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# Behavioral surveillance during and after the 2014–2016 Ebola outbreak in Sierra Leone

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# Behavioral surveillance during and after the 2014–2016 Ebola outbreak in Sierra Leone

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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**Dedication**

This doctoral thesis is dedicated to the thousands of people whose lives were sadly cut short by Ebola and to those who survived the devasting ordeal during the 2014–2016 outbreak that affected multiple countries in West Africa. It is further dedicated to the countless individuals, communities, and organizations that worked tirelessly to end the outbreak.

# ABSTRACT

**Background**: The first documented case of Ebola Virus Disease (Ebola) in Sierra Leone was confirmed in May 2014 in Kailahun district after cases had been reported in Guinea and Liberia. Ebola is transmitted through contact with infected blood, stool, and other bodily fluids. Transmission risk in West Africa was driven by traditional burials involving physical contact with corpses, caring for infected persons without adequate protection, and delaying medical care. Sexual transmission due to viral persistence in the semen of male survivors posed an additional risk. Experimental Ebola vaccine candidates were implemented to curb transmission among health workers and other high–risk individuals. Reporting of all deaths to a national toll–free line (1–1–7 system) was mandated so that burials could be handled by teams trained in infection prevention and control.

**Aim**: To understand trends in population–level Ebola knowledge, attitudes and prevention practices throughout different stages of the outbreak, acceptability of experimental Ebola vaccines at the peak of the outbreak and reporting of deaths after the outbreak ended.

**Methods**: Four cross–sectional household surveys (N=10,603) were conducted using multi–stage cluster sampling in August 2014, October 2014, December 2014, and July 2015 to measure trends in Ebola–related knowledge, attitudes, and prevention practices (KAP). In–depth interviews (N=31) and focus group discussions (N=35) were conducted with health workers, frontline workers, and community members between December 2014 and January 2014 to understand acceptability of Ebola vaccine. Population–level demand for Ebola vaccine was assessed in a national household survey in December 2014 (N=3,540). After the outbreak ended, in 2017, motivations and barriers related to death reporting were assessed through a national telephone survey (N=1,291) and in–depth interviews (N=32). Quantitative data were analyzed using multilevel and ordered logistic regression modeling to examine various associations. Content analysis was used to identify cross–cutting themes in the qualitative data.

**Results**: Ebola–related knowledge, attitudes, and prevention practices improved throughout the outbreak, especially in high–transmission regions. For example, when comparing before and after the peak of the outbreak, avoidance of physical contact with suspected Ebola patients nearly doubled in high–transmission areas (adjusted odds ratio (aOR) 1.9 [95% confidence interval 1.4–2.5]). Acceptability of Ebola vaccine was discouraged by safety related concerns but encouraged by altruistic motivation to help end the outbreak. Nationally, 74% of the public expressed high demand for Ebola vaccine, which was associated with wanting to be the first to get the vaccine compared to wanting politicians to be the first to get the vaccine (aOR 13.0; [7.8–21.6]). The number of deaths reported to the 1–1–7 system nationally in 2017 after the outbreak had ended represented nearly 12% of the expected deaths in the country versus almost 34% in 2016 and as much as 100% in 2015; albeit not accounting for potential duplicate reporting. After the Ebola outbreak, motivation to report deaths was greater if the decedent experienced one or more Ebola–like symptoms compared

to none (aOR 2.3 [1.8–2.9]. Barriers to reporting deaths after the outbreak were driven by the lack of awareness to report all deaths, lack of reciprocal benefits linked to reporting, and negative experiences from the outbreak.

**Conclusions**: Ebola prevention practices improved nationally during the outbreak in Sierra Leone, but the magnitude of improvement was greater in high–transmission regions compared to low–transmission regions. Understanding the drivers of Ebola vaccine acceptability and demand was important to inform ethical and cultural considerations in the implementation of experimental Ebola vaccines. While the 1–1–7 system was ramped up to capture nearly all deaths during the outbreak, reporting substantially declined after the outbreak ended. Failure to report deaths after the outbreak was due to lack of awareness to report all deaths and lack of perceived benefits to report in the post–Ebola–outbreak setting. Nevertheless, knowledge and experiences from the Ebola outbreak increasingly motivated people to report deaths that exhibited Ebola–like symptoms. Post–Ebola–outbreak settings offer an opportunity to implement routine mortality surveillance, however, substantial social mobilization efforts may be required to optimize reporting.

# LIST OF SCIENTIFIC PAPERS

I. **Jalloh MF**, Sengeh P, Bunnell RE, Jalloh MB, Monasch R, Li W, Mermin J, DeLuca N, Brown V, Nur SA, August EM, Ransom RL, Namageyo–Funa A, Clements SA, Dyson M, Hageman K, Pratt SA, Nuriddin A, Carroll DD, Hawk N, Manning C, Hersey S, Marston BJ, Kilmarx PH, Conteh L, Ekström AM, Zeebari Z, Redd JT, Nordenstedt H, Morgan O. Evidence of behaviour change during an Ebola virus disease outbreak, Sierra Leone. *Bulletin of the World Health Organization*. 2020;98(5):330–340B. doi: 10.2471/BLT.19.245803.

II. **Jalloh MF,** Jalloh MB, Albert A, Wolff B, Callis A, Ramakrishnan A, Cramer E, Sengeh P, Pratt SA, Conteh L, Hajjeh R, Bunnell R, Redd JT, Ekström AM, Nordenstedt H. Perceptions and acceptability of an experimental Ebola vaccine among health care workers, frontline staff, and the general public during the 2014–2015 Ebola outbreak in Sierra Leone. *Vaccine*. 2019;37(11):1495–1502. doi: 10.1016/j.vaccine.2019.01.046.

III. **Jalloh MF**, Wallace A, Bunnell RE, Carter R, Redd JT, Nur SA, Zeebari Z, Ekström AM, Nordenstedt H. Ebola vaccine? Family first! Evidence from using a brief measure on Ebola vaccine demand in a national household survey during the outbreak in Sierra Leone. *Vaccine*. 2020; 8(22):3854–3861. doi: 10.1016/j.vaccine.2020.03.044.

IV. **Jalloh MF**, Kaiser R, Diop M, Jambai A, Redd JT, Bunnell RE, Castle E, Alpren C, Hersey S, Ekström AM, Nordenstedt H. National reporting of deaths after enhanced Ebola surveillance in Sierra Leone. *PLOS Neglected Tropical Diseases*. 2020. doi: 10.1371/journal.pntd.0008624

V. **Jalloh MF**, Kinsman J, Conteh J, Kaiser R, Jambai A, Ekström AM, Bunnell RE, Nordenstedt H. Barriers and facilitators to death reporting following Ebola surveillance in Sierra Leone: Implications for sustainable mortality surveillance. Submitted.

These papers are referred to in the text by their Roman numerals [I–V].

# CONTENTS

# LIST OF ABBREVIATIONS

| | |
|---|---|
| aOR | Adjusted Odds Ratio |
| CDC | U.S. Centers for Disease Control and Prevention |
| CI | Confidence Interval |
| COREQ | Consolidated Criteria for Reporting Qualitative Research |
| CRVS | Civil Registration of Vital Statistics |
| DRC | The Democratic Republic of Congo |
| Ebola | Ebola Virus Disease |
| EFA | Exploratory Factor Analysis |
| FGD | Focus Group Discussion |
| HBM | Health Belief Model |
| HCW | Healthcare Worker |
| IDI | In–depth Interview |
| IFRC | International Federation of Red Cross and Red Crescent Societies |
| KAP | Knowledge, Attitudes, and Practices |
| MoHS | Ministry of Health and Sanitation in Sierra Leone |
| MSW | Ministry of Social Work |
| NERC | National Ebola Response Center |
| NGO | Non–Governmental Organization |
| ODK | Open Data Kit |
| OR | Odds Ratio |
| rVSV–ZEBOV–GP | Recombinant, Replication–competent, Vesicular Stomatitis Virus–based vaccine expressing the Glycoprotein of a Zaire Ebolavirus |
| SCT | Social Cognitive Theory |
| SEF | Social Ecological Framework |
| SOP | Standard Operating Procedures |
| STROBE | Strengthening the Reporting of Observational Studies in Epidemiology |
| TPB | Theory of Planned Behavior |
| UNICEF | United Nations Children's Fund |
| WFP | World Food Program |
| WHO | World Health Organization |

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# 1 BACKGROUND

## 1.1 EBOLA OUTBREAKS AND INCIDENTS BETWEEN 1976–2012

Ebolavirus is among the world's deadliest high–consequence pathogens. Although most people may not have heard about this deadly pathogen until the large 2014-2016 outbreak in West Africa, there had been over 20 documented outbreaks of Ebola Virus Disease (Ebola) across seven countries in sub–Saharan Africa between 1976 and 2012.[1–21] These prior outbreaks resulted in almost 2,300 cases and 1,500 deaths combined (Figure 1).[21] The first known outbreak of Ebola occurred in 1976 in Bumba Zone of Zaire–now the Democratic Republic of Congo (DRC). The outbreak was detected near the *Ebola River*. It resulted in 318 cases of viral hemorrhagic fever with 88% case fatality ratio (CFR).[1] A similar hemorrhagic fever occurred around the same period in 1976 in Sudan. It was subsequently attributed to the Sudan ebolavirus, which resulted in 284 cases but with a lower CFR (~52%).[2] A third strain, the Reston ebolavirus, was discovered in a primate facility in Philippines in 1989.[22] Although three workers exposed to the virus in Philippines developed antibodies against it, none experienced Ebola Virus Disease.[23] Reston ebolavirus was shortly thereafter detected in the United States in 1990 among monkeys imported from Philippines[23] – four animal handlers developed Ebola antibodies without experiencing symptoms of the disease.[24] A new strain, Taï Forest ebolavirus, infected a scientist conducting an autopsy on a Chimpanzee in 1994 in Cote D'Ivoire; he developed Ebola symptoms and later recovered from the disease.[25]  In 2007, Uganda reported a new disease–causing strain, Bundibugyo ebolavirus, which had a lower CFR (~32%) compared to Zaire and Sudan strains.[16]
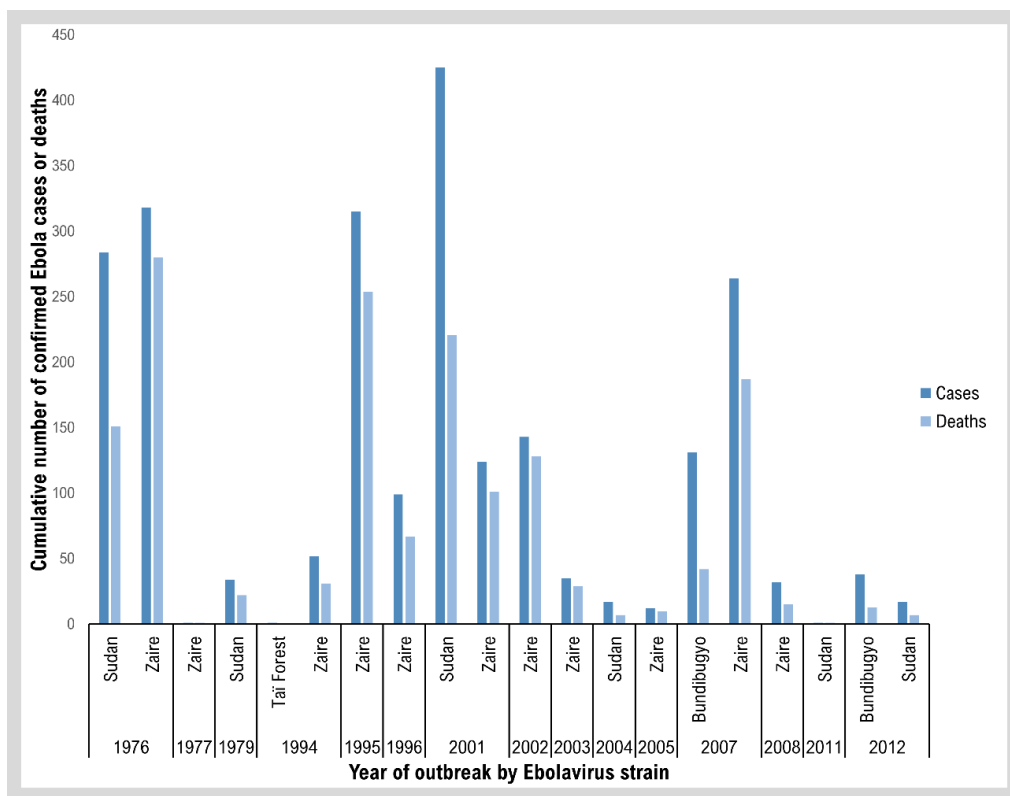


**Figure 1. Distribution of confirmed Ebola cases by the virus strain, 1976–2012**

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Several other incidents of persons becoming infected with Ebola in laboratory settings have also been documented in the United Kingdom and Russia.[26][27] Between 1976 and 2012, the highest number of confirmed Ebola cases (of any strain) was recorded in DRC (n=968), followed by Uganda (n=574) and Sudan (n=335). The Zaire ebolavirus strain was responsible for ~60% of all confirmed cases and ~70% of all confirmed deaths during this period. The average CFR for the Zaire ebolavirus outbreaks was ~79% compared to ~53% and ~33% for the Sudan and Bundibugyo strains respectively. The single outbreak of just one case of the Taï Forest ebolavirus did not result in a death. The true CFR of the Taï Forest strain is unknown because there has only been one documented case of it that did not result in a death (Table 1).

**Table 1. Documented Ebola cases and deaths by virus strain and country, 1976–2012**

| Year | Country | Cases* | Deaths* | CFR | Ebolavirus strain |
|------|---------|--------|---------|-----|-------------------|
| 1976 | DRC | 318 | 280 | 88% | Zaire |
| 1976 | Sudan | 284 | 151 | 53% | Sudan |
| 1977 | DRC | 1 | 1 | 100% | Zaire |
| 1979 | Sudan | 34 | 22 | 65% | Sudan |
| 1994 | Cote D'Ivoire | 1 | 0 | 0% | Taï Forest |
| 1994 | Gabon | 52 | 31 | 60% | Zaire |
| 1995 | DRC | 315 | 254 | 81% | Zaire |
| 1996 | Gabon | 37 | 21 | 57% | Zaire |
| 1996 | Gabon | 60 | 45 | 75% | Zaire |
| 1996 | South Africa | 2 | 1 | 50% | Zaire |
| 2001 | Gabon | 65 | 58 | 89% | Zaire |
| 2001 | Republic of the Congo | 59 | 43 | 73% | Zaire |
| 2001 | Uganda | 425 | 221 | 52% | Sudan |
| 2002 | Republic of the Congo | 143 | 128 | 90% | Zaire |
| 2003 | Republic of the Congo | 35 | 29 | 83% | Zaire |
| 2004 | Sudan | 17 | 7 | 41% | Sudan |
| 2005 | Republic of the Congo | 12 | 10 | 83% | Zaire |
| 2007 | DRC | 264 | 187 | 71% | Zaire |
| 2007 | Uganda | 131 | 42 | 32% | Bundibugyo |
| 2008 | DRC | 32 | 15 | 47% | Zaire |
| 2011 | Uganda | 1 | 1 | 100% | Sudan |
| 2012 | DRC | 38 | 13 | 34% | Bundibugyo |
| 2012 | Uganda | 11 | 4 | 36% | Sudan |
| 2012 | Uganda | 6 | 3 | 50% | Sudan |

*Data source: U.S. Centers for Disease Control and Prevention; https://www.cdc.gov/vhf/ebola/history
CFR = case fatality ratio; DRC = The Democratic Republic of Congo

Standard WHO case definitions for Ebola during an active outbreak are provided in Table 2. According to WHO guidance, Ebola case definition may be modified to reflect to the location–specific epidemiological features of the outbreak.[28]

**Table 2. Definitions of suspected, probable, and confirmed Ebola cases during an outbreak**

| Classification | Definition |
| --- | --- |
| Suspected case | A. "Any person, alive or dead, suffering or having suffered from a sudden onset of high fever and having had contact with:<br>– a suspected, probable or confirmed Ebola case;<br>– a dead or sick animal; OR<br>B. Any person with sudden onset of high fever and at least three of the following symptoms: headaches, lethargy, anorexia / loss of appetite, aching muscles or joints, stomach pain, difficulty swallowing, vomiting difficulty breathing, diarrhea, hiccups; OR<br>C. Any person with inexplicable bleeding; OR<br>D. Any sudden, inexplicable death." |
| Probable case | A. "Any suspected case evaluated by a clinician; OR<br>B. Any deceased suspected case (where it has not been possible to collect specimens for laboratory confirmation) having an epidemiological link with a confirmed case." |
| Confirmed | "Any suspected or probably cases with a positive laboratory result.<br>Laboratory confirmed cases must test positive for the virus antigen,<br>either by detection of virus RNA by reverse transcriptase–polymerase chain reaction (RT–PCR), or by detection of IgM antibodies directed against Ebola." |
| None–case | "Any suspected or probable case with a negative laboratory result. "Non–case" showed no specific antibodies, RNA or specific detectable antigens." |

Source: Standard definitions by the World Health Organization;
https://www.who.int/csr/resources/publications/ebola/case–definition/en

## 1.2   OUTBREAK IN WEST AFRICA (2014–2016)

In March 2014, the World Health Organization (WHO) declared an Ebola outbreak in Guinea – though initial cases had been suspected in Guékédou as early as December 2013.[29] The ensuing outbreak rapidly spread to neighboring Liberia and Sierra Leone,[30] and was declared a Public Health Emergency of International Concern by WHO in August 2014.[31] The outbreak in West Africa was caused by the Zaire ebolavirus.[21][29] By the time the protracted outbreak was declared over in 2016[32], 28,652 cases (suspected, probable, and confirmed) had been reported across 10 countries spanning three continents through local transmissions or imported cases, and resulted in 11,325 Ebola deaths.[33][34] Against a backdrop of fragile health systems,[35] Sierra Leone, Liberia, and Guinea were most heavily affected by the outbreak.[21] Sierra Leone recorded the highest number of cases and deaths.[34] The overall CFR across the three countries has been estimated to be ~65% among clinical cases with known outcomes.[36] Other countries with Ebola cases derived from the West Africa outbreak included Nigeria, Mali, Senegal, Spain, Italy, United Kingdom, and United States.[21] In Nigeria, prompt and effective contact tracing along with other control measures have been credited for curbing a potentially devastating outbreak in the highly populated commercial hub of Lagos in July–August 2014.[37][38] In 2018, a sixth strain, Bombali ebolavirus, was discovered in bats by researchers in Sierra Leone, but with no evidence to date of capability to cause disease in humans.[39] Sierra Leone, Guinea, Liberia, and Côte d'Ivoire are members of the Mano River

