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## Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance

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# Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance

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## Keywords

Mortality surveillance, death reporting, Ebola, EVD, outbreak, CRVS, Sierra Leone

## Abstract

**Objectives:** To understand the barriers contributing to the sharp decline in the number of deaths (of all causes) reported to a national tollfree telephone line (1-1-7) after the 2014-2016 Ebola outbreak ended in Sierra Leone and explore opportunities for improving routine death reporting as part of a nationwide mortality surveillance system.

**Design:** An exploratory qualitative assessment comprising 32 in-depth interviews. All interviews were audio-recorded, transcribed, and analysed using content analysis to identify themes.

**Setting:** Participants were selected from urban and rural communities in two districts that experienced varying levels of Ebola cases during the outbreak. All interviews were conducted in August 2017 in the post-Ebola-outbreak context in Sierra Leone when the Sierra Leone Ministry of Health and Sanitation was continuing to mandate reporting of all deaths.

**Participants:** Family members of deceased persons whose deaths were not reported to the 1-1-7 system.

**Results:** Death reporting barriers were driven by the lack of awareness to report all deaths, lack of services linked to reporting, negative experiences from the Ebola outbreak including prohibition of traditional burial rituals, perception that inevitable deaths do not need to be reported, and situations where prompt burials may be needed. Facilitators of future willingness to report deaths were largely influenced by the perceived communicability and severity of the disease, unexplained circumstances of the death that need investigation, and the potential to leverage existing death notification practices through local leaders.

**Conclusions:** The findings demonstrate the need to incentivize death reporting behaviours in a post-Ebola outbreak setting. Social mobilization and risk communication efforts may be needed to help the public understand the importance and benefits of sustained and ongoing death reporting. Localized practices for informal death notification through community leaders could be integrated into the formal reporting system to capture community-based deaths that may otherwise be missed.

## Article summary

### Strengths and limitations of this study

- This large qualitative assessment helps to explain the complex reasons for the sharp and persistent decline in death reporting levels in Sierra Leone following the 2014-2016 Ebola outbreak.
- The assessment generated novel understanding of barriers and facilitators related to death reporting with themes that may be transferrable to other post-Ebola-outbreak contexts.
- Given that mortality surveillance is a key approach for identifying existing and new public health threats, the findings can help inform strategies for engaging community members to improve death reporting level.
- It is possible that some respondents may have provided socially desirable responses in terms of facilitators to report in order to match previously heard messages during the Ebola outbreak.
- Other key stakeholders with relevant views on mortality surveillance (e.g. health workers and local officials) were not interviewed. Nevertheless, this assessment shed light on the perspectives of family members who failed to report the deaths of their loved ones as mandated by the Government.

## Introduction

A popular traditional healer in a remote village in Kailahun district in Sierra Leone became ill and suddenly died around April 30<sup>th</sup> 2014 after treating patients from neighbouring Guinea.<sup>1</sup> The Sierra Leone Ministry of Health and Sanitation (MoHS) subsequently confirmed an outbreak of Ebola Virus Disease (Ebola) on May 25<sup>th</sup> 2014, which was linked to the burial of the traditional healer in Kailahun district.<sup>2</sup> Ebola cases quickly spread to neighbouring Kenema district, making the Eastern region the initial epicentre of the outbreak in Sierra Leone.<sup>3</sup> The epicentre of the outbreak shifted from the Eastern region to the Western and Northern regions by September 2014. Over 14,000 people became infected in the country, of whom nearly 4,000 died by the time the outbreak was declared over in November 2015 by the World Health Organization (WHO).<sup>2</sup>

Traditional burials that involved various forms of physical contact with infected corpses were identified as core transmission amplifiers of the Ebolavirus.<sup>4</sup> It has been estimated that nearly three new Ebola cases resulted from every unsafe traditional burial during the outbreak in West Africa.<sup>4</sup> Containing the outbreak required prompt identification of all deaths to ensure safe burial by teams trained on Ebola infection prevention and control.<sup>5</sup> Social mobilization and risk communication efforts were implemented nationally and intensified in high-transmission districts to persuade communities to report all deaths to a national tollfree telephone line using a short dialling code, 1-1-7.<sup>6 7</sup>

Mortality surveillance is a key approach for identifying and responding to public health threats.<sup>8-11</sup> It is used to count the excess number of deaths due to an emerging health threat,<sup>12</sup> describe patterns in mortality occurrence,<sup>8 9</sup> and help to quantify causes of death in a population.<sup>11 13</sup> Mortality surveillance systems have an important role in routine surveillance<sup>8 9</sup> and in health emergency contexts such as during disease outbreaks.<sup>10 12</sup> <sup>14</sup> Death reporting through the 1-1-7 system constituted a critical component of identifying and responding to occurrences of deaths in communities to prevent unsafe traditional burials during the Ebola outbreak in Sierra Leone.<sup>14</sup>

Previous analyses of monthly reports of call volumes to the 1-1-7 system showed a substantial decline across all districts after announcing the end of the outbreak.<sup>14 15</sup> In the last year of the outbreak, the average number of deaths reported monthly to the 1-1-7 system fell from approximately 9,000 during January—October 2015, to 4,000 during the enhanced surveillance period (November 2015 to June 2016). The decline continued and reached less than 1,000 reported deaths per month in 2017.<sup>15</sup> A national telephone survey was conducted in April 2017 to investigate the motivations of those who continued to report deaths to the 1-1-7 system after Ebola outbreak ended.<sup>15</sup> Results from the survey showed that people who reported deaths were more motivated to do so when Ebola-like symptoms were present in the deceased. However, since the survey only

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3 targeted individuals who had reported a death, barriers related to reporting among those  
4 who failed to report to the 1-1-7 system were not understood. In this paper we examine  
5 death reporting barriers and explore opportunities for improving routine mortality  
6 surveillance in the aftermath of the Ebola outbreak in Sierra Leone. The study's findings  
7 can help inform mortality surveillance not only in Sierra Leone but also in other in post  
8 public health emergency settings.  
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## 11 12 **Methods**

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14 In-depth qualitative interviews were conducted with 32 purposefully selected individuals  
15 who experienced a death in their household in April-August 2017 but did not report the  
16 death to the 1-1-7 system as required by the MoHS. Interviews were conducted by trained  
17 native speakers in two districts, one urban: Western Area (n=16) and one rural: Kenema  
18 district (n=16). Audio-recordings of the interviews were transcribed and the textual data  
19 were analysed using qualitative content analysis.<sup>16</sup> COREQ guidelines are used to  
20 describe the methods of our qualitative exploratory assessment.<sup>17</sup>  
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## 24 25 **Setting**

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27 The initial purpose of the system when it was established in 2013 was to get feedback  
28 from communities on the government's Free Health Care Initiative that provides essential  
29 primary health care services at no-cost to children under five years old, pregnant women,  
30 and lactating mothers.<sup>18</sup> In August 2014, as Ebola cases began to surge, the Government  
31 repurposed the 1-1-7 line for communities to report suspected Ebola cases with a  
32 mandate that all deaths, even if not suspected of Ebola, must be reported for safe burial.<sup>14</sup>  
33 A national call center was set up for triaging the call alerts to district personnel who  
34 dispatched ambulance and burial teams.<sup>19</sup> Alpren et al. have comprehensively  
35 documented the implementation of the 1-1-7 system.<sup>14</sup>  
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41 The normalization of death reporting in Sierra Leone during the Ebola outbreak presented  
42 a unique opportunity for the country to leverage the 1-1-7 system as a foundation for  
43 strengthening civil registration of vital statistics (CRVS) in the post-outbreak context.  
44 CRVS is part of global efforts to register all births and deaths occurring in all countries.<sup>20</sup>  
45 The 2015-2024 global strategic plan for CRVS aims to have functional country systems  
46 to record all deaths so that the WHO International Classification of Disease and Injuries  
47 can be used to as "the global standard for classifying causes of death in a comparable  
48 manner over time and between populations."<sup>20</sup> Prior to the Ebola outbreak in Sierra  
49 Leone, deaths were supposed to be reported to the Office of Births and Deaths through  
50 its local district offices as per legal mandate established in the 1983 Births and Deaths  
51 Registration Act.<sup>21</sup> The pre-Ebola-outbreak death registration level remains unknown.  
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3 The paper-based CRVS death registration systems were never integrated with the digital  
4 platforms used in the 1-1-7 system during and after the outbreak.  
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8 The MoHS instituted enhanced surveillance mechanisms after the outbreak was declared  
9 over by WHO because it anticipated possible flare-ups of new Ebola cases due to sexual  
10 transmission of the Ebola virus by male Ebola survivors, which had been reported in  
11 Liberia.<sup>22 23</sup> Also, the outbreak in Guinea had not been declared over by WHO, which  
12 meant that possible importation of cases needed to be monitored, especially along border  
13 regions.<sup>24</sup> Consequently, the MoHS mandated that all deaths must continue to be  
14 reported to the 1-1-7 system to help detect possible flare-up of new Ebola cases. Death  
15 investigations during the enhanced surveillance period included buccal swabbing of  
16 corpses to test for Ebola and determine the need for safe burial.<sup>14</sup> On June 30th 2016,  
17 the MoHS announced the end of enhanced Ebola surveillance.<sup>14</sup> The radio  
18 announcement stated that starting in July 2016 all deaths were still required to be reported  
19 through the 1-1-7 system, however, only deaths that were suspected of Ebola were  
20 required to be investigated by district-based surveillance teams. Buccal swabbing of  
21 corpses stopped after enhanced surveillance ended. The MoHS aimed to have the 1-1-7  
22 transitioned into the primary mechanism for death registration and mortality surveillance  
23 in Sierra Leone including for health workers to report facility-based deaths.  
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### 31 **Sampling**

