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Developing Low-Literacy Tools for Community-Based Maternal and Perinatal Death Surveillance and Response in the Democratic Republic of Congo: A Mixed Methods Study

Meighan Mary

mmary@som.umaryland.edu

Johns Hopkins Center for Humanitarian Health

Christine Chimanuka Murhima'alika

Université Catholique de Bukavu

Christian Mugisho

Université Catholique de Bukavu

Nicole Mbula

Université Catholique de Bukavu

Pacifique Mwene-Batu

Université Catholique de Bukavu

Salomine Ekambi

Johns Hopkins Center for Humanitarian Health

Ghislain Bisimwa Balaluka

Université Catholique de Bukavu

Hannah Tappis

Johns Hopkins Center for Humanitarian Health

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Abstract

Background

Maternal and perinatal death surveillance and response (MPDSR) is a quality improvement system intended to provide a continuous process for identifying deaths, documenting and reviewing their causes and contributing factors, and implementing actions to prevent similar deaths. In settings where many births and deaths occur outside health facilities, community health workers (CHWs) often serve as the key implementors of community-based MPDSR. However, limited evidence is available on how mortality reporting tools can be adapted and evaluated for CHWs working in fragile and linguistically diverse settings.

Objective

To develop and evaluate an illustrated guide to support completion of the Democratic Republic of Congo's standardized community-based maternal and perinatal death notification form.

Methods

We conducted a sequential mixed-methods study. In Phase 1, cognitive interviews were conducted with 30 health providers and CHWs across 5 socio-culturally diverse provinces to assess face and content validity of the pictorial guide. In Phase 2, the guide was updated based on feedback and 20 CHWs in South Kivu province were trained and assessed on its use (performance and usability).

Results

Phase 1 results indicated that the pictorial guide as understandable, relevant, and useful, yet most individual images required revision. Phase 2 demonstrated high face and content validity after updates to the guide and moderate performance (77–79%) and usability (65%) scores, driven primarily by the technical content of the reporting form. CHWs reported high satisfaction and usefulness of the pictorial guide, but recommended reformatting into other illustrated tools (job aids and pictorial forms).

Conclusions

Findings suggest that illustrated tools may help address literacy, language, and comprehension barriers that can affect the quality of community-based death reporting. As such, illustrated reporting aids may represent a promising strategy for strengthening community engagement in MPDSR and improving the quality of mortality surveillance in diverse global contexts.

Background

Maternal and perinatal death surveillance and response (MPDSR) is intended to provide a continuous process for identifying deaths, documenting and reviewing their causes and contributing factors, and implementing actions to prevent similar deaths. In practice, however, implementation in many countries is hindered by underreporting, incomplete documentation, limited confidentiality and psychological safety, fear of blame, inadequate supervision, and insufficient resources to meaningfully address recommendations [1]. Gaps in identification and reporting of maternal and perinatal deaths are often most stark at the community level [2, 3], and challenges exacerbated in crisis-affected settings where health services may be disrupted, logistical constraints heightened, and trust in governance diminished [4, 5].

In settings where many births and deaths occur outside health facilities, community health workers (CHWs) may be the first, and sometimes only, link between households and government health information systems [2, 6]. Beyond their roles in health promotion, referral, and continuity of care, CHWs and other community-based actors can help identify pregnancies, follow-up on birth outcomes, and notify health systems of births and deaths that would otherwise remain undocumented. The reliability, completeness and accuracy of community-based reporting, however, varies considerably across settings [7]. Factors influencing CHW ability to perform vital health event surveillance functions include community trust, workload, supervision, and remuneration, as well as whether the procedures and tools they are expected to use are appropriate to their literacy level, training, community norms and working conditions [8–11].

The Democratic Republic of the Congo (DRC) provides poignant examples of the challenges, as well as positive impact potential of community-based maternal and perinatal death surveillance and response efforts [12–14]. As in many countries with high maternal and perinatal mortality burdens, the government has adopted MPDSR in national policy and outlined procedures for community-based surveillance [15]. However, implementation remains uneven. Our recent landscape analysis of surveillance and health information systems in crisis-affected areas of eastern DRC further showed that maternal and perinatal deaths are captured inconsistently across systems and that implementation is hindered by insufficient human and financial resources, unavailable tools, weak community–facility linkages, insecurity, and complex sociocultural dynamics that discourage reporting and review of deaths. Identified opportunities for strengthening MPDSR implementation included improved linkages between community and facility systems, developing guidelines on how to maintain minimum levels of implementation during periods of insecurity, and simplified tools for community actors [14].

