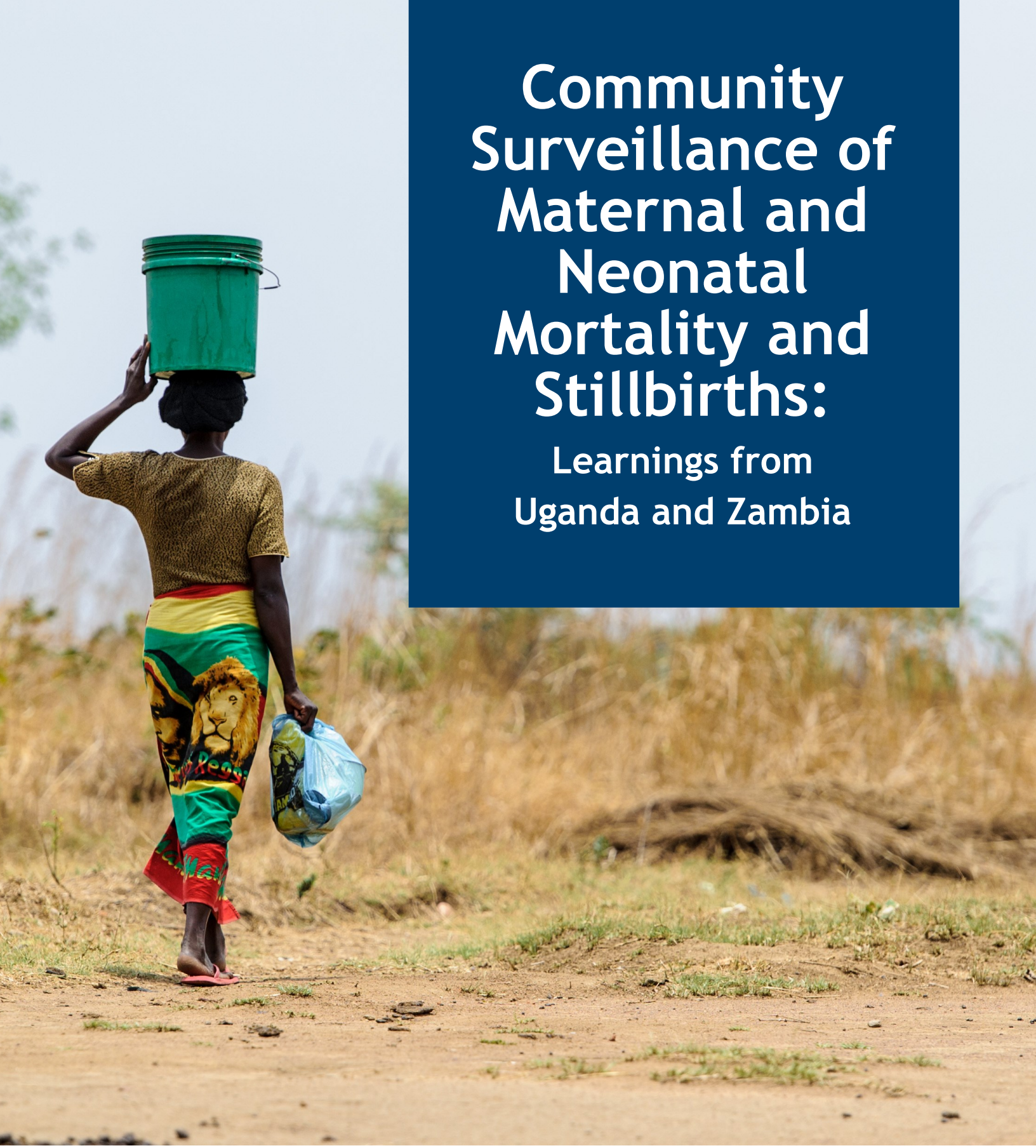
Community Surveillance of Maternal and Neonatal Mortality and Stillbirths:

Learnings from Uganda and Zambia



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Introduction

High-quality, routine data on maternal and neonatal mortality is critical to shaping effective interventions to reduce preventable deaths, but many countries lack a system for capturing information about deaths that occur outside of health facilities and are therefore lacking a complete picture of mortality. In Uganda and Zambia, the Ministries of Health (MOHs) and the Clinton Health Access Initiative Inc. (CHAI) worked together to sustainably strengthen systems for recording community-based maternal and neonatal deaths and stillbirths. In this document, we aim to share experiences and learnings from that work to provide a roadmap and recommendations for how such surveillance can be established in other settings.

Need for routine community mortality surveillance

The burden of maternal and neonatal mortality and stillbirths is unacceptably high. As of the last major tabulation of global statistics in 2017, about 295,000 women died during and following pregnancy and childbirth [1]. Sub-Saharan Africa alone accounted for roughly two-thirds (196,000) of maternal deaths, while the global maternal mortality ratio was estimated at 211 maternal deaths per 100,000 live births. The global neonatal mortality rate was 18 deaths per 1,000 live births, resulting in 2.5 million neonatal deaths, with Sub-Saharan Africa accounting for 41% of these deaths [2].

The scale of these death represents a large-scale human tragedy and cannot be fully addressed until they are properly understood. Having accurate data on how many, where and when maternal and neonatal deaths and stillbirths occur is critical to shaping policies and programs to prevent them. Mortality data systems can be used to trigger detailed reflection on the factors that lead to a specific death, such as through the Maternal and Perinatal Death Surveillance and Response (MPDSR) processes, to try to ensure the deaths are not repeated. Additionally, aggregate data over time can generate insights about trends and risk factors. While facility-based reporting systems are well-established in many countries, deaths occurring outside of facilities are typically not captured. In settings where a higher portion of births take place outside of health facilities, it is likely that an oversized proportion of maternal and neonatal deaths and stillbirths are also occurring outside of facilities. In a pooled analysis of data from 1990 to 2015 across 58 countries in Sub-Saharan Africa, 78% of births took place outside of health facilities [3]. Based on the most recent data in Uganda and Zambia, respectively, 31% and 21% of rural births took place outside of facilities [4,5].

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Various options exist outside of facility-based reporting systems to capture maternal and neonatal deaths across low- and middle-income countries (LMICs) [6,7]. The following summarizes commonly used approaches:

Demographic and Health Surveys (DHS) are the primary source for maternal and neonatal mortality rates in many LMICs. However, DHS data is only collected approximately every 5-7 years and the mortality estimates reflect the 5 years prior to the survey, so this does not represent an appropriate information source for constant monitoring and programming. Additionally, DHS surveys typically provide only national level mortality estimates, where some stakeholders may benefit from subnational detail to guide interventions and investment of resources.

Other household survey methodologies that are specifically aimed at measuring maternal mortality have been developed, such as the Reproductive Age Mortality Survey or the Sisterhood Method. Such surveys can capture detailed information, even including cause of death, but they are costly and only feasible to conduct periodically or in limited geographic areas.