32 Western Area and Kenema districts were purposefully selected for inclusion in the  
33 exploratory assessment. Both districts were chosen because of their epidemiological  
34 significance during the 2014-2016 Ebola outbreak in Sierra Leone and to allow for rural-  
35 urban variations in the sample. Western Area was selected because it had the highest  
36 number of reported Ebola cases and it has a large urban population. Kenema was  
37 selected because it was an early epicentre of the outbreak and it has a large rural  
38 population. We expected that the sociodemographic characteristics and the different  
39 experiences of Ebola in these districts would facilitate in-depth understanding of the range  
40 of reporting barriers and possible facilitators of willingness to report in the future. Within  
41 each district, we conducted eight interviews in high Ebola burden areas and another eight  
42 in low burden communities. Ebola epidemiological data from the MoHS showing  
43 estimated case counts at sub-district level guided our selection of communities. For the  
44 purpose of the assessment, we defined high Ebola burden as  $\geq 50$  cumulative cases and  
45 low Ebola burden as  $\leq 10$  cases per community.  
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53 Trained data collection teams worked with community mobilizers to help identify  
54 households that had experienced one or more deaths between April and August 2017.  
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3 The mobilizers contacted community leaders including religious leaders to inquire about  
4 deaths that occurred in the respective communities during the specified period. Based on  
5 the information gathered, the mobilizers and data collection teams visited the households  
6 referred by community leaders. For a referred household to be eligible to be included in  
7 the assessment, the death must not have been reported to the 1-1-7 system. We also  
8 used snowball sampling by asking eligible households to refer data collection teams to  
9 other households that may have experienced a death during the same period. All eligible  
10 households identified during recruitment agreed to participate in the assessment.  
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### 15 **Data collection**

16 Data collectors then continued to follow-up with the identified households to confirm  
17 eligibility, explain the purpose of the assessment, and ask for informed consent to  
18 participate. Once the eligible household was identified by the local team, informed  
19 consent was obtained from the head of the household or next of kin of the deceased. Only  
20 one interview was conducted per eligible household, and repeat interviews were not  
21 conducted. If the household head or next of kin were both unavailable, the data collection  
22 team returned to the household at least one more time before it was considered  
23 unreachable and another eligible household was approached. After obtaining informed  
24 consent from participants, the team used a structured questionnaire to gather basic  
25 demographic information about the respondent. This was followed by administering an  
26 in-depth interview using a semi-structured guide that covered two broad domains:  
27 community level practices and perceptions regarding the death; and personal  
28 experiences and perceptions regarding the death (Supplemental Material). The interview  
29 guide was pilot tested with a convenience sample of 4 respondents as part of the training  
30 of the data collection teams. Feedback from the pilot was used to improve the framing  
31 and sequencing of questions and probes.  
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40 Data collection was carried out by mixed-gender teams of interviewers and note-takers  
41 with extensive prior experience in qualitative data collection in Sierra Leone. All data  
42 collection team members were fluent in the predominant local languages of their assigned  
43 districts (Krio in Western Area, and Mende or Krio in Kenema), and had post-secondary  
44 education in social sciences or public health. All participated in a one-week training that  
45 covered informed consent, sampling procedures, best practices for conducting interviews  
46 and debriefs, and translation and transcription of audio-recordings. All interviews were  
47 audio-recorded with consent from respondents. On average the interviews lasted  
48 between 45 and 60 minutes. Interviews were conducted in a secluded area within the  
49 vicinity of the home. At the end of each interview, the interviewer and note-taker  
50 conducted a short debrief that lasted approximately 30 minutes in order to capture key  
51 topics that emerged from the discussion and to document important observations that  
52 may help to contextualize the responses. Review of the data and debrief notes indicated  
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3 that analytical data saturation was achieved after 16 interviews were conducted in each  
4 district (i.e. when meaningfully new information was no longer emerging from the  
5 interviews).  
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### 8 **Data management and analysis**

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10 The respective teams of interviewers and note-takers translated and transcribed the  
11 audio-recordings. Team members conducted peer reviews of each other's transcripts to  
12 ensure consistency in translations from local language to English. A supervisor reviewed  
13 all transcripts for translation accuracy and fidelity of meaning. However, Interview  
14 transcripts were not provided to the participants for their review or correction. The analysis  
15 was led by the lead author (MFJ) with support from co-author JC, both of whom are Sierra  
16 Leoneans with training and experience in qualitative data analysis. A web-based  
17 qualitative software, Dedoose<sup>®</sup>,<sup>25</sup> was used to support the management and analysis of  
18 the data.  
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23 An initial set of deductive codes were first generated to reflect meaning units from the  
24 questions in semi-structured interview guide. The two analysts (MFJ and JC) generated  
25 additional inductive codes from reviewing the transcripts, then proceeded to code the  
26 transcripts, independently validated each other's application of codes, and resolved any  
27 discrepancies. Textual excerpts were extracted from Dedoose<sup>®</sup> for each code. The  
28 analysts iteratively reviewed, discussed, and interpreted the coded excerpts. The final  
29 codes were organized into mutually exclusive sub-categories and categories that  
30 reflected latent grouping of concepts. An iterative, interpretative process led to the higher-  
31 level grouping of the categories into themes. Preliminary results from the qualitative  
32 analysis were presented to stakeholders in Sierra Leone including the MoHS and other  
33 surveillance partners. Feedback received from the stakeholder presentation informed our  
34 interpretation and framing of the themes.  
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### 40 **Patient and public involvement**

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42 Patients and/or the public were not involved in the design, conduct, reporting or  
43 dissemination plans of this research.  
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## 46 **Results**

### 47 **Demographic characteristics of respondents**

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49 Out of 32 respondents, 18 (56%) were female, 15 (47%) had no education or only primary  
50 school education, 8 (25%) were petty traders, and 22 (69%) self-identified as Muslim.  
51 Respondents' age ranged from 27 to 70 years; median age was 38 years. Respondents  
52 mostly comprised of relatives of deceased persons (66%), including parents (n=12),  
53 spouses (n=5), or children (n=4) (Table 1).  
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## Summary of themes

Death reporting barriers were driven by the lack of awareness to report all deaths, lack of services linked to reporting, negative experiences from the Ebola outbreak including prohibition of traditional burial rituals, perception that inevitable deaths do not need to be reported, and situations where prompt burials may be needed (Table 2). Facilitators of future willingness to report deaths were largely influenced by the perceived communicability and severity of the disease, unexplained circumstances of the death that need investigation, and the potential to leverage existing death notification practices through local leaders (Table 3).

### Barrier 1.1. Lack of awareness to report all deaths

All respondents were unaware that they were required to report the household death after the end of the enhanced Ebola surveillance. Although some respondents knew that the 1-1-7 line was still operational, they thought that only deaths that resembled Ebola needed to be reported.

*“... I do not think 1-1-7 is still existing because after Ebola we thought that was the end of 1-1-7. I’m only hearing this from you now. I always listen to the radio, but it has taken a long time I did not hear announcement that when someone dies, we are to call 1-1-7; even in the villages, that is why I did not remember to call 117.”* – respondent from Western Area district

### Barrier 1.2 Lack of reciprocal benefit

Respondents did not see a benefit to report deaths to the 1-1-7 system in a post-Ebola-outbreak setting. The notion of simply notifying 1-1-7 without any associated follow-up action or service was not appreciated by interviewees. In order to report deaths to 1-1-7, respondents said they would expect some follow-up action or service to be provided. For instance, they strongly recommended for prompt ambulance services for sick people and transportation of corpses through 1-1-7. Respondents expressed that such services would help motivate them in the future to use the system.

*“...if you take transport, like you take a taxi, to carry a [sick] person to the hospital; when you are going with him and there is traffic, they won’t give you way. But let’s say you call the 1-1-7 and the 1-1-7 comes with the ambulance, they will be able to give you way because they will take it as an emergency.”* – respondent from Western Area district

*“Then I would like them to give us ambulance in the community so when someone dies, they will be able to take the person and bury him/her quickly.”* – respondent from Kenema district

### **Barrier 1.3 Perceived inevitability of certain deaths**

Respondents consistently expressed that they would not consider reporting deaths that they perceive to be inevitable due to age, God's will, minor illness, and long-term illness or disability, drowning, or fire. They also mentioned that patients who die in a health facility do not need to be reported because they presumed that it was the responsibility of the health workers to report.

*"The illness that affects someone for so long, for example stroke [complications], which leads to death, we will not report such death. For instance, in our community, we had a man by the name of xxx [redacted] who was affected by stroke and had suffered with it for a very long time; his family had tried all forms of medication, but he did not survive. So, with this type of death the chief themselves will just give permission to the people for burial rather than reporting to 1-1-7."* - respondent from Kenema district

### **Barrier 1.4 Needing to bury promptly**

There were two main reasons why prompt burial emerged as a barrier to death reporting. Firstly, circumstances of the death influenced perceptions of when the corpse should be buried including the death of young children, someone who has been ill for a long time (despite their age), and someone who died from an accident (e.g. drowning, fire, road accident). Secondly, Muslim respondents emphasized that they need to bury the corpse within 24 hours to honour Islamic requirements; they feared that reporting may result in burial delay based on their experiences from the Ebola outbreak. One respondent gave an example of how same-day burial was done as per Islamic tradition:

*"I went straight to the Imams [at the local mosque] and notified them [of the death]. The Imam came and asked us to take the corpse to the Mosque. The corpse laid there until around twelve o'clock when they washed and wrapped it with Kasankay [white] cloth. We waited for the time ... that is two o'clock, then we went to bury him. After the burial the 'Jamat' [mosque congregation] met here [at our house], ate and prayed for him before everyone went back to their homes"* – respondent from Western Area district

### **Barrier 1.5 Negative experiences from the Ebola outbreak**

The 1-1-7 system was intricately linked to its widespread use during the Ebola outbreak in Sierra Leone and could not be separated by respondents' negative experiences with how some deaths were handled by burial teams during the outbreak.