In DRC, the main CHW cadre is Relais Communautaire (“Community Relay”, or RECO). RECO are volunteers, who are expected to conduct home visits to approximately 50 households per month, provide a minimum package of reproductive, maternal, newborn, and child health services and disease prevention, refer community members to health facilities and conduct community-based surveillance [16, 17]. Although RECOs are required to be literate, implementation research has documented the need

for training and job aids adapted for low-literacy users, and identified literacy, training, supervision, and access to practical support as important determinants of CHW performance [8, 18].

Despite the recognized importance of community-based maternal and perinatal death surveillance, limited evidence is available on how reporting tools can be adapted and evaluated for CHWs working in fragile and linguistically diverse settings. This study contributes to addressing that gap by developing and evaluating pictorial tools to support community-based reporting of maternal and perinatal deaths, including their validity across multiple linguistic settings and their usability among CHWs in rural eastern DRC.

Methods

We conducted a sequential mixed-methods study to develop and evaluate a pictorial guide to support use of the DRC Ministry of Health's (MoH) standardized community-based maternal and perinatal death notification form (available at: https://doi.org/10.6084/m9.figshare.32077818) by low literacy CHWs. Employing an iterative process, the pictorial guide was developed by the Johns Hopkins Center for Humanitarian Health and Université Catholique de Bukavu (UCB) School of Public Health research teams in collaboration with CLEAR Global illustrators. The pictorial guide was designed to support comprehension and accurate completion by CHWs with limited literacy. The pictorial guide was translated from French into four national languages of DRC (Kikongo, Lingala, Swahili, and Tshiluba) and employed images to explain each data element on the notification form, with minimal text.

The study comprised two phases: (1) cognitive interviews with maternal and neonatal health (MNH) care providers and CHWs to assess the face and content validity of the pictorial guide in August-December 2025, and (2) training on the use of the pictorial guide and standardized community-based reporting forms along with performance evaluations and a simple usability questionnaire to assess whether the pictorial guide would be acceptable and used effectively by CHWs in January – April 2026. The study was approved by the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health (IRB No. 33786) and the Ethics Committee of the Université Catholique de Bukavu (UCB/CIE/PB/012/2025) and was conducted in accordance with the principles of Declaration of Helsinki. Reporting of the study follows GRAMMS guidelines for mixed methods (checklist available at: https://doi.org/10.6084/m9.figshare.32077818).

Study setting

The first phase was carried out in five provinces selected to reflect the DRC’s linguistic and sociocultural diversity (Figure 1): Kinshasa (Lingala), Kongo Central (Kikongo), Kasaï (Tshiluba), and North Kivu and South Kivu (Swahili). One rural health zone with an active CHW program in each province was selected in collaboration with provincial health authorities: Kinkimi (Kinshasa), Kimpese (Kongo Central), Miabi (Kasai), Nyiragongo (North Kivu), and Nyantende (South Kivu). Within each selected health zone, three administrative health areas were randomly chosen, taking into account their accessibility for participant recruitment.

The second phase of the study was conducted in the rural Miti-Murhesa health zone (district), located in South Kivu province. This health zone was purposively selected as stakeholders had identified it as a priority area for future MPDSR implementation.

Study participants and sampling

Phase 1: Cognitive interviews

We used purposive sampling stratified by province and participant type to select cognitive interview participants. Within each of the five health zones, we selected three health areas and recruited one CHW and one nurse or midwife responsible for maternal and newborn health (MNH) services to participate in interviews. Eligibility criteria for nurses/midwives included at least two years of experience providing maternal or neonatal care in the selected health zone, as well as fluency in French and at least one study language (i.e., Kikongo, Lingala, Swahili, and Tshiluba). Eligibility criteria for CHWs included active engagement in CHW work during the last year, and fluency in at least one study language. We excluded MNH providers who did not reside in the study health zone and CHWs who were educated beyond secondary school, to focus on profiles representative of the target user population. In total, 30 in-depth interviews (IDIs) were conducted: six in-depth interviews per province comprising three MNH provider IDIs and three CHWs IDIs.

Phase 2: Usability assessment

We used purposive sampling stratified by educational attainment to recruit CHWs in Miti-Murhesa health zone. Eligible participants were active CHWs aged 18–49 years, fluent in Swahili or French, with educational attainment in one of two categories: partial primary education or completed primary education. CHWs with education beyond primary school were excluded. Overall, we recruited 20 participants, 10 per educational stratum. The estimated sample size was determined pragmatically based on time frame and resources available to the study, while seeking to minimize participant burden and ensure feasibility of data collection before launch of planned MPDSR efforts in Miti-Murhesa.

Data Collection

For each phase, data was collected by co-investigators at the UCB who completed research training in qualitative and quantitative methods, research ethics, and study-specific procedures prior to fieldwork.