Union—an international association for economic, social, and cultural cooperation among the four sub–regional member states.[40] The three Ebola affected countries, therefore, had a long history of cross–country collaborations before the outbreak that enabled them to eventually institute cross–border cooperation measures in key areas of responding to the Ebola outbreak including for border screenings, contact tracing, and overall sub–regional coordination. The timelines of key events during the outbreak in West Africa have been illustrated in Figure 2.
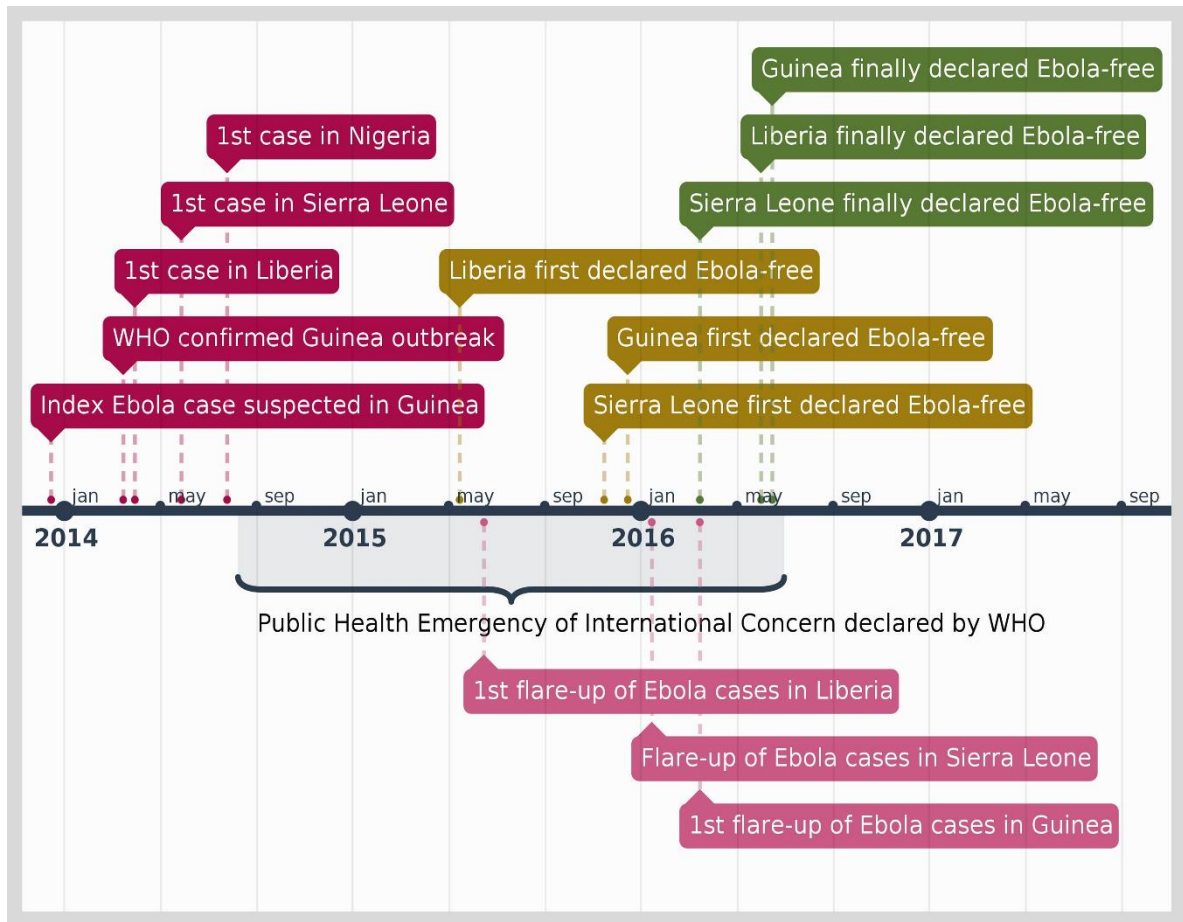


**Figure 2. Timelines of key events during the Ebola outbreak in West Africa, 2013–2016**

## 1.2.1  Transmission risks

Ebola is thought to be initially transmitted from an infected animal such as bat or nonhuman primate to human; possibly through handling or eating of infected animals (bushmeat[*]) as well as eating fruits bitten by bats.[41] Once in the human population, Ebola is transmitted from person–to–person through contact with infected blood, stool, semen, or other bodily fluids[42 43] – especially during the late stages of the disease when an infected person is most contagious.[44] Understanding the full transmission dynamics of the epidemic in West Africa is complicated partly due to the under–reporting of cases.[45] However, data from the affected countries in West Africa consistently point to Ebola transmission risks associated with traditional burial practices,[41 46–48] caring for infected persons,[41] and delays in seeking medical

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[*] Bushmeat broadly refers to wild animals that are hunted and prepared for consumption (e.g. bats and monkeys)

care.[49 50] Sexual transmissions of ebolavirus were documented[51 52] and attributed to viral persistence in the semen of male survivors.[53–58] Containing Ebola transmission requires reducing the basic reproduction number ($R_0$) by limiting the number of secondary infections derived from a case of Ebola.[59 60]

### 1.2.2   Caring for Ebola patients

Ebola infections have been widely documented among health care workers (HCWs) during the outbreak in West Africa.[49 61 62] Early during the outbreak in Sierra Leone, one study estimated that HCWs had >100 times the risk of Ebola acquisition compared to non–health workers.[61] The increased risk posed to health workers was driven by inadequate infection prevention and control measures in clinical settings.[62] A retrospective descriptive study in Sierra Leone found that most HCW Ebola infections occurred in hospital settings (47%) while some occurred in health centers or other health facilities (23%) and at home (19%). Ebola treatment units were only associated with 27% of HCW Ebola infections.[49] Family members caring for loved ones at home were also at high risk of Ebola. In some instances, home–based care may have resulted in further delay to seeking medical care among suspected patients, which contributed to household spread of the virus.[63]

### 1.2.3   Traditional funerals and burials

Traditional and religious norms for burials and funerals – such as touching, kissing, washing, and wrapping of corpses[41]  contributed to Ebola transmission risks.[46 47 64] In the West Africa outbreak, it was retrospectively estimated that every unsafe traditional burial resulted in nearly three new Ebola cases.[64] In an extreme example in Sierra Leone, 28 confirmed cases were derived from a single traditional burial of a prominent pharmacist in Moyamba district in September 2014.[46] Almost all of the 28 cases (75%) reported direct physical contact with the pharmacist's corpse. Similarly in Guinea, 62 new cases were directly linked to a single traditional burial ceremony in Kissidougou in December 2014 – the largest increase in weekly new cases of Ebola in any prefecture in Guinea.[47]

### 1.2.4   Sexual transmission and viral persistence

A cohort study in Sierra Leone found Ebola virus RNA in the semen of survivors for up to 18 months after discharge from treatment units based on quantitative reverse transcription–polymerase chain reaction testing.[65] Following the peak of the primary outbreaks in Sierra Leone, Liberia, and Guinea, sexual transmissions occurred, and were linked to viral persistence in the semen of Ebola survivors.[51 52 66] These flareups pointed to the continued risk of Ebola transmission in the subregion and the need for ongoing, robust viral hemorrhagic fever surveillance in accordance with WHO's International Health Regulations.[67]

### 1.3   OUTBREAK IN SIERRA LEONE (2014–2016)

The first known case of Ebola in Sierra Leone was confirmed on May 25th 2014 in the Eastern region of Kailahun district,[30] few kilometers from the origin of the Guinea outbreak in Guékédou. The Sierra Leone index case was traced to a traditional healer in Kpondu village (Kailahun) who treated patients from Guinea and Liberia. The traditional healer died and infected other close relatives and those who attended her funeral.[68] Within few days,

several suspected cases from Kpondu village tested positive for Ebola, and new cases were quickly confirmed in other nearby villages.[68] The outbreak rapidly spread to neighboring Kenema district, making the Eastern region the epicenter of the early phase of the outbreak and requiring massive contact tracing efforts.[69] By October 2014, the epicenter of the outbreak had strongly shifted from the Eastern region to the Western and Northern regions. New weekly cases of Ebola peaked in November 2014. The epidemic curve began a downturn in December 2014. Lower but continued number of new cases and deaths were reported in the first half of 2015 before the outbreak waned substantially. In November 2015, the WHO declared an end of the outbreak in Sierra Leone.[33] Controlling the outbreak required a comprehensive response from many sectors of government, international partners and civil society. The response comprised a number of key interventions, including incident management, surveillance, contact tracing, rapid isolation and treatment, infection control, safe burials, laboratory testing, social mobilization, risk communication and partner coordination.[70] In January 2016, a flareup of Ebola was reported in Sierra Leone and promptly controlled, and since then no more cases have been reported to date.[71]

### 1.3.1 Coordination

Figure 3 provides an illustration of the pillar structures instituted for responding to the Ebola outbreak in Sierra Leone.[72] Immediately after confirming the Ebola outbreak in Sierra Leone, the Government with support from international partners such as WHO and the US Centers for Disease Control and Prevention (CDC), established an Emergency Operations Center under the leadership of the Ministry of Health and Sanitation (MoHS).[73]
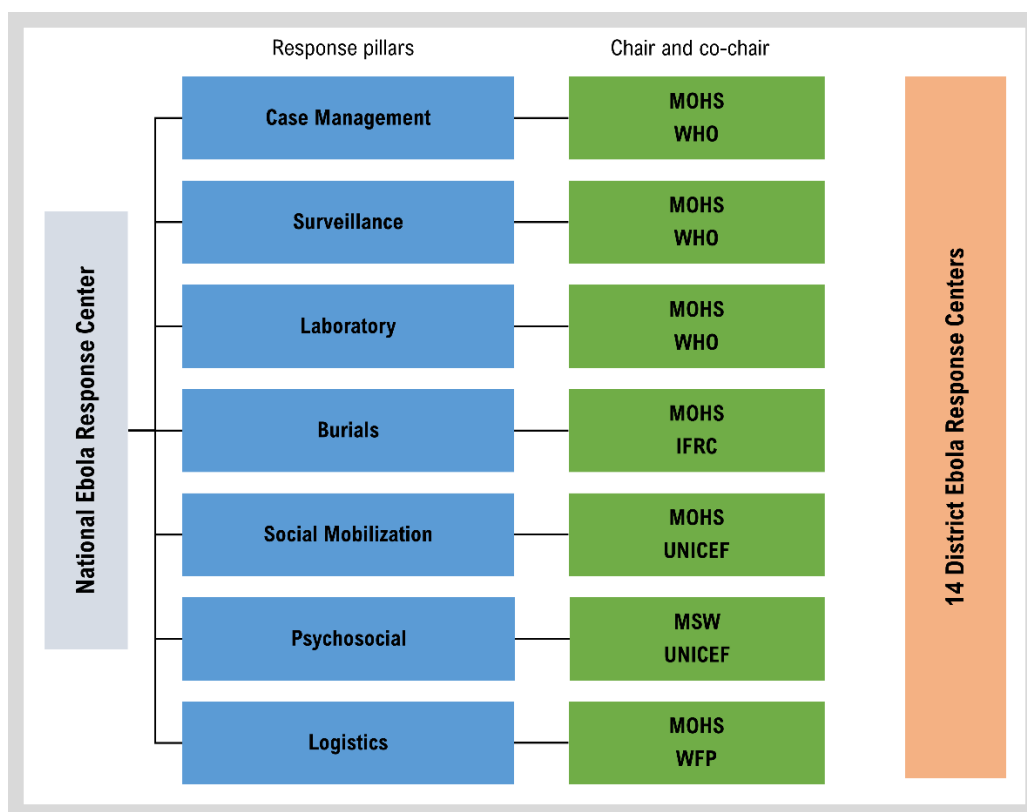


**Figure 3. Illustration of the Ebola outbreak response structure in Sierra Leone**

By June 2014, response pillars for case management, surveillance, safe and dignified burials, laboratory operations, and social mobilization were established within the Emergency Operations Center. In October 2014, near the peak of the outbreak, the National Ebola Response Center (NERC) was commissioned by the President of Sierra Leone to assume all coordination and decision–making responsibilities. Incident management structures were subsequently transitioned to the NERC, including a total of 35,000 local response staff. [73] The NERC became functional by November 2014 and established District Ebola Response Centers in each of the 14 districts in the country.

### 1.3.2  Case management

A person infected with Ebola usually experiences symptoms within two to 21 days of exposure to the virus. Early symptoms commonly occur within eight to 10 days including fever, severe headache, muscle pain, abdominal pain, and fatigue.[74] In previous outbreaks, as the disease progresses, it was documented that patients may experience unexplained bleeding, diarrhea, and vomiting. However, one study in Sierra Leone found that up to 18% of Ebola cases did not experience fever,[75] and another study revealed that bleeding was very rare such that only one out of 106 patients experienced bleeding in a non–representative sample from Kenema district between May 25 and June 18, 2014.[76] One study revealed that extreme fatigue, vomiting, diarrhea, and bleeding were significantly associated with not surviving the disease.[75] Factors associated with fatal outcomes in another study of patients included fever, weakness, dizziness, diarrhea, and elevated levels of blood urea nitrogen, aspartate aminotransferase, and creatinine. The risk of death among patients in the same study was also higher for those who were over 45 years of age and those with high viral load (10 million Ebolavirus copies per milliliter or more).[76] Ebola symptoms are similar to those of malaria, which posed challenges for screening and initial clinical case management.[77]

In Sierra Leone, patients suspected of Ebola were reported to the National Ebola Call Center through a tollfree telephone line—the 1–1–7 call system—or through local district alert systems. The 1–1–7 phone alert system was used by the Government of Sierra Leone to ensure identification of sick patients and deaths occurring in communities. The placing of sick alerts prompted the dispatch of ambulance teams to pick up and transport patients to Ebola holding centers.[78] Suspected patients were screened and tested for Ebola at holding centers. Patients who tested positive for Ebola were transferred to an Ebola treatment unit. Community care centers (with lower level of care given) were also used as alternatives to treatment units in parts of Sierra Leone.[59] Even though there were no specific treatments for Ebola, patients received supportive care including administration of intravenous fluids[†] and use of antimalarials and antibiotics to treat other potential co–occurring infections.[76] Experimental therapeutics were used in some cases, especially towards the end of the outbreak when study and treatment protocols were in place.[79 80] Patients were usually released from clinical care after two or more negative Ebola test results.

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[†] Especially in the latter stages of the epidemic; very few patients received IV fluids in the first few months.

### 1.3.3  Surveillance

Various surveillance efforts formed a key pillar of the Ebola response in West Africa.[81] Surveillance mechanisms were instituted to promptly identify suspected Ebola cases, (and their contacts) and deaths occurring in communities.[69 70 78 81] These efforts required the strengthening of data systems and human resource capacities including the training of surveillance officers and other personnel.[81] In August 2014, the Government of Sierra Leone introduced the mandatory 1–1–7 call system for reporting suspected Ebola cases and deaths occurring in communities.[82] Nearly 350,000 alerts about cases and deaths were placed through the 1–1–7 call system between September 2014 and December 2016.

#### *1.3.3.1  Contact tracing*

At the peaks of the outbreak in the three heavily affected countries, contact tracing proved to be challenging given the large number of contacts to identify and follow–up on. A retrospective analysis in Sierra Leone's Kenema district revealed that only 6% of probable and confirmed cases in the district were recorded as contacts.[69] Overall, contact tracing challenges included identifying, locating, and enrolling contacts coupled with community fear, stigma, and misconceptions.[83] Following the peak of new cases, efforts were taken by the MoHS and surveillance partners to intensify and improve the quality of contact tracing in the active transmission areas.[70] For instance, when robust surveillance efforts were mounted in response to the January 2016 flareup in Sierra Leone, 131 contacts were swiftly identified and one additional case emerged from a high–risk contact.[81]

### 1.3.4  Burials

Monitoring and responding to deaths (of any causes) consisted a major aspect of the Ebola response. In Sierra Leone, all deaths were mandated to be reported through the 1–1–7 call system or local district alert systems.[78] Once a death alert was triggered, teams specialized in safe burials and surveillance officers were dispatched to the household. Burials were then conducted according to protocols for safe and dignified burials excluding traditional practices involving direct contact with corpses.[84] Challenges with death reporting were documented, including delays in responding to death alerts and community dissatisfaction with burial protocols that prohibited traditional rituals.[84 85] Alternatives were later provided for families to observe the burial from a safe distance and have a religious leader say a final prayer before burying the corpse. The interfaith community strongly advocated for these alternatives.[86] Death reporting through the 1–1–7 system in Sierra Leone was high during the peak of active transmission of Ebola, such that nearly 10,000 calls were made on a single day in October 2014 around the peak of the outbreak.[78‡] However, death reporting levels declined as the outbreak waned in the country despite government policy requiring reporting.[78] It remains unclear what factors motivate or discourage the population to report deaths during the post–outbreak environment in Sierra Leone. It should be noted that the initial outbreak in Guinea took three months to be detected, partly due to weak mortality surveillance systems at the time. The Ebola epidemic demonstrated the need for robust surveillance systems including

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‡ Almost 100 new cases were reported daily around the peak period of the outbreak in Sierra Leone.

mechanisms for mortality surveillance to improve early detection of cluster–deaths indicative of a possible disease outbreak.[46 70 81]

### 1.3.5  Social mobilization

Social mobilization, community engagement, and risk communication were central components of the Ebola response in West Africa, and suggested to have contributed to the containment of the spiraling outbreak alongside clinical interventions.[87–90] A case study from Liberia demonstrated the positive effects of social mobilization in interrupting Ebola transmission by improving community support for contact tracing and isolation of cases.[91]

A Social Mobilization Pillar was formed in June 2014 to coordinate and guide all social mobilization, community engagement, and risk communication activities for the national Ebola response. The Social Mobilization Pillar had over 100 partners including NGOs, civil society groups, governmental ministries, and international technical support agencies such as the CDC. The Health Education Division of the MoHS chaired the Social Mobilization Pillar alongside UNICEF. The Social Mobilization Action Consortium provided broad secretariat services to the pillar with funding from the UK Department for International Development. The Pillar established four subcommittees for: (i) coordination, monitoring, and evaluation; (ii) capacity building; (iii) messaging and dissemination; and (iv) special needs (including psychosocial support).

