporting stillbirths by health workers.[23, 73, 99] The absence of data review mechanisms, including perinatal audits, and the health worker workload can also affect stillbirth measurement. In cases where stillbirth data is captured, non-standard definitions, omissions, under-reporting or misclassification of stillbirths, and other data quality issues have been reported to make the data unusable.[22, 23, 25, 99] For example, a recent study reported that for the 62 countries, accounting for 29% of all stillbirths in 2019, no high quality stillbirth data were available. The study urgently called on countries to improve recording of the timing of stillbirth and causes.

Stillbirth knowledge amongst health workers remains sub-optimal[33] with the majority of studies focusing on experience of care, clinical management or the socio-cultural aspects of stillbirths.[34-40] Very few studies mention health workers and stillbirth data,[25, 43] with one study reporting that the attitudes and beliefs of health workers are perceived barriers to stillbirth recording and reporting.[21] Additionally, there is little known information on the extent of the health workforce knowledge on stillbirth recording and reporting.

Against this backdrop, our study aimed to gain insights into health workers' knowledge and practices related to stillbirth recording and reporting in the Ashanti Region, Ghana.

Methods

Specifically, we aimed to explore the experiences, perceptions, and attitudes of health workers toward stillbirth recording and reporting; understand barriers related to stillbirth recording and reporting among health workers; and identify support mechanisms available to health workers to enable stillbirth recording and reporting.

Study setting

Data was collected in government health facilities between January to April 2023 in the Ashanti Region of Ghana. Four districts in the Ashanti region were selected for the study. The rationale for the selected region and study districts (within which the study facilities operate) are published elsewhere.[170] Briefly, the region and districts were selected based on contextual factors relating to stillbirth and related indicators such as neonatal and maternal mortality.

Within the districts, we focused on secondary-care level (hospitals) and primary-care level (health centers) government health facilities as our inclusion criteria for facility selection. The primary care-level is the first point of contact that many women have with the health care system. It is often the basis for referring complicated pregnancies to the secondary level. We excluded the one tertiary-level teaching hospital in the Ashanti Region due to previously published studies on stillbirths.[35, 149, 150] Private facilities, faith-based facilities and quasi-government (partly owned by government and another institution, usually a university or religious body) facilities were excluded. Table 1 outlines the total number of hospitals and health center facilities available in the study districts.

Eight government health facilities were selected for this study, representing one hospital and one health center per each of the four districts for the study. The rationale for facility selection was informed by four indicators – total number of deliveries, stillbirths, neonatal deaths and maternal deaths (Table 2).

An earlier related study with the District Health Directorate (DHD) provided insights into frontline health workers who deal with stillbirths and stillbirth data.[170] At the health facility-level, our primary focus was on midwives, as in this context, they are the ones primarily responsible for stillbirth cases and the associated data. In addition, we interviewed medical officers and physician assistants who provide support to midwives in stillbirth cases and health information officers who play a critical role in verifying stillbirth data. We planned to interview 4 staff members per facility, amounting to 32 interviews. Table 3 illustrates the distribution of the four types of health workers in each facility.

District	Number of Government Hospitals (Secondary-care level)	Number of Government Health Centers (Primary-care level)
Asante Akim South	**1**	**9**
Asokwa	**1**	**1**
Kumasi Metro	**3**	**2**
Sekyere South	**1**	**3**

Table 1: Total number of secondary and primary care facilities in selected districts

Hospital name	District	Level of care	Rationale for study selection	Total number of deliveries	Total number of stillbirths	Total number of neonatal deaths	Total number of maternal deaths
Hospital 1	Asante Akim South	Secondary	The facility serves as the only government hospital in the district.	1003	14	1	2
Health Center 1		Primary	Referred stillbirth cases to the government hospital.	164	1*	0*	0*
Hospital 2	Asokwa	Secondary	Reported high number of deliveries and stillbirths. The facility serves as the only government regional hospital in the district.	2720	59	21	4
Health Center 2		Primary	The facility is the only government health center in the district	114	0*	0*	0*
Hospital 3	Kumasi Metro	Secondary	Reported high number of deliveries and stillbirths. Reported low levels of neonatal and maternal deaths.	3097	42	2	1
Health Center 3		Primary	Reported one stillbirth and no maternal or neonatal deaths.	77	1*	0*	0*
Hospital 4	Sekyere South	Secondary	The facility serves as the only government hospital in the district	892	11	1	1
Health Center 4		Primary	Reported one stillbirth and no maternal or neonatal deaths.	227	1*	0*	0*

Table 2: Rationale for facility selection

2022 data as reported in the District Health Information Management System 2 (DHIMS- 2).
**2022 self-reported data during interviews and follow-up communications.*

Hospital name	Total number of midwives reported in the health facility	Number of midwives interviewed as part of this study	Total number of physician assistants reported in the health facility	Number of physician assistants interviewed as part of this study	Total number of medical officers reported in the health facility	Number of medical officers interviewed as part of this study	Total number of health information officers reported in the health facility	Number of health information officers interviewed as part of this study
Hospital 1	39	**3**	2	**1**	3	**0**	2	**1**
Health Center 1	5*	**1**	1*	**0**	0*	**0**	0*	**0**
Hospital 2	168	**3**	8	**0**	36	**0**	5	**1**
Health Center 2	16	**2**	1	**1**	0	**0**	0	**0**
Hospital 3	114	**2**	10	**0**	12	**1**	3	**1**
Health Center 3	9*†	**2**	2*	**1**	0*	**0**	0	**0**
Hospital 4	53	**2**	3	**0**	4	**1**	2	**1**
Health Center 4	12*	**2**	1*	**1**	0*	**0**	0*	**1**
Total interviewed for the study		**17**		**4**		**2**		**5**

*2022 data as reported in the District Health Information Management System (DHIMS- 2) for January - June 2023. * Indicates self-reported data from interviews and follow-up communications. † a midwife serves as the health information officer.*

Table 3: Distribution of the four types of health workers in each facility and the study sample

Procedure

Data collection was conducted by the first author who has professional experience in qualitative research and is knowledgeable in stillbirth recording and reporting, and health systems. The DHD helped introduce this study to the health facilities.[170] Once at the health facility, ethical approval documentation was presented to the facility director and the matron in charge before commencing interviews. Convenience sampling based on health worker availability during the interview period was applied.

On interview days, participants were given consent forms which were either read aloud or provided in print for self-reading. Interviews were conducted in a neutral and comfortable space once verbal consent was obtained. The interview guide (Supplementary Document 1), developed for the study was informed by literature reviews and conversations with stillbirth measurement experts.[151] A visual aid was also shared with health workers to further elicit perspectives on stillbirths (Supplementary Document 2). The interview guide was pretested and refined with the in-country team in Ghana. Interviews, lasting between 30 to 45 minutes, were conducted by the first author in Twi, the native language to the Ashanti Region, or English. Responses were paraphrased and repeated for data validation and improved creditability. All interviews were audio-recorded, transcribed verbatim, translated, and stored in a password-protected computer by the first author.

Data analysis

Thematic analyses were conducted following the Braun and Clark 6-step approach. This included familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and report production.[153]

Both inductive and deductive approaches were used for coding and thematic analyses. Three major a priori themes – experiences, perceptions, and attitudes; barriers; and support mechanisms to stillbirth recording and reporting – were identified based on literature reviews. Additional sub-themes were added as they emerged from the data. Initial coding was done by the first author, with 35% of interviews reviewed by a second coder. The authorship team provided feedback on coding and theme identification. Any differences emerging during data analysis, were resolved through discussion.

Field notes were cross-referenced with the identified themes to enhance and expand upon the findings. NVivo qualitative software facilitated data management. The study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Results

A total of 28 health workers were interviewed, comprising 17 midwives, 5 health information officers, 4 physician assistants and 2 medical officers (Table 3). Not all health facilities had a health information officer. Some health centers had 1-2 midwives and no medical officer. Some health workers declined to participate in the study due to ongoing delivery emergencies at the time of the interviews.

Saturation of data was attained after 28 interviews, revealing the following sub-themes aligned with our a priori framework (Figure 1). Under the "experiences, perceptions and attitudes to stillbirth recording and reporting" theme, the study identified sub-themes related to awareness of stillbirths and stillbirth documentation drivers. For "barriers to stillbirth recording and reporting" sub-themes identified included blame across levels of the health system, and tools and resources. Finally, for "support mechanisms available to health workers for stillbirth recording and reporting" sub-themes included engagement of facility-level staff in audits and the role of training as support mechanisms available to health workers for stillbirth recording and reporting.

Direct quotes by health worker cadre are presented to substantiate findings with the number of years of experience (YoE) indicated.

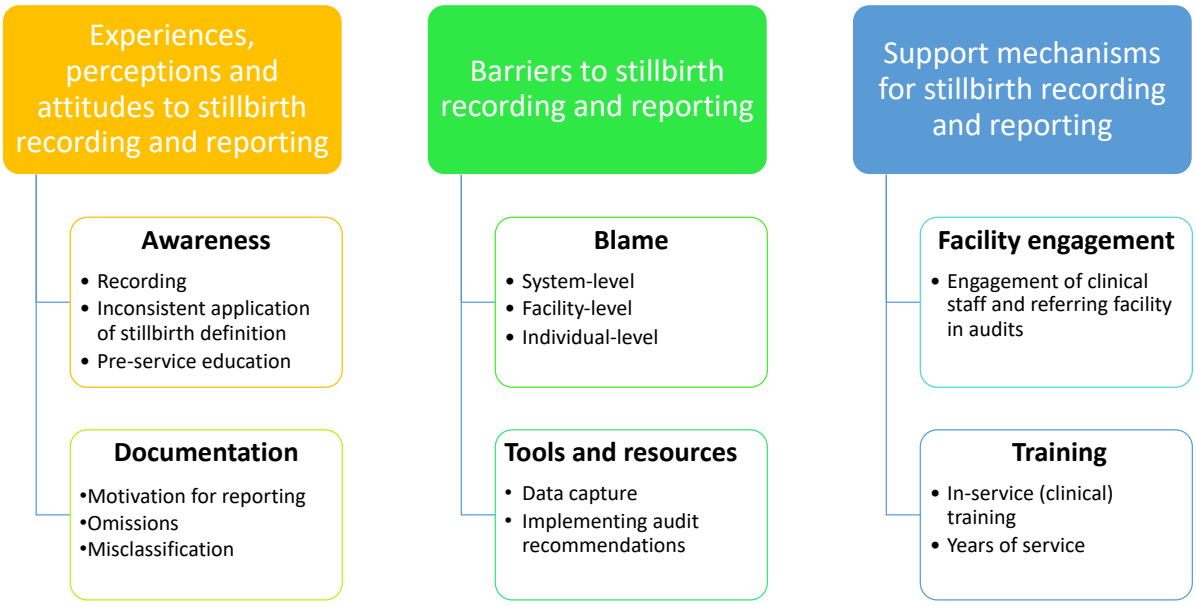

Figure 1: Study Themes

Experiences, perceptions, and attitudes to stillbirth recording and reporting

Awareness

An awareness about the importance of recording and reporting a stillbirth was common among health care workers, with the understanding that data collection is essential for identifying preventable causes and facilitating audits. This view was summarized by one midwife:

> "Recording a stillbirth really matters because … if there is no data how do we improve? (Midwife, 12YoE)."

Health workers highlighted that recording a stillbirth not only serves as an important step toward ending preventable stillbirths but also forms an integral part of the auditing process. Particularly, the processes of recording and auditing a stillbirth were perceived as interconnected. Recording a stillbirth provides the data that underpin audits.

> "When we record a stillbirth, we have to go for audit and find out the causes…some causes are preventable. You end up knowing the actual cause to prevent mothers from losing a baby whether during pregnancy or during labor (Midwife, 7 YoE)."

Another midwife shared that recording helps to identify and address health system gaps promptly to prevent stillbirths.

> "Recording a stillbirth helps us to know the number of times a stillbirth occurs in a particular month or year so that we can prepare ourselves well, and train our staff to prevent it (Midwife, 3 YoE)."

Inconsistent application of stillbirth definition

The inconsistent application of stillbirth definitions was a notable issue. Respondents demonstrated variations in their understanding of gestational age, a key data element needed to determine length of pregnancy. There were inconsistencies in the gestational age cut-off in weeks used to define stillbirth. Additionally, a few health workers were unable to describe stillbirths using gestational age, and instead, reference was made to death upon delivery.

Text Box 1 provides an overview of the definitions shared by health workers.

- "All the midwives know this definition because they know that a stillbirth is from 28 weeks ….(Midwife, 12 YoE)."
- "Normally, for a stillbirth, it could be pre-term less than 36 weeks (Midwife 6 YoE)."
- "Stillbirth is the death of a fetus after 24 weeks before or during delivery (Midwife, 10 YoE)."
- "Stillbirth means giving birth to a baby that is dead… At times too, the baby comes out but within some short time then the baby will die. I can say that when the baby dies, one week after birth then it is termed as stillbirth(Midwife, 3 YoE)."
- "…the baby dies in her uterus before the mother gives birth. It is considered a stillbirth when the baby is 28 weeks above (Midwife, 1 YoE)."
- "I will say stillbirth is the death of a baby or loss of a baby before or during delivery…before 38 weeks of pregnancy or after (Midwife, 7 YoE)."
- "It is a death of a baby; it can occur during labor or right before the onset of labor. We don't have any weeks, but it depends on the time it happens. Sometimes it happens before term and after 36 weeks too, it can happen (Midwife, 1 YoE)."
- "Stillbirth is when a fetus dies at the gestational age of 28 weeks before delivery (Midwife, 1 YoE)."
- "A stillbirth is when a baby is born without life (Midwife 9, YoE)"
- "That is when the fetus either dies within uterus or even right after birth (Midwife 7 YoE)."
- "Stillbirth is when a baby is born without any signs of life. If the baby dies after 36 completed weeks, it can be termed as a stillbirth (Midwife 7 YoE)."
- "Stillbirth is a birth of a neonate that is dead when delivered (Physician Assistant, 20 YoE)."
- "…stillbirth is a baby without any signs of life, not breathing, no respiration after 28 weeks of gestation or a baby less than 1kg (Medical Officer, 4 YoE)."

Text Box 1: Stillbirth definitions as described by some health workers.

Assessment of the fetal skin using fresh and maceration was also used to describe stillbirths.

> "Fresh stillbirth is when a baby dies immediately it is born and the macerated is when the baby dies in the uterus (Midwife, 1 YoE)

Pre-service education

Education acquired during midwifery school emerged as a key source of knowledge and information that profoundly shapes individuals' attitudes and perspectives about stillbirths. In cases where health workers received training on preventable causes of stillbirth and the definition, along with its recording, this education primarily came from midwifery and nursing training school or tertiary universities.

> "You know, we got the training from school. When you come to the facility, nobody will teach you, they know you have learnt it. Every trained midwife knows the definition of a stillbirth (Midwife, 8 YoE)."

> "We haven't gone for further education on stillbirths but during the period of schooling that is when I learned something about it. (Midwife,6YoE)."

Documentation

All health workers had a shared understanding on the facility-level processes required following a stillbirth. Once a stillbirth occurs, the attending midwife records the birth outcome in the record books, before informing the matron or midwife in-charge. The district health directorate is informed within 24 hours to initiate the audit processes within 7 days.

Motivation for reporting

In recording a stillbirth, some health workers expressed their motivation to record a stillbirth for two primary reasons. Firstly, it arises from a deep sense of compassion, driven by their commitment to doing what is morally right.

> " …Personally, I won't feel well that a baby died during my line of duty ..It will hurt me but you have a responsibility so I have to report (Midwife, 1 YoE)."

Secondly, data verification procedures established by the Ghana Health Service make it challenging for health workers to disregard a stillbirth, as the system eventually identifies, and records missed cases.

> "…if there are any discrepancies in the hard-copy, I sit down with the midwives who did the report of that particular month and find out what went wrong (Health Information Officer)."

Omissions

Increased workload among midwives was reported as a factor contributing to omissions in stillbirth reporting.

> "Sometimes it is not reported because when you have a stillbirth case and you have a lot of clients coming in for antenatal care, if you don't take care, you might switch and attend to another mother without recording what happened. With the workload, sometimes, you may forget (Physician Assistant, 5 YoE)."

The requirement to complete various record books when recording a stillbirth outcome, including but not limited to, admissions and discharge form, maternity form, antenatal care booklet, Midwife Returns Form, death notification form and the delivery form, sometimes leads to midwives omitting key information required on stillbirths in record books.

> " … recording in too many books, we sometimes forget some…Mostly the stillbirth sheet, we always forget it. It is later that we recall and get back to fill it (Midwife, 1YoE)."

Knowledge surrounding how to properly complete recording forms and legibility of handwritten forms were flagged as additional reasons for omissions.

Misclassifications

Misclassifications between fresh and macerated stillbirths, as well as stillbirths and neonatal deaths, were reported as recurring issues. Health workers identified limited knowledge as a key factor contributing to these classification gaps.

> "… I believe misclassifications occur because the person might not have adequate knowledge about what the stillbirth is or the difference between the stillbirth and the neonatal death (Midwife, 2 YoE)."

Similarly, some health workers attributed insufficient in-service experience with a likelihood to misclassify.

> "Normally if you have a new staff, like those who have just been posted, sometimes you have APGAR of one, then later on the baby will be gone. This is where sometimes they misclassify between stillbirth and neonatal death (Midwife, 14 YoE)."

Barriers

Blame

As reported by midwives, blame manifests in three layers: blame from the wider health-system level, blame at the organizational facility-level and individual-level blame.

Health system-level blame

Audits are mandated to be conducted within a week of a stillbirth occurrence and involve a multi-disciplinary team of health workers from the Regional Health Directorate, DHD and health facilities. However, midwives shared that while audits are intended to be a learning experience aimed at addressing identified shortcomings, challenges persist in their execution. These challenges relate to the language used during audit investigations.

> "The auditors shouldn't blame midwives when such an incident happens. Due to the blame, if something happens and the midwife can help, she will not risk it. She will just refer to avoid all the questioning (Midwife, 8YoE)."

> "Nobody likes audits to be honest. Most of the midwives do not like audits because sometimes they are made to feel incompetent (Medical Officer, 4YoE)."

As part of the audit process, health facilities that refer cases to the higher-level are invited to participate in the audit process. Some health workers placed blame on the referring facilities for a stillbirth outcome.

> "…most of the stillbirths we were having, were from our peripheral facilities. That is the primary care, so the level of care was not that adequate (Medical Officer, 4 YoE)

Some health workers highlighted blame can also happen for various reasons, many of these factors are associated with macerated stillbirths. In particular, midwives may choose not to report a stillbirth to avoid inflating their facility's mortality statistics.

> "You know initially, like macerated for instance, they didn't want to record because they felt that this baby didn't come with fetal heart rate so if I should record, I am going to have higher numbers and they are going to say that I am not doing my work well (Midwife, 12 YoE)."

Some midwives held the belief that lower-level facilities sometimes refer stillbirth cases to higher-level facilities late to avoid the need to document stillbirth outcomes within their own facilities.

> "Sometimes the recordings are not done because like for instance, someone will be attending antenatal somewhere in a different facility. During delivery, the person might come in here with the stillbirth. Due to that, we don't want to record to spoil our data, so sometimes we might miss that one (Midwife, 10 YoE)."