Facility-based reporting systems, such as the Health Management Information System (HMIS), provide regular data, but typically only include deaths that occur in facilities. These systems allow for sub-national data analyses, but the data available is typically in a highly aggregated form. With appropriate systems to feed data into facilities, these systems may be expanded to capture community-based reporting.

Vital registration policies and processes may be instituted or strengthened. Vital registration often exists within facility-based health reporting systems, but community-based systems must be mobilized to ensure that accurate data on community events flow into the systems.

Modelling and analytical approaches to estimate deaths can also be useful but are only as accurate as the assumptions and inputs, and these approaches cannot provide detailed insights about factors leading to specific deaths.

Beginning in 2014, CHAI collaborated with the Nigerian Federal Ministry of Health to implement a 24-month maternal and newborn health program in Kaduna, Kano, and Katsina states [8]. The program worked to strengthen quality and availability of services and link each level of the health system, ensuring that no birth was overlooked or undervalued, no matter where it occurred. In order to catalyze program monitoring and improvement efforts, the program supported the three states to reactivate dormant or non-functional community-based health information systems, building on the role of traditional leaders. After CHAI successfully transitioned out of this work in Nigeria, the data systems were sustained under the leadership of State and Federal Governments. In 2018, CHAI began the work of adapting a similar model for reproductive health programming and community mortality surveillance strengthening in Zambia and Uganda.

Community health worker Angela Katito gives a health talk on nutrition to mothers in an open air space in Katete village, Zambia. Photo by Carol Milambo Mufana.

Approach in Zambia and Uganda

In 2018, CHAI and the MOHs in Uganda and Zambia began a partnership to implement an integrated Sexual Reproductive Maternal Newborn Health (SRMNH) program in selected sub-national geographies in Uganda and Zambia [9]. Establishing community mortality surveillance systems represented an important component of the program as an intervention to contribute towards identifying trends in and preventing deaths, and as an approach towards measuring program impact. Establishing more comprehensive community-based mortality reporting represented a priority for the Ugandan and Zambian Governments. After considering the options available, programs in both countries turned to a similar approach of mobilizing existing cadres of community-based volunteers to feed maternal and neonatal death reports into facility-based or other government-supported structures.

As shown in **Figure 1**, community mortality surveillance requires four basic steps: 1) recording the community death, 2) reporting that death to and review by facility, district or other higher-level officials, 3) tracking the deaths in a functional database, and 4) using the death data to learn and improve programming. The first of these steps is unique to community mortality surveillance – we must establish responsibilities, systems, and skills to ensure that deaths get recorded and reported into facilities. Then at other steps of the process, the focus is typically around how to integrate community deaths into existing systems that focus on facility-based deaths and reviewing whether those systems are functioning optimally.

The approach in each country was tailored to the context to ensure feasibility and sustainability. **Table 1** provides a high-level summary of the community mortality systems in Zambia and Uganda, and the case studies in this document describe each country's experience in detail.

Figure 1. Key process steps and essential components for community mortality surveillance