A communication strategy and standard operating procedures (SOPs) for social mobilization were developed and implemented over the course of the outbreak in Sierra Leone. The government's post–outbreak report articulates the important role of social mobilization and community engagement: "Social mobilization is successful when there is mutual trust and respect between the leaders and their communities, which increase public participation and boost their sense of ownership."[73]

### 1.3.5.1  *Communication strategy and messaging*

The Social Mobilization Pillar, with technical support from FOCUS 1000 (a local NGO), CDC's Health Promotion Team, and UNICEF, launched a national Ebola response communication strategy in September 2014. Preliminary findings from a population–based national survey on knowledge, attitudes, and practices related to Ebola prevention and treatment directly informed the strategy. Overall, the approach called for shifting away from one–way communication (e.g. using megaphones) to multi–channel approaches grounded in evidence–based messaging to target high–risk *behaviors* and high–risk *environments*. Indicators were established for monitoring and evaluating behavioral change communication efforts implemented by partners in the Social Mobilization Pillar collectively. A comprehensive messaging guide,[92] named *Act Against Ebola*, was developed in September 2014 to operationalize the communication strategy. Based on risk communication lessons learned from CDC's response to the HIV/AIDS epidemic, Act Against Ebola emphasized specific protective and enabling behaviors.[93]

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### 1.3.5.2 Radio programming

In August 2014, a nationwide survey revealed that nearly 90% of the public received Ebola information through radio programs in Sierra Leone.[93] The Social Mobilization Pillar's strategy therefore called for prioritizing radio due to its widespread availability and frequent use among the population to receive information. For example, through the Ebola Big Idea of the Week messaging guide,[94] national radio programs were developed and simultaneously broadcast across the country to reach the population with harmonized messages promoting key Ebola protective behaviors. District and sub–district level radio programs were also implemented to allow for localized discourse through interactive formats where listeners were able to call–in with questions, comments, and feedback. BBC Media Action supported 42 radio stations across the country to strengthen local capacity, accessibility, and quality of radio programming in Sierra Leone.[95] A survey reported high listenership (68%) of two radio programs sponsored by BBC Media Action through local stations: Kick Ebola out of Sierra Leone and Kick Ebola Live.[95]

### 1.3.5.3 Engagement of religious leaders

Religion plays an important role in the lives of Sierra Leoneans. Nearly every Sierra Leonean self–identifies as either a Muslim (78%) or Christian (21%).[96] Faith–based engagement with religious leaders was therefore a key approach for social mobilization in the Ebola outbreak in West Africa, especially in promoting safe burial practices.[97] Early in the outbreak in Sierra Leone, before the engagement of religious leaders, there were instances of some religious leaders contributing to Ebola transmission by participating in unsafe burials.[98] Therefore, various interventions focused on promoting safe burial behaviors among religious leaders so that they could role model protective behaviors in their communities.[86] The Social Mobilization Pillar prioritized religious leader engagement, which was deemed critical to attaining community acceptance of Ebola protective behaviors, especially relating to adopting safe burials.[98] Over 6,000 religious leaders across the country were engaged through local grassroots structures.[86][99] The engagement included development of faith–based messages using examples and passages from the Qur'an and Bible to reinforce key Ebola prevention behaviors with an emphasis on shifting from traditional burials to safe burials conducted by specialized teams.[86][100] Faith–based organization implemented interventions that created more direct role for religious leaders in the response such as escorting burial teams, praying on corpses, and providing psychosocial counseling to bereaved families.[86][101]

### 1.3.5.4 Engagement of traditional healers

Traditional healers were rarely engaged early in the Ebola response in Sierra Leone until June 2015 when FOCUS 1000, through the Social Mobilization Pillar, convened a large–scale meeting with a diverse cross–section of national and grassroots leadership of the country's Indigenous Traditional Healers Union.[102][103] The convening was sparked by WHO and MoHS pointing to Ebola transmission chains linked to traditional healing practices for suspected Ebola patients – most notably in Port Loko and Kambia districts.[104–106] Public pressure and intensified direct advocacy and engagements with the healers' union led to their suspension of traditional healing practices. The healers leadership proposed a Bush–to–Bush Campaign to monitor secret shrines and ensure compliance of their members with the

sanction.[102] The Bush–to–Bush Campaign was then incorporated into an existing campaign (Operation Northern Push) in Port Loko and Kambia districts between June and August 2015. Following the end of the campaign, transmission chains linked to traditional healing practices were disrupted.[107]

### 1.3.5.5 Community–led Ebola action

Restless Development, an international NGO with strong local ties in Sierra Leone, oversaw the development of the Community–led Ebola Action intervention comprising practical training of local mobilizers in community action planning.[108] Trained mobilizers were paired to visit assigned communities, identify needs and challenges through dialogue, and trigger community action plans to prevent and respond to Ebola. Mobilizers made routine follow–up visits to monitor and document the progress of community action plans. Restless Development implemented the intervention in 11 mostly rural districts. The organization trained and deployed over 2,500 community mobilizers who collectively worked across nearly 9,000 rural communities and made 49,000 follow–up visits on community–led action plans by November 2015.[109] The community–led intervention was also implemented in Western Area and Kenema districts by GOAL Ireland.[109]

### 1.3.5.6 National house–to–house campaigns

Two house–to–house campaigns were implemented nationally in Sierra Leone in September 2014[82] and March 2015.[110] Each campaign lasted three days and were part of government–led efforts to intensify active case search within communities and dissemination of Ebola prevention messages through joint teams of surveillance officers, contact tracers, community mobilizers, and community leaders. Movements were restricted during the campaigns to help ensure all households and individuals were reached. During the three–day period of the first campaign in 2014, a retrospective analysis showed that 3,299 call alerts were placed to the 1–1–7 system comprising 1,296 reported deaths and 1,202 reported suspected cases. The second campaign in 2015 was launched as part of a broader initiative – Zero Ebola Campaign – leading to over 60% increase in calls placed to the 1–1–7 reporting system compared to the previous week.[110]

### 1.3.5.7 Operation Western Area Surge

In Western Area, the NERC recognized the need for more targeted efforts for active case search integrated with social mobilization through Operation Western Area Surge.[111] [112] The campaign focused on increasing community demand for Ebola services while also enhancing contact tracing and supply–side capacities such as the number of beds in Ebola treatment units and more responsive laboratory systems to test for Ebola.[111] [112]

### 1.3.5.8 Standardizing operating procedures for social mobilization

Social mobilization efforts became more streamlined and refined after the peak of the outbreak in Sierra Leone. The Social Mobilization Pillar conducted district–level microplanning workshops to develop SOPs for social mobilization in the final push in "getting to zero Ebola" in the country.[113] The SOP document outlined specific procedures and processes for social mobilization in supporting various Ebola response efforts – including

case identification, safe burials, contact tracing, and household–based quarantine – in order to ensure more effective integration with supply–side services.[113]

### *1.3.5.9 Challenges with social mobilization*

There were myriad challenges with the planning, implementation, and monitoring/evaluation of social mobilization activities during the outbreak in Sierra Leone.[73 88 99 108 113 114] First, in the early stage of the outbreak, the messaging was slow to focus on person–to–person transmission and over emphasized animal–to–human transmission. Prevention messages therefore focused on avoiding the preparation, handling, and eating of bushmeat. There was a lack of initial emphasis on the risk of unsafe burials and having physical contact with sick people at home or elsewhere in the community. The initial response was slow to engage trusted community leaders including religious and traditional leaders, and even slower to engage traditional healers. Although the Social Mobilization Pillar was established early in the outbreak, it faced challenges with getting funding to support nationwide activities and to scaleup in the high–transmission areas. Coordinating the large number of pillar members (over 100 organizations) posed additional challenges throughout the outbreak but improved over time. For instance, the messaging subcommittee became responsible for harmonizing and approving all messages that partners were disseminating through media sources and direct engagements with communities.

## 1.4   EBOLA KNOWLEDGE, ATTITUDES, AND PRACTICES

Several quantitative and qualitative assessments of the public's Ebola–related knowledge, attitudes, and practices (KAP) were conducted in Sierra Leone,[85 93 115–121] Guinea,[122–124] Liberia,[125 126] Nigeria.[127 128] In Sierra Leone, KAP surveys targeting the general public were conducted at different stages of the outbreak including as early as August 2014 and as late as July 2015. Findings from the various KAP surveys consistently pointed to high awareness of Ebola transmission and prevention but with predominant misconceptions regarding the disease. The findings from Sierra Leone were consistent with those from the other countries. A multilevel regression analysis found that, in Sierra Leone, exposure to Ebola–related information sources had a strong dose–response association with having the correct Ebola knowledge and reporting protective behaviors.[129] However, information exposure was also associated with misconceptions (but with a weaker dose–response). Trends in how Ebola–related KAP changed over time (when, where, and for whom) has not been well documented in the published literature. Moreover, differences in KAP outcomes over time between geographic regions with high– and low–transmission regions are not well understood.

## 1.5   EBOLA SURVIVORS

Although it is difficult to know the exact number of Ebola survivors during the 2014–2016 outbreak in West Africa, the WHO estimated that there may have been up to 10,000 Ebola survivors across Sierra Leone, Guinea, and Liberia.[130] Sierra Leone had the largest cohort of nearly 4,000 Ebola survivors, of whom nearly 3,000 were registered in the government's database as of March 2016.[33] Ebola survivors faced numerous challenges after their release from treatment units as they integrated back into their communities, including clinical post–Ebola syndrome,[131–139] stigmatization,[120 140] and psychological distress.[141 142] Nearly 80% of

survivors were reportedly able to access health care services in Sierra Leone as of March 2016.[33] However, current estimates for survivors' access to care are lacking. In December 2017, a local NGO (Center for Accountability and Rule of Law) filed a lawsuit on behalf of survivors against the Government of Sierra Leone that alleged misappropriation of Ebola funds and demanded greater support for survivors.[143]

### 1.5.1  Post–Ebola syndrome

Following release from treatment units, clinical sequelae have been documented among Ebola survivors, collectively termed post–Ebola syndrome, which included myalgia (muscle aches), arthralgia (joint pain), headache, abdominal pain, visual problems, weight loss, memory loss, hearing loss, insomnia, fatigue, decreased libido and depression.[131–139] In Sierra Leone, analysis of post–Ebola syndrome showed that survivors experienced musculoskeletal pain (70%), headache (48%), and visual problems (14%). Collectively, these findings point to the need for longer–term medical care and psychosocial support for survivors.

### 1.5.2  Stigma and psychosocial challenges

Moreover, Ebola survivors and their families faced stigma and discrimination as they reintegrated into communities.[120][140] Early in the Ebola outbreak in Sierra Leone, every 9 in 10 respondents in a national survey held one or more stigmatizing attitudes towards Ebola survivors such as refraining from buying fresh vegetables from a survivor shopkeeper, not accepting survivors back into communities, and thinking that survivors who are students put the class at risk of Ebola infection.[93] As the outbreak waned in Guinea, survivors continued to face stigmatization.[122] HCWs who cared for Ebola patients were also stigmatized.[140] The Ebola response in West Africa recognized the need to address the high and persistent level of stigma towards Ebola survivors. In Sierra Leone, the communication and messaging strategy was to portray survivors as heroes that should be embraced and celebrated for defeating the scourge of Ebola. Such messaging also aimed to create a more hopeful narrative that would encourage treatment seeking behaviors when Ebola was suspected as opposed to hiding patients at home, which might put other household members at risk of Ebola acquisition.[93]

The situation of Ebola survivors became further complicated when new Ebola cases were linked to viral persistence in the semen of male survivors,[53–58][65][144][145] and more evidence surfaced regarding persistence of the virus in other bodily fluids.[132][146] Several clusters of Ebola cases were later tied to sexual transmission of the disease.[51][52] Emerging messaging about sexual transmission of Ebola by survivors might have unintentionally contributed to further stigmatization of survivors and their sexual partners.[120] Interventions were instituted to screen and test the semen of male Ebola survivors[147–149] and provide behavioral counseling and support, especially around condom use among survivors and their sexual partners.[124][150]

### 1.6  EBOLA VACCINES

Experimental Ebola vaccines were implemented in Liberia,[151][152] Guinea,[153] and Sierra Leone[154–156] as part of safety, immunogenicity, efficacy clinical trials and ring vaccination efforts to reduce transmission risk among contacts (and contacts of contacts) of Ebola cases/deaths.[153] In Liberia, 1,500 adult participants were enrolled in the PREVAIL study.[151] In Guinea over 5,000 community participants were included in a ring vaccination cluster–

randomized trial, in which the vaccine was found to be 100% effective.[153]  In Sierra Leone, over 8,000 health care and front line workers participated in the STRIVE Ebola vaccine study[154 156] and over 750 in the EBOVAC–Salone study[157] (including 192 adolescents and 132 children).

Social mobilization and community engagement were cited as important considerations across all the vaccine trials in the three affected countries. More pronouncedly, a qualitative study for an Ebola vaccine trial in Kambia district highlighted strategies employed for social mobilization in gaining community–level support for the trial and addressing concerns.[158] Lessons learned from the STRIVE trial also reinforced the important role of ethical communication of risks and benefits as well as establishment of a social mobilization platform to support ethical recruitment and addressing of community concerns.

The unlicensed rVSV–ZEBOV–GP[§] vaccine was implemented under compassionate use protocols during outbreaks in Guinea, Sierra Leone, Liberia, and DRC.[159–164] In October 2019, the rVSV–ZEBOV–GP vaccine eventually received conditional marketing authorization from the European Medicines Agency[165] and was prequalified for licensing in November 2019 by the WHO through an accelerated process. In December 2019, the rVSV–ZEBOV–GP vaccine, manufactured by Merck & Co., Inc. under the tradename Ervebo®, was approved by the U.S. Food and Drug Administration for use in individuals age 18 years of age and older as a single–dose injectable vaccine packaged in 1 milliliter single–dose vials.[166] The rVSV–ZEBOV–GP vaccine is administered through the intramuscular route, preferably on the deltoid area of the non–dominant arm. The duration of protection has not yet been established. Consequently, the need for booster dose(s) remains undetermined. Other Ebola prevention and control measures are therefore recommended for individuals who receive the vaccine—including adequate PPE for HCWs. Adverse reactions to the vaccine include pain at the injection site, swelling or redness, headache, fever, muscle pain, fatigue, nausea, and joint pain. Four African countries have since licensed the Merck vaccine: DRC, Burundi, Ghana, and Zambia.[166] The availability of licensed doses of the vaccine paves the way for increasing its stockpile in countries and subregions prone to Ebola outbreaks.

An investigational Ebola vaccine regimen (Ad26.ZEBOV, MVA–BN–Filo) manufactured by Janssen Pharmaceutical Companies of Johnson & Johnson has also been used as part of clinical trials in West Africa and outbreak response in DRC.[167 168] It is a two–dose regime that combines two vaccines to stimulate an immune response to the Zaire ebolavirus. The first dose is Ad26.ZEBOV. The second dose, MVA–BN–Filo®, is administered around eight weeks from the first dose.

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[§] Recombinant, replication–competent, vesicular stomatitis virus expressing the glycoprotein of a Zaire Ebolavirus (Merck & Co., Inc).

## 1.7 OUTBREAK IMPACT

The West African Ebola epidemic had negative impacts on economies and livelihoods,[169–171] health systems,[171–173] medical care seeking behaviors for other health needs,[171–175] and population–level mental health.[176 177] In Sierra Leone, it was conservatively estimated that decreased use of health services resulted in 3,600 additional maternal, neonatal, and stillbirths between 2014 and 2015.[173] Another study in Sierra Leone revealed population–level, mental health impact showing high prevalence of symptoms of anxiety, depression, and post–traumatic stress disorder.[118] On the other hand, enormous epidemic response efforts resulted in strengthened health systems in some areas (e.g. surveillance, laboratory capacity, health workforce capacity) by the time the outbreak was declared over, which may have contributed to overall preparedness for future outbreaks.[81]

## 1.8 RATIONALE

The Ebola outbreak in West Africa shed new light on the complexities surrounding infectious disease outbreaks. It illuminated the need for social, behavioral, and communication science as an integral component of global health security in preventing, detecting, and responding to known and emerging public health threats. The methods and findings in this thesis can inform future infectious disease outbreak response actions aiming to address sociocultural perceptions and behavioral factors linked to transmission risks. In addition, the data collection instruments and methods of this thesis can be further adapted for other similar settings and contribute to preparedness efforts to undertake mixed–methods behavioral surveillance during Ebola and other infectious disease outbreaks.

# 2  AIMS

## 2.1  OVERALL AIM

To understand trends in population–level Ebola knowledge, attitudes and practices at different stages of the outbreak (Study I), acceptability of experimental Ebola vaccines at around the peak of the outbreak (Studies II–III) and reporting of deaths after the outbreak ended (Studies IV–V).

## 2.2  SPECIFIC AIMS

The specific aims of the assessments were to:

I.  Examine trends in Ebola knowledge, acceptance of safe burials, attitudes toward Ebola survivors, and uptake of prevention practices throughout the 2014–2016 Ebola outbreak in Sierra Leone (**Study I / Paper I**).

II.  Understand how experimental Ebola vaccines were perceived by health workers, frontline staff and the general public prior to any experimental Ebola vaccine trials (**Study II / Paper II**).

III.  Measure Ebola vaccine demand among the general public around the peak of the outbreak and identify predictors of Ebola vaccine demand (**Study III / Paper III**).

IV.  Describe the deaths reported to the 1–1–7 system during and after the outbreak, perceptions of the reporting system, and motivations to report deaths in a post–Ebola–outbreak setting (**Study IV / Paper IV**).

V.  Identify death reporting barriers and potential facilitators in the aftermath of an Ebola outbreak to inform strategies to improve mortality surveillance (**Study V / Paper V**).

# 3  METHODS AND MATERIALS

To address the overall and specific aims, mixed–methods behavioral surveillance approaches were employed comprising multiple population–based household KAP surveys, a telephone survey, in–depth interviews, and focus group discussions (FGDs).

## 3.1  SUMMARY

The study population, timeline, setting, design, sampling approach, and analytical methods for each of the five studies are summarized in Table 3. **Studies I–III** were conducted during the 2014–2016 outbreak in Sierra Leone while **Studies IV–V** were carried out in 2017 after the outbreak when enhanced Ebola surveillance had ended. All studies included respondents from the general public. In addition, **Study II** included HCWs and frontline Ebola staff such as ambulance drivers, burial team members, contact tracers, and community mobilizers. **Study IV** included family members and health workers who reported one or more deaths to the national 1–1–7 system after enhanced Ebola surveillance ended.  **Study V** included family members who failed to report a death to the 1–1–7 system as mandated by the Government of Sierra Leone.

**Table 3. Methodological summary of the five studies in the doctoral thesis**

| Study | Population | Timeline | Design and sampling | Outcome measures | Data analysis |
|---|---|---|---|---|---|
| DURING THE OUTBREAK | | | | | |
| **Study I** | General public | Aug 2014 – Jul 2015 | Four cross–sectional household surveys (N=10,603) using multi–cluster stage sampling | Ebola–related knowledge, attitudes, and practices | Multilevel logistic regression modeling |
| **Study II** | HCWs, frontline staff, and general public | Dec 2014 – Jan 2015 | Qualitative in–depth interviews (N=31) and focus group discussions (N=35) using purposive sampling | Perceptions and acceptability of Ebola vaccine | Qualitative content analysis |
| **Study III** | General public | Dec 2014 | Cross–sectional household survey (N=3,540) using multi–stage cluster sampling | Ebola vaccine demand | Multilevel logistic regression modeling; Exploratory Factor Analysis |
| AFTER THE OUTBREAK & ENHANCED EBOLA SURVEILLANCE ENDED | | | | | |
| **Study IV** | General public | Apr 2017 | Telephone survey (N=1,291) using stratified random sampling | Number of deaths reported over time; motivations to report deaths | Ordered logistic regression modeling |
| **Study V** | General public | Aug 2017 | Qualitative in–depth interviews (N=32) using purposive sampling | Barriers and facilitators of death reporting | Qualitative content analysis |

**Studies I, III, IV** employed quantitative methodologies. **Studies I & III** were based on population–level surveys conducted using multi–stage cluster sampling**. Study IV** was a telephone survey using stratified random sampling**. Studies II & V** employed exploratory qualitative approaches: In–depth interviews (IDIs) and focus group discussions (FGDs). The quantitative studies have been described in accordance with  guidelines for Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).[178] The qualitative studies have been described in accordance with guidelines in the Consolidated Criteria for Reporting Qualitative Research (COREQ), which is a 32–item checklist for reporting the methods and procedures used in a qualitative study.[179] Data from the three quantitative studies were analyzed using multilevel logistic regression (**Study I and III**) and ordered logistic regression (**Study IV**) modeling. The qualitative data (**Study II and V**) were analyzed using qualitative content analysis.[180]

## 3.2   STUDY SETTINGS

All five studies were carried out in Sierra Leone during the 2014–2016 outbreak of Ebola or shortly thereafter in 2017 after the end of enhanced Ebola surveillance. Sierra Leone has an estimated population of eight million people, four geographic regions (West, North, East, South), and 14 administrative districts.[181]  The country is culturally diverse with more than 20 ethnic tribes and local languages. Even though English is the official language of business, Krio is the predominant language spoken by most Sierra Leoneans, and most Sierra Leoneans identify as either Muslim or Christian.[96] Most of the population reside in rural areas, and more than half of the population are illiterate.[96]

The country endured a brutal civil war that lasted more than a decade spanning from 1991 to 2002 wherein countless children were exploited as soldiers.[182 183] During this period, most of the country's infrastructure – including health and social services systems – were destroyed. Following the war, the country entered a reconstruction phase that focused on rebuilding of health systems, especially for maternal and child health. Reconstruction efforts culminated in the government's introduction of the Free Health Care Initiative in 2010 to eliminate costs for essential health services for pregnant women, lactating mothers, and children under the age of five years old.[184 185] Despite efforts to improve the situation, Sierra Leone has one of the highest maternal mortality ratios and under–five mortality rates in the world: about 105 children per every 1,000 live births die before celebrating their fifth birthday[186] and an estimated 1,180 maternal deaths per 100,000 live births.[187] About half of the population lives in extreme poverty.[187] Part of the challenge is due to major gaps in the human resources for health: there is only one medical doctor for every 10,000 population.[187]

**Study I** was implemented to assess changes over time in Ebola–related KAP among the general public at four different stages of the outbreak in Sierra Leone (August 2014, October 2014, December 2014, July 2015). In August 2014, when the first assessment was undertaken, the epicenter of the outbreak was occurring in the Eastern region of the country

with cases mostly reported in Kailahun and Kenema districts. By October 2014, when the second assessment was conducted, the epicenter had shifted to the Western and Northern regions. At this point, all 14 districts nationally had also reported cases of Ebola. The weekly number of new Ebola cases peaked nationally in November 2014, which was right before the third assessment was undertaken in December 2014. Even though the outbreak had peaked nationally, there was an increase of new cases reported in Western region comprising the capital city of Freetown.