Organizational facility-level blame

Some midwives highlighted that senior staff tend to blame the attending junior midwife when a stillbirth occurs.

> "When a stillbirth happens, they blame you as if you intentionally did it (Midwife, 3YoE)."

The way some supervisors communicate with midwives was identified as an obstacle to reporting stillbirths.

> "I think the superiors should have a cordial relationship with their juniors so that when something occurs, they (junior staff) will be okay to report (Midwife, 8 YoE)."

Individual-level blame

All midwives shared that witnessing a stillbirth is traumatic. There is a general sense of guilt and blame when a pregnancy outcome is a stillbirth.

> "When you deliver a dead baby, it makes you feel like you did not complete your work. That is not why you came here. You came here to deliver babies. Live babies not dead babies so it is quite sad (Midwife, 1 YoE)."

The feeling of blame can affect the decision to record a stillbirth or not.

> "A lot of us go through a whole lot of trauma and other things when stillbirths happen. Because of that, most midwives do not want to record when they get a stillbirth (Midwife, 7 YoE)."

Some midwives flagged the long-term impact associated with delivering a stillbirth, which is often overlooked.

> "You need to train yourself. We do not have a psychologist here to speak to. They (supervisors) will say, it is part of the work. Nobody talks to you about it so mentally you fight through and let the process pass. I remember almost 10 years ago I had a death. For more than a year, I couldn't be myself, even though I knew it wasn't my fault (Midwife, 12 YoE)."

Tools and resources

Data capture

Tools are needed to facilitate timely and accurate recording of a stillbirth. In some health facilities, we observed that the facilities had run out of their supply of recording books. Thus, facilities improvised using a normal notebook. However, the improvised record book had key data missing, including information related to stillbirths. This observational finding was further corroborated by perspectives shared by some health workers.

> "For now the standard Form A (Midwife Returns Form) has finished and we had to improvise. You know the indicators in the standard one, are too many so at times we skip some of them. Not all the indicators can be recorded in the improvised one. In the improvised one, they (health care workers) select a few to report on (Health Information Officer)."

Audit recommendations

Implementation of audit recommendations emerged as a key bottleneck to address gaps uncovered within the system, often impending efforts to avoid preventable stillbirths and improve birth outcomes.

> "…We will go, sit there and talk about it. They (audit team) will tell us to go and see the authorities to purchase. But, in the long run, we will not get it. When the audit recommendation involves equipment or tools, we don't get (Midwife, 7 YoE)."

A few midwives flagged that though audits are useful, the documentation of audit recommendations can be challenging. One midwife shared that the audit form should be made available to all midwifery units to serve as a guidance tool during delivery.

> "We don't have the audit sheet. If I didn't go for my colleague's audit, I wouldn't have seen that book. I think every facility needs to have that book. In a way it guides you to know what you are doing. Before you even go for the audit, you know where you were at fault… (Midwife, 1 YoE)."

Support mechanisms

Facility-level engagement

All health workers emphasized the importance of audits in ensuring improvements in service delivery. Particularly, the feedback received during audits was highlighted as an educational moment to close gaps recorded in the system.

> "Just recently, I think we had one stillbirth, so we had an audit and through that, we educated ourselves about things to do so that it does not happen again (Midwife 10YoE)."

An additional support mechanism aimed at facilitating improvements within the wider health system is the engagement of health workers from the receiving and referring health facilities in audits. Health workers stressed the importance of coordination and communication within the district to improve overall quality of care.

> " When we have an audit, we notify each facility with letters to participate. Each facility is supposed to bring a representative to learn from the process so that it (stillbirths) does not occur at the peripheral levels (Midwife, 12 YoE)."

Training

Capacity building was shared as an avenue for supporting health workers in strengthening their skills in maternal and perinatal health. However, most of the capacity-building needs are focused on training related to clinical care and audits, with little to no training provided on appropriate recording of stillbirths.

> "Yes, we have had trainings on helping baby breath and other aspects to reduce stillbirth…We talk about audits...fetal heart monitoring and the steps involved...(Midwife, 12YoE)."

Some experienced health workers alluded to the fact that should training opportunities be made available to new midwives, this would ease some of the gaps with data recording.

> "An experienced person sees and acts differently from a new one so definitely experience counts a lot. If the new midwives avail themselves for training, there will not be any problems. They will also have the courage to do things to avoid stillbirth (Physician Assistant, 20 YoE)."

However, a noted challenge echoed by relatively newly posted midwives is that training opportunities are mostly available to older tenured midwives.

> "I haven't gone for stillbirth training before. Those who go for the trainings are those who have worked here for a longer period e.g., 10 years…Me? I have been here for just 3 years and never had a training (Midwife, 3YoE)."

Discussion

The study findings indicate that health workers had a good understanding of the importance of recording a stillbirth. However, variations were observed in the gestational weeks cut-off used to define stillbirths. Perspectives on stillbirths were influenced by pre-service education. Further, the findings highlight some reasons for omissions and misclassifications of stillbirths, shedding light on the motivations driving the recording and reporting of stillbirths. Challenges emerged, including blame shifting across different levels of the health system and a lack of adequate tools and resources. Further, the findings underscored the importance of active participation of health workers in audit processes and the availability of relevant training opportunities, as supportive mechanisms for improving the accuracy of stillbirth recording and reporting.

Experiences, perceptions and attitudes to stillbirth recording and reporting

A common issue surrounding stillbirths is its definition. Countries use different reporting criteria and thresholds for gestational age and birth weight.[14, 45, 171, 172] The varying definitions used across countries, and sometimes within the same country,[59] as revealed in this study, create challenges in accurately recording stillbirths and understanding the true scope of the population mortality. Despite the substantial burden of nearly 2 million third trimester stillbirths annually, stillbirths remain invisible in many national and global-level conversations. Lack of consistency in applying definitions can lead to incorrect classification of adverse pregnancy events – potentially omitting (if misclassified as miscarriage) , or misclassifying stillbirths (if misclassified as neonatal deaths) in routine data.[173] Acknowledging this gap, the United Nations Inter-agency Group for Child Mortality Estimation (UN IGME) and the WHO recently updated global guidance on defining a stillbirth in the International Classification of Disease (ICD) 11th revision; defining stillbirth as a baby born with no signs of life at 22 or more completed weeks of gestation, and distinguishing between early gestation stillbirth (at 22 to 27 completed weeks of gestation) and late gestation stillbirth (at 28 or more completed weeks of gestation).[46]Communicating better with countries on this new definition for stillbirths will assist countries to consistently and universally apply the definition to facilitate the accurate reporting and recording of stillbirths.

Both intrinsic and extrinsic motivation were shared by health workers as reasons for recording stillbirths. Intrinsic motivation aligns with the personal will to do the right thing i.e., recording the birth outcome of a stillbirth. This commitment to do what is right may stem from a commitment to provide quality health care[35, 37, 174] or professional ethics enshrined in many pledges, declarations or oaths undertaken by health care professionals.[175-178] Extrinsic motivation to record a stillbirth outcome is encouraged by external factors. In this study, we found that adhering to standards set by the Regional Health Directorate and the DHD was the crucial factor. This finding was aligned with past studies on district health management teams (DHMTs), [121, 179] as DHMTs teams conduct data quality checks on health facility data.

Our findings, consistent with previous studies, demonstrate that pre-service education plays a crucial role in shaping midwifery practices within maternity health service delivery.[180, 181] Consequently, there was no significant difference between responses from health workers in hospitals and those in primary care facilities. Reflecting on the varied definitions shared by midwives in this study, it is important for the Ghana Health Service and the Nursing and Midwifery Council of Ghana to review the pre-service education curricula. This review is necessary to ensure

the latest definition of stillbirth alongside its appropriate recording and reporting are thoroughly incorporated into the educational programme.[26] Well-trained midwives are more inclined to record and report stillbirth cases thereby facilitating the implementation of necessary evidence-based interventions to address gaps.

Barriers to stillbirth recording and reporting.

A perinatal audit is the process of capturing information on the number and causes of mortality with a view to improve the care provided to mothers and babies.[127] Key elements of this audit cycle include identifying the death, reporting the death, reviewing the death and taking action. Health workers acknowledged that "if there is no data, how do we improve," yet taking action to address gaps remains challenging, particularly in procuring essential tools. Perinatal audits are means to improve the quality of health service delivery and birth outcomes.[182] Thus, without taking action, pre-existing unfavorable attitudes toward stillbirth data collection and a lack of data ownership may persist, hindering the progress to improve stillbirth recording and reporting.[183] The impact of perinatal audit relies on successfully closing the audit loop. Mere recording of stillbirths and its causes is insufficient. Improvement in quality of care occurs when the solutions to identified problems are effectively implemented. Key strategies proposed within existing literature to promote a positive culture for perinatal audits include explaining the purpose, process and how to conduct blame-free audit with implementation tools available at all levels of the health system.[122]

The importance of a blame-free culture for health workers is well documented in the literature.[121, 122] At the broader health system level, we found that blame was an essential element of audit processes. This finding contradicts the intended purpose for which audits were designed. When blame and punishment exist, health workers shared they feared reporting mortalities. A blame environment assigns blame rather than understanding the root causes of mortalities and focuses on individual errors rather than systemic issues. A shift in culture from one of blame to one of learning and improvement is needed to ensure that health workers feel comfortable to record, report, review and implement key actions to improve birth outcomes.

Another component of blame was at the referral-level. Some health workers blamed lower-level facilities for referring stillbirth cases at the last moment for fear of punitive measures or avoiding recording such cases in their own facilities. This culture of downstream blame aligns with two case studies from India.[184] One study found that mortality was under-reported due to fear of punitive actions. This fear led to late referrals, mainly to prevent punishment.[120] Higher facilities struggled with patient referrals, and if a patient experienced adverse outcomes within their facility, they often shifted the blame onto providers from lower-level facilities. The Ghana Health Service is currently addressing this downstream blame culture by engaging referral health facilities within the audit process.

At the organizational health facility-level, blame culture was identified as one of the areas needing urgent attention.[122] Health workers flagged issues of blame arising from other clinical staff. Of note, most senior midwives blamed issues on stillbirth recording on junior staff. Junior midwives, in contrast, expressed their reluctance to report stillbirths due to the punitive language used by senior staff members. When such a culture exists, studies have shown that health workers often

chose not to report issues on quality of care because reporting an incident brings the risk of conflict with other colleagues.[185] Literature suggests that blaming people, focusing on mistakes, and yelling are demotivating factors for obstetric care.[186] However, successful supervision during clinical care was associated with higher clinical experience. In the Northern Ghana, researchers found that a positive relationship between supervisor and student creates a positive learning environment.[187] In such cases, health workers are open to reporting mortalities and discussing the outcomes with supervisors.

At the individual level, blame can lead to demoralized health workers. This can affect motivation, job satisfaction, and overall performance, impacting the quality of health services. A blame environment promotes a culture of omitting or under-reporting stillbirths.

Support mechanisms for stillbirth recording and reporting.

Health workers acknowledged the critical role played by learning and feedback mechanisms as part of audit processes. However, to realize this, a collective shift from a blame-oriented culture to one focused on learning and improvement is required.[121] One study argued that individuals should be willing to continually seek lifelong learning. Simultaneously, at the health systems level, policies and protocols should be designed to cultivate an environment promoting professionalism and continuous development.[188]

Disparities in in-service training opportunities, determined by years of service, influenced the selection of participants for training sessions. Junior midwives expressed their interest in receiving training; however, these opportunities were not consistently provided, often being prioritized for senior staff members. A study examining task-sharing in the African region recommends ensuring equal access to in-service training for all staff members.[189] Equal opportunities to in-service training ensures that all midwives are trained on standardized protocols and best practices for stillbirth recording.

Limitations

This study exclusively focused on government health facilities despite, private health facilities constituting 40.2% of health facilities in Ghana. We recommend conducting further studies involving health workers in the private sector. Furthermore, our study focused on one region in Ghana. To obtain a comprehensive understanding of the situation in the country, further research across diverse regions is needed, noting that health workers frequently undergo rotations across various regions in Ghana.

Reflexivity

Having a deep contextual awareness of Ghana, as well as being a native of the Ashanti Region, may have influenced how NAMA phrased questions in the native dialect of the Ashanti Region, and which questions from the semi-structured interview guide NAMA chose to probe further. The cultural familiarity of NAMA likely shaped the interactions with study participants, potentially leading them to respond in ways they believed the researcher, as a fellow Ghanaian, would understand or approve of. To address potential biases, NAMA asked questions in various ways to

cross-check the consistency of responses and reduce the impact of her own assumptions. Additionally, as a Ghanaian female, NAMA may have been biased toward interviewing more females (particularly midwives) than males working in health facilities. This feeling could be linked to shared gender experiences and an implicit comfort level, which might have influenced the dynamics of the interviews. To ensure a more comprehensive sampling, NAMA made a conscious effort to include a diverse range of health workers involved in stillbirth measurement, recognizing that different cadres may have unique insights that could otherwise be overlooked. Furthermore, NAMA's advanced training in public health, health systems and extensive knowledge of maternal and child health issues, including stillbirth, may have influenced the data analysis, particularly in determining which thematic areas to focus on. The expertise of NAMA in health systems could have led to the prioritization of certain findings over others (for example, a focus on systemic issues rather than clinical care) guided by professional background and prior experiences. This potential for bias was mitigated by continuously reflecting on how NAMA's positionality influenced the research process. Additionally, 35% of interviews were reviewed by a second coder and additional feedback on coding and theme identification were provided by the authorship team. Furthermore, the role of power dynamics is also acknowledged. Being viewed as an "outsider," i.e., an external researcher inquiring about the sensitive topic of stillbirths, may have influenced the responses provided by study participants. Active listening (listening without interruption) and adjusting interview techniques (such as how questions are phrased) helped address some of the potential biases.

Implications for action

Five actions are proposed to improve stillbirth recording and reporting at the health facility level. Proposed actions necessitate close coordination with health facility staff and the district health management teams.

Firstly, strengthen capacity of midwives and health workers on the definition for stillbirth, the types of stillbirths and its appropriate recording and reporting. Additionally, this recommendation includes a review of the pre-service nursing and midwifery education curricula. Secondly, periodically review audit protocols to ensure that a non-punitive approach is emphasized during reviews/audit meetings, trainings, and supportive supervision visits. Thirdly, review the health workforce training tracking system/sheet to ensure that equal opportunities are provided to all midwives for capacity strengthening opportunities. Fourth, when recommendations are made during audits, ensure that effective action is taken to close the audit loop. Finally, emphasize as part of audit process shared accountability, coordination, and communication between levels of the health system.

Conclusion

This study highlighted the critical role of frontline health workers in recording stillbirths. To obtain reliable national data on stillbirths, we first need to understand the health worker stories that underpin stillbirth data. This is the first in-depth analysis of the issue. There is a need for comprehensive global efforts to fully understand why stillbirths remain significantly under-represented in worldwide data tracking, obscuring the true magnitude of this issue.

Declarations

Ethics approval and consent to participate

Ethical approval was provided by Ghana Health Service (GHS, Reference: GHS-ERC 025/07/22) and the London School of Hygiene and Tropical Medicine (LSHTM, Reference: 28017). Approval was also granted by one of the study hospitals, functioning as a regional referral hospital (KSH./RESH-50).

Study participants were provided with a consent form (Supplementary document 3) and an information sheet (Supplementary document 4) outlining the intended scope of the research. Informed consent was obtained from all subjects.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the study are available from the corresponding author on reasonable request.

Competing interest

None

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Author contributions

Conceptualization: NAMA, YBO, HB, DJ
Formal Analysis: NAMA
Investigation: NAMA
Methodology: NAMA, YBO, HB, DJ
Supervision: YBO, HB, DJ
Validation: NAMA, YBO
Visualization: NAMA
Writing-original draft: NAMA
Writing–review & editing: DJ, HB, YBO, KFO, EKA, RLR

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Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
DHD	District Health Directorate
DHIMS-2	District Health Information Management Systems 2
DHMT	District Health Management Team
GHS	Ghana Health Service
ICD	International Classification of Disease
LSHTM	London School of Hygiene and Tropical Medicine
UN IGME	United Nations Inter-agency Group for Child Mortality Estimation
UNICEF	United Nations Children's Fund
YoE	Years of Experience

7 Chapter 7 Critical Discussion

The overall aim of this thesis was to investigate health systems factors influencing stillbirth measurement, and to provide recommendations to improve stillbirth recording and reporting. This research addressed this aim by exploring three key objectives: 1) reviewing the legislative environment in countries to understand stillbirth recording and reporting, 2) understanding stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of the DHMT, and 3) gaining insights into practices and challenges related to stillbirth recording and reporting from the perspective of health workers in public health facilities in the Ashanti Region of Ghana. The three objectives culminated in the development and publication of three papers.

7.1 Research paper 1 summary of key findings: Global Stillbirth Policy Review – Outcomes and Implications ahead of the 2030 Sustainable Development Goal Agenda

An articulated national policy sets the strategic direction and goals for a country, guiding the development of policies that address stillbirth issues. Once formulated at the national level, these policies are then translated into action and implemented at the sub-national level.

Key findings across 155 countries that responded to the WHO RMNCAH policy survey 2018-2019 and over 800 reviewed national policy documents highlight that:

- Fewer than one-fifth of countries have set a SBR target, with higher percentages reported for U5M (71.0%) and neonatal mortality (68.5%).
- Two-thirds (65.8%) of countries reported a national maternal death review panel.
- Two-thirds of countries have a national policy requiring review of neonatal deaths.
- Less than half (43.9%) of countries have a national policy that requires stillbirth occurrences to be reviewed.
- Globally, nearly all countries (94.8%) have a national policy that requires every death to be registered.

    - However, only 45.5% of reviewed national policy documents mention registering stillbirths.
- Across countries, the four most used data sources to compare RMNCAH mortality rates include: WHO websites and reports; national health statistics databases; national population-based surveys, and civil registration and vital statistics systems.
- Countries that are signatories to global initiatives on stillbirth reduction have established national targets.
- Only five countries had national policy documents recommending training of health workers in filling out death certificates using the International Classification of Diseases (ICD)-10 for stillbirths.

In summary, both WHO and UNICEF argue for "strong political will, sound policies, and targeted investments along the continuum of care for every mother and child…to prevent millions of stillbirths, maternal, and neonatal deaths and to ensure a bright future for every baby."[6] The global stillbirth policy review revealed that overall gaps remain in how stillbirths are positioned within national documents, and stillbirths largely remain invisible in national policy documents. Countries are more likely to have prioritized U5M and neonatal mortality targets than stillbirths. This is aligned with the increased progress witnessed in the areas of U5M and neonatal mortality. Regarding measurement, the inclusion of stillbirths in national RMNCAH-related policies encourages standardized data collection mechanisms for stillbirths and facilitates the development of capacity-building tools and clinical guidelines to guide quality service delivery. It is often said that what does not get counted does not get prioritized. However, for stillbirths to be counted, they first need to be prioritized.

Accurate and comprehensive data is essential for understanding the prevalence, causes, and trends of stillbirths, enabling evidence-based decision-making and resource allocation at both the national-level and at the sub-national levels.