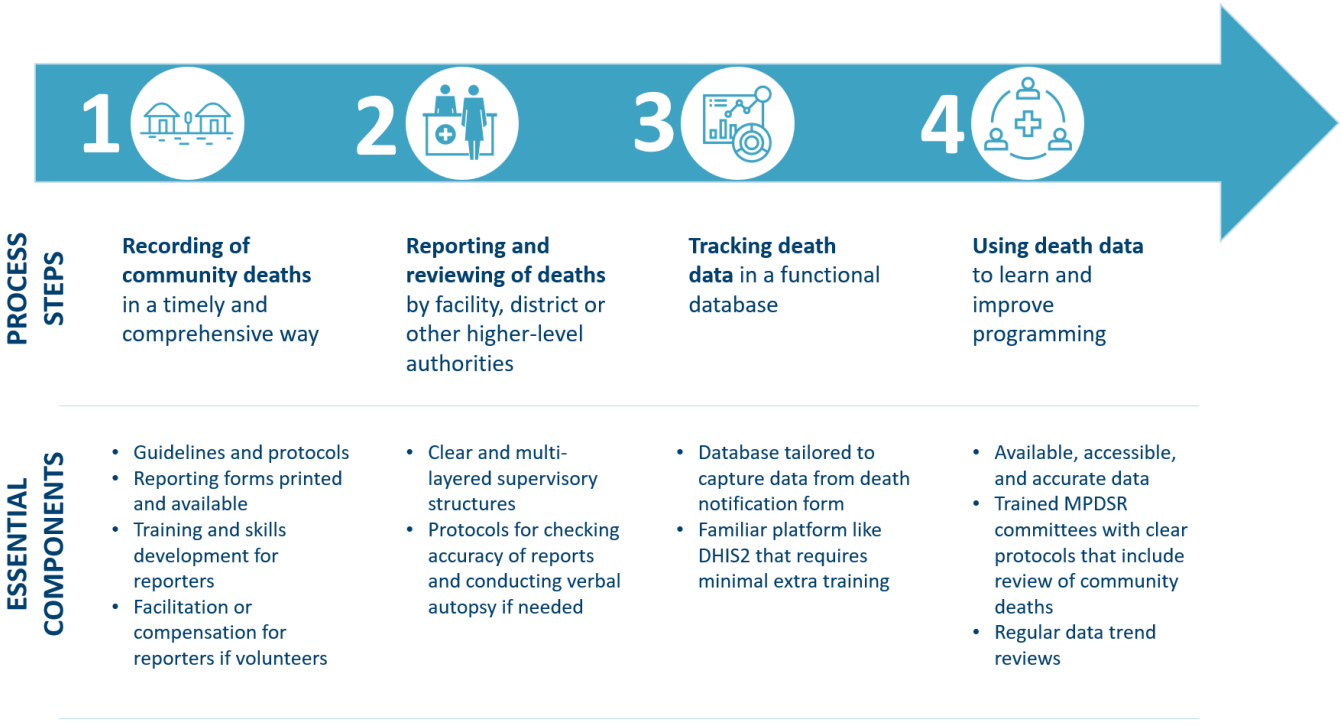

Table 1. Overview of community mortality systems in Zambia and Uganda

System dimension	Zambia	Uganda
Existing backbone the community mortality surveillance built on	In 2016, the government approved a training manual for Safe Motherhood Action Groups (SMAGs), which outlines how this group of volunteer community health workers should track maternal and neonatal deaths and other birth outcomes. However, at the time, no system or plans existed for SMAGs to report the information they tracked in for broader availability and use.	In 2017, the government issued MPDSR guidelines that laid out a process whereby maternal and perinatal deaths that happened in the community were meant to be officially notified and reviewed using a verbal autopsy process, but these protocols had not been functionalized in practice.
Individuals responsible for recording deaths	Safe Motherhood Action Groups (SMAGs) (community health volunteers focused on reproductive health)	Village Health Teams (VHTs) (community health volunteers focused on primary and preventive care)
Individuals responsible for supervision and higher-level reporting	Community Health Assistants affiliated with health facilities and other facility staff oversee SMAGs and receive reports, which are passed to District Health Information Officers for data entry.	Parish Coordinators and Health Assistants affiliated with health facilities oversee VHTs and receive reports, which are passed to District Biostatistician for data entry.
Scope of data in community mortality surveillance system	Reports include information on all births and maternal and neonatal deaths and stillbirths, regardless of where they occur, as well as information on ANC and community meeting attendance	Death notification registry tracks each maternal and neonatal death and stillbirth that occurs in the community Reports also track death data in aggregate form
Frequency and level of data reported	Monthly reports show the aggregate number of specified outcomes and data elements per facility catchment area.	Death notifications submitted on a rolling basis with detailed information about each death. Aggregated data is also submitted quarterly in the HMIS 097 form which captures community-based services.
Reporting and data use platform	DHIS2	DHIS2
Linkages with Maternal and Perinatal Death Surveillance and Response (MPDSR) systems	Health facility staff conduct verbal autopsies to gather more information on community deaths. District-level MPDSR committees review community-based maternal and perinatal deaths that occur in the district.	Health Assistants from facilities conduct verbal autopsies to gather more information on community deaths. Facility-level MPDSR committees review community-based maternal and perinatal deaths that occur in that facility's catchment area.

Recommendations for establishing community mortality surveillance

The following includes general recommendations and considerations for establishing community mortality surveillance based on experiences in Zambia and Uganda:

Build on existing system and structures. To ensure sustainability and efficiency, community mortality surveillance should be built off existing guidelines or policies and should work through existing structures and stakeholders. In developing plans for a community mortality surveillance, a first step should include an assessment of the strengths and gaps of existing mechanisms. This and all processes related to setting up a system should engage relevant MOH stakeholders to establish ownership from the outset.

Consider trade-offs between aggregate and detailed reporting. Reporting of aggregate data (showing the number and type of deaths that occur in a time period or catchment area) may be easier to maintain over time but is also more limited in its use and the ability to verify or cross-check data quality. On the other hand, more detailed reporting (including information about the cause and circumstances of death and contact information for individuals involved) provides a wealth of information for detailed reviews, but forms may be more difficult to complete. Challenges may emerge in data quality of the data in detailed death reporting forms or in sustaining reporting. Deciding which approach is appropriate will require careful consideration of the context and data needs.

Plan for long-term integration into facility-based reporting. HMIS reporting, whereby health facilities report monthly on services provided and key health outcomes, is well-established in most countries with clear forms, deadlines, and roles. It may require years to integrate a place for community-based reporting into these large-scale systems, since forms are only revised and printed periodically. And prior to form revisions, many governments will want to see that the community-based mechanisms to report deaths into facilities can be activated and operationalized. For these reasons, it may be necessary to establish a pilot surveillance system in a limited geographic area with some features that operate in parallel to HMIS (such as a separate electronic data capture system). But integration with HMIS is often an appropriate long-term goal to allow sustainability and scale.

Establish multi-layered supervisory systems. To cover large geographic areas and population, large numbers of primary reporters will be needed (such as community volunteers). But monitoring the quality and consistency of reporting from such a group will require groups of individuals at other levels of the health system to have well-defined roles in oversight and support. Mapping out and documenting these roles is critical.

Data accessibility is critical for enabling use. Dashboards and scorecards enabling data visualization and broad access are essential to encouraging use of data to inform programming. In the case of these programs, uptake and use of dashboards was not immediate – for some stakeholders, it took several years and multiple engagements to build comfort with and enthusiasm for the dashboards.

Way forward

Every single maternal and neonatal death and stillbirth is a personal and societal tragedy, but when these deaths are recorded in strong data systems that are linked to active learning platforms, they can contribute to efforts to target interventions to prevent future deaths. Routine mortality data is all too often only available for facility-based deaths, leaving a big blind spot with regard to community mortality. In order to make progress towards the Sustainable Development Goals, we must establish sustainable systems that capture community-based maternal and neonatal deaths and stillbirths and enable action to mitigate the factors that led to the deaths.

Strengthening community-based mortality tracking can also provide a foundation for other community -based data systems. When community-based volunteers and health workers are regularly making household visits and reporting into robust data systems that are routinely monitored, feedback loops are created involving the use of data for programmatic decisions and continual improvement in data quality. Community vaccine outreach, malaria treatment, and screening for non-communicable diseases are just a few examples of interventions that can be integrated with this type of mortality surveillance.

Acknowledgements and contacts

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Aniset Kamanga, CHAI Zambia SRMNH team (akamanga@clintonhealthaccess.org)

Micheal Lyazi, CHAI Uganda SRMNH team (mlyazi@clintonhealthaccess.org)

Margaret Prust, CHAI Analytics and Implementation Research Team (mprust@clintonhealthaccess.org)

Healthcare providers in front of Matumbo Rural Health Clinic in Shiwang'andu District, Zambia. Photo by Dominic Mukumbila.

References

1. Trends in maternal mortality: 2000 to 2017: estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division. Geneva: World Health Organization; 2019. Available from: https://www.unfpa.org/featured-publication/trends-maternal-mortality-2000-2017
2. Hug L, Alexander M, You D, Alkema L; UN Inter-agency Group for Child Mortality Estimation. National, regional, and global levels and trends in neonatal mortality between 1990 and 2017, with scenario-based projections to 2030: a systematic analysis [published correction appears in Lancet Glob Health. 2019 Sep;7(9):e1179]. Lancet Glob Health. 2019;7(6):e710-e720. doi:10.1016/S2214-109X(19)30163-9.
3. Doctor HV, Nkhana-Salimu S, Abdulsalam-Anibilowo M. Health facility delivery in sub-Saharan Africa: successes, challenges, and implications for the 2030 development agenda. BMC Public Health. 2018;18(1):765. Published 2018 Jun 19. doi:10.1186/s12889-018-5695-z.
4. Uganda Bureau of Statistics (UBOS) and ICF. 2018. Uganda Demographic and Health Survey 2016. Kampala, Uganda and Rockville, Maryland, USA: UBOS and ICF.
5. Zambia Statistics Agency, Ministry of Health (MOH) Zambia, and ICF. 2019. Zambia Demographic and Health Survey 2018. Lusaka, Zambia, and Rockville, Maryland, USA: Zambia Statistics Agency, Ministry of Health, and ICF.
6. Graham WJ, Ahmed S, Stanton C, Abou-Zahr C, Campbell OM. Measuring maternal mortality: an overview of opportunities and options for developing countries. BMC Med. 2008;6:12. Published 2008 May 26. doi:10.1186/1741-7015-6-12.
7. Mgawadere F, Kana T, van den Broek N. Measuring maternal mortality: a systematic review of methods used to obtain estimates of the maternal mortality ratio (MMR) in low- and middle-income countries [published correction appears in Br Med Bull. 2017 Jun 1;122(1):1]. Br Med Bull. 2017;121(1):121-134. doi:10.1093/bmb/ldw056.
8. Sloan NL, Storey A, Fasawe O, Yakubu J, McCrystal K, Wiwa O, et al. Advancing Survival in Nigeria: A Pre-post Evaluation of an Integrated Maternal and Neonatal Health Program. Matern Child Health J. 2018;22(7):986-997. doi:10.1007/s10995-018-2476-3.
9. Kamanga A, Ngosa L, Aladesanmi O, Zulu M, McCarthy E, Choba K, et al. (2022) Reducing maternal and neonatal mortality through integrated and sustainability-focused programming in Zambia. PLOS Glob Public Health 2(12): e0001162. https://doi.org/10.1371/journal.pgph.0001162.