**Studies II–III** were undertaken in the backdrop of plans to investigate the safety and efficacy of candidate Ebola vaccines among health workers and frontline Ebola staff. **Study II** was conducted to qualitatively understand perceptions and acceptability of experimental Ebola vaccines, and was conducted with health workers, frontline Ebola staff, and the general public in five districts that were experiencing Ebola transmission. The assessment was carried out in December 2014 around the peak of the outbreak, and before any Ebola vaccine had been introduced in the country. Although plans to introduce Ebola vaccine trials commenced in October 2014, the first clinical trial of a candidate Ebola vaccine was not implemented until April 2015.[154] **Study III** was carried out to quantitatively describe Ebola vaccine demand and identify associated predictors of demand among the general public in December 2014.

**Studies IV–V** were conducted in 2017 after the Ebola outbreak had been declared over in Sierra Leone in November 2015. However, in January 2016, a flare–up of Ebola occurred in the country, which was linked to sexual transmission due to viral persistence in an Ebola male survivor. Although the flare–up was promptly contained, it reinforced the need for vigilance in surveillance systems to identify and respond to emerging threats of new cases. **Study IV** was carried out in April 2017 with household members from the general public and health workers who had reported a death to the 1–1–7 system established by the government. Lastly, **Study V** was conducted in August 2017 with family members who had a death in their household but failed to report such death to the 1–1–7 system as per government policy. The purpose of the government policy was to inform efforts to strengthen routine mortality surveillance with additional considerations for improving civil registration of vital statistics (CRVS). Following nearly two years of national reporting of all deaths as part of Ebola mortality surveillance, Sierra Leone had a unique opportunity to strengthen the death registration component of CRVS. As part of global efforts spearheaded by WHO, CRVS systems aim to register all births and deaths occurring in a country. The 1983 Births and Deaths Registration Act[188] provides the legal basis for the Government of Sierra Leone to mandate reporting and registration of all deaths in the country.

## 3.3    DESIGN, SAMPLING AND DATA COLLECTION

### 3.3.1    Study I / Paper I

**Study I** was based on four cross–sectional, household surveys that were conducted at different stages of the Ebola outbreak in Sierra Leone (Figure 4). The first survey was conducted in August 2014, the second in October 2014, the third in December 2014, and the fourth in July 2015. The peak of weekly new cases of Ebola cases occurred in November 2014. The first two surveys were conducted before the peak while the last two were carried out after the peak. All four surveys employed multi–stage cluster sampling wherein primary sampling units (clusters) were randomly selected with probability proportional to size from a sampling frame of enumeration areas in the 2004 Sierra Leone Census.
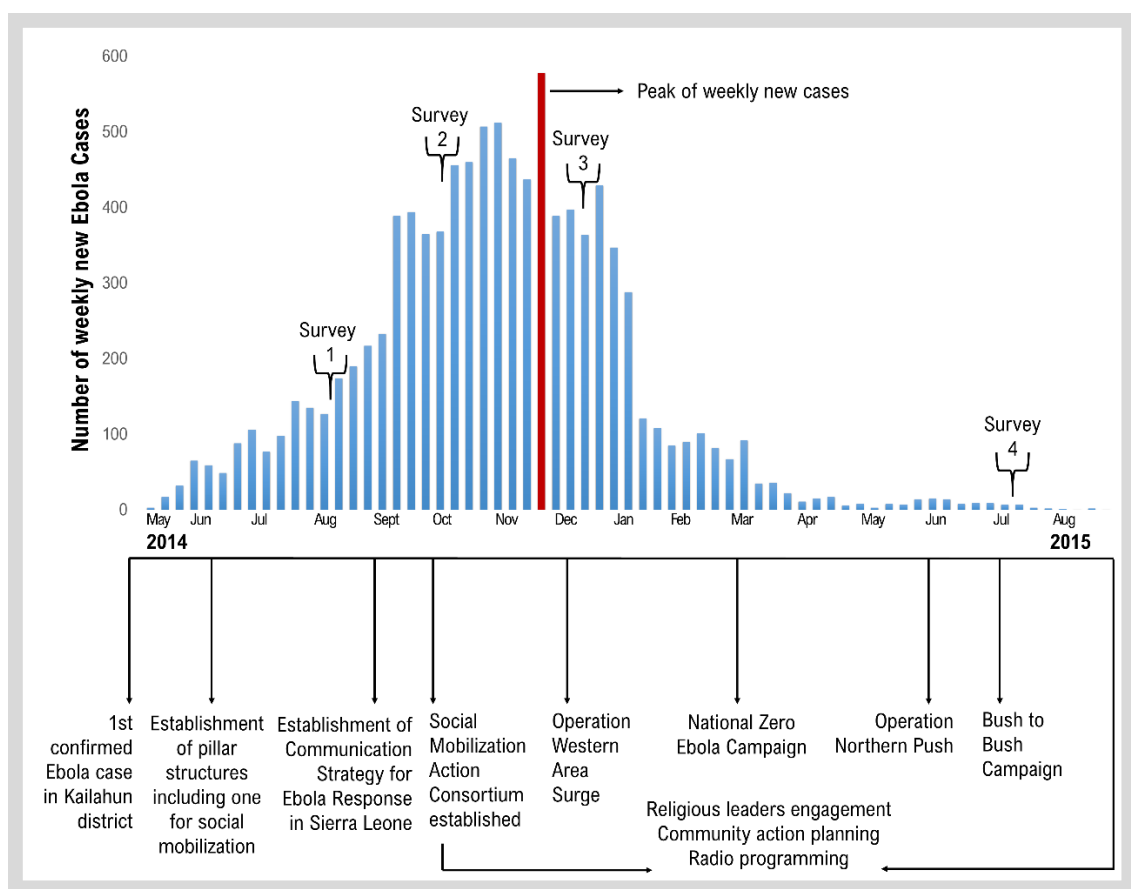


**Figure 4. Distribution of weekly new Ebola cases against a timeline of surveys in Study I and key social mobilization activities, Sierra Leone, May 2014 – August 2015**

Within clusters, a systematic sampling approach was used to select households.[189] A sampling interval was calculated for each cluster (number of households in the cluster divided by the number of households to be sampled). After a random household was selected as the starting point, the sampling interval was then used to select additional households in the cluster. On average, 20 households were approached for inclusion in each cluster. Within households, two individuals were approached for consent to participate in the survey: (i) the head of the household and (ii) a randomly selected household member who was either an

adult woman (≥25 years of age) or a young person (15–24 years of age). Data collectors administered a structured questionnaire after obtaining informed consent (Figure 5).
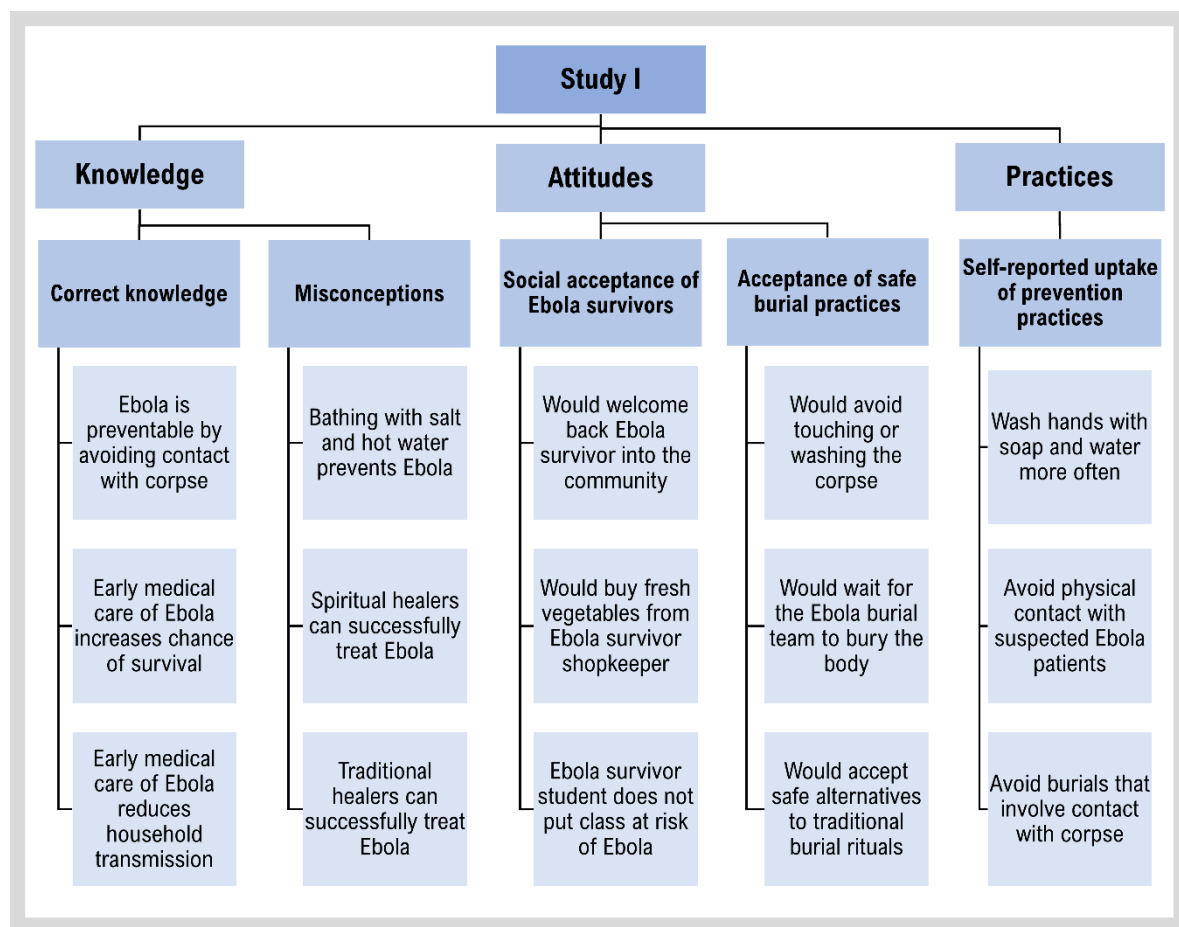


**Figure 5. Outcomes of Ebola–related knowledge, attitudes, and practices measured in Study I**

Items in the initial questionnaire were informed by the broader literature on KAP assessments for other communicable diseases.[190–193] The questionnaires were pilot tested to inform improvements in item–sequencing and local understanding of terminologies for each round of data collection. Under the supervision of local linguists, the questionnaires were translated orally into the commonly spoken local languages during the training of data collection teams. A local NGO, FOCUS 1000, collected the data with technical support provided by other outbreak response partners including CDC and UNICEF. A paper–based questionnaire was used in the first survey; however, all subsequent surveys were done digitally using Open Data Kit (ODK) software application installed in Android tablets.

### 3.3.2 Study II / Paper II

**Study II** comprised IDIs with public health leaders (N=31), FGDs with HCWs and frontline staff (N= 20), and FGDs with members of the general public (N=15). Participants were purposively selected from five districts that were experiencing high transmission of Ebola during October to December when the STRIVE Ebola vaccine trial was being planned in Sierra Leone. All participants were purposefully selected. The IDI participants needed to hold

a leadership role at the national or district level to be eligible for inclusion. Specific categories of HCWs and frontline workers were eligible for inclusion. To be eligible for the FGDs, HCWs needed to be a nurse, medical doctor, or community health officer while frontline workers had to be a burial team member, cleaner, community mobilizers, or ambulance drivers. From the general public, adult participants were eligible for participation in one of three categories of FGDs with adult men aged 25 years or older, adult women aged 25 years or older, or young persons of either sex aged 18–24 years.

FOCUS 1000 recruited participants. In each district, HCWs and frontline workers were recruited from two health facilities (one district hospital and one other peripheral health unit). For the FDGs with members of the general public, participants were recruited from venues such as marketplaces and community centers. Data collection was carried out by trained interviewers and notetakers with prior experience conducting qualitative research in Sierra Leone. The interview and facilitation guides covered attitudes and beliefs about Ebola, perceptions and attitudes about experimental Ebola vaccine and vaccine trial, factors that may influence vaccine trial participation, and preferred communication channels and influencers. Data collection staff only recorded the interview if respondents consented to the recording. IDIs with the public health leaders and FGDs with health workers were mainly conducted English while FGDs with frontline workers and community members were mostly done in Krio. The data collectors debriefed together to discuss and immediately document key themes and observations from the IDIs and FGDs.

### 3.3.3 Study III / Paper III

**Study III** utilized a subset of data from the third survey in **Study I** that was conducted in December 2014 before the implementation of clinical trials of candidate Ebola vaccines in Sierra Leone. The design, sampling, and data collection followed the previous description outlined in Study–1. **Study III** focused on items related to Ebola vaccine demand among the general public. Ebola vaccine demand was captured by three Likert–type items to measure: 1) the perceived need for an Ebola vaccine; 2) willingness to take an Ebola vaccine for oneself if offered; and 3) normative beliefs about family members' willingness to take an Ebola vaccine if offered. In addition, perceptions of who should be the first recipient of an Ebola vaccine were measured wherein the respondents had an option to choose from one of the following categories: me/my family, health care workers, burial teams, political leaders, pregnant women, children, the team that is offering the Ebola vaccine to others, people who live in the worst affected areas, or other.

### 3.3.4 Study IV / Paper IV

**Study IV** comprised two components. The first component was a quantitative description of the number of deaths reported to the national 1–1–7 system, which eHealth Africa managed on behalf of the MoHS during and after the Ebola outbreak in Sierra Leone.[194] For this

component, the data comprised monthly unadjusted aggregated data of death alerts placed to the 1–1–7 national call center during a five–year period between September 2014 and September 2019. The second component was a cross–sectional, telephone–based survey with individuals age 18 years and above who reported a death to the 1–1–7 system after the end of enhanced Ebola surveillance (starting in July 2016) in Sierra Leone. Survey respondents were randomly selected from a stratified sampling frame of individuals that collectively reported 7,025 deaths to the 1–1–7 system between December 2016 and April 2017. Duplicate deaths[**] were removed from the sampling frame (less than 5% of all deaths). The final sampling frame was stratified by region of residence of the person who reported the death (West, North, East, South).

To inform the development and refinement of the survey questionnaire, an FGD was conducted with a convenience sample of 12 respondents in Freetown.  The questionnaire was piloted with a sample of 25 conveniently selected individuals from the four geographic regions. Respondents in the pilot were excluded from the final selection of respondents in the survey to prevent repeat–interview bias. Sociodemographic items included region of residence, sex, age, education, religion, and occupation. Explanatory items included circumstances surrounding the death including the nature of death (accident–related, possible stillbirth, possible maternal death), signs and symptoms, place of death, and treatment seeking history within the month prior to dying, and past Ebola experience. The main outcome measure was motivation to report a death the 1–1–7 system. Response categories of motivations included to find out the cause of death, protect self or others from possible infection, obey government policy/law, obtain burial permit (to allow traditional burial), obtain death certificate, and others. Respondents could select multiple reasons for calling to report the death. Trained interviewers administered the telephone survey to respondents through a softphone system installed on a computer. Interviewers used ODK software[195] installed on computer tablets to store the responses provided by interviewees. Interviews lasted 15–20 minutes on average.

### 3.3.5  Study V / Paper V

**Study V** used an exploratory qualitative approach that consisted of in–depth interviews with individuals who had a death in their household between April and August 2017 but failed to report the death to the 1–1–7 system as mandated by the Government of Sierra Leone. The 32 interviews were carried out in Western Area district (n=16) and Kenema district (n=16). Kenema was the early epicenter of the outbreak and has a large rural population. Western Area recorded the highest number of cumulative Ebola cases during the outbreak and its inhabitants mostly reside in urban areas. Within districts, the sample was further stratified so that eight interviews were conducted in communities that had $\geq 50$ Ebola cases and the

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[**] Defined as reporting of a single death by two or more people.

remaining eight were conducted in communities that had $\leq 10$ cases Ebola cases as of the end of the outbreak. Within communities, households that experienced one or more deaths between April and August 2017 (after the end of the Ebola outbreak and end of enhanced Ebola surveillance), were identified by trained data collectors with help from local community mobilizers. The household death must not have been reported to the 1–1–7 system in order to be eligible. Snowball sampling was used to identify additional households that may have been missed by community mobilizers. In each selected eligible household, one interview was conducted with the household head or next of kin of the deceased person. Trained teams of interviewers and notetakers conducted the interviews in local languages. The interview guides covered topics on community level practices and perceptions regarding the death as well as personal experiences and perceptions regarding the death. All interviews were audio–recorded, and on average, the interviews lasted about an hour. The interviewer and notetaker debriefed to discuss key themes and observations from the interview.

## 3.4 DATA ANALYSIS

### 3.4.1 Study I / Paper I

The pooled data from the four surveys were analyzed in Stata version 15 SE (College Station, TX: StataCorp LLC), and the use of multi–stage sampling was accounted for using the SVY command.[196] To understand the potential effects of population–changes in KAP on the containment of the Ebola outbreak in Sierra Leone, differences in outcomes between high– and low–transmission regions were examined before and after the national peak of the outbreak in November 2014. Two binary explanatory variables were created. In the first variable, respondents in surveys conducted in August 2014 and October 2014 were categorized as before the peak whereas respondents in surveys conducted in December 2014 and July 2015 were categorized as after the peak (Figure 6). In the second variable, official case counts from WHO were used to delineate the respondents' region of residence into high–transmission regions and low–transmission regions.[33] This resulted in categorization of the Western and Northern regions as high–transmission ($\geq 3,000$ cases per region) and Eastern and Southern regions as low–transmission ($\leq 1000$ cases per region).