*"The family would not get access to the corpse or even go close to it. So this knowledge had existed within people that 1-1-7 is not a call to make in order to get help in the burial"*

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3 *of their loved ones. They will only come to do whatever they feel like, whether it is in a*  
4 *respectful way or not; they don't care. So, with that, people in the community do not favour*  
5 *the 1-1-7. Because how we expect them to bury our loved ones it's the opposite [that they*  
6 *will do].” – respondent from Kenema district*  
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10 Most participants cited that burial methods used to bury their loved ones during the Ebola  
11 outbreak discouraged them from reporting to 1-1-7.  
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14 *“This 1-1-7 line...I don't want it. I want us to be respecting the [dead] people because the*  
15 *1-1-7 was not burying our people properly. So, we are burying our people. Let government*  
16 *leave it [burial] up to us. If a doctor check the body [that's fine], but don't let the 1-1-7 -*  
17 *come here until we have buried the corpse” – respondent from Kenema district*  
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20 Dissatisfaction with burial methods was coupled with discontent about delays by burial  
21 teams when they were responding to death alerts during the Ebola outbreak.  
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24 *“Like during the Ebola time if you call...they [burial teams] will not come [on time]. They*  
25 *will abandon them for some time before coming to take the person. All they care about is*  
26 *for the people to call them... They need to put more efforts into how they respond and*  
27 *treat the people with respect” – respondent from Western Area district*  
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31 Fear of being quarantined was also mentioned as a barrier for reporting deaths to 1-1-7  
32 as well as the sounds made by the ambulances and spraying of the house with chlorine,  
33 which were all associated with Ebola-related stigma. Respondents expressed that just  
34 the thought of 1-1-7 alone would usually bring back bitter memories of Ebola.  
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38 *“The first time I heard about 1-1-7 was during Ebola and each time I hear about 1-1-7 I*  
39 *think about Ebola at once. The moment they talk about 1-1-7, it's a worry for me because*  
40 *during that period, when people see 1-1-7 coming, everybody would run away. When they*  
41 *come to a place, they will spray chlorine all over and everybody avoided body contact like*  
42 *nobody's business, and that worried us too much. That is why we hardly forget about 1-*  
43 *1-7” – respondent from Western Area district*  
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#### 46 **Facilitator 1.1 Presence of Ebola-like symptoms**

47 Knowledge gained during the Ebola outbreak influenced respondents' perceptions of the  
48 deaths that should be reported to the 1-1-7 system after the outbreak ended. Participants  
49 expressed that they would report a death if it resembled Ebola or Lassa fever, especially  
50 in situations where the person bled before dying.  
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3 *“For any death pertaining to what government told us [we need to report]. That of a bad*  
4 *disease like Ebola, Lassa fever...The people around will not even dare to touch the*  
5 *person, because it is a transferable disease and it is more common in Eastern Province.”*  
6 *– respondent from Kenema district*  
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### 10 **Facilitator 1.2 Sudden and unexplained deaths**

11 Sudden and unexplained deaths wherein the person was not previously sick were  
12 perceived as needing to be reported to the authorities for further investigations.  
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14 *“Like I said before, when someone dies abruptly, and nothing was wrong with him [before*  
15 *dying]. I will just be looking at him, I will not have the knowledge to know the cause of*  
16 *death, I will not have the machine to show that this is the sickness that caused the death*  
17 *or whether he just fell down and died or whether he just sat down and died. When you go*  
18 *to a medical person [through 1-1-7], he can confirm that this is the cause of the death. If*  
19 *the doctor has confirmed that for real he has died, what can I do?” - respondent from*  
20 *Western Area district*  
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### 25 **Facilitator 1.3 Existence of other local reporting mechanisms**

26 Informing local leaders—such as religious leader, chiefs, and village headmen—about  
27 the death was a common practice that most respondents mentioned. In Kenema, some  
28 participants cited that informing local and traditional heads granted them permission for  
29 burial without needing to report to the 1-1-7 system. The reporting of these deaths to only  
30 local leaders showed that respondents were generally willing to report the deaths but only  
31 did so in localized ways outside of the 1-1-7 system.  
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35 *“Well you will have to go and say to the chief or authority that someone has died amongst*  
36 *us. The chief will ask what happened to that person. The chief will ask you... and you will*  
37 *say [something like] it was a cold, or after two three days I noticed that this person was*  
38 *ill. God has taken his life. This is the way he died. The chief will ask you; and you should*  
39 *answer. You have the chance to report to the police station. You have the chance to*  
40 *report to the chief. And you have the chance to call the family members” – respondent*  
41 *from Kenema district*  
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## 47 **Discussion**

48 In the aftermath of the Ebola outbreak in Sierra Leone, we identified barriers that  
49 prevented people from reporting deaths to the authorities, and we also explored  
50 facilitators that would encourage death reporting as part of routine mortality surveillance.  
51 Barriers uncovered in our assessment were linked to a lack of awareness to continue  
52 reporting all deaths after enhanced Ebola surveillance ended as well as the lack of  
53 reporting benefits. Respondents were unaware of the requirement to continue reporting  
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3 all deaths after the enhanced surveillance period, and they were under the impression  
4 that only deaths resembling Ebola should be reported to the 1-1-7 system. Consequently,  
5 other deaths that were not suspected of Ebola were not reported to the 1-1-7 system. A  
6 separate assessment found that after the outbreak ended, people were more motivated  
7 to report deaths to the 1-1-7 system if Ebola-like symptoms were present in the  
8 decedent.<sup>15</sup> Our findings further demonstrated that although respondents did not report  
9 deaths through the 1-1-7 system as mandated by their government, they informed local  
10 councils and local leaders about the deaths. Therefore, integrating localized practices for  
11 death reporting into routine surveillance mortality systems may help optimize the number  
12 of deaths captured. Respondents complained about the lack of any reporting benefits  
13 associated with death reporting in a post-Ebola-outbreak context. They wanted  
14 ambulance services to be linked to 1-1-7 reporting as done during the outbreak.  
15 Contextually, past experiences from the Ebola outbreak served as both facilitators and  
16 barriers. Past outbreak experiences reinforced the importance of reporting when Ebola is  
17 suspected to avoid transmission risks. On the other hand, past experiences that involved  
18 dissatisfaction with how burials were handled during the outbreak may have discouraged  
19 reporting to the 1-1-7 system.  
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27 Despite efforts to promote reporting of all deaths during the outbreak, communities  
28 continued to express dissatisfaction with how their loved ones were buried and there were  
29 instances of secret burials that occurred outside of the safe burial process, which may  
30 have been due to discontent with safe burials or wanting to comply with secret society  
31 practices.<sup>26 27</sup> Although dissatisfaction persisted regarding Ebola safe burial processes,  
32 communities were willing to comply with reporting because they wanted to help end Ebola  
33 transmission in the country.<sup>28</sup> In the waning period of the Ebola outbreak in 2015, an  
34 assessment of the community event-based surveillance showed that over 12,000 reports  
35 were submitted and investigated, out of which 287 met case-definition for suspected  
36 Ebola and 16 were confirmed positive for Ebola.<sup>29</sup> In that assessment, it was revealed  
37 that community event-based surveillance detected four new Ebola cases that were not  
38 epidemiologically linked and could have gone undetected.  
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44 The Ebola outbreak was tragic in many ways as demonstrated by the thousands of lives  
45 lost and the unquantifiable suffering inflicted upon the people of Sierra Leone. The pain  
46 and misery they endured was evident in our assessment when they talked about their  
47 experiences during the outbreak. Even though people were sometimes dissatisfied with  
48 how the burials were handled or delayed, they recognized that it was to their benefit to  
49 have a safe burial to avoid household transmission risk. Nevertheless, normalizing death  
50 reporting during the outbreak required gaining the trust of communities by engaging them  
51 to appreciate the benefits of reporting. The halting of ambulance services after the Ebola  
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3 outbreak ended prompted people to question why those services were only provided  
4 during the outbreak response.  
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7 The principle of *positive reciprocity* has been well established in social psychology,<sup>30-32</sup>  
8 which implies that people become motivated to comply with a request when they receive  
9 something in-return for their action. This notion is also supported in the health behaviour  
10 literature. For instance, applications of the Health Belief Model have shown that the  
11 perceived benefit associated with a behaviour is a strong predictor of engaging in the  
12 behavior.<sup>33 34</sup> Our findings are consistent with notions of reciprocity and perceived benefit  
13 such that respondents expressed that they will be willing to report deaths if tangible  
14 benefits are provided for complying (e.g. ambulance services).  
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19 The normalization of death reporting during the outbreak was a new opportunity for Sierra  
20 Leone to establish CRVS after the outbreak ended. Realizing this potential for a functional  
21 CRVS system<sup>35</sup> would require a strong social mobilization component to ensure optimal  
22 community-based reporting. It has been documented that surveillance and laboratory  
23 systems from the Ebola outbreak in West Africa served as a springboard for strengthening  
24 health systems as part of global health security efforts to prevent, detect, and respond to  
25 disease threats.<sup>36</sup> Sierra Leone was able to leverage Ebola surveillance infrastructure to  
26 strengthen Integrated Disease Surveillance and Response for epidemic-prone  
27 diseases.<sup>37</sup> The same could be done for transitioning the 1-1-7 system into a routine  
28 mortality surveillance tool.  
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### 33 **Limitations**

34 The exploratory qualitative assessment is subject to several limitations. The results are  
35 not generalizable beyond the 32 individuals interviewed. While this is an inherent  
36 limitation to most qualitative research, it is important to note that we never intended to  
37 produce generalizable results. Instead, our aim was to generate in-depth understanding  
38 of barriers and facilitators of death reporting with themes that may be transferrable to  
39 other local contexts. It is possible that some respondents may have provided socially  
40 desirable responses in terms of facilitators to report in order to match previously heard  
41 messages during the Ebola outbreak. Because theoretical sampling was not used, as  
42 done in grounded theory approaches for example,<sup>38</sup> other individuals outside of family  
43 members (e.g. health workers, local city council officials) were not interviewed. Additional  
44 research with more diverse stakeholder may help shed light on additional barriers and  
45 facilitators.  
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### 52 **Conclusion**