Uganda

Community mortality surveillance case study

Context

In Uganda, CHAI and the Ministry of Health (MOH) partnered to implement an integrated Sexual Reproductive Maternal and Newborn Health (SRMNH) program in six districts across two of the most underperforming regions (Central 2 and Western) covering a total 100,000 births per year. The six target districts (Kagadi, Kakumiro, Kibaale, Kassanda, Mityana and Mubende) were drawn from a cluster of forty districts with the highest burden for neonatal mortality, unmet need for family planning (FP), and teenage pregnancy (**Figure 2**). Support was provided to all 131 public sector health facilities in these districts from January 2018 to December 2021.

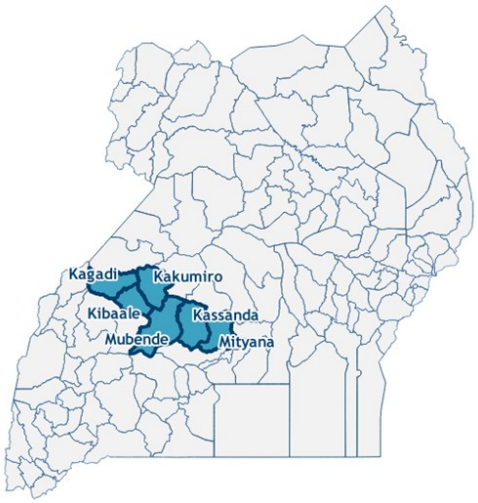

Figure 2. Map of six program-supported districts in Uganda

Policies, structures, and challenges existing prior to program

Nationally, the Government of Uganda (GOU) aims to strengthening and functionalizing mortality surveillance to enhance the country's capacity to detect, report promptly, and effectively respond to public health emergencies and priorities to reduce mortalities. But when this SRMNH program launched in 2018, there was no functional system to systematically report on deaths that occur in the community or during transport between facilities. Maternal and neonatal deaths and stillbirths that occur in health facilities were reliably tracked in the national Health Management Information System (HMIS), which is hosted on the DHIS2 platform. In 2017, the government issued Maternal and Perinatal Death Surveillance and Response (MPDSR) guidelines that laid out a process whereby maternal and perinatal deaths that happened in the community were meant to be officially notified and reviewed using a verbal autopsy process, but these protocols had not been functionalized. The GOU also had plans to move towards comprehensive registration of pregnancies, births, and deaths through national civil registration and vital statistics (CRVS) system but had limited resources available as of 2018 to advance this goal at a national scale.

In Uganda, there are volunteer community health workers called Village Health Teams (VHTs) that provide home visits and health management services to bridge the gap between communities and health facilities. At least one VHT is assigned to each village, and they are supervised by Parish Coordinators (PCs) that work at Health Center IIs (the lowest level health facility type). As VHTs conduct household visits to provide health education, they identify women who are pregnant or have a newborn and notify any deaths of WRA in the covered districts. This information is recorded in the VHT Register, which is the national register for community household and health data, and then summarized in the MOH HMIS 097 quarterly report which gets entered in DHIS2. However, VHT training across Uganda varies substantially and follow-up from the VHT supervisors is inconsistent, leading to variable quality and completeness in HMIS 097 reporting.

According to the 2017 MPDSR guidelines, VHTs were responsible for notifying PCs and Health Assistants (HAs) of any maternal or neonatal death or stillbirth in the community within 48 hours of the event using

the Community Death Notification Forms for Babies Born Dead or Newborn Deaths (0-28 days) and for Women of Reproductive Age (15-49 years). However, in practice notifications were inconsistently completed due to lack of training and accountability for VHTs. Deaths that were notified were not comprehensively available as a data source for understanding mortality trends. Notified WRA deaths were meant to receive screening and verbal autopsy by an HA to determine if it was a maternal death and capture other key information about the circumstances of the death, but HAs often lacked training and resources to complete these steps.

MPDSR guidelines indicated that MPDSR committees at each facility were meant to review deaths at that facility and in the community catchment area of the facility. However, many facilities did not have functional MPDSR committees, particularly at the primary health care level, due to lack of training, absence of forms, and limited accountability. Where these committees did exist, they typically did not review community deaths because the notification and verbal autopsy process that should have referred deaths to the MPDSR committees was not functioning.

Healthy mom and baby at Kasambya Health Center III, Uganda.

Table 2. Key stakeholders engaged in community mortality surveillance in Uganda

Stakeholder	Level	Number engaged in program districts	Role
Village Health Teams (VHTs)	Village	3,000	• Notify their supervising PCs and HAs within 48 hours of any stillbirth, neonatal death, or death of a woman of reproductive age (WRA) using standard government notification forms • Record community maternal deaths in the HMIS 097 form on a quarterly basis
Parish Coordinators (PCs)	Parish / Health Center II	502	• Provide direct supervision to VHTs • Ensure effective communication with HAs when a death occurs
Health Assistants (HAs)	Subcounty / Health Center III	124	• Verify and screen community WRA deaths within 7 days to determine whether it was a maternal death • In the case of community maternal deaths, conduct a verbal autopsy (VA) to collect information by the MPDSR committee
District Health Teams (DHTs)	District	6	• Conducts quarterly data reviews and audits to ensure accuracy of reported data. • Follow-up of actions from MPDSR team • Community engagement to prevent future death of similar nature
Reproductive and Infant Health Division	National	n/a	• Supervisory role, call for experience sharing from districts at national level, ensuring review and actioning of MPDSR recommendations for reported death

Approach

In the program-supported districts, the SRMNH program built on existing government systems and guidelines to establish a community mortality reporting. **Table 2** provides information about the key stakeholders engaged in this work in Uganda.