The pooled KAP survey data were first descriptively analyzed to show frequencies, proportions, and 95% confidence intervals (CIs) of proportions for the KAP outcomes. This was followed by the fitting of multilevel logistic regression models with random intercepts accounting for the random effects of geographic clusters. The models were adjusted for region of residence (high–transmission; low–transmission); gender (male, female); age (15–24 years, >= 25 years); education (no education, primary education, secondary or above); and religious affiliation (Muslim, Christian). In all models, an interaction term was then added to examine the effects of temporal and geographic interactions on the KAP outcomes. Odds ratios (ORs) and their corresponding 95% CIs were calculated to estimate the odds of the

KAP outcomes. Testing for statistical significance was based on a two–sided Wald–type test with level of significance set to $\alpha = 0.05$.
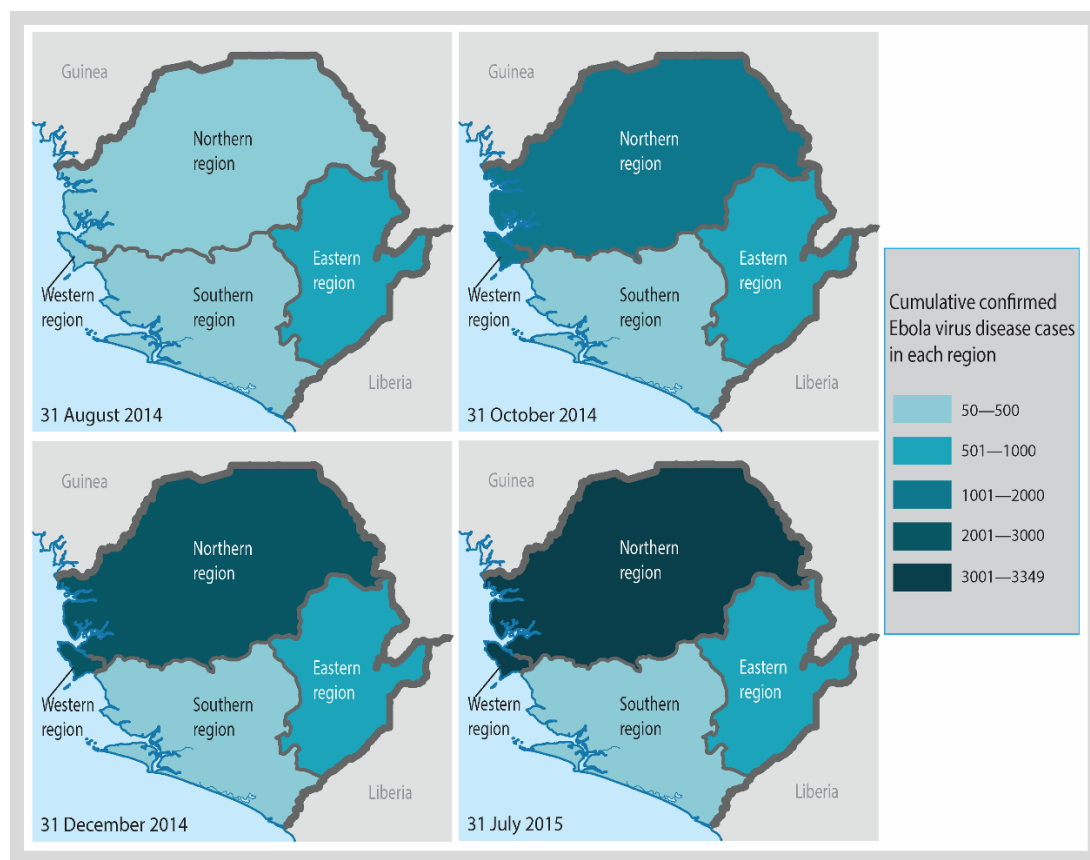


**Figure 6. Distribution of cumulative Ebola cases against the timeline of the four surveys in Study I, Sierra Leone, August 2014 – July 2015**

### 3.4.2  Study II / Paper II

The data were analyzed using qualitative content analysis.[180] Interview transcripts were imported into Dedoose version 8.3.17 web–based platform[197] (Manhattan Beach, CA: SocioCultural Research Consultants). Texts in the transcripts were coded to reflect condensed meaning units after iterative reading of the transcripts. The codes were then categorized to reflect a higher–level grouping of concepts. Finally, themes that cut across multiple categories of codes were identified.

### 3.4.3  Study III / Paper III

The data were analyzed in Stata version 15 SE (College Station, TX: StataCorp LLC). A new variable was created to calculate the composite score for Ebola vaccine demand with possible scores ranging from three (3) to eleven (11) based on the three brief Likert–items. The mean score was computed and used to dichotomize the variable into *low demand* ($\leq$ sample mean) and *high demand* (> sample mean). A multilevel logistic regression model was then used to examine the associations between perceptions of who should be the first recipient of an Ebola vaccine and expressing a high demand for an Ebola vaccine. The response category

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indicating "politicians" was set as the reference category because it was hypothesized that those wanting politicians to be the first recipients of an Ebola vaccine may have had lower demand for the vaccine compared to other respondents who said "me/my family" for example. To adjust for demographic variations, the following covariates were included in the model: sex, age, education, occupation, and religion. The sociodemographic characteristics included in the models have been previously shown to be associated with vaccine uptake.[198–200] Testing for statistical significance was based on a two–sided Wald–type test with level of significance set to $\alpha = 0.05$.

In addition, to examine construct validity, psychometric attributes of the three brief items used to measure Ebola vaccine demand were assessed using Exploratory Factor Analysis (EFA). Principal–component factors extraction method was used in the EFA.[201] Factor loadings, the proportion of variance explained by extracted factors, and a Scree plot of eigenvalues were examined. Kaiser–Meyer–Olkin measure was used to determine sampling adequacy.[201] Reliability was assessed based on the internal consistency of the three items with a Cronbach's alpha value $\geq 0.7$ set as the threshold for acceptable scale reliability.[202]

### 3.4.4 Study IV / Paper IV

In the first part of the analysis, the aggregated monthly number of deaths reported to the 1–1–7 system were descriptively analyzed and plotted onto a bar graph using Microsoft Excel (version 2016) to show monthly death reporting trends during the Ebola outbreak (September 2014–October 2015), post–outbreak enhanced surveillance (November 2015–June 2016), and post–outbreak routine surveillance (July 2016–September 2019). The monthly trends did not account for potential duplicate reports given the aggregated format of the data.

In the second part of the analysis, data from the telephone survey were analyzed using Stata version 15 SE (College Station, TX: StataCorp LLC). Two composite binary exposure variables were then generated. First, a binary variable was generated to indicate if Ebola–like symptoms (fever, diarrhea, vomiting) were present in the decedent (coded 0 for none and 1 for one or more such symptoms). Second, a binary variable was generated for knowing someone who died from Ebola, survived Ebola or quarantined due to Ebola during the 2014–2016 outbreak (coded 0 for none and 1 for one or more such experiences). In addition, a composite outcome variable was created for scoring motivations expressed by respondents, which ranged from zero (0) to six (6) depending on the number of motivations expressed. Ordered logistic regression models were fitted to estimate ORs and their 95% CIs for various associations between explanatory variables and the number of death reporting motivations cited by respondents. Specifically, the model was fitted to examine associations between motivations to report the death and (a) experiencing Ebola–like symptoms before dying, (b) previously calling the 1–1–7 line during the outbreak, and (c) knowing someone who died from Ebola, survived Ebola, or was quarantined due to Ebola during the outbreak in Sierra Leone. The following covariates were included: respondents' geographic region of residence,

sex, age, education, religion, health worker status) and the decedents' sex, age, and religion. Educational attainment and occupation of the decedents were excluded in the models due to their high frequencies of missing values. The covariates in the model were assessed for collinearity, and geographic region of residence of the decedents was excluded because it was collinear with region of residence of the person who reported the death. Testing for statistical significance was based on a two–sided Wald–type test with level of significance set to α = 0.05.

### 3.4.5  Study V / Paper V

The data were analyzed using qualitative content analysis[180] as described in the second study. In summary, the interview transcripts were imported into the Dedoose version 8.3.17 web–based platform[197] (Manhattan Beach, CA: SocioCultural Research Consultants) for qualitative data management and analysis. Texts in the transcripts were coded to reflect condensed meaning units after iterative reading of the transcripts. The codes were then categorized to reflect a higher–level grouping of concepts. Finally, two themes that cut across multiple categories showed barriers and facilitators related to death reporting after the end of enhanced Ebola surveillance in Sierra Leone.

### 3.5  ROLE IN STUDIES

The role of the doctoral candidate in the five studies has been outlined in Table 4. To summarize, he was in Sierra Leone throughout the 2014–2016 Ebola outbreak working with FOCUS 1000 and collaborating with CDC on data collection for **Studies I–III**. He joined CDC in 2016 and led **Studies IV–V**. Across all studies in this thesis, he led or substantially contributed to the design, data collection, and data analysis. He led the writing of the constituent doctoral **Papers I–V**.

**Table 4. Description of role of the doctoral candidate in the various studies**

|  | Design | Training of data collectors | Data collection | Data analysis/ interpretation |
|---|---|---|---|---|
| **Study 1** | Led | Led | Supervised | Led |
| **Study 2** | Contributed | Contributed | Supervised and conducted 20% of interviews | Led |
| **Study 3** | Led | Led | Supervised | Led |
| **Study 4** | Led | Led | Supervised | Led |
| **Study 5** | Contributed | Led training | Supervised | Led |

# 4 ETHICAL CONSIDERATIONS

Conducting data collection during the outbreak presented cross–cutting ethical challenges. First, there was a need to balance the rigor of the research designs with the need to avoid excluding at–risk persons from life–saving interventions. Even though experimental designs would have yielded the most scientifically sound evidence, they posed serious ethical problems. Consequently, observational designs were used in all the studies. Close attention was paid to how informed consent was obtained to avoid creating a false perception of immediate and direct benefit by participating in the studies. Given that respondents sometimes shared with data collectors that they had engaged in risky practices that contributed to Ebola transmission risks (e.g. washing of a corpse), thoughtful measures were taken to protect their identities so that outbreak response authorities would not levy punitive actions against them. Personal identifying information were removed from all datasets and no paper trail linking respondents' identities to their responses were kept.

Verbal consent was frequently required due to low literacy in Sierra Leone. Moreover, there was a need to ensure the safety of the data collection staff to protect them from possible Ebola acquisition risks. Safety SOPs were implemented, and all staff were trained on how to protect themselves from possible exposures to the Ebolavirus. For instance, all data collection staff were trained to avoid all physical contact with study participants (including handshakes), maintain social distancing, avoid entering the residence of participants, and practice frequent handwashing with soap and water between interviews.

Each of the studies posed unique ethical challenges that required tailored, mitigating actions. In **Studies I & III**, interviews were conducted with random samples from the general public at different points of the protracted Ebola outbreak. Data collection staff sometimes encountered sick people suspected of Ebola in households they visited during recruitment. There was a need to ensure that such households were not excluded from the studies to avoid introducing systematic bias in the sample while also ensuring the safety of data collection staff. Moreover, data collectors had an ethical responsibility to inform the heads of such households to refer sick persons through the established toll–free 1–1–7 line to get ambulance service. The KAP questionnaires contained several questions regarding behavioral intentions to report sick people and deaths to the alert line. To avoid biasing the results by providing information about the alert line upfront, data collectors were trained to wait to do so after the interview ended. Similarly, respondents frequently had questions for the data collection teams regarding various aspects of Ebola prevention and treatment. At the end of the interviews, data collectors gave respondents an opportunity to ask questions. This meant that data collectors had to be equipped with basic knowledge of Ebola transmission, prevention and treatment so that they could accurately answer questions posed at the end of the interviews. When data collectors were not able to answer certain questions at the end of the interview,

they asked the inquiring respondents to call the 1–1–7 tollfree line where trained personnel would address Ebola questions and concerns.

In **Study II**, it was agreed upon ahead of time how to deal with questions that might arise from the interviews in the FGDs and IDIs regarding experimental Ebola vaccines. At the end of data collection, a factsheet was provided to each participant with information regarding what was known about the candidate Ebola vaccines. Data collectors also documented questions raised, which were shared with the staff involved in planning the vaccine trial. In addition, data collectors had to clarify that participation in the formative research did not influence one's future chances in getting enrolled in the trial to receive an experimental Ebola vaccine. Despite these clarifications, it remained unclear how formative research participants were motivated by the perception that they may improve their chances of receiving an experimental Ebola vaccine.

In **Studies IV–V**, unique ethical dimensions were considered because interviews were conducted with individuals who had recently experienced the death of a loved one – usually a close family member. Data collectors were trained to carefully and respectfully ask questions in ways that minimized evoking negative emotional reactions among respondents. However, there was no way of knowing how the assessment might have caused emotional distress for bereaved participants. In **Study V**, respondents feared the possible consequences for not reporting the deaths as required by the Government of Sierra Leone. Data collectors were trained to assure respondents that their identities would not be revealed to the authorities. Careful steps were taken to ensure that all data were de–identified, and that anonymity was always maintained in the reporting of the data.

A further reflection on the ethical issues confronted in the respective studies point a key lesson learned regarding the conduct of research during a spiraling outbreak. It became clear that the research team is even more so the gatekeeper of research ethics because of the chaos, desperate need for rapid data collection to inform the outbreak response, and the immediate threat of disease transmission, of a potentially lethal disease. Research subjects might become motivated to participate in a study due to the ongoing disease threat during the outbreak. Careful steps must be taken to avoid unintentional use of the heightened outbreak environment to tacitly coerce individuals into participating into research studies. In low literacy populations, such as in Sierra Leone, verbal consent in the local language should be an option to ensure that every participant fully understands and can weigh the risks and benefits of their participation in the research. Under normal research conditions, the researcher needs to be 'removed' from the research to ensure objectivity and avoid introducing biases. However, in an outbreak condition, the researcher might even become part of the outbreak response. For instance, the presence of data collectors in households during interviews sparked questions from the local community that data collectors had an ethical obligation to address to avoid creating misconceptions or interfering with prevention or treatment programs.

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In sum, during a spiraling and chaotic outbreak, the drive to *do good* may unintentionally create conditions that *do harm* if researchers are not careful about how their studies are designed and implemented. The principle of *justice* should be carefully balanced because research conducted on directly affected populations may be disproportionately used for the "greater good" of mostly unaffected population. Directly affected persons participating in research during outbreaks ought to be *treated equally* as would have done with the mostly unaffected population or during times of non–outbreak conditions. Unequal treatment should not be allowed in the guise of a chaotic outbreak setting. Emergency situations, including outbreaks, should never be used as an excuse for violating ethical research principles. There is always a choice to *do good, avoid harm, ensure justice, and respect autonomy*.

## 4.1 ETHICAL APPROVALS

All studies in the thesis received ethical approval by the Sierra Leone MoHS and CDC. **Studies I–III** received research approval by the Office of Ethics and Scientific Review Committee in the Sierra Leone MoHS. **Studies IV–V** were deemed as non–research and approved by both the Sierra Leone MoHS and CDC as routine public health surveillance.

# 5 RESULTS

Ebola–related KAP outcome improved over time, especially when comparing results from surveys conducted before the peak of the outbreak (August and October 2014) and after the peak of the outbreak (December 2014 and July 2015). However, some improvements in KAP outcomes were more pronounced in the high–transmission regions compared to the low transmission–regions in the country. (**Paper I**)

Safety concern was the most recurring barrier to Ebola vaccine acceptability including the fear that the vaccine may cause Ebola. This was followed by additional concerns regarding the effectiveness of the vaccine in the context of persistent Ebola transmission risk to health workers during the outbreak. Despite these barriers, altruism emerged as a major motivating factor in wanting to participate in an Ebola vaccine trial to help disrupt transmission during the outbreak. (**Paper II**)

About three-quarters of all respondents nationally (74%) expressed high demand for Ebola vaccines during the outbreak in Sierra Leone. We found that perceptions of who should be the first to take the vaccine if made available to the public was strongly associated with Ebola vaccine demand. The psychometric properties of the ultra–brief measure of Ebola vaccine demand showed acceptable reliability and evidence of a single construct with acceptable factor loadings. (**Paper III**)

Analysis of monthly data of deaths reported to the 1–1–7 system showed that on the last month of enhanced surveillance (June 2016)[††], nearly 4,000 deaths were reported compared to <2,500 in the month immediately after (July 2016). The monthly numbers of reported deaths continued to plummet and reached as low as 1,550 in January 2017, 673 in January 2018, and 586 in January 2019. In the survey, we uncovered that people who reported deaths were mainly motivated to comply with the Government's mandate to report all deaths. After adjusting for potential confounders, motivation to report was strongly associated with the presence of Ebola–like symptoms in the decedent. (**Paper IV**)

After the end of the Ebola outbreak, death reporting barriers were mainly due to lack of awareness of the mandate to report all deaths and lack of perceived benefits to report. However, in the future, respondents expressed willingness to report deaths to the government if reciprocal benefits such as ambulance services are provided for reporting. (**Paper V**)

## 5.1 EBOLA KNOWLEDGE, ATTITUDES, AND PRACTICES

In **Study I**, a total of 10,603 respondents across four rounds of data collection consented to participate: 1,413 in the first survey in August 2014; 2,086 in the second survey in October 2014; 3,540 in the third survey in December 2014; and 3,564 in the fourth survey in July

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[††] Enhanced surveillance lasted from November 8th 2015 to June 30th 2016.

2015. The response rate was 98% overall across the four rounds of interviews. In the pooled sample: 50% of the respondents were female; 44% of the respondents had no formal education; 67% of the respondents identified as Muslim; 21% of the respondents were farmers; and 23% of the respondents were students. (**Paper I**)

### 5.1.1  Changes in knowledge and misconceptions

Correct knowledge of Ebola prevention was high as early as August 2014, but the misconceptions were also common. For example, between August 2014 and July 2015, knowledge that Ebola is preventable by avoiding contact with corpses increased from 85% to 95% while the misconception that bathing with salt and hot water prevents Ebola decreased from 42% to 15% (Table 5).

### 5.1.2  Changes in social acceptance of Ebola survivors

Social acceptance of Ebola survivors was low in August 2014 in the early stages of the outbreak (less than 35% for each of the three measures) but improved very rapidly by October 2014. Between August and October 2014, the proportion of respondents expressing willingness to welcome Ebola survivors into their communities increased from 22% to 85%, which further increased to 89% by July 2015 when the last survey was conducted (Table 5).

### 5.1.3  Changes in acceptance of safe burial practices

Three measures on acceptance of safe burials were first introduced in the second KAP survey conducted in October 2014. At this period, intention to avoid touching or washing the corpse was high (90%). Alternatives to traditional burials were accepted by 64% of respondents in October 2014 but increased to 86% in December 2014 after the outbreak peaked (Table 5).

### 5.1.4  Changes in self–reported prevention practices

In all surveys, nearly every respondent reported uptake of at least one Ebola prevention practice ($\geq$95%). Between August 2014 and July 2015, handwashing with soap increased from 66% to 89%. The most notable increase in self–reported avoidance of suspected Ebola patients and corpses occurred between October and December 2014 (Table 5).