53 Respondents misunderstood the *policy of reporting all deaths* after the end of enhanced  
54 Ebola surveillance in Sierra Leone, which may have been due to communication gaps in  
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3 the government's official announcement of the mandate. We found that respondents  
4 perceived that only suspected Ebola deaths should be reported to the 1-1-7 system. The  
5 lack of awareness to *report all deaths* and the lack of perceived reporting benefits were  
6 the main reasons for failure to report the deaths. Given that Sierra Leone is now several  
7 years removed from the Ebola outbreak, our results reinforce the need to review its death  
8 reporting policy to make sure it is aligned with the post-outbreak context where prevention  
9 of Ebola transmission may no longer sufficiently motivate people to report deaths in their  
10 household as was done during the outbreak. The post-outbreak death reporting policy  
11 should consider integrating tangible benefits for those who report. We found that  
12 ambulance services may help incentivize people to report while also minimizing any  
13 disruptions to the traditional burial processes. Existing practices for informal death  
14 notification through local leaders should also be leveraged to capture community-based  
15 deaths that may be missed by the formal reporting system. Improving routine death  
16 reporting may be supported by well-planned social mobilization efforts to educate  
17 communities about the death reporting policy, promote the reporting benefits, and  
18 facilitate optimal compliance.  
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27 difficult circumstances. This paper is dedicated to the memories of the loved ones.  
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### 31 **Contributors**

32 MFJ led the conceptualization and design of the assessment with contributions from JK,  
33 RK, and HN. MFJ trained and supervised data collectors. MFJ analysed the data with  
34 guidance from JK and HN. All co-authors contributed to the interpretation of the results.  
35 MFJ led the writing of the manuscript with contributions from all co-authors. The final  
36 version of the manuscript was approved by all co-authors.  
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43  
44

### 45 **Competing interest**

46 The authors have none to declare.  
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### 49 **Data availability**

50 All relevant data are presented. No additional data available.  
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### 53 **Ethics approval**

54 The assessment was approved by the Sierra Leone MoHS as a routine public health  
55 activity. In addition, the Center for Global Health at the U.S. Centers for Disease Control  
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3 and Prevention approved the assessment as a program evaluation activity (CGH HSR  
4 Tracking # 2017-327).  
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### 7 **Disclaimer**

8 The findings and conclusions in this report are those of the authors and do not  
9 necessarily represent the official position of the U.S. Centers for Disease Control and  
10 Prevention, Karolinska Institutet, eHealth Africa, or Sierra Leone Ministry of Health and  
11 Sanitation.  
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## TABLES

**Table 1. Sociodemographic characteristics of respondents, Sierra Leone, 2017**

Characteristic	Number of respondents (N = 32)
<b>Sex</b>	
Female	18
Male	14
<b>Education</b>	
None or primary only	15
Secondary or higher	17
<b>Religion</b>	
Muslim	22
Christian	10
<b>Occupation</b>	
Petty trader	8
Skilled labor	7
Private business	4
Teacher	3
Student	3
Unemployed	3
Driver / bike rider	2
Farmer	1
Civil service	1
<b>Age (years)</b>	
Median = 38	
21-30	6
31-40	15
41-50	4
51-60	6
61-70	1

**Table 2. Thematic area on barriers to reporting deaths in the aftermath of the Ebola outbreak, Sierra Leone, 2017**

Code	Category	Theme
1.1.1 Reporting only required during Ebola	1.1 Lack of awareness to report all deaths	Barriers to reporting deaths in the aftermath of the Ebola outbreak
1.1.2 No more need to report to 1-1-7		
1.1.3 Only Ebola-like deaths should be reported		
1.2.1 No services for people while alive	Lack of reciprocal benefit	
1.2.2 Too much focus on dead people		
1.2.3 Nothing done for sick people		
1.2.4 Nothing happens if you report		
1.2.5 No help with burial		
1.2.6 Just a government line		
1.3.1 Old-age / God's time	1.3 Perceived inevitability of certain deaths	
1.3.2 Minor illness		
1.3.3 Long-term illness or disability		
1.3.4 Death occurred in health facility		
1.4.1 Islamic requirement to bury within 24 hours	1.4 Needing to bury promptly	
1.4.2 Body recovered from drowning		
1.4.3 Body recovered from fire		
1.4.4 Young child		
1.4.5 Sick for long time		
1.5.1 Wanting to forget about 117	1.5 Negative experiences from the Ebola outbreak	
1.5.2 Reporting brings sadness to family		
1.5.3 Painful memory of Ebola		
1.5.4 Burial delays during Ebola		
1.5.5 Restrictions on traditional burials		
1.5.6 Fear of quarantine		
1.5.7 Fear of ambulance		
1.5.8 Line was used during Ebola		
1.5.9 Don't like the number		

**Table 3. Thematic area on facilitators of future intention to report deaths, Sierra Leone, 2017**

Code	Category	Theme
1.1.1 Resembling Ebola	1.1 Presence of Ebola-like symptoms	Facilitators of willingness to report deaths in the future
1.1.2 Resembling Lassa		
1.1.3 Bleeding before dying		
1.2.1 Sudden death without illness	1.2 Sudden and unexplained death	
1.2.2 Wanting to know cause of death		
1.3.1 Informing chief	1.3 Existence of other local reporting mechanisms	
1.3.2 Informing religious leaders		
1.3.3 Informing elders		
1.3.4 Inform City Council for burial permit		
1.3.5 Informing Office of Births and Deaths for death certificate		



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## Supplemental Material: Interview Guide

### Part A: Community Level Practices and Perceptions

#### **1. What usually happens after someone dies in this community (who does what/when/how)?**

- Probe: What are the most important things to do immediately after someone dies?
- Probe: How is the funeral usually handled / who participates?
- Probe: How is the burial usually handled / who participates?
- Probe: Who is notified of the death, and when and how are they notified?
- Probe: To what extent does the type of death influence how the funeral/burial is handled, and who is informed about it?

#### **2. Who conducts/helps with the funeral/burial?**

- Probe: Please tell us why these particular people engaged

#### **3. Overall, what is the current practice for reporting deaths to authorities (local, district, national 1-1-7) in this community?**

- Probe: What types of deaths are supposed to be reported?
- Probe: When should the death be reported, and to whom?
- Probe: How should the death be reported?
- Probe: What usually happens after the death is reported?

#### **4. What usually discourages people from reporting the death of a loved one or neighbor?**

- Probe: is there any type of death that people are inclined not to report? What are the reasons for this?
- Further probe for:
  - Time of death
  - Burial delay
  - Age of the deceased
  - Religious reasons
  - Other
- Probe: What questions do you have for authorities about reporting deaths?

#### **5. What would encourage or motivate you to report the death of a loved one or neighbor to 117 in the future?**

- Probe: What types of deaths are you most likely to report? What are the reasons for this?
- Probe: What should be done differently to improve reporting?
- Probe: What new things would you like to see happen?
- Probe: Who can help improve death reporting in this community, if any?

### Part B: Personal Experience and Perceptions

Thanks for your responses. I appreciate your openness and willingness to discuss these issues. You already told you us that you did not report the recent death of your loved one. Now, I would like to learn more about that particular situation.

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**6. Please describe for me the circumstances surrounding the death of your loved one.**

- Probe: What was their health situation in the months leading up to their death?
- Probe: What signs/symptoms were reported or shown leading to the death?
- Probe: Were there suspicious aspects of the illness? If so, please describe them.
- Probe: What type of care had they received (traditional vs medical, etc)?
- Probe: Where and when did the death occur?

**7. Please describe for me the steps that you or the family took after the death:**

- Probe: What did you or the family first do? Why was this important?
- Probe: Who did you inform about the death? And how were they informed?
- Probe: How long did it take from time of death to the time of burial?

**8. Tell us more about burial processes:**

- Probe: Did you get permission for the burial? If so, how and from whom did you get approval to carry out the burial?
- Probe: Where was the body buried (public site vs private vs family land)?
- Probe: What ceremonies were conducted during the burial? (*note to interviewer: don't ask about any specific secrete ceremonies or ritual*)
- Probe: Who participated in the burial? Why were their participation important?

**9. When you hear "1-1-7" what comes to mind?**

- Probe: What are your opinions of 117?
- Probe: Do you think this number should be kept or change?
- Probe: Please tell us why it should be kept or changed.
- Probe: How can the 117 system be improved?

**10. Please tell me the reason why you decided not to report the death to the 1-1-7 National Call Center:**

- Probe: Understanding of government requirements to report all deaths to 117 (or lack thereof)?
- Probe: Concerns about funeral/burial delays?
- Probe: Nature or circumstances of the death?
  - Accident and pregnancy related
  - 'Natural causes'
  - Death that resembles Ebola or Lassa
  - Age of the deceased

**11. Would you consider reporting the death of a loved one to 117 in future?**

- Probe: If so please tell us what may have changed since the present case
- Probe: What types of deaths are you most likely to report? What are the reasons for this?
- Probe: What should be done differently?
- Probe: What new things would you like to see happen?
- Probe: Who can help improve death reporting in this community?

Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance

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For peer review only

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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## Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance

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# Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance based on an exploratory qualitative assessment

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## Keywords

Mortality surveillance, death reporting, Ebola, outbreak, civil registration of vital statistics, Sierra Leone, West Africa



## Abstract

**Objectives:** To understand the barriers contributing to the more than three-fold decline in the number of deaths (of all causes) reported to a national tollfree telephone line (1-1-7) after the 2014-2016 Ebola outbreak ended in Sierra Leone and explore opportunities for improving routine death reporting as part of a nationwide mortality surveillance system.