Phase 1: Cognitive interviews

Cognitive interviews were conducted using a semi-structured interview guide (available at: https://doi.org/10.6084/m9.figshare.32077818). Each participant received the original community-based maternal and perinatal death reporting tool and the pictorial guide at least one day before the interview. During the interviews, participants evaluated the face and content validity of the pictorial guide. Interviews were conducted in French and/or the predominant local language, lasted approximately 60

minutes, and were audio-recorded. Written informed consent was obtained from all participants prior to their participation.

After analysis and interpretation of Phase 1 findings, the research team integrated participant feedback and updated the formatting and imagery of the pictorial guide in collaboration with CLEAR Global.

Phase 2: Usability assessment

For the usability assessment phase, CHWs underwent a one-day training session on the standardized reporting tool and the updated pictorial guide. Training included didactic sessions on community-based maternal and perinatal death reporting processes, review of standardized form and pictorial guide content, and practice completing forms with the assistance of the pictorial guide.

Following the training, each participant took part in practice cases of maternal or perinatal deaths simulated by co-investigators of the UCB research team. A total of six role play scenarios (3 maternal death and 3 perinatal death cases) were developed by the research team to reflect common cases of community-based maternal and perinatal mortality that occur in the DRC (available at: https://doi.org/10.6084/m9.figshare.32077818). Each CHW was randomly assigned to 3 of the 6 scenarios. Using the standardized scenarios, trained research team members portrayed family members reporting maternal or perinatal death cases, and CHWs were tasked with completing the MoH community-based death reporting form based on information provided during each simulation, with support of the pictorial guide, as needed. Performance was scored for accuracy in completing the reporting form against the reference standard, with one point awarded for each correctly completed item (maximum score: 17 points per maternal death scenario and 16 for perinatal death scenarios).

After completing the simulations, all participants completed a structured survey assessing usability of the pictorial guide. Surveys were administered by the research team using KoboCollect and lasted approximately 15 minutes.

Data Analysis

Phase 1: Cognitive interviews

Audio recordings were transcribed verbatim and, where necessary, translated into French. Transcripts were analyzed using Dedoose software (version 9.0). Thematic content analysis was conducted using a codebook developed *a priori* based on key validity constructs: relevance and clarity of the images, cultural appropriateness, comprehensiveness, and comprehensibility of the pictorial guide.

The relevance and clarity of key images were assessed using the Content Validity Index, a 4-point rating scale from 1 (not relevant / not clear) to 4 (highly relevant / very clear) [19]. The item-level content validity index (I-CVI) was calculated by dividing the number of participants who rated each item a 3 or 4 by the total number of participants. For the purpose of this study, items with an I-CVI ≥0.70 were considered acceptable and items with an I-CVI below 0.70 were redesigned.

Phase 2: Usability assessment

All statistical analyses were conducted using Stata version 18 (StataCorp, College Station, TX). Descriptive statistics were performed to assess CHW performance scores. For each CHW, the average scores for maternal death scenarios and perinatal death scenarios were calculated. Performance scores by scenario are also presented. Descriptive statistics were conducted to assess the usability, content validity, and perceived benefits of the pictorial guide, along with participants' satisfaction. Usability was measured by adapting the System Usability Scale [20]; participants responded to a series of 10 items using a 5-point Likert scale. Positively oriented questions were scored from 0 to 4 (strongly disagree to strongly agree) and negatively oriented questions were scored 0 to 4 (strongly agree to strongly disagree). Item level scores were summed and multiplied by 2.5 for a total usability score out of 100 points.

Differences in performance and usability scores by educational level (some primary vs graduate primary) were evaluated using chi-square (χ^2), Fisher's exact, and Mann-Whitney U tests, when appropriate. $P<0.05$ were considered statistically significant.

Results

Table 1 summarizes the study participants' characteristics. All Phase 1 participants (MNH providers and CHWs) had experience with maternal and neonatal health care and MPDSR. Most participants were female (60%) and had a secondary or graduate-level education (97%). In Phase 2, CHW participants (n = 20) had limited experience with maternal and newborn health (35%) and no prior exposure to MPDSR.