**Table 5. Changes in knowledge, attitudes, and protective behaviors, at four different months of the Ebola outbreak, Sierra Leone, August 2014 – July 2015**

| | Aug 2014 N=1,413 | | Oct 2014 N=2,086 | | Dec 2014 N=3540 | | Jul 2015 N=3564 | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| **Knowledge** | | | | | | | | |
| 1. Ebola is preventable by avoiding contact with corpse | 1182 | 85 | 1959 | 94 | 3414 | 97 | 3327 | 93 |
| 2. Early medical care of Ebola increases chance of survival | 1254 | 90 | 1938 | 93 | 3372 | 95 | 3419 | 96 |
| 3. Early medical care of Ebola reduces household spread | 1284 | 91 | 1942 | 94 | 3258 | 92 | 3294 | 93 |
| **Misconception** | | | | | | | | |
| 4. Bathing with salt and hot water prevents Ebola | 571 | 42 | 717 | 35 | 1117 | 32 | 534 | 15 |
| 5. Spiritual healers can successfully treat Ebola | 275 | 20 | 278 | 13 | 207 | 6 | 145 | 4 |
| 6. Traditional healers can successfully treat Ebola | 80 | 6 | 66 | 3 | 66 | 2 | 46 | 1 |
| **Social acceptance of survivors** | | | | | | | | |
| 7. Would welcome back Ebola survivor into the community | 312 | 22 | 1772 | 85 | 3170 | 90 | 3169 | 89 |
| 8. Would buy fresh vegetables from Ebola survivor shopkeeper | 447 | 32 | 1462 | 71 | 2934 | 83 | 2974 | 84 |
| 9. Ebola survivor student does not put class at risk of Ebola | 452 | 33 | 1488 | 72 | 2541 | 72 | 2504 | 70 |
| **Acceptance of safe burial practices** | | | | | | | | |
| 10. Would avoid touching or washing the corpse˟ | – | – | 1873 | 90 | 3362 | 95 | 3415 | 96 |
| 11. Would wait for the Ebola burial team to bury the body˟ | – | – | 1787 | 86 | 3404 | 96 | 3402 | 96 |
| 12. Would accept safe alternatives to traditional burial rituals˟ | – | – | 1334 | 64 | 3049 | 86 | 2823 | 80 |
| **Self–reported prevention practices** | | | | | | | | |
| 13. Uptake of one or more Ebola protective practice | 1344 | 95 | 2022 | 97 | 3439 | 97 | 3455 | 97 |
| 14. Wash hands with soap and water more often | 917 | 66 | 1701 | 82 | 2790 | 78 | 3056 | 89 |
| 15. Avoid physical contact with suspected Ebola patients | 498 | 35 | 737 | 35 | 1538 | 43 | 1122 | 33 |
| 16. Avoid burials that involve contact with corpse˟ | – | – | 569 | 27 | 1673 | 47 | 1700 | 49 |

*August 2014: total valid responses ranged from 1371 to 1409; missing values excluded (<3% of total responses); October 2014: total valid responses ranged from 2070 to 2086; missing values excluded (<1% of total responses); December 2014: total valid responses ranged from 3534 to 3540; missing values excluded (<1% of total responses); July 2015: total valid responses ranged from 3455 to 3563; missing values excluded (<4% of total responses).˟ Item not included in the first survey in August 2014 but introduced in subsequent survey.

### 5.1.5  Interaction between time and place

When compared to the low–transmission regions, there were larger improvements in the high–transmission regions regarding intention to wait for a burial team and self–reported avoidance of physical contact with suspected Ebola patients (Table 6). Intending to wait for a burial team was almost three times greater in high–transmission regions (aOR 6.2; 95% CI 4.2–9.1) versus in low–transmission regions (aOR 2.3; 95% CI 1.4–3.8) when comparing the odds ratios before and after the peak of the outbreak. Increased avoidance of physical contact with suspected Ebola patients was also documented in high–transmission areas (aOR 1.9; 95% CI 1.4–2.5) when comparing before and after the peak of the outbreak (Table 6).
(**Paper I**)

**Table 6. Temporal and geographic interactions in predicting intention to wait for a burial team and avoidance of physical contact with suspected Ebola patients, Sierra Leone, August 2014 – July 2015**

| Interaction between time and place | Intention to wait for burial team if family member died | | Self–reported protective practice of avoiding physical contact with suspected Ebola patients | |
|---|---|---|---|---|
| | Odds ratio[&] (95% CI) | P value† | Odds Ratio[&] (95% CI) | P value† |
| In high transmission regions after the peak compared to before the peak | 6.2 (4.2–9.1) | 0.000 | 1.9 (1.4–2.5) | 0.000 |
| In low transmission regions after the peak compared to before the peak | 2.3 (1.4–3.8) | 0.001 | 0.8 (0.6–1.2) | 0.283 |
| Before the peak in low transmission regions compared to high transmission regions | 4.1 (2.6–6.5) | 0.000 | 3.6 (2.4–5.2) | 0.000 |
| After the peak in low transmission regions compared to high transmission regions | 1.5 (1.0–2.3) | 0.038 | 1.5 (1.2–2.0) | 0.004 |
| After the peak in low transmission regions compared to before the peak in high transmission regions | 9.6 (6.1–15.2) | 0.000 | 2.9 (2.1–4.0) | 0.000 |

[&]Log odds of KAP outcome = $\beta 0 + \beta 1$(stage of outbreak) + $\beta 2$(region) + $\beta 3$(stage of outbreak x region) + $\beta 4$(education) + $\beta 5$(sex) + $\beta 6$(age) + $\beta 7$(religion) + cluster random intercept;
†Wald statistical p value from the regression models.

## 5.2 ACCEPTABILITY OF EBOLA VACCINES

In **Study II**, a total 31 respondents consented to participate in the interviews and 316 respondents in the 35 FGDs (184 HCWs and frontline workers in 20 FGDs and 132 members from the general public in 15 FGDs).

In **Study III**, a total of 3,540 respondents from the general public agreed to participate in the survey: 49% were females, 33% were between 15–24 years old, 34% had no education, and 66% identified Islam as their religion.

### 5.2.1 Perceptions of experimental Ebola vaccines as a function of trust

Perceptions of the long–standing childhood immunization program in Sierra Leone had a positive influence on how respondents perceived the experimental Ebola vaccines. Specifically, the perceived benefits of childhood vaccines in curbing polio and other vaccine–preventable diseases reinforced trust in vaccines in general. (**Paper II**)

> *"Marklate [vaccine] has been a good thing for us in the country. I remember when we had polio but now it's a thing of the past. We always make sure to get our children vaccinated to help them live a strong and healthy life. Without polio vaccine, we would have been dealing with so many disabled children who grow to face so many challenges in life"* – general public member from Western Area district.

Members of the general public did not know the difference between licensed vaccines (e.g. those offered in the childhood immunization program) and experimental vaccines. HCWs and frontline workers who would have become the first to receive Ebola vaccines were largely viewed as the most trusted sources of information about the vaccine. (**Paper II**)

*"I believe that the medical workers are the best to talk to people [about the vaccine] because they would have taken the vaccine. So therefore, people will believe them that the vaccine won't kill them." – general public member from Port Loko district.*

### 5.2.2 Safety concerns and efficacy uncertainties as major barriers to accepting any experimental Ebola vaccine

Safety was the most serious concern to regarding willingness to take an experimental Ebola vaccine if offered. Specifically, respondents were worried that the vaccine could cause Ebola or result in serious adverse events after getting vaccination, including the fear of possible death. (**Paper II**)

*"...we don't want them to start with the health workers because if they were to die [from taking the vaccine] who will be there to save lives? Many of our colleagues have died during this Ebola [outbreak], so doing the test on us health workers has a question about who will survive in case of any adverse reactions." – surveillance officer, Bombali.*

Although HCWs and frontline workers had concerns about the efficacy of Ebola vaccines, they expressed willingness to volunteer in pending clinical trials if offered to participate. Doubts about the efficacy of the vaccine reinforced the need to continue using personal protective equipment after getting vaccinated. (**Paper II**)

*"I will still continue using the PPE to see first how the vaccine works. I cannot take any risks at this point" – burial team member from Bombali district.*

### 5.2.3 Influence of altruistic intentions and positive vaccination experiences on acceptance of experimental Ebola vaccines

The threat posed by the ongoing outbreak and the high Ebola transmission risk posed to HCWs and frontline workers motivated them to altruistically be willing to participate in an Ebola vaccine trial to help end the outbreak. (**Paper II**)

*"I would be comfortable to do so [accept an experimental Ebola vaccine] in the context of trying to solve a problem, reduce the risk to humanity and give our people the chance to end a disease that has had catastrophic effects on our lives" – medical doctor from Western Area district.*

### 5.2.4 Quantifying public demand for Ebola vaccines

In **Study III**, 93% of respondents from the general public agreed that an Ebola vaccine was necessary to fight the outbreak, 78% expressed that they were very likely to accept an Ebola vaccine for themselves, and similarly, 77% expressed that their family members would be very likely to accept an Ebola vaccine. If an Ebola vaccine became available, 37% said HCWs should be the first to take the vaccine, which was followed by saying me or my family (26%), politicians (14%), the team that is offering the vaccine to others (10%), and people who live in worst affected areas (8%). (**Paper III**)

The aggregated Ebola vaccine demand score ranged from 3 to 11 (mean=10). After dichotomizing the score into high demand ($>$ mean) and low demand ($\leq$ mean), 74% of

respondents expressed high demand for an Ebola vaccine. Expressing high demand for an Ebola vaccine was 13 times greater among those who said "me or my family" when compared to those who cited politicians (aOR 13.0; 95% CI 7.8–21.6) when asked who should receive the vaccine first. On the other hand, expressing high demand was not significantly different between respondents who said the team offering Ebola vaccine versus those who said politicians should be the first to take the vaccine (aOR 1.4; 95%CI 0.9–2.1) (Table 7). (**Paper III**)

**Table 7. Multilevel logistic regression model for expressing high demand for Ebola vaccine among respondents in a national household survey, Sierra Leone, December 2014**

|  | Multivariable Model | |
| --- | --- | --- |
|  | aOR ‡ (95%CI) | P value † |
| **Perceived first recipient** | | |
| *Politicians* | *Reference* | |
| Me/my family | 13.0 (7.8–21.6) | 0.000 |
| Pregnant women | 5.7 (1.9–17.5) | 0.003 |
| Children | 4.7 (2.4–9.1) | 0.000 |
| People who live in worst affected areas | 2.9 (1.7–5.1) | 0.000 |
| Healthcare workers/burial teams | 2.0 (1.4–2.8) | 0.000 |
| Other | 2.0 (0.9–4.2) | 0.051 |
| The team offering an Ebola vaccine | 1.4 (0.9–2.1) | 0.157 |
| **Geographic region** | | |
| *Western Area* | *Reference* | |
| North Province | 1.4 (0.8–2.3) | 0.188 |
| Eastern Province | 1.8 (0.9–3.4) | 0.057 |
| Southern Province | 1.1 (0.5–2.5) | 0.891 |
| **Gender** | | |
| *Male* | *Reference* | |
| Female | 0.9 (0.8–1.1) | 0.426 |
| **Age** | 1.0 (0.9–1.0) | 0.242 |
| **Education** | | |
| *None* | *Reference* | |
| Primary | 1.1 (0.8–1.5) | 0.633 |
| Secondary or higher | 1.6 (1.2–2.1) | 0.001 |
| **Religion** | | |
| *Islam* | *Reference* | |
| Christianity | 1.0 (0.6–1.7) | 0.881 |

# N=3,290 respondents; 250 (7%) had one or more missing responses that were excluded
‡ Adjusted odds ratio (aOR) is adjusted for region of residence, sex, age, education, and religion
† Wald statistical p value from multiple logistic regression model
CI = confidence interval

Among the sociodemographic covariates in the multilevel model, only education was associated with expressing high demand for an Ebola vaccine when comparing those with secondary education or high versus those with no education (aOR 1.6; 95%CI 1.2–2.1) (Table 7). (**Paper III**)

### 5.2.5 Reliability and construct validity of Ebola vaccine demand measure

The three items used to measure Ebola vaccine demand demonstrated acceptable scale reliability (Cronbach's alpha = 0.79) (Table 8). (**Paper III**)

**Table 8. Reliability testing for the brief measure of Ebola vaccine demand, Sierra Leone, December 2014**

| Item | Observations | Sign | Item–test correlation | Item–rest correlation | Interitem correlation | alpha |
|---|---|---|---|---|---|---|
| Perceived need | 3479 | + | 0.7187 | 0.3774 | 0.9297 | 0.9636 |
| Intention to accept | 3467 | + | 0.9224 | 0.8019 | 0.3375 | 0.5047 |
| Normative belief | 3435 | + | 0.9144 | 0.7763 | 0.3778 | 0.5484 |
| Test scale | | | | | 0.5491 | 0.7851 |

In EFA, one factor was retained with all three items having factor loadings >0.5. The single factor explained 71% of the variance (Table 9). (**Paper III**)

**Table 9. Eigenvalues and proportion of variance explained by extracted factors in the brief measure of Ebola vaccine demand, Sierra Leone, December 2014**

| Factor | Eigenvalue | Difference | Proportion | Cumulative |
|---|---|---|---|---|
| Factor 1 | 2.15 | 1.34 | 0.71 | 0.71 |
| Factor 2 | 0.79 | 0.72 | 0.26 | 0.97 |
| Factor 3 | 0.07 | . | 0.03 | 1.00 |

### 5.3 MORTALITY SURVEILLANCE

**In the first part of Study IV**, analysis of monthly numbers of death reported to the national 1–1–7 system showed a steep decline after the outbreak and enhanced mortality surveillance ended. In the year we conducted the survey (2017), a total of 11,642 deaths were reported to the 1–1–7 system compared to 32,469 in 2016 and 117,036 in 2015 (Figure 7).

With an approximate population of 8 million and a national crude death rate of 11.9 per 1000 population,[203] 95,000 deaths may be expected occur yearly in Sierra Leone. Based on these parameters, albeit not accounting for potential duplicate reports, the number of deaths reported in 2017 may have maximally represented nearly 12% of the expected deaths in the country versus much higher levels in 2016 (almost 34%) and 2015 (over 100%). (**Paper IV**)

**In the second part of Study IV**, 1,291 (97%) respondents consented to participate in the survey out of the 1,330 successfully reached by telephone from a random sample of 4,300 eligible individuals selected from the national 1–1–7 database of death reporters. Out of the sample of respondents, 85% were male, 11% had no formal education, 64% identified as Muslims, 56% were family members of the decedents, 52% had previously called the 1–1–7 line at least once during the 2014–2016 Ebola outbreak in Sierra Leone, 49% personally knew someone who died from Ebola, 50% personally knew someone who survived Ebola, and 58% personally knew someone who was quarantined due to Ebola exposure. (**Paper IV**)
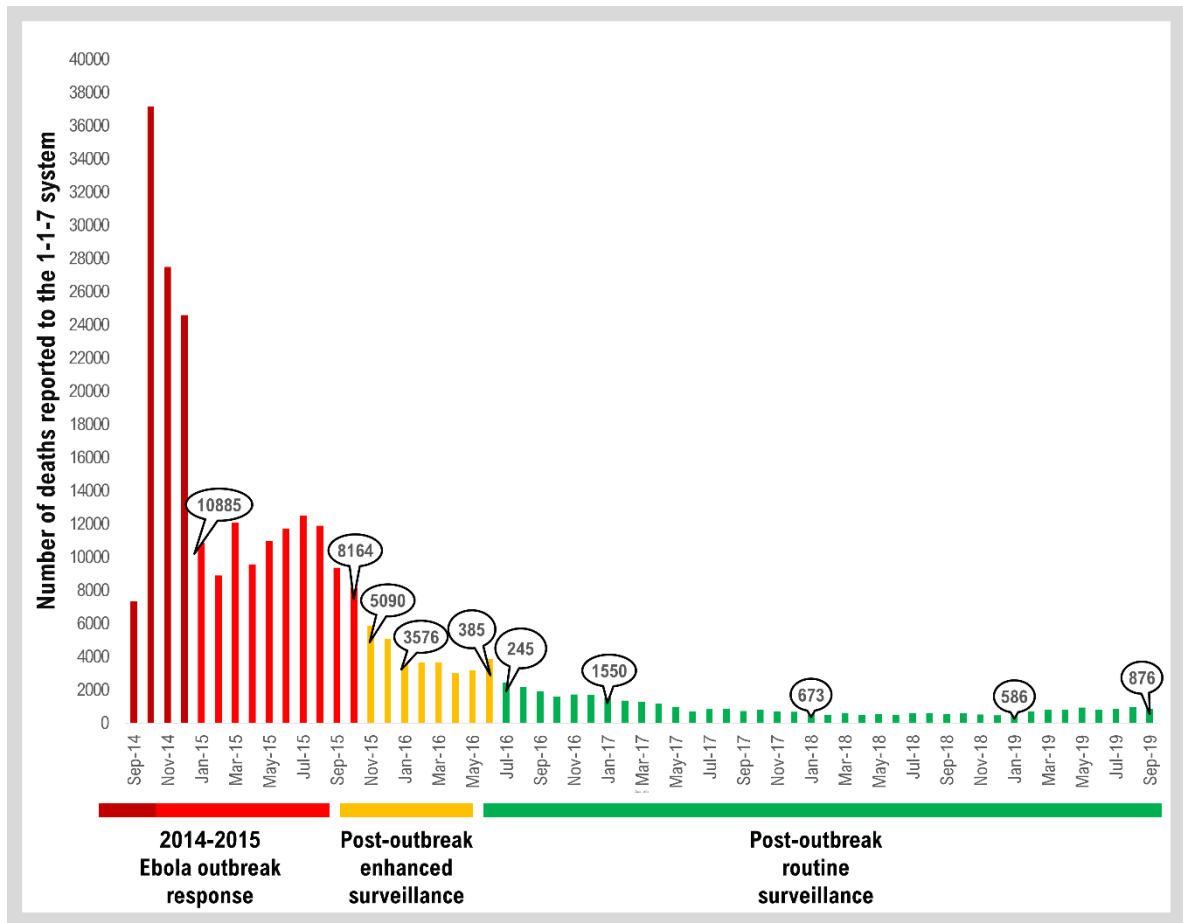
**Figure 7. Monthly number of deaths reported to the 1–1–7 system, Sierra Leone, 2014–2019**

### 5.3.1 Deaths reported after the Ebola outbreak

**In the second part of Study IV**, among the sample of 1,291 decedents, 55% were males, 54% had no education, 79% were Muslims, and 42% were at least 50 years old.  Women of reproductive age made up 29% (n=376) of the decedents, of whom 6% (n=24) were pregnant at the time of the death. Another 127 deaths (10%) were infants. Accident–related deaths comprised 5% (n=59) of all deaths. In terms of health–seeking behavior before dying, 83% of decedents reportedly received some form of treatment—mainly from health facilities (82%). Frequently cited symptoms that the decedents purportedly experienced within the past month of dying were fever (32%), joint pain (21%), headache (20%), and abdominal pain (16%). Nearly a third of decedents (31%), reportedly experienced Ebola–like symptoms (fever, diarrhea, or vomiting) before dying. (**Paper IV**)