Improvements were made to strengthen surveillance practices across the data reporting and use pathway, and particularly in four steps of that pathway (introduced in Figure 1). The status of community mortality surveillance systems as of 2018 and following strengthening work is summarized in **Table 3.**

Recording of community deaths in a timely and comprehensive way: VHTs are the critical link between health facilities and the community, ensuring that referrals for health services and sensitization is conducted and deaths and other key outcomes are reported. The government of Uganda relies on partners to conduct VHT trainings, and therefore the status of VHTs across regions of the country can vary widely. CHAI supported training for over 3,000 VHTs. The training included basic VHT competencies, as well as a special module for mortality surveillance. (See VHT Training Participant Manual for more information about the training content). Because a lack of printed forms was a barrier to VHTs reporting deaths, CHAI also printed the Community Death Notification Forms. The forms were made available in triplicate to reduce the risk of forms getting lost in the reporting chain and these triplicate books were distributed to VHTs through HAs after training.

Reporting and reviewing of deaths by facility, district or other higher-level authorities: Once deaths are recorded, efforts were needed to ensure that the data was expeditiously reported to higher-level officials. From the triplicate reporting book, one copy of each death notification form was meant to stay with the VHT, and the other two copies were meant to go to the PC and HA. Initially, quarterly VHT meetings were held at the sub-county level as a chance to ensure that none of the death notification forms were missed for onward reporting and to review completeness of forms. To support meeting attendance, each VHT received a quarterly reimbursement of UGX 20,000 for transport and UGX 1,000 for airtime, in keeping with government policies on VHT mobilization. While these meetings were useful in the beginning to re-enforce training, they also caused some confusion on reporting timelines and process, and ultimately were not necessary or feasible during the COVID-19 lockdowns. After quarterly meetings were eliminated, the VHTs continued to receive a quarterly reimbursement of UGX 1,000 for airtime, which was distributed after each VHT submitted quarterly reports. In the context of COVID and without quarterly meetings, PCs and HAs were required to do more coordination of VHTs by phone, so PCs and HAs each received UGX 5,000 per month as an airtime reimbursement.

HAs were trained in their role in next conducting a verbal autopsy of those deaths. Initially, verbal autopsies required household visits, for which HAs received a UGX 30,000 transport reimbursement. During the COVID-19 pandemic, a shift was made towards phone-based verbal autopsies with family members, which made it more feasible for HAs to consistently carry out this step within the recommended seven days.

Tracking death data in a functional database: Data on community deaths was reviewed, cleaned, and ultimately appeared in several databases. No electronic system existed to retain data from death notification forms submitted by VHTs to HAs, so the program developed a DHIS2 database. HAs submitted the death notification forms to District Biostaticians for entry into DHIS2. The verbal autopsy summaries developed by HAs were submitted directly to the facility MPDSR committee. In order to encourage facility MPDSR committees to review community-based deaths, the government included a data element in the HMIS DHIS2 system for recording community death reviews. Finally, the VHTs were also asked to report aggregate community mortality data in the HMIS 097 forms. Data was regularly reviewed and triangulated across sources by the program team, and the follow-up process from these reviews served to reinforce training.

Using death data to learn and improve programming: Systems and processes for data use were strengthened as well. MPDSR committees are the most proximal forum for review and action on individual deaths, but the committees were not functioning well. The MPDSR committees were strengthened by establishing committees at all facilities, training members, and printing tools. District-level MPDSR committees were also trained to oversee the facility-level reviews. Once the committees were functional, they could also review community deaths based on the death notification and verbal autopsy information coming in from VHTs and HAs. Many MPDSR committees also began holding community dialogues to gather community perspectives on issues related to community maternal and perinatal deaths.

Table 3. Summary of community mortality surveillance status in Uganda

Surveillance step	Status and challenges prior to 2018	Status after surveillance strengthening
Recording of community deaths in a timely and comprehensive way	Guidelines requiring that Village Health Teams (VHTs) report deaths and death notification forms were approved by the government, but VHTs were often not trained and lacked forms.	• Over 3000 VHTs trained on mortality surveillance (as a part of general VHT training) • Death notification forms printed in triplicate books and distributed to VHTs
Reporting and reviewing of deaths by facility, district or other higher-level authorities	Guidelines existed for VHTs to report to Parish Coordinators (PCs) and Health Assistants (HAs), but this occurred inconsistently, and forms could get lost. HAs were meant to conduct verbal autopsies but lacked resources and training to do so.	• Triplicate books allowed for multiple copies of death notifications to be shared or retained, preventing data loss • Quarterly VHT meetings were initially held to ensure all deaths were recorded • Airtime reimbursements provided to VHTs, HAs, and PCs • HAs were trained in verbal autopsy and began conducting phone-based VA
Tracking death data in a functional database	No database existed for district level tracking of death notifications. VHTs were asked to report community maternal and neonatal deaths quarterly in the HMIS 097 form, but reporting was inconsistent.	• Database established in DHIS2 to capture death notification form data • Aggregated community death reporting in HMIS 097 was strengthened by training and availability of forms • Data cleaning and follow-up conducted at least monthly to address missing or inconsistent items; follow-up served to reinforce training and improve on-going submissions
Using death data to learn and improve programming	Because of the challenges with data quality and consistency, community mortality data was not reviewed regularly.	• Detailed death notification data available with permission through DHIS2 system • Improved death notification reporting led to more accurate aggregate death reporting in HMIS 097 • MPDSR system expanded to include community deaths as reported through surveillance

At a higher-level, the detailed death notification data was available to authorized individuals in the DHIS2 platform. Because DHIS2 is used by the government for HMIS data, the system was easy to navigate without additional training. Death notification data includes personally identifiable details about individuals, so the website was not made widely available, but individuals such as District Biostatisticians were authorized to use it to present trends to key audiences such as District Health Teams and triangulate data with other sources. Another key source of community mortality data is the HMIS 097 form, and that aggregate level reporting was enhanced by the improvements in the death notification reporting process and the triangulation of data from the detailed death notification form data.

Key challenges and learnings

This work faced a number of challenges and evolved to mitigate those challenges as described below:

Feasibility in scope of reporting: Initially the surveillance system in Uganda was established to capture all births and deaths but given the large populations and/or large geographic areas in some facility catchment areas, it was very difficult for VHTs to reliably report all births. A decision was taken in 2019 to shift to having VHTs report the deaths only. While they still were asked to follow all pregnant women, focusing on documentation and reporting for the deaths only allowed for higher data accuracy for that data. To calculate mortality rates, we used an estimated births values based on infant immunization data, which has near complete coverage in Uganda.