Table 1
Participant Characteristics

		Phase 1: Cognitive Interviews		Phase 2: Usability Assessment	Total (N = 50)
		Health providers (N = 15)	CHWs (N = 15)	CHWs (N = 20)	
Region	South Kivu	3	3	20	26
	North Kivu	3	3	0	6
	Kongo Central	3	3	0	6
	Kinshasa	3	3	0	6
	Kasai Oriental	3	3	0	6
Sex	Female	7	11	10	28
	Male	8	4	10	22
Education	None	0	0	0	0
	Primary	0	1	20	21
	Secondary	0	9	0	9
	University	15	5	0	20
Self-reported functional literacy	French	15	9	2	26
	Swahili	6	6	20	32
	Lingala	7	7	0	14
	Tshiluba	3	3	0	6
	Mashi	2	3	10	15
	Kikongo	6	4	0	10
	Kikumu	1	0	0	1
	Kihunde	1	0	0	1
	Kinande	1	0	0	1
	English	1	1	0	2
Experience providing maternal and perinatal healthcare		15	15	7	37
Previous experience with MPDSR		15	15	0	30

Phase 1: Cognitive Interview Findings:

Cognitive interviews with maternal and perinatal health providers and CHWs in five provinces provided actionable feedback to improve the face and content validity of the pictorial guide (Table 2). Overall, there was strong positive agreement across participants regarding the comprehensibility and comprehensiveness of the pictorial guide. Participants shared that the guide was easy to understand and well-designed with a clear and logical flow. Participants expressed satisfaction with the thorough explanations and comprehensive imagery to support completion of the MoH standardized reporting forms. However, the length of the guide was seen as a potential deterrent for implementation. Maternal and neonatal health providers and CHWs provided suggestions to further improve the imagery, emphasizing that images depicting administrative or geographic units (i.e., health zones and health areas) and the timing of perinatal death were hard to understand. They also suggested expanding upon the images depicting causes of deaths to show a wider range of maternal danger signs and complications.

Table 2
Face and Content Validity and Perceived Usefulness of the Pictorial Guide

Themes	Participant perspectives
Comprehensibility	***Health providers and CHWs*:** **• Participants shared that the guide was easy to understand, well-designed with clear and logical flow** **• However, participants reported imagery depicting geographic units (i.e., health zones, health areas, etc.) and the timing of perinatal death (in utero, during delivery, or after birth) were hard to understand** **• Most participants agreed that training must accompany the guide to maximize effectiveness**
Comprehensiveness	**Health providers and CHWs**: • Thorough explanations and imagery • Further expansion of imagery of maternal danger signs, complications, and/or cause of deaths suggested
Cultural appropriateness	**Health providers and CHWs**: • Strong agreement on the cultural relevance of the guide • Some suggestion on adaptions to images included: cultural adaptation to housing and clothing of depicted women • Acceptable translation quality but dialect used for translation was more complex and academic than vernacular spoken in local communities
Perceived usefulness	**Health providers**: Mixed views on usefulness • Images were a key accessibility feature, allowing those who struggle to read to still grasp the core messages around maternal death and community surveillance. • Sections requiring written responses may still be difficult for someone who cannot read or write. • Basic literacy is already a standard selection criterion for CHWs, so the guide is more useful for those who can read. **CHWs**: Strong agreement on usefulness • Images make the guide accessible to those with low literacy • Also useful for literate CHWs who could use images to explain the content to low literacy CHWs and community members responsible for responding to the questions
Anticipated challenges for CHW use	**Health providers and CHWs**: • Language accessibility: translate guide needs to be well adapted to the local vernacular

Themes	Participant perspectives
Comprehensibility	***Health providers and CHWs*:** **• Participants shared that the guide was easy to understand, well-designed with clear and logical flow** **• However, participants reported imagery depicting geographic units (i.e., health zones, health areas, etc.) and the timing of perinatal death (in utero, during delivery, or after birth) were hard to understand** **• Most participants agreed that training must accompany the guide to maximize effectiveness**
	• Some communities may be suspicious of data collection activities, assuming there is a hidden financial motive behind the process. • Length of the guide **Health providers**: • Production and distribution of multiple copies across community groups and health facilities. **CHWs**: • Vulnerability of paper documents to weather damage in the field
Recommendations	**Health providers and CHWs**: 1. Provide training on the guide for both CHWs and health providers so health facility staff can support CHW use. 2. Produce flipbook versions to facilitate exchange with community members 3. Adapt the guide into other local languages (e.g., Kikongo or Mashi) **Health providers**: 4. Introduce guides using peer mentoring: pairing weaker CHWs with stronger ones during fieldwork. **CHWs**: 5. Ensure distribution to every CHW 6. Offer financial motivation to encourage sustained engagement. 7. Laminate the guide to minimize weather damage in the field

Participants also agreed that the pictorial guide was culturally relevant. Overall, imagery accurately reflected the DRC context. Minor adaptations to imagery were suggested including modifying the clothing of women depicted in the guide and better distinguishing the housing and infrastructure found in urban and rural locations. In addition, translation of the guide into local languages (i.e., Kikongo,

Lingala, Swahili, and Tshiluba) was deemed adequate. However, participants highlighted that the dialect used for translation was more complex and academic than vernacular spoken in local communities.