7.2 Research paper 2 summary of key findings - District health management and stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

Once policies are developed and validated at the national level, it is up to the sub-national level to translate and implement the policies. Sub-national teams, particularly DHMTs, ensure that the intended vision and priorities from the national level are adapted to local contexts and effectively carried out in specific regions, tailoring the response to the diverse needs and circumstances found within their districts.

Findings from the second paper reveal that Ghana seeks to achieve a SBR of 12 or fewer stillbirths per 1,000 total births by 2030. The country also has an established electronic health information management system (DHIMS-2). The RHD/DHD operating under the Ghana Health Service are responsible for translating the national policies at the sub-national level. Specific to RMNCAH-related indicators including stillbirths, the RHD/DHD is responsible for data collection, analysis, and reporting into the DHIMS-2. The RHD/DHDs also provide support to health facilities in terms of planning and budgeting, resource allocation, health service delivery quality and perinatal audits.

Across the 15 key informants interviewed from the Ashanti RHD/DHD, key findings included:

- Stillbirth definitions varied, with members of the RHD/DHD commonly referring to stillbirths using 20 weeks and 28 weeks gestational age.
- Many RHD/DHD used fresh and macerated skin appearance to describe the timing surrounding a stillbirth with very little knowledge of the difference between antepartum and intrapartum stillbirths. Some health care workers (district health officer, public health nurse) were able to differentiate between antepartum and intrapartum stillbirths. However, some auxiliary health workers (health information officers and surveillance officers) were unable to differentiate between the two.
- The RHD/DHD plays key roles in stillbirth data collection including conducting quality checks, conducting perinatal audits, and managing the DHIMS-2.
- Blame was present in the interviews with RHD/DHDs where midwives were blamed for many of the errors in stillbirth measurement.
- Gaps including manual data transfer, limited knowledge of stillbirth terminology, audits being conducted for only late-gestation stillbirths, and closure of the DHIMS-2 were noted by study participants to affect the quality of stillbirth data.

- The implementation of stillbirth audits at the district level was identified as positive for stillbirth recording and reporting.
- Engagement of the private sector was called for recognizing that private health facilities make up 40.2% of health facilities in the Ashanti Region. Although private facilities are mandated to report on mortalities such as stillbirth, this is not always the case.
- Similarly, data integration between the DHIMS-2 and the CRVS was called for, acknowledging that stillbirths that occur at the community-level are sometimes reported in the CRVS.
- Funding constraints affect the depth of support offered from the RHD/DHD level to health facilities. Particularly, the frequency of audits when a stillbirth happens is reduced.

In summary, the second paper provided insights into the key role played by RHD/DHD in stillbirth recording and reporting. Though Ghana has established a stillbirth definition (a stillbirth is defined as a baby delivered with no signs of life (gasping, heartbeat or limb movements) after 28 completed weeks of pregnancy [128]), this definition is not widely known amongst the RHD/DHD teams who manage the DHIMS-2 platform, which provides the data that informs many national and global level policies and actions. Similarly, RHD/DHD, who manage stillbirth data in data systems, have limited knowledge of stillbirth terminologies. This limitation could potentially mean that, beyond ensuring the numerical consistency between the manual stillbirth register and DHIMS-2, a comprehensive analysis is not conducted on the data to inform the types of support rendered to health facilities. This could have implications for the quality of stillbirth data reported in health management information systems. Finally, without complete information from private facilities on the stillbirth burden, stillbirths will remain under-reported in routine health information systems.

7.3 Research paper 3 summary of key findings - "If there is no data, how do we improve?" Exploring health workers, stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

To further understand stillbirth recording and reporting, a key component of this research approach was to gain insights from the individuals who initially collect the stillbirth data, which is then recorded in registers and notification forms, before being reported in the DHIMS-2.

Interviews with 28 health workers, including midwives, medical officers, physician assistants, and health information officers, across four secondary-care and four primary-care health facilities in the Ashanti Region of Ghana revealed that:

- Health workers have a varied understanding in terms of what a stillbirth entails. Stillbirth was described using various gestational age thresholds, including 24 ,28 ,36, and 38 weeks. Some health workers made no reference to the gestational age when referring to stillbirths.
- Similar to the RHD/DHD interviews, very few workers described stillbirth including antepartum or intrapartum fetal deaths. Many referred to stillbirths using assessment of the fetal skin using fresh and maceration.
- Awareness of stillbirths and their related terminologies is shaped by pre-service education particularly those received during midwifery school, university, or nursing college.
- Blame was identified as a systemic issue. It manifested in perinatal audits, where the language used during audits is punitive. Furthermore, at the organizational level, senior midwives blamed junior midwives for errors in stillbirth data. Additionally, blame was leveled upon at the individual level.
- Data-quality issues concerning stillbirths included omissions, as demonstrated by increased workload, misclassifications due to limited knowledge, and under-reporting due to fear of blame.
- A key bottleneck reported was the limited implementation of audits due to insufficient resources such as financing.
- Support mechanisms within health facilities for stillbirth recording and reporting included engaging facility staff, as well as peripheral health facilities, in the practice of perinatal audits. Additionally, in-service training opportunities were identified as enablers to support stillbirth recording and reporting.

In summary, the accuracy of stillbirth recording is dependent on the health worker documenting the birth outcome. Achieving quality data on stillbirth requires that health workers account for each birth event, document the vital status at birth, and record key information such as gestational

age or birth weight. The final paper in this study investigated the factors contributing to gaps reported in stillbirth data, including those on under-reporting, misclassification, and omissions.

To enhance data systems and make stillbirth data more reliable, it is essential to understand what information health workers are recording for stillbirths. Examining health worker perspectives on stillbirths offers valuable perspectives on the quality of recorded data for stillbirths. This examination provides insights into the strengths and limitations of the current data capture processes and systems for stillbirth.

7.4 Policy and practice disconnect – integrated discussion of the three papers.

This section examines the integrated findings across the three objectives/papers using the WHO Health Systems Building Blocks Framework, also referred to as the WHO Health Systems Framework. [190] The WHO Health Systems Framework is discussed first, as that is the lens through which the critical discussion section is framed. This is then followed by a discussion of the enablers facilitating stillbirth recording and reporting, as well as barriers hindering its progress.

As previously mentioned, since this thesis does not address the clinical aspects of stillbirths, the service delivery building block was not examined.

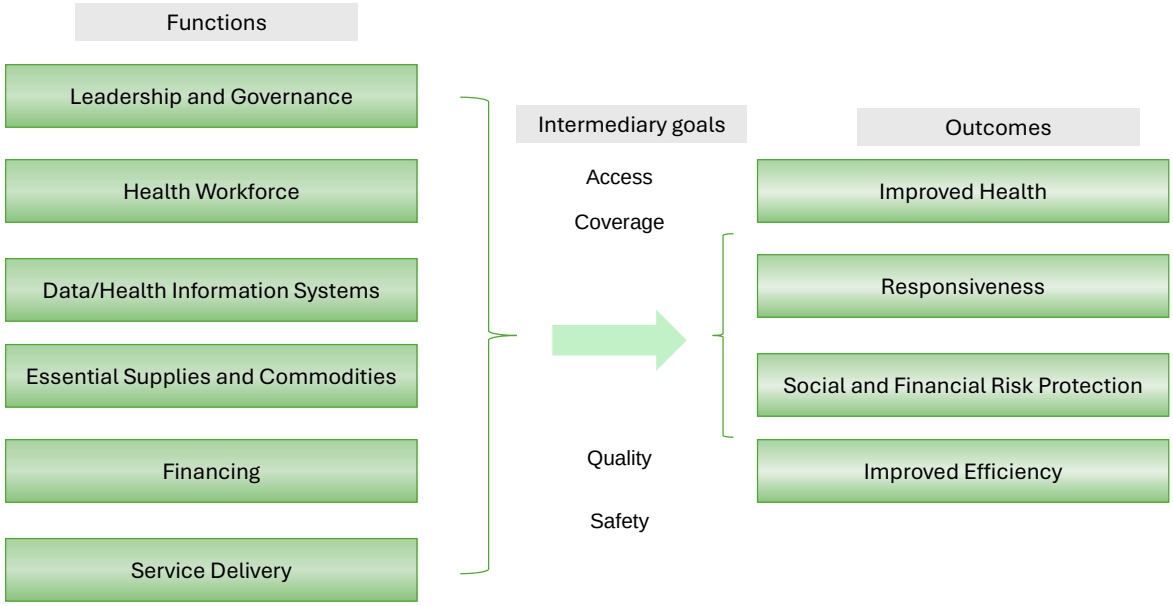
7.4.1 Health systems building blocks

The selection of the health systems blocks is informed by the WHO Health Systems Framework which was developed in 2007. [27] The Framework argues that six functions are essential to improve the health systems performance in a country (Figure 11). Having all these functions in place will lead to improved outcomes including better health, better responsiveness of the health system, improved social and financial risk protection as well as improved efficiency. However, the six functions need to be unpinned by intermediary goals including ensuring access and coverage, as well as quality and safety. Access ensures that health services are within reasonable reach when needed (also known as physical accessibility), people can pay for health services without going into financial hardship (also known as financial affordability) and that these health

services are acceptable i.e. people are willing to seek the services. Coverage, on the other hand, is only possible once access is obtained. Universal health coverage relates to the goal that all people obtain the health services they need without risking financial hardship from unaffordable out-of-pocket payments. [191] Quality and safety align with the mentality that health services and interventions delivered should not do any harm. [35, 37, 174-178] Figure 11 provides an overview of the WHO Health Systems Framework.

Figure 11: WHO Health Systems Building Blocks

Figure adapted from World Health Organization, Monitoring the Building Blocks of Health Systems: A Handbook of Indicators and Their Measurement Strategies. 2010: Geneva, Switzerland. [190]



The health systems building blocks, including *leadership/governance*, highlight the importance of strong leadership, good governance, and strategic policy development to coordinate activities. *Health workers* are key in providing the quality health services needed as well as serving as the first point for data collection for stillbirths. This building block is concerned with staffing, training, and support for health workers. Similarly, *data/health information systems* are key in producing the data needed to inform decision-making and prioritize stillbirths. Data/information systems are

concerned with how to monitor health trends, assess the performance of health systems, and guide policy decisions. *Essential medicines and technologies* facilitate accurate measurement of stillbirths. This block deals with issues related to the procurement, distribution, and rational use of essential commodities. *Financing* is key to mobilizing and allocating financial resources to facilitate a reduction in stillbirths. Within the context of this thesis, *service delivery* is seen as the output of the earlier five building blocks working together to ensure that health services that are provided are safe, effective, and people centered, informed by accurate stillbirth data.

The Health Systems Framework has been widely used to assess the performance of health systems globally and to guide investments in health systems strengthening. [192, 193] Though the building blocks are multi-faceted and distinct, they are also interconnected and interdependent. [190, 194-196] For example, without essential commodities, health workers cannot measure pre-, post-, and during pregnancy outcomes. Without health workers, there will be no quality maternity service delivery. The Health Systems Building Blocks enable the examination of the interconnected and interdependent relationships between the inputs needed to improve the performance of the health system, as well as intermediary goals and outcomes. This approach facilitates a comprehensive and holistic analysis of how the different blocks influence stillbirth recording and reporting.

Several studies have highlighted the critical importance of utilizing the Framework to understand the performance of health systems as well as the interdependent nature of all the building blocks. In Indonesia, the Framework was utilized to evaluate the district-level impact of health governance decentralization. [197] In using the Framework, the authors were able to determine that health workforce, financing, and service delivery were the most affected by decentralization efforts. These three areas were hampered by issues of accessibility and coverage, as illustrated by reported inequities in seeking maternal and child health services. In India, a study found that barriers to accessing child immunization were due to financing constraints and limited healthcare workers. [198, 199] Additionally, a study from Ghana reported gaps in financing and the influence of the health workforce on how health service delivery is administered. [200] In Zambia, the Framework was used to evaluate health outcomes following mentorship by community members at the district level. The study found that weaknesses reported in one building block had a cross-cutting effect on the other building blocks. Specifically, service delivery gaps were linked to limitations in the

health workforce, supplies, information flow, governance, and finance. Of note, supply-side barriers relating to staff shortage, health worker attitude, poor relationships between the community and health staff, lack of trust, and increased waiting times affected service delivery. The authors argue that the building blocks allow for system-wide approaches in assessing the performance of health system strengthening interventions. [138] In Ethiopia, the building blocks allowed for identifying the improvements needed across the health system. The authors also found that the framework served as a good basis to inform the selection of the health-related SDG objectives. [201]

Beyond geographic settings, the Framework has been used as the foundation for several programmatic areas, including population health, disease burden and health emergencies. For population health, the Health Systems Framework was used to inform the development of the WHO Quality Of Care Standards for Improving the Quality Of Maternal and Newborn Care in Health Facilities. [202] A scoping review of RMNCAH policies alongside in-person interviews in South Sudan revealed that gaps in the implementation of policies were mainly due to the weaknesses identified in different health system building blocks. Key bottlenecks in the system hindering RMNCAH policy implementation were related to shortages in the health workforce, insufficient availability of medicines and supplies, and low national funding. The scoping review suggests that improvements are needed in building health workforce capacity, establishing governance and accountability mechanisms, and increasing the national budget for RMNCAH strategies. [203] Most recently, the WHO Health Systems Framework was used to evaluate the global response to COVID-19. In doing so, the authors acknowledged that the Framework was a useful starting point for identifying strengths, gaps, and potential areas for reform. In applying the Framework, the authors determined that fragmented funding; non-transparent pricing of medications and supplies, substandard quality standards, and disparities in procurement and distribution; as well as inadequate leadership were critical factors in the delayed response to the COVID-19 pandemic. [29]

Since the publication of the WHO Health Systems Framework, it has also been subject to criticism. The allocation of equal weight to all six building blocks assumes that each holds equal importance. [204] However, a study argues that governance serves as a foundational pillar enabling the

performance of other building blocks, including the information system. [29] This finding is further supported by papers published as part of this thesis. [151, 170] Another criticism of the WHO Health Systems Framework is its increased focus on the supply-side of the health system, emphasizing institutions with inadequate attention to the demand side, i.e., the human element or experience of care. There has been a call to integrate community roles into the WHO Health Systems Framework, as many studies highlight how healthcare delivery increasingly occurs at home and within the community. [205] Recognizing the vital role of communities in health systems, the WHO issued the Integrated People-Centered Health Services Framework in 2016, urging countries to transition from health systems designed for diseases and programmes to those centered around the person. [206]. Similarly, power dynamics among various actors can significantly influence health system performance. One paper argued that the relationships between actors, particularly the influence they exert, guide actions, and underpin relationships among system actors and elements, should be carefully addressed within the Health Systems Framework. [207] Furthermore, to provide quality health services for all, the focus has to be on the users of health services. In 2018, a report from the Lancet Commission on High-Quality Health Systems put forth a new framework, building on the WHO Health Systems Framework but emphasizing the user experience, and how people benefit from healthcare. [208] Finally, the need for country specificity has also been flagged as an area of improvement. In Kazakhstan, the WHO Health Systems Framework was used to access health care reforms towards quality Universal Health Coverage. The paper argued that though the framework is useful in assessing the multiple interrelated areas, the framework requires contextualization and adaptation to the country needs as well as technical areas of improvement. [209]

7.4.2 Leadership and governance

As a foundational building block, leadership and governance arrangements create the enabling environment needed to reduce stillbirths. Also, leadership and governance shape policies, define targets and facilitate standards development and monitoring. Across 155 countries, national stillbirth rate targets were developed in 32 countries (21.9%), with a greater number of countries having established national targets for under-five mortality (100 countries out of 155) and neonatal mortality (102 countries of 155) [1, 4, 5] [151]. Countries participating in global initiatives, such

as the *Every Newborn Action Plan* (ENAP) and the Quality of Care Network, have all established stillbirth rate targets, signaling the critical importance of global level initiatives in influencing country action on stillbirths. [210] [12] Specifically, in Ghana a national target for stillbirth has been defined aligned with the goals of the ENAP. The goal of the ENAP is to achieve 12 stillbirths or fewer per 1,000 total births. [9, 10, 18, 104] Additionally, a clear criterion has been defined in Ghana for measuring stillbirth, as a baby delivered with no signs of life (gasping, heartbeat or limb movements) after 28 completed weeks of pregnancy. [128]

While Ghana has created an enabling policy environment to reduce stillbirths, with a defined stillbirth rate target and a standard definition, there remains a disconnect between national policy directives and sub-national implementation. The Ghana Health Service's definition of stillbirth at 28 weeks, a crucial benchmark for accurate measurement, remains unfamiliar to several health workers. Many health workers at the district and facility level described stillbirths using different definitions, including the use of varied gestational age limits, with 20, 24, 28, 32, and 36 weeks commonly used. Similarly, fresh and macerated stillbirths were used to describe stillbirths more so than the recommended terminology of antepartum and intrapartum stillbirths.

The unfamiliarity of health workers with the defined national policy and definition presents challenges for stillbirth measurement. Using various gestational thresholds `limits the information recorded in routine health management information systems. [45] For example, health workers who recognize stillbirths only as late gestation stillbirths (fetal deaths occurring after 28 weeks) may only record and report these stillbirths, choosing not to record early gestation stillbirths (defined as stillbirths occurring between 22 weeks and 27 weeks) because they are unaware that these are also part of the overall stillbirth definition. These health workers may potentially misclassify early gestation stillbirths as miscarriages. [24, 89, 92] The inconsistency in the application of definitions may result in the inaccurate categorization of stillbirth outcomes, which could either result in their exclusion (if erroneously labeled as miscarriages) or in the misclassification of stillbirths (if wrongly categorized) in standard data collection processes. [173]

Similarly, some health workers referred to stillbirths using skin appearance. The use of fetal skin appearance is not an accurate marker to classify stillbirths. Though fetal skin appearance has been

used historically to describe stillbirths, [99, 211, 212] this approach is subjective depending on the assessment administered by the attending health worker. The recommendation emerging from WHO and UNICEF is to use the absence of fetal heart activity on auscultation or ultrasound on admission to the labor ward. [13, 46]

Perinatal audits help identify cases where stillbirths could have been prevented, facilitating continuous learning, driving data-driven decision-making, and enhancing collaboration among different cadres of health workers. [127] Globally, countries recognize the importance of audits with 68 out of 155 countries having policies in place to conduct stillbirth reviews or audits. Within the study country, this is further supported by the Ghana Health Service which mandates, with clear guidelines, that audits be conducted for late-gestation stillbirths between 28 weeks or more and seven days of delivery. [213] The focus on 28 weeks or more, is done due to capacity of the local health system in Ghana to count such babies and deliver needed service delivery interventions to avert stillbirth outcomes. [127] In reviewing the existing national guidelines, it is noted that guidance is not provided regarding the system-wide tendency to assign blame to health workers during the audit process. While language is provided on avoiding punitive language within the national guidelines, a how-to process guide would be useful to ensure that those conducting the audits are properly trained. [121, 122] When blame exists as part of audit processes, health workers may fear reporting cases of stillbirths, thereby leading to under-reported cases of stillbirths or omissions of stillbirths in record books and routine health information management systems. [185] [186, 187, 214] Additionally, blaming health workers during audits complicates the collection of high-quality data on stillbirths. It results in health workers not feeling accountable for the data, which can impede efforts to enhance how stillbirths are documented and reported.[183]

As part of the audit process, key consideration should be given to minimally invasive tissue sampling (MITS), which helps in understanding the causes of stillbirth. MITS has evolved to support evidence generation regarding the cause of death, including for stillbirths, in many low- and middle-income countries. MITS is a medical procedure used to collect tissue samples from deceased individuals in a way that is less invasive than traditional autopsies. It involves multiple core tissue biopsies of the brain, left and right lungs, and liver using specialized needles. [215] These samples are then analyzed to determine the cause of death. MITs are useful in resource-

constrained settings. [215-217] In 2019, a study from a secondary-tertiary hospital in South Africa found that using MITS provided detailed information on stillbirth for 117 of 129 (90.7%) cases, including an underlying maternal cause in 63.4% (n = 83) and an immediate fetal cause in 79.1% (n = 102) of cases. [217]

Specific to Ghana, the law mandates that the cause of death should be recorded in the case of fetal death. However, there is limited data on determining the cause of death for stillbirths in Ghana. [149, 218] MITS can provide detailed information on the causes of stillbirth to inform audit recommendations and help ensure that stillbirths are reduced. However, this approach needs to account for the training required and the costs associated with scaling up this technology.