Reliance on VHTs for death reporting: VHTs do important work in Ugandan communities, but they are

Village Health Team (VHT) members in Kakumiro District, Uganda gathered following a training in September 2018.

volunteers with limited remuneration and training. This program provided compensation to VHTs to enhance accountability of engagement. While these incentives do present sustainability questions, this was in line with the way that the VHT cadre had been set up and mobilized in the past – large-scale change in the cadre, such as compensation by the public sector, would be needed to change the model. Even after training, there were data inconsistencies and missing items in their reporting; it took several years of individualized follow-up and coaching to improve the overall quality of data, which was time-intensive for the CHAI team. VHT attrition was also a challenge, though communities were able to select a replacement VHT and provide cascaded training from other VHTs.

Adjusting operations for the COVID-19 pandemic: Uganda was affected by particularly severe lockdowns during the COVID-19 pandemic with schools being closed for nearly two years and many other activities not permitted in that time. The initial implementation of this surveillance work involved in-person quarterly VHT meetings and in-person verbal autopsy of deaths, both of which became infeasible. While the quarterly VHT meetings were planned to ensure that all death notifications were collected and to verify data, we learned that having reporting options directly through HAs and through quarterly meetings actually caused some confusion. A move towards reliance on reporting through HAs, along with phone-based follow-up and verification was ultimately an improvement. HAs were also able to conduct verbal autopsies by phone to avoid travelling to households, which means that these verbal autopsies are more sustainable without outside resources for field visits.

Responding quickly to changing mortality trends: During the program period, there was an increase in maternal deaths in one district due to management and staffing challenges. The focus of this program on interrogation of routine data allowed for the change in mortality trends to be swiftly identified, investigated and mitigated. While the increase in maternal mortality was an undesirable outcome, it was a valuable test of role of the mortality surveillance system.

Sustainability and way forward

Since 2018, some important advances have been made at the national level towards increasing availability of community mortality data, but further investments will be needed to scale up the necessary structures nationally and maintain activities.

The VHTs are at the heart of efforts to record community-based deaths in Uganda because they are active in the community and aware of key health events among the population. VHTs are recognized by the government, but they are trained, provided with registers and forms, and reimbursed for their work only when an implementing partner is active in their district or for special government programs that require community outreach, such as immunization campaigns or bednet distribution. While the VHT HMIS 097 quarterly reporting is a national MOH requirement, the completeness of this data may vary depending on whether partners have provided support to VHTs such as printing the registers. In the aftermath of this program, facility staff have recognized the valuable role played by VHTs, and many facilities are choosing to allocate funding received by facilities from a World Bank Results-Based Financing (RBF) for VHT reimbursements for activities. These RBF funds can therefore serve to maintain the mobilization of VHTs in program districts. But it should be noted that in other districts where VHTs have not recently been trained by a partner, it may be difficult for facilities to use RBF funds to activate and train the cadre.

The policies and data infrastructure exist now for community mortality reporting. VHT death notifications trigger verbal autopsies and MPDSR reviews of community deaths. MPDSR committees at each facility are expected to report reviews of community-based deaths in the facility-based HMIS reporting, and VHTs report community deaths in the quarterly HMIS 097 form. These actions are made possible through strengthened capacity across stakeholder groups – from the VHTs that notify deaths, to the HAs that screen them, the district biostatisticians that manage and review data, and the MPDSR committees that prompt responsive action. This program provided a demonstration of what strong community mortality reporting can look like in Uganda, but in order to ensure death reporting and reviews occur in response to government policies, skills and abilities of individuals within the health system must be maintained in program districts and strengthened elsewhere.

A Village Health Team (VHT) member attends a meeting in Malangala, Uganda.

Zambia

Community mortality surveillance case study

Context

In Zambia, CHAI and the Ministry of Health partnered to implement an integrated Sexual Reproductive Maternal and Newborn Health (SRMNH) program in all twelve districts of Northern Province covering a total population of approximately 1.5 million with an estimated 64,000 births per year. Support was provided to 143 public sector health facilities in Northern Province (of approximately 180 as of 2018) from January 2018 through December 2021. Northern Province is a very rural province, so long distances, limited infrastructure, and sparsely distributed population meant that the barriers to quality of care seen across the other provinces are significantly amplified in this region. As a result of these factors, Northern Province was one of the poorest performing areas in Zambia on SRMNH related indicators.

Figure 3. Map of program-supported Northern Province, Zambia

Policies, structures, and challenges existing prior to program

As of 2018, births and deaths taking place at health facilities in Zambia were reliability reported monthly in HMIS using the DHIS2 platform. While the proportion of births taking place in health facilities was increasing at the time (from 67% in the 2014 Demographic and Health Survey [DHS] to 84% in the 2018 DHS), a view of the facility-based data only was certainly missing some births and deaths.

The Government of Zambia (GOZ) had taken some steps to lay the foundation for community-based tracking of mortality and birth outcomes. In 2016, the GOZ approved a training manual for Safe Motherhood Action Groups (SMAGs), which outlines how this group of volunteer community health workers should track maternal and neonatal deaths and other birth outcomes. Across Northern Province, SMAGs were already designated by many communities to act as community health volunteers with a specific focus on reproductive health. SMAG members work in the catchment areas of all health centers and health posts; there were 135 facilities at this level that were directly supported by the SRMNH program in Northern Province and the catchment area of those sites was divided into over 1,200 zones (30 to 90 households) with at least one SMAG member meant to be covering each zone. The SMAG are meant to conduct monthly household visits to identify and record information on women of reproductive age (WRA), 15-49 years, women who are pregnant or has a newborn, and any deaths. In some communities SMAG members had received some basic training to help them support mothers and provide referrals to facilities, though training levels varied. The 2016 SMAG training manual approved by the MOH included a Pregnancy Registry and a Birth Outcomes Registry that SMAGs were meant to populate in the course of their household visits to pregnant and post-partum women. But these registries were not being widely printed and made available to SMAGs, and no system existed for SMAGs to report the information they tracked in for broader availability and use.

A national Maternal and Perinatal Death Surveillance and Response (MPDSR) policy was in place, indicating that facility-level MPDSR

committees were meant to meet to review any deaths in the catchment area of that facility. District, provincial, and national MPDSR committees provide secondary review. But in practice, very few facility reviews were happening, especially for community deaths, due to lack of skills, forms, and accountability. But provinces did compile weekly surveillance reports on maternal and perinatal deaths. These reports included some community deaths if the health facility staff compiling the report happened to be aware of the death, but no process existed for systematically ensuring that all community deaths were reflected in the MPDSR weekly surveillance reports. While the MPDSR weekly surveillance report data was a valuable source of information, the data was only available on a limited basis in Word document summaries, but no robust electronic database existed.

Safe Motherhood Action Group (SMAG) members attending a quarterly meeting near Nsumbu Rural Health Centre in Chilubi District, Zambia.