The relevancy and clarity of key images was assessed using CVI scores (Table 3). Only one of 17 images scored > 0.70 (the image related to the question about the mother's marital status). For the most part, CVI scores were higher for CHWs compared to health providers. Lower scores reported by health providers were focused on the need of text to accompany the pictures, rather than the images themselves, contrary to the purpose of a pictorial guide developed for low literacy CHWs. Nonetheless, participants provided extensive feedback which was integrated into an updated version of the guide in advance of Phase 2.

Table 3
Content Validity Index (CVI) Scores of Key Images within the Pictorial Guide

Images for Questions in Reporting Form	I-CVI Score[a]			Image Revisions Based on Feedback
	Health providers (N = 15)	CHWs (N = 15)	Total (N = 30)	
Location: Urban/Rural	0.53	0.47	0.50	Cultural adaptations to housing to differentiate between urban, rural and geographic units
Geographical units: Health zone or health aire [b]	0.33	0.43	0.38	
Age of mother	0.40	0.53	0.47	Cultural adaptations to clothing of mother to better reflect differences in ages
Marital status of mother	0.60	0.87	0.73	No changes implemented
Mother's Occupation	0.53	0.57	0.55	Cultural adaptations to clothing of mother
Mother's education	0.33	0.53	0.43	Adaptation to school building images according to local context
Number of children	0.40	0.53	0.47	Reordering images of children from eldest to youngest
Number of pregnancies [b]	0.53	0.43	0.48	Reordering images of pregnant women and cultural adaptation to clothing
Age of pregnancy [b]	0.53	0.64	0.59	Cultural adaptations to clothing of mother
Antenatal care consultations	0.40	0.67	0.53	Change image to depict woman at ANC visit, instead of just health center building
Referral to health facility [b]	0.36	0.60	0.48	Adaptation to health building images according to local context
Date and time of death (maternal or perinatal) [b]	0.79	0.60	0.69	Change image to use local calendar (starts with Monday)
Probable cause of maternal death [b]	0.50	0.67	0.58	Cultural adaptations to clothing of mother, expansion of images to depict range of primary causes of maternal deaths
Probable cause of perinatal death [c]	0.27	0.67	0.44	Expansion of images to depict range of primary causes of perinatal deaths

Images for Questions in Reporting Form	I-CVI Score[a]			Image Revisions Based on Feedback
	Health providers (N = 15)	CHWs (N = 15)	Total (N = 30)	
Period of maternal death [b]	0.67	0.57	0.62	Change image to use local calendar (starts with Monday)
Period of perinatal death [d]	0.69	0.67	0.68	Change image to use local calendar (starts with Monday)
Location of maternal death [b]	0.60	0.53	0.57	Cultural adaptations to clothing of mother

[a] Content Validity Index (CVI) is a 4-point scale: 1: The image is not relevant and not clear, 2: The image is somewhat relevant and needs some revision, 3: The image is quite relevant and clear, and 4: The image is highly relevant and clear. The item level content validity index (I-CVI) score was computed as the proportion of MNH providers or CHWs rating each item 3 or 4. The I-CVI values range from 0 to 1; for this study we considered I-CVI ≥ 0.70 as acceptable and relevant and I-CVI < 0.70 as needing revision.

[b] N = 29; one participant did not provide clear answer during interview

[c] N = 28; two participants did not provide clear answer during interview

[d] N = 25; five participants did not provide clear answer during interview

Participants also shared their perspectives on the usefulness of the pictorial guide along with anticipated challenges and recommendations for implementation (Table 2). While CHWs strongly agreed on the guide's usefulness for low literacy actors, health providers had mixed views. Some health providers emphasized that the images were a key accessibility feature, allowing those who struggle to read to still grasp the core messages around mortality and community surveillance, while others shared that sections of the MoH reporting form that required written responses may still be difficult for someone who cannot read or write.

Key challenges anticipated in use of the guide included language accessibility, length of the guide, and community suspicion of data collection around death. Additionally, health providers warned of issues related to mass production and distribution and CHWs raised concerns about the vulnerability of paper documents in the field. To mitigate these potential issues, participants recommended training on the pictorial guide for both CHWs and health providers to ensure sustainability and ongoing support to the CHW workforce. Participants also recommended transforming the pictorial guide into a flipbook to facilitate exchange with community members. Health providers suggested introducing a peer mentoring system whereby CHWs are paired during fieldwork. Additionally, CHWs encouraged distribution of laminated guides to their entire workforce and financial motivation for sustained engagement. All participants recommended translating the guide into more local languages (e.g., Kikongo and Mashi) for larger reach in DRC.