### 5.3.2 Motivations to report deaths after the Ebola outbreak

**In the second part of Study IV**, motivations to report deaths were identified among people who reported deaths to the 1–1–7 system in Sierra Leone. The most frequently cited motivations to report were to obey government policy (82%), find out the cause of death (37%), obtain burial permit (29%), and protect self or others from infection (26%) (Figure 8).
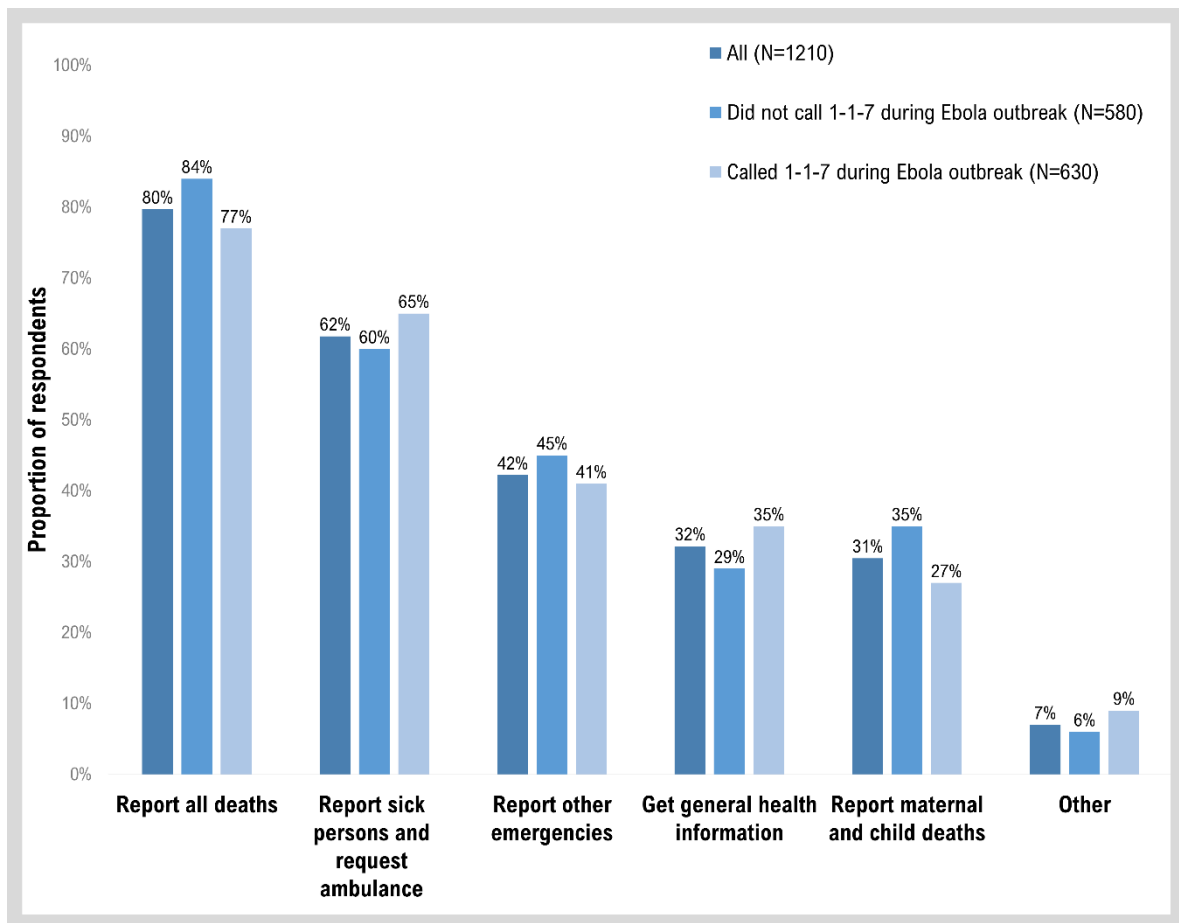
**Figure 8. Motivations for future reporting deaths to the 1–1–7 system, Sierra Leone, 2017**

Compared to respondents who did not report deaths that exhibited Ebola–like symptoms, those who reported such deaths had more than a two–fold increase in the odds of being motivated to report (Table 10). (**Paper IV**)

**Table 10. Ebola–like symptoms and past Ebola experiences and as determinants of death reporting motivations, Sierra Leone, April 2017**

| | Motivations to report* | |
|---|---|---|
| | aOR (95%CI) | P value † |
| **Person who died: Experienced symptoms of fever, diarrhea, or vomiting before dying** | | |
| No | *Reference* | |
| Yes | 2.26 (1.78–2.87) | 0.000 |
| **Person who reported the death: Previously called 1–1–7 line during the outbreak** | | |
| No | *Reference* | |
| Yes | 1.0 (0.79–1.27) | 0.972 |
| **Person who reported the death: Knew someone who died, survived, or was quarantined due to Ebola during the outbreak** | | |
| No | *Reference* | |
| Yes | 0.94 (0.73–1.21) | 0.631 |
| *Total of 1,096 respondents included in the model (complete cases); 195 excluded due to missing data for one or more variables. † Wald statistical p value from ordered logistic regression model. AOR = adjusted for all main exposure variables plus region of residence, sex (of respondent and deceased person), age (of respondent and deceased person), education (of respondent), religion (of respondent and deceased person), occupation (of respondent). | | |

### 5.3.3 Barriers to reporting deaths

In **Study V** among people who failed to a report a death to the 1–1–7 as mandated by the government after the end of enhanced Ebola surveillance, barriers to reporting were driven by the lack of awareness to report all deaths, lack of reciprocal benefits linked to reporting, negative experiences from the Ebola outbreak, perception that inevitable deaths do not need to be reported, and situations where prompt burials may be needed. (**Paper V**)

> *"... 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*

> *"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*

> *"This 1–1–7 line…I don't want it. I want us to be respecting the [dead] people because the 1–1–7 was not burying our people properly. So, we are burying our people. Let government leave it [burial] up to us. If a doctor checks the body [that's fine], but don't let the 1–1–7 – come here until we have buried the corpse" – respondent from Kenema district*

### 5.3.4 Strategies to improve death reporting

In the telephone survey with death reporters, 94% of respondents expressed that they would like the Government of Sierra Leone to keep the 1–1–7 system in place. They also stated their preferences for future uses of the 1–1–7 system (Figure 9).
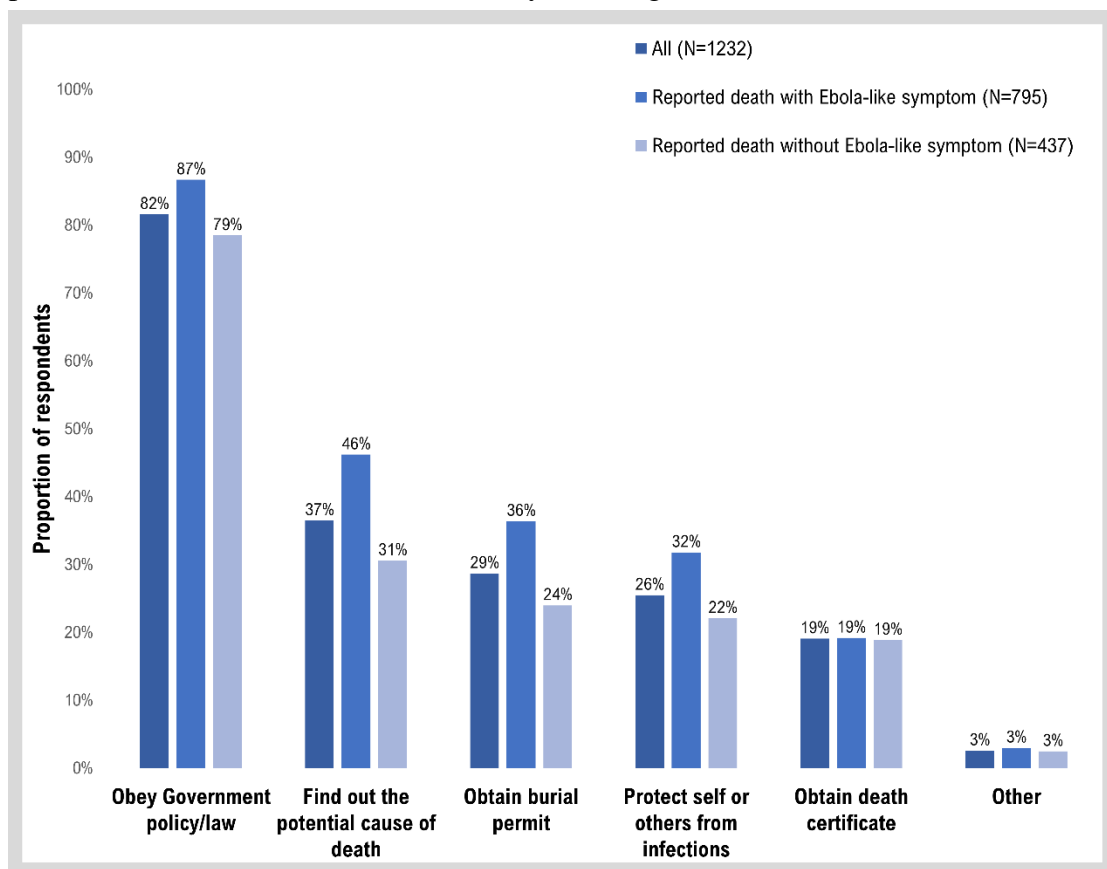


**Figure 9. Preferences for future uses of the 1–1–7 system, Sierra Leone, 2017**

Overall, 80% of the respondents cited that they wanted the system to be used for death reporting of all deaths, which was more common among those who never used the 1–1–7 system during the Ebola outbreak compared to those who did. (**Paper IV**)

In the qualitative assessment, facilitators of willingness to report deaths in the future included the presence of Ebola–like symptoms in the decedent, occurrence of sudden and unexplained deaths, and the existence of other local reporting mechanisms. (**Paper V**)

> *"For any death pertaining to what government told us [we need to report]. That of a bad disease like Ebola, laser fever…The people around will not even dare to touch the person, because it is a transferable disease and it is more common in eastern province." – respondent from Kenema district*

> *"Like I said before, when someone dies abruptly, and nothing was wrong with him [before dying]. I will just be looking at him, I will not have the knowledge to know the cause of death, I will not have the machine to show that this is the sickness that caused the death or whether he just fell and died or whether he just sat down and died. When you go to a medical person [through 1–1–7], he can confirm that this is the cause of the death. If the doctor has confirmed that for real, he has died, what can I do? I just have to go to City Council to obtain the burial permit because I cannot go ahead and bury someone without the knowledge of the government." – respondent from Western Area district*

# 6 DISCUSSION

**Study I** showed that nearly every Ebola KAP outcome improved over time, especially when comparing before and after the peak of the outbreak, and some improvements were more pronounced in the high–transmission regions compared to the low transmission–regions during the outbreak. **Study II** revealed that perceptions of experimental Ebola vaccines influenced trust or mistrust of the clinical trials of Ebola vaccines that were under planning. Safety concerns were major barriers to hypothetically agreeing to participate in an Ebola vaccine trial. However, altruistic intentions to help end the outbreak and prior positive experiences with childhood vaccines influenced willingness to want to volunteer for an experimental Ebola vaccine. **Study III** demonstrated the high public demand for Ebola vaccines as expressed by 74% of respondents nationally around the peak of the outbreak. Perceptions of who should be the first to take the vaccine if made available to the public was significantly associated with Ebola vaccine demand among the public. The psychometric properties of the brief measure of Ebola vaccine demand provided evidence of acceptable reliability and construct validity. Analysis of monthly data of deaths reported to the 1–1–7 system in **Study IV** pointed to a sharp decline after the outbreak and enhanced mortality surveillance ended. In the survey in **Study IV**, it was further uncovered that people who reported deaths were mainly motivated to comply with the Government's mandate to report all deaths, and motivations to report were more pronounced if Ebola–like symptoms were present in the decedent. **Study V** then highlighted important barriers for why some people failed to report deaths to the 1–1–7 system after the outbreak and enhanced mortality surveillance had ended. Death reporting barriers were primarily driven by lack of awareness of the government's mandate to report all deaths and lack of perceived reciprocal benefits to report. Consequently, willingness to report deaths to the government may be enhanced if reciprocal benefits such as ambulance services are provided for reporting.

## 6.1 INTERPRETATION OF FINDINGS

### 6.1.1 Improvements in Ebola knowledge, attitudes, and practices

Behavior change at large–scale during outbreaks were not well understood prior to the Ebola outbreak in West Africa. The West Africa Ebola outbreak did not have a blueprint to follow because of its scale and complexity. **Study I** represents the first population–level evaluation of changes in Ebola–related KAP at different stages of an Ebola outbreak. Previously, mathematical models have been used to quantify the potential role of behaviors in containing the outbreak. Use of real–time data from an actual Ebola outbreak to answer the question of when and where behavior changed has not been done so far in any of the affected countries. This is because such data are limited. Out of the three Ebola–affected countries in West Africa, Sierra Leone was the first to conduct a nationwide household KAP survey in August 2014 several months before the peak of the outbreak.[93] Three more follow–up surveys, using the same methodology and repetition of core items, were implemented at different stages of

the outbreak including right before the peak (October 2014), right after the peak (November 2014), and near the end of the outbreak in the country (July 2015). Lessons from the KAP surveys in Sierra Leone also directly informed similar KAP assessments in Liberia and Guinea but those were one–off data collection efforts.[122][125] The data analyzed and presented in **Study I** provide an opportunity to adapt the methods and data collection instruments in future outbreaks of Ebola.

### 6.1.2  Demand for Ebola vaccine during an outbreak

In **Study III**, the level of Ebola vaccine acceptability in Sierra Leone among the general public was similar to other assessments in the country, Guinea, and DRC. A survey among general public participants in Sierra Leone's Western Area Rural district in March 2015 revealed that 73% of respondents were willing to take an Ebola vaccine if provided free–of–charge but only 27% were willing to do so if they had to pay for it.[204] A national household survey in August 2015 in Guinea found similar levels of acceptability of Ebola vaccines such that that 86% of respondents perceived that an Ebola vaccine was needed to help end the outbreak while a similar proportion (84%) were willing to accept the vaccine if it became available to them.[205] In 2018 in DRC, Ebola ring vaccination efforts (vaccination of contacts and contacts of contacts of exposed people) were met with challenges underpinned by institutional mistrust and misinformation about the vaccine.[206] There has been documented instances of outright refusals of Ebola vaccines in the outbreaks in West Africa and DRC.[163][207] The high public demand for Ebola vaccine documented in **Study III** may have been driven by the perceived threat posed by the widespread transmission, which is consistent with the finding that respondents with high demand for the vaccine were more likely to express that the vaccine should first be offered to them and their families if it became available.

### 6.1.3  Informing ethical and culturally responsive Ebola vaccination strategies

While the findings from **Study III** were important in quantifying Ebola vaccine demand among the general public around the peak of the outbreak, the qualitative results from **Study II** provided more in–depth understand regarding potential barriers and motivations related to Ebola vaccine demand in the context of ongoing planning of Ebola vaccine trials.  The preliminary findings from **Study II** were particularly useful in informing ethical and culturally responsive communication strategies for informed consent processes in the STRIVE Ebola vaccine trial in Sierra Leone, which eventually enrolled more than 8,000 participants in less than a year.[154][156]

The 2019 licensing of the Ebola vaccine by the U.S. Food and Drug Administration is major step in cementing the important role that vaccination strategies will play in outbreaks of Ebola.[166] The need to continue to monitor the behavioral drivers of Ebola vaccine uptake should remain a global health security priority. The brevity, reliability, and construct validity of the three items used to measure Ebola vaccine demand in **Study III** present an opportunity

for rapidly adapting and incorporating these items into other planned assessments during future Ebola outbreaks.

### 6.1.4 Transitioning Ebola death reporting systems for routine mortality surveillance

After the Ebola outbreak in Sierra Leone ended in November 2015, a key aspect of the enhanced surveillance instituted by the Government was to sustain the reporting of all deaths to the national 1–1–7 system as was done during the outbreak period. **Study IV** showed that the reporting level dropped during the enhanced surveillance period, and that the 1–1–7 maximally captured 34% of the total expected deaths compared to about 100% of the expected deaths in 2015 during the last year of the outbreak. After enhanced Ebola surveillance ended in June 2016, reporting levels continued to plummet and eventually stabilized to capturing about 12% of the expected deaths. Because the aggregated monthly summary data did not account for potential duplicate reports of deaths, the lower reporting level may have been influenced by fewer duplicate reporting after the outbreak. Given the lack of unique identifiers in the source database for the 1–1–7 call center it may never be possible to understand the role of duplicate reporting. However, it is plausible that duplicate reporting was mainly predominant in 2014 during the early stages of the outbreak in Sierra Leone when ambulance teams were sometimes slow to respond to death alerts. Multiple household members or others from the community may have kept calling the 1–1–7 system to report the same death to get a safe burial team to respond to the death.

## 6.2 THEORETICAL GROUNDING OF THE FINDINGS

Glanz et al. have described the role of theories in explaining health–related behaviors,[208] which have been further synthesized by the U.S. National Institutes of Health.[209] The findings from the respective studies in this thesis are enhanced when theoretical concepts are applied to them; namely Health Belief Model (HBM), Theory of Planned Behavior (TPB), Social Cognitive Theory (SCT), and Diffusion of Innovation. These theories generally assume that behavior change, or behavior adoption, is a rational process; as such they are considered cognitive–behavioral theories. Given the chaotic setting of the spiraling outbreak where fear played an important role, behavior adoption may not have always been an entirely rational process as outlined in cognitive–behavioral theories such as HBM, TPB, and SCT. Affective factors such as emotions likely influenced both prevention and risk behaviors in ways that are still not well understood. Media effects may have contributed to both cognitive and emotional drivers of behaviors. It is important to note that no single theory alone can sufficiently explain behavior, especially in the context of a complex Ebola outbreak that people, their governments, and society were grappling with at an unprecedented pace.

The Social Ecological Framework (SEF) asserts that behaviors are influenced through multiple levels of the social ecology: individual, interpersonal, community, institution and policy.[208] A single health behavior theory usually explains behavior at one of these levels.

However, to fully understand the drivers of behavior, multiple theories may be applied across multiple levels of the SEF. In Table 1, the SEF has been used to guide the grouping of theories and their linkages to the key findings in Studies I–V of the thesis.

**Table 11. Theoretical linkages of the findings using the Social Ecological Framework**

| Level | Theory | Study | Relevant behavioral concepts |
|---|---|---|---|
| Individual | Health Belief Model | Studies I–V | Perceived susceptibility, perceived severity, perceived benefits, perceived costs, cue to action, self–efficacy |
| | Theory of Planned Behavior | Studies I–V | Subjective norm, perceived behavioral control, behavioral intention |
| Interpersonal | Social Cognitive Theory | Study I | Reciprocal determinism, observational learning (modeling) |
| Community | Diffusion of Innovation | Studies I, IV, V | Innovation, communication channels, social systems, time |

### 6.2.1  Health Belief Model

*The Health Belief Model* is relevant to the findings from all five studies in the thesis in explaining behavior change at the individual level of the SEF. To summarize, the HBM states that behavior change is driven by the perceived threat (perceived susceptibility and perceived severity of a disease), perceived benefits and costs, cues to action (e.g. reminders), and self–efficacy (confidence to perform the behavior).[208][209]

In **Study I**, a complex interplay of the HBM constructs likely played a role in influencing uptake of Ebola prevention behaviors. As people observed their family members, neighbors, and health workers acquire Ebola and then often die, the perceived threat of Ebola transmission may have motivated people to practice frequent handwashing and to avoid physical contact with corpses and suspected Ebola patients. However, additional research is needed to empirically understand the relationship between Ebola risk perceptions and Ebola prevention behaviors. Cues to action in the form of reminders may have reinforced the promoted action. People in Sierra Leone were exposed to various information sources (radio, television, posters, etc.) reminding them to engage in the promoted prevention behaviors (e.g. handwashing, reporting suspected Ebola patients, avoiding traditional burials).[129] Physical cues were also used such as handwashing stations. Over time, people likely increased their self–efficacy to perform the promoted behaviors, which may have been accomplished through multiple attempts of executing the behavior or by receiving social support interventions such as those provided by community leaders and peers during the outbreak.