Table 4. Key stakeholders engaged in community mortality surveillance in Zambia

Stakeholder	Level	Number engaged in program districts	Role
Safe Motherhood Action Groups (SMAGs)	Zone (within a health facility catchment area)	1,450	• Make visits to pregnant and post-partum women up to 42 days after delivery to share and collect information • Fill out Pregnancy and Birth Registries on an on-going basis • On a monthly basis, SMAGs from each facility meet to complete aggregate form for the facility • One SMAG from each facility is designated as the "Data SMAG" to lead the aggregation process
Community Health Assistants (CHAs)	Health facility (selected)	153	• Collect forms monthly from SMAGs and do basic quality checks (if no CHA exists at a facility, this is done by other facility staff)
Facility in-charges	Health facility	134	• Submit aggregate SMAG forms to the district at the same time as the monthly HMIS submission
District Health Information Officers (DHIOs)	District	12	• Receive and store paper-based aggregate SMAG forms and enter data electronically into DHIS2 • Regularly view data in dashboard to assess quality and trends
Senior Health Information Officer (SHIO)	Province	1	• Regularly view data in dashboard to assess quality and trends
Chief Safe Motherhood Officer	National	1	• Aggregates all provincial mortality data every week and coordinates the national SMAG program

Approach

In Northern Province, the SRMNH program built on existing government systems and guidelines to establish a community mortality reporting system. Table 4 provides information about the key stakeholders engaged in this work in Zambia.

With the Government of Zambia, CHAI worked to operationalize a system for data collected by SMAGs to be aggregated and reported for wider use in understanding the levels and community maternal and newborn mortality for purposes of program evaluation and broader programming and policy making. Improvements were made to strengthen surveillance practices across the data reporting and use pathway, and particularly in four steps of that pathway, which are described below and in Table 5.

Recording of community deaths in a timely and comprehensive way: The Pregnancy Registry and a Birth Outcomes Registry from the 2016 SMAG training manual were updated and pictures were added to improve understanding and use on the part of SMAGs with limited literacy. These tools were printed for regular use by SMAGs. SMAGs work in close collaboration with the health facilities to ensure that all newly identified expectant mothers are captured by the SMAGs upon confirmation of their pregnancy. SMAGs follow women who reside in the catchment area of their zone, regardless of where key events take place, so all births and deaths, occurring within the health facility and community level, are recorded by the SMAG in the Pregnancy Register and Birth Register.

Reporting and reviewing of deaths by facility, district or other higher-level authorities: While SMAGs are intended by the government to be available in every zone, this was not always the case due to turn-over and lack of updated training. 50% of zones in Northern Province were found to be without a trained SMAG, so general SMAG training was held to increase coverage. Every month, the SMAGs associated with each health facility gather to aggregate the data from the Pregnancy and Birth Outcomes Registry in the newly-developed Monthly Aggregate Form. Data are aggregated after the birth or adverse event has occurred (e.g., stillbirth or maternal death). Data aggregation is done under the supervision of the Data SMAG. Once the data has been aggregated, the zonal monthly aggregate forms are collected by the Community Health Assistant, where available, or Facility-In-Charges, for basic quality checks (e.g., making sure each field is complete), and the forms are submitted to the District Health Information Officers for data entry into the MNHSS DHIS2 database and review on the dashboards. On a quarterly basis, all SMAGs from each district also convened for a meeting, which served to review performance and data trends. SMAGs were reimbursed 80 ZMW for a transport and lunch allowance for each quarterly meeting, and they also received gumboots, raincoats, and bags at the outset of the program. Unlike in Uganda, these quarterly meetings were able to continue throughout the COVID-19 pandemic with precautions such as masking and outdoor meetings.

In addition to recording information in the Monthly Aggregate Forms on a monthly basis, more rapid reporting is needed in the case of a death to trigger action. Identification of suspected maternal, perinatal and late neonatal deaths in the communities is followed by immediate notification to the facility in charge within 48 hours. Following updated SMAG training, SMAGs are responsible for notifying the health facility in-charge within 48 hours of any deaths among women of reproductive age or infants occurring within the community. Community alert forms are filled in at the facility which will prompt healthcare worker to follow up. The health facility in-charge must physically verify the death and where it occurred within 7 days. Verbal autopsy is usually done within 4 to 6 weeks to allow for the mourning period of the community. Prior to the program, the community alert forms were not being used so follow-up efforts often fell through the cracks, and verbal autopsy was not consistently occurring. The health facility in-charge refers all probable deaths to be reviewed by the facility MPDSR Committee to identify cause of death and any other factors that may have contributed to that death. CHAI supported facilities to designate MPDSR committee members, provided training, and printed forms for MPDSR committees.

Tracking death data in a functional database: A web-based system for electronic data entry of monthly aggregate data was developed using the DHIS2 platform. Since this is the same platform used for HMIS data, stakeholders were already familiar with its functioning. Monthly Aggregate Forms were transmitted from SMAGs to CHAs and then to health facility in-charges. Health facility in-charges typically send their monthly HMIS forms to District Health Information Officers (DHIOs) to be entered electronically, and they began to include the SMAG Monthly Aggregate Forms in this process. DHIOs would then enter the data on a monthly basis. Meanwhile, in the case of a death, the health facility in-charge or his/her designee (a clinician cadre) also conducted a verbal autopsy to understand circumstances of death and possible medical causes of death. The data were reviewed by the Facility Committee, which reviews the verbal autopsy data and compiles recommendations and immediate actions to the district to prevent a similar death. Any deaths would also be included in MPDSR weekly surveillance reports submitted by the health facility in-charge to the provincial leadership.

Table 5. Summary of community mortality surveillance status in Zambia

Surveillance step	Status and challenges prior to 2018	Status after surveillance strengthening
Recording of community deaths in a timely and comprehensive way	Pregnancy and Birth Outcomes Registry forms for use by community health volunteers (Safe Motherhood Action Groups [SMAGs]) were approved but not widely printed or used.	• The Pregnancy and Birth Outcomes Registry forms were adjusted to include pictorial images for SMAGs with low literacy. Forms were printed and SMAGs were trained in their use.
Reporting and reviewing of deaths by facility, district or other higher-level authorities	No trained SMAG in ~50% of zones. No forms or process existed for SMAGs to report the data recorded in Pregnancy and Birth Outcomes Registry forms at any higher level.	• General training for SMAGs to increase coverage. A Monthly Aggregate Form was created such that a "Data SMAG" from each facility led a monthly process to aggregate all data from that facility. • Quarterly meetings of SMAGs at the district level with transport and lunch reimbursement provided.
Tracking death data in a functional database	No database existed for district level tracking of Pregnancy and Birth Outcomes Registry data. Some community maternal and perinatal deaths were reported in the MPDSR weekly surveillance reports, but reporting was inconsistent.	• A DHIS2-based platform was created to capture data coming from the SMAG Monthly Aggregate Forms. Data is entered by DHIOs.
Using death data to learn and improve programming	Because of the challenges with data quality and consistency, community mortality data was not reviewed regularly.	• Data is reviewed by CHAI, facility in-charges, and DHIOs to ensure completeness and accuracy. CHAI also supported monthly reviews of reporting rates and alignment of maternal death reporting across available data sources.