Phase 2: Usability Assessment

Feedback from the cognitive interviews in Phase 1 were implemented to improve the pictorial guide in advance of Phase 2 (available at: https://doi.org/10.6084/m9.figshare.32077818). Testing on the updated pictorial guide yielded moderate performance scores (Table 4). Among 20 participants, the average score for simulated maternal death scenarios was 13.20 out of 17 (equivalent to 77.65%) compared to 12.65 out of 16 (79.06%) for perinatal death scenarios. Participants scored best on Scenario 2 (maternal death case) and Scenario 4 (perinatal death case). Overall, participants scored lowest on open-ended questions that required written responses to describe the death case. Performance scores did not statistically differ by education level (some primary vs. completed primary school).

Table 4
Average Performance Scores (N = 20)

Maternal death scenarios	**Total (N = 20)**
	13.20 (7.5–17); 77.65%
Perinatal death scenarios	12.65 (8–16); 79.06%
Scenario Scores	13.58 (9–17); 77.88%
Scenario 1 (maternal death)[a]	13.67 (7–17); 80.41%
Scenario 2 (maternal death)[b]	12.77 (8–16); 75.12%
Scenario 3 (maternal death)[c]	13.09 (7–16); 81.81%
Scenario 4 (perinatal death)[d]	12.00 (9–16); 75.00%
Scenario 5 (perinatal death)[e]	12.00 (9–16); 75.00%
Scenario 6 (perinatal death)[f]	
Notes: data reported as mean (range) of performance score; proportion out of total score (17 for maternal; 16 for perinatal)	
[a] *Scenario 1: randomly assigned to 12 participants*	
[b] *Scenario 2: randomly assigned to 9 participants*	
[c] *Scenario 3: randomly assigned to 13 participants*	
[d] *Scenario 4: randomly assigned to 11 participants*	
[e] *Scenario 5: randomly assigned to 7 participants*	
[f] *Scenario 6: randomly assigned to 8 participants*	

Participants in Phase 2 also completed a survey to assess their perceptions of usability, usefulness, and satisfaction with the pictorial guide as well as reassess content validity after modifications made in Phase 1. The pictorial guide scored moderate usability (65.38 out of 100; Table 5), driven by participant scores related to the technical content and formatting required by the MoH (i.e., study team was not authorized to alter the reporting form to include images on the form; only a separate pictorial guide was authorized). All participants agreed that they would use the guide frequently and that the information in the MoH form was well integrated into the guide. All participants also disagreed that the guide was unnecessarily complex and had inconsistencies. However, most participants reported that they would need the support of a technical person to be able to use the maternal and perinatal death reporting form and pictorial guide (60%), they would need to learn a lot before I could effectively use the maternal and perinatal death reporting form and pictorial guide (85%) and that the maternal and perinatal death reporting form and pictorial guide very cumbersome to use (95%). No statistically significant differences were found in usability scores by education level.

Nonetheless, results confirmed that the adaptations to the guide's imagery responded to prior feedback. All participants reported that the images clearly depicted the question in the reporting form and were relevant to their context. Users also reported high satisfaction (100%) and perceived usefulness of the pictorial guide (≥ 95%).

Table 5
User perceptions of updated pictorial guide (N = 20)

Average Usability Score	**Total (N = 20)**
	65.38 (50-72.5)
Components of Usability Score	
Proportion of participants reporting agree/strongly agree:	20 (100)
I would use the maternal and perinatal death reporting form and pictorial guide frequently	15 (75)
The maternal and perinatal death reporting form and pictorial guide was easy to use	20 (100)
The information in the maternal and perinatal death reporting form and pictorial guide well integrated	13 (65)
Most people would learn to use the maternal and perinatal death reporting form and pictorial guide quickly	17 (85)
I felt confident using the maternal and perinatal death reporting form and pictorial guide	
Proportion of participants reporting disagree/strongly disagree:	20 (100)
The maternal and perinatal death reporting form and pictorial guide was unnecessarily complex	8 (40)
I would need the support of a technical person to be able to use the maternal and perinatal death reporting form and pictorial guide	20 (100)
There was too much inconsistency in the maternal and perinatal death reporting form and pictorial guide.	1 (5)
The maternal and perinatal death reporting form and pictorial guide very cumbersome to use.	3 (15)
I needed to learn a lot before I could effectively use the maternal and perinatal death reporting form and pictorial guide.	
Content Validity of Images	
Images in the guide clearly depict the question in the reporting form[a]	20 (100)
Images in the guide relevant to your context[b]	20 (100)
Perceived Benefits of Pictorial Guide[c]	
Using the pictorial guide improved my understanding of the questions on the maternal and perinatal death reporting form.	19 (95)
The pictorial guide would improve the accuracy of data collected by RECOs with low literacy.	20 (100)