Across national policy documents reviewed in 66 countries, reporting of stillbirth data from private facilities was mentioned by only two countries. This highlights a major gap in reporting stillbirths from private health facilities, recognizing that private health facilities account for approximately 40% of antenatal and childbirth care service delivery in LMICs. [219, 220]. Ghana provides a clear example of a situation where policies exist, but actions at the lower levels contradict what is stated in the policy. Despite existing policies, Ghana still faces reporting gaps in stillbirth data from the private sector. Even though private health facilities in the Ashanti Region are required to report stillbirth data to the DHD, this requirement was not always fulfilled. This situation in Ghana could lead to the under-reporting of stillbirths in routine health management information systems and an under estimation of the actual burden of stillbirths. [221] To enhance stillbirth data collection and reporting, it is critical to give equal consideration to both public and private health facilities when addressing stillbirth measurement.

7.4.3 Health workers

Health workers are the backbone of service delivery and are key to providing quality care to mothers and babies during pregnancy. Health workers play a key role at the point of care and throughout the stillbirth data continuum, from the occurrence of a stillbirth to the routine health management information system, and ultimately in how data is used to inform decision-making.

In Ghana, health workers were acutely aware of the importance of preventing stillbirths, particularly the provision of quality care to avert stillbirth outcomes. [40, 222-225] This is an important outcome of the study as health workers who recognize the importance of preventing stillbirths and quality of care are more inclined to prioritize activities like data collection, analysis, and utilization. This, in turn, could lead to the collection of quality stillbirth data.

Globally, only 8 out of 66 countries have policies in place for training health workers to fill out death certificates using defined measurement criteria such as the ICD-10 or 11. In practice, training opportunities, including pre-service education and in-service training, provide health workers with improved knowledge and awareness, strengthen clinical skills, empower health workers, and enhance their ability to collect, analyze, and interpret data. [180, 181] Within the Ghanaian context, pre-service education served as an important foundation for building stillbirth knowledge among health workers. The midwifery education system in Ghana offers varied pathways for individuals to obtain knowledge on stillbirths. [226] These pathways include a two-year college programme and a four-year university programme. In Ghana, the two-year college programme provides a more condensed and focused curriculum, while the four-year university program offers a more comprehensive and in-depth education.

Specific to in-service training in Ghana, though training exists for health workers, this is mainly centered on strengthening clinical skills – an important element of stillbirth prevention, with limited opportunities for learning about stillbirth measurement. Moreover, health workers in this thesis research in Ghana acknowledged the importance of complementary approaches to training including coupling capacity building workshops with onsite support mechanisms such as supportive supervision, coaching, and mentoring. [227] This finding is aligned to outcomes from another study looking at strategies to improve health worker performance. The study found that multifaceted strategies aimed at supervision, management techniques, and training, as well as the combination of group problem-solving and training, frequently yielded significant results in improving health worker performance. [208, 228]

Traditionally, global literature surrounding the experience of care related to stillbirth, has centered on building the capabilities of health workers to counsel mothers following a stillbirth. [33, 62, 94,

95, 154]. We found alignment with the published studies and existing Ghanaian national documents where policies exist on communication and counseling to mothers following a stillbirth. Health workers who participated in objectives 2 and 3 of this thesis highlighted that opportunities exist for health workers to provide counseling to mothers and families. However, on the contrary, from the health worker's perspective, counseling to health workers following a stillbirth is lacking. Past studies have highlighted that grief counseling surrounding the events of an unexpected maternal death is important to build the morale of health workers. [229] In the Ashanti Region of Ghana, a past study on coping with maternal deaths by health workers found that providing counseling support following a maternal death can help health workers process their emotions, prevent burnout, and continue delivering compassionate care. [230] When challenges related to dealing with grief and blame are not addressed by the health worker, the absence of interventions by the health system could result in poor maternal health outcomes, as evidenced by the study from Ghana. Similarly, health workers who are demoralized because of grief may be less motivated to accurately report stillbirths due to the emotional toll.

Counseling for health workers can be organized by understanding their specific needs, establishing a counseling programme at the regional or district health directorate level, recruiting and training counselors, and encouraging health facility staff to consult these professionals. [231, 232] These are noted strategies for health workers dealing with grief in the workplace. Additionally, peer-support groups grounded in confidentiality and trust have also been shown to support the mental wellbeing of health workers. [233-236]

Finally, a limited health workforce directly impacts the recording of stillbirths due to the increased workload placed on the available staff. In contexts where health workers are scarce, the capacity to adequately document stillbirth cases become strained. This strain often arises from the numerous responsibilities that health workers already juggle, leaving them with limited time and resources to dedicate to thorough stillbirth recording and reporting processes. For instance, a study emphasized that in low-resource settings, such as many countries in sub-Saharan Africa and South Asia, health facilities often face severe shortages of skilled birth attendants. [14] This shortage contributes to an increased workload for the available health workers, affecting their ability to consistently and comprehensively document stillbirth cases. Furthermore, inadequate staffing

levels in health facilities are a significant barrier to improving maternal and newborn health outcomes, including the accurate recording of stillbirths. [52, 237-239] In such environments, health workers may struggle to prioritize data collection amidst their primary health service delivery duties.

7.4.4 Data/health information systems

Data/Health information systems are key for stillbirth recording and reporting providing the foundation for data collection, analysis, and dissemination. These processes are essential for monitoring trends and informing evidence-based interventions to reduce stillbirth rates. Across objectives 2 and 3, the research revealed that there is a good understanding of the stillbirth recording processes at the sub-national level with data-quality checks performed by district health teams on routine health management information systems to assure the quality of the data produced.

As part of the global stillbirth policy review, countries highlighted that the top four data sources used to compare maternal, newborn, child, and adolescent mortality rates, were WHO websites and reports; national health statistics databases; national population-based surveys and Multiple Indicator Cluster Surveys; and CRVS. In Ghana, health workers who collect the data to inform timely frontline interventions for service delivery use the DHIMS-2 and the Open Data Kit more frequently. [82, 85-87] In the long term, the information captured within DHIMS-2 informs policy formulation. [240]

Within the stillbirth policy review, 21 out of 66 countries reported that death data recorded on stillbirths at health facilities or at the community level need to be provided to the national statistics office, civil registration system, or equivalent bodies. At the operational sub-national level in Ghana, obtaining stillbirth information captured within the DHIMS-2 is only available to a small number of officials, such as health information officers or district health managers. Accessing the information in DHIMS-2 by other sectors is difficult and requires the completion of long paperwork to obtain the necessary information. Similar findings were recorded in a global scoping review of 500 documents where a study revealed that accessing stillbirth information stored within

the district health information system poses significant challenges. [241] The study found that access to this data is restricted to a limited number of officials, primarily health information officers or district health managers. This restricted access not only impedes transparency but hinders cross-sector collaboration and evidence-based decision-making processes. Further, other sectors outside the health sector face barriers to accessing vital stillbirth data, with cumbersome paperwork requirements often acting as a deterrent. This administrative hurdle not only delays access to critical information but also undermines the effectiveness of multi-sectoral approaches aimed at comprehensively addressing stillbirths. Addressing these challenges requires concerted efforts to streamline data-sharing mechanisms and enhance interoperability between routine health management information systems and other relevant sectors. [242]

At the sub-national level in Ghana, a disconnect was observed between the actions carried out by the district health management teams and the interviews conducted with health workers in health facilities. Data quality checks performed by the district health teams do not eliminate the possibility of misclassification, omissions, and under-reporting of stillbirth cases reported at the sub-national level. At the sub-national level in Ghana, a disconnect was observed between the actions carried out by the district health management teams and the interviews conducted with health workers in health facilities. Data quality checks performed by the district health teams do not eliminate the possibility of misclassification, omissions, and under-reporting of stillbirth cases reported at the sub-national level in the DHIMS-2. As demonstrated in the second published paper of this thesis (Figure 2), DHIMS-2 reported inconsistent mortality numbers. The differences in mortality rates (as reported in DHIMS-2) between the various districts could be attributed to the gaps identified in DHIMS-2. Issues related to the paper-based transfer of data from the original primary source at the health facility level to the health information system at the district level could pose data quality challenges. This statement is consistent with findings from past studies reported in Ghana and across the African continent, [145, 243, 244] as well as the findings from the Ashanti Region of Ghana, as reported in Chapters 5 and 6 of this thesis. Similarly, another study from Ghana concerning neonatal mortality data in DHIMS-2 reported errors in the data captured at both the health facility level and in DHIMS-2 across 8 districts. [243] The reported gaps contributing to errors in DHIMS-2 included inaccurate numbering of the registers, collation of the facility data before the end of the month, inadequate supply of registry books, incomplete data capturing, and

lack of periodic data verification. The study from Ghana concluded that errors in the data were primarily committed during the collation of the primary data, a finding that aligns with feedback from health workers in the Ashanti Region involved in this thesis.

As an example, the level of skilled deliveries was reported as a percentage in the DHIMS-2 system. However, one district reported a percentage exceeding 100%, indicating a reporting error within DHIMS-2 and highlighting the system's susceptibility to data quality issues. There is a need for quality control mechanisms, such as data validation, to correct these inaccuracies. Regular data validation at the health facility and district levels will facilitate timely and accurate recording and reporting. A recent study from Ghana concluded that health facilities with functioning data validation teams were more likely to report quality data (data that is complete, accurate, and timely) into DHIMS-2. [245] Similar findings were also reported in Tanzania. [246]

Studies have highlighted the complexities associated with data quality assurance mechanisms within health systems. For instance, a study in South Africa emphasized the challenges in ensuring accurate reporting of stillbirths, particularly in resource-limited settings where data management systems may be inadequate. Despite efforts to implement data quality checks, inconsistencies in reporting practices persist due to various factors such as limited training, insufficient supervision, and inconsistent data recording protocols. [125, 247] Furthermore, a global study underscored the importance of addressing data quality issues at the sub-national level to improve the reliability and completeness of stillbirth reporting. [5] While district health management teams play a key role in conducting checks and balances, their efforts may not always translate into accurate stillbirth documentation due to systemic challenges and gaps in capacity-building at the lower facility levels.

7.4.5 Essential commodities

Essential commodities are needed to count babies accurately. In the global stillbirth policy review, 90% (out of 155 countries) of countries had a national policy or guideline for essential medicines and equipment. This emphasizes the perceived importance of having adequate resources to address

stillbirths and improve maternal and newborn health outcomes. [127] Moreover, 80% of countries had the key commodities required to prevent stillbirths.

Ghana is one of the countries that indicated the availability of policies on essential commodities in the global stillbirth policy review. However, at the operational sub-national level in Ghana, challenges exist in implementing these policies effectively. Health workers highlighted that audit recommendations often include the procurement of essential commodities to address identified gaps in service delivery and stillbirth measurement. Despite these recommendations, the actual procurement of these commodities frequently falls short, leading to persistent challenges in service provision and accurate stillbirth reporting. Failing to complete the audit process, which involves six important steps such as identifying cases, gathering details about causes of death, analyzing findings, implementing recommendations, and evaluating the process, [182] will allow the lack of understanding of the importance of stillbirth recording and reporting, along with a general lack of ownership of stillbirth data, to persist. [183] The effectiveness of perinatal audits depends on completing all the steps of the audit process, including the timely procurement of essential commodities when required. Simply recording stillbirths and their causes is not enough, without the necessary follow-up actions. [248, 249]

7.4.6 Financing

Available financing facilitates the processes required for stillbirth recording and reporting. From the stillbirth policy review, countries participating in global health initiatives such as the Quality of Care Network and *Every Newborn Action Plan* have all set targets to reduce stillbirth rates. These initiatives have exerted influence on the political priority for stillbirth, injecting much-needed attention into the maternal and child health financing space, including a key focus on stillbirths.

In Ghana, though the share of government expenditure allocated to health was 13.4% in 2020, [250] this falls short of the 2001 Abuja Declaration goals, which encouraged African countries to devote at least 15% of their national budgets to health. [251] Despite Ghana's failure to meet the 2001 Abuja Declaration target, the government remains the primary funding source for health

expenditures. In 2023, external financing amounted to $305,075,859 compared to the over one billion USD allocated to health by the Government of Ghana (see Figure 12 and Table 12). [250] A key outcome of the increased financing for the free maternal health care policy is the impact of additional funding on the implementation of the policy, which in 2020 was revealed to result in a 45% reduction in the neonatal mortality rate. [252] The maternal health care policy was introduced in 2008 to eliminate financial barriers to accessing maternal health services, which are critical in reducing stillbirths and improving maternal health outcomes. [253] The primary goal of the policy is to increase the utilization of facility deliveries and to improve maternal and newborn care in general. [254]

Ensuring equitable distribution of the resources to assure quality maternity services, particularly at the regional and district levels varies. My investigation at the sub-national level revealed that regional and district health managers perceive government spending on health as limited. This perception highlights the complexities and inadequacies in financing health services at the local level. A study conducted in South Africa shed light on the challenges faced by health workers in policy change implementation, particularly in maternal health. Nurses expressed feeling excluded from the implementation process, citing a focus on the demand side experience of care, primarily for mothers, with insufficient consideration of social, financial, and human resources, including health worker incentives.[255]

While Ghana has made strides in maternal and child health policies and initiatives, challenges remain in ensuring variation looking at financing both the supply service delivery aspect of care, which includes data systems, as well as the demand side of care. Addressing these challenges requires comprehensive strategies on adequate resource allocation mechanisms and involving health workers in policy formulation and implementation processes.

Figure 12: 2023 funding source for health in Ghana.

Figure 12 is reproduced with permission (See Annex 14).[250]

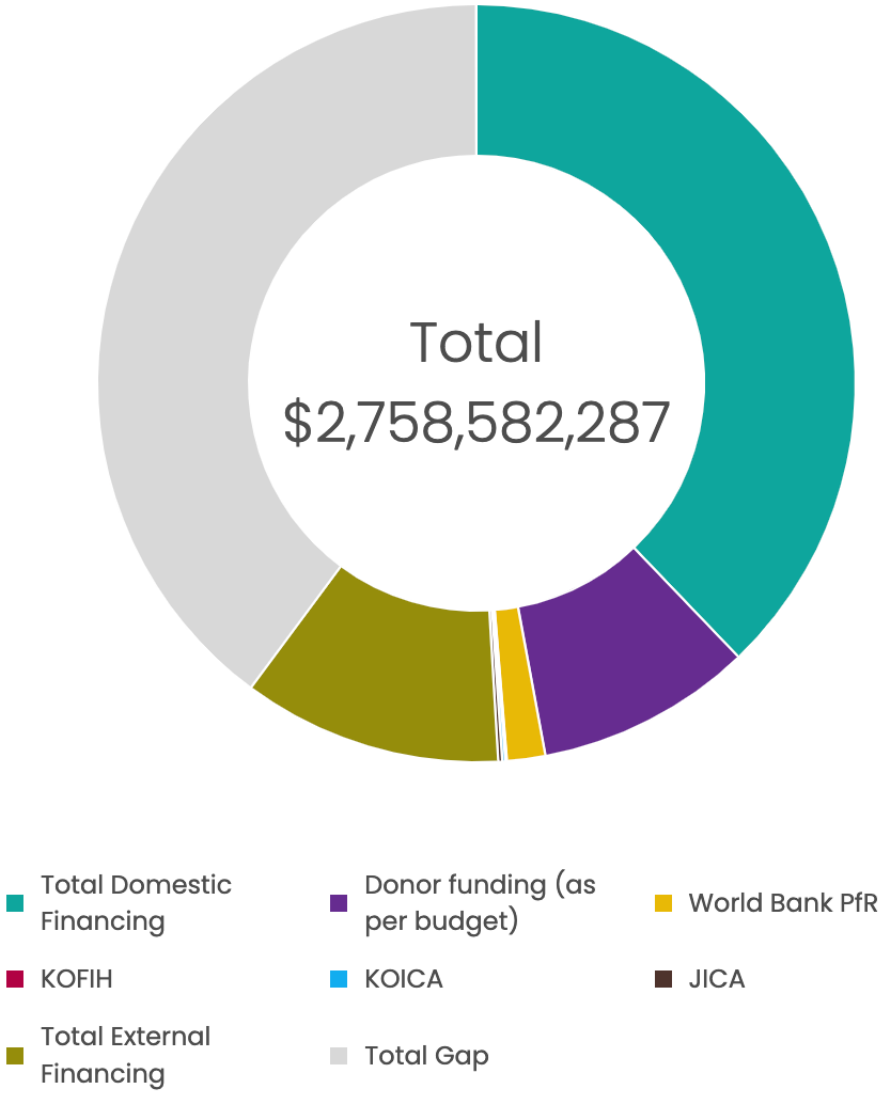


Table 12: 2023 funding source for health

Adapted from the *Global Financing Facility Data Portal for Ghana [250]*

Country: Ghana	
2023 Funding Source	Value
Total Domestic Financing	$1,044,505,988
Donor funding (as per budget)	$254,705,859

World Bank (Program for Results)	$45,250,000
The Korea Foundation for International Healthcare	$1,500,000
Korea International Cooperation Agency	$3,620,000
Japan International Cooperation Agency	$4,874,581
Total External Financing	$305,075,859
Total Gap	$1,099,050,000

7.4.7 Integrated findings

Table 13 presents a summary of the integrated findings from the three papers/objectives, mapping each of the findings to the relevant health system building blocks.

Table 13: Integrated findings across the three objectives of the thesis

n_t in the table refers to the total number of countries. Associated paper(s) for each finding are reflected in parenthesis.