**Design:** An exploratory qualitative assessment comprising 32 in-depth interviews (16 in Kenema district and 16 in Western Area). All interviews were audio-recorded, transcribed, and analysed using content analysis to identify themes.

**Setting:** Participants were selected from urban and rural communities in two districts that experienced varying levels of Ebola cases during the outbreak. All interviews were conducted in August 2017 in the post-Ebola-outbreak context in Sierra Leone when the Sierra Leone Ministry of Health and Sanitation was continuing to mandate reporting of all deaths.

**Participants:** Family members of deceased persons whose deaths were not reported to the 1-1-7 system.

**Results:** Death reporting barriers were driven by the lack of awareness to report all deaths, lack of services linked to reporting, negative experiences from the Ebola outbreak including prohibition of traditional burial rituals, perception that inevitable deaths do not need to be reported, and situations where prompt burials may be needed. Facilitators of future willingness to report deaths were largely influenced by the perceived communicability and severity of the disease, unexplained circumstances of the death that need investigation, and the potential to leverage existing death notification practices through local leaders.

**Conclusions:** Social mobilization and risk communication efforts are needed to help the public understand the importance and benefits of sustained and ongoing death reporting after an Ebola outbreak. Localized practices for informal death notification through community leaders could be integrated into the formal reporting system to capture community-based deaths that may otherwise be missed.

## Article summary

### Strengths and limitations of this study

- This large qualitative assessment helps to explain the complex reasons for the sharp and persistent decline in death reporting levels in Sierra Leone following the 2014-2016 Ebola outbreak.
- The assessment generated novel understanding of barriers and facilitators related to death reporting with themes that may be transferrable to other post-Ebola-outbreak contexts.
- Given that mortality surveillance is a key approach for identifying existing and new public health threats, the findings can help inform strategies for engaging community members to improve death reporting level.
- It is possible that some respondents may have provided socially desirable responses in terms of facilitators to report in order to match previously heard messages during the Ebola outbreak.
- Other key stakeholders with relevant views on mortality surveillance (e.g. health workers and local officials) were not interviewed. Nevertheless, this assessment shed light on the perspectives of family members who failed to report the deaths of their loved ones as mandated by the Government.

## Introduction

A popular traditional healer in a remote village in Kailahun district in Sierra Leone became ill and suddenly died around April 30<sup>th</sup> 2014 after treating patients from neighbouring Guinea.<sup>1</sup> The Sierra Leone Ministry of Health and Sanitation (MoHS) subsequently confirmed an outbreak of Ebola Virus Disease (Ebola) on May 25<sup>th</sup> 2014, which was linked to the burial of the traditional healer in Kailahun district.<sup>2</sup> Ebola cases quickly spread to neighbouring Kenema district, making the Eastern region the initial epicentre of the outbreak in Sierra Leone.<sup>3</sup> The epicentre of the outbreak shifted from the Eastern region to the Western and Northern regions by September 2014. Over 14,000 people became infected in the country, of whom nearly 4,000 died by the time the outbreak was declared over in November 2015 by the World Health Organization (WHO).<sup>2</sup>

Traditional burials that involved various forms of physical contact with infected corpses were identified as core transmission amplifiers of the Ebolavirus.<sup>4</sup> It has been estimated that nearly three new Ebola cases resulted from every unsafe traditional burial during the outbreak in West Africa.<sup>4</sup> Containing the outbreak required prompt identification of all deaths to ensure safe burial by teams trained on Ebola infection prevention and control.<sup>5</sup> Social mobilization and risk communication efforts were implemented nationally and intensified in high-transmission districts to persuade communities to report all deaths to a national tollfree telephone line using a short dialling code, 1-1-7.<sup>6 7</sup>

Mortality surveillance is a key approach for identifying and responding to public health threats<sup>8</sup> in both high income countries<sup>9</sup> and low- and middle-income countries<sup>8 10-12</sup> as part of routine surveillance<sup>10 11</sup> as well as in health emergency contexts including during disease outbreaks.<sup>8 9 13</sup> Mortality surveillance systems have been relied upon to count the excess number of deaths due to an emerging health threat,<sup>9</sup> describe patterns in mortality occurrence,<sup>10 11</sup> and help to quantify causes of death in a population.<sup>12</sup> Governments' vital registration systems have been used for national mortality surveillance purposes to monitor and describe deaths occurring in a country. In addition, or alternatively, sample-based mortality surveillance systems have been used to generate nationally representative data on deaths. Vital registration systems and sample-based systems have been combined into an integrated mortality surveillance system.<sup>10</sup> In other instances, mortality surveillance systems have focused on sub-population groups (e.g. children) within geographically defined sub-national units.<sup>12</sup>

In Sierra Leone, death reporting through the 1-1-7 system constituted a critical component of identifying and responding to occurrences of deaths in communities to prevent unsafe traditional burials during the Ebola outbreak.<sup>13</sup> Previous analyses of monthly reports of call volumes to the 1-1-7 system showed a substantial decline across all districts after announcing the end of the outbreak.<sup>13 15</sup> In the last year of the outbreak, the average

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3 number of deaths reported monthly to the 1-1-7 system fell from approximately 9,000  
4 during January—October 2015, to 4,000 during the enhanced surveillance period  
5 (November 2015 to June 2016). The decline continued and reached less than 1,000  
6 reported deaths per month in 2017.<sup>15</sup> A national telephone survey was conducted in April  
7 2017 to investigate the motivations of those who continued to report deaths to the 1-1-7  
8 system after Ebola outbreak ended.<sup>15</sup> Results from the survey showed that people who  
9 reported deaths were more motivated to do so when Ebola-like symptoms were present  
10 in the deceased. However, since the survey only targeted individuals who had reported a  
11 death, barriers related to reporting among those who failed to report to the 1-1-7 system  
12 were not understood. In this paper we examine death reporting barriers and explore  
13 opportunities for improving routine mortality surveillance in the aftermath of the Ebola  
14 outbreak in Sierra Leone.  
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## 20 **Methods**

21 In-depth qualitative interviews were conducted with 32 purposefully selected individuals  
22 who experienced a death in their household in April-August 2017 but did not report the  
23 death to the 1-1-7 system as required by the MoHS. Interviews were conducted by trained  
24 native speakers in two districts, one urban: Western Area (n=16) and one rural: Kenema  
25 district (n=16). Audio-recordings of the interviews were transcribed and the textual data  
26 were analysed using qualitative content analysis.<sup>16</sup> COREQ guidelines are used to  
27 describe the methods of our qualitative exploratory assessment.<sup>17</sup>  
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## 33 **Setting**

34 The initial purpose of the system when it was established in 2013 was to get feedback  
35 from communities on the government's Free Health Care Initiative that provides essential  
36 primary health care services at no-cost to children under five years old, pregnant women,  
37 and lactating mothers.<sup>18</sup> In August 2014, as Ebola cases began to surge, the Government  
38 repurposed the 1-1-7 line for communities to report suspected Ebola cases with a  
39 mandate that all deaths, even if not suspected of Ebola, must be reported for safe burial.<sup>13</sup>  
40 A national call centre was set up for triaging the call alerts to district personnel who  
41 dispatched ambulance and burial teams.<sup>19</sup> Alpren et al. have comprehensively  
42 documented the implementation of the 1-1-7 system.<sup>13</sup>  
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48 The normalization of death reporting in Sierra Leone during the Ebola outbreak presented  
49 a unique opportunity for the country to leverage the 1-1-7 system as a foundation for  
50 strengthening civil registration of vital statistics (CRVS) in the post-outbreak context.  
51 CRVS is part of global efforts to register all births and deaths occurring in all countries.<sup>20</sup>  
52 The 2015-2024 global strategic plan for CRVS aims to have functional country systems  
53 to record all deaths so that the WHO International Classification of Disease and Injuries  
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3 can be used to as “the global standard for classifying causes of death in a comparable  
4 manner over time and between populations.”<sup>20</sup> Prior to the Ebola outbreak in Sierra  
5 Leone, deaths were supposed to be reported to the Office of Births and Deaths through  
6 its local district offices as per legal mandate established in the 1983 Births and Deaths  
7 Registration Act.<sup>21</sup> The pre-Ebola-outbreak death registration level remains unknown.  
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9 The paper based CRVS death registration systems were never integrated with the digital  
10 platforms used in the 1-1-7 system during and after the outbreak.  
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14 The MoHS instituted enhanced surveillance mechanisms after the outbreak was declared  
15 over by WHO because it anticipated possible flare-ups of new Ebola cases due to sexual  
16 transmission of the Ebola virus by male Ebola survivors, which had been reported in  
17 Liberia.<sup>22 23</sup> Also, the outbreak in Guinea had not been declared over by WHO, which  
18 meant that possible importation of cases needed to be monitored, especially along border  
19 regions.<sup>24</sup> Consequently, the MoHS mandated that all deaths must continue to be  
20 reported to the 1-1-7 system to help detect possible flare-up of new Ebola cases. Death  
21 investigations during the enhanced surveillance period included buccal swabbing of  
22 corpses to test for Ebola and determine the need for safe burial.<sup>13</sup> On June 30th 2016,  
23 the MoHS announced the end of enhanced Ebola surveillance.<sup>13</sup> The radio  
24 announcement stated that starting in July 2016 all deaths were still required to be reported  
25 through the 1-1-7 system, however, only deaths that were suspected of Ebola were  
26 required to be investigated by district-based surveillance teams. Buccal swabbing of  
27 corpses stopped after enhanced surveillance ended. The MoHS aimed to have the 1-1-7  
28 transitioned into the primary mechanism for death registration and mortality surveillance  
29 in Sierra Leone including for health workers to report facility-based deaths.  
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### 37 **Sampling**