Average Usability Score	**Total (N = 20)**
	65.38 (50-72.5)
Using the pictorial guide would make it easier for RECOs to collect information on maternal and perinatal deaths in their communities.	20 (100)
Satisfaction[c]	
I am satisfied with the training I received on the pictorial guide and reporting form and pictorial guide.	20 (100)
I am satisfied with the pictorial guide.	20 (100)
Notes: Usability score reported as mean (range); remaining indicators reported as n(%) [a] Proportion of participants reporting 'clear' or 'very clear' [b] Proportion of participants reporting 'relevant' or 'very relevant' [c] Proportion of participants reporting 'agree' or 'strongly agree'	

Discussion

Our study contributes learning in an area where evidence has been limited: the development, validation, and adaptation of illustrated tools to assist low-literacy CHWs in maternal and perinatal death surveillance. Across five provinces, both CHWs and MNH providers generally regarded the pictorial guide as understandable, relevant, and useful. At the same time, content-validity testing showed that most individual images required revision, and CHW performance after training remained moderate. An important lesson from the cognitive interviewing phase is that visual meaning is item-specific and contextually interpreted. Only the marital-status image reached the prespecified acceptable I-CVI threshold, while images representing geographic units, timing of death, and probably causes of death required revision. This is consistent with research showing that locally developed and iteratively tested images are more readily understood than generic or imported pictograms and reinforces the importance of not only field-testing reporting tools and job aids to confirm contextual appropriateness, but of validating that the tool conveys the information intended [21, 22].

Results of usability testing in South Kivu suggest that the pictorial guide can help improve understanding of the government's standard community-based reporting forms, but completing written response fields may remain difficult for users with limited literacy. This is consistent with broader evidence that pictorial records can support health issue identification and documentation, but their effectiveness depends on complexity of response options, training, and support for implementation [21, 23]. Although approval to modify the standardized form was not obtained for this study, the findings provide evidence to support further advocacy efforts with the DRC MoH to facilitate the scale-up of community-based maternal and

perinatal death reporting through the use of the pictorial guide or a revised form incorporating simplified illustrated questions.

Interestingly, participants noted that the guide could be useful for facilitating discussions with bereaved families. A recent realist review on community engagement in MPDSR underscores the importance of visualizing information for community actors to allow for open discussion and critical reflection on death cases [3]. This suggests that community-based mortality surveillance in DRC could be strengthened by expanding the toolkit of CHW job aids to include both a family-facing pictorial discussion aid, as well as a simplified reporting interface with integrated images, simplified response options, and clear pathways for escalation of uncertain cases.

Participants' requests for additional training, peer mentoring, mass provision of illustrated tools, and lamination of materials to protect against weather damage point to implementation conditions that will shape whether adoption of the pictorial guide will have practical benefits, independent of further design changes. Similarly, participant concerns that communities might suspect a hidden financial motive behind data collection activities serve as a reminder that vital event surveillance is only useful to the extent that data collected is reviewed, informs actions to prevent future deaths, and actions are communicated or visible to the communities they are intended to serve [1, 5]. Evidence from a formative study in Eastern DRC reinforces this position and underscores the importance of culturally optimized MPDSR systems that account for socio-cultural interpretations and practices around death with active two-way community engagement and communication [24].

Our findings have important implications for strengthening community-based MPDSR in the DRC. The demonstrated face and content validity of the pictorial guide, together with its acceptability and usability among CHWs, suggests that illustrated tools may help address literacy, language, and comprehension barriers that can affect the quality of community-based death reporting. Additional implementation research is needed to pilot test the pictorial guide under routine programmatic conditions and across diverse geographic and linguistic contexts within the DRC to assess its impact on the completeness, accuracy, and timeliness of community-based maternal and perinatal death reporting. Transformation of the pictorial guide into job aids and illustrated reporting forms should also be undertaken with further testing. Such research would provide the evidence needed to guide policy decisions on the integration and scale-up of pictorial job aids to strengthen community-based mortality surveillance and ultimately support national efforts to reduce preventable maternal and perinatal deaths.