Health Systems Building Blocks	Enablers for stillbirth recording and reporting, identified across Papers 1-3	Gaps for stillbirth recording and reporting, identified across Papers 1-3
Leadership/ Governance	• SBR targets set in countries (Paper 1), particularly countries who are signatories to global initiatives (ENAP, QoC Network), including Ghana with a clear target and criteria for stillbirth measurement (Paper 2). • Stillbirth review processes are mandated in countries (44% of n_t=155) (Paper 1), and Ghana has a clear policy specifying when audits should be conducted for stillbirths (Papers 2 & 3).	• The existence of policies does not mean sub-national service delivery actors are aware of the mandate (GHS 28 weeks definition not known to all health workers) (Paper 1-3). This lack of awareness is leading to variations in stillbirth definition, affecting accurate measurement (gestational age, ante-partum and intrapartum, fresh and maceration) (Paper 2 and 3). • Globally audit mandates exist (Paper 1). In Ghana, there is a system-wide tendency to assign blame (during audits). • Lack of private sector engagement (Papers 1-3)
Health workers	• In-service training through mentoring, coaching and supportive supervision exists for health workers. Training is often centered on clinical care (Paper 3). • Varied pathways to obtain midwifery education – 2-years in college vs four-years at university (Paper 2 &3), with pre-service education shaping the	• Limited number of countries (8% of n_t=66) have policies in place for training of health workers in filling out death certificates using a defined measurement criteria i.e. ICD-10 (Paper 1). Similarly, in Ghana, limited opportunities exist for in-service training on proper measurement of stillbirth and its recording and reporting (Paper 3).

	foundations of stillbirth recording and reporting (Paper 3). • Policies in place for training health workers on communication and counseling to mothers following a stillbirth (Paper 1). • Acknowledgement of the importance of preventing stillbirths, the linkages between quality of care and stillbirth outcomes, and the importance of recording a stillbirth (Papers 2&3).	• Lack of training on avoiding blame/punitive language and emotional support to health workers when dealing with stillbirths (Paper 3), though policies exist for training health workers on communications and counseling to mothers by health workers (Paper 1). • Limited health workforce numbers affect stillbirth recording due to increased workload (Papers 2 &3).
Data/Health Information Systems	• Data quality checks are administered by the RHD/DHD for facility-level data (Paper 2). • Countries use national statistics systems and CRVS as key resources to compare stillbirth rates/numbers (Paper 1). • In Ghana, the DHMIS-2 and ODK mainly used by health workers in Ghana (Paper 2&3) • Good understanding of stillbirth recording and reporting protocols in the study country (Paper 2&3). • 20 out of 66 countries required sharing individual death records on stillbirth between central and district/regional health directorate levels (Paper 1). Similar findings were reported at the sub-national level (Paper 2).	• Data-quality checks administered by the RHD/DHD (Paper 2) facilitate accurate reporting at the facility-level though misclassifications, omissions, and under-reporting still exist (Paper 3). • Limited integration of stillbirth data between the formal service delivery system (DHIMS-2/ODK) and other sectors e.g. CRVS and statistics (Paper 2 and 3), though countries reported that CRVS and national statistics services are commonly used to compare stillbirth rates/numbers (Paper 3) • Data recorded on stillbirth at the facility-level is mandated to be reported to CRVS and statistic agencies in 32% of countries (n_t=66) (Paper 1), however in Ghana, information in the DHIMS-2 is not easily accessible by other agencies such as the CRVS or statistics system (Paper 2) .
Essential Supplies/ Commodities	• Key commodities required for stillbirth prevention are in place (Paper 1) in almost all countries (90% of n_t=155).	• Audit implementation stagnates when the recommendations require procurement of essential commodities (Paper 3)

Financing	• Engagement of countries in global health initiatives aimed at reducing SBR (e.g. quality of care network, ENAP) facilitate funding to stillbirth reduction (Paper 1)	• Perceived limited domestic funding for stillbirths (Paper 2) • Funding from donors often earmarked to specific areas (Paper 2)

7.5 Counting the invisible – a theory of change for improving stillbirth recording and reporting

A theory of change explains how a given intervention or a set of actions interact to bring about improvements toward a desired outcome. [125, 247, 256, 257] A theory of change as an appropriate framework for improving stillbirth recording and reporting is proposed for three reasons. First, a theory of change aids in identifying solutions to effectively tackle the underlying causes that impede progress, guiding decisions on the most appropriate approaches to pursue. Causes for the poor-quality data reported for stillbirths are complex as demonstrated in this thesis. Second, improving stillbirth recording and reporting involves engagement from a broad range of stakeholders including those in the public health sector as well as the private sector, and a range of sectors including finance, procurement, statistics, and many others. Third, a theory of change fosters learning on the actions and interventions taken to improve stillbirth recording and reporting.

The theory of change allows for an analytical perspective allowing for the stillbirth measurement framework to be tested and lessons learned to improve assumptions made. A theory of change also forms the basis of main frameworks including a results chain and a log frame. The structure of the theory of change is presented below. [258, 259]

- Inputs refer to the materials, funds, and human resources dedicated to improving stillbirth recording and reporting. These are the resources allocated to support the implementation of stillbirth recording and reporting activities.

- Process refers to the series of steps, activities, or procedures undertaken to achieve a particular goal or outcome. It involves the systematic execution of tasks and activities to move from inputs to outputs.

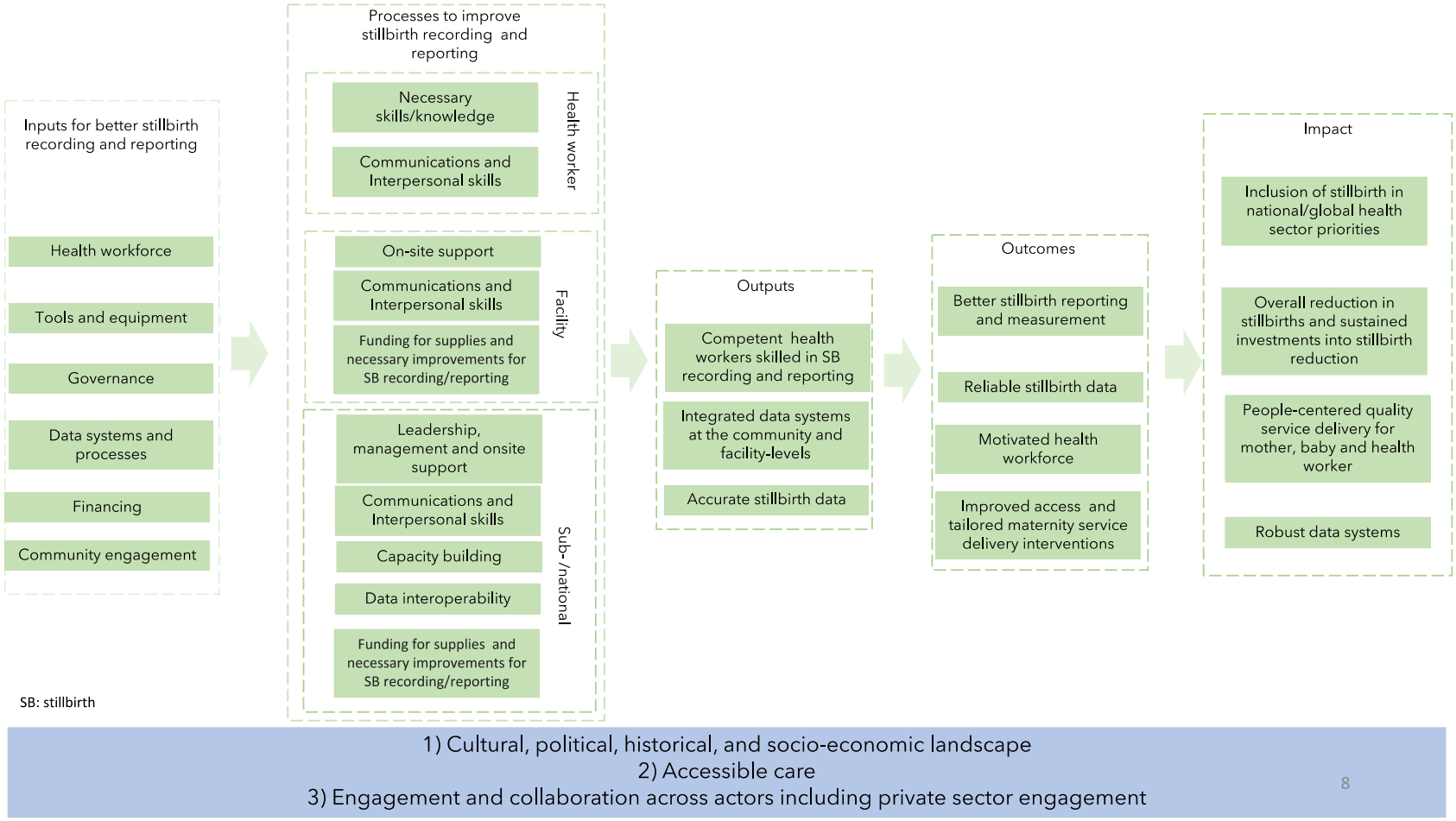
- Outputs are the measurable products, services, or deliverables generated as a result of the activities and processes undertaken to improve stillbirth recording and reporting.

- Outcomes are the changes, effects, or benefits resulting from the produced outputs. They represent the short-term or intermediate changes in behavior, attitudes, knowledge, or conditions that occur as a result of improving stillbirth recording and reporting.

- Impact refers to the broader and long-term effects or changes. It represents the ultimate goal or desired change to achieve sustained improvements in stillbirth recording and reporting.

A theory of change for improving stillbirth recording and reporting is presented in Table 14. The theory of change is informed by the literature review, the three objectives/papers, as well as the critical discussion section presented earlier.

Table 14: Theory of change for improving stillbirth recording and reporting.



In the following sections, key components of the theory of change are elaborated upon.

7.5.1 Inputs

Inputs are underpinned by the six building blocks of the health system which are discussed at length in earlier parts of this thesis.

Missing from the building blocks is community engagement, which is increasingly seen as critical in improving pregnancy outcomes. Attention to community engagement in stillbirth prevention has increased since 2000, with communities becoming more involved in the development of governance arrangements such as policies, plans, and strategies to reduce maternal and newborn mortalities, including stillbirths. Aligned with this, community engagement interventions have also been advocated for in the planning and monitoring process for health. [260, 261] Community engagement involves collaborating with individuals who share geographical proximity, specific interests, or similar circumstances to address challenges impacting their welfare. It aims to facilitate community participation in stimulating social change. [262] A study from Bolivia highlighted the critical importance of community engagement in improving perinatal health outcomes. By engaging community members, perinatal mortality was reduced by 30% at a sub-national district level. [263] Similarly, across India, Nepal, Bangladesh, and Malawi, evidence suggested that participatory women's groups in service delivery and policy setting, benefit the survival chances of neonates. [264] Broader lessons learned from community participation in maternal and child health programmes highlight that strategies to improve maternal and child health outcomes should include community engagement as a key pillar of sub-national and facility-level interventions. Specifically, community engagements promote greater decision-making power, empower communities, and ensure that facilities improve in care and healthy-seeking behavior. [265]

The engagement of communities in maternal and child health service delivery, including stillbirth reporting, allows for communities to report stillbirths that may have occurred outside health facilities. Community health workers, skilled birth attendants, local officials and family members are crucial allies for liaising with the community and reporting any stillbirths to nearby CRVS

offices and health facilities. Investigating stillbirths at the community level would require a verbal autopsy. [266] Verbal autopsy is a systematic post-mortem interview with the relatives of the deceased regarding the health history, signs, and symptoms of the fatal illness, potentially identifying the cause of death. [267] Verbal autopsy can provide valuable insights into stillbirth at the community level, especially in countries where a medically certified cause of stillbirth is not available. Challenges reported for verbal autopsy include recall bias, stigma, and trauma. [91, 92, 266] Similar challenges are also reported in Ghana for verbal autopsy. [268, 269] Furthermore, key components of investigating stillbirths at the community level would also include the engagement of community health workers or skilled birth attendants, home visits, and community awareness programmes.

7.5.2 Processes

To enhance stillbirth recording and reporting, health workers require not only essential clinical skills and knowledge but also effective communication and interpersonal skills. While clinical proficiency is key for delivering quality maternal and child health services, successful outcomes in these areas also hinge on robust communication abilities. A scoping review examining strategies to improve interpersonal communication within maternal and child health settings found that coupling interpersonal skills with clinical expertise facilitated the adoption of clinical interventions within 42 days after birth. [270]

Specific to stillbirth recording and reporting, communication between health workers and mothers, as well as among different health worker cadres, is important. Communication between the health worker and the mother ensures that the health worker can document all the circumstances surrounding a stillbirth. In South Africa, findings from a control group of 25 women who had a stillbirth, showed that mothers receiving the intervention facilitated by health worker engagement used different coping mechanisms to deal with the severity of their loss, elaborating on their pregnancy journey. [271] Furthermore, communication among health workers ensures that stillbirth data, which passes through multiple cadres including midwives, health information officers, and district officers, work collaboratively to accurately document and report a stillbirth.

Data interoperability plays a vital role in providing a comprehensive picture of the stillbirth burden. As highlighted in the literature review of this thesis, several data systems capture stillbirth data including health management information systems, CRVS and population-based surveys. Interoperability facilitates the harmonization of data from different sources, allowing for a more accurate assessment of the prevalence, causes, and trends of stillbirths. For instance, in Ghana, DHIMS-2 collects routine health facility data, while CRVS records vital events such as births and deaths at the population level. Population-based surveys, on the other hand, provide valuable insights into community perceptions and experiences related to stillbirths.

Interoperability between data systems functioning in one health system can overcome fragmentation and duplication of efforts in stillbirth data collection and reporting. [93] This integration enables policymakers and health workers at the sub-national level to access timely and reliable data for evidence-based decision-making and targeted interventions aimed at reducing the stillbirth burden. [272]

Leadership and management across all levels of the health system are important to build health workforce capacity for effective maternal and neonatal health services including stillbirths. In the Morogoro Region of Tanzania, a focus on leadership and management training at the sub-national level resulted in health facilities improving their organizational performance by nearly 80% for 15 out of 19 facilities. [273] Similarly, across all three papers of this thesis, findings suggest that leadership and management influence prioritization and accurate stillbirth recording and reporting.

The importance of on-site support mechanisms, such as training/capacity building, mentoring, supportive supervision, coaching, and funding, is adequately captured throughout this thesis.

7.5.3 Outputs

The combination of the outlined inputs as well as the process will lead to:

- Competent health workers skilled in stillbirth recording and reporting.
- Integrated data systems pulling information from the community level as well as the facility level.

- Accurate stillbirth data.

7.5.4 Outcomes and Impact

In the intermediate to long-term, the identified inputs, processes, and outcomes will lead to –

Outcomes

- Better stillbirth measurement including improved documentation on the circumstances surrounding a death, as well as accurate recording of gestational age, cause of stillbirth, and other relevant clinical information.
- Reliable stillbirth data informed by the collection of holistic information from robust data collection mechanisms, including routine health information management systems, surveillance systems, population-based surveys, and vital registration systems.
- Motivated health workforce, who document complete and accurate information on stillbirth outcomes without fear of blame and find ways to improve future outcomes.
- Improved access to and tailored maternity service delivery interventions, guided by collected and analyzed data to inform service delivery interventions and adapt healthcare services to meet the diverse needs and preferences of pregnant women and their families.

Impact:

- Inclusion of stillbirth in national and global health sector priorities.
- Overall reductions in stillbirths and sustained investments into stillbirth reduction.
- People-centered quality service delivery for mother, baby, and the health worker
- Robust data systems that collect, manage, analyze, and disseminate quality data timely, effectively, and efficiently.

7.5.5 Foundations

The proposed inputs and processes leading to immediate outputs, intermediate outcomes and long-term impact need to be carefully considered within the country or national operating context. Three foundations are proposed:

One, the cultural, political, and socio-economic landscape significantly shapes attitudes, perceptions and experiences on stillbirths. Thus, efforts to improve stillbirth recording and reporting need to carefully consider these elements. [10, 28, 52, 91] Culture encompasses the shared beliefs, values, traditions, customs, language, and social practices that characterize a particular community or society. The political landscape refers to the structure, organization, and dynamics of political institutions, governance systems, and power relations within a country. Socio-economic factors include social structures, demographics, and education. The socio-economic landscape shapes pregnancy experience and stillbirth outcomes. [274]

Two, stillbirth recording and reporting are facilitated when women can access and seek care at either the health facility level or the community level. Without access to health services, obtaining stillbirth data becomes difficult. As previously mentioned in this thesis, access ensures that health services are within reasonable reach when needed (also known as physical accessibility), people can pay for health services without going into financial hardship (also known as financial affordability) and that these health services are acceptable i.e. people are willing to seek the services. [136]

Third, engagement and collaboration across all sectors, including the private sector which is increasingly playing a large role in maternity service delivery (globally one in five births happens in private facilities). [275] Engaging with the private sector in stillbirth recording and reporting is a requirement to understand the total population burden of stillbirths

8 Chapter 8 Conclusion

8.1 Recommendations for action

As the world progresses toward the SDG 2030 agenda, the maternal and child health community has placed a spotlight on ensuring that countries with the highest burden of stillbirth rates achieve the ENAP target of 12 or fewer stillbirths per 1,000 total births. Producing high-quality reliable data on stillbirth will guide countries on interventions, as well as strategies to apply to reduce the stillbirth burden. This thesis highlights that to improve the quality and availability of stillbirth data, health-systems strengthening – focused on improving leadership and governance, strengthening health workforce capabilities, increasing financing, building robust data/health information systems, and ensuring the availability of essential commodities – are needed.

The thesis outlines recommendations for policy-level and operational sub-national actors, including the district and facility-level.

Recommendations for policy-level actors

1. Within countries, close the gaps in stillbirth registration by using a standard definition for stillbirths. Ensuring a well-defined national definition for stillbirth aligns with the recent recommendation from WHO using the 22-week threshold.
2. Explicitly incorporate stillbirth and its definition into RMNCAH policies and plans.
3. Undertake policy reviews of RMNCAH plans and guidelines, as well as pre-service education curricula, and ensure that training of health workers to record and register stillbirths and their causes according to internationally recognized standards such as ICD-11 is included. For in-service training, this action should apply to all health facilities including public and private facilities and at the community level.
4. Ensure that policies and plans adequately include guidance on audit implementation, with careful processes outlined for a no-blame audit process and include counseling and grief support for health workers.

5. Develop simple communication and advocacy materials making the case for stillbirth policy improvements for policymakers.
6. Invest resources and improve the reporting infrastructure at the country level with clear protocols for health workers and ensure data on stillbirths is easily shared between different actors.
7. Ensure policies do not remain detached from frontline efforts by including adequately financed implementation plans at the facility and district levels,
8. Conduct periodic policy and implementation review meetings as well as capacity-building workshops with the sub-national actors to ensure that policy development is informed by implementation, as well as policies are adequately being translated at the sub-national level.
9. Develop interoperable data systems that provide a holistic picture of the stillbirth burden from the facility level to the community level.
10. Put in place mechanisms to ensure that private sector facilities report stillbirth data.

Recommendations for sub-national district-level actors

1. Ensure the effective implementation of national-level guidance on stillbirths at the sub-national level.
2. Allocate adequate resources to stillbirths at the sub-national level to facilitate stillbirth recording and reporting, including necessary follow-up actions following an audit.
3. Organize capacity-building workshops with health facilities to sensitize and translate national recommendations and policies on stillbirths into action at the sub-national level.
4. Ensure that capacity-building moments are followed up with on-site support mechanisms such as supportive supervision, mentoring, and coaching, while focusing on grief counseling for health workers, and omitting blame language when dealing with recording and reporting of stillbirths.
5. Ensure that facility-level health workers have equal opportunities for in-service training on RMNCAH-related areas including stillbirth recording and reporting.
6. Facilitate peer-to-peer learning about stillbirths between health workers, and across health facilities.