Using death data to learn and improve programming: Several mechanisms exist for data review and quality checks. Through each step of the reporting process, through Data SMAGs, to CHAs, health facility in-charges and DHIOs, each level of stakeholder is responsible for reviewing data and ensuring that it appears accurate and complete, especially with regard to deaths. Additionally, CHAI supported monthly reviews of data that focused on a) the percentage of zones and facilities reporting and b) the alignment of reporting of maternal deaths in the SMAG data, the HMIS, and the MPDSR weekly surveillance reports. If there were any data gaps or discrepancies, CHAI worked with the district health information officers and the maternal and child health coordinators to identify the issues using hard copy forms (e.g., Was it an aggregation problem? Was it due to submission of incomplete data?) and corrected as needed. In the DHIS2 system capturing SMAG monthly aggregate data, datasets and dashboards made it easy for stakeholder to review data and investigate trends. This data was presented to stakeholders in regular meetings.

Key challenges and learnings

This work faced a number of challenges and evolved to mitigate those challenges as described below:

Community coverage by SMAGs: Particularly at the beginning of the program, we found that only about 50% of zones had a trained, activated SMAG member. Throughout the program, SMAG coverage was an on-going challenge to a lesser degree. Even after training was provided at the start of the program, turn-over and other changes required that a small number of new SMAGs be trained in an on-going way. During the program, MOH officials saw the value of SMAGs and the impact that they can have in their communities, and districts are committed to maintaining and increasing coverage of trained SMAGs.

Population migration and movement: Throughout Zambia, it is common that if women are living away from their own family, they may travel back at the time of a birth. In Northern Province, we noted over the course of the program that a substantial number of maternal deaths occurring involved women residing in other provinces of Zambia or even in Tanzania.

Pregnant women travelling into an area may not be known to the local SMAG member and may therefore not be receiving the same level of outreach or have familiarity with the health facilities in the area. Efforts should be made to ensure that SMAGs and health facility resources are extended to all women, even if they are travelling outside of their place of formal residence.

Alignment and streamlining of multiple sources of death data: There are multiple ways in which maternal and perinatal deaths are tracked in Zambia, and each data source may have some weaknesses that could be strengthened by triangulation with other data. As of 2022, HMIS data now includes maternal deaths in the community and facility and perinatal deaths in the facility, which is an important expansion in reporting. The MPDSR weekly surveillance reports include community and facility maternal and perinatal deaths, and the 2021 MPDSR Guidelines require that district level staff conduct monthly checks to ensure alignment in the number of maternal and perinatal deaths reported in MPDSR weekly surveillance reports and HMIS.

Linkages with MPDSR audit process: The MPDSR committees are the more proximal and immediate forum in which the health system learns from and improves based on the circumstances that led to deaths. The program strengthened systems by which MPDSR committees are notified of community deaths and verbal autopsies provide information for MPDSR reviews. MPDSR committees were trained and provided with forms to facilitate meetings. These efforts go a long way in improving functionality of the MPDSR system, but on-going challenges continue related to follow-up on MPDSR committee recommendations. Additionally, the MPDSR weekly surveillance reports are still maintained in Word and Excel files. An MPDSR electronic database in under development by the government but not yet functional, and this system only tracks deaths but does not provide a formal platform for tracking follow-up on recommendations.

Adjusting operations for the COVID-19 pandemic: Northern Province experienced lockdowns and several waves of COVID-19 cases. Throughout the COVID-19 pandemic, SMAGs generally continued to make household visits because SMAGs were considered essential workers, and their reporting continued as well. CHAI supported procurement of personal protective equipment for SMAGs and health care workers to allow them to do their work safely. Reporting of community-based health outcomes became even more critical during the pandemic period because there was a reduction in health-seeking behaviors at health facilities.

Sustainability and way forward

In 2019, the former Republican President of Zambia, H.E. Dr. Edgar Chagwa Lungu made a declaration on maternal and perinatal deaths as a public health emergency in Zambia, demonstrating high-level political commitment to the wellbeing of mothers and newborns. To translate this declaration into policy and action and to ensure that avoidable maternal and perinatal deaths are prevented, strong systems are needed to conduct outreach to communities to referral clients for health services, record community deaths, and review deaths, taking action on factors that contributed to the deaths. This program provided a demonstration for how such systems can be established and scaled up nationally.

SMAGs are at the heart of community outreach, sensitization, and reporting. In Northern Province, the program period demonstrated how valuable SMAGs can be, and nearly all districts have now allocated government funds towards maintaining SMAG training, printing of registers, and other SMAG-related resource needs. At a national level, community mortality surveillance was prioritized by the government in the RMNHCAH costed roadmap. The SMAG reporting forms, including the Pregnancy and Birth Outcomes tracker

Community Health Assistant (CHA) providing community-based services and supervision of community volunteers in Chibombo District, Zambia. Photo by Carol Milambo Mufana.

Market near Makola Health Post in Mpulungu District, Zambia. Photo by Dominic Mukumbila.

and monthly aggregate form, and been adopted nationwide, and the government will need to continue to invest in maintaining the SMAG cadre as a strong asset to the health system.

As of 2021, reporting of community maternal deaths has been included in HMIS based in part on the experience of this program in showing the feasibility of this type of reporting. Data reported by SMAGs is now feeding into HMIS nationwide. With the addition of community maternal deaths in the HMIS system, the DHIS2 platform developed for this program is no longer in use, but that system was able to influence the current state of reporting. While community maternal deaths will be tracked in HMIS, community perinatal deaths are not yet included in HMIS, and this should be explored for the future with the data also coming from SMAGs. Other data included in the SMAG monthly aggregate forms also does not get reported up to an electronic database, but the facilities can review and use it at the local level.

Reporting of deaths without action and learning will not lead to change in health outcomes, so strong MPDSR processes are critical. In December 2020, the World Health Organization (WHO) supported a workshop for the MOH and partners to review the new MPDSR guidelines, and new guidelines have been disseminated beginning through a two-week training for key officials in each province. The new guidelines place greater emphasis on verbal autopsy and reviews of community deaths, which is enabled by stronger SMAG reporting systems to alert MPDSR committees to the deaths. Stronger MPDSR process has let to community mobilization and interventions that increase facility births. The new MPDSR guidelines also lay out a clear process for triangulation of data on maternal and perinatal deaths between MPDSR and HMIS records.

These management systems improvements have the potential for substantial and long-lasting impact on the factors that contribute to mortality. Continued investments are needed in training the individuals that support these systems and ensuring the availability of critical resources like registers.