Participants in **Study II** made clear that they were mainly willing to accept an experimental Ebola vaccine to protect themselves and their patients to help end the outbreak. They weighed the perceived benefits against the perceived cost of accepting an experimental vaccine. Although there were no financial costs, other perceived costs that emerged included serious adverse events following vaccination including the fear of death as a result of taking an experimental vaccine. The findings from **Study II** were therefore important to ensure ethical

communication of the risks and benefits to potential participants of Ebola vaccine trials to guide the informed consent processes, procedures, and framing of language.

In **Study III**, Ebola vaccine demand was greatest among those who thought they or their families should be the first to get the vaccine if it became available, and nearly everyone said an Ebola vaccine was necessary to help end the outbreak. These findings are consistent with the perceived benefits of an Ebola vaccine helping to curb the outbreak, especially given that **Studies II–III** were conducted around the peak of the outbreak when the perceived threat of Ebola transmission may have been pronounced in the population.

Motivations to report deaths were greater among respondents in **Study V** who reported a death where the decedent experienced Ebola–like symptoms. These respondents may have perceived a benefit to report to avoid transmission if the death turned out to be Ebola. In **Study V**, respondents also expressed willingness to report deaths suspected of Ebola or due to other contagious infections. Consistent with HBM's construct on perceived benefit, positive reciprocity also helps explain the expectation expressed by respondents in **Study V** that reciprocal in–kind benefits (such as ambulance services) should be provided to incentivize death reporting.[210][211]

### 6.2.2  Theory of Planned Behavior

Like HBM, *Theory of Planned Behavior* is a cognitive–behavioral, expectancy theory that attempts to explain behavior adoption through the formation of behavioral intentions that are influenced by attitudes toward the behavior, subjective norm (expectations of important people), and perceived behavioral control (one's ability to exert control over the behavior).[208][209] TPB explains behavior change at the individual level of the SEF.

In **Study I**, the findings showed consistent improvement in behavioral intentions regarding safe burials, which were associated with improvements in attitudes toward safe burials. While perceived behavioral control was not directly assessed in **Study I**, the increased acceptance of safe alternatives was likely an indication of increased perceived behavioral control among respondents. Safe alternatives, such as allowing family members to observe the burial and having a religious leader say a final prayer, may have made people feel more in–control of the burial even though they were prohibited from having physical contact with the corpse. Replacing the risky behavior with safe practices likely enhanced families' perceived control over the burial.

**Studies II–III** provided evidence to suggest that attitudes toward Ebola vaccines influenced behavioral intentions to accept the vaccine if offered, which is consistent with the assertion of TPB. In **Study III**, the normative belief that family members would accept an Ebola vaccine was associated with intention to accept an Ebola vaccine for oneself.

In **Studies IV–V**, decisions to report or not report deaths to the 1–1–7 system after the outbreak ended may have been driven by subjective norms. People who reported deaths to the 1–1–7 system cited that they were mostly motivated to obey the government's mandate to report all deaths while those who failed to report said they were unaware of any such requirement. Among those who did not report, they perceived that the reporting system was only used during the Ebola period. Perceived behavioral control may have also played a role in reporting behaviors. In **Study IV**, the results showed that respondents who wanted to see the 1–1–7 system continued for death reporting purposes were more likely to not have called the line during the outbreak period. Past negative experiences from reporting deaths through the system – such as burial delays – may have reduced the perceived behavioral control among those who reported during the outbreak.

### 6.2.3 Social Cognitive Theory

*Social Cognitive Theory* explains behavior change or adoption at the interpersonal level of the SEF through the reciprocal tendencies between people and those they are surrounded by in their social networks – including family members, neighbors, and community leaders. The SCT strongly highlights the effects of social learning through observations (or role modeling) on behavior.[208][209] In applying the SCT to the findings, particularly those from **Study I**, the increased acceptance of safe burial behaviors was likely influenced by intrinsic social learning as well as through extrinsic social mobilization including role–modeling and promotion of safe burials by respected religious leaders.

### 6.2.4 Diffusion of Innovations

Novel interventions were required to be implemented at large scale during the Ebola outbreak. The most consequential, perhaps, was the introduction of safe burials that replaced unsafe traditional burials. Safe burial was an 'innovation' because it was new to Sierra Leoneans as a result of the outbreak. *Diffusion of Innovations* usually looks at the voluntary spread and uptake of "new products, ideas, and social processes."[209] Even though safe burials were mandated by the Government of Sierra Leone, compliance was suboptimal in the initial stages of the outbreak. In fact, it has been estimated that about three new Ebola cases emerged from every unsafe burial during the outbreak in West Africa.[64] The novel practice of safe burial needed to be diffused at an optimal level to minimize household and community spread of the Ebolavirus. In doing so, the theory suggests that the communication channels, social system, and time are critical constructs for behavior adoption.[209] For instance, the use of trusted religious leaders and community leaders to communicate the need for and benefits of safe burials may have contributed to catalyzing adoption of safe burials. Such messages likely propagated through social networks and over time became widely accepted.

## 6.3 METHODOLOGICAL CONSIDERATIONS

### 6.3.1 Study designs and sampling

All the studies were based on observational designs with cross–sectional data collected at different points during the outbreak (**Studies I–III**) and after the outbreak (**Studies IV–V**). Given the fast–evolving context of the Ebola outbreak, the cross–sectional data only reflected snapshots from the specific data collection period. Considerations were not given to doing longitudinal data collection because it was anticipated that repeat–interviews with the same individuals may have influenced the responses over time. For example, in **Studies I–III**, at the end of each interview, an Ebola factsheet was provided to interviewees as part of ethical obligations during a widespread outbreak. Therefore, the post–interview provision of a factsheet may have influenced Ebola–related KAP outcomes if data collection was instead done with cohorts of individuals using a longitudinal design. However, having multiple cross–sectional rounds of data collection in **Study I** was important to establish trends over time in Ebola KAP outcomes at the population–level.

The exploratory qualitative design in **Study II** had major strengths in that perceptions of experimental Ebola vaccines were obtained from multiple categories of participants (HCWs, frontline workers, and the general public). Qualitative data collection was useful in eliciting in–depth understanding of complex and nuanced issues that otherwise may be missed by quantitative assessment. A grounded theory approach, which was not used in **Study II**, may have allowed for more theoretical grounded results. For instance, use of theoretical sampling would have meant conducting follow–up interviews with the same respondents to clarify aspects of the prior interviews and selecting subsequent respondents based on analysis of data from previous interviews as part of the theory formation process. A grounded theory approach was not used because it is usually time and resource intensive. Given the fluidity and fast pace of the outbreak, a more rapid exploratory qualitative design was deemed the most suitable to meet the study objectives. In **Study II**, specific information on respondents' individual level experiences with Ebola was not collected, which limits the understanding of how variability in Ebola experiences may have potentially influenced perceptions and hypothetical acceptability of experimental Ebola vaccines.

**Studies IV–V** were designed to complement each other in trying to understand motivations (**Study IV**) and barriers (**Study V**) to reporting deaths in the aftermath of the Ebola outbreak following the end of enhanced Ebola surveillance in Sierra Leone. A major strength of **Study V** is the deployment of a national telephone–based survey using the computerized softphone system installed at the 1–1–7 call center in Freetown. Without precedent for doing telephone surveys in Sierra Leone, the sample size calculation needed to assume a conservative response rate. In the end, 1,330 respondents out of the 4,300 randomly selected phone numbers from the 1–1–7 database were reachable by phone after three attempts. While the sample obtained (1,291 respondents) was sufficiently large to allow for the planned analysis,

it remains unclear if systematic biases were introduced due to the non–response rate. Specifically, the differences between those who were not reached versus the sample obtained cannot be ascertained. For instance, people with phones that consistently remained switched off and hence unreachable could have been of lower socioeconomic status. Continuity in electrical power supply is a challenge in Sierra Leone. Therefore, poor people may have been more likely to suffer from power outages that prevented them to keep their phones charged. It is unclear if and how having fewer poor respondents in the sample may have influenced the results. Across all population groups, other mundane reasons such as losing of phones or changing of phone numbers may also explain why some numbers could not be reached after multiple attempts on different times of the day.

**Study V** was conducted as a follow–up to **Study IV** and used an exploratory qualitative approach to understand death reporting barriers among people who failed to report a death as mandated by the Government after the end of the enhanced Ebola surveillance period. A key strength of the study design was the selection of two districts that had epidemiological importance during the outbreak period; whereas Kenema district was part of the initial epicenter in the region, Western Area hosts the capital city where the highest number of Ebola cases were reported. It is therefore plausible that barriers unique to the other 12 districts were missed in the assessment.

### 6.3.2  Internal validity and implications for causal inference

Internal validity looks at the rigor of a study's design and the extent to which a causal relationship can be inferred between the independent variables and the outcomes.[212] Various threats to internal validity arise when confounding variables not accounted for in the study may have been responsible for the observed outcomes. There are seven major threats to internal validity[212 213]: *history* (e.g. historical events that influence the study outcomes); *maturation* (e.g. aging of the study's participants); biases due to repeated *testing* (e.g. participants learn from previous test itself); *instrumentation* (e.g. changes to how the outcomes are measured); *regression* (e.g. participant with extreme outcome scores regress to the mean); *selection biases* (e.g. lack of randomization that leads to differences between groups in the study); and *attrition* due to the differential loss of participants over time.

All studies in this thesis employed observational designs, which posed limitations to establish causal relationship between independent variables and the measured outcomes. Experimental designs were either not feasible or suitable for numerous reasons. Randomization of people into intervention and control groups would have meant withholding life–saving interventions on Ebola prevention from people in the control group who were at risk of getting infected with Ebola. It was therefore unethical, and perhaps impractical, to randomize communities or individuals into behavior change interventions during a widespread outbreak.

As a result, while major interventions implemented during the outbreak have been outlined in the various constituent papers in this thesis, an attempt to make a causal link between these

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interventions and the changes in the observed outcomes over the course of the outbreak is not appropriate. This is an inherent limitation across the board when attempting to identify the drivers of behavior change during an ongoing large–scale outbreak such as the Ebola outbreak in Sierra Leone. Such limitation reinforces a larger point that researchers in an outbreak setting cannot always opt for the most scientifically rigorous designs because at–risks persons may be denied life–saving interventions and treatment. Notwithstanding limitation of using a non–experimental design, the data from the serialized cross–sectional national behavioral surveys in **Study I** provide novel evidence in trying to answer the big–picture questions regarding when and where behavioral changes occurred during the largest outbreak of Ebola in recorded history.

In future outbreaks, there is a need to develop and test novel methods to assess the effects of interventions on prevention and treatment behaviors, and in turn, to further try to establish effects of uptake in behaviors on containment of the outbreak. The estimates of trends in population–level behavioral outcomes from Sierra Leone may be integrated into future mathematical models looking to predict the impact of behaviors on containing Ebola outbreaks. So doing would represent an important methodological advancement given that past mathematical models scarcely used actual behavioral surveillance data in the modeling parameters.[214]

### 6.3.3  External validity and implications for generalizability

External validity largely deals with the generalizability of a study's results.[212] Probability sampling was used in **Studies I, III, & IV** whereby respondents were randomly selected from respective sampling frames. In **Studies I & III**, national population–based samples were obtained using multi–stage cluster sampling whereas in **Study IV** a stratified national random sample of death reporters was obtained. Therefore, the results from **Studies I, III, & IV** may be considered generalizable but with some limitations. Notably, the first KAP survey in **Study I** only contained nine out of the 14 districts, and respondents with secondary school education were overrepresented in the pooled sample from the four surveys. Differences between or across geographic regions could not be accounted for based on the delineation of Ebola cases alone for high– versus low–transmission regions. Moreover, the multistage sampling strategy in **Study I** may not have yielded a representative sample of households and individuals in urban settings. Notwithstanding this limitation, the sample from the pooled KAP surveys largely mirrored the population of people aged 15 years and above in Sierra Leone when compared to results from the Sierra Leone Demographic and Health Survey conducted in 2013.[96] The sample of deaths reported obtained in **Study V** largely mirrored the demographic characteristics of deaths nationally as per the most recent census mortality data.[181] In **Studies II & V**, the findings cannot be generalized due to the use of non–probability sampling. Purposive sampling was used in the qualitative studies. However, it should be noted that generalization was not the purpose of the qualitative assessments.

Instead, the studies aimed to obtain rich understanding and subjective interpretations regarding nuances and complexities related to experimental Ebola vaccine acceptance and failure to report deaths to the 1–1–7 system.

### 6.3.4 Construct validity and implications for meaning

The KAP survey questionnaire items used in **Study I** were not psychometrically validated to ascertain construct validity prior to their deployment given the urgency of the outbreak. However, all items were pilot–tested and revised accordingly to improve the framing, wording, and sequencing of the items to enhance their understanding among respondents. Adaptations of the Sierra Leone KAP items in Guinea and Liberia produced similar results, which suggests the suitability of using these items during the outbreak in West Africa. Acceptable internal consistency and evidence of a single construct that measured Ebola vaccine demand was demonstrated in **Study III**, which used a subset of the dataset from **Study I** (i.e. the third KAP survey). The extent to which the Ebola vaccine demand scale in **Study III** may predict uptake of Ebola vaccine could not be determined because respondents had not been offered the vaccine at the time of the assessment. Nevertheless, the findings from Sierra Leone are consistent with the results from a survey of Ebola vaccine recipients in DRC, which showed that institutional trust predicted the intention to accept an Ebola vaccine.[163] In **Study IV**, FGDs were conducted to inform the development of the items to include in the telephone survey, which was followed by piloting of the items with a convenience sample. These steps enhanced the framing, wording, and sequencing of the items. Psychometric validation was not deemed necessary given that the items were each aiming to capture single indicators, respectively.

### 6.3.5 Social desirability bias

Across all studies in the thesis there was a potential for respondents to provide responses that reflected messages they received through community engagement and risk communication efforts. However, it was difficult to discern specific instances where social desirability may have occurred during data collection. One potential area is in **Study I** when respondents were asked if they had taken any actions to prevent Ebola. Nearly everyone said "yes" to this question. However, given the scale of the outbreak, it may be reasonably expected that everyone had tried to take some action to stay safe from Ebola. We anticipated this potential social desirability bias and followed–up with an open–ended question asking respondents to specifically cite the actions that they had taken. Interviewers were trained to not read any of the options but instead to just use a simple probe: "What else have you done to stay safe?" They probed until the interviewee gave an exhaustive list of all the actions that he/she had taken to prevent Ebola. The pre–coded response options in the questionnaire also included actions that were not proven prevention behaviors (e.g. drinking of traditional herbs to prevent Ebola). This allowed data collectors to capture a diverse range of possible responses.

In **Study II**, while the FGDs offered the advantage of individuals sharing experiences and building off each other's insights, participants may have been less likely to express attitudes that differed from emerging group consensus. These potential limitations were mitigated by facilitation techniques that strived to offer equal opportunity to all participants to freely express their views on the range of issues discussed. In **Studies II & V**, especially, power relations between participants and interviewers may have influenced the responses generated,[215] including the potential for social desirability bias or withholding of information. In **Study IV**, most respondents who reported a death said they did so to obey the Government's mandate to report all deaths. It is challenging to discern if respondents provided socially desirable responses to match their perceived expectations of the interviewers and/or to reflect messages communicated to them by their government. The potential for respondents to predominantly provide socially desirable responses may have been reduced by having experienced and well–trained data collection teams who facilitated openness in dialogue. Open–ended probes were used to follow–up on statements made by participants by asking them: "can you tell me more about that?" Facilitators were trained to explicitly encourage participants to be candid in their responses and to ensure that every participant had an opportunity to contribute to the discussion. These facilitation techniques may have helped to mitigate some of the social desirability bias.

# 7  CONCLUSIONS

It is feasible to conduct serialized population–level assessments of behavior change during a complex outbreak of Ebola. Knowledge, attitudes, and prevention practices improved nationally during the outbreak in Sierra Leone, and the magnitude of improvement was greater in high–transmission regions when compared to low transmission regions. With the available data, it is impossible to discern the impact of behavior change on containment of the outbreak in Sierra Leone. However, the results presented in the thesis are consistent with mathematical modeling demonstrating that behavior change played an important role in bringing the outbreak to an end.[89] The temporal and geographic estimates of improvements in Ebola–related behavioral intentions and prevention practices documented in this thesis can inform behavioral parameters in future mathematical models attempting to understand and predict the epidemiology of an Ebola outbreak or other similar infectious disease outbreaks.

Understanding the drivers of Ebola vaccine acceptability and demand was important to inform ethical and cultural considerations in the implementation of experimental Ebola vaccines in Sierra Leone. Health workers should not be viewed separately from the communities where they live and work. Social dynamics in their communities shape the behaviors of health workers. When coupled with qualitative data, a brief measure of vaccine demand may be useful in outbreak settings where rapid data collection can inform real–time vaccination strategies to help contain the outbreak.

While the 1–1–7 system was ramped up to capture most deaths during the outbreak, reporting substantially declined after the outbreak ended. Failure to report deaths after the outbreak was mainly due to lack of awareness to report all deaths and lack of perceived benefits to report in the post–Ebola–outbreak setting in Sierra Leone. Knowledge and experiences gained from the Ebola outbreak may have been responsible for the increased motivation to report deaths that exhibited Ebola–like symptoms after the Ebola outbreak ended in Sierra Leone. Post–Ebola–outbreak settings offer an opportunity to implement routine mortality surveillance, however, substantial social mobilization efforts may be required to optimize reporting.

Community engagement is a process, and behavior change may take some time to be realized at the optimal level needed to slow down the epidemiological curve of an Ebola outbreak. Emphasis should be placed on the high–risk behaviors (i.e. avoiding contact with suspected patients and corpses) from the early stages of the outbreak. Intensified social mobilization should be prioritized in the high–transmission regions to help translate knowledge and intentions into behavior change.

# 8  RECOMMENDATIONS

- Social mobilization should be prioritized early as a critical pillar of an Ebola outbreak response and must be informed by data on behavioral insights.

- Use of mixed–methods behavioral surveillance assessments should be considered early and throughout an Ebola outbreak to inform interventions, strategies, and policies.

- Looking into the future, standardized indicators and methods for measuring Ebola–related KAP should be adopted by Ebola outbreak–prone countries and regions in order to facilitate comparable understanding of prevention behaviors within and across countries and populations.

- Novel research and evaluation designs are needed to better establish the effects of social mobilization on improvements on Ebola–related KAP.

- Ebola outbreak responses need to prioritize structured and well–planned engagements with communities in order to facilitate uptake of prevention behaviors such as avoidance of unsafe traditional burials and caregiving practices.

- Implementing experimental vaccines during an outbreak require complex ethical and cultural considerations. With the advent of a licensed Ebola vaccine, future Ebola vaccination strategies during outbreaks also need to be informed by in–depth understanding of local barriers and facilitators of vaccine uptake.

- People should be made aware of the benefits and potential risks of receiving an experimental Ebola vaccine in ways that are ethically responsible and culturally appropriate to avoid tacit coercion in the guise of a chaotic outbreak environment where the perceived disease threat is heightened among the population.

- If death reporting is mandated after an Ebola outbreak has ended, the government should ensure that the death reporting policy is clearly communicated to the public using plain language.

- Reporting benefits need to be incorporated into routine mortality surveillance and communicated to the public to incentivize optimal reporting.

- Localized and informal practices for death notification to community leaders, including religious leaders, should be leveraged to expand the number of deaths captured in a mortality surveillance system.

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