38 Western Area and Kenema districts were purposefully selected for inclusion in the  
39 exploratory assessment. Both districts were chosen because of their epidemiological  
40 significance during the 2014-2016 Ebola outbreak in Sierra Leone and to allow for rural-  
41 urban variations in the sample. Western Area was selected because it had the highest  
42 number of reported Ebola cases and it has a large urban population. Kenema was  
43 selected because it was an early epicentre of the outbreak and it has a large rural  
44 population. We expected that the sociodemographic characteristics and the different  
45 experiences of Ebola in these districts would facilitate in-depth understanding of the range  
46 of reporting barriers and possible facilitators of willingness to report in the future. Within  
47 each district, we conducted eight interviews in high Ebola burden areas and another eight  
48 in low burden communities. Ebola epidemiological data from the MoHS showing  
49 estimated case counts at sub-district level guided our selection of communities. For this  
50 assessment, we defined high Ebola burden as  $\geq 50$  cumulative cases and low Ebola  
51 burden as  $\leq 10$  cases per community.  
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5 Trained data collection teams worked with community mobilizers to help identify  
6 households that had experienced one or more deaths between April and August 2017.  
7 The mobilizers contacted community leaders including religious leaders to inquire about  
8 deaths that occurred in the respective communities during the specified period. Based on  
9 the information gathered, the mobilizers and data collection teams visited the households  
10 referred by community leaders. For a referred household to be eligible to be included in  
11 the assessment, the death must not have been reported to the 1-1-7 system. We also  
12 used snowball sampling by asking eligible households to refer data collection teams to  
13 other households that may have experienced a death during the same period. All eligible  
14 households identified during recruitment agreed to participate in the assessment.  
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### 20 **Data collection**

21 Data collectors then continued to follow-up with the identified households to confirm  
22 eligibility, explain the purpose of the assessment, and ask for informed consent to  
23 participate. Once the eligible household was identified by the local team, informed  
24 consent was obtained from the head of the household or next of kin of the deceased. Only  
25 one interview was conducted per eligible household, and repeat interviews were not  
26 conducted. If the household head or next of kin were both unavailable, the data collection  
27 team returned to the household at least one more time before it was considered  
28 unreachable and another eligible household was approached. After obtaining informed  
29 consent from participants, the team used a structured questionnaire to gather basic  
30 demographic information about the respondent. This was followed by administering an  
31 in-depth interview using a semi-structured guide that covered two broad domains:  
32 community level practices and perceptions regarding the death; and personal  
33 experiences and perceptions regarding the death (Supplemental Material). The interview  
34 guide was pilot tested with a convenience sample of 4 respondents as part of the training  
35 of the data collection teams. Feedback from the pilot was used to improve the framing  
36 and sequencing of questions and probes.  
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44 Data collection was carried out by mixed-gender teams of interviewers and note-takers  
45 with extensive prior experience in qualitative data collection in Sierra Leone. All data  
46 collection team members were fluent in the predominant local languages of their assigned  
47 districts (Krio in Western Area, and Mende or Krio in Kenema), and had post-secondary  
48 education in social sciences or public health. All participated in a one-week training that  
49 covered informed consent, sampling procedures, best practices for conducting interviews  
50 and debriefs, and translation and transcription of audio-recordings. All interviews were  
51 audio-recorded with consent from respondents. On average the interviews lasted  
52 between 45 and 60 minutes. Interviews were conducted in a secluded area within the  
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3 vicinity of the home. At the end of each interview, the interviewer and note-taker  
4 conducted a short debrief that lasted approximately 30 minutes in order to capture key  
5 topics that emerged from the discussion and to document important observations that  
6 may help to contextualize the responses. Review of the data and debrief notes indicated  
7 that analytical data saturation was achieved after 16 interviews were conducted in each  
8 district (i.e. when meaningfully new information was no longer emerging from the  
9 interviews).

### 14 **Data management and analysis**

15 The respective teams of interviewers and note-takers translated and transcribed the  
16 audio-recordings. Team members conducted peer reviews of each other's transcripts to  
17 ensure consistency in translations from local language to English. A supervisor reviewed  
18 all transcripts for translation accuracy and fidelity of meaning. However, interview  
19 transcripts were not provided to the participants for their review or correction. The analysis  
20 was led by the lead author (MFJ) with support from co-author JC, both of whom are Sierra  
21 Leoneans with training and experience in qualitative data analysis. A web-based  
22 qualitative software, Dedoose<sup>®</sup>,<sup>25</sup> was used to support the management and analysis of  
23 the data.  
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28 An initial set of deductive codes were first generated to reflect meaning units from the  
29 questions in semi-structured interview guide. The two analysts (MFJ and JC) generated  
30 additional inductive codes from reviewing the transcripts, then proceeded to code the  
31 transcripts, independently validated each other's application of codes, and resolved any  
32 discrepancies. Textual excerpts were extracted from Dedoose<sup>®</sup> for each code. The  
33 analysts iteratively reviewed, discussed, and interpreted the coded excerpts. The final  
34 codes were organized into mutually exclusive sub-categories and categories that  
35 reflected latent grouping of concepts. An iterative, interpretative process led to the higher-  
36 level grouping of the categories into themes. Preliminary results from the qualitative  
37 analysis were presented to stakeholders in Sierra Leone including the MoHS and other  
38 surveillance partners. Feedback received from the stakeholder presentation informed our  
39 interpretation and framing of the themes.  
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### 45 **Patient and public involvement**

46 Patients and/or the public were not involved in the design, conduct, reporting or  
47 dissemination plans of this research.  
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## 51 **Results**

### 52 **Demographic characteristics of respondents**

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3 Out of 32 respondents, 18 (56%) were female, 15 (47%) had no education or only primary  
4 school education, 8 (25%) were petty traders, and 22 (69%) self-identified as Muslim.  
5 Respondents' age ranged from 27 to 70 years; median age was 38 years. Respondents  
6 mostly comprised of relatives of deceased persons (29 out of 32), including their parents  
7 (n=12), spouses (n=5), children (n=4) (Table 1).  
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## 10 11 12 **Summary of themes**

13 Death reporting barriers were driven by the lack of awareness to report all deaths, lack of  
14 services linked to reporting (e.g. provision of ambulance services), negative experiences  
15 from the Ebola outbreak including prohibition of traditional burial rituals, perception that  
16 inevitable deaths do not need to be reported, and situations where prompt burials may be  
17 needed (Table 2). Facilitators of future willingness to report deaths were largely  
18 influenced by the perceived communicability and severity of the disease, unexplained  
19 circumstances of the death that need investigation, and the potential to leverage existing  
20 death notification practices through local leaders (Table 3). We did not observe any  
21 substantive differences in the thematic findings between the two districts and areas within  
22 districts.  
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### 27 28 **Barrier 1.1. Lack of awareness to report all deaths**

29 All respondents were unaware that they were required to report the household death after  
30 the end of the enhanced Ebola surveillance. Although some respondents knew that the  
31 1-1-7 line was still operational, they thought that only deaths that resembled Ebola  
32 needed to be reported.  
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36 *"... I do not think 1-1-7 is still existing because after Ebola we thought that was the end*  
37 *of 1-1-7. I'm only hearing this from you now. I always listen to the radio, but it has taken*  
38 *a long time I did not hear announcement that when someone dies, we are to call 1-1-7;*  
39 *even in the villages, that is why I did not remember to call 117."* – respondent from  
40 Western Area district  
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### 43 44 **Barrier 1.2 Lack of reciprocal benefit**

45 Respondents did not see a benefit to report deaths to the 1-1-7 system in a post-Ebola-  
46 outbreak setting. The notion of simply notifying 1-1-7 without any associated follow-up  
47 action or service was not appreciated by interviewees. To report deaths to 1-1-7,  
48 respondents said they would expect some follow-up action or service to be provided. For  
49 instance, they strongly recommended for prompt ambulance services for sick people and  
50 transportation of corpses through 1-1-7. Respondents expressed that such services  
51 would help motivate them in the future to use the system.  
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3 *“...if you take transport, like you take a taxi, to carry a [sick] person to the hospital; when*  
4 *you are going with him and there is traffic, they won't give you way. But let's say you call*  
5 *the 1-1-7 and the 1-1-7 comes with the ambulance, they will be able to give you way*  
6 *because they will take it as an emergency.” – respondent from Western Area district*  
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10 *“Then I would like them to give us ambulance in the community so when someone dies,*  
11 *they will be able to take the person and bury him/her quickly.” – respondent from Kenema*  
12 *district*  
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### 14 **Barrier 1.3 Perceived inevitability of certain deaths**

15 Respondents consistently expressed that they would not consider reporting deaths that  
16 they perceive to be inevitable due to old age, God's will, and long-term illness or disability.  
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20 *“The illness that affects someone for so long, for example stroke [complications], which*  
21 *leads to death, we will not report such death. For instance, in our community, we had a*  
22 *man by the name of xxx [redacted] who was affected by stroke and had suffered with it*  
23 *for a very long time; his family had tried all forms of medication, but he did not survive.*  
24 *So, with this type of death the chief themselves will just give permission to the people for*  
25 *burial rather than reporting to 1-1-7.” - respondent from Kenema district*  
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### 29 **Barrier 1.4 Needing to bury promptly**

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31 There were two main reasons why prompt burial emerged as a barrier to death reporting.  
32 Firstly, circumstances of the death influenced perceptions of when the corpse should be  
33 buried including the death of young children, someone who has been ill for a long time  
34 (despite their age), and someone who died from an accident (e.g. drowning, fire, road  
35 accident). Secondly, Muslim respondents emphasized that they need to bury the corpse  
36 within 24 hours to honour Islamic requirements; they feared that reporting may result in  
37 burial delay based on their experiences from the Ebola outbreak. One respondent gave  
38 an example of how same-day burial was done as per Islamic tradition:  
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43 *“I went straight to the Imams [at the local mosque] and notified them [of the death]. The*  
44 *Imam came and asked us to take the corpse to the Mosque. The corpse laid there until*  
45 *around twelve o'clock when they washed and wrapped it with Kasankay [white] cloth. We*  
46 *waited for the time ... that is two o'clock, then we went to bury him. After the burial the*  
47 *'Jamat' [mosque congregation] met here [at our house], ate and prayed for him before*  
48 *everyone went back to their homes” – respondent from Western Area district*  
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### 52 **Barrier 1.5 Negative experiences from the Ebola outbreak**