Recommendations for facility-level

1. Ensure that mutual respect, accountability and compassion grounds communication with other health workers when discussing stillbirths.
2. Seek out opportunities to learn about and apply strategies on stillbirth prevention, particularly its recording and reporting.
3. Attend counseling and grief support sessions when offered by the facility leadership or the sub-national authorities specific to health workers.

8.2 Original contribution to the evidence base

Across all three papers, and to the best of my knowledge after an extensive review of the existing literature on stillbirths, this thesis introduces new contributions to the field of stillbirth measurement. The thesis reviews unexplored aspects of stillbirth research, offering fresh perspectives, methodologies, and insights that advance the understanding of stillbirth measurement.

From a review of the literature, no global policy review has been conducted on stillbirths. This study represents an original effort to comprehensively understand the legislative environment regarding stillbirths across 155 countries. While the policy survey conducted by the WHO broadly assessed RMNCAH actions implicated in national documents, the data specific to stillbirths was not thoroughly analyzed. Additionally, the WHO did not review the national documents to ascertain the scope of stillbirth legislation within the survey. Therefore, this study marks the first global policy review focused specifically on stillbirths. This exploration of the policy landscape provides key insights into why stillbirths remain invisible in national and global level conversations. It highlights that what is not prioritized in policy or legislation is unlikely to receive attention at the lower levels of the health system.

In addition to the global stillbirth policy review, the in-country primary data collection yielded new evidence concerning the critical role of health systems in recording and reporting stillbirths. This research sheds light on the human factors and systems challenges associated with stillbirth

recording and reporting. To the best of my knowledge, no previous study has carefully examined the pivotal role played by DHMTs in stillbirth data collection, recording, and reporting. The local data used to inform national and global stillbirth strategies is derived from the electronic data capturing system managed by the DHMT, such as the health management information systems (e.g. DHIMS-2 in Ghana). Therefore, the DHMTs understanding of stillbirth recording and reporting is imperative to inform national authorities and global intervention actions aimed at improving stillbirth data collection.

Finally, the third paper in this study presents the first case example, providing deeper insights into the experiences, perceptions, and attitudes of health workers in stillbirth recording and reporting. This qualitative exploration contributes to a richer understanding of the human element involved in the recording and reporting process, an area that has been relatively unexplored in the existing literature. Improving the skills of health workers in the recording and reporting of stillbirths is a foundational step in strengthening stillbirth data systems. Without targeted interventions to address the skills of health workers in stillbirth measurements, efforts aimed at enhancing data systems for stillbirths will remain disconnected from local realities and risk being ineffective. It is essential to recognize that the effectiveness of any initiative to improve stillbirth data hinges on the active involvement and accurate practices of health workers. As health workers are on the frontline of data collection and reporting, their competencies play a key role in shaping the reliability, quality, and comprehensiveness of stillbirth data systems.

8.3 Translating research into action – collaboration with the Ghana Health Service and SARAH

Findings from the research have been shared with the Ghana Health Service and the Ashanti Regional Health Directorate. Through the research, the Ashanti Regional Health Directorate is developing a funding proposal to be shared with donors operating within the Region to support a capacity-building workshop and quarterly supportive supervision, mentoring and coaching sessions focused on stillbirth measurement. I am providing technical expertise and guidance to the RHD in the development of the proposal as well as subsequent training modules on stillbirth measurement. The workshop will focus on the RHD/DHD as well as the facility-level health

workers. Initially, the workshop will start in the Ashanti Region before it is scaled up to the rest of Ghana, working jointly with the Ghana Health Service.

Across sub-Saharan Africa, I am engaged in a five-country project with the Stillbirth Advocacy and Research in Africa Hub (SARAH) as a technical advisor. The five-country project supported by UNICEF and Africa Centers for Disease Control and Prevention (CDC) aims to strengthen stillbirth data systems in African countries (Namibia, Ethiopia, Uganda, Malawi, and Tanzania). The findings from this thesis and overall research methodology will inform the design of the research protocols being taken forward in the five countries. The three key objectives of the research project with SARAH include: 1) investigate national policies, processes, and practices related to stillbirth data in three country case studies: Rwanda, Uganda and Malawi; 2) monitor and support the implementation of data strengthening interventions in Namibia and Ethiopia; and 3) investigate surveillance systems in African countries in partnership with the Africa CDC.

The collaborations with the Ghana Health Service, Ashanti Regional Health Directorate, and SARAH, ensure that I use the research from the thesis to feed into a larger body of work across the African Region.

Finally, the knowledge gathered from this research is already contributing to my professional development. I have led health systems country planning assessments and workshops to better understand how experiences from sub-national/district-level teams and facility health workers could be leveraged to inform the review and redrafting of new health sector -wide strategies aimed at improving the preparedness and resilience of the health system.

9 References

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10 Appendices

10.1 Annex 1 Global stillbirth policy review - WHO approval

From: **KATWAN, Elizabeth** katwane@who.int
ubject: RE: [EXT] Follow-up: Data request: 2018-2019 Global Reproductive, Maternal, Newborn, Child and Adolescent Health Policy Survey
Date: March 30, 2021 at 6:45 PM
To: Nana Mensah Abrampah Nana.Mensah-Abrampah@lshtm.ac.uk
Cc: MORAN, Allisyn Carol morana@who.int

EK

Dear Nana,

Please find attached requested data in STATA.

Best regards,
Liz

From: KATWAN, Elizabeth
Sent: Tuesday, March 30, 2021 6:06 PM
To: Nana Mensah Abrampah <Nana.Mensah-Abrampah@lshtm.ac.uk>; MORAN, Allisyn Carol <morana@who.int>
Cc: Debra Jackson <Debra.Jackson@lshtm.ac.uk>
Subject: RE: [EXT] Follow-up: Data request: 2018-2019 Global Reproductive, Maternal, Newborn, Child and Adolescent Health Policy Survey

Dear Nana,

I will share with you the data in STATA. Is that format okay? As you only marked that you will be accessing the data, kindly do let us know if you will need to share this dataset with your team, as we will required signed data sharing agreements from them as well.

As discussed, there are some data quality concerns with a few of the survey questions you requested (CC_11, CC_57). While you could potentially verify some of the information from CC_11 through documents, it will be difficult for you to do so for CC_57 as you may not have access to reports on HMIS indicators.

Best regards,
Liz

From: Nana Mensah Abrampah <Nana.Mensah-Abrampah@lshtm.ac.uk>
Sent: Monday, March 29, 2021 8:42 PM
To: MORAN, Allisyn Carol <morana@who.int>; KATWAN, Elizabeth <katwane@who.int>
Cc: Debra Jackson <Debra.Jackson@lshtm.ac.uk>
Subject: Re: [EXT] Follow-up: Data request: 2018-2019 Global Reproductive, Maternal, Newborn, Child and Adolescent Health Policy Survey

Dear Allisyn –

Many thanks for sharing this good news. I look forward to hearing from Gerard tomorrow.

On the related indicators you highlight below, once I have a review of the data, I will come back to you to request for some of your time to learn about the overall approach taken for the maternal and newborn findings and see how best to use those findings to inform the stillbirth work.

Kind regards,
Nana

10.2 Annex 2 Global stillbirth policy review - LSHTM approval

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636
www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Ms Nana Afriyie Mensah Abrampah

LSHTM

6 October 2021

Dear Nana Afriyie ,

Study Title: Global policy review - stillbirth policy outcomes and implications ahead of the 2030 SDG agenda

LSHTM ethics ref: 26502

Thank you for your application for the above research, which has now been considered by the Observational Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

The committee are happy to give a favourable opinion assuming that the analyses proposed here enabled by WHO agreeing to give access to the survey data does not fall outside of that which the countries originally consented to. Please could you confirm this to RGIO.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Mensah-AbrampahNana CV_ May 2021	31/05/2021	1
Protocol / Proposal	Data validation guidance paper	21/08/2021	1
Protocol / Proposal	Global stillbirth policy review_overview	21/08/2021	1
Other	Research_Ethics_online_training_certificate	21/08/2021	1
Information Sheet	32f	29/08/2021	1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

[redacted]

Professor Jimmy Whitworth
Chair

10.3 Annex 3 Certificate of Research Ethics

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

This is to certify that

Nana Mensah Abrampah

successfully completed the

Research Ethics

e-learning course

with a score of

95.00 %

Comprising of modules covering:

- Introduction to the History of Research Ethics
- Fundamental Ethical Principles, including:
  - Respect for persons
  - Beneficence
  - Justice
- Responsibilities of Research Ethics Committees
- Understanding Vulnerability
- Privacy and Confidentiality

On

May 10, 2021

Provided by

London School of Hygiene & Tropical Medicine

This course meets the requirements for protection of human subjects training required by individuals involved in the design and/or conduct of National Institutes of Health (NIH) funded human subjects research.

10.4 Annex 4 Document review process for objective 1

- Step 1: Open the main folder with all available documents.

- Step 2: Review the excel sheet named Metadata_WHO_SRMNCAH_PolicySurvey_2018_2019_data.xlsx with the original survey responses provided by countries to the selected questions. This is the secondary data information collected by WHO.

- Step 3: Open the primary data collection sheet with the adjusted questions and familiarize yourself. This sheet is the one needing completion.

- Step 4: Open the link for the national documents to be reviewed. The national documents are grouped by WHO regional office categorization and then country listing.

- Step 5: For the adjusted questions in the primary data collection sheet, for each country, review all the national documents that are in English with the associated search words: still, stillbirth, still birth, fetal, foetus, fetus, foetal. The review of national documents will be conducted using the associated search terms. For example, once a national document is open, use the command: ctrl + f (for windows) or command + f (for Mac) to search the document using the search terms. Use the operational definitions captured below as a guide when reviewing the document.

- Step 6: Record the response in the appropriate cell following review of national level documents. Use the guidance provided before recording the response.

    - If stillbirth is identified as addressed per question in the national document, include 1 for yes in the excel sheet labeled adjusted_primary_data
    - If stillbirth is not specifically mentioned in national documents, enter 0 for no in the adjusted_primary_data sheet.
    - If no national document is available, place 99 in the cell.
    - If the national document is not in English, place 2 in the cell.

- Step 7: Under the folder “Documents relating to stillbirth specifically” add any national policy/plan/guideline/strategy that stillbirth is mentioned. Note: the folder is grouped by region.

Operational definitions

Area	*Definition*
Fetal death	*Fetal death is death of a fetus prior to its complete expulsion or extraction from a woman, irrespective of the duration of pregnancy.*
Antepartum fetal death	*Antepartum fetal death is a fetal death before the onset of labor. If vital status of the fetus at the onset of labor is unknown, consider it was antepartum if there is presence of signs of maceration at the time of delivery.*
Maceration	*Maceration describes the degenerative changes that occur in stillbirths retained in the utero after death, and the earliest signs are in the form of discoloration and peeling of the skin, leaving regions of raw tissue.*
Intrapartum fetal death	*Fetal death during labor. If vital status of the fetus at the onset of labor is unknown, consider it was intrapartum if there is fresh skin appearance or no signs of maceration at the time of delivery.*
Stillbirth	*Stillbirth is the complete expulsion or extraction from a woman of a fetus, following its death prior to the complete expulsion or extraction, at 22 or more completed weeks of gestation.*
Antepartum stillbirth	*Complete expulsion or extraction from a woman of a fetus following an antepartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more.*
Intrapartum stillbirth	*Complete expulsion or extraction from a woman of a fetus following an intrapartum fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500 grams or more.*

Fresh stillbirth	*Complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin showing no signs of maceration (fresh appearance).*
Macerated stillbirth	*Complete expulsion or extraction from a woman of a fetus following a fetal death at 22 or more completed weeks of gestation; or if gestational age is not available with a birth weight of 500g or more with skin showing signs of maceration.*

10.5 Annex 5 Ghana Health Service ethical approval letter for objective 1 and 2

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.

My Ref. GHS/RDD/ERC/Admin/App 120/391
Your Ref. No.

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Digital Address: GA-050-3303
Mob: +233-50-3539896
Tel: +233-302-681109
Email: ethics.research@ghsmail.org
28th July, 2022

Nana Afriyie Mensah Abrampah
London School of Hygiene and Tropical Medicine
38 Rue Antoine Carteret, Geneva Switzerland

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	**GHS-ERC: 025/07/22**
Study Title	Stillbirth Recording and Reporting: A Qualitative Study in the Ashanti Region of Ghana.
Approval Date	28th July, 2022
Expiry Date	27th July, 2023
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

- Submission of a yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

You are kindly advised to adhere to the national guidelines or protocols on the prevention of COVID -19.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

[redacted]
Dr. Cynthia Bannerman
(GHS-ERC Chairperson)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

10.6 Annex 6 LSHTM ethics approval letter for objective 2 and 3

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United Kingdom
Switchboard: +44 (0)20 7636 8636

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Observational / Interventions Research Ethics Committee

Ms Nana Afriyie Mensah Abrampah
LSHTM

24 November 2022

Dear Ms Nana Afriyie Mensah Abrampah

Study Title: Stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

LSHTM Ethics Ref: 28017

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Mensah-AbrampahNana CV_ May 2022	30/05/2022	1
Other	Research_Ethics_online_training_certificate	30/05/2022	1
Protocol / Proposal	Protocol	19/09/2022	1
Protocol / Proposal	Study questionnaire	19/09/2022	1
Protocol / Proposal	Zoom considerations	19/09/2022	1
Covering Letter	Cover letter Ethics Resubmission_docx	19/09/2022	1
Protocol / Proposal	Data Management Plan for Research Students	19/09/2022	2
Local Approval	Ghana Ethics Approval letter	27/09/2022	1
Information Sheet	Consent Form	06/11/2022	2
Information Sheet	Project information leaflet for regional and district health officers	06/11/2022	2
Information Sheet	Project _Information sheet for health facility workers	06/11/2022	2
Covering Letter	Cover letter Ethics Resubmission_Nov 2022_docx	06/11/2022	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

[redacted]

Professor David Leon and Professor Clare Gilbert
Co-Chairs

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

Improving health worldwide

10.7 Annex 7 Additional approval obtained from a regional referral hospital

In case of reply the number and the date of this letter should be quoted

My Ref. No: KSH/RESH- 50
Your Ref. No:
Tel. . 0507842165/0501297292
Fax :03220 35169

E-mail: rh.ar@ghsmail.org

GHANA HEALTH SERVICE
KUMASI SOUTH HOSPITAL
P. O. BOX 1908
KUMASI

17TH FEBRUARY, 2023

THE CHAIRPERSON
GHANA HEALTH SERVICE
ETHICS REVIEW COMMITTEE
ACCRA

RE: PERMISSION TO CONDUCT RESEARCH

This serves to formally inform you that the under mentioned student of London School of Hygiene and Tropical Medicine' has been granted permission by the Kumasi South Hospital to conduct the study.

Students Name: **Nana Afriyie Mensah Abrampah**

Title: **"Stillbirth Recording and Reporting: A Qualitative Study in the Ashanti Region of Ghana".**

Thank you.

[redacted]

GYAMFI YEBOAH
CHIEF HEALTH SERVICE ADMINISTRATOR
For: MEDICAL DIRECTOR

10.8 Annex 8 Semi-structured interview guide for the RHD/DHD

1. Regional Health Directorate

Theme 1: Background

1. Tell me about your current role in the Regional Health Directorate?
    Probe:
    - What does your job entail in relation to stillbirth or perinatal deaths?

Theme 2: Experience, perception, attitudes

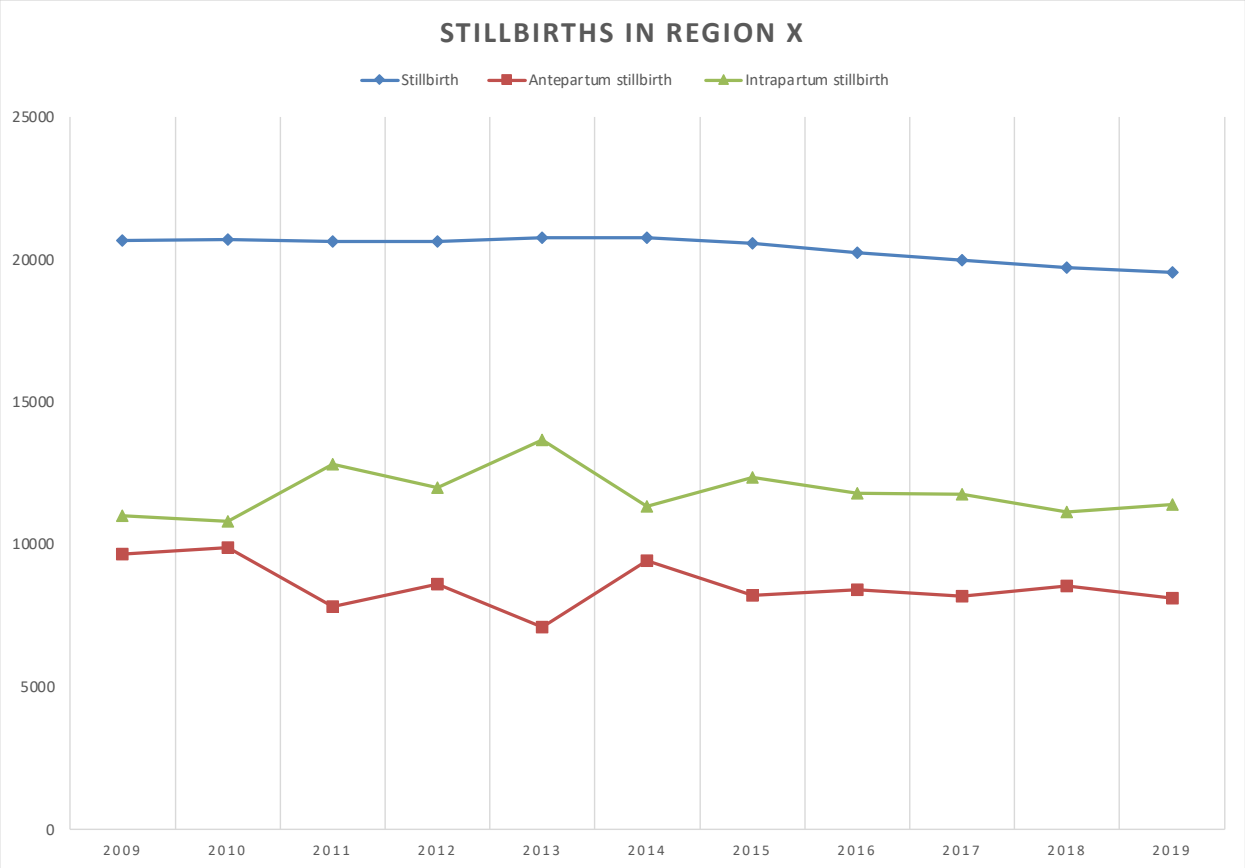
1. Could you please tell me what you understand about what a stillbirth is?
2. What is needed to prevent a stillbirth?
    Probe
    - Clinical knowledge and tools/equipment.
    - Why is it important to prevent stillbirths?