Several limitations should be noted when interpreting the findings from this study. First, while cognitive interviews were conducted within five socio-cultural and linguistically diverse provinces, the relatively small sample may have limited representativeness of the entire country. Similarly, the small sample size for Phase 2 testing was pragmatically driven and was not large enough to detect differences by subgroups nor be generalizable to the larger population. In our design, the performance evaluations were conducted shortly after training, which may have overestimated actual field performance due to the influence of recent instruction and supervised assessment conditions. Additionally, responses to the

cognitive interviews and usability questionnaires may have been subject to social desirability bias, with participants providing favorable responses because of their involvement in the study. Finally, because the pictorial guide was evaluated alongside the existing standardized community-based reporting form and the form itself could not be modified, the study was unable to determine whether performance and usability scores were attributable solely to the pictorial guide or whether further gains could be achieved through integration of pictorial elements into the reporting tool itself.

Conclusions

Our study provides a blueprint for the iterative development, validation, and adaptation of illustrated MPDSR reporting tools in resource-constrained settings. The positive validity, usability, and performance findings suggest that the pictorial guide can support CHWs in overcoming literacy and comprehension barriers associated with standardized reporting forms. As such, illustrated reporting aids may represent a promising strategy for strengthening community engagement in MPDSR and improving the quality of mortality surveillance in diverse global contexts.

Abbreviations

CHW	Community Health Workers
CVI	Content Validity Index
DRC	Democratic Republic of Congo
I-CVI	Item-level Content Validity Index
IDI	In-depth Interview
MNH	Maternal and neonatal health
MoH	Ministry of Health
MPDSR	Maternal and Perinatal Death Surveillance and Response
RECO	Relai Communautaire – “Community Relays”
UCB	Université Catholique de Bukavu

Declarations

*Ethics and consent:*The study was approved by the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health (IRB No. 33786) and the Ethics Committee of the Université Catholique de Bukavu (UCB/CIE/PB/012/2025). Written informed consent was obtained from all participants in advance of data collection.

Consent for publication: Not applicable.

*Data availability statement:*Quantitative data is available at: https://doi.org/10.6084/m9.figshare.32077818. Qualitative data is available from corresponding author upon signing of data sharing agreement.

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*Author Contributions:*Conceptualization: MM, CCM; Data Curation: MM, CCM, CM, NM; Formal analysis: MM, CCM, CM, NM, SE; Methodology: MM, CCM, PM, GBB, HT; Project administration: MM, CCM, PM, GBB, HT; Supervision: CCM, PM, GBB; Writing – original draft: MM, CCM, HT; Writing – review & editing: all authors.

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Figures

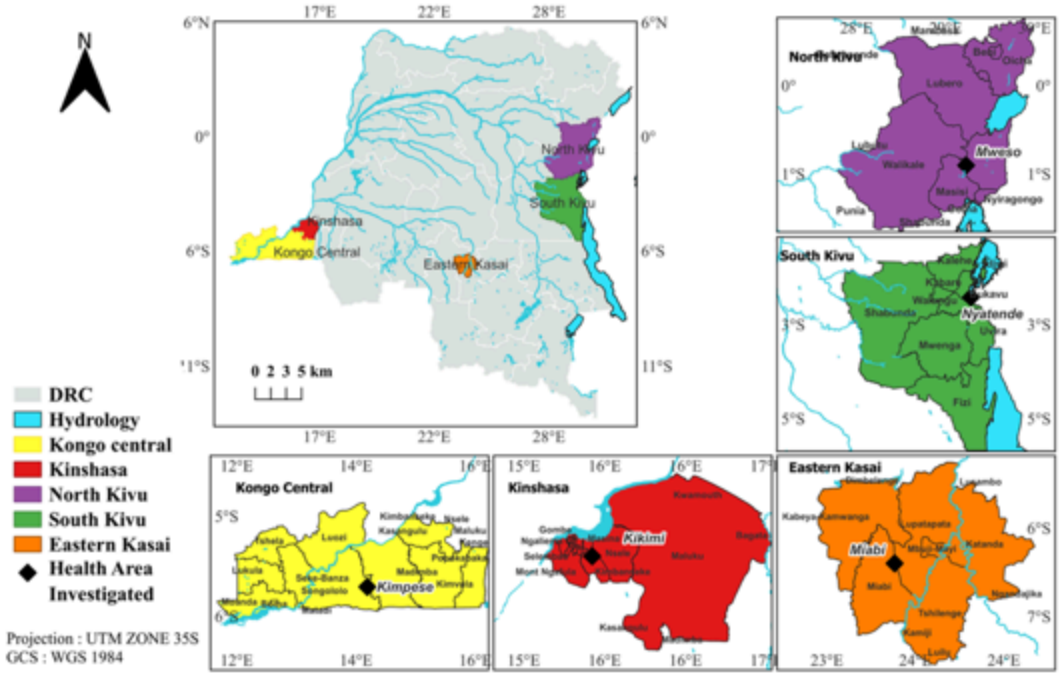

Figure 1

Map of Study Locations