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3 The 1-1-7 system was intricately linked to its widespread use during the Ebola outbreak  
4 in Sierra Leone and could not be separated by respondents' negative experiences with  
5 how some deaths were handled by burial teams during the outbreak.  
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8 *"The family would not get access to the corpse or even go close to it. So this knowledge*  
9 *had existed within people that 1-1-7 is not a call to make in order to get help in the burial*  
10 *of their loved ones. They will only come to do whatever they feel like, whether it is in a*  
11 *respectful way or not; they don't care. So, with that, people in the community do not favour*  
12 *the 1-1-7. Because how we expect them to bury our loved ones it's the opposite [that they*  
13 *will do]."* – respondent from Kenema district  
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17 Most participants cited that burial methods used to bury their loved ones during the Ebola  
18 outbreak discouraged them from reporting to 1-1-7.  
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21 *"This 1-1-7 line...I don't want it. I want us to be respecting the [dead] people because the*  
22 *1-1-7 was not burying our people properly. So, we are burying our people. Let government*  
23 *leave it [burial] up to us. If a doctor check the body [that's fine], but don't let the 1-1-7 -*  
24 *come here until we have buried the corpse"* – respondent from Kenema district  
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28 Dissatisfaction with burial methods was coupled with discontent about delays by burial  
29 teams when they were responding to death alerts during the Ebola outbreak.  
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32 *"Like during the Ebola time if you call...they [burial teams] will not come [on time]. They*  
33 *will abandon them for some time before coming to take the person. All they care about is*  
34 *for the people to call them... They need to put more efforts into how they respond and*  
35 *treat the people with respect"* – respondent from Western Area district  
36  
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38

39 Fear of being quarantined was also mentioned as a barrier for reporting deaths to 1-1-7  
40 as well as the sounds made by the ambulances and spraying of the house with chlorine,  
41 which were all associated with Ebola-related stigma. Respondents expressed that just  
42 the thought of 1-1-7 alone would usually bring back bitter memories of Ebola.  
43  
44

45 *"The first time I heard about 1-1-7 was during Ebola and each time I hear about 1-1-7 I*  
46 *think about Ebola at once. The moment they talk about 1-1-7, it's a worry for me because*  
47 *during that period, when people see 1-1-7 coming, everybody would run away. When they*  
48 *come to a place, they will spray chlorine all over and everybody avoided body contact like*  
49 *nobody's business, and that worried us too much. That is why we hardly forget about 1-*  
50 *1-7"* – respondent from Western Area district  
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## 54 **Facilitator 1.1 Presence of Ebola-like symptoms**

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3 Knowledge gained during the Ebola outbreak influenced respondents' perceptions of the  
4 deaths that should be reported to the 1-1-7 system after the outbreak ended. Participants  
5 expressed that they would report a death if it resembled Ebola or Lassa fever, especially  
6 in situations where the person bled before dying.  
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9  
10 *“For any death pertaining to what government told us [we need to report]. That of a bad*  
11 *disease like Ebola, Lassa fever...The people around will not even dare to touch the*  
12 *person, because it is a transferable disease and it is more common in Eastern Province.”*  
13 *– respondent from Kenema district*  
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### 16 **Facilitator 1.2 Sudden and unexplained deaths**

17 Sudden and unexplained deaths wherein the person was not previously sick were  
18 perceived as needing to be reported to the authorities for further investigations.  
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21 *“Like I said before, when someone dies abruptly, and nothing was wrong with him [before*  
22 *dying]. I will just be looking at him, I will not have the knowledge to know the cause of*  
23 *death, I will not have the machine to show that this is the sickness that caused the death*  
24 *or whether he just fell down and died or whether he just sat down and died. When you go*  
25 *to a medical person [through 1-1-7], he can confirm that this is the cause of the death. If*  
26 *the doctor has confirmed that for real he has died, what can I do?” - respondent from*  
27 *Western Area district*  
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### 31 **Facilitator 1.3 Existence of other local reporting mechanisms**

32 Informing local leaders—such as religious leader, chiefs, and village headmen—about  
33 the death was a common practice that most respondents mentioned. In Kenema, some  
34 participants cited that informing local and traditional heads granted them permission for  
35 burial without needing to report to the 1-1-7 system. The reporting of these deaths to only  
36 local leaders showed that respondents were generally willing to report the deaths but only  
37 did so in localized ways outside of the 1-1-7 system.  
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42 *“Well you will have to go and say to the chief or authority that someone has died amongst*  
43 *us. The chief will ask what happened to that person. The chief will ask you... and you will*  
44 *say [something like] it was a cold, or after two three days I noticed that this person was*  
45 *ill. God has taken his life. This is the way he died. The chief will ask you; and you should*  
46 *answer. You have the chance to report to the police station. You have the chance to*  
47 *report to the chief. And you have the chance to call the family members” – respondent*  
48 *from Kenema district*  
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## 53 **Discussion**

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3 In the aftermath of the Ebola outbreak in Sierra Leone, we identified barriers that  
4 prevented people from reporting deaths to the authorities, and we also explored  
5 facilitators that would encourage death reporting as part of routine mortality surveillance.  
6 Barriers uncovered in our assessment were linked to a lack of awareness to continue  
7 reporting all deaths after enhanced Ebola surveillance ended as well as the lack of  
8 reporting benefits. Respondents were unaware of the requirement to continue reporting  
9 all deaths after the enhanced surveillance period, and they were under the impression  
10 that only deaths resembling Ebola should be reported to the 1-1-7 system. Consequently,  
11 other deaths that were not suspected of Ebola were not reported to the 1-1-7 system. A  
12 separate assessment found that after the outbreak ended, people were more motivated  
13 to report deaths to the 1-1-7 system if Ebola-like symptoms were present in the  
14 decedent.<sup>15</sup> Our findings further demonstrated that although respondents did not report  
15 deaths through the 1-1-7 system as mandated by their government, they informed local  
16 councils and local leaders about the deaths. Therefore, integrating localized practices for  
17 death reporting into routine surveillance mortality systems may help optimize the number  
18 of deaths captured. Respondents complained about the lack of any reporting benefits  
19 associated with death reporting in a post-Ebola-outbreak context. They wanted  
20 ambulance services to be linked to 1-1-7 reporting as done during the outbreak.  
21 Contextually, past experiences from the Ebola outbreak served as both facilitators and  
22 barriers. Past outbreak experiences reinforced the importance of reporting when Ebola is  
23 suspected to avoid transmission risks. On the other hand, past experiences that involved  
24 dissatisfaction with how burials were handled during the outbreak may have discouraged  
25 reporting to the 1-1-7 system.  
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35 Despite efforts to promote reporting of all deaths during the outbreak, communities  
36 continued to express dissatisfaction with how their loved ones were buried and there were  
37 instances of secret burials that occurred outside of the safe burial process, which may  
38 have been due to discontent with safe burials or wanting to comply with secret society  
39 practices.<sup>26 27</sup> Dissatisfaction with the burial process derailed community trust to report  
40 deaths. Although dissatisfaction persisted regarding Ebola safe burial processes,  
41 communities were willing to comply with reporting because they wanted to help end Ebola  
42 transmission in the country.<sup>28</sup> In the waning period of the Ebola outbreak in 2015, an  
43 assessment of the community event-based surveillance showed that over 12,000 reports  
44 were submitted and investigated, out of which 287 met case-definition for suspected  
45 Ebola and 16 were confirmed positive for Ebola.<sup>29</sup> In that assessment, it was revealed  
46 that community event-based surveillance detected four new Ebola cases that were not  
47 epidemiologically linked and could have gone undetected.  
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53 The Ebola outbreak was tragic in many ways as demonstrated by the thousands of lives  
54 lost and the unquantifiable suffering inflicted upon the people of Sierra Leone. The pain  
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3 and misery they endured was evident in our assessment when they talked about their  
4 experiences during the outbreak. Even though people were sometimes dissatisfied with  
5 how the burials were handled or delayed, they recognized that it was to their benefit to  
6 have a safe burial to avoid household transmission risk. Nevertheless, normalizing death  
7 reporting during the outbreak required gaining the trust of communities by engaging them  
8 to appreciate the benefits of reporting. The halting of ambulance services after the Ebola  
9 outbreak ended prompted people to question why those services were only provided  
10 during the outbreak response.  
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15 The principle of *positive reciprocity* has been well established in social psychology,<sup>30-32</sup>  
16 which implies that people become motivated to comply with a request when they receive  
17 something in-return for their action. This notion is also supported in the health behaviour  
18 literature. For instance, applications of the Health Belief Model have shown that the  
19 perceived benefit associated with a behaviour is a strong predictor of engaging in the  
20 behavior.<sup>33 34</sup> Our findings are consistent with notions of reciprocity; respondents  
21 expressed that they will be willing to report deaths if tangible benefits are provided in  
22 return for complying with reporting.  
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27 Although it took time to establish trust between the Government and communities to  
28 achieve high level of death reporting during the Ebola outbreak,<sup>13 35 36</sup> communities had  
29 eventually come to expect certain services in return after reporting a death (transportation  
30 to the burial ground and laboratory testing of the corpse) and information (communication  
31 of laboratory results to the family).<sup>13 28 35</sup> Although similar services may not be feasible or  
32 applicable in the routine mortality surveillance environment, there is an opportunity at the  
33 community level to provide aggregated information about the deaths back to the  
34 community (e.g. through community leaders and community-based organizations) as a  
35 form of reciprocal action to foster dialogue on addressing community level health  
36 threats.<sup>37</sup> Another key finding from our assessment is that people want help for sick family  
37 members who are still alive. Linking the country's expanding fleet of 170 ambulances<sup>38</sup>  
38 with the 1-1-7 tollfree line could help promote a feeling of reciprocity in addressing other  
39 health needs in the community for people experiencing health emergencies.  
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### 45 **Limitations**