Theme 3: Stillbirth Data Collection/Recording and Use of Stillbirth Data

1. Could you tell me how does your region defines a stillbirth?
    Probe:
    a. Do you know if the definition varies by region in Ghana? Does it vary by district in the Ashanti Region?
2. How is data on stillbirths collected and reported?
    Probe:
    a. What available tools or reviews do you have to support tracking stillbirth rates in the region?
        Probe
        - Tell me about the templates or protocols or guidelines for reporting stillbirth in the region?
        - What about perinatal audits or integrated mechanisms with maternal mortality reviews or neonatal reviews? How often do these occur?

    b. Can you tell me about how the regional level is organized for data analysis, quality checks, interpretation, and use for stillbirths?
        Probe:
        - What is the process flow for stillbirth data? Who is involved? What is the communication and coordination between these individuals?
        - When stillbirth data is reported at the facility and district-level, how is the data transferred to the regional-level?
        - How is the data shared with the national level (Ghana Health Service or Ministry of Health)? What about other national agencies (e.g., national statistical office, CRVS stakeholders etc.?)
        - Do you give feedback to districts for improvement? Are there learning sessions held with the districts to understand the data and address gap areas? Is this individually with regions or jointly?
        - How are decisions made for funding allocation and programme allocation?

3. What functioning surveillance systems are there for monitoring the number of stillbirths in the region?
   Probe
   - Perinatal audit (MPDSR), Health Information Management Systems, District Health Information Software, civil registration and vital statistics, population surveys, others?
   - Does the data reported to these surveillance systems include an indicator on stillbirth?
4. Looking at this visual prompt of stillbirth measurement over a period, tell me what you see?



Theme 3: Leadership and support mechanisms

1. Does recording and reporting a stillbirth matter?
2. Are there formal mechanisms in place in the region for the district health directorate in reducing stillbirths?
   Probe
   - Do these mechanisms include recording and reporting stillbirth?
   - What about mentoring, supportive supervision, coaching and capacity building for stillbirths or perinatal health/child health or maternal health? How often do these occur?

- Do you know if women and community members are engaged in stillbirth education and awareness?

3. Can you tell me about the regional strategy/plan for Health? Does this include stillbirth reduction? What about improving stillbirth recording and reporting?
4. Is there funding allocated to improving maternal/ newborn health (and hence perinatal outcomes)?

   Probe

   - Stillbirth reduction at the regional level?
   - What about stillbirth recording and reporting?
   - Are you aware of any other available funding to improve stillbirth data and reporting infrastructure at the district-level?

5. Are there any improvement projects or initiatives at the regional level to reduce stillbirths, or include a focus on stillbirth?

   Probe

   - What about stillbirth recording and reporting?

2: District Health Directorate

The interview guide for the DHD is adapted from the RHD interview guide with the addition of one question, marked as new.

Theme 1: Background

1. Tell me about your current role in the District Health Directorate?

   Probe

   - What does your job entail in relation to stillbirth or perinatal deaths?

2. *New.* Can you tell me about how the district team is organized?

   Probe

   - How many DHD officers are assigned to the perinatal or child health? What about stillbirth? Does this include a focus stillbirth recording and reporting?

Theme 2: Experience, perception, attitudes

1. Could you please tell me what you understand about what a stillbirth is?
2. What is needed to prevent a stillbirth?

   Probe

   - Clinical knowledge and tools/equipment.
   - Why is it important to prevent stillbirths?

3. What is your perception of the leaderships' commitment toward prioritizing reducing stillbirths?

   Probe

   - District level and regional health directorate

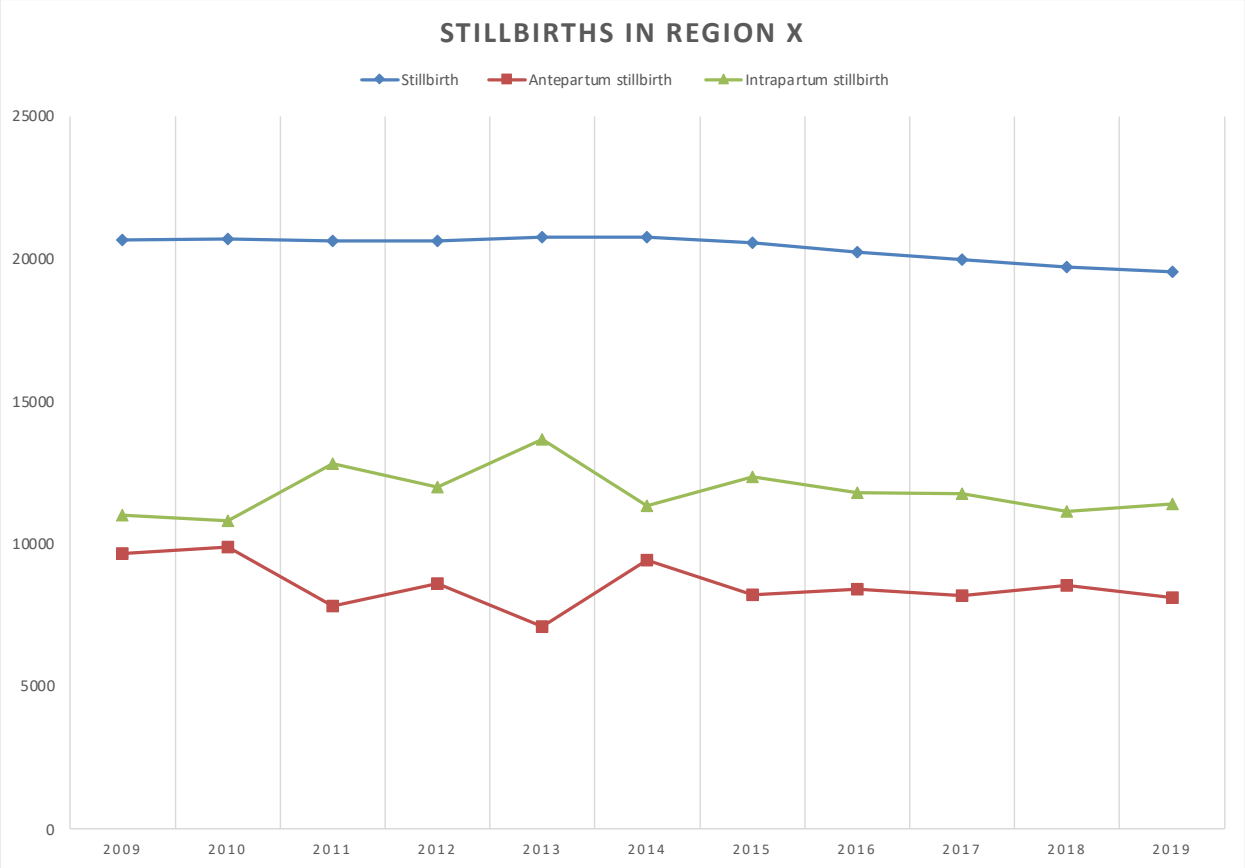
Theme 3: Stillbirth Data Collection/Recording and Use of Stillbirth Data

1. Could you tell me how does your district defines a stillbirth?

   Probe:

- Does it vary by district in the Ashanti Region?

2. How is data on stillbirths collected and reported?
   Probe:
   - What available tools or reviews do you have to support tracking stillbirth rates in health facilities in the district?
     Probe:
     - Tell me about the templates or protocols or guidelines for reporting stillbirth in the district?
     - What about perinatal audits or integrated mechanisms with maternal mortality reviews or neonatal reviews? How often do these occur?
   - Can you tell me about how the district level is organized for data analysis, quality checks, interpretation, and use for stillbirths?
     Probe:
     - What is the process flow for stillbirth data? Who is involved? What is the communication and coordination between these individuals?
     - When stillbirth data is reported at the facility level, how is the data transferred to the district-level?
     - How is the data shared with the regional health directorate?
     - Do you give feedback to facilities for improvement? Are there learning sessions held with the districts to understand the data and address gap areas? Is this individually with facilities or jointly across facilities?
     - How are decisions made for funding allocation and programme allocation?
3. What functioning surveillance systems are there for monitoring the number of stillbirths in the region?
   Probe:
   - Perinatal audit (MPDSR), Health Information Management Systems, District Health Information Software, civil registration and vital statistics, population surveys, others?
   - Does the data reported to these surveillance systems include an indicator on stillbirth?
4. Looking at this visual prompt of stillbirth measurement over a period, tell me what you see?



Theme 3: Leadership and support mechanisms

1. Does recording and reporting a stillbirth matter?
2. Are there formal mechanisms in place in the district for facility health workers in reducing stillbirths?

    Probe:

    - What about mentoring, supportive supervision, coaching and capacity building for stillbirths or perinatal health/child health or maternal health? How often do these occur?
    - Do these mechanisms include recording and reporting stillbirth?
    - Do you know if women and community members are engaged in stillbirth education and awareness?

6. Can you tell me about the regional or district strategy/plan for Health? Does this include stillbirth reduction? What about improving stillbirth recording and reporting?
7. Is there funding allocated to improving maternal/ newborn health (and hence perinatal outcomes)?

    Probe:

    - Stillbirth reduction at the regional or district level?
    - What about stillbirth recording and reporting?

- Are you aware of any other available funding to improve stillbirth data and reporting infrastructure at the district-level?

8. Are there any improvement projects or initiatives at the district level to reduce stillbirths, or include a focus on stillbirth?

   Probe

   - What about stillbirth recording and reporting?

10.9 Annex 9 Semi-structured interview guide for health facility workers

Health Facility

Theme 1: Background

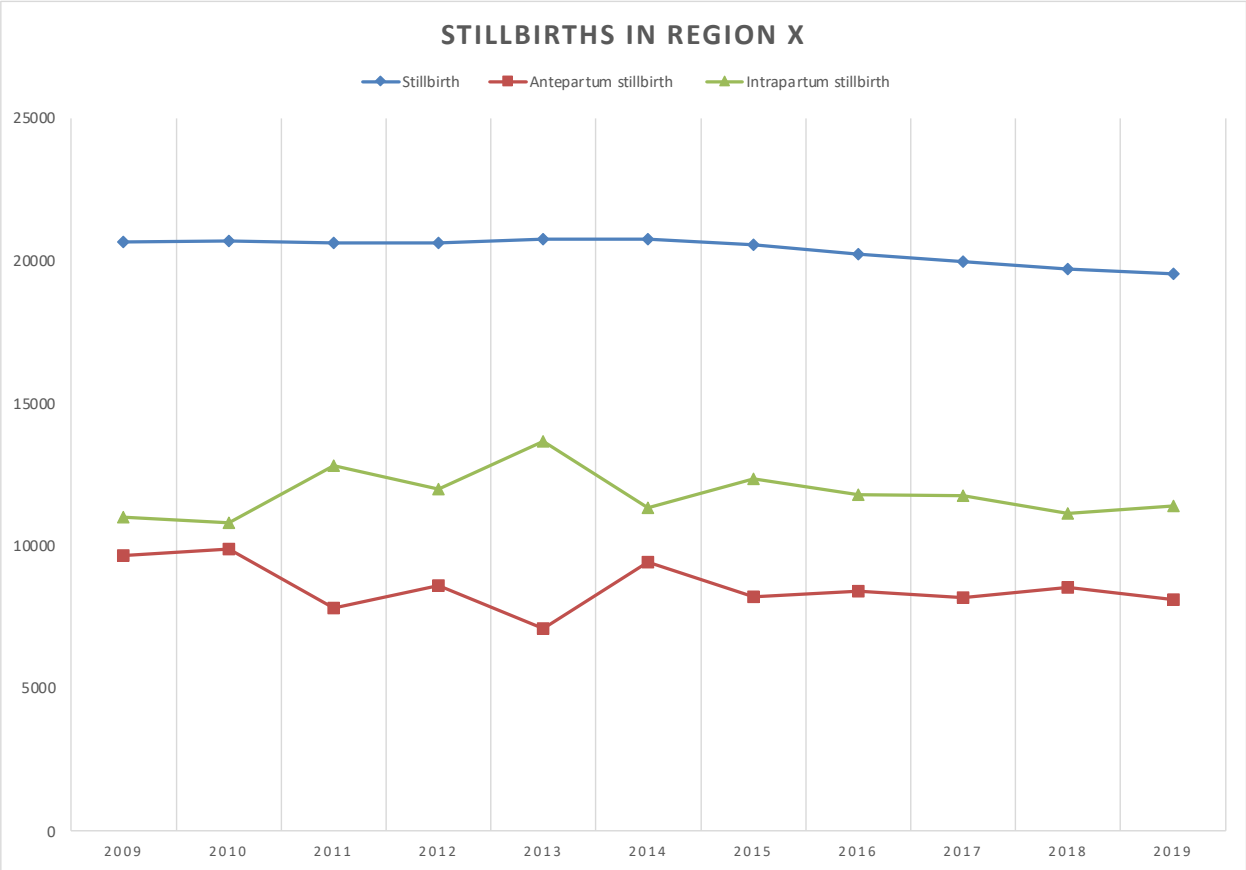
1. Tell me about your current role in relation to stillbirth or perinatal deaths?
2. What is your role in stillbirth recording and reporting?

Theme 2: Experience, perception, attitudes

1. Could you please tell me what you understand about what a stillbirth is?
2. What is needed to prevent a stillbirth?
   Probe
   - Clinical knowledge and tools/equipment.
   - Why is it important to prevent stillbirths?
3. Does recording and reporting a stillbirth matter? Why/why not?

Theme 3: Stillbirth data collection/recording and use of stillbirth data

1. Could you tell me how does your health facility defines a stillbirth?
   Probe:
   - Does this definition vary according to the health worker?
2. How is data on stillbirths collected and reported?
   Probe:
   - What is the process flow for recording and reporting a stillbirth? Who is involved? What is the communication and coordination between these individuals?
   - When stillbirth data is reported at the facility level, how is the data transferred to the district-level?
   - Do you receive feedback from the district level for improvement? Are there learning sessions held with health workers to understand the data and address gap areas? Is this at the facility-level or from the district-level?
   - How is data on stillbirth used at the facility-level?
3. What available tools or reviews do you have to support track stillbirth rates in the facility?
   Probe
   - Tell me about the templates or protocols or guidelines for reporting stillbirth in the facility?
   - What about perinatal audits or integrated mechanisms with maternal mortality reviews or neonatal reviews? How often do these occur?
   - Does this include an indicator on stillbirth?
4. Looking at this visual prompt of stillbirth measurement over a period, tell me what you see?



Theme 4: Leadership and support mechanisms

1. What is your perception of the facility-leaderships' commitment toward prioritizing reducing stillbirths?

   Probe

   - Could you tell me about the facility strategy/plan for Health? Does this include stillbirth reduction? What about improving stillbirth recording and reporting?
   - Is there funding allocated to stillbirth reduction at the facility-level? What about stillbirth recording and reporting?
   - Are there any improvement projects or initiatives at the facility- level to reduce stillbirths, or include a focus on stillbirth or stillbirth related areas? (maternal/newborn health)? What about stillbirth recording and reporting?

2. Are there resources or formal mechanisms in place in the facility to support facility health workers in reducing stillbirths?

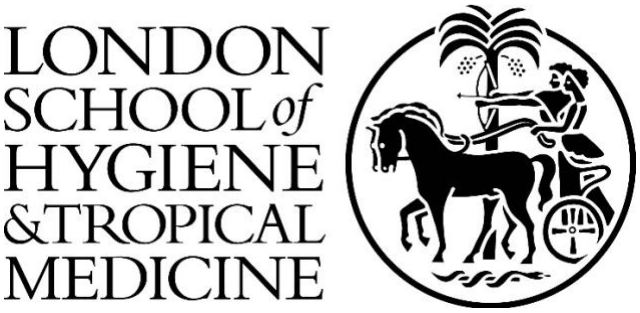
   Probe

   - What about mentoring, supportive supervision, coaching and capacity building for stillbirths or perinatal health/child health or maternal health? Do these include stillbirth reduction? How often do these occur?
   - Do these mechanisms include recording and reporting stillbirth?
   - Do you know if women and community members are engaged in stillbirth education and awareness?

Theme 5: Barriers

1. What are some of the challenges you have encountered with stillbirth reduction?
   Probe
   - What are the specific challenges related to stillbirth recording and reporting?
   - Have you tried any solutions to address these challenges encountered?
2. Could you tell me if you feel comfortable when recording and reporting a stillbirth?
   Probe
   - Why, why not?
   - Are you encouraged or discouraged to report it?

10.10 Annex 10 Data management plan



Data Management Plan for Research Students

Project title	**Counting the invisible: health systems factors influencing stillbirth measurement and reporting**
Author name	Nana A. Mensah Abrampah
Supervisor	Prof Debra Jackson
Contact email	nana.mensah-abrampah@lshtm.ac.uk
Date of last edit	1 January 2024

- **DESCRIBE YOUR RESEARCH**

1. What digital resources – data, code, collection tools, etc. - will you collect/obtain and use?

The three objectives of the study include – 1) Review the legislative environment in countries to understand stillbirths recording and reporting. 2) Understand stillbirth recording and reporting in the Ashanti Region of Ghana from the perspective of the district health management team (DHMT). 3) Gain insights into the practices and challenges related to stillbirth recording and reporting from the perspective of health workers in public health facilities in the Ashanti Region of Ghana.

Secondary and primary data for objective one will be retrieved from country responses to the 2018 – 2019 global WHO RMNCAH policy survey. Primary data for objective two and three will be collected by the researcher at the health facility and district-level using key-informant interview guides. Secondary data for objectives two and three will be informed by national RMNCAH policies/strategies documents in Ghana.

For objective two, 21 members of the RHD/DHD district level will be interviewed. For objective three, 32 health workers will be interviewed.

The digital resources required are STATA 16 and R for analyzing the quantitative data produced. NVivo 14, a protected computer with a recording function, and Microsoft Word document will be used for the thematic qualitative analysis for objective two and three.

2. What hardware and software will be used in your research?

Objective 1: STATA 16 for data collection and analysis. R for some visualization.
Objective 2: NVivo 14, a computer with embedded recording function and Microsoft Word for data collection and analysis.
Objective 3: NVivo, a computer with embedded recording function and Microsoft Word for data collection and analysis.

3. What data-related activities will be performed during the research?

Task		Description
Objective 1	Ethical clearance	Obtain ethical clearance.
	Data extraction and review	Review country responses and national documents.
	Data analysis and write-up	Analyze extracted data in STATA 16 and write-up findings. Develop visualization using R.
Objective 2 and 3	Develop protocols	Develop protocols for in-country study. Seek ethical clearance.
	In-country data collection	Collect primary data (interviews) and secondary data (national documents) at country-level.
	Data analysis	Analyze qualitative data using NVivo and Microsoft Word.
	Data write-up	Develop and write findings.

4. What quality checks will you perform to ensure resources are fit for purpose?

Internal quality control will be done by:

Objective 1 –

- The researcher is working with a team to review national documents. A document review guidance sheet (standardized data validation protocol) was developed to ensure consistency across all reviewers.

Objective 2 and 3 -

- Developing a standardized protocol (information leaflet, consent form and key informant interview guide) with clear instructions for consistency across all interviews.
- Taking multiple samples. i.e., obtaining multiple key informant interviews.

- Key informant interviews will be recorded and transcribed into Microsoft Word, a structured and purposive database will be established to capture input data.
- The information shared by health workers will be recorded verbatim to ensure true reflection of health worker perspectives. This will ensure data authenticity.
- All health workers will be assigned a unique ID during recording, transcriptions, and write-up.