46 The exploratory qualitative assessment is subject to several limitations. The results are  
47 not generalizable beyond the 32 individuals interviewed. While this is an inherent  
48 limitation to most qualitative research, it is important to note that we never intended to  
49 produce generalizable results. Instead, our aim was to generate in-depth understanding  
50 of barriers and facilitators of death reporting with themes that may be transferrable to  
51 other local contexts. It is possible that some respondents may have provided socially  
52 desirable responses in terms of facilitators to report to match previously heard messages  
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3 during the Ebola outbreak. Because theoretical sampling was not used, as done in  
4 grounded theory approaches for example,<sup>39</sup> other individuals outside of family members  
5 (e.g. health workers, local city council officials) were not interviewed. Additional research  
6 with more diverse stakeholder may help shed light on additional barriers and facilitators.  
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## 10 **Conclusion**

11 Respondents misunderstood the *policy of reporting all deaths* after the end of enhanced  
12 Ebola surveillance in Sierra Leone, which may have been due to communication gaps in  
13 the government's official announcement of the mandate. We found that respondents  
14 perceived that only suspected Ebola deaths should be reported to the 1-1-7 system. The  
15 lack of awareness to report all deaths and the lack of perceived reporting benefits were  
16 the main reasons for failure to report the deaths. The post-outbreak death reporting policy  
17 should consider integrating community level benefits to encourage reporting. Existing  
18 practices for informal death notification through local leaders should also be leveraged to  
19 capture community-based deaths that may be missed by the formal reporting system. For  
20 example, establishing a reporting mechanism through trusted local religious and  
21 traditional leaders could help to strengthen reporting levels since these leaders are almost  
22 immediately notified of deaths that occur in their communities. Improving routine death  
23 reporting may be supported by well-planned social mobilization efforts to educate  
24 communities about the death reporting policy, promote the reporting benefits, and  
25 facilitate optimal compliance.  
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36  
37

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39 MFJ led the conceptualization and design of the assessment with primary support from  
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53  
54

## 55 **Competing interest**

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3 The authors have none to declare.  
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### 6 **Data availability**

7 All relevant data are presented. No additional data available.  
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9

### 10 **Ethics approval**

11 The assessment was approved by the Sierra Leone MoHS as a routine public health  
12 activity. In addition, the Center for Global Health at the U.S. Centers for Disease Control  
13 and Prevention approved the assessment as a program evaluation activity (CGH HSR  
14 Tracking # 2017-327).  
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### 17 **Disclaimer**

18 The findings and conclusions in this report are those of the authors and do not  
19 necessarily represent the official position of the U.S. Centers for Disease Control and  
20 Prevention, Karolinska Institutet, eHealth Africa, or Sierra Leone Ministry of Health and  
21 Sanitation.  
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## TABLES

**Table 1. Sociodemographic characteristics of respondents, Sierra Leone, 2017**

<b>Characteristic</b>	<b>Number of respondents (N = 32)</b>
<b>Sex</b>	
Female	18
Male	14
<b>Education</b>	
None or primary only	15
Secondary or higher	17
<b>Religion</b>	
Muslim	22
Christian	10
<b>Occupation</b>	
Petty trader	8
Skilled labor	7
Private business	4
Teacher	3
Student	3
Unemployed	3
Driver / bike rider	2
Farmer	1
Civil service	1
<b>Age (years)</b>	
Median = 38	
21-30	6
31-40	15
41-50	4
51-60	6
61-70	1
<b>Relationship to the deceased person</b>	
Parent	12
Spouse	5
Child	4
Grand parent	3
Non-relative	3
Sibling	3
Other relative	2

**Table 2. Thematic area on barriers to reporting deaths in the aftermath of the Ebola outbreak, Sierra Leone, 2017**

Code	Category	Theme
1.1.1 Reporting only required during Ebola	1.1 Lack of awareness to report all deaths	Barriers to reporting deaths in the aftermath of the Ebola outbreak
1.1.2 No more need to report to 1-1-7		
1.1.3 Only Ebola-like deaths should be reported		
1.2.1 No services for people while alive	Lack of reciprocal benefit	
1.2.2 Too much focus on dead people		
1.2.3 Nothing done for sick people		
1.2.4 Nothing happens if you report		
1.2.5 No help with burial		
1.2.6 Just a government line		
1.3.1 Old-age / God's time	1.3 Perceived inevitability of certain deaths	
1.3.2 Long-term illness or disability		
1.4.1 Islamic requirement to bury within 24 hours	1.4 Needing to bury promptly	
1.4.2 Body recovered from drowning		
1.4.3 Body recovered from fire		
1.4.4 Young child		
1.4.5 Sick for long time		
1.5.1 Wanting to forget about 117	1.5 Negative experiences from the Ebola outbreak	
1.5.2 Reporting brings sadness to family		
1.5.3 Painful memory of Ebola		
1.5.4 Burial delays during Ebola		
1.5.5 Restrictions on traditional burials		
1.5.6 Fear of quarantine		
1.5.7 Fear of ambulance		
1.5.8 Line was used during Ebola		
1.5.9 Don't like the number		

**Table 3. Thematic area on facilitators of future intention to report deaths, Sierra Leone, 2017**

Code	Category	Theme
1.1.1 Resembling Ebola	1.1 Presence of Ebola-like symptoms	Facilitators of willingness to report deaths in the future
1.1.2 Resembling Lassa		
1.1.3 Bleeding before dying		
1.2.1 Sudden death without illness	1.2 Sudden and unexplained death	
1.2.2 Wanting to know cause of death		
1.3.1 Informing chief	1.3 Existence of other local reporting mechanisms	
1.3.2 Informing religious leaders		
1.3.3 Informing elders		
1.3.4 Inform City Council for burial permit		
1.3.5 Informing Office of Births and Deaths for death certificate		

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## Supplemental Material: Interview Guide

### Part A: Community Level Practices and Perceptions

#### **1. What usually happens after someone dies in this community (who does what/when/how)?**

- Probe: What are the most important things to do immediately after someone dies?
- Probe: How is the funeral usually handled / who participates?
- Probe: How is the burial usually handled / who participates?
- Probe: Who is notified of the death, and when and how are they notified?
- Probe: To what extent does the type of death influence how the funeral/burial is handled, and who is informed about it?

#### **2. Who conducts/helps with the funeral/burial?**

- Probe: Please tell us why these particular people engaged

#### **3. Overall, what is the current practice for reporting deaths to authorities (local, district, national 1-1-7) in this community?**

- Probe: What types of deaths are supposed to be reported?
- Probe: When should the death be reported, and to whom?
- Probe: How should the death be reported?
- Probe: What usually happens after the death is reported?

#### **4. What usually discourages people from reporting the death of a loved one or neighbor?**

- Probe: is there any type of death that people are inclined not to report? What are the reasons for this?
- Further probe for:
  - Time of death
  - Burial delay
  - Age of the deceased
  - Religious reasons
  - Other
- Probe: What questions do you have for authorities about reporting deaths?

#### **5. What would encourage or motivate you to report the death of a loved one or neighbor to 117 in the future?**

- Probe: What types of deaths are you most likely to report? What are the reasons for this?
- Probe: What should be done differently to improve reporting?
- Probe: What new things would you like to see happen?
- Probe: Who can help improve death reporting in this community, if any?

### Part B: Personal Experience and Perceptions

Thanks for your responses. I appreciate your openness and willingness to discuss these issues. You already told you us that you did not report the recent death of your loved one. Now, I would like to learn more about that particular situation.

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**6. Please describe for me the circumstances surrounding the death of your loved one.**

- Probe: What was their health situation in the months leading up to their death?
- Probe: What signs/symptoms were reported or shown leading to the death?
- Probe: Were there suspicious aspects of the illness? If so, please describe them.
- Probe: What type of care had they received (traditional vs medical, etc)?
- Probe: Where and when did the death occur?

**7. Please describe for me the steps that you or the family took after the death:**

- Probe: What did you or the family first do? Why was this important?
- Probe: Who did you inform about the death? And how were they informed?
- Probe: How long did it take from time of death to the time of burial?

**8. Tell us more about burial processes:**

- Probe: Did you get permission for the burial? If so, how and from whom did you get approval to carry out the burial?
- Probe: Where was the body buried (public site vs private vs family land)?
- Probe: What ceremonies were conducted during the burial? (*note to interviewer: don't ask about any specific secrete ceremonies or ritual*)
- Probe: Who participated in the burial? Why were their participation important?

**9. When you hear "1-1-7" what comes to mind?**

- Probe: What are your opinions of 117?
- Probe: Do you think this number should be kept or change?
- Probe: Please tell us why it should be kept or changed.
- Probe: How can the 117 system be improved?

**10. Please tell me the reason why you decided not to report the death to the 1-1-7 National Call Center:**

- Probe: Understanding of government requirements to report all deaths to 117 (or lack thereof)?
- Probe: Concerns about funeral/burial delays?
- Probe: Nature or circumstances of the death?
  - Accident and pregnancy related
  - 'Natural causes'
  - Death that resembles Ebola or Lassa
  - Age of the deceased

**11. Would you consider reporting the death of a loved one to 117 in future?**

- Probe: If so please tell us what may have changed since the present case
- Probe: What types of deaths are you most likely to report? What are the reasons for this?
- Probe: What should be done differently?
- Probe: What new things would you like to see happen?
- Probe: Who can help improve death reporting in this community?

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For peer review only

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**