5. How will you address ethical & legal issues within your research?

Detailed information on ethics is provided.

6. What documentation will be created to ensure resources can be understood?

Objective 1

- A standardized data validation protocol has been developed.

Objective 2 and 3:

- An information leaflet detailing the overview, objectives, risks, and benefits, alongside privacy and confidentiality of the study will be made available to facility health workers and district health officers.
- All facility health workers and district health officers who participate in the study will be requested to consent. To ensure that the selected language is understood at the facility and district-level, the researcher will work closely with a health worker from the selected country to simplify the language.
- An interview guide will be developed to ensure consistency of interviewing and capturing the information.

STORAGE AND SECURITY

7. Where will resources be stored at key stages of your research?

All data including capture, processing, analysis, and other stages, will be stored in the researcher's Sharepoint OneDrive, provided by LSHTM. This is a password protected drive linked to the student's email.

8. What labeling conventions will you apply to manage your resources?

Files will be saved using the naming convention: title of document, date of document (day, month and year), version of document (V1) and revision of version, if applicable (V1. R1).

For key informant interviews, original source documents will be labeled with the facility health worker or district health officer unique ID, facility-name and date of interview. For example: health worker 1_ABC hospital_ May 10 2021.

9. How will you keep data safe and secure? (choose one or more)

Only anonymised data will be used - personal, sensitive, or otherwise confidential data is not needed for the research	Yes	Store personal details in a separate secure location & link it via an identifier		Delete personal & confidential details at earliest opportunity (specify when below)	
Use digital storage that require a username/password or other security feature	Yes	Physical security (such as locked cabinet or room)		Protect portable devices using security features, e.g. biometric	Yes
Encrypt storage devices	Yes	Encrypt during transfer	Yes	Avoid cloud services located outside EU	Yes
Take 'Information Security Awareness training'		Ensure backups are also held securely	Yes		
Notes:					
Identify additional steps you will take to avoid, reduce, or eliminate risks that may affect your resources.					
No personal details that link any information back to a health worker will be collected.					

- **ARCHIVING & SHARING**

10. What resources should be kept as evidence of your research?

The resources that will be retained include data provided for the global policy review and anonymized key informant interview data.

All research protocols will be retained and shared with interested parties undertaking relevant research work. Outputs from the research will be published in open-access journals to ensure wide reach of research findings.

11. Where will these resources be hosted?

All files intended for sharing may be hosted in the LSHTM data repository. Internal and confidential files will be hosted on the LSHTM Secure Server.

12. When will the resources be made available? (choose one or more)

During the research life		At the same time as findings are published in an academic journal	Yes	A set time after research end, e.g. 12 months. Specify below	
Resources already available (provide details below)		On completion of my thesis		Other (provide details below)	
Further information / Other					

13. How will you make other researchers aware that the resources exist?

Publish a metadata record describing the resources in a repository or other catalogue		Obtain a Digital Object Identifier (DOI) or other permanent ID	Yes
Cite resources in future research papers, e.g. in the data access statement or reference list	Yes	Cite resources in project reports	Yes
Publish a description for the project website		Write and publish a Data Paper	
Add resources to a list of your academic outputs	Yes		
Other measures / Further details			
All papers from the thesis will be published in open-source peer-reviewed journals.			

14. What steps will you take to ensure resources are easy to analyze and use in future research? (choose one or more)

Prepare a codebook or other documentation that provides an accurate description of content		Store resources in open file formats such as CSV, Rich Text, etc. See https://www.ukdataservice.ac.uk/manage-data/format/recommended-formats	
Write a user guide that provides a high-level overview of research		Apply a standard license that allows a broad range of uses (e.g., Creative Commons, Open Data Commons)	Yes

Designate a corresponding author / data custodian who will handle data-related questions	Yes	Use domain-specific standards that make it easy to import and analyse data	
Other / Further information			

15. If resources can be made available, but not openly, what conditions on access/use must be met?

If resources are to be made available, the requestor will need to sign a data sharing form indicating that they will not share the original data publicly.

RESOURCING

16. What are the primary data management challenges in your research?

Uncertainty on data management practice and data security.

17. How can LSHTM & others help you to better manage your data?

Providing guidance on continued data management and data security.

10.11 Annex 11 Information leaflet for RHD/DHD and facility health workers

RHD/DHD

The Information Sheet provides information about the research for participants to make an informed decision of whether to participate in the study or not. It outlines the nature of the research, what the research involves, risks, benefits, compensation.

Title of Study: Stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

Introduction: My name is Nana Afriyie Mensah Abrampah. I am a PhD student at the London School of Hygiene and Tropical Medicine, and I am conducting the above study as principal investigator. My email address is nana.mensah-abrampah@lshtm.ac.uk.

Background and Purpose of research: Many women experience a stillbirth. Every 16 seconds, one stillbirth occurs. Three in four stillbirths occur in sub-Saharan Africa or Southern Asia. Though the burden is high, stillbirths are preventable with the right quality care provided by the health workers. Stillbirths can be fresh or macerated, with gestational age, birth weight and length providing an indication of whether a stillbirth has occurred. Stillbirths are often not counted or misclassified due to similarities with other fetal or neonatal deaths.

Better stillbirth measurement and reporting may help to provide reliable data on stillbirth. This in turn can increase investments and identify appropriate interventions to reduce stillbirths. The regional health directorate and district health officers play a role in improving stillbirth reporting as they attend to data emerging from the facility-level and other data sources at the district-level (civil registration and vital statistics, and population surveys). The district-level also serves as the link between the national and facility-levels for monitoring of priority health conditions. We want to understand stillbirth recording and reporting amongst the regional health directorate team and the district health management team. We are therefore doing a study to understand this.

Nature of research: You have been chosen to participate in this study because you are a regional health directorate representative in the Ashanti Region or district health officer working in [insert district name] responsible for management of health, monitoring and evaluation, surveillance or Reproductive, Maternal, Child and Adolescent Health (RMNCAH) within this district. District health officers with these responsibilities are being invited to participate. The total number of district health officers recruited for this study will be around 16 participants and all members of the regional health directorate leadership team.

The interview will include questions on experience, perception, and attitude of the regional health directorate (who oversee the district health management team), and the district health management teams on stillbirth recording and reporting. In addition, given that a key role of district health management teams is routine data collection, we will explore data use on stillbirth at the district level and available support mechanisms to facilitate stillbirth recording and reporting.

Duration /what is involved: The interview is optional. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. For you to take part, you must agree to participate in the study. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your standing in the region/district.

If you choose to take part, the interview will take 45 minutes to 1 hour. The interview will be done by the researcher online. If you agree to take part in the study, we will expect you to be available for the interview and to answer the questions posed by the researcher truthfully.

If you choose to take part, the interview will take 45 minutes to 1 hour. The interview will be done by a researcher over Zoom. Please see the attached Zoom privacy document for further information.

Potential Risks: If you choose to participate in the study, you will need to be available for one session for 45 minutes to 1 hour. Some people may find it difficult to find the time for this session. Other health workers may approach you and have queries about the study. Should you be approached, please do share this information leaflet or refer the health worker to the researcher.
Benefits: We cannot promise the study will help you but the information we get might help improve the measurement and reporting of stillbirths.

Costs and compensation: There will be no direct costs incurred or provided by participating in the study.

Confidentiality: If you join the study, some parts of data collected for the study will be looked at by authorized persons from the London School of Hygiene & Tropical Medicine. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the health center will have your name and address removed so that you cannot be recognized from it.

Information that identifies you will not be collected. Only demographic information, including health worker cadres, facility-type, and years in service will be collected. All information provided during the interview will be secured safely on a computer. All information collected from you will be kept confidential.

Voluntary participation/withdrawal: Participation is voluntary, and participants have the right to decline to participate and also withdraw from the study at any time without penalty and without having to give any reasons.

Outcome and Feedback: The researcher intends to write a report of the results and publish them in a scientific journal. The researcher will hold a virtual meeting over zoom to present the results of the study, which you will be invited to attend. You will not be identified in any report, publication or presentation.

Funding information: There is no funding agency for the study. The London School of Hygiene and Tropical Medicine, UK, is organizing this study.

Sharing of participants Information/Data: The principal investigator will have access to all the data.

Provision of Information and Consent for participants: A copy of the information sheet and consent form will be made available to you to sign if you agree to participate in the study.

Who to Contact for Further Clarification/Questions: If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions, please email nana.mensah-abrampah@lshtm.ac.uk . If you remain unhappy and wish to complain formally, you can do this through Debra.Jackson@lshtm.ac.uk or Nana Abena Apatu (ethics.research@ghsmail.org).

Health Facility

The Information Sheet provides information about the research for participants to make an informed decision of whether to participate in the study or not. It outlines the nature of the research, what the research involves, risks, benefits, compensation.

Title of Study: Stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana

Introduction: My name is Nana Afriyie Mensah Abrampah. I am a PhD student at the London School of Hygiene and Tropical Medicine, and I am conducting the above study as principal investigator. My email address is nana.mensah-abrampah@lshtm.ac.uk.

Background and Purpose of research: Many women experience a stillbirth. Every 16 seconds, one stillbirth occurs. Three in four stillbirths occur in sub-Saharan Africa or Southern Asia. Though the burden is high, stillbirths are preventable with the right quality care provided by the health workers. Stillbirths can be fresh or macerated, with gestational age, birth weight and length providing an indication of whether a stillbirth has occurred. Stillbirths are not counted or often misclassified due to similarities with other fetal or neonatal deaths.

Better stillbirth recording and reporting may help to provide reliable data on stillbirth. This in turn can increase investments and identify appropriate interventions to reduce stillbirths. Health

workers play a role in improving stillbirth reporting as they attend to the women pre, during and post- birth, and record stillbirths should they occur in the maternity or hospital registry. We want to understand stillbirth recording and reporting amongst health workers. We are therefore doing a study to understand this.

Nature of research: You have been chosen to participate in this study because you are a health worker working in [insert health facility name and district]. Midwives, physician assistants, medical officers and health information officers are being invited to participate. The total number of health workers recruited for this study will be 32 participants.

The interview will include questions on the experience, perception, and attitude of health workers on stillbirth recording and reporting. Further, we will also explore the support sources and barriers for health workers on stillbirth recording and reporting.

Duration /what is involved: The interview is optional. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. For you to take part, you must agree to participate in the study. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your standing at the health facility

If you choose to take part, the interview will take 30 minutes to 1 hour. The interview will be done by the researcher at the health facility or another convenient location for you. If you agree to take part in the study, we will expect you to be available for the interview and to answer the questions posed by the researcher truthfully.

Potential Risks: If you choose to participate in the study, you will need to be available for one session for 30 minutes to 1 hour. Some people may find it difficult to find the time for this session. Other health workers may approach you and have queries about the study. Should you be approached, please do share this information leaflet or refer the health worker to the researcher.
Benefits: We cannot promise the study will help you but the information we get might help improve the measurement and reporting of stillbirths.

Costs and compensation: There will be no direct costs incurred or provided by participating in the study.

Confidentiality: If you join the study, some parts of data collected for the study will be looked at by authorized persons from the London School of Hygiene & Tropical Medicine. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the health center will have your name and address removed so that you cannot be recognized from it.

Information that identifies you will not be collected. Only demographic information, including health worker cadres, facility-type, and years in service will be collected. All information provided during the interview will be secured safely on a computer. All information collected from you will be kept confidential.

Voluntary participation/withdrawal: Participation is voluntary, and participants have the right to decline to participate and also withdraw from the study at any time without penalty and without having to give any reasons.

Outcome and Feedback: The researcher intends to write a report of the results and publish them in a scientific journal. The researcher will hold a meeting in your health facility to present the results of the study, which you will be invited to attend. You will not be identified in any report, publication or presentation.

Funding information: There is no funding agency for the study. The London School of Hygiene and Tropical Medicine, UK, is organizing this study.

Sharing of participants Information/Data: The principal investigator will have access to all the data.

Provision of Information and Consent for participants: A copy of the information sheet and consent form will be made available to you to sign if you agree to participate in the study.

Who to Contact for Further Clarification/Questions: If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions, please email nana.mensah-abrampah@lshtm.ac.uk . If you remain unhappy and wish to complain formally, you can do this through Debra.Jackson@lshtm.ac.uk or Nana Abena Apatu (ethics.research@ghsmail.org)

10.12 Annex 12 Consent form

Title of Project: **Stillbirth recording and reporting: a qualitative study in the Ashanti Region of Ghana**

Name of researcher responsible for project: **Nana Afriyie Mensah Abrampah**

Statement	**Please initial or thumbprint each box**
I confirm that I have read and understood the information sheet dated……..for the above named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without my/the participant's legal rights being affected.	
I understand that relevant sections of my data collected during the study may be looked at by authorized individuals from LSHTM, where it is relevant to my/the participant's taking part in this research. I give permission for these individuals to have access to these records.	
I understand that data about/from me/the participant may be shared via a public data repository or by sharing directly with other researchers, and that I will not be identifiable from this information	
I agree to me/the participant taking part in the above-named study.	
I have read the foregoing information through the project information sheet, or it has been read to me in a language that I understand. I have had the opportunity to ask questions; and any question I have asked has been answered to my satisfaction. I consent voluntarily to participate in this study and understand that I have the right to withdraw from the study at any time without in any way, it affecting my further medical provision.	
I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and all questions satisfactorily explained to me in a language I understand English/Asante Twi. I fully understand the contents and any potential implications as well as my right to change my mind (i.e. withdraw from the research) even after I have signed this form. I voluntarily agree to be part of this research.	

Printed name of participant	Signature of participant (or thumbprint/mark if unable to sign)	Date

STATEMENT OF WITNESS

The participant/representative is unable to sign. As a witness, I confirm that all the information was given and the participant/representative consented to taking part.

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the language, he/she understood, English/ Asante Twi.

I confirm that he/she was given the opportunity to ask questions/seek clarifications and same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Printed name of witness	Signature	Date

INVESTIGATOR STATEMENT AND SIGNATURE

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed.

Printed name of person obtaining consent/researcher	Signature	Date

10.13 Annex 13 Zoom considerations for objective 2

Overview:

- To ensure the interviews do not come at a cost to the researcher and study participants, the interview will be held on voice over internet protocol, using Zoom.
- Ahead of the Zoom interview, the study participant is advised to ensure they are in a safe space where they feel comfortable to speak openly on the study topic.
- The researcher will use her personal school computer with all data stored on the LSHTM secured SharePoint drive, with password protection.
- The researcher is 2 hours ahead of the local time in Ghana. All interviews will be held at a suitable time for the study participant. Please inform the researcher of a suitable date and time.
- The risks associated with conducting the interview over Zoom is poor connectivity or the study participant not showing up. To mitigate these risks, you are asked to share your WhatsApp information, a voice over internet protocol which has end-to-end encryption. Further, you are asked to identify a primary and secondary date and time for the interview.
- There are no anticipated breaches of privacy or confidentiality. A privacy document is included to ensure confidentiality.
- A secure link to join the interview room in Zoom will be shared days ahead of the interview. A password will be required to join the Zoom room. The researcher will review all requests to join the interview zoom before approving any request.
- Informed consent is required. You can sign the consent form or agree verbally during the zoom interview. The researcher will ask if you consent before starting the interview process.
- A study leaflet is attached to provide a background of the study. Please read this document before consenting.
- If a participant withdraws from the study, the recording on Zoom will be deleted and an email sent to Zoom to permanently delete the record.
- All recordings, with approval from the participant will be saved on the LSHTM SharePoint drive and not on the Zoom platform.

Privacy considerations:

- For guidance on joining Zoom meeting: https://support.zoom.us/hc/en-us/articles/201362193
- Due to limited connectivity, video will only be used when bandwidth allows.
- Should you choose to use video, please follow the below guidance to start video or change your background, if needed:
    - Start video:
        - Click the Start Video button in the menu bar at the bottom of the window to begin your video stream.
        - Click the Stop Video button to stop sharing your video stream.
        - To choose a different webcam or adjust your video settings, click the up arrow to the right of the Video icon and select Video Settings
    - Change background:
        - Sign into the Zoom desktop client.
        - Select "Settings."
        - Select "Virtual Background."
        - Check "I have a green screen" (If you do not have a green screen, download the package for the virtual background when prompted).
- Follow the below commands to change your name:
    - To change your name after entering a Zoom meeting, click on the “Participants” button at the top of the Zoom window.
    - Next, hover your mouse over your name in the “Participants” list on the right side of the Zoom window. Click on “Rename”.
- Enter the name you would like to appear in the Zoom meeting and click on “OK”

10.14 Annex 14 Permissions to reproduce

From: **repository** repository@who.int
Subject: Re: [EXT] Request to include diagram in thesis: Health sector contributions towards improving the civil registration of births and deaths in low-income countries
Date: April 4, 2024 at 6:10 PM
To: Nana Mensah Abrampah Nana.Mensah-Abrampah@lshtm.ac.uk
Cc: MENSAH ABRAMPAH, Nana Afriyie abrampahmn@who.int

Dear Nana,

Thank you for your e-mail.

As you can see below the publication's copyright, you don't need permission to include the diagram you mentioned in your doctoral thesis. However, you do need to cite the source:

Health sector contributions towards improving the civil registration of births and deaths in low-income countries: guidance for health sector managers, civil registrars and development partners

ISBN (WHO) 978-92-4-002056-6 (electronic version)
ISBN (WHO) 978-92-4-002057-3 (print version)
ISBN (UNICEF) 978-92-806-5211-6

Suggested citation. Health sector contributions towards improving the civil registration of births and deaths in low-income countries: guidance for health sector managers, civil registrars and development partners. Geneva: World Health Organization and the United Nations Children's Fund (UNICEF), 2021. Licence: CC BY-NC-SA 3.0 IGO.

Best regards,

IRIS Team
Library & Digital Information Networks
World Health Organization
Geneva, Switzerland
Email: repository@who.int
Web: https://iris.who.int

From: **GFFsecretariat** gffsecretariat@worldbank.org
Subject: RE: Permission to include graph in thesis
Date: April 5, 2024 at 3:04 PM
To: Nana Mensah Abrampah Nana.Mensah-Abrampah@lshtm.ac.uk

***** This message originated outside LSHTM *****

Dear Nana,

Thank you for your email and checking with us. This is fine to include in your thesis.

Best of luck,

GFF Secretariat
W www.globalfinancingfacility.org
@theGFF

GLOBAL FINANCING FACILITY

WORLD BANK GROUP

From: Nana Mensah Abrampah <Nana.Mensah-Abrampah@lshtm.ac.uk>
Sent: Thursday, April 4, 2024 8:15 AM
To: GFFsecretariat <gffsecretariat@worldbank.org>
Subject: Permission to include graph in thesis

> You don't often get email from nana.mensah-abrampah@lshtm.ac.uk. Learn why this is important

[External]
Dear GFF secretariat –

Greetings. I am a final year PhD student at the London School of Hygiene and Tropical Medicine. I am finishing up my thesis on stillbirth measurement in Ghana, and would like to include the below data point from GFF on Ghana in my thesis.

I write to seek your permission to include the below diagram obtained from https://data.gffportal.org/country/ghana within the thesis. Proper citation including a note that the “image was reproduced with permission” will be included in the thesis.

I look forward to hearing from you.

Kind regards,
Nana

The End